Medication free treatment for people with psychosis:

An explorative study of user perspectives on increased accept and support for patients choosing to discontinue anti-psychotic medication as

Christine Henriksen Ødegaard

Thesis for the degree of Philosophiae Doctor (PhD)
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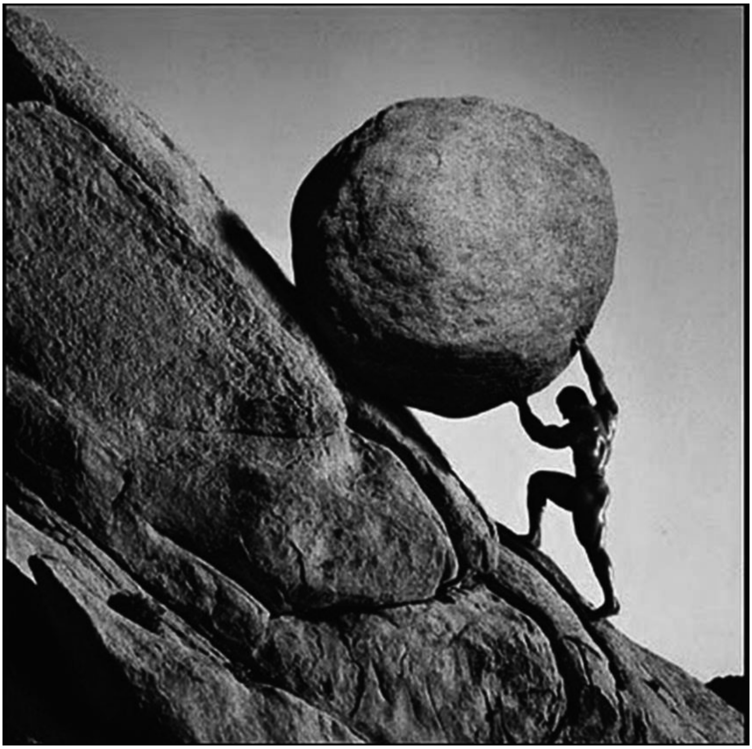

Sisyphus. Credit: Gerard Van der Leun.

Føles som jeg er i helvete
Styggen på ryggen har blitt en av mine nærmeste
På skulder'n min og minner meg på
Hvor jævla skeis det herre livet mitt går
Er det rart jeg er redd
Når styggen på ryggen er han jeg prater med mest?
Oppå skulder'n min og sier at jeg kommer ingen vei her i livet

-OnklP

Scientific environment

This research project is a collaboration between several departments at the University of Bergen, the Centre of International Health (CIH) at the department of Global Public Health and Primary Care, the Department of Clinical Psychology, and The Grieg Academy Music Therapy Research Centre (GAMUT).

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HELSE BERGEN
Haukeland University Hospital

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believing in promoting the user perspectives within the difficult discussion regarding the use of anti-psychotic medication.

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Summary

Background: Medication-free (MF) treatment for psychosis in Norway is the result of a joint initiative from several user organisations based on the debated use of anti-psychotic medication, and the wish for more person-centred care and greater self-determination. MF treatment aims to increase patient autonomy, reduce pharmacological treatment, and increase psychosocial support options. The medication-free treatment services were not designed to promote one treatment choice over another. In practical terms, patients choosing this treatment program are free to use or not use medications following their needs, but aims to reduce or discontinue their anti-psychotic medication.

Objective: This study aimed to provide comprehensive insight into the user and provider experiences with the medication free treatment program in Bergen, Norway.

Methods: This was a qualitative study using in-depth interviews with people with psychosis, focus group discussions with staff from the mental health care institutions, and participant observation in music therapy. Four experts by experience were invited as co-researchers.

Findings: Patients described their relationship with therapists as improved and significant. Treatment was a learning process of their personal patterns of suffering, and motivation for self-agency in the recovery process was important.

The therapists were preoccupied with managing resources; their role in the therapy; and patient choices. Music therapy was described as a flexible, recovery-oriented treatment.

Conclusions: Medication-free treatment facilitated learning experiences regarding the choice of treatment, focusing on increased self-agency and motivation. It is supportive towards patient choices, and appears to improve the relationship between the patient and the caregiver.

Democratization of treatment choices challenges the level of professional discretion when caregiver and patient have conflicting goals, possibly causing therapists to feel disempowered in and alienated from their work.

Music therapy offers choices continuously, in collaboration with the therapist, but also contingent depending on circumstances. There is a potential for improved implementation.

Norsk sammendrag

Bakgrunn: Medisinfri behandling for psykose i Norge er et resultat av et felles initiativ fra flere brukerorganisasjoner basert på den debatterte bruken av antipsykotiske medisiner, og ønsket om mer personsentrert behandling og større selvbestemmelse. Medisinfri behandling har som mål å øke pasientens autonomi, redusere medikamentell behandling og øke psykososiale støttemuligheter. Medikamentfri behandling var ikke utformet for å fremme ett behandlingsvalg fremfor et annet. I praksis står pasienter som velger dette behandlingsprogrammet fritt til å bruke eller ikke bruke medisiner etter deres behov, men må ha et klart mål om å redusere eller slutte med antipsykotisk medisinering.

Mål: Denne studiens mål var å gi omfattende innsikt i brukerens og helsepersonells erfaringer med det medisinfrie behandlingsprogrammet i Bergen, Norge.

Metoder: Dette er en kvalitativ studie som brukte dybdeintervjuer med personer med psykose, fokusgruppesamtaler med ansatte tilknyttet medisinfri behandling, og deltakende observasjon i musikkterapi. Fire erfaringseksperter ble invitert som medforskere.

Funn: Pasientene beskrev sitt forhold til terapeutene som viktig og forbedret. Behandlingen ble en læringsprosess av deres personlige lidelsesmønstre. Motivasjon for å ta kontroll over

egen tilfriskningsprosess var viktig. Terapeutene var opptatt av å forvalte ressurser; sin egen rolle i terapien; og ulike pasientvalg. Musikkterapi ble beskrevet som en fleksibel og recovery-orientert behandling.

Konklusjoner: Medisinfri behandling la til rette for læringserfaringer angående behandlingsvalg med fokus på økt egenstyring og motivasjon. Behandlingen fremstår støttende for ulike pasientvalg, og ser ut til å forbedre forholdet mellom pasient og helsepersonell.

Demokratisering av behandlingsvalg utfordrer nivået av faglig skjønn når helsepersonell og pasient har motstridende mål. Dette kan føre til at terapeuter føler seg maktesløse i og fremmedgjort fra arbeidet sitt.

Musikkterapi tilbyr valg fortløpende, i samarbeid med terapeut, men også avhengig av omstendigheter. Det er et potensial for forbedret implementering.

List of Publications

1. Oedegaard CH, Davidson L, Stige B, Veseth M, Blindheim A, Garvik L, Sørensen JM, Søraa Ø, Engebretsen IMS. "It means so much for me to have a choice": a qualitative study providing first-person perspectives on medication-free treatment in mental health care. BMC Psychiatry. 2020 Aug 8;20(1):399. doi: 10.1186/s12888-020-02770-2. PMID: 32770965; PMCID: PMC7414551.

2. Oedegaard CH, Ruano AL, Blindheim A, Veseth M, Stige B, Davidson L, Engebretsen IMS. How can we best help this patient? Exploring mental health therapists' reflections on medication-free care for patients with psychosis in Norway. International Journal of Mental Health Systems. 2022 Apr 4;16(1):19. doi: 10.1186/s13033-022-00529-8. PMID: 35379290.

3. Christine Henriksen Oedegaard, Ingunn Marie Stadskleiv Engebretsen, Marius Veseth, Anne Blindheim & Brynjulf Stige (2022) Health care workers' perspectives on the challenges and possibilities of music therapy within medication-free treatment services, Nordic Journal of Music Therapy, DOI: 10.1080/08098131.2022.2115530

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List of abbreviations:

IMR	Illness Management and Recovery
IPS	Individual Placement and Support
AP Medication	Antipsychotic Medication
ACT	Assertive Community Treatment
FACT	Flexible Assertive Community Treatment
MI	Motivational Interview
STC	Systematic Text Condensation
SLB	Street Level Bureaucrats
MF	Medication Free
NAPHA	Nasjonalt kompetansesenter for psykisk helsearbeid

Operational definitions

Autonomy:

Autonomy concerns the regulation of behavior by the self, or the ownership of one’s behavior, as opposed to behavior being controlled by forces perceived as outside the self. When individuals are autonomous, their behavior is self-organised and self-endorsed, and their actions are experienced as fully voluntary and authentic. The opposite of autonomy is feeling pressured, coerced, or compelled to act by forces or pressures perceived as external to the self (Legate & Ryan, 2014). There are important ethical issues regarding patient autonomy in psychiatry. In ordinary circumstances, the clinical duty of care to protect life and health is trumped by the duty to respect autonomy. Because of its possible effect on levels of competence, serious mental illness reverses the moral logic of the duties of care. Here, the patient's capacity may become so reduced that respect for autonomy no longer legitimately trumps protection (Doyal & Sheather, 2005). Among psychological frameworks, autonomy is central to self-determination theory, arguing that autonomy is a basic and universal psychological need essential for motivation and well-being (Legate & Ryan, 2014). Ethical discussions on autonomy versus protection are important for the implementation of medication-free treatment, as this treatment aims to increase patient autonomy.

Medication free (MF) treatment:

MF treatment aims to increase patient autonomy, reduce medicinal treatment, and increase psychosocial support options. In practical terms, MF treatment in Western Norway Regional Health Authority aimed to improve health care for all patients with psychosis by tailoring treatment to individual preferences and integrating more evidence-based psychosocial interventions into existing services in district psychiatric clinics. The treatment options offered included, but were not limited to, individual psychotherapy including cognitive therapy, Illness Management and Recovery (IMR) groups, individual job support (IPS), music therapy, and physiotherapy including groups for workout. The services were designed to support whichever choice the patient made regarding both medication and psychosocial support options. The focus was on increasing users' involvement and sense of ownership of therapy, as well as improving the patient-therapist alliance. The services were not designed to promote one treatment choice over another.

Music Therapy:

Music therapy used in psychiatric treatment is considered to promote recovery, and treatment should start in as early a phase as possible aiming to reduce negative symptoms for patients with psychosis. The treatment must be carried out by therapists with approved education in music therapy, and it received the highest level of recommendation in the guidelines for treatment of psychosis (Helsedirektoratet, 2013).

The empiric data used for this study is both from focus groups discussing music therapy as treatment including individual and group therapy. Additionally, this study has empiric data from participant observation with a patient attending individual music therapy. Both individual music therapy and group therapy is common.

Illness Management and Recovery (IMR):

IMR is an evidence-based, structured and manual-based treatment for groups with 5-8 participants. IMR is based on recovery principles, psychoeducation, cognitive techniques, motivational interview methodology and pedagogy, and can strengthen knowledge and self-management of psychosis (McGuire et al., 2014).

IPS – Individual Placement and Support:

IPS aims to support people with severe mental health difficulties into employment. Employment is an important part of recovery for individuals with schizophrenia. The employment rate for this group is as low as 10% in Norway (Evensen et al., 2017). IPS involves intensive, individual support, a rapid job search followed by placement in paid employment, and time-unlimited in-work support for both the employee and the employer. Studies show that competitive employment is attainable for individuals with schizophrenia (Evensen et al., 2017).

Therapist:

The mental health care staff consists of health care workers with different professional backgrounds, including, but not limited to, psychiatrists, psychologists, music therapists, nurses, social educators, physiotherapists, occupational therapists, and social workers. In this study, when we refer to “therapists”, we include all mental health care workers.

Shared decision-making:

Shared decision-making is a strategy for including patients in therapeutic processes. In other medical fields, this strategy has improved patient satisfaction and health outcome (Hamann et al., 2003). For this study, the model used is a model where the therapist takes an active role reporting information and treatment possibilities to the patient, and can recommend an option. The patient receives the information and judges on possible harms and benefits of the options, and discusses the preferences with the therapist. The decision on which therapy to use is made together. Specifically, when the choice of medication is made, this is a shared decision-making between the psychiatrist and the patient. For psycho-social support therapies this process normally takes place between the designated responsible therapist, who can be both a psychiatrist, a psychologist, or a psychiatric nurse. Within music therapy, this process takes place more or less continuously between the music therapist and the patient.

Street-level bureaucrats:

To better understand how therapists actively shaped the way public policy on medication-free services was implemented, we used Lipsky's theoretical framework regarding street-level bureaucrats (SLB) (Lipsky, 2010). Lipsky defines street-level bureaucracies as agencies whose workers, named SLB, interact with, and have wide discretion over, the dispensation of benefits or the allocations of public sanctions. Mental health workers provide benefits and sanctions to their patients, and have the authority and agency to make and carry out discretionary decisions with relative autonomy from management. Hence, we define mental health workers as street-level bureaucrats.

Personal Recovery: The notion of personal recovery was originally proposed by the mental health consumer/survivor movement as an alternative to existing notions of clinical recovery. Personal recovery refers not to clinical improvement of symptoms, but to living a full life in the presence of disorder.

User:
Patient in mental health care in the past or in the present

Provider:
Health care system or staff providing mental health care

Psychosis:
The word psychosis is used to describe conditions that affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode. During a period of psychosis, a person’s thoughts and perceptions are disturbed and the individual may have difficulty understanding what is real and what is not. Symptoms of psychosis include delusions (false beliefs) and hallucinations (seeing or hearing things that others do not see or hear). Other symptoms include incoherent or nonsense speech, and behavior that is inappropriate for the situation. A person in a psychotic episode may also experience depression, anxiety, sleep problems, social withdrawal, lack of motivation, and difficulty functioning overall (NIMH, 2022).

1. Introduction

Psychiatric treatment of severe mental illnesses is often subject to a public and professional debate focusing on the use of forced treatment, the use of medication and its side effects, and (lack of) user involvement. Medication-free treatment is a politically instigated project, which can be considered an answer to this debate. The aim of this study was to provide comprehensive insight into the user and provider experiences with the medication free treatment program implemented in Bergen, Norway. In the following chapter, key background topics and areas will be introduced, and existing literature published on medication-free treatment will be presented.

1.1 Schizophrenia and psychosis

Psychotic disorders comprise a heterogeneous group of disorders including schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, substance-induced psychotic disorder, brief psychotic disorder, and psychotic disorder not otherwise specified.

Table 1: List of diagnoses included in the broad term “psychosis” in this study (ICD 10):

F 20	Schizophrenia
F 20.0	Paranoid schizophrenia

F 20.1	Hebephrenic schizophrenia
F 20.2	Catatonic schizophrenia
F 20.3	Undifferentiated schizophrenia
F 20.4	Post-schizophrenic depression
F 20.5	Residual schizophrenia
F 20.6	Simple schizophrenia
F 20.8	Other schizophrenia
F 20.9	Schizophrenia, unspecified
F 21	Schizotypal disorder
F 22	Persistent delusional disorders
F 22.0	Delusional disorder
F 22.8	Other persistent delusional disorders
F 22.9	Persistent delusional disorder, unspecified
F 23	Acute and transient psychotic disorders
F 23.0	Acute polymorphic psychotic disorder without symptoms of schizophrenia
F 23.1	Acute polymorphic psychotic disorder with symptoms of schizophrenia
F 23.2	Acute schizophrenia-like psychotic disorder
F 23.3	Other acute predominantly delusional psychotic disorders
F 23.9	Acute and transient psychotic disorder, unspecified
F 24	Induced delusional disorder
F 25	Schizoaffective disorders
F 25.0	Schizoaffective disorder, manic type
F 25.1	Schizoaffective disorder, depressive type
F 25.2	Schizoaffective disorder, mixed type
F 25.8	Other schizoaffective disorders
F 25.9	Schizoaffective disorders, unspecified
F 28	Other nonorganic psychotic disorders
F 29	Unspecified nonorganic psychosis

These disorders are characterised by delusions, hallucinations, disorganised thoughts, and abnormal motor behaviour. Lifetime prevalence estimates vary widely across populations.
Studies have found that schizophrenia has a global prevalence just below 1% (Janoutová et al., 2016; Kahn et al., 2015). Schizophrenia, though a disputed diagnosis, is one of the most burdensome and costly illnesses worldwide, accounting for 1.1% of the total disability adjusted life years (DALY’s) (Hjorthoj et

al., 2017; Kahn et al., 2015; Os, 2016; Theodoridou & Rössler, 2010). People diagnosed with schizophrenia was found in a Danish study to lose the equivalent of 73% of healthy life per year (HeLP) (Weye et al., 2021). This severe mental illness is associated with difficulties such as inability to work, social disability and drug abuse (Tandon et al., 2009).

Severe mental illnesses have generally a negative effect on life expectancy. Patients with schizophrenia have significant reduced life expectancy than the general population (Heiberg et al., 2018; Hjorthoj et al., 2017; Laursen et al., 2014). The increased risk of premature death is due to both natural (aging and diseases) and unnatural causes (homicide, suicide and accidents) including mainly cardiovascular disease, respiratory diseases, and suicide (Olfson et al., 2015). Attempts to establish causality has been inconclusive and current understanding mentions multifactorial causality, including lifestyle factors and genetic vulnerability (Mullins et al., 2019; Strømme et al., 2021).

Treatment guidelines worldwide recommend the use of antipsychotic medication (Hasan et al., 2013; Lally & MacCabe, 2015). An important treatment challenge is the considerable antipsychotic medication non-adherence rate, which is as high as 40–75% (Lacro et al., 2002). Service users are often against using medication (Moncrieff et al., 2009). Other general treatment recommendations include the use of psychotherapy

and substantial psychosocial support.
Studies on the effect of treatment with antipsychotic medication have at times contradictory outcomes. Increased survival for those who use antipsychotic medication (Hui et al., 2018; Tiihonen et al., 2018; Vermeulen et al., 2017), and poor long-term outcome for those who choose to discontinue their medication (Ran et al., 2015) have been found. On the other hand, dose reduction/discontinuation of antipsychotic medication has in some studies been found to be superior to maintenance treatment for long-term recovery, and guided discontinuation might succeed (Harrow & Jobe, 2007; Harrow et al., 2021; Wunderink et al., 2013; Wunderink et al., 2007) according to some studies. Based on this knowledge, there is a need to further investigate which individuals are able to maintain stability without medication, who experience medication-related adverse effects, and who finds the use of antipsychotic medication useful. For a complete investigation, the need to include the service user perspective is highlighted (Bjornestad et al., 2017).
Taking into consideration human rights, the use of antipsychotic medication has also raised a debate about patients’ autonomy in choices about their own health, including their right to treatment when unable to take care of themselves as well as forced medication when they are too ill to consent (Juan Mendez, 2017).

1.2 The concept of recovery and the user organisations

Several user organisations are engaged in the debate, mainly opposing the use of antipsychotic medication, and in particular the use of forced medication (Fellesaksjonen, 2011). The user organisations claim that it is not possible to generalise how antipsychotic medication works for the individual, therefore each patient should have an option to choose if medication should be a part of the treatment.

The global recovery movement works to change mental health policy and practice based on the perspectives of people with mental illnesses, and recognises the ability of people with mental illnesses to participate in the mainstream of society (Davidson, 2016). User organisations within mental health care all over the world share the ideology of the recovery movement. From the users' perspective, personal recovery is different from clinical recovery. The first implies being able to live a full life in the presence of disorder, the latter implies absence of symptoms. User organisations are advocating for person-centred care, greater self-determination for those with mental illnesses, and an enhanced focus on restoring functioning for individuals above and beyond symptom reduction (Davidson, 2016; Davidson et al., 2007; Fellesaksjonen, 2011).

Implementing the Recovery ideology in clinical practice pose challenges and questions. The table below is one attempt to point out the direction of a recovery-oriented clinical practice:

TABLE 4—DRAFT PRACTICE GUIDELINES FOR RECOVERY-ORIENTED BEHAVIORAL HEALTH CARE

Domain	Degree to which practices . . .	Sample standards
Primacy of Participation	Place emphasis on the participation of people in recovery and their loved ones in all aspects and phases of the care delivery process.	People in recovery comprise a significant proportion of an agency's board of directors. Administration enforces ethical practice through supervision and proactive human resource oversight.
Promoting Access and Engagement	Facilitate swift and uncomplicated entry into care and identify and remove barriers to receiving care; address basic needs.	People can access a wide range of services from many different points. Staff examine organizational barriers or other obstacles to care before concluding that a client is noncompliant with treatment.
Ensuing Continuity of Care	Ensure continuity of the person's most significant healing relationships and supports over time and across episodes and agencies.	Motivation is no longer viewed as a pre-condition for treatment but as one outcome of interventions oriented to address pre-action stages of change. People have a flexible array of options from which to choose which allow for a high degree of individualization.
Employing Strengths-Based Assessment	Balance critical needs that must be met with the resources and strengths that people possess to assist them in the process.	An individual's needs are not captured by a label or diagnosis, but by an accurate description of his or her functional strengths and limitations. Strengths-based assessment is conducted as a collaborative process and all assessments in written form are shared with the individual.
Offering Individualized Recovery Planning	Are based on an individualized, multidisciplinary recovery plan developed in collaboration with the person and any others that s/he identifies as supportive.	The planning process solicits the individual's unique goals and these are documented in the plan in the individual's own words. The person's cultural background, identity, and other social affiliations are incorporated and addressed in all aspects of recovery planning.
Functioning as a Recovery Guide	Remove personal and environmental obstacles to recovery, link the person to the community, and, where not available naturally, serve as a mentor in processes of recovery.	Providers are willing to offer practical assistance in the community contexts in which their clients live, work, and play. Efforts are made to identify sources of incongruence between the person and his or her environment and to increase person-environment fit.
Identifying and Addressing Barriers to Recovery	Identify and address characteristics in the service system and the community, as well as factors intrinsic to the person's behavioral health condition(s), that unwittingly contribute to the creation and perpetuation of chronicity and disability.	Providers are aware of the importance of stigma and discrimination in the lives of people with behavioral health disorders. A person's symptoms are explored not only in terms of the difficulties they pose, but also in terms of their potentially adaptive function in his or her efforts to cope with the illness and other life stressors. Delusions, for example, may be understood as one component of a person's efforts to understand his or her experiences of hallucinations and disordered thought processes.
Community Mapping and Development	Involve a participatory process of mapping the resources and capacities of a community as a means of identifying existing, but untapped or overlooked, resources and potentially hospitable places in which contributions of a person with a disability will be valued.	People in recovery are viewed primarily as citizens rather than as clients and recognized for the gifts, strengths, skills, and resources they have to contribute to community life. Institutions do not duplicate services that are widely available in the community through individuals and associations.

This table was presented in an article describing challenges from four years of efforts in the state of Connecticut (US) to reorient its health system to promoting recovery (Davidson et al., 2007). This description displays important principles and values that need to be considered when implementing recovery into mental health care practice.

NAPHA (National competence centre for mental health work in Norway) published a report in 2013 on available knowledge about recovery oriented practices (Borg, 2013). The report concludes that there are disparate practices in the mental health field that are referred to as recovery-oriented, with no common standards. It also describes how the concept of recovery has changed, from a personal process for someone with mental illness, towards a social process emphasising contextual living and environmental conditions. Further, it is argued that the recovery perspective involves a paradigm shift from pathology to a basic understanding that people with mental health challenges gets better, and that a supportive social and cultural context is important for the recovery process. Recovery oriented mental health and welfare services emphasise hope and faith in the person's resources and potential, in the person's possibilities for a life beyond mental health problems, and equality and cooperation.

The protocol for medication-free treatment in Bergen contains the following statement: “Emphasis is placed on cooperation between patient and therapist. Treatment is tailored to the patient's needs, own choices and priorities. The aim is to contribute to increased mastery and participation in society.” (My translation.) This description of the aim for implementing medication-free treatment is in line with the recovery philosophy, as described above.

1.3 Implementation of medication-free treatment in Norway

The implementation of medication-free treatment for psychosis in Norway is the result of a joint initiative from several user organisations. They introduced the debate on efficacy of antipsychotic medication as a part of the treatment for severe psychiatric illness to politicians in Norway, in particular the Health Minister at that time, Bent Høye (Fellesaksjonen, 2011). The demand was to avoid the use of forced medication, and use of medication based on persuasion or pressure. Further, the requirement was that the basic treatment should include a safe place to be, a bed to sleep in, regular meals and people to talk with. Finally, their aim was to develop a culture for medication-free treatment, and strengthen a scientific field (psychiatry) in the need for knowledge expansion. These demands were among other based on the research mentioned above where the efficacy of anti-psychotic treatment was debated on both the short term as well as the long term outcomes (Harrow & Jobe, 2007; Harrow et al., 2021; Hui et al., 2018; Tiihonen et al., 2018; Vermeulen et al., 2017; Wunderink et al., 2013; Wunderink et al., 2007). For instance, the Harrow and Jobe 2007 article identified “a subgroup of schizophrenia patients who did not immediately relapse while off antipsychotics and experience intervals of recovery”. This knowledge has led to the search for patients who should not be introduced to, or forced to use anti-psychotic medication.

This initiative and dialogue eventually spurred new guidelines for treatment for mental illness, including a medication-free treatment choice for patients with psychosis (Helsedirektoratet, 2013). This change in mental health care in Norway can be considered a recovery-based reform in mental care focusing on patients’ human right to decide about their own care, aiming to avoid coercive measures like forced medication, and increasing the choice of treatment options. A study from eastern Norway stated that the medication-free model builds a bridge between a more conventional, research-based understanding of mental disorders based on the stress-vulnerability model, and more recent recovery-oriented directions with the main focus on the participant's own experiences, self-determination, recovery and increased quality of life (Standal, 2018).

