

To Choose or not to Choose? -User Perspectives on Medication Free Treatment for Persons With Psychosis: a Qualitative Study

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Abstract

Abstract: Background: Norway recently changed national policies in psychiatry emphasizing the right for persons with psychosis to choose medication-free treatment. Long-term anti-psychotic medication is debated, in terms of effectiveness and side effects. New guidelines generate increased treatment options for patients with severe mental illness. Methods: This study explore users' experiences with treatment choices in this unique context. We interviewed eleven patients diagnosed with psychosis about their experiences of choosing treatment, analysing the transcribed data team based and stepwise. Results: Findings show how choosing treatment appears to be a complicated process with many influencing factors. Emerging themes were about the dialogue between patient and therapist, the importance of having a treatment choice, difficulties choosing the unknown not knowing what helps, choice influenced by the level of experience with in particular medication, and coercive measures contrasting the freedom of choice. Conclusion: The freedom to choose was perceived important, but the complexity of choosing showed how optimal care might not always equal the freedom to choose. Aiming for optimal care, we need to consider how involuntary admission and other coercive measures are used, and possibly improved, in order to care without further traumatizing people who are already in extreme distress. Ethical approval: 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).

Background

Norway recently changed national guidelines in mental health services in order to ensure persons experiencing psychosis with access to medication-free treatment, within the law defining responsible treatment (1). In 2017 the Norwegian law of psychiatric health care also changed, giving patients' rights to refuse treatment as long as they are able to give informed consent, provided there is no danger to the person's life, or to the health or life of others (2). When a patient does not meet these criteria, they are typically admitted to an acute ward. In Norway, patients who decline medication have to be observed for five days before physicians can apply for permission to force medication against the person's wishes (3).

The new guidelines 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 (4). On the one hand, psychiatrists argue that medication works, and is in most cases the best option. This perspective is supported by some studies showing that long-term anti-psychotic treatment is associated with increased survival (5-7), and that patients who do not take medication may have a poor long-term outcome as compared to patients who do (8). Severe mental illnesses, like schizophrenia, also have a substantial negative effect on life expectancy (9). In Norway, the National Centre for Suicide Research and Prevention recently published findings on deaths caused by suicide committed by patients in psychiatric care. Between 2008 and 2015, 1910 patients in psychiatric care committed suicide. This is 43% of all suicides committed in Norway over the same period (10).

On the other hand, some studies show that dose reduction/discontinuation of AP is superior to maintenance treatment for long-term recovery (11), and that a guided discontinuation of medication might be successful (11, 12). The debate rises many questions, including who can manage without medication (13), are research and treatment without anti-psychotic use ethically responsible (14), and when does AP do more harm than help (15, 16), especially considering their side-effects?

Finally, there is the important aspect of human rights, particularly involuntary treatment in psychiatry. Norway was recently criticized for the misuse of such treatment, including the use of forced AP, by the United Nations Commission on Human Rights appointed Special Rapporteur on torture (17). WHO published in 2018 a report from Europe looking into areas for improvement in the mental health service delivery and care. They found that quality of life, human rights, and reinclusion in society were often compromised by inhumane institutional practices in many countries in Europe, including the neighbouring countries Denmark and Finland (18). However, the report did not include any information from Norway. But the aspect of human rights also raises the question about the right to treatment (19). The debate spirals into the fundamental problem

emerging where the right to decide about your own health (argued mainly by the user organisations) collides with the right to be taken care of if you are sick (argued mainly by health professionals).

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, primarily against the use of involuntary treatment and AP medication, focusing on patients' human right to decide about their own care. 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. The user groups in Norway questioned the necessity for coercive measures in the health care systems, and in particular the use of involuntary AP medication in psychiatric care contexts. They argued that if this medication does not work for all persons with psychosis, then each person should be trusted to choose whether they need medication as part of their overall care. It should be noted that service user organizations are not categorically against medicines, accepting that some people might benefit from AP but that it should be their choice.

