

“It means so much for me, to have a choice.” First person perspectives on medication free treatment in mental health care: a qualitative interview study

Christine Henriksen Oedegaard (✉ christine.oedegaard@helse-bergen.no)

University of Bergen <https://orcid.org/0000-0003-4738-7962>

Larry Davidson

Yale University School of Medicine

Brynjulf Stige

Universitetet i Bergen Griegakademiet Institutt for musikk

Marius Veseth

Universitetet i Bergen

Anne Blindheim

Haukeland Universitetssjukehus

Linda Garvik

Hvite Ørn (user organization)

Jan-Magne Tordenhjerte Sørensen

Hvite Ørn (user organization)

Øystein Søråa

Hvite Ørn (user organization)

Ingunn Marie Stadskleiv Engebretsen

Universitetet i Bergen Det medisinsk-odontologiske fakultet

Research article

Keywords: Recovery, communication, decision making, lived experience, schizophrenia, medication, quality of care.

Posted Date: January 24th, 2020

DOI: <https://doi.org/10.21203/rs.2.12942/v2>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Version of Record: A version of this preprint was published on August 8th, 2020. See the published version at <https://doi.org/10.1186/s12888-020-02770-2>.

Abstract

Background: In 2016, Western Norway Regional Health Authority started to integrate more evidence-based psychosocial interventions into existing mental health care, emphasizing the right for persons with psychosis to choose medication-free treatment. This change emerged from the debate on the use of anti-psychotic medication regarding effectiveness and adverse effects. Aspects beyond symptom reduction, like interpersonal relationships, increased understanding of one's own pattern of suffering, hope and motivation, are all considered important for the personal recovery process.

Methods: This study explores if these aspects were present in the users' descriptions of their recovery processes within the medication free treatment program in Bergen, Western Norway. We interviewed ten patients diagnosed with psychosis eligible for medication free services about their treatment experiences. Data were analyzed using Attride Sterling's thematic network approach.

Results: Findings show a global theme relating to personal recovery processes facilitated by more psychosocial treatment options, with three organizing sub-themes: Interpersonal relationships between patient and therapist; the patient's understanding of personal patterns of suffering; personal motivation for self-agency in the recovery process. Informants described an improved relationship with therapists compared to previous experiences. Implementing more evidence-based psychosocial interventions integrated into existing mental health services facilitate learning experiences regarding the choice of treatment, in particular discontinuation of medication, and appears in this study to support increased self-agency and motivation for the informants in their personal recovery process.

Conclusion: Health care in Norway is perhaps one step closer to optimizing the care for people with psychosis, allowing more choice and in this improving the dialogue and hence the interpersonal relationship between the patient and the therapist. Personal patterns of suffering are allowed to be explored within a system aiming to support and to have a higher level of acceptance of discontinuation of medication. This develops the need for personal agency in the treatment regimen, with more focus on personal coping strategies, and more personal responsibility for the recovery process.

Background

Since 2011, mental health user organizations in Norway have fought for treatment options without the use of psychotropic medication. In 2015, the Norwegian Health Minister urged the four regional Health Authorities to offer medication free treatment to persons experiencing psychosis, within the law defining responsible treatment (1). In 2016 The Western Norway Regional Health Authority started the medication free project, implementing more psychosocial interventions into existing mental health care services in outpatient clinics.

The medication free treatment requirement emerged from the debate on the use of anti-psychotic medication (referred to as AP) as a part of the treatment for severe psychiatric illness (2). On the one hand, AP medication is recommended short term to reduce positive psychotic symptoms and long-term to

reduce risk of relapse (3-5). AP is in some studies associated with increased survival (6-8), and discontinuation with poor long-term outcome (9) including increased risk of violence (10, 11). Severe mental illnesses, like schizophrenia, have a substantial negative effect on life expectancy, together with increased risk of suicide (12-14), also related to lack of adherence to antipsychotic medication (15, 16).

On the other hand, studies show that dose reduction/discontinuation of AP is superior to maintenance treatment for long-term recovery (17, 18), and that a guided discontinuation of medication might be successful (17, 19). Adverse effects of AP medication have been suggested to increase the risk of early death (20-24). The debate raises important questions regarding treatment recommendations, and patients need to consider potential benefits as well as adverse effects when choosing to use AP medication or not (25-28).

Discontinuation of AP medication for people with severe mental illness is more often described in the literature as non-adherence rather than an integrated part of a treatment regimen in collaboration with psychiatrists. There are relatively few studies focusing on the first person perspective in the implementation of new treatment programs in mental health care (29), and personal accounts of a treatment program integrated in existing services aiming to support patients choosing to discontinue anti-psychotic medication, have not to our knowledge previously been published.