Haukeland University hospital explains the need for this treatment option in the following quote from their web-site dedicated to medication-free treatment (my translation):

For people who receive psychosomatic care, it is recommended to try out antipsychotic medication. However, some users do not achieve the desired effect, or they may find that side effects stand in the way of the personal effort needed to get better. Several users say that they have experienced not being given a real treatment option without antipsychotics (Health Bergen, 2021).

The medication-free treatment option must demonstrate that there are alternatives, and provide structure and quality assurance for the best possible treatment. Real user participation can promote ownership of the treatment, strengthen cooperation with the health service, and facilitate a better life.

The four Health Trusts in Norway chose different lines of approach on how to provide mental health patients with medication free treatment options. The only Health Trust not dedicating a certain number of beds to this kind of treatment was Health West. Their focus was that they wanted to improve the treatment for psychosis for all the patients, claiming that only a few available beds would make the selection of patients who could choose this option difficult. Instead, management decided to implement medication free treatment for patients with psychotic symptoms in all the district psychiatric clinics, enhancing the general treatment for psychosis (Øvernes, 2019).

1.4 Medication-free treatment – for whom and how?

On the website managed by Haukeland University hospital, the following defines targeted patients for medication-free treatment (my translation):

The medication-free treatment offer applies to those who want to reduce or end the use of antipsychotics. In addition, the responsible therapist in the specialist health service must consider it as justifiable. This means, among other things, that you are not in danger for yourself or others, and that you understand the consequences of this choice. Medication-free treatment is voluntary, and you have to make an active personal effort during the treatment.

Treatment measures are available to anyone with a psychosis, whether or not they are using medication. People under compulsory mental health protection also have the right to be heard and to participate in their own treatment (Health Bergen, 2021).

All adult patients within the Bergen catchment area who are suffering from psychosis and are not subject to coercive treatment can choose medication-free treatment. Patients who are subject to coercive treatment can choose psychosocial treatment options, but are not free to discontinue medication without consent from the psychiatrist or the court, if they are sentenced to treatment. The treatment options include, but are not limited to, individual psychotherapy focusing on cognitive therapy, family therapy, Illness Management and Recovery (IMR) groups, individual job support (IPS), music therapy, and physiotherapy and exercise (Health Bergen, 2021). Some of these options, like individual music therapy, are to some extent limited by availability, but most options are available within a reasonable period. Treatment is voluntary, with no mandatory components.

The choice of psychosocial treatment methods within the medication-free treatment offer is based on the national guidelines, which provide the strongest recommendations for a number of psychosocial treatment measures for psychosis, and grade them highly in relation to the evidence base. A Norwegian group of experts based the recommendations in the national guideline on a systematic review and quality assessment of relevant literature as well as academic, experience-based and contextual assessments (Helsedirektoratet, 2013). The recommendations are in accordance with the international standard for professional guidelines. Recommended treatment includes cognitive behavioural therapy (level of evidence: 1a, recommendation: A), psychodynamic therapy (2a, B), single family groups (1b, A), multifamily groups (1a, A), music therapy (1a, A), physical exercise (1b, A), individual job support (1a, A), social skills training (1a, A) and cognitive therapy (1b,B) (Helsedirektoratet, 2013; Oevernes, 2019). Medication-free treatment should follow the guidelines provided for treating psychosis, allowing a careful discontinuation of the medication, and adding more psychosocial treatment options to support the patient in this process. This means the patient aims at discontinuing medication, but this is a process allowing dosage reduction and increase following patient wishes and symptom load.

The model of decision-making between the patient and therapist in the district psychiatric centers where this study took place is a model of shared decision-making. The therapist takes an active role reporting information and treatment possibilities to the patient, and can recommend an option. The patient receives the information and judges on possible harms and benefits of the options, and discusses the preferences with the therapist. The decision on which therapy to use is then made together. Specifically, when choosing medication, this is a shared decision-making between the psychiatrist and the patient. For psychosocial support therapies, this process normally takes place between the designated responsible therapist, who can be either a psychiatrist, a psychologist, or a psychiatric nurse. Health Bergen developed and implemented a new digital tool for shared decision-making for psychosis in 2019, as part of the medication-free project. This tool introduces medication-free treatment as one treatment option. The tool is available at helsenorge.no. However, the patients and therapists interviewed for this study did not have this tool available.

1.5 Music therapy – an example of medication-free treatment

Music therapy is one treatment method recommended in the Norwegian health care guidelines for patients suffering from psychosis since 2013 (Helsedirektoratet, 2013), and implemented actively in Health Bergen as a part of the medication free treatment project.

This study focus on music therapy as a treatment method as it is considered a relational method supplementing the usual treatment methods in the field. Music therapy is also considered recovery and user oriented with a high degree of user participation (Mössler et al., 2011).

To become a music therapist there are two Norwegian educational courses. One is the Norwegian Academy of Music, where the study is composed of a one-year study program in Music and Health at the bachelor's level and a two-year master's study program in music therapy. The admission requirement for the one-year study program is two years of relevant higher education and a passing entrance examination. The Grieg Academy offers a 5-year integrated master's degree in music therapy. Admission requirements are study competence and passing the entrance exam.

The guidelines emphasises that music therapy is particularly effective in reducing negative symptoms (Gold, 2007; Gold et al., 2009; Helsedirektoratet, 2013; Mössler et al., 2011; Stige & Aarø, 2012). Further, it is emphasised that the effect of such treatment is present for six months after the intervention has ended. Finally, it is also stated that music therapy is just as effective for patients who are admitted to inpatient units, as for those receiving outpatient treatments. Music therapy receives the highest recommendation in the guidelines (1A): Music therapy promotes recovery, and treatment should start at an early a stage as possible with the aim to reduce negative symptoms. Therapists with an approved education in music therapy must perform the treatment (Helsedirektoratet, 2013).

1.6 Medication-free treatment: the literature

The politically instigated implementation of medication-free treatment has been criticised for lack of evidence (Røssberg, 2016; Yeisen et al., 2019).

Treatment approaches for psychosis, including the use of antipsychotic medication and the effectiveness of psychotherapy, is debated both between researchers and clinicians as well as in the society at large. Disagreements often evolves around the understanding of what causes mental illness, biology or environment, brain chemistry or personal trauma.

In 2016, the Knowledge Centre for the Health Services in the Norwegian Institute of Public Health conducted a systematic literature search evaluating publications of systematic reviews and meta-analysis on treatment of psychosis. The purpose was to find research on the effectiveness of non-pharmacological interventions for people with severe mental disorders seeking a non-pharmacological treatment option. In 2017 the Norwegian Institute of Public Health published a report based on the previously mentioned literature search, finding no studies which had evaluated the effect of psycho-social treatment without concomitant use of anti-psychotic medication compared with psycho-social treatment with concomitant use of anti-psychotic medication (Holte HH, 2017). They concluded that the effects of treatment without the use of anti-psychotic medication was uncertain.

Other examples of known treatment facilities searching for improving the treatment for psychotic disorders, are among others the Chestnut Lodge studies and follow-up, the Soteria project, Open Dialogue, and in Norway, Kastanjebakken (Carpenter & Buchanan, 2002; Fretheim A, 2017; McGlashan, 1984; McGlashan & Carpenter, 2007; Mosher, 1999; Varvin, 1991). The search for improved treatment for this patient group suffering from complex and heterogeneous symptoms has been going on for decades.

Chestnut Lodge was a small, private psychiatric hospital, specialising in long-term in-patient treatment of severely ill psychotic and bipolar patients and the hearth of important studies on the effect of psychotherapy for patients with schizophrenia. The second part of the known Chestnut Lodge follow-up study by McGlashan, focused on long-term outcome of schizophrenia and affective disorders (McGlashan, 1984). 72% (n=446) of the patients treated at Chestnut Lodge between 1950 and 1975 were followed up an average of 15 years. Each patient received intensive psychoanalytically oriented psychotherapy 4–5 times per week. Antipsychotic medication were not available in America until the late 1950s and used sparingly at Chestnut Lodge until the 1970s (McGlashan & Carpenter, 2007). McGlashan found that about two thirds of the schizophrenic patients were functioning marginally or worse at follow-up, compared with one third of the unipolar cohort (McGlashan, 1984). This indicated low efficacy of psychotherapy on schizophrenia.

In 1986, Stone published a re-evaluation of the use of explorative psychotherapy in schizophrenia spectrum patients, based on a long term follow up study with 563 patients admitted between 1963 and 1976 at the New York State Psychiatric Institute. Results indicated that fewer than 20% of the patients functioned at a fair or good level, more than 50% led lives with marginal functioning or were incapacitated, and 20% had committed suicide (Stone, 1986). These results are in line with the McGlashan study.

The Soteria Project was inspired by the treatment philosophy at Kingsley Hall in London in 1964. Kingsley hall was a place were mental illness was considered a normal reaction to a sick society, and psychosis was a variety of normality. Anti-psychotic medication was not used. Inspired by this, Loren Mosher aimed to find a treatment with minimal or no use of anti-psychotic medication for the Soteria-model (Carpenter & Buchanan, 2002; Mosher, 1999). A systematic review on the Soteria project was published in 2008, urging for more research as the existing studies were inconclusive (Calton et al., 2008). The same was the case for another systematic review published in 2009 (Lloyd-Evans et al., 2009). Critics of this project claims that identifying medication avoidance as quality improvement is speculation based on ideology (Carpenter & Buchanan, 2002). Further, they concluded that Soteria House demonstrated an alternative to hospitalised care “but chose ideology over influence and opposition over integration”, suggesting the need for improved cooperation between opposing stakeholders.

In the late 1970’s there was a small psychotherapeutic unit called Kastanjebakken at Gaustad hospital in Norway, treating mostly people with schizophrenia. This was a so-called treatment resistant patient group where everyone had previously been hospitalised. They received frequent psychodynamic therapy, and psychodynamically based milieu therapy focusing on interpersonal relations and integrated family work. All patients received medication, but avoided the use of medication as crisis intervention (Hauff et al., 2002). 13 patients were transferred to other treatment units during the stay due to acute crises or episodes of violence, and about half dropped out the treatment plan. 17% of the remaining showed no signs of improvement. One subgroup showed effect of psychotherapy and needed little use of medication, but prediction was difficult. The level of function before admission appeared to be a good predictor of the outcome of treatment. (Varvin, 1991). They concluded that psychotherapeutic inpatient programs could be beneficial to patients with higher levels of global functioning at the start of treatment, but detrimental to other patients (Hauff et al., 2002).

Open Dialogue is a combination of family therapy together with a psychodynamic oriented therapy. Psychosis is understood as a result of psychological trauma, rather than the biopsychosocial model. The aim is to reach the patient early, and to avoid medication. A narrative review from 2012 found the method promising, but more research was warranted (Gromer & Psychiatry, 2012). Studies on this method can be criticised for lack of rigour, and the systematic literature search by Folkehelseinstituttet concluded that the knowledge base was weak and that they do not have confidence in the author's conclusion (Fretheim A, 2017).

An editorial by Mueser in 1990 considering the available research on psychodynamic treatment proposed a moratorium on such treatment, based on “the failure of empirical investigations to demonstrate that psychodynamic treatment is effective for schizophrenics, and the development of other interventions that controlled studies suggest improve outcome (…)” (Mueser & Berenbaum, 1990).

In 2000, Wayne Fenton wrote an article aiming to provide an overview of major historical trends in the psychotherapy of schizophrenia, and to review randomised clinical trials (RCT) that have evaluated individual psychotherapy for schizophrenia (Fenton, 2000). Interestingly for this study, one of the chapters are entitled Efficacy of Individual Psychotherapy: Trials in the Drugs Versus Psychotherapy Paradigm (1960-1975). As medication was introduced, psychiatry became increasingly divided into adherents of the “psychodynamic” or “biological” approaches, which stirred an acrimonious ideological debate on the efficacy of each treatment method. Several RCT’s were carried out, most included a no-medication cell. Summarising these trials, the results suggested among other conclusions that no study provided evidence to support the efficacy of individual psychotherapy as a sole treatment for schizophrenia.

However, the discussion continues. A study from 2018 found that Cognitive Therapy (CT) and Cognitive Behavioural Therapy (CBT) was an acceptable and effective treatment for people with psychosis who did not wish to use Anti-Psychotic medication (Morrison et al., 2012; Morrison et al., 2018).

The literature indicates a lack of evidence for the use of psychotherapy without concomitant use of medication. The societal and professional debate and emphasis on treatment using psychosocial therapy with or without concomitant anti-psychotic medication for patients with psychosis tend to fluctuate over time. This study suggests an ongoing shift towards reinforced emphasis on the use of psychosocial treatment measures and increased accept for patients’ desire to stop medication.

Since medication-free treatment was initiated by the Norwegian government, several studies have been initiated, resulting in published literature on the subject. In 2019, an article containing psychiatrists' reflections on the medication-free program was published (Yeisen et al., 2019). They concluded that despite all the pressure that the psychiatrists reported being exposed to, this did not affect their professional integrity in treatment decisions. They believed that this treatment option would aggravate negative attitudes towards medication and worsen existing adherence issues. Another critique asserts that with medication-free treatment, the patient does not choose between treatment options but determines by him- or herself what useful treatment is. In their view, this treatment is a step towards a 'reverse stigma’, which denies patients the right for proper treatment and care. (Fountoulakis & Souliotis, 2019).

A study located in the East of Norway found that negative effects of medication and unavailable alternatives in ordinary health care were important reasons for wanting medication-free treatment (Standal et al., 2021). Further, they concluded that their study had shed light on why there was a demand for separate medication-free units, and clinicians were advised to be mindful of the effect of power imbalances in their interactions with the service users.

In the Bergen area, a study in addition to the present study was initiated to look at the quantifiable data from the medication-free treatment project. In 2021, MD PhD Maria Fagerbakke Strømme published an article on mortality and non-use of antipsychotic drugs after acute admission among patients with schizophrenia (Strømme et al., 2021). This was done as a prospective total-cohort study, and not on patients registered in a medication-free treatment course. They found that non-use of antipsychotic drugs was associated with a twofold increase in mortality risk in patients with schizophrenia. In 2022, Strømme published a second article on the medication-free project, stating that the use of benzodiazepines and antipsychotic drugs were inversely associated with acute readmission risk among patients with schizophrenia (Strømme, Mellesdal, et al., 2022). Also, compared with non-use, the use of antipsychotic drugs was associated with reduced risk of readmission. The third article from Strømme focused on overactive, aggressive, disruptive and agitated (OADA) behavior associated with the use of psychotropic medications in patients with schizophrenia (Strømme, Bartz-Johannesen, et al., 2022). They found that the use of antipsychotics and antidepressants was associated with reduced risk of readmission with OADA in patients with schizophrenia.

In addition to these published articles, there are some reports generated from the medication-free treatment project. One is from Health West, written by the project leader at the time, Leif-Arvid Øvernes, translated title “Medication-free treatment courses for people with psychotic disorders” (Øvernes, 2019). In this report, 104 patients were registered as “medication-free”, and 81 were evaluated combining data from their journal with structured interviews with their therapists. I developed the scoring forms and completed this data collection, together with the project leader. The conclusion of this report was that the patients had 50% more close follow-up in medication-free treatment than they had the year before. According to the therapists, 40% of the treatment courses were scored as favorable, 30% moderate and 30% unfavorable, considering the outcome retrospectively. Medication-free treatment course was considered to have a positive effect on the alliance and the patient's sense of ownership of the treatment.

The Competence Center for Lived Experience and Service Development (KBT) has also published several reports from their evaluation of the medication-free treatment projects in Norway. In 2018, they published (translated title) “Healthy without medication”, where they evaluated all the different medication-free treatment projects in Norway. The Bergen project was criticised among other things for not offering a separate ward for the patients who chose medication-free treatment. They were also concerned about to which degree the patient’s choice was prioritised over the professional responsibility (Bjørgen, 2018).

Medication-free, or non-pharmacological treatment is widely understood within psychiatry as treatment without using medication, as a clear prerequisite. However, this is not the case for the use of this term in this study. As a qualitative, explorative study focusing on the user and therapists experiences, the term medication-free treatment is to be understood as it has been defined by Health Bergen and presented to the users: A treatment not necessarily without using medication, but where the user aims to reduce or discontinue the use of anti-psychotic medication. Further, that the treatment offered focuses on mentioned psycho-social therapies to support the user in the effort of discontinuing anti-psychotic medication. The project intended to clarify for the users the option of choosing treatment without medication, aiming to provide medication primarily because it was the best alternative and not in the absence of medication-free treatment options (see attached protocol). The process of choosing treatment was planned to take place as shared decision-making together with the patient.

2. Rationale/Justification

Patients suffering from psychosis is an important patient group for several reasons. The onset of psychotic disorders often occurs at an early age, during adolescence or young adulthood (de Girolamo et al., 2012). Psychotic disorders often instigate lifelong personal suffering, and elevated risk of early death (Strømme et al., 2021). The illness requires resource demanding follow-up and care from the society. There is an ongoing debate regarding the treatment and follow-up of these patients, which also goes back a long way historically. Psychotic patients have been exposed to inexpedient medical and psychodynamic treatment, sometimes involuntary. User organisations globally keep demanding greater patient autonomy and freedom to choose treatment options, including the use of medication. The user initiative in Norway instigated new policy and guidelines for treatment of psychosis, which was criticised for lack of scientific evidence for the change (Røssberg, 2016; Røssberg et al., 2017). The history of psychiatric and societal treatment of those suffering from serious mental illness is largely characterised by abuse, neglect, or other forms of harm in many high-income countries. This happened regardless of if the treatment was about institutionalization (too much), deinstitutionalization (too little), criminalization (societies' level of endurance), or lobotomy (abuse). Despite well intentioned reforms, policies and treatment, Daugherty and co-authors describes how mental health care is like a Sisyphean task, with a recurrent tendency toward maltreatment (Daugherty et al., 2020).

In huge parts of the world, mental health care is characterised by lack of basic competence, human capital and resources. Personal despair and stigma are closely intertwined with mental health disorders (WHO, 2021, 2022; World Health Organization, 2018), both in low and middle income countries as well as high income countries. To improve treatment for this vulnerable group of patients there is a need to avoid possible polarisation of professional perspectives and treatment approaches. Therefore, experiences with implementation of treatment policies should be evaluated in search of a continuous improvement, avoiding the mentioned recurrent tendency of maltreatment.

The background for this thesis was a need to bring forward and understand the user and provider perspectives on the politically instigated medication-free treatment project in Bergen, Norway. Further, the aim was to evaluate and disseminate possible positive and negative impacts on an individual level of this implementation, focusing on the personal experiences.

3. Aims and research questions

3.1 General objectives

This study aim to provide comprehensive insight into the user and provider experiences with the medication free treatment program in Bergen, Norway.

3.2 Specific objectives

1. To obtain and explore first person perspectives on medication free treatment in mental health care (Paper 1)

2. To explore mental health workers overall experiences with the implementation of medication free treatment (Paper 2)

3. To provide a deeper insight into the role of music therapy as treatment for psychosis from patient and therapists' perspectives
   (Paper 3)

4 Methods

4.1 Study design

This qualitative study includes semi-structured, in-depth interviews with people with psychosis who were registered for medication-free treatment. Qualitative methods such as in-depth interviews aim at understanding and representing the experiences of people as they encounter, engage, and live through situations (Elliott et al., 1999; Malterud, 1993; Stige et al., 2009).

The study also included the use of focus groups with staff from the mental health care institutions.

Additionally, I performed participant observation in music therapy, taking ethnographic notes of the experience.

This study also employed a service user involved approach (Veseth et al., 2017; Veseth et al., 2012). Following this approach, the research team had a phenomenological aim to explore the lived experiences of personal recovery processes within mental health care where medication-free treatment for psychosis was an option.

4.2 Place

This study was done within the Health West region in Norway, within the city of Bergen, focusing on three district psychiatric centres; Bjørgvin, Øyane and Kronstad. Having my office at Kronstad meant that I got access to more data collection from this centre than from the others. Kronstad was the first psychiatric district centre implementing medication free treatment as a pilot intervention, focusing on a new day care unit offering a variety of therapies for patients with psychosis. This was a natural place to start recruiting, as the other centres did not have the same number of registered patients wishing to discontinue their use of anti-psychotic medication.

Early on in the study, I contacted the music therapist at Bjørgvin, and joined his music therapy session for groups, doing participant observation. Through this initiative, I recruited two informants from this centre.

Øyane is situated geographically a bit outside the city, and I never succeeded in recruiting informants from this centre. This does not mean that they do not have medication free options for their patients.

4.3 Epistemology, ontology and axiology - methodological considerations

I have used an interpretative, or constructivist understanding of the nature of reality and its characteristics (the ontology), where I believe multiple realities are constructed and exist within people's minds at the same time. Knowledge (the epistemology) is as such co-constructed by the researcher and research subjects together. In this co-construction my underlying values and biases (the axiology) should be openly declared and transparent throughout the study (Creswell & Poth, 2018).

Phenomenology is the study of “phenomena”, the appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. Qualitative research aims at understanding and representing the experiences of people as they encounter, engage and live through situations (Malterud, 1993; Stige et al., 2009). This study used a service user involved approach (Moltu et al., 2012; Veseth et al., 2012) developed within a hermeneutic-phenomenological epistemology. This means that there was a phenomenological aim in exploring and describing the lived experiences of choosing a medication free treatment for psychosis, and one must recognise that the attempts of doing so inevitably will be interpretations.

As a researcher, I bring my perspectives and my interpretations of the reality surrounding us into my work. In order to reduce the risk of bias caused by potential prejudges related to the researchers own experience with treating patients with psychotic symptoms, it was considered an advantage if the main researcher in the project was someone with a background other than a mental health worker. My educational background is from cultural science, which studies the everyday culture and how people create existential purpose within this culture. Qualitative methodology is essential in this study, and I did qualitative interviews as a part of my master thesis. I believe reality is not fixed, but different for each individual, shaped by experiences and personal perspectives.

I hoped to bring a multidisciplinary, although qualitative, perspective into the field of psychiatry. I am personally influenced by my experiences, such as my education as well as by being married to a psychiatrist. Both my background as well as the three supervisors from three different faculties at the University of Bergen, a professor in global health with focus on mental health, a psychologist, and a professor in music therapy, influenced the study.

4.4 User participation

In order to ensure the respect of the users' complex views on the issue of this study, we invited four experts by experience to become co-researchers on this project. Three of these co-researchers are from a user organisation called Hvite Ørn, and one was working at the district psychiatric centre Kronstad as an experience consultant. They have been involved in the study from participating in preparatory phases of the study (developing the protocol and research questions and discussing the semi-structured interview guide), data analytic phases (participating in the team-based analysis) as well as dissemination of the results (participating in writing articles and presenting the research project). We believe this involvement enhance the quality of the study through this collaborative research process.

4.5 Theoretical framework used in article 2

People come to street-level bureaucracies, such as health care facilities, as individuals with unique personalities, experiences and circumstances in their lives. In the encounters with street-level bureaucracies, they are transformed into clients through a social process in the effort of making them fit into standardised definitions of units consigned to specific bureaucratic slots. Lipsky calls this process the social construction of the client (Lipsky, 1980). In the context of medication-free services, patients are clients who enter potentially conflict-based relationships with health care providers, in this context named Street Level Bureaucrats (SLB). Conflicts occurs when SLB and patients clash over objectives, and they have different levels of resources with which to negotiate paths forward. Clients seek services and benefits, and SLB seek control over the process of providing them. In the context of new treatment options emphasising patient choice, the social construction of the client is aiming toward a more horizontal and less hierarchical structure.

According to Lipsky, SLB often must navigate the tension between what is demanded from them professionally, by both patients and management, and what they are able to provide within the given conditions. Large caseloads, ambiguous agency goals, and inadequate resources strain health care staff, while the demand for services tends to increase with the supply. In this context, resource constraints can obstruct their tasks. If the tension becomes too demanding, SLB may experience feelings of alienation from their work, because they experience a loss of control over situations they are expected to handle. This may lead to feeling dissonance, and when this dissonance between objectives and capabilities is too great, SLB may develop coping mechanisms to shield them from the implications of the gap. Such coping mechanisms includes disowning their responsibility towards their patients, consciously or subconsciously, and emphasising the division between work and private life. This alienation from their work leads to dissatisfaction with the job, in turn affecting commitment to patients and their agencies.

4.6 Participants for in-depth interviews

The participants recruited for in-depth interviews were people with psychosis within the Health Bergen catchment area. Ten of them had an active wish to discontinue their anti-psychotic medication now or in the future, and therefore they had chosen a medication free pathway within the mental health service. One of the informants had no wish to discontinue the medication, but nevertheless was an active user of music therapy with strong opinions on both medication and psychosocial treatment. However interesting perspectives and insightful learning this patient provided, we chose to exclude this interview from the analysing process, as we believe the information strength from one patient having this view was not satisfactory to be included. We still believe this interview gave insight that was valuable for further probing for the rest of the interviews, which came after this, four in all.