Methods

Aim:

The medication free treatment service generates increased treatment options and more options are implicitly related to more choices. Thus, a key question in this study was to examine the degree to which the option to choose was perceived as a real choice by patients in The Western Norway Regional Health Authority in Bergen, Norway. The study elaborates on the following research question:

- How are people with psychosis experiencing the meaning of choice when offered medication free mental health treatment? Which underlying personal, social, and cultural factors influence patient choice?

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 health policy varied across the four Health Authorities in Norway 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 allowing choice on all units.

Design

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. Personal accounts of such a collaborative experience have to our knowledge not been previously published. Hence we chose to perform 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 (20-22). This study also used a service user involved approach (23, 24) developed within a hermeneutic-phenomenological epistemology. This means that we have a phenomenological aim in exploring and describing the lived experiences of choosing a medication free treatment for psychosis, and that we recognize that our attempts at doing so inevitably involve interpretations.

Researchers and user-involvement

The first author has a master in cultural science, and has no health professional background. This was viewed as an advantage as diagnostic terms and criteria would not become a part of the mind-set during the interview. However, she is familiar with psychiatry as a profession as she has been working closely with psychiatrists in previous research projects. 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 the respect of the complexity of user's views on the issue of this study, the research team invited four experts by experience to become co-researchers on this project. Three of these co-researchers are from a user organization called Hvide 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 (25). We believe this involvement enhances the quality of the study also through development of a meta-perspective on the research process (23, 24, 26).

Procedure

The protocol for this study was developed in collaboration with the user organization and supervisors. The semi-structured interview guide 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. We aimed to keep within the frame of the topic guide, but also to give opportunities to probe deeper when necessary.

The first author conducted the interviews and made notes of her experiences after each interview. She obtained 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. The interviews varied in length from approximately 45 to 90 minutes. All interviews were tape recorded and transcribed by the first author. 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.

Participants

The participants were people with psychosis who had chosen a medication-free mental health service in Health Bergen. All but two participants were either in a medication-free treatment course, or discontinued a medication-free treatment course. Two participants were using medication as part of their treatment regimen without clear intention to discontinue. All participants were informed about the study in advance by their therapist, who gave them written information provided by the first author. 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. Participants who were approached by the first author all agreed to be interviewed. The participants were to a certain degree selected in order to vary in age (25-45) and gender (five women and six 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 resting room, or the room used for music therapy. One patient chose to be interviewed at home.

(See Table 1 in the Supplementary Files)

Data analysis

Attride-Sterling's Thematic Network Analysis (27) 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 (27). 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 analyzing process. The codes inductively emerged from the text, and then basic themes common across the interviews were identified. The basic themes were grouped by related conceptual content into organizing themes, like “treatment components” and “personal recovery.” This entire process and coding frame was further developed in an iterative way by the first author and some of the co-researchers discussing and changing codes from one theme to another. The organizing 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. Then the rest of the interviews were analyzed using the developed coding frame. The global theme was deductively defined reflecting the research question, linking the global theme to the objectives of the research. The result of this process, 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. For data analyzing purposes, we have used the NVivo software program (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 12 Plus).

Results

Findings: To choose or not to choose – choice, recovery, or coercive treatment

In the analysing process, we found the following coding frame and themes inductively emerging from the text concerning communication, choice, treatment components, and recovery processes:

Table 2 Relevant codes and themes from the analysing process:

Codes	Basic themes	Organizing themes	Global themes
Information	Communication	Treatment components: communication skills and choices to make	To choose or not to choose; Personal recovery processes and patient choices
Doctor			
Power play			
Take you seriously			
Safe			
Choose the unknown	Factors influencing choices		
Choice and experience			
Choice and medication			
Choice and stigma			
Choice and insight			
Choice and coincidence			
Choice and coercion			
Choice and pressure			
Freedom of choice and responsibility			
Freedom of choice and human dignity			
Do it myself	Getting experienced with life with an illness	Personal recovery in process	
In recovery			
Worked well			
Do stupid things			
Coping			

The findings concerning the topic of choice and treatment experiences using key quotes from the basic themes are described in the following:

Communication: the key to a good relationship between professionals and patient

Generally, a feeling of trust and confidence in the therapists were dominant experiences shared by the informants. One described the characteristics of a good relationship with the therapist and other health care professionals as: "...it's people who take you seriously, and see your abilities beyond being a patient, and try to figure out how they best can help you."