The introduction of optional medication free treatment for psychosis is a recovery-based reform of mental care based on advocacy work from service user organizations. The global recovery movement works to change mental health policy and practice based on the perspectives of people with mental illnesses. It has roots in both the user organisations and the wider civil society (30). Qualitative studies and meta-syntheses have shown how important aspects beyond symptom reduction alone are for the recovery process. Such aspects include interpersonal processes, increased understanding of one's own pattern of suffering, and more hope and motivation leading to self-agency in the treatment process (31-34). We believe there is a need to explore if these aspects were present in the users' descriptions of their recovery processes within the medication free treatment program in Bergen, Western Norway.

Methods

Site

The Norwegian health system is largely a public health system funded by the government, organized into four regional Health Authorities. The implementation of the new medication free health policy in 2016 varied across these four Health Authorities with regard to options to choose between and number of beds prioritized for it. The Western Norway Regional Health Authority was the only Health Authority not dedicating a certain number of beds to this treatment. Instead, their aim was to improve the treatment for all patients with psychosis by tailoring treatment to individual preferences and implementing evidence-based psychosocial interventions integrated into existing services in outpatient clinics. The services were designed to support whichever choice the patient made, focusing on increasing user involvement and a sense of ownership to the therapy, as well as improving the alliance. It was not designed to promote one

choice over the other. The medication free project established a website with information (35), and held a conference as well as local seminars at the different clinics to inform staff. All patients who are above 18 years old, not restricted by coercive measurements, and within the admission area, are eligible for medication free services.

Design

This was a qualitative study which included semi-structured, in-depth interviews with people with psychosis who were registered for this treatment. Qualitative methods like in-depth interviews aim at understanding and representing the experiences of people as they encounter, engage, and live through situations (36-38). This study also employed a service user involved approach (32, 39) developed within a hermeneutic-phenomenological epistemology. This means that we have a phenomenological aim in exploring and describing the lived experiences of personal recovery processes within mental health care where medication free treatment for psychosis is brought forward. Further, we recognize that our attempts at doing so inevitably involve interpretations.

Researchers and user-involvement

The first author has no health professional background. This was viewed by our collaborating user organization "Hvite Ørn" (a Norwegian descriptive name for a white eagle), as an advantage as diagnostic terms and criteria would hopefully less become a part of the mind-set during the interview. Together with the first author, the supervisors and co-authors of this article constitute an interdisciplinary research team including a professor in music therapy, an associate professor in psychology, a professor in psychiatry, and a professor in medicine.

In order to ensure respect of the complexity of the user's views on the focus of this study, the research team invited four experts by experience to become co-researchers on this project. Three of these co-researchers are members of the user organization "Hvite Ørn" and the fourth works as peer support staff. They have been involved in the study from the preparatory phases (developing the protocol and research questions and discussing the semi-structured interview guide) through data analytic phases (participating in the team-based analysis) to dissemination of the results (participating in writing articles and presenting the research project). Studies have shown user involvement to be useful in improving research questions, ensuring interventions remain 'user friendly', and improving the selection of outcome measures (40). We believe this involvement enhances the quality of the study also through development of a meta-perspective on the research process (32, 39, 41).

Procedures

The protocol for this study was developed in collaboration with the user organization and supervisors. The semi-structured interview guide (supplementary file) was also a result of a close collaboration between co-researchers and the supervisors, as well as the first author. The interview guide comprised four main topics; the informants' life stories, their meetings with the health care system, their experiences

of the freedom to choose, and their thoughts about the future. Within each of these, there were several open-ended questions and possibilities to probe to elicit narratives of experiences.

The first author conducted the interviews and made notes of her experiences after each interview. She obtained informed written consent to participate in the study, and ensured the well-being of each participant after the interview. None of the participants expressed a need for further support. Eleven participants were interviewed during fall 2017 and spring 2018, one was excluded from the analyzing process for this article as the informant had no intention of discontinuing medication. The interviews varied in length from approximately 45 to 90 minutes. All interviews were tape recorded and transcribed by the first author.

Participants

The participants were people with psychosis registered as patients in one of three outpatient clinics in the mental health services in Health Bergen. Six participants were in a medication free treatment course, while four had chosen to start medication again after having reduced or discontinued their medication in collaboration with their psychiatrist.

All participants were informed about the study by their therapist, orally and in writing. The therapists assessed eligibility for this study following the inclusion criteria of being above 18 years of age, able to give an informed consent, having psychosis as a part of their presentation, as well as being a patient at one of three outpatient clinics. They also had to be actively engaged in medication free services. This could be exercise, music therapy, job support, or other group therapy sessions.

The participants were purposefully selected in order to vary in age (25-45) and gender (five women and five men), as well as past treatment histories, to ensure diverse patient experiences. The informants could choose where they preferred to do the interview. Most chose to be interviewed at the outpatient clinic, in either the first author's office, a quiet room or the room used for music therapy. One patient chose to be interviewed at home.