Inclusion criteria for the patients were above 18 years of age, and able to give an informed consent, as well as being a patient at one of the three district psychiatric centres. The participants were intended to be of maximum variation with different backgrounds, age and gender, as well as past treatment histories. The range in age was from 25 to 45 years, and almost equally divided when it comes to gender. The participants were quite young; this may have been due to their increased availability compared to elderly patients.

Patients treated for psychotic symptoms are a highly diverse group, and the treatment needs to be flexible following fluctuations in symptoms and other needs. In Bergen, the Health Trust has chosen to provide all patients with psychotic symptoms with a variety of non-pharmacological treatments, not only those who choose to have a medication free treatment course. Some of the patients I interviewed started out as medication free patients, either having discontinued the medication by themselves, or stepwise with help from the therapists. Some later had to use medication again because their health deteriorated, while others have been medication-free patients up to this date (See table 1, article 1, for details).

4.7 Participants for the focus groups:

The participants in the first focus group were psychiatrists and psychologists, two men and four women, age range from about 40 to 70. The participants in the second group were one nurse, one physiotherapist, two occupational therapists, and one social educator, two men and three women, age range from about 30 to 60 years old. The participants in the third group were all music therapists, one woman and five men, age range from about 20 to

60 (See table 1, article 2, for details).

4.8 Data Collection for participant observation

In order to provide a deeper understanding of the social processes in therapy sessions, we included participant observation as one perspective of this study. Participant observation means the researcher participates in the context to be studied, with the aim of describing the problem from an insider perspective (Malterud, 2017). Paul Atkinson describes how this requires "to make a certain personal as well as intellectual commitment" from the researcher, and further, "to exploit one's full range of capacities in order to make sense of a given social world" (Atkinson, 2015). This includes to be observant, to take the role of the other, to listen, to learn and to imitate, according to Atkinson. At the beginning of the study, I aimed to do participant observation in Illness Management and Recovery groups, and in music therapy groups. This turned out to be too complicated, as it became too hard to get a written consent from all the different participants. Many were severely ill, and had little trust in me as a researcher. I participated in several group sessions, both in music therapy and IMR, observing and learning to get a better understanding of the social processes and therapy methods in such groups.

I got the informed consent for my participant observation in individual music therapy from one particular patient. I was then able to participate in and take observational ethnographic notes from seven individual music therapy sessions with this patient, using and analyzing ethnographic notes from six of them after getting the signed form of consent. This participant observation took place at a district psychiatric center in Bergen. It lasted over a period of about three months, approximately one session every week except when sessions were canceled.

4.9 Data management

After each in-depth interview, I immediately uploaded the sound file to the research server at Haukeland University Hospital, and deleted it from the recording device. The transcriptions were also only stored securely on the research server. The research server has a backup and protection managed by the IT-section of Haukeland Hospital.

The signed consent forms were stored in a folder in a locked cupboard in my office, which was unlocked only when I was there. The key to the demographic data and names of the participants was uploaded as a separate file to the key server at Haukeland Hospital. Here each participant was given a number, which was the only reference I used in the transcriptions. My supervisors all had to sign a contract with Haukeland Hospital in order to get access to the data. My co-researchers only read transcripts where the patient had a number. We also discussed the importance of confidentiality in case they would recognise any patients. One of my co-researchers was working as an experience consultant at Kronstad district psychiatric centre, and had signed a contract of confidentiality. At one time, I participated in a PhD course learning about data analysis, where I brought and shared transcriptions with two fellow students. These transcriptions were de-identified beforehand, as I removed all names of both people and places that was mentioned during the interview.

For data analysing purposes I used the NVivo software program. De-identified transcripts was printed and shared with the supervisors and the four co-researchers for the purpose of transparency and co-analysis and likewise destructed.

4.10 Data analysis

For this study, there were four sequences of data analysis. First, we aimed to address the objective of the research question exploring the first person experiences on recovery within the medication free treatment regime. The source of data was the in-depth interviews with selected patients. In order to address our second research objective, to explore mental health workers experiences with the implementation of medication free treatment, we analysed the data from our focus groups. We chose to study the focus groups twice, focusing first on the general experiences of all the health care workers within the medication free treatment, making out the data for our second article. Thereafter, we analysed the focus groups with the specific aim to discern the role of music therapy as treatment for psychosis within medication free treatment.

Finally, the fourth sequence of analysis dealt with the ethnographic notes from the participant observation, aiming to provide readers with a condensed summary of my experiences, intending to convey what music-therapy can “be a case of”. This summary is presented in the third article.

4.11 In-depth interviews and Thematic Network Analysis

I analysed the data collaborating with both supervisors and co-researchers, using Attride-Sterling’s Thematic Network Analysis, which is a way of organising a thematic analysis of qualitative data. Thematic analyses seek to unearth the themes salient in a text at different levels, and thematic networks aim to facilitate the structuring and depiction of these themes (Attride-Stirling, 2001). I did the first coding together with two fellow

PhD students on a PhD course, forming a coding framework based on the textual data from the three first interviews. We dissected the text into manageable and meaningful text segments, guided by the theoretical interests of the study, as well as the salient issues that arose in the interviews. Then these textual primary codes were grouped into more abstract basic themes, like “symptoms” and “addiction”. Again, these basic themes were grouped into organising themes, like “illness”. This entire process and coding frame was further developed in an iterative way with mainly the co-researchers, discussing and changing codes from one theme to another. The organising themes were named and renamed for a better fit, until the team felt the final product was representative for all views, and no essential information was lost in the process. Then the rest of the interviews were analysed using the developed coding frame. The global theme was deductively defined fitting with both the inductively defined themes and the research question. Codes were then translated into English.
Examples of relevant coding is provided in table 2 in article 1.

4.12 Focus groups and Systematic Text Condensation

I chose Systematic Text Condensation (STC) (Malterud, 2012) as analysing tool for the focus groups. This is a method inspired by Giorgi's psychological phenomenological analysis (Giorgi, 2009). It is a thematic, cross-case strategy suited for exploratory analysis, consisting of five steps: identifying preliminary themes; identifying meaning units; sorting the meaning units into code groups; abstracting condensates from code groups and subgroups; and generating synthesised accounts from the condensates. For the first article, Anne Blindheim (expert-by-experience and co-researcher), Ingunn Engebretsen (IMSE: main supervisor) and I read the transcripts, and each of us found between five and eight preliminary themes relevant across all three focus groups. Further, we agreed to prioritise five of the most substantial themes. IMSE and I sorted the meaning units, identifying those potentially related to the previously chosen themes. We elaborated on the names and keywords of the code groups together during coding to develop understanding. I wrote the text condensates, reducing the content of the meaning units into a condensate that retained the participants' terminology. I left out meaning units that could not be naturally incorporated in the condensate, but some were reorganised into another theme. A few were found not to be relevant for the chosen themes and study question. I discussed each of the condensates with AB and IMSE. This analytical process resulted in three themes: managing available resources; the role of the therapist; and treatment practices and experiences. To finalise the analysis process, I rewrote the condensates into the results section, returning iteratively to the original transcribed text to check the validity of each meaning unit in the condensate. In this process, I translated the text into English.

For the third article STC was still the chosen analysing tool, and the procedure mainly the same. However, since this process involved different persons, I chose to elaborate on this process as well. Brynjulf Stige (BS: co-supervisor, professor in music therapy) read the transcripts of the focus groups, focusing mostly on the focus group with music therapists. We each found between five and eight preliminary themes relevant for the role of music therapy within the medication free treatment regime. After a thorough discussion of all the suggested themes, we decided to focus on five of them. I sorted the meaning units, identifying those related to the chosen themes and subthemes, using NVivo as a tool. In this process, the names and keywords for each code group were changed and elaborated to enhance the understanding of the topic. I wrote the text condensates based on each code group, reducing the content of the meaning units into a condensed text retaining most of the participants' original wording. Meaning units that could not be incorporated in the condensate were left out based on lack of relevance for the chosen theme or study question, or reorganised into a different theme or subtheme. I discussed the condensates and themes with

BS and IMSE, and reorganised the information into synthesised accounts of the main concerns for the therapists as we agreed on an improved understanding of the data.

4.13 Participant observation, ethnographic notes and Atkinson

Each of the individual music therapy sessions, where I was allowed to do participant observation, lasted for about one hour. I wrote down the experience as detailed as possible following guidelines and advice from Emerson; “Writing Ethnographic Fieldnotes” (Emerson, 1995), immediately after each session. To analyze this, I chose an ethnographic approach, inspired by Atkinson’s ideas of not focusing too much on specific data or method of analysis, to be able to learn more and possibly make sense of the interaction patterns and relational matters of music therapy. Ethnography provides the tool to demonstrate how these are means of social work getting done, of social order being constructed, and of social experience being shared (Atkinson, 2015). I aimed to do this through encounters with people familiar with music therapy, and the sharing of this social experience. Researchers derive theories and hypothesis from a variety of sources, including our exposure to a phenomena and engagement in a field of research. Field observations might yield analytic ideas of “what this is a case of”. These ideas further provides a "sensitising concept" that can inform further data collection. We aimed for an analyzing process taking into account the complexity of the research field, integrating as much experience as possible into the following course of the study. The analysis of the ethnographic notes from sessions with a participant providing consent was initiated by a summary of the notes written by me. BS read the original notes, and commented on the summary. As we agreed on necessary changes, I rewrote it accordingly. This was done as an iterative process until we thought the condensed summary of this experience contained the required information and essential descriptions of the participant observation of music therapy within medication free services. This summary is presented as a narrative in article 3.

4.14 Ethical considerations

The Regional Ethics Committee for Medical Health Research (REK sør-øst 2017/736) defined this study as health service research and according to the Norwegian Health Research legislation, the local data protection officer for Bergen Health Trust approved the study in July 2017 (2017/8692). All data has been treated in accordance with ethical and legal guidelines, ensuring anonymity and confidentiality for the participants. One of the inclusion criteria for participation was to be capable of giving an informed consent. This was done by getting the therapists to decide if the patient was well enough to participate and understand what they consented to. I went to morning meetings where the therapists were gathered to discuss the patients, and reminded them about the project, and then if there were any eligible candidates, we would discuss the ability to consent before the patient was involved. The patients were offered written information as well as the possibility to meet me and ask any questions they might have prior to the interview. When they were ready for the interview, they got a written consent form, which we talked through, and I highlighted every time that perhaps the most troubling about the consent was that they gave me the possibility to read their medical journal. I stressed this in order to make sure they understood this was a part of the study, even though it was not likely to be much used. Still, nobody changed their mind after reading the consent form. I had one interview with a young woman who cried a lot during the almost 60 minutes we spent together. Some of the questions I asked were about their experience with coercive measures, and this could be a difficult topic. I always asked the patient after the interview if everything was ok, as an attempt to get any feedback on possible need for help if they experienced the interview as stressful. All the patients were connected with one of three district psychiatric centres in Bergen, each having a dedicated therapist who they could contact and talk to if they had any problems after the interview. None of the informants were in need for additional help because of the interview.

5. Findings

This chapter summarises key findings related to the main research questions in the study. Specifically, patients' experiences of recovery and choice following this new treatment option (article 1), the health care workers' experience with and role in medication-free treatment (article 2), and finally the role of music therapy within this new treatment context (article 3). For a richer detailed description, I refer to the PhD manuscripts. The following table summarises the study and results.

Table 2: Summary of research questions, informants, data, analysis and findings (see next page):

Overview of thesis and research articles.			
Study purpose and main research question	This study aim to provide comprehensive insight into the user and provider experiences with the medication free treatment program in Bergen, Norway.		
	Article 1	Article 2	Article 3
Title	"It means so much for me to have a choice": a qualitative study providing firstperson perspectives on medication-free treatment in mental health care	How can we best help this patient? Exploring mental health therapists' reflections on medication-free care for patients with psychosis in Norway	Health care workers' perspectives on the challenges and possibilities of music therapy within medication-free treatment services
Research question	The aim was to investigate the patients' experience of personal recovery following the new treatment options and choices presented within the medication-free treatment system.	The aim was to explore the tension between policy and practice in order to examine how mental health care workers in Bergen dealt with, and reflected on, their role in implementing medication-free treatment.	We aimed to explore music therapists' and other health care workers' perspectives on working with patients who choose music therapy within the context of medication-free treatment options.
Informants	11* patients suffering from psychosis	17 therapists working with medication free treatment for patients with psychosis.	Music therapists and other health care professionals working with patients with psychosis within the medication free treatment system. Participatory fieldnotes from individual music therapy sessions.
Data	11* in-depht semi-structured interviews	3 focusgroups	3 focusgroups and ethnographic notes
Analysis	Thematic network analysis. Coding/categorisation	Systematic Text Condensation. Coding/categorisation	Systematic Text Condensation. Coding/categorisation
Results	Participants described an improved relationship with therapists compared to previous experiences. Integrating more evidence-based psychosocial interventions into existing mental health services facilitated learning experiences regarding the choice of treatment, particularly the discontinuation of medication, and appeared to support participants' increased self-agency and motivation in their personal recovery processes.	Following Norway's new policy was challenging for the therapists in our study, particularly balancing a patient's needs with treatment guidelines, the legal framework and available resources. Therapists had an overarching wish to help patients through cooperation and therapeutic alliance, but their alliance was sometimes fragile, and the therapists worried about patients' conditions worsening.	The informants from the FGD's described music therapy as having a high degree of treatment flexibility providing a continuous process of choices. The collaborative choices both among staff members as well as between patient and staff were experienced as important for treatment outcome. Patients worsening or stagnating increased the significance of contingent choices.

*11 patients, but one were excluded in the analyzing process =10.

5.1 The patient perspective on medication-free treatment

Ten face-to-face in-depth interviews with patients suffering from psychosis were analysed with the aim to investigate their experience of personal recovery following the new treatment options and choices presented within the medication-free treatment context. Analysis generated a global theme relating to personal recovery processes facilitated by the provision of more psychosocial treatment options, with three organising subthemes: interpersonal relationships between patients and therapists, the patient's understanding of personal patterns of suffering, and personal motivation for self-agency in the recovery process.
One important finding from the face-to-face interviews was that all the informants stated in one way or another that they felt it was important to have a choice regarding the treatment.

> P2: "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."

The freedom of choice was regarded as generally positive by all the patients, as a contrast to not having the options they would wish for. In this regard, medication-free treatment was perceived to provide them with an increased amount of choice in their treatment regimen.

The participants shared a positive impression of the communication, and an improved relationship with their current therapists compared to previous experiences.

Integrating more psychosocial interventions into existing mental health services facilitated learning experiences regarding the choice of treatment, particularly the discontinuation of medication, and appeared to support participants' increased self-agency and motivation in their personal recovery processes.

Personal patterns of suffering could be explored within a system aiming to support and have a higher level of acceptance for the discontinuation of medication. The medication-free treatment regime requires a high level of personal agency focusing on personal coping strategies and personal responsibility for the recovery process.

> P2: "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."

5.2 The therapists' reflections on medication-free treatment

We invited health care professionals to participate in three focus discussion groups (FDG) to examine how mental health care workers in Bergen dealt with, and reflected on, their role in implementing the new policy regarding medication-free treatment. We chose to use Michael Lipsky's theory of street level bureaucrats to explore the possible tension between policy and practice for the informants. The three main themes evolved around managing available resources; the role of the therapist; and treatment practices and experiences.

Following the new policy implementing medication-free treatment was challenging for the therapists. They shared how balancing the patient's needs with treatment guidelines, the legal framework and available resources could be difficult. They all had an overarching wish to help patients preferably through cooperation and therapeutic alliance.

> Mental health Nurse: "Yes, what helps, in a way, right? That is always the question, how can we help this patient in the best way possible, with or without medication."

The alliance was sometimes experienced as fragile. The therapists worried about patients' conditions worsening. They had a clear intention to respect and accept patient choices, although accepting a patient choice could include a sense of resignation.

5.3 The role of music therapy within this new treatment context

In the last part of this study, the aim was to explore music therapists' and other health care workers' perspectives on professional work with mental health patients who specifically chose music therapy within the context of medication-free treatment options. For this purpose, I included the narrative from the participant observation of six individual music therapy lessons together with the FDG's, particularly focusing on the third FDG with music therapists.

A main finding was the descriptions on the process-oriented nature of music therapy, with flexible treatment characteristics. Further, we focused on how processes related to the choice of using music therapy unfolded within this new treatment regime, from the perspectives of both music therapists as well as other health care staff. Finally, we discussed key challenges for complex therapeutic relationships, treatment needs, and discontinuation of therapy.

5.3-1 Participant observation – what music therapy can "be a case of"

The summary of my participant observation provides insight both on how positive music therapy comes across for certain patients regarding acceptability, turn out and alliance, but also describes the possible dilemmas regarding lack of progress in a patient's recovery process, including the challenging task of prioritising and decision making on when to end therapy.

6. Discussion

6.1. Methodological and ethical considerations

In this chapter, I will assess the methods used in this study, discuss reflexivity, study design, and other factors influencing the conclusions.

Reflexivity – the researcher’s preconceptions and choices

Assessing Qualitative methods needs a high degree of transparency to achieve the necessary trustworthiness essential to justify such studies (Malterud, 2017). The researcher need to be aware of and disclose preconceptions and choices relevant for the study.

Along with the decision to implement medication-free treatment was a requirement of evaluation, with the prerequisite to collaborate closely with service user organisations. In accordance with input from the service users in Hvite Ørn, it was decided to fund a PhD candidate to accomplish a qualitative study. The researcher should not have a medical education or training, in order to avoid an automatic medical perspective on the shared stories from the users. This was highlighted by the user organisation as important in order to capture the lived experiences of choosing and utilising the medication-free treatment from a research perspective not influenced by the regular health system caretakers and researchers' way of thinking.

Imposing such restrictions on a research project is unusual. This request stems from the scepticism these user organisations have towards psychiatry and psychiatric treatment. Globally, such scepticism among user organisations is also known as the anti-psychiatry movement, which has a long history (Crossley, 1998; Haack & Kumbier, 2012). However, this movement is said to have evolved from a radical view towards participatory involvement in mental health systems, resulting in recovery-oriented approaches (Ostrow & Adams, 2012; Toms, 2020). I understand the choice of a non-medical researcher as an attempt to increase the trustworthiness off this study among the users. This aim to avoid a particular medical way of thinking, could potentially have contributed to a shift of the equilibrium towards the opposite direction for the study. Having a researcher without a medical training or professional background could lead to misunderstandings and lack of relevant contextualisation.

The research process, including data collection and analysis, has inevitably been influenced by my background and values. I have a masters' degree in cultural science (ethnology) which studies the everyday and how people create meaning in life. This training has made me tuned in to and value the lived experiences of people in systems where the individual sometimes get lost. Although the participants in my study wished for a disputed treatment, their life experiences made it important for them to have the option of not using pharmacological treatment. I believe that their perspectives are important to consider and should be granted weight in this debate.

My research résumé started in 2008 and forward, as I got involved in the transcultural task force in the International Society of Bipolar Disorders, resulting among other things in an article (Oedegaard et al., 2016). I'm also politically engaged, and I'm currently a city council representative for the green party in Bergen. However, a researcher's perspectives and approach are shaped not only by their education but also by their life experiences (Malterud, 2017). Therefore, it is relevant to disclose my marriage to a psychiatrist. This circumstance would necessarily expose me to the "medical way of thinking", but also provide a source of insight and knowledge from a profession deeply involved in the research topic. As I engaged myself in this project, I believe both my husband and I debated the pros and cons with an open mind. His shared experiences from working in psychiatry were often characterised by his heart for the patients, and sometimes frustration over system limitations. Both of us were mostly preoccupied with finding the best way to help patients. The user organisation Hvite Ørn, involved in this project, was familiar with this circumstance, and had no objections.

During the interviews with the users, I emphasised that I had no medical training, to clarify the difference between a therapist and me. I often shared some personal information, which can be necessary to gain trust and an atmosphere of mutual openness, including being married to a psychiatrist. None of the informants reacted negatively to this information, to my knowledge. On the contrary, this and other information about me personally seemed to facilitate the informants' sharing of personal information.

During the focus group discussions, I had the role as moderator, and one of the supervisors had the role as secretary. My personal knowledge about psychiatry could have influenced the probing questions more than it influenced the topic guide, as this was developed in collaboration with the entire research team. It could both help in asking questions of insight, but also bias the perspectives. Having a secretary who could correct and ask other probing questions as they felt like was a way to counteract this risk.

The data were analysed in collaboration with representatives from the users and the supervisors, also counteracting personal biases. This process sometimes revealed diverging perspectives on statements, which the team then discussed and incorporated in further analysis.

I consider the research team, namely representatives from Hvite Ørn, and also my co-researcher Anne Blindheim, as well as my supervisors from different professions, to have provided me with sufficient input and relevant discussions to counteract serious biases.

The study design

There are many ways to shape a study in one or the other direction. Defining the study question, inviting specific co-researchers, developing the topic guides, choice of informants, the analysing process, these and more are elements of the research process which are prone for influence.

Aiming to explore both patients' and therapists' perspectives on the implementation of medication-free treatment within mental health care services in Bergen, we chose a qualitative set of methods. We chose in-depth interviews with patients to investigate their views on medication free treatment, held together with their previous and present experiences with psychosis, and their search for recovery.

The interview guide was developed in collaboration with the co-researchers to avoid potentially offensive wording, and to include topics important to the user organisations. The aim was to provide the interviewer with open topics, and possible optional probing questions, only guiding without restraining the interviewer from following the emerging topics during the interview. However, some questions could be perceived as leading, depending on the context, such as the optional probing question “Some say they are afraid of truthfully describing their mental state, because they worry they won’t get the treatment they want, but might be forced to use medication, or even be coercively admitted. Have you had such thoughts?” This question expresses the doubts user organisations have regarding psychiatric treatment, and was important to address for the co-researchers. It is clear that this might have spurred thoughts in this regard which would not have been spurred in the same way without this question.

Interpretation is an integral part of qualitative methods, and many factors will influence an interview. My presence as a person, the chosen place, the mental state of the participant and their respective previous experiences are such factors influencing their perception of the situation and questions asked. To counteract possible biased angling of these questions, I repeatedly assured the informants how there were no right or wrong answers.

We chose focus group discussions (FGDs) to invite the therapists within the mental health services aiming to implement medication free treatment to share their experiences with this change of guidelines. The interview guide for these discussions were also developed and discussed with representatives from Hvite Ørn, and my co-researcher Anne Blindheim. I acted as moderator and one of the supervisors as secretary for these FGDs. This methodology seek a broader perspective and counteracts preconceptions in the dialogue.

Finally, we aimed to provide a deeper understanding of music therapy, and how it unfolds within this treatment regimen, by using participant observation. Music therapy has been recommended since 2013 in the official Norwegian guidelines for treating people experiencing psychosis (Helsedirektoratet, 2013). Music therapy provides recognised benefits of a recovery-oriented practice (Solli et al., 2013) focusing on relational and resource-oriented work (Ruud, 2010). Therefore, music therapy serves as an example of the recovery orientation within the medication-free treatment. The choice of using participant observation was based on a wish to triangle the research process, regarding both research methods as well as participant perspectives. It is a method which poses particular emphasis on the researchers ability for reflexivity. Additionally, it demands a personal ability to build trust and "blend inn" with the informants. In this study, here was an aim to participate in group therapy, both music and IMR. However, this turned out to be too difficult, as group members were different from week to week, which made getting an informed consent from all participants impossible. After participating in three music therapy groups without getting the necessary consent we decided to give up on groups for research purpose. I decided to continue participating only to learn and in this way increase my understanding of what music therapy was. I went there about once a week for three months. The same happened with the IMR group, where I participated five times. Neither of these groups are part of the empiric data used in this study, but the experience gave me insight into music therapy and the IMR method.

For the participant observation in individual music therapy, I succeeded in getting the informed consent from one participant. This method requires that the researcher spend time together with the informants. The music therapist was present at all times. I took the role as audience, listening to the music they played. This seemed acceptable for the patient. I kept a close dialogue with the music therapist to make sure my presence did not disturb them. Also, I asked the music therapist to validate my notes two times, to make sure mistakes were corrected, and to ensure a mutual trusting dialogue between us. I believe the participation in groups gave me insight helping me approaching the informants, but also in asking relevant probing questions for both in-depth interviews and the focus group discussions. However, I struggled in the task of analysing the ethnographic notes, as I felt it challenging to keep a necessary analytic distance to the data. I discussed this thoroughly with my supervisors, and we decided on an analytic approach were both my supervisor in music therapy and I co-analysed the data to ensure a more distanced perspective on these notes.

Internal validity – does this study answer the study questions?

Qualitative methods is and was often criticised for its subjective nature and absence of facts (Malterud, 2001), perhaps more within the medical research tradition than other research areas. To a certain limit, checklists can serve as a tool to cover essential aspects for qualitative studies, such as COREQ (Tong et al., 2007). Evaluation is important to ensure quality, but the variety of methodologies in qualitative research indicate that general checklists or shared criteria for evaluation are problematic. Hence, other approaches have been suggested, such as EPICURE (Engagement, Processing, Interpretation, Critique, Usefulness, Relevance, Ethics) which encourages reflexive dialogue through the use of an evaluation agenda (Stige et al., 2009). Assessing this study, I have mainly drawn upon the work of Malterud from 2017, although I recognise how the evaluation process could have been expanded through other approaches (Malterud, 2017). All research is about answering questions, and the concept of internal validity is about whether the researcher has drawn the right conclusions from the data or not. What can this study say something about?