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 was another important issue mentioned regarding trust and communication. One participant described his psychiatrist as very available and easy to reach, and he felt he took part in the decisions concerning his treatment:

“I really like that here. I can talk with (name) in the hallways, and if I have to schedule another appointment, or... Yes. Very easy (...) 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.”

The participants mostly described an open and dynamic dialogue with the therapists, however, these perceptions were dependent on both characteristics of the therapists and participants. The same participant as above continued with how he didn't like this same psychiatrist at all in the beginning of the relationship, talking about how important it was to trust the therapist: “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.”

Asked if he thought this had any connection with his symptoms, he confirmed this, and said he was very sceptical towards strangers when he was ill. In this way, the participant's illness and change of symptom severity might affect the experience of the quality of the communication.

There were also examples of distrust and choosing not to mention 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,” especially when she wanted to change her medication: “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.”

Despite mostly having confidence in the therapist, the imbalance of power sometimes described complicated communication. Some participants seemed to lack self-confidence in their meetings with the therapist, describing a feeling of hopelessness. Another participant talked about how choices, in this case about how to discontinue her medication, would be made during a communicative session with her therapist: “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.” Her choice can be seen as the result of a negotiating process, in which the therapist wants her to stay in therapy if she wants to discontinue the medication, and only then “be allowed to be psychotic.” The patient does not want to disappoint the caretaker, and takes her advice.

Factors influencing choices: to choose the unknown

Some topics were more often mentioned by the informants than others, like choosing treatment without knowing what would heal them. One informant described the task of choosing both for himself as well as for his next of kin as hard: “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.” Choosing seemed to be particularly difficult for those new to the health care system, like the young patients experiencing their first episode of psychosis. They did not know what would help, which of course made the task of choosing the unknown very difficult.

Participants in this study also could choose between several additional important treatment components, such as cognitive therapy, illness management and recovery skills training, individual job placement and support, music therapy, exercise, and one or several families in group therapy. Many of these services were unfamiliar to them, which also made it hard to choose something you don't know much about. Participants reported perceiving it as rather arbitrary as to what type of service one could get, and not so much as a ‘real choice’ that they had made. Not all services were available instantly, and furthermore, not all services were equally often suggested by the therapists. Said one person: “I feel it's kind of random which services you

are offered, and where you wind up, really. And if you get a service that helps, in a way, but it is of course difficult to know what helps.”

Some of the informants did not want any treatment regardless of whether the different services offered were purported to be relevant or not. One participant illustrated this point when he said: “They do seem nice and everything, but to me the main goal is to get out of this outpatient clinic. It doesn’t matter if they do sports, it doesn’t matter if... I’m done, I want to be over with this.”

This choice may have been influenced by the desire not to be sick and to go back to life as it was before being affected by illness. Other external factors influencing choices are pressure from one’s family or work situation: Said one person: “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.” This informant discontinued her medication in collaboration with her psychiatrist, but became ill again. Her present choice was influenced by this experience of her not managing well without medication, as well as her wish to stay well in order to keep her new job.

Factors influencing choices: the process of becoming experienced using medication

Navigating medication is difficult in many senses, as suggested by one participant:

“But there is no definite answer to what happens when you are taking a pill. And I think it affects what you think, what happens. Like, compared to forced medication, and voluntarily medication, or voluntary, you might feel a bit of pressure, that matters. 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.”

This informant described a complex relationship with his medication, to a certain extent characterized by fear of unknown effects of a pill, and a fear of side effects shared by most of the informants. Also, the description of how medication can get the blame for all the problems in a person’s life, but then finding that discontinuing the medication doesn’t make the problems disappear, was also familiar to several informants. Quitting medication was not described as an easy way out of a life with illness.