Data analysis

The transcribed text was analysed using Attride-Sterling's (2001) thematic network approach. This was done in a team-based way as all co-authors were invited to read and comment on the raw, anonymized transcripts as well as being a part of the coding process. Attride-Sterling's Thematic Network Analysis (42) provides procedures for conducting analysis of interview data, enabling methodological systematization of textual data, facilitating the disclosure of each step in the analytic process, aiding the organization and presentation of the analysis, and allowing a sensitive and rich exploration of a text's structures and patterns (42). The first author did the first coding together with two fellow PhD students not otherwise involved in the study, forming a coding framework and discussing the possible thematic network from the three first interviews. This procedure is considered to strengthen the credibility of the chosen codes, as it enhances a rigorous data analysis process. The codes emerged from the text, and the

basic themes common across the interviews were identified. The basic themes were grouped by related conceptual content into organizing themes that were “interpersonal relationships”, “patterns of suffering” and “motivation and personal agency in the recovery process.” This entire process and coding frame was an iterative process. The themes were named and renamed for a better fit, until the team felt the final product was representative of all views, and no essential information was lost in the process. The final global theme reflect the research question, via codes, basic themes and organizing themes. The translated coding frame relevant for this article is displayed in Table 2. Codes and themes were translated into English by the first author, along with key quotes used to illustrate the findings. We used the NVivo software program for data management (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 12 Plus).

Ethics

The Regional Ethics Committee for Medical Health Research (REK southeast 2017/736) defined this study as health service research and hence according to the Norwegian health research legislation, the study was to be approved by the local data protection officer. The data protection officer for Health Bergen approved the study in July 2017 (2017/8692).

Findings

The data analysis from codes to global theme is illustrated in Table 2. This result section is structured according to the organizing themes: Interpersonal relationships between patient and therapist, the patient’s understanding of personal pattern of suffering, and personal motivation for self-agency in the recovery process.

Interpersonal relationships between therapists and patients

Asking the informants in this project about their reasoning for their choices, they expressed uncertainty both regarding treatment options available to them and explanations for their choices. Answers like “I’m not sure” and “I don’t remember” was quite common. One mentioned lack of information regarding rights to complain about the treatment:

“She could have informed me better about my rights, if I disagreed with her. (...) I had to figure that out by myself.”

Inadequate information includes lack of information, withheld information and an underestimated need for repeated information. Importantly, some informants reported that it seemed rather arbitrary what type of service that was offered and not so much as a ‘real choice’. Not all services were available, and furthermore, not all services were suggested by the therapists:

“I feel it’s kind of random which services you are offered, and what you end up getting, really, and if you get a service that helps, in a way. But it is of course difficult to know what helps.”

Treatment choices were thus suggested limited by availability and the information provided by the therapist, as well as the individual need for repeated information when illness and symptoms might affect the memory (43). This put forward a need for increased focus on shared decision-making.

However, the level of information is not the only parameter on the quality of an interpersonal relationship, which is considered important for the outcome of the therapy (44). Trust is vital in promoting this. In this study, the informants shared an overall feeling of confidence in the therapists. On questions about who they would trust getting advice from concerning their treatment choices, all mentioned their current therapist, along with other key persons in their life. Availability of the therapist was closely linked with descriptions of a positive relationship. One participant described his psychiatrist as easy to reach, and he felt he could take part in decisions concerning his own treatment:

“I really like that here. I can talk with (name) in the hallways, and if I have to schedule another appointment, or (...). Sometimes we talk for ten minutes without having an appointment, and I get a new prescription, and just talk. We do talk about different mood stabilizers, and what he recommends, and such. So it might be that I will start a new medication again that I told him that I wanted to consider.”

Nevertheless, there were also some examples of distrust and not mentioning sensitive issues to avoid uncomfortable situations. This could be talking about worsening of symptoms, or wishing to change or discontinue a medication. One informant described powerlessness in the relationship and the communication as a “game”:

“So I kind of picture that ‘NO’ ahead of me. And then I think, is it any use to bring it up, they decide. So, it’s kind of a game, I feel, where he has the power and I don’t have much to say.”

Building trust could take time. Several informants described having had trust issues with the therapist or health care system in general, often linked to a period of worsening and admissions, but then being able to repair the relationship over time. One participant described this:

“Yes, well, he has been there quite long, through the worst of times, I mean ... the psychiatrist. It’s quite special. Now I think he is nice, but in the beginning I didn’t think he was nice at all (...) I didn’t like him.”

The informants reported that their illness and change of symptom severity could affect the experience of the quality of the relationship.

Despite the experienced trust, when it came to the discontinuation processes the informants reported being presented with certain conditions. Therapists could accept the wish to discontinue AP, however not without substituting it with other treatment:

“The impression I get is that, I will be allowed to be psychotic if I want to, but then I have to do other stuff, in order to maintain wellness in the psychoses. So then she talked about music therapy, and that it would be a good way to stay in therapy.”

In this way, therapists are substituting medication with other treatment options available.