The gathered empiric data in this study are drawn from interviews with people experiencing psychosis, and therapists working with this patient group. This are all second hand stories told and experienced by the informants, and not by the researcher, and as such prone for sources of error.

The primary aim for the first article was to explore and convey their experiences with choosing medication-free treatment. Therapists actively working with implementing this treatment suggested possible informants. Hence, these informants were perhaps more aware of having this choice than other patients within the same health care system, and not representative. Nevertheless, the concept of choice was difficult to grasp for the informants, as illness often do not leave room for choosing. Understanding how to approach and probe for experiences of choosing that felt relevant for the informants developed over time. This means that the angling and intensity of probing for these questions changed from the first to the last interview.

I consider the experiences the informants have shared as important in nuancing the perspective on the complexity of choosing when experiencing psychotic symptoms, and therefore relevant for answering our first research question.

Our second research aim was to explore mental health workers experiences with medication free treatment. The participants in the focus group discussions with health care personnel were invited through the head of the clinic, and they were able to do this during their working hours. Even though the main theme for the focus group discussions were the concrete stories and experiences with working with medication free treatment, as a moderator I was not always able to avoid the conversation to drift into opinions and political discussions, particularly for the health care workers. Dividing the groups by level of education (see table 1 Focus group participants, p. 5. in the second article for details) facilitated a trusting environment, with open sharing of unsafe situations as well as positive stories of patients getting well, but some stories presented a level of severity that might have put stories that were more beneficial in the shade. The groups facilitated rich discussions across different wards and different work assignments, and across different professions. Using the Lipsky theory helped in sorting and analysing the information, and framed the stories into a comprehensive depiction on the working situation for the health care personnel. I consider the experiences the informants shared as important to convey the complexity and strenuous work health care personnel are living through, and therefore relevant for answering our second research question.

Additionally, I have participated in and observed one patient in music therapy, also experiencing psychosis. As mentioned above, participant observation posed some challenges in groups. The aim was to provide a deeper insight into the role of music therapy as treatment for psychosis from patient and therapists' perspectives. Even though I did not succeed in gathering data from music therapy groups, I learnt from observing them. This also provided an arena for recruiting patients using music therapy for the in-depth interviews. Several of the interviewed patients had experience with using music therapy, and I probed for such stories. The focus group discussion with music therapists lasted longer than the other two, and gave rich data. The participant observation with one patient went as planned, and provided extensive ethnographic notes. These different sources of data offer in sum a rich foundation for analysis and insight into the role of music therapy as treatment for psychosis. Hence, we believe the chosen methods are suitable to provide answers to the aims of our study.

External validity – a discussion of transferability

Like most qualitative studies, the sample size is small, which limits generalizability. Instead, this discussion is about the transferability of this study, the range and limitations for application of the study findings, beyond its context. This involves the choice of informants, the relevance of the gathered data, and if the described context is recognizable and useful for policy makers, user organisations and health care personnel. Usefulness and relevance are aspects closely interlinked.

The health care personnel suggested participants for the in-depth interviews to make sure they were able to provide an informed consent. The age range was between 25 and 50 years old, most of the patients were in their 20s and 30s, and men and women were equally represented.

Some aspects would point at less transferability. Most of the informants were patients at one specific outpatient clinic for psychosis. The level of function is higher among outpatients than those admitted for inpatient treatment. Even though the age range was wide, most of the informants were quite young, and did not have a long history of admissions.

Other aspects points at a higher degree of transferability. All of the informants had experienced severe psychotic symptoms and inpatient treatment, most of them had experienced coercive measures. On average was the level of functioning quite low, even though several had been or were still working.

All the informants had experience with using anti-psychotic medication, and all but one had a wish to discontinue the use of this medication. The informant who did not wish to discontinue the medication was excluded from further analysis. The shared experiences were diverse, and both negatively and positively angled regarding the use of medication. These aspects are important for the transferability, and therefore I consider the experiences of the participants in this study to be transferrable to patients with psychosis searching for other treatment methods than medication.

Further, there is a need to discuss the relevance of the gathered data, and usefulness of the study findings. The aims for this study were to explore and convey the experiences people with psychosis and therapists had with the medication-free treatment offered. The policy makers were convinced of the necessity of this project by the user organisations (Helse og omsorgsdepartementet, 2015). As previously mentioned, it was required to evaluate the politically instigated medication-free treatment project, which led to this study. The user organisations required someone without medical training to be the main researcher, based on their scepticism towards psychiatric treatment. This study has explored the first person experiences with medication-free treatment, conveying complex and nuanced perspectives on challenges and advantages with this treatment offer, with findings applicable to settings beyond the study context.

When the therapists' shared their perspectives in the second part of this study, the treatment program was still at the beginning of its implementation. This might have had the advantage of the participants being highly aware of the changes that were about to take place. A challenging aspect would be that it was too new for them to have been sufficiently acquainted with these changes. The participants mostly worked at the same district psychiatric centre, having different professional backgrounds. The music therapists came from different district psychiatric centres. The participants were of a wide age range, and men and women equally represented. I find the selected participants were relevant representatives for therapists working with people with psychosis at district psychiatric centres.

We were able to gather rich data from the three focus group discussions, with in general active participation from all the informants. The theoretical framework was helpful in the analysing process, providing tools for structuring the information. I consider it relevant and useful for the policy makers and the health care personnel to increase the awareness regarding the participants' wish to help the patients, and emotional struggles when professional expectations could not be achieved.

It is important to recognise that evaluating the implementation process and content of the medication free treatment project was not the aim for this study, nor to look into if the project affected the level of use or non-use of anti-psychotic medication among psychiatric patients in general.

The interdisciplinary team

The team of three supervisors having different professional backgrounds gave the study a broader perspective on the topic. Feedback related to psychological questions, music therapy and medical questions have been thoroughly discussed and integrated in the study, from the choice of study questions to the analysing and dissemination process.

Experts by experience as part of the research team

To ensure respect for the complexity of users' views on the topic of this study, we aimed for close collaboration with service users. A user organisation called Hvite Ørn was invited to be part of the research team from the beginning. Jan-Magne Sørensen, Øysten Søraas and Linda Garvik are members in Hvite Ørn, and all co-researchers in this study. In addition, Anne Blindheim, who was working as an expert-by-experience in the medication-free project at Haukeland University Hospital, was invited to be part of the team. The co-researchers were involved in the study from the preparatory phases (developing the protocol and research questions and discussing the semi-structured interview guide) through the data analytic phases (participating in the team-based analysis) and the dissemination of the results (participating in writing articles and presenting the research project).

The initial protocol was developed mainly with the feedback from the leader of Hvite Ørn, Jan-Magne Sørensen. We had one meeting with all the co-researchers and the supervisors after the start-up of the study, where we discussed the study questions and the participation of the co-researchers. All the co-researchers participated in developing and suggesting changes in the interview guide, and new questions were added in this process. After the data was collected, all the co-researchers were invited to discuss and comment on the transcribed and anonymised in-depth interviews and focus groups, and we received feedback from all four. For this purpose, the co-researchers were invited to a personal meeting, either together with other co-researchers or by themselves, whichever worked for the individual time schedule. This process provided an expanded perspective on possible interpretations of the data.

During the process of dissemination, it was more difficult to receive feedback from all the co-researchers, as this was often done by e-mail. In hindsight, we should have had more personal meetings to ensure the full participation. However, Anne Blindheim was working close by, and this was a huge advantage as we got to know each other well, and could discuss various challenges in the project on a daily basis.

A systematic review of outcome and experiences with patients involved as co-researchers was published in 2020. The conclusion pointed at indications on how collaboration efforts were prioritised at the expense of knowledge outcomes and scientific quality in such studies (Malterud & Elvbakken, 2020). For the present study, no alterations of methods were done to facilitate the collaboration. However, not all the co-researchers were as involved in the entire research process as would be considered ideal. The potential for improvement regarding the involvement of the co-researchers would be in striving for an even closer collaboration, having more personal meetings and discussions face-to-face.

To get funding for research in Norway today, collaboration with user organisations is mostly required. It is important to acknowledge that there are challenging aspects with involving users as co-researchers. Researchers and research institutions have obligations towards clients, financiers and collaboration partners. In the same way, other research actors have obligations towards researchers and research institutions. Research ethics balances norms of transparency and independence against demands for usefulness and social relevance. This balance is important to monitor closely, as imbalance could jeopardise research integrity.

For the co-researchers in this study, worsening and longer hospital admissions for some made them unavailable. This could have been a critical challenge for this study, given the time constraints of the PhD period.

The participation of co-researchers in this study has overall contributed to strengthening the patient perspective from the choice of questions in the interview guide, through the analysing process, to participation in conferences and co-authorship on published articles. From my perspective, this collaboration was not pursued at the cost of either knowledge outcomes or scientific quality for the study. Rather, it was crucial for ensuring the credibility of the research and mitigating potential sources of bias.

Our conclusions and suggestions are within the methodological limitations, we believe to yield a high degree of trustworthiness considering the breath of methods, and the interdisciplinary team involved. The involvement of experts-by-experience has helped to ground the project from the chosen aims and questions, the analysing process, to the dissemination of the findings.

6.2 Discussion of findings

This study aimed to provide comprehensive insight into the user and provider experiences with the medication-free treatment program in Bergen, Norway. This chapter will discuss the key findings, related to the relevant research and literature, in the following order: The patients' experiences of recovery and choice following this new treatment option; the health care workers' experience with and role in medication-free treatment; and the role of music therapy within this new treatment context. Medication-free treatment was a policy based on patient and human rights demands, and this was in the medical environment perceived as less adherent to traditional evidence based medicine policy creation (Fellesaksjonen, 2011; Juan Mendez, 2017; Røssberg, 2016). Alongside the implementation of this new guideline and practice, it was required to evaluate the possible outcomes, resulting in studies like the present one. To provide a clearer picture of the possible advantages and challenges following the findings in this study, this will be presented at the end of this chapter.

The patients' perspective

Medication-free treatment provides more options for treatment for the patients. More options give patients a higher likelihood to find a treatment that is perceived useful and more tailored to their needs. In this study, the participants all expressed how it was important to have a choice regarding their own treatment (Oedegaard et al., 2020).

This freedom of choice was related to how medication-free treatment provided the patients with an increased amount of choice of various psychosocial treatment measures in their treatment regimen. Such treatment has been found to have lower drop-out rates than pharmacological treatment (Villeneuve et al., 2010), suggesting a higher acceptability among patients. Offering both an increased number of treatments to choose from, and focusing on psychosocial methods, the medication-free project provides evidence-based measures to improve treatment adherence.

The perceived freedom of choice was also related to the more supportive attitude towards their wish to discontinue the medication. Having a freedom of choice delivers on the demand from the user organisations to provide an option to choose if medication should be a part of the treatment (Fellesaksjonen, 2011).

The freedom of choice was contrasted to the shared previous experience of not having a choice in their treatment. Considering the high degree of drop-out and non-adherence for patients suffering from psychosis (Semahegn et al., 2020), the implementation of medication-free treatment was an attempt to mend this gap in mental health care. Previous research shows that when patients are given choices about their care, they are more likely to engage in treatment, to adhere to interventions, and experience better outcomes (Davidson et al., 2012). Participants in this study chose treatment without medication mostly because of previous experiences with side-effects, or they did not want to or felt the need for using medication. Another study on medication-free treatment from Eastern Norway found how negative effects of medications and difficulty in obtaining alternatives were important reasons for wanting medication-free treatment. Some believed that taking medications did not fit with their concept of their problem and recovery (Standal et al., 2021). In this study, the participants contrasted the medication-free treatment with previous treatment, when they did not have the same options. Most of them shared that side effects was a reason to discontinue the medication, which is in line with the Standal study. Further, several expressed how they felt that using medication made them feel like they had failed somehow, also similar to the Standal finding. The use of anti-psychotic medication seemed to be stigmatising for patients. Medication-free treatment might add to this stigma, invoking a hope of coping without medication. This might affect the process of choice, and need to be considered, as research shows that social and self-stigma is a factor in non-adherence to antipsychotics (Townsend et al., 2022). Another critique asserts that with medication-free treatment, the patient does not choose between treatment options but determines by him- or herself what useful treatment is. In their view, this treatment is a step towards a 'reverse stigma’ that denies patients the right to be considered as such and deprives them of the right for proper treatment and care. Instead, it puts them at the jurisdiction of the much cheaper and ineffective social services (Fountoulakis & Souliotis, 2019). More options can be challenging. In this study, factors influencing treatment choices included fear of the unknown, and perceived positive aspects of symptoms. The participants conveyed how it could be difficult to know what helps (Oedegaard et al., 2020). This is in line with research showing how preferences of patients for how decisions should be made can vary depending on patient characteristics and therapeutic situations (Priebe et al., 2019). Further, research has shown how patient choices are influenced by elements such as trust, intuition, emotion and beliefs (Vos et al., 2018). Hence, the process of choosing treatment is far from straightforward. Some of the participants in this study chose to stop the tapering of anti-psychotic medication, or go back on anti-psychotic medication, because their symptoms worsened. For these patients, such change of treatment happened within the same department and with the same therapists as within the medication-free treatment course. This seamless transition seem to be more patient-friendly than if they would have to change therapist and department to obtain this change of treatment.

All of the participants in this study expressed a positive or improved communication and relationship with their therapist compared to previous experiences. This is in line with the report by Øvernes, concluding that the medication-free treatment course had a positive effect on the alliance (Øvernes, 2019). In this way, medication-free treatment seemed to provide improved alliance and relationship between patient and therapist, which is considered important for the recovery process (Ljungberg et al., 2015; Priebe et al., 2011).

This contrasts with research pointing at mental health care as patriarchal without much user involvement (Morant et al., 2018). A review from 2019 states how there is extensive evidence that a more positive patient–clinician relationship is associated with better adherence and more favourable clinical outcomes across treatments (Priebe et al., 2019).

The medication-free treatment regime requires a high level of personal agency focusing on personal coping strategies and personal responsibility for the recovery process. A higher degree of user involvement is considered a step towards a recovery-oriented mental health care (Petersen et al., 2012). In this sense, medication-free treatment is a recovery-oriented treatment, aiming to support patients' motivation for autonomous living and personal recovery. Autonomy concerns the regulation of behavior by the self, or the ownership of one's behavior, as opposed to behavior being controlled by forces perceived as outside the self. One definition states how autonomous individuals are self-organised and self-endorsed, and their actions are experienced as fully voluntary and authentic. The opposite of autonomy is feeling pressured, coerced, or compelled to act by forces or pressures perceived as external to the self (Legate & Ryan, 2014). Central to the idea of patient autonomy is the right to decide about their own life, and choice of treatment. In general healthcare, there are a few known exceptions of patient autonomy, regarding particular communicable diseases and parents' right to decide on behalf of their children. In psychiatry, particularly coercive measures challenges patient autonomy. Hence, the level of patient autonomy in psychiatry depends on the level of symptoms and to which degree there is a need to protect the patient or the society from harm. Other relevant considerations regarding patient autonomy in psychiatry is the difference in power between the therapist and the patient, resulting in how user organisations worry that patients are pressured into taking medication

(Fellesaksjonen, 2011). In this study, the participants shared how they were motivated to “do the job” to get better (Oedegaard et al., 2020). This indicates an increased sense of ownership of the treatment, which is also found in the report from Øvernes (Øvernes, 2019). However, a high degree of self-agency and autonomy could be counterproductive with increased risk of personal failure. Affected by severe mental illness, it can be difficult to maintain motivation in the process of recovery, including the use of coping strategies. The use of coping strategies needs to be closely monitored, as studies have shown associations between these and self-stigma in schizophrenia (Holubova et al., 2016). There are important ethical issues regarding patient autonomy in psychiatry. In ordinary circumstances, the clinical duty of care to protect life and health is trumped by the duty to respect autonomy. Because of its possible effect on levels of competence, serious mental illness reverses the moral logic of the duties of care. Here, the patient's capacity may become so reduced that respect for autonomy no longer legitimately trumps protection (Doyal & Sheather, 2005). Among psychological frameworks, autonomy is central to self-determination theory, arguing that autonomy is a basic and universal psychological need essential for motivation and well-being (Legate & Ryan, 2014). Ethical discussions on autonomy versus protection are important for the implementation of medication-free treatment as this treatment aims to increase patient autonomy, which is regarded important to obtain personal recovery.

Medication-free treatment aims for a higher acceptance of discontinuation of medication, focusing on a democratic shared decision-making where the therapist and patient decides on which therapy to use together (Hamann et al., 2003; Oedegaard et al., 2020). Shared decision making is seen as a mechanism for decreasing the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being (Hamann et al., 2003). The therapist takes an active role reporting information and treatment possibilities to the patient, and can recommend an option. The patient receives the information and judges on possible harms and benefits of the options, and discusses the preferences with the therapist. Specifically, when choosing medication, this is a shared decision-making between the psychiatrist and the patient. For psychosocial support therapies, this process normally takes place between the designated responsible therapist, who can be either a psychiatrist, a psychologist, or a psychiatric nurse. Within music therapy, this process takes place more or less continuously between the music therapist and the patient.

Essential preconditions for shared decision-making are self-determination of the patients and their right to an optimal explanation of the illness and its treatment possibilities (Hamann et al., 2003). The model of shared decision-making aims at increasing the autonomy of psychiatric patients, also hoping to improve pharmacological adherence (Hamann et al., 2003). Possible limitations of the use of shared decision-making for patients with psychosis are whether the patients believe they are ill or not, which phase of the illness they are currently experiencing, possible disorganisation of thought, and paranoid symptoms. Studies suggest that a successful implementation of shared decision-making depends on the use of decision aids. Such an aid was not implemented until 2019, after the interviews of this study was carried out. (website: Nytt samvalsverktøy for psykose)

In this study, participants were positive towards a more involving decision-making process. The process of shared decision-making corresponds with recommended approaches to enhance the relationship with and the recovery process of the patient (Duncan et al., 2010; Slade, 2017). This facilitates a learning experience particularly regarding individual need of anti-psychotic medication.

Numerous studies provide evidence on the positive effects of various psychosocial treatment measures. Examples of such treatment are supportive psychotherapy, Cognitive

Therapy/Cognitive Behavioural Therapy (Nowak et al., 2016), family therapy (McFarlane, 2016), group therapy (Burlingame et al., 2020), supported employment (Evensen et al., 2017), exercise (Girdler et al., 2019), music therapy (Geretsegger et al., 2017; Gold, 2007; Gold et al., 2006; Gold et al., 2005) and more. Findings from these studies suggest outcomes like improved alliance and increased autonomy and motivation for treatment, similar to the findings from this study. Findings from our study cannot be distinguished from positive effects of the regular psychosocial treatment offered, and are not necessarily the effect of the explicit medication-free treatment course. One additional concern with these findings is how shared experiences of improvements or worsening were simply connected to the patient's phase of illness, without considering other potentially relevant factors. However, aiming to convey the user's experience with choosing a medication-free treatment, the findings are relevant and useful to understand the importance of emphasising choice regarding medication.

The therapists' perspective

Within the constraints of a bureaucratic system of health care delivery, there is a need for prioritising the resources, even in Norway (Wisløff, 2015). Norway spends about 5% of GDP on mental health care, placing us among the five countries in Europe with the highest level of expenses (OECD, 2021). More options, as provided within the medication-free treatment, are resource demanding. In this study, it could be challenging for the therapists to take the role as a “street level bureaucrat”, representing the gate keepers for prioritised resources (Oedegaard et al., 2022). Particularly, balancing the patient’s needs with treatment guidelines, the legal framework and available resources could be demanding.

In a bureaucratic health care delivery system, health care delivery requires both human interaction and care, but also professional distance to assure equal treatment, with an equal distribution of the benefits. The delivery of street-level policy through bureaucracy, as explained by Michael Lipsky, depends on health care workers’ ability to embrace this paradox (Lipsky, 1980). Resource constraints in this regard would be limited availability of therapy sessions, or patients expressing needs the health care system is not rigged to meet. It is well known that family members caring for relatives with schizophrenia experience a high level of burdens (Lippi, 2016), indicating how the health care system is unable to meet all patient needs.

The therapists expressed a fear of relapse, particularly for patients without insight, or with no wish to stay in therapy regardless of options. This is in line with a study sharing how psychiatrists believed that this treatment option would aggravate negative attitudes towards medication and worsen existing adherence issues (Yeisen et al., 2019). The risks related to discontinuation of antipsychotic medication was confirmed in the study by Maria F. Strømme, finding that non-use of antipsychotic drugs was associated with twofold increased mortality in patients with schizophrenia (Strømme et al., 2021). Strømme also found how the use of antipsychotic drugs protected against acute readmission, and also against readmissions with overactive, aggressive, disruptive and agitated behavior (Strømme, Bartz-Johannesen, et al., 2022; Strømme, Mellesdal, et al., 2022). Hence, our finding on shared distress regarding the safety of the patients was also seen in Strømme's study. The KBT report expressed criticism to which degree the patient's choice was prioritised over the professional responsibility (Bjørgen, 2018). The present study confirms how balancing these demands were a challenge for the therapists. The therapists all had an overarching wish to help patients preferably through cooperation and therapeutic alliance. They felt compelled to accept and respect the patient's choice even when they considered it would possibly lead to deterioration of the patient's health and quality of life. In turn, it seemed accepting these patient choices could lead to therapists distancing themselves from their key function; to safeguard their patients from harm. This is in line with research showing how a gap between ideals of good care and a harsher reality may lead to moral distress, causing health care staff to distance themselves from their patients and inner selves (Jansen et al., 2020). This study confirms the challenging balance between the distress considering possible worsening, and an acceptance of patient choices even when they are contrary to what they would have considered best treatment.

The findings regarding the patient perspective, who were positive towards "having a choice" regarding their treatment, particularly their medication, and a more involving decision-making process, needs to be discussed in light of the findings from the therapists' perspective. Therapists were positive towards having more treatment options for their patients, but worried about deleterious effects of discontinuing the medication. All the therapists expressed a wish to help the patients, regardless of choice of medication. When patients chose treatments the therapists considered unhelpful, and further described how they saw an increased number of patients on the streets, it suggests an attempt to reconcile the need to both protect the patient as well as the society. Being on the street would normally not be considered helpful for the patient, nor for the society.

The therapists expressed a risk of becoming more distanced, but the patients conveyed how their relationships with their therapists were improved compared to previous experiences. This might indicate both that the therapists have not developed a more distanced way of treating the patients within the timeframe for this study, or that they are able to shield their patients from such feelings. In this study, they expressed how they had to accept patient choices, which then seems to be the “accepting” atmosphere experienced by the patients.

Several studies have explored the moral distress experienced by health care workers in psychiatry, including psychiatrists. This distress is the state experienced when moral choices and actions are thwarted by constraints (Austin et al., 2008). Studies have shown how psychiatrists are struggling ‘to do the right thing’ for patients within a society that places unrealistic demands on their capability. These demands does not consider the complexity of reality, where psychiatrists are expected to both care for persons with serious mental disorders, and protect the public from possible harm. In the 1970s the term “double agent,” both in psychotherapy and in medicine, came to signify the clinician’s joint responsibilities to the patient and the state (Strasburger et al., 1997). The current study reproduces this aspect of being the responsible therapist, but no findings points at a less supporting or accepting relation, or diminishing alliance, between the therapists and patients, rather the contrary. However, the time frame might have affected these findings, and the possible alienation from the task conveyed by the therapists should be re-evaluated and considered for added supportive measures.

The role of music therapy in medication-free treatment

Medication-free treatment differs from treatment as usual in the explicit and expressed patient aim of discontinuing their medication during the treatment course, or only using non-pharmacologically based treatments as a part of their treatment course after having discontinued their anti-psychotic medication. However, the non-pharmacological treatments offered are the same as within treatment as usual, and includes as mentioned psychotherapy, group therapies, work support, exercise and more. In this study, music therapy was described as a process-oriented treatment with a high degree of flexibility focusing on and supporting patient choices. Music therapy fits well within this treatment regimen, as it is flexible and adaptive in shape and content, and perceived more enjoyable and less as traditional therapy by the patients (Solli & Rolvsjord, 2014). Findings from the focus group discussions in this study showed how the collaborative choices that unfolded between patient and therapist in music therapy was considered important for treatment outcome (Oedegaard et al., 2022). The informants described sometimes complex therapeutic relationships related to the individual treatment needs, and discontinuation of therapy.

Advantages and challenges related to the implementation of medication-free treatment

Evaluating the medication-free treatment regime naturally focuses on advantages and challenges. With this intention, the findings, which are discussed above, are regrouped in the table below, focusing on experienced and shared advantages and challenges found in this study.