Another informant explained how he knew his delusions included medication in a way that led him to discontinuation, feeling the pills were poison, or pains and aches in his body were perceived as severe side effects killing him. He continued to explain his thoughts about forced medication: “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 sceptical if I were ... That is, I would have had delusions about it, being forced to take medications I did not think were good for me.”

The informants often described the effect and side effects different medications had, and sometimes symptoms that they felt they could live with. Having no symptoms might not be the ultimate goal for all patients, like the one 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.”

Gaining experience with the various effects medication has on your body makes you perhaps more capable of choosing. Some informants described how hearing voices made them feel accompanied, and how they felt lonely without them. These symptoms were an integrated part of the person, and it felt wrong suddenly to live without them. In this case, choice is influenced by a person’s goal of keeping “the good part” of the illness.

Some of the informants aborted the medication free treatment. This means that they had started or completed the discontinuation of the medication, but then they went back on it later. Learning to understand what works for the individual is often done by practical experience. One informant discontinued his medication, but felt he needed it again; as he said: “I think that someday I can stop. I think that if I discover the right sort of evidence then I can quit the medication. 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.”

Factors influencing choices: coercion and freedom of choice

All of the informants emphasized the value of having a choice in their treatment when asked directly if they felt this was important. 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 human in a wider perspective.”

In contrast to having the freedom to make choices, involuntary admission to the hospital was a treatment component the informants frequently described in various ways:

“Then I was admitted, because they noticed I had one of those episodes again. And it was still like I was kind of absentminded. A bit ... paranoid tendencies again, sceptical towards people around me. But I wonder if the psychosis would have lasted a shorter period of time if I hadn’t been admitted. Because that made everything more stressful. When you are admitted, you are locked up, sort of. And I think I really need to feel free when I’m psychotic, that I can do as I please.”

Another participant described her admission as: “So then I just had to be there, and I didn’t feel it helped being there, because I had no problems, so ... Those people in there were suicidal, and really upset, and like...” Later in the interview she was asked whether it got any better with time: “But I felt safe after a while. So now, when I think about it, it was somehow cosy, too. Because it is, you eat, you watch television, and ... But it gets really boring in the long run.”

All but one of the informants described more or less traumatic experiences with coercive admission. But the admission experience seems for some to incorporate both the trauma of being forcefully brought to the hospital and medicated in many cases, as well as over time the recognition of being in need of help, and somehow getting that help through coercive admission and treatment. One informant, for example, described how coercive admission was helpful, but at the same time, she had a wish for more choices in that situation:

“I believe it is important to be allowed to choose, because it is your future, your life we are talking about. But if you are too sick so you can’t choose, than we have forced [treatment], and that is a good thing, because it helped me at the time, so I’m all for it. But if you can choose something else, or choose at all, are well enough, or ... Then I think it is very important to be allowed to consider different options, and be allowed to choose something else, if it doesn’t work for you.”

Experiences of treatment and the process of personal recovery

Recovery-oriented pathways often require personal agency and responsibility in order to improve one’s life. Several participants expressed a feeling of having to “do the work” themselves. 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. These constituted a regime of coping strategies many of the informants believed they had to stick to in order to stay well. Choice of coping strategy implies a risk of failure, and with the freedom to choose comes responsibility. Said one person: “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.”

However, choices influenced by symptoms and illness might not allow for a free, deliberate choice. This informant describes the process of worsening symptoms, and how the care team was 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 involved learning how to gain control of symptoms so they do not interfere with the lives people want. But this is learned through making both good and bad choices in order to find out what works and what doesn't. Sometimes people want to choose without the help from others, relying on their own experience and expertise. Said one participant: "So, I have been very determined to deal with all of this by myself. (...) So I have been very independent." Asked if this meant she didn't share with the therapist how bad the symptoms were sometimes, she confirmed this: "Yes, believing it would be better. So I have thought that in time things would improve. Because I remembered from previously that I recovered. And I always have." This informant had a plan with many coping strategies involved to avoid getting ill, a plan developed together with the therapist. But at a certain point, she felt the need to cope on her own, and not involve other people in her decisions on what to do. This strategy might have two outcomes; one person copes and gets well again without help, but others may get worse. Both outcomes might be valuable lessons in the process of recovery.