Personal patterns of suffering and how choices are made

Participants in this study could choose between an increased number of treatment components, such as cognitive therapy, illness management and recovery skills training (IMR), individual job placement and support (IPS), music therapy, exercise and family group therapy. All of the informants confirmed the importance of having a choice in their treatment when asked directly. One informant said:

“It means so much, for me, to have a choice. Yes. To choose. To choose in psychiatry is incredibly important. And that they see possibilities. That it is not always that particular intervention, that one and only particular medication, you know! Because ... they have to see the person in a wider perspective.”

Many of the mentioned services were unfamiliar to the informants, which made it hard to choose, both for the person as well as for their family or peers:

“I don’t know what they would have chosen for me. It’s hard to say. If you don’t completely understand, or if you don’t know exactly yourself, what actually helps.”

Increased psychosocial intervention options within mental health care were in this study intended to enable discontinuation of medication in a supportive setting. Yet, quitting medication was not an easy way out in a life with illness. The informants in this study were all struggling with different medication issues. Many described use of medication characterized by fear of unknown and adverse effects as the in the quote below:

“But there is no definite answer to what happens when you are taking a pill. (...) Because ... then you might think all your problems are due to the medication. And then you think they will go away when the medicine is gone, and then you quit on your medication, and then they don’t go away.”

Thus the informants recognized that taking medication is complex. Using medication may result in adverse effects, but discontinuing may not be an easy solution. One informant explained how he knew his delusions included medication, feeling the pills were poison, and the pain and aching in his body were perceived as severe adverse effects killing him. This led to a wish to discontinue medication. Particularly forced medication was associated with delusions:

“And ... I don’t think I would have taken any medication if I just got forced to do it. I think I would have become very skeptical if I was ... That is, I would have had delusions about it, being forced to take medications I did not think were good for me.”

Wishing to discontinue medication might stem from delusions for some, however side effects from the use of AP must be recognized. Side effects experienced by the informants included losing control over body parts, one mentioned a feeling of drowning, most talked about gaining weight and feeling tired:

“I think it really sucks that I become more tired when I use that medication, and I also feel a bit like a failure when I use it. It’s like I have a defect.”

Patterns of suffering are individual, and gaining experience with the various effects medication has on one’s body is a learning process. Not everybody wanted to reduce all symptoms of their illness, like the one participant who said:

“Perphenazine works too well. It removes too much of the psychosis. When I’m psychotic I’m more friendly. I get more ... naïve? I become ... they called it pronoid. I sort of haven’t said completely goodbye to the psychosis yet.”

Other informants also described a similar relationship with their symptoms, in how hearing voices made them feel accompanied, and how they felt lonely without them.

Four of the informants in this study had aborted the discontinuation of the medication at the time of the interview. One informant described this experience, learning what worked for him:

“I think that someday I can stop. (...) But I know it is smart to use medication too. It sort of soothes the psychosis, so it makes it easier to cope, and do stuff. So the medication helps, no arguing there.”

Outside factors, like having work, were also important to consider in the process of learning about one’s own pattern of suffering:

“But I can’t risk getting ill again, since I have a job now ... So I can’t risk losing my job ... As long as I get just a little bit of Abilify, I’m safe. It might be that I could have coped on an even lower dose ... we’ll see. I might consider that.”

The complex learning process involves getting experienced with your own illness; the symptom load, the adverse effects, and the outside factors, all contributing to decision-making about treatment options.

Motivation and personal agency in the recovery process

Recovery-oriented pathways require personal agency and responsibility in order to improve one’s life. Several participants expressed a feeling of having to “do the work” themselves:

“I have to do the work. I think a lot of people have helped me along the way, now it’s just me who has to do the work. That’s how I feel. And I intend to do it.”

This meant they had coping strategies such as avoiding too much stress, or staying away from drugs, or keeping the daily routine of sleep, rest, and eating well. Taking responsibility for one’s well-being implied risk of failure. Their coping strategies were challenged by their symptoms and illness. One informant described how the worsening of symptoms pushed away the care team so that they were unable to intervene:

“What happened to me first was that I started to be a bit bitter at psychiatry in general, I didn’t want anything to do with them at all. So I think it was a bit unfortunate they didn’t catch me at once, because I sent some messages to one of the ... They didn’t know what to do, they said, then. But I think it was quite unfortunate they didn’t catch earlier that I was ill.”

Much of the therapy involves learning how to live with the symptoms. Sometimes people want to choose without the help from others, relying on their own experience and expertise, as one said:

“So, I have been very determined to deal with all of this by myself. (...) So I have been very independent.”

The risk concerning the need for independency when this involves not telling carers about symptoms is worsening getting out of control. Still, another outcome would be to increase the level of independent living. Both outcomes might offer valuable lessons in the process of recovery.

Many of the participants’ hopes for the future evolved around managing one day at the time. Some mentioned work, studies and perhaps having a family. One informant described her thoughts about her life:

“Now I just want to figure out the everyday life, and how to be around myself, and be ... in my own company ... And have a good time with myself, be happy with who I am, and sort of ... get a self-image that fits with reality, and ... not be so hard on myself as I have been.”