Table 3: Summary of key advantages and challenges with medication free treatment by data collection method:

Data collection method	Research questions	Main perspectives	Results	
			Advantages	Challenges
In-depth interviews with participants	To obtain and explore first person perspectives on medication free treatment in mental health care	Choices Coping-strategies	-Important to have the freedom of choice -Improved relationship with caregiver(provider) -Increased self-agency facilitating learning processes	-Difficult to choose Risk of self-stigma with a higher degree of responsibility.
Focus groups with therapists	To explore mental health workers overall experiences	Services Resources	-More treatment options for patients More psycho-social support	-Resource demanding -If worsening, difficult to get into

	with the implementation of medication free treatment			position to treat -Therapists may experience alienation from their tasks when unable to safeguard patients.
Focus discussion groups focusing on music therapy	To provide a deeper insight into the role of music therapy as treatment for psychosis from patient and therapists’ perspectives	Implementation	Music therapy: -an important tool in the toolbox for the care team -improved relationships with patients -More accessible, not seen as regular treatment	Music therapists_ -Fear of being in charge of considering possible worsening. -Difficult to decide when to end therapy. -Need better integration with the care team.
Participant observation taking ethnographic notes (individual music therapy)			High acceptance of treatment, with high turn out	Difficult to know when to end therapy

The purpose of this table was simply to provide the reader with an overview of advantages and challenges conveyed by both patients as well as therapists throughout this study. The informant's perspective often defines whether something is a challenge or an advantage, or both at once, and the attempt of sorting their thoughts into these two categories is clearly a simplification. For example, 'choice' was seen as an advantage from the patient perspective and a challenge from the provider perspective, and there were shared nuances on the topic from both groups of informants. As discussed above, this is not a nuanced picture, but helps in creating an overview of the themes presented and discussed, which can be conveyed as simplified "pros and cons" in the debate regarding the implementation of medication-free treatment.

7. Conclusions

Integrating more evidence-based psychosocial interventions into existing mental health services facilitated learning experiences regarding the choice of treatment, including medication, focusing on increased self-agency, responsibility and motivation in the recovery processes.

Medication-free treatment is supportive towards patient choices, and appears to improve the dialogue and relationship between the patient and the caregiver.

This democratization of treatment choices challenges the level of professional discretion. Empowering patients restricts health carers’ room for decisions when caregiver and patient have conflicting goals. Balancing the wish to help and professional responsibility with perceived lack of resources and troublesome patient choices may lead to therapists feeling disempowered in and alienated from their work.

Music therapy represents the recovery philosophy, with a high degree of flexibility and freedom of choice. These choices are made continuously, in collaboration with the therapist, but also contingent depending on circumstances. There is a need for increased knowledge on the potential and limits of music therapy among co-workers.

8. Implications/Recommendations

From a patient perspective, we recommend an increased level of psychosocial interventions and support for patients suffering from psychosis, to increase the freedom of choice and facilitate possible empowering of the individual able to make use of this freedom. Pure medication-free treatment wards should pay attention to the possible changing needs patients with psychotic disorders might have, and consider offering adequate medication following symptom load for a more seamless transition following the patient’s treatment needs, to avoid acute and serious worsening of the symptoms.

The implementation of music therapy for patients with psychosis is advantageous; however, the integration of this treatment has potential for improvement on both a competency level for the care team, but also for the music therapists in developing its usefulness and role within the care team. Also, we believe further use of shared decision making based on the principles of person-centered care (level of symptoms, personal experiences and individual preferences) can be beneficial. To optimise the potential outcome, continuity over time in developing interpersonal relationships between patients and therapists is highly recommended. A designated specialist or team responsible for follow up after discharge, which should be easy to reach for the patient could facilitate continuity and needs to be considered at system level. To avoid possible alienation from their work, therapists need more support in their tasks, and a management which is capable of considering and explaining the full medical academic rationale for the implementation of new treatment guidelines.

For future research, a key factor is how therapists consider patients' capacity for giving an informed consent in decisions regarding (forced) treatment. Future research should also look into how medication-free treatment and similar treatment measures possibly affects the total cost-benefit accounts of mental health care in Norway.

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“It means so much for me to have a choice”: a qualitative study providing first-person perspectives on medication-free treatment in mental health care

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Abstract

Background: In 2016, the Western Norway Regional Health Authority started to integrate more evidence-based psychosocial interventions into the existing mental health care, emphasizing the right for persons with psychosis to choose medication-free treatment. This change emerged from the debate on the effectiveness and adverse effects of the use of antipsychotic medication. Aspects beyond symptom reduction, such as 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 whether these aspects were present in users’ descriptions of their recovery processes within the medication-free treatment programme in Bergen, Western Norway. We interviewed ten patients diagnosed with psychosis who were eligible for medication-free services about their treatment experiences. Data were analysed using Attride-Stirling’s thematic network approach.

Results: The findings show a global theme relating to personal recovery processes facilitated by the provision of more psychosocial treatment options, with three organizing subthemes: interpersonal relationships between patients and therapists, the patient’s understanding of personal patterns of suffering, and personal motivation for self-agency in the recovery process. Participants described an improved relationship with therapists compared to previous experiences. Integrating more evidence-based psychosocial interventions into existing mental health services facilitated learning experiences regarding the choice of treatment, particularly the discontinuation of medication, and appeared to support participants’ increased self-agency and motivation in their personal recovery processes.

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

Keywords: Recovery, Communication, Decision making, Lived experience, Psychosis, Medication, Quality of care

Background

In 2015, the Norwegian Health Minister, following the advice of user organizations, urged the four regional health authorities to offer medication-free treatment to persons experiencing psychosis [1]. In 2016, the Western Norway Regional Health Authority started integrating more psychosocial interventions into existing mental health care services in district psychiatric centers to comply with this guideline. The provision of increased psychosocial intervention options within mental health care was intended to enable patients wishing to discontinue medication to do so in a supportive setting. This change in mental health care emerged from the debate on the use of antipsychotic medication (referred to as AP medication) as a part of the treatment for severe psychiatric illness [2]. On the one hand, AP medication is recommended in the short term to reduce positive psychotic symptoms and in the long term to reduce the risk of relapse [3–5]. In some studies, AP medication has been associated with increased survival [6–8], and the discontinuation of AP medication has been associated with poor long-term outcome [9], including increased risk of violence [10, 11]. Severe mental illnesses, such as schizophrenia, have a substantial negative effect on life expectancy, together with an increased risk of suicide [12–14], which is also related to a lack of adherence to antipsychotic medication [15, 16]. The discontinuation of AP medication is often described as non-adherence rather than as an integrated part of a treatment regimen in collaboration with psychiatrists.

On the other hand, studies show that the dose reduction/discontinuation of AP medication is superior to maintenance treatment for long-term recovery [17, 18] and that the 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 deciding whether to use AP medication [25–28].

The introduction of optional medication-free treatment for psychosis is a recovery-based reform of mental care based on advocacy work by 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 user organizations and wider civil society [29]. Qualitative studies and meta-syntheses have shown the importance of aspects beyond symptom reduction for the recovery process. Such aspects include interpersonal processes, increased understanding of one's own pattern of suffering, and increased hope and motivation, which lead to self-agency in the treatment process [29–32]. There are relatively few studies focusing on the first-person perspective in the implementation of new treatment programmes in mental health care [33], and to our knowledge, no studies with personal accounts of treatment programmes integrated in existing services aiming to support patients in choosing to discontinue antipsychotic medication have been published.

We believe there is a need to explore whether aspects known to be important for the recovery process are present in users' descriptions of their treatment experiences within the medication-free programme in Bergen, Western Norway. Hence, this study aims to use qualitative methods to investigate the experience of recovery following new treatment options and choices.

Methods

Site

The Norwegian health system is largely a public health system. It is organized into four regional health authorities, which each chose different approaches for the implementation of the medication-free treatment programme. The Western Norway Regional Health Authority aimed to improve health care for all patients with psychosis by tailoring treatment to individual preferences and integrating more evidence-based psychosocial interventions into existing services in district psychiatric centers. The treatment options offered were individual psychotherapy including cognitive therapy, Illness Management and Recovery (IMR) groups, individual job support (IPS), music therapy, and physiotherapy, including various groups for exercise. The services were designed to support whichever choice the patient made regarding both medication and psychosocial options. The focus was on increasing users' involvement and sense of ownership of therapy, as well as improving the patient-therapist alliance. The services were not designed to promote one treatment choice over another. The medication-free project established a website with information [34] 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 that included semi-structured, in-depth interviews (topic guide available, see Additional file 1) with people with psychosis who were registered for medication-free treatment. Qualitative methods such as in-depth interviews aim at understanding and representing the experiences of people as they encounter, engage, and live through situations [35–37]. This study also employed a service user-involved approach [30, 38] developed within a hermeneutic-phenomenological epistemology. Following this approach, the research team had a phenomenological aim to explore and describe the lived experiences of personal recovery processes within mental health care where medication-free treatment for psychosis has been proposed. Further, the co-authors recognize that our attempts to adopt such an approach inevitably involved interpretations.

Researchers and user involvement

The first author has no health professional background, which was preferred by our collaborating user organization. Together with the first author, the supervisors and co-authors of this article constituted an interdisciplinary research team including a professor in music therapy, an associate professor in psychology, a professor in psychiatry, and a professor in medicine.

To ensure respect for the complexity of users' views on the topic of this study, the research team invited four experts by experience to be 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 were involved in the study from the preparatory phases (developing the protocol and research questions and discussing the semi-structured interview guide) through the data analytic phases (participating in the team-based analysis) and the 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 that interventions remain "user friendly," and improving the selection of outcome measures [39]. The authors believe this involvement enhanced the quality of the study through the development of a meta-perspective on the research process [30, 38, 40].

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 covered four main topics: the participants' life stories, their encounters with the health care system, their experiences of the freedom to choose, and their thoughts about the future. Within each of these topics, there were several open-ended questions and potential probes to elicit participants' narratives of their experiences.

The first author conducted the interviews and made notes of her experiences after each interview to promote reflexivity and to be able to better remember the setting and ambiance of the interview at a later date. She obtained informed written consent from each participant 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, and one was excluded from the analysis process for this article, as the informant had no intention of discontinuing medication. The interviews varied in length from approximately 45 to 90 min. All interviews were tape recorded and transcribed by the first author.

Participants

The participants were people with psychosis registered as patients in one of two district psychiatric centers for 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 therapists, orally and in writing. The therapists assessed eligibility for this study following the inclusion criteria of being above 18 years of age, being able to give informed consent, presenting with psychosis, and being a patient at one of the three district psychiatric centers. The participants also had to be actively engaged in medication-free services, which could be exercise, music therapy, job support, or other group therapy sessions.

The participants were purposefully selected to vary in age, gender, and past treatment histories to ensure diverse patient experiences (see Table 1 for details). There were five females and five males; nine were aged 25–40 and one 45–50. The number of admissions varied from 0 to 5 (6 participants) and 10–20 (3 participants), and

Table 1 Participant details

Patient	Diagnosis	Known medication, including previous and discontinued	Treatment at the time of the interview
P1	F20 Paranoid schizophrenia	Olanzapine long-acting injection	Aborted medication free, IMR, FACT, AFR, MI, psychotherapy.
P2	F20.3 Schizophrenia	Aripiprazole long-acting injection, Buprenorphine	Aborted medication free, AP medication, IPS, IMR, psychotherapy.
P3	F23.3 Acute paranoid psychosis	Olanzapine	Discontinued, medication free, psychotherapy.
P4	F29 Unspecified nonorganic psychosis	Aripiprazole, Quetiapine	Discontinued AP, music therapy, IMR, group therapy, psychotherapy
P5	F25.1 Schizoaffectiv disorder, depressive type	Aripiprazole, Lithium	Low dosage AP, music therapy, art therapy, ACT, psychotherapy.
P6	F23.9 Acute and transient psychosis	Escitalopram	Discontinued, medication free, psychotherapy.
P7	F25.1 Schizoaffectiv disorder, depressive type	Quetiapine	Discontinued, medication free, IPS, IMR, psychotherapy.
P8	F20.0 Paranoid schizophrenia	Aripiprazole, Sertraline	Aborted medication free, IMR, IPS, group therapy, psychotherapy.
P9	F41.9 Unspecified anxiety. Previously F22.0 Paranoid psychosis	Amisulpride	Discontinued, medication free, IMR, IPS, psychotherapy, exercise.
P10	F25 Schizoaffectiv disorder, manic type	Aripiprazole long-acting injection	Aborted medication free, excercise, FACT, psychotherapy.

Abbreviations: *IMR* Illness Management and Recovery; *IPS* Individual Placement and Support; *AP* Medication: Antipsychotic Medication; *ACT* Assertive Community Treatment; *FACT* Flexible Assertive Community Treatment; *MI* Motivational Interview

one had 20–30 admissions. Age of introduction to psychiatric healthcare varied from 17 to 41. The participants could choose where they preferred to do the interview. Most chose to be interviewed at the district psychiatric center, 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. In Table 1, the term "aborted medication free" means the patient had an intention to discontinue AP medication but decided to go back on AP medication for some reason and did not report any immediate intention to discontinue the medication again at the time of the interview. "Discontinued" means the patient had succeeded in discontinuing AP medication and did not express the intention of or need for using AP medication again at the time of the interview.

Data analysis

The transcribed text was analysed using Attride-Stirling's [41] thematic network approach. The text analysis was conducted as a team, with all co-authors being invited to read and comment on the raw, anonymized transcripts as well as be part of the coding process. Attride-Stirling's thematic network analysis [41] provides procedures for conducting analysis of interview data, enabling the 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 the structures and patterns of a text [41]. The first author (CO) performed the first coding together with two fellow PhD students who were not otherwise involved in the study, forming a coding framework and discussing the possible thematic network based on the first three interviews. This procedure is considered to strengthen the credibility of the chosen codes, as it enhances the rigour of the data analysis process. The codes emerged from the text, and CO, together with the fellow PhD students, identified the basic themes common across the interviews. After this initial coding, the coding framework was further developed as an iterative process with most co-authors collaborating and providing feedback. The basic themes were grouped based on their related conceptual content into the following organizing themes: "interpersonal relationships," "patterns of suffering" and "motivation and personal agency in the recovery process." The research team openly discussed interrater agreement and disagreement, taking care to emphasize the importance of the feedback from the experts by experience. This process also gave the co-authors the opportunity to provide information and understanding based on their various professional backgrounds. 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 reflected the research question via the codes, basic themes and organizing themes. The translated coding frame relevant for this article is displayed in Table 2. The codes and themes, along with key quotes used to illustrate the findings, were translated into English by the first author. The research team used the NVivo software program for

Table 2 Relevant codes and themes from the analysis using Attride-Stirling's thematic network analysis [41]

Codes	Basic themes	Organizing themes	Global theme
Information – treatment options and rights	Communication skills	Interpersonal relationships between therapists and patients	Personal recovery processes facilitated by more psychosocial treatment options within mental health care – medication-free treatment programme
Doctor, trust and availability			
Power play	Potential difficulties		
Substituting AP medication with other treatment			
The importance of having a choice	Processes of treatment choices	Patterns of suffering and how choices are made	
Choosing the unknown			
Choosing medication; effects, side effects			
Getting experience	Developing personal illness understanding, considering consequences		
Worsening: not an easy way out			
Outside factors, keep work and family			
Expectations; do it myself	Personal responsibility for recovery	Motivation and personal agency in the recovery process	
Coping strategies			
Doing stupid things			
Being independent, not telling	Future life hopes and thoughts, independence in life and treatment situations		
Dreams and hopes; work, studies, family			
Not being hard on myself			

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; hence, according to the Norwegian health research legislation, the study was approved by the local data protection officer. The data protection officer for Health Bergen approved the study in July 2017 (2017/8692).

Results

The data analysis framework, from the codes to the global theme, is illustrated in Table 2. This results section is structured according to the organizing themes: interpersonal relationships between patients and therapists, 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

When the participants in this project were asked about their reasoning for their choices, they expressed uncertainty both regarding the treatment options available to them and explanations for their choices. Answers such as "I'm not sure" and "I don't remember" were quite common. One participant mentioned a lack of information regarding a patient's rights to complain about the treatment:

> P9: "She could have informed me better about my rights; if I disagreed with her. (…) I had to figure that out by myself."

Inadequate information included a lack of information, withheld information and an underestimated need for repeated information. Importantly, some participants reported that the type of service offered seemed rather arbitrary rather than a "real choice." Not all services were available, and furthermore, not all services were suggested by the therapists:

> P4: "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 to be limited in terms of availability and the information provided by the therapist, as well as the individual need for repeated information when illness and symptoms might affect memory [42]. This finding indicated a need for increased focus on shared decision making.

However, the level of information is not the only parameter of the quality of an interpersonal relationship that is considered important for the outcome of the therapy [43]. Trust is vital for therapy outcomes. In this study, the participants shared an overall feeling of confidence in their therapists. In response to questions about who they would trust to provide advice about their treatment choices, all participants mentioned their current therapist, along with other key persons in their lives.

The availability of the therapist was closely linked with descriptions of a positive patient-therapist relationship. One participant described his psychiatrist as easy to reach, and he felt he could take part in decisions concerning his own treatment:

> P7: "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. Such uncomfortable situations could include talking about the worsening of symptoms or wishing to change or discontinue a medication. One participant described powerlessness in the relationship and talked about communication as a "game":

> P2: "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 participants described having had trust issues with the therapist or health care system in general, often linked to a period of worsening and their admission, but then being able to repair the relationship over time. One participant described this process:

> P7: "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 participants reported that their illness and change in symptom severity could affect the experience of the quality of the relationship.

Despite the experienced trust, in regard to the process of the discontinuation of medication, the participants reported being presented with certain conditions. Therapists could accept their wish to discontinue AP medication, but not without substituting the medication with other treatment:

> P5: "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 substituted medication with other available treatment options.

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 (IMR) skills training, individual job placement and support (IPS), music therapy, exercise and family group therapy. All of the participants confirmed the importance of having a choice in their treatment when asked directly. One participant said,

> P2: "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 participants, which made it hard to choose, both for the participants as well as for their family or peers:

> P4: "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."

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

> P1: "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 participants recognized that taking medication is complex. Using medication may result in adverse effects, but discontinuing may not be an easy solution. One informant explained that he knew his delusions included delusions about medication, making him believe that the pills were poison and that the pain and aching in his body were severe adverse effects killing him. These delusions led to a wish to discontinue medication. In particular, forced medication was associated with delusions:

> P7: "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 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 have stemmed from delusions for some of the participants; however, the side effects from the use of AP medication must be recognized. Regarding the experienced side effects, some participants reported losing control over their body parts, one participant mentioned a feeling of drowning, and most participants talked about gaining weight and feeling tired:

> P10: "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 that medication has on one's body is a learning process. Not all participants wanted to reduce all symptoms of their illness; for example, one participant said,

> P5: "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 completely said goodbye to the psychosis yet."

Other participants also described a similar relationship with their symptoms, such as that hearing voices made them feel accompanied and that they felt lonely without them.

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

> P8: "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, such as having to work, were also important to consider in the participants' processes of learning about their own patterns of suffering:

> P10: "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 becoming experienced with one's own illness; the symptom load, the adverse effects, and the outside factors all contribute to decision making about treatment options.

Motivation and personal agency in the recovery process

Recovery-oriented pathways require personal agency and involve a responsibility to improve one's life. Several participants expressed a feeling of having to "do the work" themselves:

> P2: "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."

By having to "doing the work," the participants meant they had to employ coping strategies such as avoiding excess stress; staying away from drugs; or maintaining a daily routine of sleeping, resting, and eating well. Taking responsibility for their well-being implied a 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:

> P10: "What happened to me first was that I started to be a bit bitter toward psychiatry in general; I didn't want anything to do with them (the care team) 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 them … They didn't know what to do, they said then. But I think it was quite unfortunate they didn't catch on earlier that I was ill."

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

> P2: "So, I have been very determined to deal with all of this by myself. (…) So, I have been very independent."

When the need for independence involves not telling carers about one's symptoms, there is a risk of the worsening of symptoms becoming out of control. Nevertheless, 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 or perhaps having a family. One informant described her thoughts about her life:

> P5: "Now, I just want to figure out 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 saw herself in 10 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 the participant's need to not be so "hard on herself" as a coping strategy, which is consistent with her understanding of her own vulnerability, as well as her fear of not surviving the illness. The task of both surviving psychosis and maintaining 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 who are eligible for outpatient treatment in Bergen. The participants in this study shared a generally positive impression of their interpersonal relationships and communication with their current therapists. Developing trust with the therapist was 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 that therapists have made to meet patients' needs and present higher acceptance of patient choices. This result is in contrast to those of other studies on collaboration between therapists and patients [44–46]. However, potential difficulties that participants cited 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 on outpatient clinics in 2007, users reported a need to improve the level of information on available treatment options [47]. It seems there is still room for improvement in information flow. A digital tool for shared decision making for people with psychosis was developed in 2018–2019 and was launched in August 2019 to be implemented in the Western Norway Health Region to improve these issues [48].

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 strengths and vulnerabilities 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 [49]. This is in line with the present study findings, which showed that factors influencing treatment choices, particularly those regarding medication, included a fear of the unknown, delusions, "not knowing what helps," and the beneficial aspects of symptoms. One of the participants shared that 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 for a mental illness may be stigmatizing [50], but the participants did not otherwise mention stigma surrounding psychiatric illness as much as expected, even when the first author probed on this topic during the interviews.

Personal responsibility and motivation for the recovery process was highlighted by most of the participants, often associated with an extensive focus on coping strategies. The participants generally concluded that they "need to do the work on their own" in their recovery processes. They regarded their coping strategies as important tools to keep their symptoms under control. Several of the implemented treatment options focus largely on coping strategies. The emphasis on coping strategies needs to be closely monitored, as studies have shown significant associations between self-stigma and coping strategies in schizophrenia [51, 52].

Thoughts about the future included both hope for independent living as well as a certain resignation to facing life with an illness. The learning processes that resulted from the choices participants had made sometimes came with a cost. Four participants had aborted the discontinuation of medication, as they were not able to cope with the symptoms without medication, with some experiencing adverse events as a result. Others felt they coped well and were satisfied with a life with lower dosages of AP medication or without AP medication. These findings show how increased psychosocial intervention options support personal recovery processes such as increased self-agency and motivation, which is in line with findings from other studies [53, 54]. However, it is important to take into consideration the possibility of risk related to 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 participants, and the interviews were performed soon after the implementation of the treatment programme had commenced. Therefore, the health system and services may not have been fully acquainted with the change at the time of the interviews. However, this study provides first-person perspectives on choosing treatment within a health care system undergoing change through the implementation of more recovery-oriented treatment options. It is important that context-specific users' perspectives are considered in the research on the implementation of new treatment programmes.

Conclusions

Health care in Norway is perhaps one step closer to optimizing care for people with psychosis, allowing for more patient choice and improving the dialogue and hence the interpersonal relationship between the patient and the carer. Within a more supportive system, personal patterns of suffering can be explored in relation to factors that are known to facilitate personal recovery. Such a system 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 include the recommendation of an increased level of psychosocial interventions and shared decision making in mental health care that are adapted based on the level of symptoms, experience and individual preferences. Additionally, it is important to take into consideration the importance of continuity over time in developing interpersonal relationships between patients and therapists.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12888-020-02770-2.

Additional file 1. Short topic guide used for the in-depth interviews with the patients, translated from Norwegian.

Abbreviations

AP Medication: Antipsychotic medication; IMR: Illness management and recovery; IPS: Individual placement and support; ACT: Assertive community treatment; FACT: Flexible assertive community treatment; MI: Motivational interview

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Declarations

The funding body had no role in the design of the study, or in the collection, analysis, or interpretation of data, nor in writing the manuscript.

Authors' contributions

CO: Main researcher and author. LD: advisor for the study and contributor to writing the article. BS, MV: supervisors of the study and contributors to analysing data and writing the article. AB, LG, J-MS and ØS: contributors to developing the protocol and the interview guide and analysing the data. IMSE: major supervisor of the study and contributor to writing the article. All authors read and approved the final manuscript.

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Availability of data and materials

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

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; hence, according to the Norwegian health research legislation, the study was 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 stored securely only 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 signed a form declaring their informed consent to participate in the study.

Consent for publication

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

Competing interests

The authors declare that they have no competing interests.

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RESEARCH **Open Access**

How can we best help this patient? Exploring mental health therapists' reflections on medication-free care for patients with psychosis in Norway

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Abstract

Background: Since 2015, Norwegian Regional Health Authorities have followed new government policy and gradually implemented medication-free services for patients with psychosis. The aim of this qualitative study was to explore the tension between policy and practice, and how health care workers in Bergen reflect on their role in implementing medication-free treatment.

Methods: We performed three focus group discussions including 17 therapists working within medication free services, asking about their experiences with this new treatment program. We used Systematic Text Condensation for data analysis. The findings were discussed using Michael Lipsky's theoretical framework on the role public health workers play in policy implementation.

Findings: Following Norway's new policy was challenging for the therapists in our study, particularly balancing a patient's needs with treatment guidelines, the legal framework and available resources. Therapists had an overarching wish to help patients through cooperation and therapeutic alliance, but their alliance was sometimes fragile, and the therapists worried about patients' conditions worsening.

Conclusions: Democratization of treatment choices, with the aim of empowering patients in mental health care, challenges the level of professional discretion given that patients and therapists might have conflicting goals. Balancing the desire to help, professional responsibility, the perceived lack of resources, and certain patient choices created conditions that can leave therapists feeling disempowered in and alienated from their work.

Trial registration: N/A.

Keywords: Norway, Health care delivery, Psychosis, Policy implementation, Street-level bureaucrats, Medication-free treatment

Background

Over recent decades, there has been a shift from a paternalistic role of the physician acting in the assumed best interest of the patient toward an increased emphasis on the will of the patient [1]. In this paradigmatic shift, the focus on decisional capacity and patients being seen as right holders is increasingly important in mental health

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care. Human rights activists criticize the use of coercive treatment and disempowerment of the patient and emphasize the individual freedom to choose treatment [2]. However, patients' freedom to choose treatment within mental health care can be demanding for health workers, because they have a professional obligation to protect the patient and the community from harm and must take these perspectives on treatment and care into account [3, 4].