Many of the participants' hopes for the future seemed vague, tending more toward getting by one day at a time. One informant described her thoughts on how to enjoy her life in a better way as: "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, as well as a fear of not surviving the illness. The task of surviving psychosis and keeping hope for a better future is not an easy one.

Discussion

In medicine, diagnosis usually directs treatment options. Getting a diagnostic framing of your struggles brings into play a set of rights and treatment guidelines. The psychiatric diagnostic system is constantly debated (28), but diagnoses are also a tool to provide patients with evidence-based and available treatments defined for that particular illness. But even when there is a diagnosis, there often are also choices to be made. Choosing tailor-made treatments for the individual patient is a complex process with many influencing factors. Studies of medical decision-making show that patient choices often are not necessarily based on rational grounds, but rely also on trust, intuition, emotion, and beliefs (29). This complexity is reflected in the various experiences about choice and health care decisions participants have shared in this study. For instance, some were afraid of the side effects caused by medication, and at the same time explained how this also could be a part of their psychosis, like delusions about medication being poison to their bodies. Some felt pressured into accepting treatment by therapists or relatives, but at the same time understood that this pressure came from a place of love and concern for them. In addition, lack of information about available services and "not knowing what helps" are important factors influencing choices according to the informants in this study.

Experiences of side-effects, like gaining weight or feeling tired, can to some degree influence people's choice of staying on medication or not (30). Our informants were to a large extent worried about the possible side-effects from the medications. In particular, those who had experienced severe side-effects were sceptical. Further, a few of the informants shared how they felt defeated by having to take pills for an illness in the brain, as if it were a physical defect. Stigma surrounding psychiatric illness or medication was otherwise not often mentioned by the informants. However, it is well known that there is a lot of stigma to mental illness, and some studies have suggested that having to use medication because of a mental illness may be as stigmatizing as having the diagnosis (31). This might influence how people choose to perceive medication.

A few of the participants talked about medication working too well, taking away too much of the symptoms. For instance, they felt lonely without hearing voices, or enjoyed being "a little bit" psychotic. Believing symptoms are helpful to you, or protect you somehow, thus might also influence the choice of medication.

Further, findings in this study point toward the importance of a good relationship and skilled communication between therapist and patient in the process of choosing treatment. This corresponds well with other studies concerning the impact this relationship has on the effectiveness and outcome of the treatment (32, 33). Contrary to somatic medicine, diagnosing a mental illness largely depends on the words exchanged and clinical investigation, as there are no physical tests giving thresholds for any psychiatric diagnosis. In addition, the treatment often consists of therapeutic dialogue. Thus, in mental health care the therapist-patient relationship and communication is perceived as important factors for patient outcomes. All but one of the informants described good or improved communication with their current therapists as compared to previous encounters with mental health care, perhaps indicating the effort therapists are now making to meet the needs patients have. But medication free services are available to patients able to make an informed consent, and not to patients in coercive treatment. Consequently the informants in this study are among those who at the time of this study are less disabled by their illness. This should be considered with respect to that most of the informants explained how they felt involved in the treatment decisions, choosing treatment approaches, discussing medication, doses, and discontinuation, and how they felt the therapist was available to them. Still, this contrasts with other studies in which there was no evidence of choice in medication use (34).

Communication was also described to be influenced by severity of symptoms, to the degree that paranoid thoughts would interfere with the dialogue and make it difficult to maintain a therapeutic alliance. This could typically cause withdrawal, and the patient to avoid scheduled treatment sessions, and, as described in the result section, bitterness and paranoid thoughts towards therapists or mental health services in general. This is a phase in which the patient is experiencing a worsening of symptoms, but often is unable to accept the need for help. In Norway, the new legislation then determines that if this happens, forced treatment cannot occur unless the patient's life is in danger, or he/she is a danger to the life or health of others. This underlines the importance of the alliance, as the patient would have to have a significantly higher level of symptoms than before this legislation was changed to be subjected to coercive measures. This phase is potentially dangerous to patients, as a therapeutic alliance is no guarantee to retaining a patient in care.