The same informant continued when asked where she sees herself in ten years:

“I hope I’m not dead ... No, I hope I’m alive, that’s the only thing I hope for. I can’t say I have any ... I hope I’m ok. I would have loved to have a husband, and family, but that’s kind of distant to me.”

This quote expresses both a need not to be so “hard on oneself” as a coping strategy consistent with an understanding of her own vulnerability, as well as a fear of not surviving the illness. The task of surviving psychosis and keeping hope for a better future is demanding.

Discussion

The integration of medication free services into existing services has resulted in more treatment options for all persons with psychosis eligible for outpatient treatment in Bergen. The informants in this study shared a generally positive impression of their interpersonal relationships and communication with their current therapists. Developing trust with the therapist were said to depend on the level of symptoms as well as continuity in the relationship over time, and the relationships were described to have improved compared to previous experiences. These findings might indicate an increased effort therapists are making to meet the patients’ needs, and more accept for patient choices. This is in contrast to other studies on collaboration with the therapists, where less shared decision-making was found (45-47). However, potential difficulties were a perceived lack of information about rights and treatment options available, as well as some avoidance of sensitive topics in the therapeutic dialogue. According to a

Norwegian report from outpatient clinics in 2007, users reported a need to improve the level of information on available treatment options (48). It seems there is still room for improvement of the information flow. A digital tool for shared decision-making for people with psychosis has been developed in 2018-2019, and was launched in August 2019 to be implemented in the Western Norway Health Region to improve these issues (49).

The process of choosing treatment was described as complex, with many influencing factors. Each person shared individual stories displaying a reflexive understanding of their individual strength and vulnerability, linked with increasing understanding of the illness, including considerations of potential consequences of worsening symptoms. Studies of health care decision-making have shown that patient choices seldom are based on reasoning alone. Elements such as trust, intuition, emotion and beliefs also matter (50). This is in line with this study where factors influencing treatment choices particularly regarding medication were described as a fear of the unknown, delusions, "not knowing what helps", and symptoms being helpful. One of the informants shared how she felt defeated by having to take pills for an illness in the brain, as if she had a physical defect. Some studies have suggested that having to use medication because of a mental illness may be stigmatizing (51), but the informants otherwise did not mention stigma surrounding psychiatric illness as much as expected, even when probing for it during the interviews.

Personal responsibility and motivation for the recovery process was highlighted by most of the informants, often associated with extensive focus on coping strategies. The informants generally concluded that they 'need to do the work on their own' in their recovery process. Their coping strategies were regarded as important tools in order to keep symptoms under control. Several of the implemented treatment options focus largely on coping strategies. This needs to be closely monitored as studies have shown significant associations between self-stigma and coping strategies in schizophrenia (52, 53).

Thoughts about the future included both hope for independent living as well as a certain resignation facing life with an illness. The learning processes evolving from the choices made sometimes came with a cost. Four informants had aborted the discontinuation, not coping with the symptoms without medication, some with adverse events as a result. Others felt they coped well, and were satisfied with a life with lower dosages or without AP medication. These findings show how increased psychosocial intervention options support personal recovery processes like increased self-agency and motivation, which is in line with findings from other studies (54, 55). However, it is important to take into consideration the possibility of risk regarding both the discontinuation process, and potential self-stigma in the use of coping strategies.

This study has strengths and limitations. It had a limited number of informants, and the interviews were done early after the implementation of the treatment program had commenced. This means that the health system and services may not be fully acquainted with the change at the time of the interviews. Thus, our data does not facilitate to judge the health service change after the integration of the medication free services into the mental health care. However, this study provides important views from

the first person in their treatment choices within the shift of focus provided by added treatment options and professional accept for and collaboration regarding discontinuation of medication. It is important that the context specific users' perspectives are considered in the research on implementation of new treatment programmes.

Conclusion

Health care in Norway is perhaps one step closer to optimizing the care for people with psychosis allowing more choice, and in this improving the dialogue and hence the interpersonal relationship between the patient and the carer. Personal patterns of suffering are allowed to be explored within a more supportive system regarding known factors facilitating personal recovery. This demands a higher level of personal agency in the treatment regimen, more focus on personal coping strategies and more personal responsibility for the recovery process.

Clinical implications from this study would be to recommend an increased level of psychosocial interventions and shared decision-making in mental health care, adapted with regards to level of symptoms, experience and individual preferences. Additionally, it is important to take into consideration the importance of continuity over time in developing the interpersonal relationship between patients and therapists.

Declarations

Ethics approval and consent to participate:

The Regional Ethics Committee for Medical Health Research (REK southeast 2017/736) defined this study as health service research and hence according to the Norwegian health research legislation, the study was to be approved by the local data protection officer. The data protection officer for Health Bergen approved the study in July 2017 (2017/8692). All data were treated in accordance with ethical and legal guidelines, ensuring anonymity and confidentiality for participants. Sound files and transcriptions were only stored securely on the research server managed by the IT-section of Haukeland University Hospital. De-identified transcripts were printed and shared with the supervisors and the four co-researchers. The key to the demographic data and names of the participants were stored separately on a secure key server. All participants have signed a form declaring their informed consent to participate in the study.