Health care in Norway is government funded. As in most health care systems, the delivery of care is subject to the prioritization of available resources, including the type of medication provided, to available psychosocial treatment options. Available resources depend on both the Regional Health Authorities' priorities and government policy. The Minister of Health in Norway established a policy in 2014, stating that mental health care should increase more than health care for physical illness in terms of both the use of resources and level of treatment activity within each region. The success of this policy is debated, as resources provided for somatic (physical) health care still increase more than for mental health care [5]. Resources within mental health care have mainly been reallocated from inpatient to outpatient treatment [6], and there has been limited increase in the total level of resources. Further, it is generally understood that patients with psychosis or schizophrenia are a resource-demanding patient group. In 2018, a report from the Norwegian Directorate of Health showed that 10% of the adult patients in mental health care used 76.7% of the resources for that sector. The report also states that patients with schizophrenia are overrepresented within this group [7].

Schizophrenia spectrum disorders represent severe mental illnesses that imply a high global disease burden and disability [8], and are often treated with pharmacotherapy [9]. In 2011, service user organizations came together to lobby for medication-free services within the Norwegian mental health care system [10]. This service requirement also emerged from the debate on the effectiveness and adverse effects of antipsychotic medication (AP) used as part of the treatment for severe mental illness [11–32]. The debate on the implementation of medication-free treatment was polarized, with professionals arguing against it, pointing at research showing that medication works, and a lack of scientific support for the new guidelines [33]. The Norwegian government agreed with user organizations that medication-free services should be a priority, and in 2015, the Norwegian Regional Health Authorities began allocating resources and introducing these services for patients with psychosis, within the constraint of the law defining responsible treatment [34]. The law provides constraints implying that all patients 18 and above, who are able to give an informed consent and are not subject to coercive treatment, can choose medication-free treatment. If the patient is sentenced by court to coercive treatment, or the patient is considered to lack ability to give an informed consent, and/or is considered dangerous, patients are not allowed to discontinue their medication if their therapist consider medication necessary. Medication-free treatment aims to support patients wishing to discontinue their medication in a safe environment.

Medication-free treatment in Bergen is provided in district psychiatric clinics, generating more psychosocial treatment options for people suffering from psychosis. The treatment options consist of recovery-oriented services such as peer support, supported employment, and illness self-management [35]. It is a recovery oriented reform of mental care focusing on the patient's human right to make decisions regarding their treatment [36–39]. The staff consists of health care workers with different professional backgrounds, including, but not limited to, psychiatrists, psychologists, music therapists, nurses, social educators, physiotherapists, occupational therapists, and social workers. In this study, when we refer to "therapists", we include all mental health care staff. Providing patients with medication-free treatment options is considered by both policy makers and user organizations to be a step toward recovery-oriented care. This includes increased patient autonomy and democratization of the patient–therapist relationship, focusing on shared decision-making, which is defined as a form of patient–therapist communication in which both parties are acknowledged to bring expertise to the process and work in partnership to make a decision [40].

Frontline health workers in this study translated new laws, guidelines, and treatment options into practice in everyday health care delivery as part of the medication-free treatment project. Their role as mediators and interpreters of policy helped shape its implementation. To our knowledge, there is only one previously published paper focusing on psychiatrists' perspective in the implementation of medication-free treatment [41], and no study specifically focusing on the therapists' role as front line workers translating new policies into treatment practice in this regard. To better understand how these therapists actively shaped the way public policy on medication-free services was implemented, we used Lipsky's theoretical framework regarding street-level bureaucrats (SLB) [42]. He defines street-level bureaucracies as agencies whose workers, the SLB, interact with, and have wide discretion over, the dispensation of benefits or the allocations of public sanctions. Mental health workers provide benefits and sanctions to their patients and have the authority and agency to make and carry out discretionary decisions with relative autonomy from management.

This provides a useful theoretical framework for interpreting the role mental health care providers play in policy implementation. Our aim was to explore how mental health care workers in Bergen dealt with, and reflected on, the challenges in implementing this new policy regarding medication-free treatment.

Method

Study context

This study was performed in Bergen, a city in western Norway, where the implementation of medication-free services was launched as a project in September 2017. That project aimed to standardize this type of care, to ensure that all district psychiatric centers offered the same psychosocial treatment options.

All adult patients within the Bergen catchment area who are suffering from psychosis and are not subject to coercive treatment can choose medication-free treatment. Patients who are subject to coercive treatment can choose to participate in the various psychosocial treatment options but are not free to discontinue medication without consent from the psychiatrist or the court. Choices regarding treatment alternatives, like individual music therapy, are to some extent limited by availability, but most options are available within a reasonable time frame. Treatment is voluntary, with no mandatory components. Medication-free treatment should follow the guidelines otherwise provided for treating psychosis, allowing a careful discontinuation of the medication, and adding more psychosocial treatment options to support the patient in this process. This means the patient aims at discontinuing medication, but this is a process allowing dosage reduction and increase following patient wishes and symptom load.

In Norway, music therapy is highly recommended in the guidelines for psychotic disorders, referring to high evidence rating supporting it as treatment. Music therapists are mental health workers with a high degree of independence in the performance and choices regarding the treatment of their patients. At times, they may end up being the only therapist seeing a patient on a regular basis, and they can choose to increase or decrease the frequency of therapy, and ask for more or less support from the other mental health care team members regarding patients' needs. Thus, we believe music therapists meet the criteria as SLB, and were included in a separate focus group discussion.

Theoretical framework

People come to street-level bureaucracies, such as health care facilities, as individuals with unique personalities, experiences and circumstances in their lives. In the encounters with these bureaucracies, they are transformed into clients through a social process in the effort of making them fit into standardized definitions of units consigned to specific bureaucratic slots. Lipsky calls this process the social construction of the client [42]. In the context of medication-free services, patients are clients who enter potentially conflict-based relationships with SLB because they may clash over objectives and because both parties have different levels and amounts of resources with which to negotiate paths forward. Clients seek services and benefits, and SLB seek control over the process of providing them. In the context of new treatment options emphasizing patient choice, the social construction of the client is aiming toward a more horizontal and less hierarchical structure.

According to Lipsky, SLB often must navigate the tension between what is demanded from them professionally, by both patients and management, and what they are able to provide within the given conditions. Large caseloads, ambiguous agency goals, and inadequate resources strain mental health providers, while the demand for services tends to increase with the supply. Hence, tasks may often be hampered by resource constraints. If the tension becomes too demanding, SLB may experience feelings of alienation from their work, because they experience a loss of control over situations they are expected to handle with authority. This may lead to feeling dissonance, and when this dissonance between objectives and capabilities is too great, SLB may develop coping mechanisms to shield them from the implications of the gap. Such coping mechanisms includes disclaiming their responsibility towards their patients, consciously or subconsciously, and emphasizing the division between work and private life. This alienation from their work leads to dissatisfaction with the job, in turn affecting commitment to patients and their agencies.

Study design

This was a qualitative study performed as part of a doctoral project exploring patient and therapist perspectives on medication-free treatment of psychosis. Qualitative methods are research strategies to describe, analyze and interpret experiences of people as they encounter, engage and live through situations, providing diversity and nuances for the scientific knowledge pool. We chose focus group discussions to explore purposely selected therapists' experiences, attitudes and perspectives with the implementation of medication-free treatment for people with psychosis.

Recruitment

To recruit participants for the two first focus groups we approached the directors of the three public district psychiatric centers within the Bergen area, who supported the initiative. The directors provided us with a list of names of key personnel involved in the medication-free treatment, all working with patients suffering from psychosis within a district psychiatric center in Bergen. We sent an e-mail with an invitation to participate to the therapists on the list. All the invited participants (n = 12) agreed to participate and provided informed consent prior to study participation. One person could not participate for personal reasons on the day of the discussion.

Music therapists were invited in a separate focus group discussion, where we also included music therapists from three adjacent private clinics that worked with medication-free treatment in collaboration with the public clinics. The music therapists were all recruited through the POLYFON Knowledge Cluster for Music Therapy, where both the public and the private clinics were members. All agreed to participate (n = 6) and provided informed consent prior to participation.

Table 1 Focus group participants

Focus group 1, December 2017 District Psychiatric Clinic Psychiatrists and psychologists	Focus group 2, June 2018 District Psychiatric Clinic Bachelor-level education	Focus group 3, June 2018 University of Bergen Music therapists
Moderator: CHO Secretary: MV	Moderator: CHO Secretary: MV	Moderator: CHO Secretary: BS
P* 1: Male 60–70 Psychiatrist	P1: Male, 40–50 Mental health nurse	P1: Male, 30–40 Master of music therapy
P2: Male, 40–50 Psychologist	P2: Female, 30–40 Physiotherapist	P2: Male, 50–60 PhD in music therapy
P3: Female, 50–60 Psychologist	P3: Female, 50–60 Occupational therapist	P3: Female, 20–30 Master of music therapy
P4: Female, 40–50 Psychiatrist	P4: Female, 40–50 Social educator	P4: Male, 20–30 Master of music therapy
P5: Female, 40–50 Psychologist	P5: Male, 40–50 Occupational therapist	P5: Male, 30–40 Master of music therapy
P6: Female, 40–50 Psychiatrist		P6: Male, 30–40 Master of music therapy

* *P* participant

Participants

We held three focus group discussions in autumn 2017 and spring 2018 with health personnel, as shown in Table 1.

The participants in the first focus group were psychiatrists and psychologists, two men and four women, age range from about 40 to about 70. The participants in the second group were one nurse, one physiotherapist, two occupational therapists, and one social educator, two men and three women, age range from about 30 to about 60 years old. The participants in the third group were all music therapists, one woman and five men, age range from about 25 to about 50.

Data collection

The first two focus groups lasted for 60 min, while the last had additional questions specifically concerning music therapy and lasted for 90 min. Participants were clustered according to their professional background to create a familiar and safe environment for the free sharing of experiences. We followed Malterud's recommendations for organizing the focus groups to determine number of participants, length, and moderator/secretary roles, and also for using a thematic questionnaire, by asking for concrete incidents and stories [43]. The questionnaires are available as supplementary material. The first author audiotaped and transcribed the focus group discussions.

The qualitative design prompted verbal interaction and elaborate discussions between health personnel, who shared their experiences with the medication-free treatment program. We asked the participants to describe their experiences discussing treatment choices with patients, and their ways to approach shared decision making. Further, we asked the participants to share their worst experiences treating patients, concerning drop-out, and/or worsening. The focus group topic guide was open for both positive as well as negative consequences of the implementation of medication free therapy. Finally, we asked how they experienced the level of available resources and support from the management.

Data analysis

For analysis purposes, we used Systematic Text Condensation (STC) [44], a method inspired by Giorgi's psychological phenomenological analysis [45]. This is a thematic, cross-case strategy suited for exploratory analysis, consisting of five steps: identifying preliminary themes; identifying meaning units in this case concerning therapists' challenges and concerns regarding medication-free treatment; sorting the meaning units into code groups; abstracting condensates from code groups and sub-groups; and finally, generating synthesized accounts of the main concerns for the therapists. The main author and two co-authors read the transcripts, and each found between five and eight preliminary themes relevant across all three focus groups. Further, they prioritized five of the most substantial themes. The main author and one co-author organized the meaning units, identifying those potentially related to the previously chosen themes. We elaborated on the names and keywords of the code groups during coding to develop understanding. The main author wrote the text condensates, reducing the content of the meaning units into a concentrated text or short story describing the main views expressed in the focus group discussions regarding the specific meaning units within the chosen themes, retaining the participants' terminology as much as possible. Meaning units that could not be incorporated in the condensate were set aside, with some reorganized into other themes, and some excluded due to lack of relevance. Each of the condensates was discussed with two co-authors. The analytical process resulted in three themes: managing available resources; the role of the therapist; and treatment practices and experiences. To finalize the analysis process, the condensate was rewritten into the results section, returning iteratively to the original transcribed text to check the validity of each meaning unit in the condensate. In this process, the main author translated the text into English, validated by two co-authors.

To remain close to the voice of the users, experts-by-experience were co-researchers throughout the entire research process from design to dissemination of this study, including the analyzing process. The findings were discussed using Lipsky's theory presented above.

Ethical clearance

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

Results

Analysis as described in the method section revealed three main themes; managing available resources; negotiating the role of the therapist; and treatment practices and experiences. The following are condensates based on the coded meaning units from the three focus group discussions.

Managing resources in the mental health services

The participants described patients with psychosis in general as requiring significant resources, and several expressed an impression that medication-free patients were often among those requiring more resources than patients who used medication. They worried about relapses, and the process of recovering after relapses was described as time consuming for patients suffering from psychosis, with months of inpatient treatment. When patients were believed to be worsening, the focus was to increase the support in every way possible, if the mental health care team could get into position to treat. This was described as a challenge, as patients worsening often refused help before they were acutely admitted, and the worry was this would be non-voluntary. During this type of admissions, the treatment was described to secure the patients' life and health in the acute department. For patients experiencing periods of worsening, the focus was on stabilizing inpatient treatment with sleep, rest, and medication. Inpatient departments in the district psychiatric clinics did not have a systematic medication-free treatment regimen, although they offered cognitive behavioral therapy (CBT), nutrition management, and physiotherapy. The pressure on available beds often led to patients being discharged as soon as possible, often as soon as they were well enough to utilize treatment methods other than stabilizing measures.

The participants considered it important to provide medication-free patients with extended support and close follow-up to avoid worsening and possibly acute admissions, but described situations when it was difficult to agree on replacing medication with other treatment options:

> *Psychologist: When the patients have insight and cooperate using treatment options other than medication, then it works fine, you make it work. However, if there is no insight, and they do not want to or are unable to utilize other treatment options, then it gets difficult.*
>
> *Moderator: What do you do then?*
>
> *Psychologist: Then you search in the available "menu", really, and see if there is anything that could work, kind of meet the needs, depending on the treatments offered.*

All patients were thought to benefit from all or several of the treatment measures implemented, but the capacity of the therapy, including group size and available therapists, was limited. Regular discussions related to prioritizing medication-free patients over patients using medication took place:

> *Music therapist: And then, it is like, ok, but should they be prioritized more for music therapy, or should everyone get the same. And I think considering our workload, do we really have the resources to provide more for those choosing a medication-free treatment course? Not really. And then it is a challenge considering how music therapy also is a resource, because patients come and go, there are waiting lists, and then the waiting list is not all rigid, right, so, if someone arrives and we see that, this one has to get it (music therapy), then this person gets ahead of others.*

Therapists tried to motivate medication-free patients to stay connected with the clinic and in treatment by pushing them to attend some form of therapy regularly. They believed that this pressure to attend led to less motivated patients in therapy, and subsequently to frustration for both patient and therapist, especially when patients did not attend therapy sessions:

> *Music therapist: For patients actively choosing medication-free treatment, it is important to consider if it is responsible treatment, which is what the doctor keeps in the back of their mind. I have thought about it a lot in those situations—you have to replace it [medication] with something. So, that depends on an agreement; now you have to use music therapy, or other options, right? And then this is when you see they stop coming. (…) How long should I wait, and let them come now and then, sometimes a month between sessions. Then, it is not so responsible. Then, you have to do something.*

Therapists could not use resources on treatment measures that after a given time had no effect on the symptoms or functioning of the patient, and they often had to consider how long they should wait before giving the opportunity to the next patient on the waiting list. This contrasted with the understanding that this patient group needed to spend time in new settings before feeling safe, and that the treatment alliance needed to develop over time for the treatment process to succeed.

Patients with psychosis in general were said to often need close follow-up over time outside the hospital, in facilitated school or workplaces, practical aid, and social activation, and medication-free patients were sometimes described to be very resource demanding in this regard. A problem with discharging patients was the increased need for relatives to provide support, because public health services did not provide enough:

> *Mental health nurse: The question is how long you can impose on family or others to keep such a close contact, because public health care does not offer that much in everyday life.*

The therapists also described how many patients had small or no family or networks and relied on the health personnel taking care of them. Participants also felt they could not discharge patients if the patients had nowhere to go, so they avoided to discharge and stretched the guidelines to do this. Several mentioned a lack of adapted housing offered by the municipality as the worst problem when discharging patients:

> *Moderator: Have you been out checking on the living conditions for your patients?*
>
> *Psychologist: Some are homeless.*
>
> *Psychiatrist: Yes, they live in the inpatient clinic, right, the clinic is supposed to be used by patients in need of acute admission [but] those who need acute admission are hindered, because patients in need of adapted housing cannot be discharged—they would perish.*

Patients living in the clinic are more resource demanding, and medication was described to often be a stabilizing factor allowing the patients to be discharged and be able to make use of the housing they were offered.

Negotiating the role of the therapist between guidelines and patient relationships

All therapists in our study assessed the patients' stories and their previous medical history to adjust the treatment according to their specific needs, both regarding pharmacological and non-pharmacological treatment. They focused on providing the patients with thorough information about recommended treatment and the options available to them to make an informed choice. The main goal was to help the patients by providing descriptions of treatment practice:

> *Mental health nurse: But it has been tried with several approaches, and of course, here medication is a part of the treatment, but it has never been the idea that medication should be the only treatment. Our main focus has been cognitive therapy, that for that matter is medication-free treatment. But then, several struggles with utilization of this in a period when it is all chaos, right? (…) Because we know that some really has good effect of the medication, and others don't.*
>
> *Moderator: Yes. And what do you do with those who do not have any effect of the medication?*
>
> *Mental health Nurse: Yes, what helps, in a way, right? That is always the question, how can we help this patient in the best way possible, with or without medication.*

The psychiatrists in our study, responsible for the medication, reported that medication-free treatment was something they had always practiced, and they cooperated with patients who chose to reduce or discontinue medication:

> *Psychiatrist: It has never been a problem to work towards a pause or discontinuation of medication with patients who have insight, who relate to the ill-*

> *ness, who can warn us about worsening, who do not have problems becoming dangerous; this was not a problem even before this [medication-free treatment] was initiated.*

The psychiatrists emphasized that when medication was prescribed, it was generally together with psychotherapy, and not as the only treatment. The aim was to give accurate information about benefits and adverse effects and find the correct medicine and dosage for each patient. Additionally, the psychiatrists were preoccupied with identifying and helping those who experienced little or no effects of the medication. The psychiatrists emphasized their flexible attitude towards medication as they thought the patients, and the user organizations working to implement medication-free treatment, often misunderstood this.

All the health care workers in our study, regardless of professional background, emphasized the importance of keeping a good relationship with the patient, cooperating as much as possible:

> *Occupational therapist: Because they should see us as a part of a health-care system wanting to help them. We should not be pushy, we should not be there just because they happen to be referred to us, but we should actually want to help them, show empathy, and be available.*

The role held by different health care workers in mental health services changes in accordance with the phases of the patient's illness and how their symptoms fluctuate. In this study, therapists described how assessing a patient's insight could be complicated and difficult, along with their ability to give informed consent, and the potential danger they posed to themselves or others. Official treatment guidelines required appropriate and professional treatment approaches:

> *Psychologist: It can be quite tricky with the young patients, who may have had several episodes, and then they want to discontinue the medication, and in a way, you can discuss it, but the guidelines are quite clear, having several episodes in a row is not an indication for quitting medication right away, at least.*

The therapists concluded that following guidelines for when to use medication could be an obstacle to obtaining, and maintaining, a good relationship with the patients.

Collaborating about treatment strategies and choices

The therapists reported that they were sometimes surprised by patients coping well without medication, thereby admitting being unable to predict possible outcome of discontinuation for all patients. They believed including several perspectives on treatment in team-based decision-making was important, leaning on each other's competence and varying connection and alliance with the patient. One music therapist described how other therapists used him when the patient was interested in music, so they could reach a position where other treatments could be provided. The music therapist was able to build a therapeutic relationship with the patient before other health care team members could, and this alliance could then be used to add other treatment types as the patient felt safer. This could avoid the patient falling out of treatment. He emphasized how it was important to be a team, and not to be the only responsible health care worker, especially when patients appeared unstable:

> *Music therapist: But then it is so important not be alone. (...) It's easy for me to say "I do not feel competent to consider this. I need somebody else to engage." I can tell them what I have observed, but if I feel somebody else needs to get involved, they do. That gives a sense of security.*

The participants emphasized the importance of spending time figuring out what were the real priorities for each patient and discussing pros and cons for each treatment decision that was made. The best option was to reach an agreement in cooperation with the patient on a long-term treatment plan, even if they were sometimes impatient to get well. This became increasingly complicated if the patients did not want to use medication but managed poorly without it:

> *Psychologist: But then he becomes so sick he is no longer capable of taking care of himself. Then it's not possible to cooperate without medication, because he would just disappear, he wouldn't utilize the other treatment options.*

In situations where the patient was lacking insight, or when, for some reason, they did not want treatment or contact with the health system, the fear of the patient worsening was challenging for all the therapists. They described how it was difficult to see patients on the street, living under terrible housing conditions, or listening to relatives talking about upsetting outcomes. However, the intention to respect and accept patient choices was clear, although it included a sense of resignation related to their wish to help:

> *Psychiatrist: ... and it is visible in the streets that some people make bad choices, and I believe we must learn to think that, ok, we do our best, but in the end the patient decides, unless they are dangerous.*

Discussion

The therapists in this study described treatment strategies when coping with managing resources and situations where needs were difficult to meet. Patients who chose medication-free treatment were reported to need extended support and other treatment measures with close follow-up to succeed. The therapists communicated how their role was based on an overarching wish to help patients, which was difficult to balance with conformance to guidelines, laws, and available resources in treatment practice. Shared decision-making and spending time considering patient preferences was perceived to be important in the treatment process. The alliance was sometimes fragile, and periods of patients worsening were worrisome.

Discretion and prioritizing

Health care services are paradoxical in the sense that care is delivered by people to people, requiring human interaction and caring, but also delivered through a bureaucracy, which invokes a model of detachment and equal treatment under conditions of resource limitations and constraints. The delivery of street-level policy through bureaucracy depends on health care workers' abilities to embrace this paradox [42]. One example of resource deficiency from our study was the lack of adapted housing within the municipality. This kept patients admitted longer than needed. Specialist mental health supported housing is considered key to a graduated level of care from institutionalized to independent living in the community [46]. The participants in this study wanted to secure the best solution to the problem of housing for their patients. The problem of discharging was solved by keeping patients in care longer than the guidelines suggested was necessary. This occurred because mental health therapists feared their patients would perish without necessary support once they were outside the institution. This stretching of their allowed discretion was possible because SLB, such as these mental healthcare therapists, are able to use and interpret rules and constraints that are externally imposed upon them to achieve their preferred ends [42]. Other examples of resource deficiency were waiting lists to attend music therapy, or simply patients having needs that the mental care system could not meet. Often, this meant that the relatives were more burdened with taking care of their own than the therapists would consider sustainable in the long term. Research has shown that family members caring for relatives with schizophrenia experience a high level of objective and subjective burdens [47]. Additionally, scholarship suggests a higher degree of relapse and mortality when patients discontinue anti-psychotic medication [48]. Hence, the therapists worried this burden would increase when patients chose to discontinue medication.

Patients who chose medication-free treatment in this study were considered to need extended support and treatment measures, and it was believed that success required close follow-up. The implementation of medication-free services in Bergen has enlarged the available treatment options in district psychiatric clinics. The therapists indicated that they discussed problems with prioritizing medication-free patients over other patients. Careful consideration of individual needs was perceived to be the best way to decide whether or not the patient needed medication and was the main tool for prioritizing treatment measures. This process was supposed to be mainly controlled by patient wishes and perceived needs, rather than the therapists' discretion.

Psychosocial support measures are recommended, and are already validated as efficient in the recovery process for patients suffering from severe mental illness, including schizophrenia. Evidence based measures are available and constitutes a so-called "menu" from which the therapists can make informed choices and present to the patient [49]. The process of shared decision-making corresponds with recommended approaches to enhance the relationship with and the recovery process of the patient [40]. At the same time, it is shown how discontinuing anti-psychotic medication might have a negative impact regarding relapses, defined as increased hospitalization, and mortality. Psychosocial measures are resource demanding, and will inevitably meet requirements of cost-effectiveness in a health care system with limited funding. These requirements will be managed by therapists, as SLB, trying to balance both the implementation of a more resource-demanding treatment, held together with the increased risk of patients worsening and hence needing more resources in their follow-up. Prioritization is a part of the difficult task balancing human care with the demand for equal treatment within limited resources. Medication-free treatment seems to require more human resources, as well as additional human and other resources for close follow-up if a patient is worsening. This stands in conflict with cost–benefit demands of the Norwegian mental healthcare system and its guidelines on the use of resources. Efficiency in resource use is an organization-centered goal, and requires that SLB prioritize in their role as gatekeepers. This may affect elements of care for their patients.

Ambiguity and complexity

SLB typically have jobs with conflicting and ambiguous goals [42]. Within mental health care, this might be even more evident when patients (i) claim they are not sick, and hence do not need treatment, (ii) are not satisfied with the treatment they are offered and therefore do not want their help, and/or (iii) are subjected to coercive treatment. All these aspects were raised by the therapists in our study, although coercive treatment only as something to avoid. In health care systems, the defined goal is to provide the best possible treatment and care for all patients, a client-centered goal. A person experiencing a physical illness, like cancer or heart disease, is most likely to seek professional help. However, for mental health care, it is paradoxical that higher symptom load would predict a lower likelihood for that person to seek help [50]. Hence, the client-centered goal might be challenging to achieve when patients do not want the help they are offered.