Optimal care and choices to make

Given the complexity of decision-making for persons experiencing psychosis, there may be a need for further reflection on the prominent role played by personal choice when it comes to taking AP during times of extreme distress. Mol (35) raises questions about the wisdom of leaving such important decisions up to individuals who may be swayed by factors irrelevant or extraneous to the illness they are experiencing. She suggests that personal choice does not always accord well with the vicissitudes of living with a disease. She proposes instead a "logic of care" in which patients seek what brings improvement and avoid what does not. This logic of care is a logic of a collective, where health care professionals and patients are working together to improve the patient's life, taking into account the unpredictable body influenced by an illness. Having psychotic experiences does not mean you are unable to take care of yourself, and choose your treatment wisely, but some patients experiencing psychosis end up harming themselves or others. According to Mol, the possibility of death and misery should not be left out of the equation but should be attended to and subjected to professional care. In this study several of the informants described coercive admissions as painful, but retrospectively considered them to have been necessary. The tipping point between being able to give informed consent and not may at times be a thin line, difficult for health care professionals to define. This line defines when coercive measures can be used and not. One consequence of the change of legislation might be that patients become sicker before they get admitted, perhaps leading to more painful and traumatic admissions as the level of symptom severity might be a factor in the perception of what happens.

But offering more choices, in the form of medication-free treatment, appears to be opening the door for improving communication between patient and therapist, provided the therapist is facilitating what can at times be uncomfortable and difficult discussions. This finding is consistent with a recent meta-analysis where patients preferred professionals who considered AP medication as one of many tools to achieve personal recovery (36), and a cornerstone of the recovery-oriented practice framework being to increase people's choice and self-determination in their health care (37, 38). Consistent with these findings, people in Norway now have the right to choose what kind of mental health treatment they will put to use in

their lives – and what treatment they will not utilize, within the limits of responsible treatment as operationalized in national guidelines.

Still, keeping in mind how the informants in this study pointed towards themselves as the “only one to do the job” in the process of recovery, it is important also to consider the risk of feeling guilty if this process takes difficult turns. This resonates with other studies on patient distress, in which elements of self-criticism and self-blame were present in several participants’ accounts (39). Shame and guilt are strong factors in people’s (lack of) self-esteem, and the system of health care should not add to these troublesome feelings, but rather have the possibility to take responsibility for patients not able to take care of themselves.

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 communication between the patient and the carer. At the same time, it is important to take into account the complexity of choice as shown in this study, and how optimal care may not always equal the freedom to choose, described in the theme concerning coercive measures. If we are aiming for optimal care we need to take into close consideration how involuntary admission and other coercive measures, in particular coercive medication and restraints, are used, and possibly improved, in order to care without further traumatizing people who are already in extreme distress.

Strengths and limitations:

The research team behind this study is multidisciplinary both in terms of professional background but also in having four co-researchers who are experts by experience. We believe this brings in a wider set of perspectives into play, and creates a better environment for improved research. People with psychosis and their experiences of the treatment of choice, or not, is a topic in need for further investigation, as the debate surrounding coercive treatment persists. There is a gap between the professional and the user perspectives on usefulness of treatment regimens, and a need to understand why. This study is a step towards a better understanding of the complexity of choice, and provides clinicians with a user perspective on what is going on in the dialogue between therapist and patient. This might lead to a better understanding of which factors are influencing treatment choices, and increase awareness.

The study is limited in describing the implications of introducing medication free treatment in Norway. This is both due to the limited number of informants, and the short time span this treatment model has been implemented. There is a need to further study both the medical outcomes for patients as well as the continued variations of experiences of the users, social, cultural and personal factors influencing choices, and shared decision making. In addition, there is a need to further investigate the role of the health professionals in this process.

List Of 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

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.

Competing interests:

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

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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.

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Table 1

Due to technical limitations, table 1 is only available as a download in the supplemental files section.

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