Consent for publication:

All participants have signed a form declaring their informed consent to publish results from the study.

Availability of data and materials:

The dataset that support the findings of this study consists of in-depth qualitative patient interviews, which are not publicly available due to confidentiality reasons. The entire coding frame developed from these interviews is available from the corresponding author on reasonable request. The interview guide is available as a supplementary file.

Competing interests:

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding:

The first author was supported by a grant from Health Bergen Health Authority, Norway.

Authors contributions:

CØ: Main researcher and author.

LD: advisor for the study and contributor in writing the article.

BS, MV: supervisors for the study, contributors in analysing data and writing of the article.

AB, LG, J-MS and ØS: contributors in developing the protocol, the interview guide, and analysing the data.

IMSE: Major supervisor for the study and contributor to the writing of the article.

All authors read and approved the final manuscript.

Acknowledgements: Not applicable

Abbreviations

AP: anti psychotic medication

IMR: Illness Management and Recovery

IPS: Individual Placement and Support

ACT: Assertive Community Treatment

FACT: Flexible Assertive Community Treatment

MI: Motivational Interview

References

1. Helse og omsorgsdepartementet CD, Cathrine Meland,. Medikamentfrie tilbud i psykisk helsevern - oppfølging av oppdrag 2015 <https://www.regjeringen.no/no/dokumenter/medikamentfrie-tilbud-i-psykisk-helsevern—oppfolging-av-oppdrag-2015/id2464239/>: www.regjeringen.no;; 2015 [Public information from the Norwegian government about health care services.]. Available from: <https://www.regjeringen.no/no/dokumenter/medikamentfrie-tilbud-i-psykisk-helsevern—oppfolging-av-oppdrag-2015/id2464239/>.
2. The Lancet P. The medication debate: time to change the record. *The Lancet Psychiatry*. 2018;5(10):769.
3. Leucht S, Tardy M, Komossa K, Heres S, Kissling W, Salanti G, et al. Antipsychotic drugs versus placebo for relapse prevention in schizophrenia: a systematic review and meta-analysis. *Lancet* (London, England). 2012;379(9831):2063-71.
4. Tiihonen J, Mittendorfer-Rutz E, Majak M, Mehtala J, Hoti F, Jedenius E, et al. Real-World Effectiveness of Antipsychotic Treatments in a Nationwide Cohort of 29823 Patients With Schizophrenia. *JAMA psychiatry*. 2017;74(7):686-93.
5. Buchanan RW, Kreyenbuhl J, Kelly DL, Noel JM, Boggs DL, Fischer BA, et al. The 2009 schizophrenia PORT psychopharmacological treatment recommendations and summary statements. *Schizophrenia bulletin*. 2010;36(1):71-93.
6. Tiihonen J, Tanskanen A, Taipale H. 20-Year Nationwide Follow-Up Study on Discontinuation of Antipsychotic Treatment in First-Episode Schizophrenia. *The American journal of psychiatry*. 2018;175(8):765-73.
7. Hui CLM, Honer WG, Lee EHM, Chang WC, Chan SKW, Chen ESM, et al. Long-term effects of discontinuation from antipsychotic maintenance following first-episode schizophrenia and related disorders: a 10 year follow-up of a randomised, double-blind trial. *The lancet Psychiatry*. 2018;5(5):432-42.
8. Vermeulen J, van Rooijen G, Doedens P, Numminen E, van Tricht M, de Haan L. Antipsychotic medication and long-term mortality risk in patients with schizophrenia; a systematic review and meta-analysis. *Psychological medicine*. 2017;47(13):2217-28.
9. Ran MS, Weng X, Chan CL, Chen EY, Tang CP, Lin FR, et al. Different outcomes of never-treated and treated patients with schizophrenia: 14-year follow-up study in rural China. *The British journal of psychiatry : the journal of mental science*. 2015;207(6):495-500.
10. Buchanan A, Sint K, Swanson J, Rosenheck R. Correlates of Future Violence in People Being Treated for Schizophrenia. *The American journal of psychiatry*. 2019;176(9):694-701.
11. Witt K, van Dorn R, Fazel S. Risk factors for violence in psychosis: systematic review and meta-regression analysis of 110 studies. *PloS one*. 2013;8(2):e55942.
12. Hjorthoj C, Sturup AE, McGrath JJ, Nordentoft M. Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis. *The lancet Psychiatry*. 2017;4(4):295-301.
13. Sher L, Kahn RS. Suicide in Schizophrenia: An Educational Overview. *Medicina* (Kaunas, Lithuania). 2019;55(7).