The ambiguity of the task also surfaces in the relationship the therapists have with their patients. Clients of most bureaucratic systems, including health care systems, are non-voluntary; street-level bureaucracies provide essential services that citizens cannot obtain elsewhere. Hence, patients in mental health care may be non-voluntary in more than one sense; both as a client of a bureaucratic system providing an essential service unobtainable elsewhere, but also as a person suffering from an illness where their help seeking behavior is largely affected by the symptom load as described in the paradox above.

The therapists in this study, although expressing an overarching aim to help patients, felt ambiguity when balancing improved patient influence and their ability to provide essential services. When patients understand the concept of help differently than the therapist, their role was to resolve these conflicting perceptions, and to provide treatment perceived as acceptable and useful to the patient within the available resources. Providing patients with thorough information about treatment choices, including medication, was important. SLB in our study interpreted intensified information sharing as a way to fulfill the need and demand for shared decision-making [51].

Critics of medical authority in mental health services have described the Norwegian system as one that uses patriarchal ways of communication rather than patient-centered decision-making [52, 53]. This study indicates the participants intended to promote a democratic mode of decision-making, which is consistent with a study that explored psychiatrists' attitudes toward shared decision-making [54]. The therapists in this study emphasized the importance of spending time carefully considering pros and cons together with the patient to avoid hasty decision-making, and to accept patient choices even when they worried about the outcome.

In this context of emphasizing choice and shared decision-making, the social construction of the client–SLB relationship aims toward a more horizontal structure. However, shared decision-making is at the core of the conflict between the two possibly diverging perceptions of the kind of help needed and can be difficult to negotiate. Society and management expect professional discretion and responsibility in decisions affecting health care delivery. As such, the options offered must be within the scope of available resources, laws, and guidelines. Because there are resource and time constraints, health personnel should be provided with a range of relevant treatment options, from which they can build an appropriate treatment menu for each patient, process the information and produce an appropriate response to patient needs [42]. In this study, this is described as the treatment 'menu' presented to the patient. This is a way to reduce the complexity of treating mental illness to a manageable level of choices for the health personnel, but runs the risk of reducing the influence of the patient if the patient is presenting needs outside of the available "menu". The structure of the simplification or routines in presenting a "menu" of choices creates a low-level decision-making environment, where the frame is politically determined, and the presentation of choices is at the discretion of the therapist. In this sense, the SLB in this study shape medication-free policy, allocating available goods and services, ideally, but not necessarily, based on mutual consent of patient needs.

Concerns within the therapeutic alliance

In mental health care provision, the patient's level of symptoms and illness largely dictate which law and guidelines are at play. Many of the therapists in our study expressed how they worried about their patients worsening, because of the possible implications for the patient, and for the change in relationship and responsibility for the therapist. One participant described how a patient became so sick he could no longer take care of himself. This implies the therapist must take on a different role, where shared decision-making is no longer perceived as useful and forced treatment has to be considered. In this phase of psychosis, when a patient's paranoid tendencies and withdrawal from interactions with others may lead them to avoid therapy, the therapists in our study became concerned about their patients' safety and sought ways to keep them in treatment using their agency as SLB. Additionally, patients may have delusions about what might work to reduce their symptoms and ask for measures outside treatment guidelines and resources. However, denying a patient's request can be highly uncomfortable [55], and requires specific skills from the therapist. This becomes especially complicated when patient safety is conditioned by the fragile alliance between health personnel and the patient [56]. Although the therapeutic alliance is suggested to be a key component in successful mental health care delivery [57, 58], some studies have found no evidence that alliance predicts the outcome of complex psychiatric treatment for patients with psychosis [59]. Nevertheless, this provides a backdrop for how health care workers understand and interpret their role, particularly when therapists in this study worried about patients worsening and quitting all therapy. When the relationship with one therapist was endangered by turning down patient requests, use of other health care team members was described as a way to remain in a position to treat the patient. Communicating limitations in patient choices while maintaining a good relationship with the patient is a challenging dilemma in mental health care delivery.

When patients chose to withdraw from treatment, even if the therapist perceived their symptoms as worsening, the therapists in their roles as SLB in our study felt they had to respect and accept the patients' choice. Acceptance of a patient's choice that may lead to deterioration in their somatic, mental, social, or physical quality of life may be interpreted as alienation from therapists' key function, which is to safeguard all their patients. This is similar to the findings from a recent study of sources and features of moral distress experienced by acute psychiatric nurses. The feeling of being squeezed between ideals of good care and a harsher clinical reality caused bad conscience, feelings of inadequacy, and emotional numbness. The study concluded with how moral distress may lead to reduced quality of care with nurses distancing and disconnecting themselves from their patients and their inner selves [60]. The implementation of medication-free treatment was by many psychiatrists in particular not regarded as based in a scientific view on professional and good care of patients with severe mental illness [41]. This debate is well known in the society [61]. Hence, when there is an experienced dissonance between objectives (cure/help the patient) and capabilities (personal and resource/system-related limitations), workers develop mechanisms such as alienation to shield them from the implications of the gap between expectations and accomplishment [42]. In our study, the implementation of the medication-free treatment might have added to the range of treatments and the emphasis on shared decision making for the patients, but it may also be resource demanding and a source of worry and distress for the therapists.

Reflexivity, strengths, and limitations

This article focuses on how therapists experience the challenges regarding the implementation of medication-free treatment, rather than the opportunities provided by the same policy change. This limitation of the study scope gives more space to explore these challenges. The down side is the lack of focus on the positive aspects given in the data, including the possibilities provided by such a change of policy. Additionally, we need to include the experiences of other stakeholders, such as relatives and patients in addition to already existing studies on this topic [62, 63].

The researcher's background and position will inevitably influence the outcome of a study by affecting choice of topic, choice of methods, and framing of findings and conclusions. Contemporary theory of knowledge disputes the belief of the neutral observer [64]. Reflexivity has been a guiding principle that has given our interdisciplinary team of coauthors room to discuss and reflect on all aspects of the study, from design to dissemination. Importantly, experts-by-experience were co-researchers throughout the entire research process, which we believe has strengthened the trustworthiness of the study, providing feedback from the most important voices, the users of the health care system.

The scope of the data collection was limited to one context in Norway, and we cannot assume that our findings are similar in other implementation settings. However, the use of theoretical framework structured our interpretation and presentation to focus common themes in policy implementation in health care workers' roles, such as democratization of the therapist–patient relationship, level of discretion, and management of resources.

Choosing Lipsky's theoretical framework has helped clarify how health workers are affected by policy implementation and how they navigate the ways in which they decided to put it into practice in their everyday work. Nevertheless, this framework was developed in the 1960s and 1970s in the United States. The differences in cultures, health systems and contexts could have affected the interpretation. Additionally, this framework may not have been sufficient in addressing some important aspects, such as different professional roles and the relationship between workers and management [65]. Professional roles influence the level of discretion, the level of freedom granted and cooperation between workers and management, and it would have been interesting to explore how different health workers perceived the influence of their professional background and hierarchical situation on their experience of medication-free treatment implementation. This was, however, not the topic of the study.

At the time of the focus groups discussions, the implementation of medication-free services was just starting. This might have affected the extent to which health care workers had experience with and felt familiar with patients choosing to discontinue their medication. On the other hand, this may have led to policy implementation and changes in practice being fresh in the mind of the participants.

For future research, we suggest looking into one key factor in decisions regarding treatment, which is how therapists consider patients' capacity for giving an informed consent.

Conclusion

Health personnel in this study experienced all the ambiguity and complexity that the work of SLB entails because the democratization of treatment choices in mental health care challenges the level of professional discretion. While the aim is to empower patients, this restricts the SLB ability to make decisions and can be perceived as lowering their agency. The implementation of a recovery-oriented medication-free treatment in daily practice in this study resulted in conflicting goals. Balancing the wish to help and professional responsibility with perceived lack of resources and troublesome patient choices created the conditions that may lead to therapists feeling disempowered in and alienated from their work.

Abbreviations

AP: Antipsychotic medication (AP); SLB: Street-level bureaucrats (SLB); STC: Systematic Text Condensation (STC); CBT: Cognitive behavioral therapy (CBT.

Supplementary Information

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Additional file 1. Topic guide for focus group discussions 1 and 2.

Additional file 2. Topic guide for focus group discussion 3.

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Authors' contributions

CHO: First author, main writer of the article, main researcher. ALR: Theoretical advisor on Michael Lipsky, article writing. AB: Advisor on user perspectives, data analyzing, contributor to writing the article. MV: supervisor of the study, advisor on methodology and psychological perspectives, article writing. BS: Supervisor of the study, advisor on methodology and music therapy, article writing. LD: International collaborator and overall advisor on the study, and contributing to writing and proof reading of the article. IMSE: Main supervisor of the study, data analyzing, writing of the article. All authors read and approved the final manuscript.

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Availability of data and materials

The transcribed focus groups are not publicly available for confidentiality reasons, but anonymized Norwegian transcripts can be made available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The Regional Ethics Committee for Medical Health Research (REK sør-øst 2017/736) defined this study as health service research and hence according to the Norwegian Health Research legislation, the study was approved by the local data protection officer for Health Bergen in July 2017 (2017/8692). We provided all invited personnel with information on the study by e-mail before the focus groups, and secured a signed informed consent from each participant.

Consent for publication

N/A

Competing interests

None.

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Health care workers' perspectives on the challenges and possibilities of music therapy within medication-free treatment services

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ABSTRACT

Introduction: In 2015, the Norwegian Regional Health Authorities introduced the possibility for people with psychotic disorders to choose medication-free services, with music therapy as a treatment option. This study aimed to explore the health care workers' perspectives on challenges and possibilities of music therapy within these services.

Method: This is a qualitative study by an interdisciplinary research team, including experts by experience. Ethnographic notes provide data from participant observation with one patient using music therapy, describing what music therapy can be "a case of". Focus group discussions (FGDs) with health care workers, including music therapists, explore their experiences with music therapy and medication-free treatment. These were transcribed and analyzed using systematic text condensation in a stepwise, iterative process involving co-authors to ensure reflexivity.

Results: The summary from the participant observation provides the reader with background information on how music therapy can unfold in mental health care. The informants from the FGDs described music therapy as having a high degree of treatment flexibility providing a continuous process of choices. The collaborative choices both among staff members as well as between patient and staff were experienced as important for treatment outcome. Patients worsening or stagnating increased the significance of contingent choices.

Discussion: The strengths of music therapy, such as its acceptability and flexibility, also represent challenges, including dilemmas of prioritization, challenges when ending therapy, and the need for close collaboration when assessing a patient's worsening. There is a potential for improving the implementation of music therapy into the existing health care teams.

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KEYWORDS Music therapy; mental illness; recovery; choice; medication-free

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Background

Schizophrenia, though a disputed diagnosis, is one of the most burdensome and costly illnesses with psychosis as a core symptom worldwide, accounting for 1.1% of the total disability adjusted life years (DALY's; Hjorthoj et al., 2017; Kahn et al., 2015; Os, 2016; Theodoridou & Rössler, 2010). In a recent study from Denmark, people diagnosed with schizophrenia missed the equivalent of 73% of healthy life per year (HeLP) because of their mental illness and substance use disorders (Weye et al., 2021). Guidelines for treatment of psychosis recommend the use of anti-psychotic medication (Helsedirektoratet, 2013; Keepers et al., 2020). Discontinuation of such medication occurs in collaboration with therapists but is more often described in the literature as non-adherence (Tessier et al., 2017). Non-adherence is often considered a major challenge and cause of relapse and hospitalization. Studies have shown that anti-psychotic medication non-adherence among patients living with schizophrenia is high, and influenced by complex factors related to illness, treatment, and level of social support. Studies recommend to address these factors to enhance treatment stability and adherence (Semahegn et al., 2020).

In 2015, the Norwegian Regional Health Authorities introduced the possibility for people with psychotic disorders, including schizophrenia, to choose medication-free services, within the constraint of the law defining responsible treatment (Helse- og omsorgsdepartementet et al., 2015). The aim was to generate more psychosocial treatment options for people experiencing psychotic disorders, and to give patients choosing to discontinue medication a safe and supportive environment to do so. This treatment option would provide an alternative to self-induced non-adherence, when patients stop using anti-psychotic medication on their own. All the district psychiatric centers in the Bergen region, Norway, provide optional medication-free treatment. This is the context of this study of therapist experiences of the reform instigated by the health authorities, although the participants in this study also worked with patients outside of the medication-free treatment regime.

This change of approach towards a higher acceptance of discontinuation of medication within mental health care was spurred by advocacy work by user organizations (Fellesaksjonen, 2011). There is research suggesting that absence of anti-psychotic medication predicts a higher probability of recovery in the long term (Harrow et al., 2021). Medication-free services are considered to be a step towards a more recovery-oriented treatment practice, advocating for person-centered care and greater self-determination for those with severe mental illness (Davidson, 2016; Davidson et al., 2007). Greater self-determination implicates a greater choice of treatment, which was the intention of adding more psychosocial treatment options within medication-free services. Research has shown how patients with mental health diagnoses receiving their preferred treatment demonstrate a lower dropout rate and improved therapeutic alliance (Windle et al., 2020). Hence, more treatment options should reduce the costs of premature dropout and disengagement.

Music therapy has been recommended since 2013 in the official Norwegian guidelines for treating people experiencing psychosis (Helsedirektoratet, 2013). All district psychiatric centers in the Bergen region have gradually implemented music therapy between 2013 and 2020, some as part of the medication-free treatment project (Oevernes, 2019; Tuastad & Myrhaug, 2020). Music therapy provides recognized benefits of a recovery-oriented practice (Solli et al., 2013), and Norwegian music therapy practices focus on relational and resource-oriented work aimed at building identity, coping strategies, and capacities and possibilities for community participation (Ruud, 2010). Flexible practices highlighting human rights, user involvement, and citizenship are typical (Stige & Aarø, 2012).

A report from the Norwegian Institute of Public Health (Bjerkan & Leiknes, 2016) summarized five different systematic reviews (Gold et al., 2006, 2005, 2009; Lee & Thyer, 2013; Mössler et al., 2011) on the therapeutic effect of music therapy. They concluded that music therapy as addition to treatment as usual for patients with schizophrenia possibly has a better effect than standard care on general health, mental health and social functioning. However, there was a lack of long-term studies to prove the effect over time. This is similar to a Cochrane systematic review from 2017 and a meta-analysis from 2020, where authors found moderate- to low-quality evidence suggesting that adjunct music therapy improves the global state, social functioning, and quality of life of people with schizophrenia or schizophrenia-like disorders (Geretsegger et al., 2017; Jia et al., 2020). A Danish RCT from 2021 compared the effect of music-listening groups with the effect of music therapy groups on negative symptoms for patients with schizophrenia. They found no difference between the two groups, however, both groups experienced significant reduction in PANSS negative subscale score (Pedersen et al., 2021). A review from 2019 concluded that music therapy is a valuable and undervalued method of non-pharmacological support for patients with various psychiatric disorders (Witusik & Pietras, 2019).

There are many ways of conducting music therapy. Factors suggested to be of particular importance to succeed when working with acute adult psychiatric in-patients are the frequency of therapy, structure of the session, consistency of contact and the therapeutic relationship (Carr et al., 2013). Factors such as musical–social engagement and shared decision-making (participatory and music-centered practice) are highlighted in the literature on more community-oriented music therapy (Stige & Aarø, 2012). Hence, music therapy is a treatment with a high degree of flexibility in both form and content. This creates an opportunity for music therapists to provide an individualized and flexible treatment option based on patients' choices and preferences in mental health care.

As outlined above, this study is situated in a clinical context where music therapy is offered as treatment for people with psychosis who can choose to discontinue medication. To our knowledge, there is no previous research published on how music therapists are involved in and experience the politically instigated implementation of medication-free services for patients with psychosis. We believe this provides an opportunity to explore therapist experiences with patients choosing to use music therapy as a part of their discontinuation process, as well as with those who chose to use music therapy as concomitant treatment with medication.

We aim to reveal both possibilities and challenges for music therapy within this setting, and the focus of this study is to explore music therapists' and other health care workers' perspectives on professional work with mental health patients who choose music therapy within the context of medication-free treatment options.

Method

Study context

The Norwegian health system is largely public, and organized into four regional health authorities. These entities chose different approaches for the implementation of the medication-free treatment program. The Western Norway Regional Health Authority comprising the Bergen region aimed to improve health care for all patients with psychosis by integrating more psychosocial interventions into existing services in district psychiatric centers. The treatment options offered were among others individual psychotherapy, Illness Management and Recovery groups (IMR), individual job support (IPS), occupational therapy, music therapy, and physiotherapy. The focus was on supporting patients' choice and increasing users' involvement and sense of ownership of therapy. All patients who are above 18 years old, not restricted by coercive measurements, and within the admission area are eligible for these medication-free services.

Study design and data collection

This study was part of a larger qualitative PhD project exploring patient and therapist perspectives on medication-free treatment of psychosis. The full study consisted of in-depth interviews with patients (Oedegaard et al., 2020), focus group discussions (FGDs) with therapists (Oedegaard et al., 2022), and participant observation with a patient in music therapy. For this study, information was gathered from the participant observation and the part of the FGDs specifically relevant for the aim of revealing possibilities and challenges for music therapy within medication-free services. The participants for FGD number 3 were purposely selected to reach the necessary strength of information for this aim, which therefore constitutes the main source of information for this study. The participant observation served as a learning experience providing the first author with a deeper knowledge of how music therapy unfolds within mental health care, thus informing in particular the facilitating of FGD number 3. We believe that a condensed summary of this experience will give the reader a similar insight and understanding for what music therapy within mental health care can be "a case of", and further a deeper understanding of the following analysis and discussion of the FGDs.

Participant observation

Participant observation means the researcher participates in the context to be studied, with the aim of describing the problem from an insider perspective (Malterud, 2017). This requires "to make a certain personal as well as intellectual commitment" by the researcher, and further, "to exploit one's full range of capacities in order to make sense of a given social world". (Atkinson, 2015, p.35). This includes to be observant, to take the role of the other, to listen, to learn and to imitate, according to Atkinson (Atkinson, 2015). For the participant observation, we asked a music therapist to suggest a suitable patient, meaning above 18, able to give an informed consent, and living with a psychotic disorder. The patient also needed to be willing to accept having a stranger in the room during therapy. The first author was invited to participate in one music therapy session, to gain trust with the chosen patient. We obtained a written, informed consent before the next session. The first author participated in and took observational ethnographic notes from seven individual music therapy sessions with this particular patient. This participant observation took place at one district psychiatric center in the Bergen region. It lasted over a period of about three months, at a rate of approximately one session every week except when sessions were canceled. Each session lasted for about one hour. The first author wrote down the experience in as much detail as possible immediately after each session. A condensed summary of these experiences provides an introduction to the findings.

We chose an ethnographic method, inspired by Atkinson's (2015) broad analytic and presentational approach, to be able to learn more and possibly make sense of the interaction patterns and relational matters of music therapy. Ethnography provides the tool to demonstrate how these are means of social work getting done, of social order being constructed, and of social experience being shared. We aimed to do this through encounters with people familiar with this treatment, and the sharing of this social experience (Atkinson, 2015; Emerson, 1995).

Focus groups

We gathered information from three focus group discussions with altogether 17 participants. FGD number 1 and FGD number 2 lasted for about 60 minutes. FGD number 3 lasted for about 90 minutes, as we had additional questions specifically regarding the role of the music therapists. Demographic and professional details on the participants can be studied in Table 1.

The focus group discussions were performed following Malterud's recommendations (Malterud, 2012a), including the use of a topic guide asking for concrete stories, provided as supplementary material. The main author was moderator and a co-author secretary for the FGD, facilitating the discussion and sharing of experiences. In this

Table 1. Focus group participants.

Focus group discussion 1 (FGD1), December 2017 District Psychiatric Clinic Psychiatrists and psychologists	Focus group discussion 2 (FGD2), June 2018 District Psychiatric Clinic Bachelor-level education	Focus group discussion 3 (FGD3), June 2018 University of Bergen Music therapists
Moderator: CHO	Moderator: CHO	Moderator: CHO
Secretary: MV	Secretary: MV	Secretary: BS
P*1: Man 60–70** Psychiatrist	P1: Man, 40–50** Mental health nurse	P1: Man, 30–40** Master of music therapy
P2: Man, 40–50 Psychologist	P2: Woman, 30–40 Physiotherapist	P2: Man, 50–60 PhD in music therapy
P3: Woman, 50–60 Psychologist	P3: Woman, 50–60 Occupational therapist	P3: Woman, 20–30 Master of music therapy
P4: Woman, 40–50 Psychiatrist	P4: Woman, 40–50 Social educator	P4: Man, 20–30 Master of music therapy
P5: Woman, 40–50 Psychologist	P5: Man, 40–50 Occupational therapist	P5: Man, 30–40 Master of music therapy
P6: Woman, 40–50 Psychiatrist		P6: Man, 30–40 Master of music therapy

*P: Participant **Age range. We chose to provide an age range rather than the correct age of each participant to increase confidentiality.

way, the moderator and secretary could act as each other's control to make sure all participants were heard.

Relevant information regarding music therapy from all the FGDs was included.

Analysis of participant observation

Field observations might yield analytic ideas of "what this is a case of". From such ideas "sensitizing concepts" might emerge to inform further data collection (Atkinson, 2015). We aimed for a process of analysis that would take into account the complexity of the research field. The analysis of the ethnographic notes from the music therapy sessions was initiated by a summary of the notes written by the first author. The last author read the original notes, and commented on the summary. As we agreed on necessary changes, the first author rewrote it accordingly. This was done as an iterative process until the summary contained the required information and essential descriptions of the first author's observation of music therapy within medication-free services.

Analysis of focus groups

For analysis purposes, we used Systematic Text Condensation (STC), a method described by Malterud, inspired by Giorgi's psychological phenomenological analysis (Giorgi, 2009; Malterud, 2012b). This is a thematic, cross-case strategy suited for exploratory analysis, consisting of five steps. The first author and the last author read the transcripts, and each found between five and eight preliminary themes relevant across the focus groups. The teamwork then yielded five main themes after a thorough discussion of all the suggested themes. The first author sorted the meaning units, identifying those related to the chosen themes and subthemes, using NVivo as a sorting tool, yielding one code group for each theme. In this process, the names and keywords for each code group were changed and elaborated to enhance the understanding of the topic. The first author wrote the text condensates based on each code group, reducing the content of the meaning units into a condensed text retaining most of the participants' original wording. Meaning units that could not be incorporated in the condensate were left out based on lack of relevance for the chosen theme or study question, or reorganized into a different theme or subtheme. The first author discussed the condensates and themes with the last author and the second author, and finally reorganized the information into three main themes with corresponding synthesized accounts of the main concerns for the therapists, as we agreed on an improved understanding of the data. These synthesized accounts constitute the key findings presented within the findings section below: Music therapy as a flexible process: continuous choices; Music therapy and medication-free treatment: collaborative choices; and Music therapy in complex situations: contingent choices.

Ethical considerations

The Regional Ethics Committee for Medical Health Research (REK sør-øst 2017/736) defined this study as health service research and hence according to the Norwegian Health Research legislation, the study was approved by the local data protection officer for Bergen Health Trust in July 2017 (2017/8692). All participants signed forms providing informed consent to participate.

Findings

Participant observation: What music therapy can "be a case of"

We have provided the summary of the ethnographic notes from the participant observation as a case example in italics below for readers who would like to have a deeper insight into what a music therapy session can "be a case of". We believe mental health care staff would find this useful in their understanding of what music therapy can entail, and hence helpful for their understanding of this study and for presentation of this therapy to their patients.

I was looking forward to meet the patient, Tom, and finally start the planned participant observation. The music therapist and I met Tom at the reception at the district psychiatric center. I was told he got there in a taxi every time to attend the sessions, some of which his psychologist would join, playing the bass guitar.

He seemed a bit shy, but smiled. When asked, he expressed that he had nothing against me being there. We went down in the basement, where the music therapy room was. Tom chatted a little with the music therapist and seemed comfortable. In the beginning of the session, Tom and the music therapist talked about what they had done the last time and if he had done anything in particular regarding music in between the sessions. Then they planned the activity for the next hour together.

Usually, Tom started by approaching an instrument, normally the electric guitar and once the piano, and then he began improvising. The music therapist sat behind the drums, and, adapting to the patient, gave rhythms and a frame to the music. It was clear that they were used to the setting, and knew each other well. They would exchange glances and little nods and smiles to change the music – increasing or decreasing the tempo, for instance, and sometimes they would just laugh at their own performance.

I sat in a chair watching, enjoying the music. I was impressed with Tom's musical competence, he seemed quite lost at arrival, but now he was really at ease, performing with skill. It seemed they could go on and on forever improvising music, and I was later told they sometimes could play for 15–20 minutes in one go. I applauded when they stopped, and told Tom how impressed I was. I really tried to show how much I enjoyed being part of this, and I got the impression that he enjoyed having an audience.