14. Sartorius N, Jablensky A, Korten A, Ernberg G, Anker M, Cooper JE, et al. Early manifestations and first-contact incidence of schizophrenia in different cultures. A preliminary report on the initial evaluation phase of the WHO Collaborative Study on determinants of outcome of severe mental disorders. *Psychological medicine*. 1986;16(4):909-28.
15. Hor K, Taylor M. Suicide and schizophrenia: a systematic review of rates and risk factors. *Journal of psychopharmacology (Oxford, England)*. 2010;24(4 Suppl):81-90.
16. Tiihonen J, Wahlbeck K, Lonnqvist J, Klaukka T, Ioannidis JP, Volavka J, et al. Effectiveness of antipsychotic treatments in a nationwide cohort of patients in community care after first hospitalisation due to schizophrenia and schizoaffective disorder: observational follow-up study. *BMJ (Clinical research ed)*. 2006;333(7561):224.
17. Wunderink L, Nieboer RM, Wiersma D, Sytema S, Nienhuis FJ. Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose reduction/discontinuation or maintenance treatment strategy: long-term follow-up of a 2-year randomized clinical trial. *JAMA psychiatry*. 2013;70(9):913-20.
18. Harrow M, Jobe TH. Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: a 15-year multifollow-up study. *The Journal of nervous and mental disease*. 2007;195(5):406-14.
19. Wunderink L, Nienhuis FJ, Sytema S, Slooff CJ, Knegtering R, Wiersma D. Guided discontinuation versus maintenance treatment in remitted first-episode psychosis: relapse rates and functional outcome. *The Journal of clinical psychiatry*. 2007;68(5):654-61.
20. Joukamaa M, Heliövaara M, Knekt P, Aromaa A, Raitasalo R, Lehtinen V. Schizophrenia, neuroleptic medication and mortality. *The British journal of psychiatry : the journal of mental science*. 2006;188:122-7.
21. Waddington JL, Youssef HA, Kinsella A. Mortality in schizophrenia. Antipsychotic polypharmacy and absence of adjunctive anticholinergics over the course of a 10-year prospective study. *The British journal of psychiatry : the journal of mental science*. 1998;173:325-9.
22. Bralet MC, Yon V, Loas G, Noisette C. [Cause of mortality in schizophrenic patients: prospective study of years of a cohort of 150 chronic schizophrenic patients]. *L'Encephale*. 2000;26(6):32-41.
23. Loas G, Azi A, Noisette C, Yon V. [Mortality among chronic schizophrenic patients: a prospective 14-year follow-up study of 150 schizophrenic patients]. *L'Encephale*. 2008;34(1):54-60.
24. Murray-Thomas T, Jones ME, Patel D, Brunner E, Shatapathy CC, Motsko S, et al. Risk of mortality (including sudden cardiac death) and major cardiovascular events in atypical and typical antipsychotic users: a study with the general practice research database. *Cardiovascular psychiatry and neurology*. 2013;2013:247486.
25. Francey SM, Nelson B, Thompson A, Parker AG, Kerr M, Macneil C, et al. Who needs antipsychotic medication in the earliest stages of psychosis? A reconsideration of benefits, risks, neurobiology and ethics in the era of early intervention. *Schizophrenia research*. 2010;119(1-3):1-10.

26. Correll CU, Detraux J, De Lepeleire J, De Hert M. Effects of antipsychotics, antidepressants and mood stabilizers on risk for physical diseases in people with schizophrenia, depression and bipolar disorder. *World psychiatry : official journal of the World Psychiatric Association (WPA)*. 2015;14(2):119-36.
27. Moncrieff J, Cohen D, Porter S. The psychoactive effects of psychiatric medication: the elephant in the room. *Journal of psychoactive drugs*. 2013;45(5):409-15.
28. Moilanen JM, Haapea M, Jaaskelainen E, Veijola JM, Isohanni MK, Koponen HJ, et al. Long-term antipsychotic use and its association with outcomes in schizophrenia - the Northern Finland Birth Cohort 1966. *European psychiatry : the journal of the Association of European Psychiatrists*. 2016;36:7-14.
29. Flanagan EH, Davidson L, Strauss JS. Issues for DSM-V: incorporating patients' subjective experiences. *The American journal of psychiatry*. 2007;164(3):391-2.
30. Davidson L. The Recovery Movement: Implications For Mental Health Care And Enabling People To Participate Fully In Life. *Health affairs (Project Hope)*. 2016;35(6):1091-7.
31. Bjornestad J, Bronnick K, Davidson L, Hegelstad WtV, Joa I, Kandal O, et al. The central role of self-agency in clinical recovery from first episode psychosis. *Psychosis*. 2017;9(2):140-8.
32. Veseth M, Binder PE, Borg M, Davidson L. Toward caring for oneself in a life of intense ups and downs: a reflexive-collaborative exploration of recovery in bipolar disorder. *Qualitative health research*. 2012;22(1):119-33.
33. Young SL, David S. Ensing. . "Exploring Recovery from the Perspective of People with Psychiatric Disabilities.". *Psychiatric Rehabilitation Journal*. 1999; 22.3:219-31.
34. Moltu C, Stefansen J, Notnes JC, Skjolberg A, Veseth M. What are "good outcomes" in public mental health settings? A qualitative exploration of clients' and therapists' experiences. *International journal of mental health systems*. 2017;11:12.
35. Foretak HBH. Medikamentfritt behandlingstilbod Health Bergen Public Website2017 [cited 2019 28. November]. Medication Free Services in Health Bergen, Norway]. Available from: <https://helse-bergen.no/avdelinger/psykisk-helsevern/medikamentfritt-behandlingstilbod>.
36. Elliott R, Fischer CT, Rennie DL. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British journal of clinical psychology*. 1999;38 (Pt 3):215-29.
37. Malterud K. Shared Understanding of the Qualitative Research Process. *Guidelines for the Medical Researcher*. *Family Practice*. 1993;10(2):201-6.
38. Stige B, Malterud K, Midtgarden T. Toward an agenda for evaluation of qualitative research. *Qualitative health research*. 2009;19(10):1504-16.
39. Veseth M, Binder P-E, Borg M, Davidson L. Collaborating to stay open and aware: Service user involvement in mental health research as an aid in reflexivity. *Nordic Psychology*. 2017;69(4):256-63.
40. Trivedi P, Wykes T. From passive subjects to equal partners: qualitative review of user involvement in research. *The British journal of psychiatry : the journal of mental science*. 2002;181:468-72.

41. Moltu C, Stefansen J, Svisdahl M, Veseth M. Negotiating the coresearcher mandate - service users' experiences of doing collaborative research on mental health. *Disability and rehabilitation*. 2012;34(19):1608-16.
42. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qualitative Research*. 2001;1(3):385-405.
43. Mollon J, David AS, Morgan C, Frissa S, Glahn D, Pilecka I, et al. Psychotic Experiences and Neuropsychological Functioning in a Population-based Sample. *JAMA psychiatry*. 2016;73(2):129-38.
44. Horvath AO, Del Re AC, Flückiger C, Symonds D. Alliance in individual psychotherapy. *Psychotherapy*. 2011;48(1):9-16.
45. Geyt GL, Awenat Y, Tai S, Haddock G. Personal Accounts of Discontinuing Neuroleptic Medication for Psychosis. 2017;27(4):559-72.
46. Goss C, Moretti F, Mazzi MA, Del Piccolo L, Rimondini M, Zimmermann C. Involving patients in decisions during psychiatric consultations. *The British journal of psychiatry : the journal of mental science*. 2008;193(5):416-21.
47. Goossensen A, Zijlstra P, Koopmanschap M. Measuring shared decision making processes in psychiatry: skills versus patient satisfaction. *Patient education and counseling*. 2007;67(1-2):50-6.
48. Groven G, Iversen H, Bjertnæs ØA, Helgeland J, Holmboe O, Nasjonalt kunnskapssenter for h, et al. Brukererfaringer med poliklinikker for voksne i psykisk helsevern : nasjonale resultater i 2007 og utvikling fra 2004 2008.
49. Oevernes LA. Mitt valg - My choice - shared decision-making and psychosis Helsenorge.no2019 [Digital shared decision-making tool]. Available from: <https://minhelse.helsenorge.no/samvalg/verktoy/psykose/mitt-valg>.
50. Vos IML, Schermer MHN, Bolt ILLE. Recent insights into decision-making and their implications for informed consent. *Journal of Medical Ethics*. 2018.
51. Berna F, Goritz AS, Llorca PM, Vidailhet P, Fond G, Moritz S. Would I take antipsychotics, if I had psychotic symptoms? Examining determinants of the decision to take antipsychotics. *Progress in neuro-psychopharmacology & biological psychiatry*. 2017;77:155-63.
52. Holubova M, Prasko J, Hruby R, Latalova K, Kamaradova D, Marackova M, et al. Coping strategies and self-stigma in patients with schizophrenia-spectrum disorders. *Patient preference and adherence*. 2016;10:1151-8.
53. Holubova M, Prasko J, Hruby R, Kamaradova D, Ociskova M, Latalova K, et al. Coping strategies and quality of life in schizophrenia: cross-sectional study. *Neuropsychiatric disease and treatment*. 2015;11:3041-8.
54. McCabe R, Healey PGT. Miscommunication in Doctor-Patient Communication. *Topics in cognitive science*. 2018;10(2):409-24.
55. Hansen H, Stige SH, Davidson L, Moltu C, Veseth M. How Do People Experience Early Intervention Services for Psychosis? A Meta-Synthesis. *Qualitative health research*. 2018;28(2):259-72.

Tables

Due to technical limitations, tables 1 and 2 are only available as a download in the supplemental files section.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Tables.docx](#)
- [COREQChecklistitmeanssomuchforme.pdf](#)
- [Interviewguidepatientsenglish.docx](#)