Tom had a severe schizophrenia diagnosis, lived in an apartment in a house owned by his parents, and had a very low level of functioning with no school or work on a daily basis. The only time he got out was to attend the music therapy sessions once a week. The music therapist gave me some background information about Tom's process, which helped me understand the session:

The music therapist told me that he tried to encourage Tom to play together with other patients, and hopefully form a band. I got the impression that this had been a regular topic over time. Tom just kept saying he liked it as it was, and had no interest in playing with other people than the therapist(s). I wanted to do an interview with him to gain a deeper understanding of his views on his health and the music therapy, but he did not want that. I participated in seven similar sessions, and I tried to ask some questions at the end of a couple of sessions, as I wanted to learn what the music therapy *meant to him, and how he reflected around the effect of it. I asked if he enjoyed the sessions, which he confirmed.*

The music therapist said it was the only therapy Tom would attend and he was always on time. I asked Tom if the therapy had an effect on his state of mind somehow, and he described it to be the peak of the week. However, it was like a similar low line all the week, a short peak, and then it would drop to the same level just after the session. The music therapist confirmed how the therapy had lasted over a couple of years, but the patient had not changed much in his personal recovery process.

The impression was that Tom's level of functioning had not improved, and that for him music therapy was not helping in a process of recovery aiming for a more active and self-supporting life. The music therapist was a bit frustrated about this, and unsure of how to go forward. On the other hand, music therapy seemed to be important, as this was the only time of the week Tom got out and was engaged in some sort of activity. The prioritizing forward seemed unclear and difficult, as there were waiting lists to attend to. The therapist considered it to be a certain risk for Tom, however, to end music therapy, as he would lose his only activity outside of his home.

This is a description of individual music therapy with one particular patient. The weekly session was an important part of his life, and appeared to be therapeutic regarding level of functioning and negative symptoms during the session. On the other hand, there were no clear improvements of functioning transferrable to other domains in his life, such as practical and social arenas, even though the therapy had lasted for a long time, which the therapist interpreted as stagnation for the patient's recovery process. Thus, this particular narrative illustrates a tension where the aim of the therapy – namely improved social and practical functioning – and the reality did not correspond. The therapist was hence experiencing frustration and dilemmas in prioritizing his resources.

Focus group discussions: The role of music therapy within services providing medication-free treatment for patients experiencing psychosis

In the focus group interviews, we asked the therapists to describe their experience with providing medication-free treatment. The music therapists were asked to describe in more detail the characteristics of music therapy within mental health care. The following findings emphasize the information from the focus group with music therapists, but include information from all the groups.

The key findings involve how the process-oriented nature of music therapy is described, including its flexible and personalized treatment characteristics. This is followed by how processes related to the choice of using music therapy unfold within a new frame of medication-free treatment, from the perspectives of both music therapists as well as other care staff. Finally, key challenges are discussed related to the complexity of therapeutic relationships, treatment needs, and discontinuation of therapy.

Music therapy as a flexible process: Continuous choices

One important issue raised by both music therapists and other therapists was that many patients who did not want to attend any other treatment still wanted music therapy.

> "In my experience this is a form of treatment that reaches those patients who are not capable of using or want to use the other types of therapy we offer. Some patients experiencing severe withdrawal and negative symptoms, who are passive and lack insight into their illness might still be interested in trying this therapy. It seems to strengthen the alliance. Additionally, the patients seem more available both emotionally and cognitively during and sometimes after music therapy. The problem is actually the availability of this therapy, as few patients get it during their admission." (FGD2, P1, psychiatrist)

According to the music therapists, the patients' positive attitude towards music therapy was often instigated by the flexibility of this treatment:

> "The user participation is strong in music therapy. So, the fact that I had the space to let her take control was important to her. And then it was another person who told me that it was (because it was) so flexible in music therapy, because I asked him, should we have an aim, work with something specific, and he didn't want that, he just wanted to come and see how he felt that day, and go along with that in the session. If he wanted to play music, or if that would be too difficult that day, if we should rather listen to music, and talk about . . . yes. So that flexibility was highly appreciated." (FGD3, P4, music therapist)

The patient pathway was said to be paved with many different choices. For instance, patients had to choose the profile of their own therapy process, regarding type of music and expression mode. According to the music therapists, the patients had different needs and wishes for choosing the content of their music therapy sessions. Some wanted to explore the period in time when they first experienced psychotic symptoms, by playing the music they listened to at that time and talk about what happened to them. Others wanted to work with their current difficulties, like psychotic symptoms. Many patients did not want to focus on the illness at all; they just wanted to focus on the music.

Music therapists described the therapy provided also to be flexible in format. Music therapy groups were described to afford positive possibilities in several aspects, providing a sense of connection, where patients helped and supported each other. These groups could be very different from each other in size, content and threshold for entering. When starting certain band-like groups, the therapists attempted to find patients who could fit together both regarding levels of musicality and choices of expression. Other groups had a lower musical threshold for participating, similar to musical gatherings. Listening groups could work for almost all patients, as participation only required choosing a song. Some groups were open, meaning people could choose to stay or leave during the time the group lasted.

Music therapists in the inpatient department described how patients who were too sick to join kept their door open and chose to listen to the music from inside their room. It was described as helpful to have music therapy activities in common areas, with concerts performed by patients or the therapist, for instance. This could provide an uplifting ambiance for the rest of the day, for both staff and patients, and facilitated a nice activation and new relationships between patients. Some departments also used music actively when the music therapist was not present, by singing or listening to music together with the patients:

> "We use music in the ward when we gather the patients; they can sing along or just listen. We use music listening as a way to reach patients, and see how this can be a way to build relations with those who are hard to reach otherwise." (FGD2, P1, mental health nurse)

In the outpatient department, therapists described that many patients were too sick to be able to join a group, or were unable to be in the same group. Some patients found it socially demanding to join a group. For the music therapists, it could be challenging to introduce new members particularly to smaller groups, if the dynamics felt excluding to the new member. In such groups, fixed patterns and social codes could be difficult to overcome, when the original group members did not include new members in conversations, or otherwise displayed behaviors of social exclusion.

When patients were not eligible to participate in a group for reasons like level of symptoms or lack of groups that matched the particular needs of the patient, individual therapy was suggested. Some patients stayed in therapy for two to three years. Music therapy students and/or colleagues of the music therapist, such as a psychologist, could sometimes join these sessions. The music therapists described how this provided variation, musically and socially, but there was no further elaboration on this in the focus group discussions.

Music therapy and medication-free treatment: Collaborative choices

We asked the participants about the processes regarding patient choices of therapy within the new clinical setting that includes medication-free treatment. One music therapist wanted to share the experience he had with a patient wishing to discontinue his medication:

> "I would like to tell you a success story about a very ill patient, with great interest in music. He wanted to discontinue his medication, but every time he tried, he got sicker. I started to have one therapy session a week with him, and then we increased it to two because we saw he benefitted from it. When he seemed ready to start in a group, I went outside the clinic and found a suitable candidate through other music therapists. He was very nervous about it, but we went to see the other patient together. We worked a few months to establish them as a band, and now they play without me." (FGD3, P2, music therapist)

The informants described several different scenarios on how choices regarding music therapy were made with increased focus on and acceptance for discontinuation of medication. Some patients would ask for music therapy themselves, because they considered intuitively that music therapy would be useful for them. When referenced or upon admission, the staff would typically suggest available options based on what was considered beneficial for the patient. Then it was the patient's decision to accept or decline the suggestion. Information regarding the treatment options was considered dependent on the knowledge of the referring staff. According to the music therapists, both patients and staff members other than music therapists often had little knowledge about music therapy. These therapists' knowledge and assessment of the patient's need could affect the presentation of choices, and therefore patient choices and treatment decisions.

The music therapists described how they had the impression of psychiatrists being disconcerted facing patients choosing medication-free treatment. To ensure that the patient would have some therapeutic support in the process of discontinuing their medication, psychiatrists sometimes referred patients to music therapy, even when they had not expressed any interest. In this way, the psychiatrists pushed patients a bit around in the treatment "menu" in an effort to keep the patient in treatment in a possibly troublesome phase of the illness during discontinuation of medication, propelling the patient choice. This could lead to music therapists experiencing treatment processes as demanding:

> "I feel that when they come and ask me, this is a medication-free treatment course, I need some help here, we are stuck, then I feel I need to prioritize that patient. And those patients I have that have been referred to me in that way are perhaps those with the least turn-up, because they don't have that burning passion for music. I will not say they do not have any outcome from the therapy, but it is far more demanding for me, it takes more planning, it is more challenging to see it through, at least for me. And then, I'm thinking, should I really prioritize those who might not get that much out of it, who are not passionate about it, but are kind of pushed into it because they are in a medication-free treatment course?" (FGD3, P3, music therapist)

Music therapists described how they often played an important role in the beginning of a treatment course, especially when the health care team were not able to get into a position to treat otherwise. Many patients who struggled with negative symptoms could be interested in choosing music therapy, even though they did not make use of other treatment options. In these situations, the music therapist could start building a relationship, and other treatment options could be suggested and accepted as the patient felt safer.

> "They use me a lot in the beginning, they can't get into a position to treat, and he is interested in music therapy, can he get an appointment, and if I have time, he will. Then we start building the relationship, and eventually we succeed in adding other treatment options. That works."
> (FGD3, P1, music therapist)

Patients could also appear more emotionally and cognitively available during music therapy and sometimes afterwards, which could open for a better alliance and dialogue regarding further choices of treatment.

The alliance formed during music therapy was said to be transferable in many cases, and highlighted as important for the rest of the health care team to recognize and use as a resource. It was perceived challenging for the music therapists when other therapists in the care team, like the psychologist or psychiatrist, were replaced. This could be due to staff finding new jobs, pregnancy leaves, or similar reasons. With a new person taking over the responsibility for the treatment, it could be time-consuming to build a new relationship. The quality of the collaboration both among staff members as well as between patient and staff was considered important for treatment outcome. Also, collaboration constituted the basis for the therapists' safety, as being alone with patients experiencing a high level of paranoid symptoms had to be carefully considered, as it could constitute a risk for the therapist.

Patients often needed extended support to take the step to participate in activities or groups outside of the clinic. The music therapists described how they used their personal and work-related network to find patients that matched criteria like musical interest and personality. They spent time outside of the clinic with the patients to consolidate the relationship before they could manage without the support of the therapist.

Music therapy in complex situations: Contingent choices

The informants were asked to share how they experienced challenges regarding music therapy within the frame of medication-free treatment.

The music therapists expressed a perceived increase in the general level of symptoms and illness after the introduction of medication-free treatment. The symptom load was experienced as a bit higher for the patients not using anti-psychotic medication than for those who did. It could be more demanding for the patients to focus on the music therapy sessions if they were struggling with symptoms like anxiety and restlessness. At times very sick people were referred to music therapy, which made the therapy harder to carry out, with less attendance and participation in the sessions. Less anxiety and paranoid thoughts made it easier to keep a good relationship. On the other hand, increased use of medication could result in less engagement in the music.

Some therapists had positive experiences with patients who used medication on a regular basis and music therapy at the same time, as they appeared more stable regarding attendance, and less challenging relationally with less paranoid thoughts. However, when patients attended therapy over a long period, the recovery process seemed quite similar for both patient groups, those using medication as well as for those who had discontinued. This was depending on whether they managed to stay in therapy or dropped out. Therapists worried about the latter, as absence of treatment could have adverse effects on the patient's life in their opinion.

The music therapists described themselves to be among those in the health care team who respected the users' decisions more than other team members, for instance, in discussions about discontinuation of medication. Also, the music therapists described themselves as professionals who mediated the recovery perspective more than other team members. When other team members disagreed, the argument often evolved around the topic of what constitutes "responsible treatment." Music therapists expressed a need to be humble in such discussions, considering the possibility of the patient worsening.

There was an experienced need to prioritize medication-free patients ahead of other more stable patients, especially if they were without other treatment options. If a patient's condition worsened, music therapists considered it to be a heavy responsibility to decide when to take action. The music therapists did not feel competent to consider illness progress on their own if they were the only one having regular contact with the patient. Hence, it was perceived very important to have a health care team to ask for support and help to observe or add measures if there were reasons to worry about a patient.

The music therapists described how therapy sessions could become a negative experience for some patients if it got too emotional. Sometimes the patient could express feelings of being afraid of or reluctant towards stopping the therapy, if the roles had become unclear and the relationship too close, as this quote illustrates:

> " I have also stopped treating patients when I have felt it did not work out, and they have been very hurt. This is no fun for either of us, but it is no good to keep on doing something that does not work."
> (FGD3, P3, music therapist)

The therapist conveyed how it could be stressful to end therapy, when people are expressing hurt feelings. However, ending therapy needed to be done if criteria of progress were not reached, or the therapist considered the therapy not to be useful for the patient. Losing an important social meeting and regular activity could be negative and experienced as a personal rejection. Therefore, preparing the patient on boundaries for the music therapy was perceived very important.

Patients could develop patterns in individual therapy that were difficult to deviate from, and hence it could be difficult to promote a connection with other patients with the aim to form a group or band. However, the relationship between patient and therapist was often described as supportive and strong. For some patients, this relationship could be sufficient, and a group or band too difficult to relate to.

The music therapists expressed how they felt it was important to challenge patients and work with social skills and problems through music therapy, even though the patients would not have chosen to dare to do so with no pressure. This could, for instance, be to participate in a band, hold a concert, or otherwise take steps towards aims they had agreed on. It could be difficult to consider the balance between the freedom to choose and to challenge a patient's limits:

> " . . . a challenge can be how they sometimes need to be challenged, I believe. If they are allowed to always decline every suggestion, they might need that too, but to simply accept that every time means they can keep up that kind of defense even when it could have been useful for them. When I have taken the chance, ok, but try anyway, you know, it surpasses that free choice by making it harder to turn down the suggestion, but afterwards (. . .) they seemed to be happy about it."
>
> (FGD3, P5, music therapist)

The music therapist expressed a need to evaluate the therapeutic effectiveness for each patient, as they saw how not all patients had as much use of music therapy in their struggle for progress in personal and clinical recovery. Considering each patient's personal outcome of music therapy had to be held up against to which degree it was responsible treatment to put pressure on that person's limits, for instance, regarding social participation. On the other hand, it could be considered poor treatment not to put some pressure on the patient if this challenge would improve the therapeutic outcome.

Discussion

In this study exploring health care workers' perspectives on music therapy within the context of medication-free treatment, music therapy was said to provide flexibility and continuous choices for patients. Medication-free treatment presented new contexts for collaborative choices and experiences for music therapists as part of the interdisciplinary health care teams. Participants explained how lack of knowledge among co-workers regarding music therapy as treatment could be challenging, as well as increased referrals of people with more severe symptoms. Music therapists explained how they often took the role of promoting the recovery philosophy in the team, and the role as a relationship builder that the rest of the team could lean on. Choices were explained to be contingent on situations, available resources, professional competences and the patient's level of symptoms, presenting both challenges as well as possible solutions. In the following, we will elaborate on the three themes presented in the findings section, and relate them to the existing literature.

Continuous choices

The music therapists expressed many different angles of approach, regarding both format and content of the therapy. This is in line with other research showing that this therapy has no conclusive models (Carr et al., 2013). This variation and freedom to shape the therapy to the needs of the individual is both positive regarding the level of flexibility, but also potentially negative regarding the possible variation of therapeutic quality. To optimize the use of music therapy, the academic and clinical training and careful selection of intervention techniques are essential to correspond with the particular needs of the patient group (Stegemann et al., 2019). The flexibility was said to instigate a positive attitude towards the therapy from patients otherwise reluctant regarding treatment, providing a pathway of individual choices. This is in line with research showing how patients enjoy music therapy, as it is not experienced as traditional therapy (Solli & Rolvsjord, 2014). Music therapy could then open the door for patients into other treatment options, as the patient over time would feel more safe and familiar with the health care team. Previous research indicates that music therapy is a feasible and effective treatment for patients with low motivation for therapy (Gold et al., 2013). Also, low drop-out rate is believed to be a positive side of music therapy (Hannibal et al., 2012).

Collaborative choices

As music therapy has been increasingly implemented into treatment as usual for patients with psychosis, there is a need for increased knowledge among music therapists' coworkers to understand the nature of this treatment. Specifically, regarding changes due to medication-free treatment, participants raised three important issues in this study. First, patients off medication could appear more affected by their symptoms, and hence more difficult to reach during music therapy sessions. Second, increased use of medication could affect patients' level of effort and participation during the music therapy sessions. Third, therapists noticed increasing numbers of referrals to music therapy of more ill people with limited musical interest, due to the need for keeping those wishing to discontinue medication in some treatment for safety reasons.

Psychiatrists and psychologists are often gatekeepers to available treatment, and lack of knowledge may infer inadequately based referrals, or no referrals, based on the gatekeeper's recommendations to the patients. This could result in patients not being referred to music therapy even though they could have found it useful, but also referring patients to music therapy when they are somehow unable to cope with the demands of the therapy. Patients with interest in music are more likely to find it useful, but this should be interpreted very broadly, and is not necessarily linked to musical skills (Ansdell et al., 2010).

This expressed concern for referrals was said to be due to lack of information provided for the gatekeepers. However, studies have suggested how resistance towards change, staff attitudes and lack of user involvement can be reasons for poor implementation of recovery-oriented services (Lorien et al., 2020), such as music therapy.

To create conditions that can nurture the patient's passion for music seems to be key when the music therapists in this study talk about how and why they adjust their practices to circumstances and requests. This is in line with previous theorization of how music works in music therapy (Ansdell, 2016; Stige & Aarø, 2012). The health care team also need to know how and when to take advantage and make use of the positive relational, emotional and cognitive impact music therapy can have on a patient experiencing negative symptoms. The quality of the patient–therapist alliance is well known to be of importance for the outcome of treating severe mental illness (Ljungberg et al., 2015).

Contingent choices

One challenge mentioned by the music therapists was difficulties with ending the therapy. Issues regarding termination of therapy are well known from psychotherapy, where unmet expectations and unresolved alliance ruptures are described (Curran et al., 2019). Music therapists need to be aware of and have competence with problems with ending therapy in general, as well as regulating emotions after certain sessions. Music therapy emphasizes the importance of the relational quality between the therapist and the patient; hence it should be equally important to find good ways to end a relationship that most likely is experienced as more than a purely professional one.

One therapist mentioned how ending therapy was “no fun for either of us.” Even though music therapy not necessarily is “fun” work for the therapist, we believe this indicates a level of personal stress as the relationship gets too close. The mutual similarities between psychotherapy and music therapy indicate the importance of taking into account the sometimes challenging relational dynamics, and to focus on interpersonal sensitivity and reflexivity (Witusik & Pietras, 2019). The findings suggest that sensitivity to context is essential too. Consider, for instance, the case example with Tom’s music therapy process presented initially in the findings section. Dilemmas concerning discontinuation of music therapy go beyond narrowly considering the effects of the intervention or the relational complexities of the collaboration, because music therapy within the context of medication-free treatment options sometimes is the only therapy on offer that the patient chooses to use.

Also, it was challenging for the music therapists to observe and assess which actions were needed when a patient was worsening. In these situations, it was important to be part of a health care team to find adequate solutions. There is a risk of relapse or worsening for patients who choose to discontinue their anti-psychotic medication, with potentially negative impact on several parameters for the individual (Hor & Taylor, 2010; Schooler, 2006; Strømme et al., 2021). This risk needs to be closely monitored, and assessed on a regular basis by the team, including the medically responsible psychiatrist.

Strengths, limitations and future research

Implementing medication-free treatment for people with psychosis, including the use of music therapy, is an innovative approach in mental health care. To our knowledge, this is the first research project about music therapy within a setting of medication-free treatment, exploring available data that could inform future collaborative processes between therapists and patients. In this study, we could have asked more explicitly about and probed for music therapy in focus group one and two, to further illuminate various health care personnel’s perspectives on the use of music therapy in this context. Future research should look into the intricacies of the relationships between musical possibilities and various challenges in person, system, and situation, including the user perspective in mental health care, and the experienced usefulness of music therapy. There is a need to look further into the relationship between the music therapist and the patient as a dyad over time, to improve the understanding of how choices are made in various situations. Given that the results of this study revealed that access to information about music therapy sometimes was very limited, further research on the use of tools for shared decision making would be very relevant, when such tools include music therapy as one treatment option.

Conclusion

Music therapy within medication-free treatment represents the recovery philosophy, with a high degree of flexibility and individual freedom of choice. We found three main themes on how these therapeutic choices are made; continuously through the entire process, in collaboration with the therapist, but also contingent on circumstances such as level of sickness and available resources. There is a potential to improve the implementation of music therapy in health care teams. Increased knowledge on the potential and limits of music therapy among co-workers is needed, including the role as a relationship builder that the rest of the team could lean on. A continuous quality assurance of their therapeutic work is required. Finally, the music therapists need support in assessing stagnation and potential worsening of the patient's condition.

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Availability of data and materials

The transcribed focus groups are not publicly available for confidentiality reasons, but anonymized Norwegian transcripts can be made available from the corresponding author on reasonable request.

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Vedlegg

HELSE BERGEN
Haukeland universitetssjukehus

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

BETYDNINGEN AV Å KUNNE VELGE MEDIKAMENTFRI BEHANDLING FOR PASIENTER MED PSYKOSELIDELSER- EN KVALITATIV UTFORSKNINGSSTUDIE

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å undersøke brukeres erfaringer med å delta i det medikamentfrie behandlingstilbudet i Helse-Bergen. Målet med studien er å svare på hvordan opplevelsen av å kunne velge et medikamentfritt behandlingsalternativ er for mennesker med psykoselidelser, hvilken rolle valgfrihet har i tilfriskningsprosessen, og hvordan brukernes opplevelser ved å delta i dette behandlingsprogrammet er sammenliknet med personalets. Som bruker av det medikamentfrie tilbudet, eller deltager i et behandlingstilbud der også pasienter som har valgt behandling uten medikamenter deltar, er du derfor bedt om å være med i studien. Studien er finansiert av Helse Bergen og forankret i Kronstad DPS, som også er ansvarlig for studien.

HVA INNEBÆRER PROSJEKTET?

Dette er en kvalitativ studie med bruk av dybdeintervjuer. Prosjektansvarlig vil foreta to dybdeintervjuer med brukere av behandlingstilbudet, ett i starten av behandlingen, og for de pasientene som har valgt behandling uten medikamenter også ett oppfølgingsintervju etter ca ett år. På noen av intervjuene vil en medforsker som også er bruker delta. Intervjuene vil bli tatt opp på bånd. Informanten vil selv kunne velge tid og sted for intervjuet så langt det er mulig. Intervjuet kan vare fra en halv til halvannen time.

I studien vil vi innhente og registrere opplysninger om deg som er bruker av behandlingstilbudet. Det vil være demografiske opplysninger, som navn, alder, yrke og bosted. Vi ønsker også å innhente opplysninger fra din journal. I tillegg vil vi lagre intervjuene, og bruke anonymisert informasjon du der gir i videre analyser i prosjektet.

MULIGE FORDELER OG ULEMPER

Studien vil ikke påføre andre ulemper enn den tiden intervjuene tar.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet alle opplysninger og intervjuer med deg, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Christine Ødegaard, mobilnummer +47 90091979, e-post: christine.odegaard@helse-bergen.no.

Hvis du ønsker å trekke deg fra studien vil det ikke få noen innvirkning på den videre behandlingen av deg.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt. Prosjektslutt er satt til 13. juli 2020.

OPPFØLGINGSPROSJEKT

Ved å delta i prosjektet samtykker du også til at prosjektleder kan kontakte deg igjen for eventuelle oppfølgingsprosjekt. Aktuelt tidsrom for dette vil være fra år 2020 til 2025.

GODKJENNING

Prosjektet er godkjent av personvernombudet i Helse Bergen, ref. 2017/8692.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato

Signatur

Rolle i prosjektet

HELSE BERGEN
Haukeland universitetssjukehus

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

BETYDNINGEN AV Å KUNNE VELGE MEDIKAMENTFRI BEHANDLING FOR PASIENTER MED PSYKOSELIDELSER- EN KVALITATIV UTFORSKNINGSSTUDIE

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å undersøke behandleres erfaringer med det medikamentfrie behandlingstilbudet i Helse-Bergen. Målet med studien er å svare på hvordan opplevelsen av å kunne velge et medikamentfritt behandlingsalternativ er for mennesker med psykoselidelser, hvilken rolle valgfrihet har i tilfriskningsprosessen, og hvordan brukernes opplevelser ved å delta i dette behandlingsprogrammet er sammenliknet med personalets. Som behandler i det medikamentfrie tilbudet er du derfor bedt om å delta i studien. Studien er finansiert av Helse Bergen og forankret i Kronstad DPS, som også er ansvarlig for studien.

HVA INNEBÆRER PROSJEKTET?

Dette er en kvalitativ studie med bruk av fokusgrupper. Prosjektansvarlig vil sammen med en psykolog og medhjelper på prosjektet gjennomføre fokusgrupper med behandlere som jobber med det medikamentfrie tilbudet til pasienter med psykoselidelser. Fokusgruppene vil bli tatt opp på lydbånd som hjelp for prosjektleder til ikke å miste verdifull informasjon. Fokusgruppen kan vare fra en til halvannen time.

I studien vil vi registrere noen opplysninger om deg. Det vil være demografiske opplysninger, som navn, alder, og rolle i det medikamentfrie behandlingstilbudet. I tillegg vil vi transkribere og lagre informasjon gitt i fokusgruppene, og bruke anonymisert informasjon du der gir i videre analyser i prosjektet.

MULIGE FORDELER OG ULEMPER

Studien vil ikke påføre andre ulemper enn den tiden intervjuene tar.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet alle opplysninger om deg, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Christine Ødegaard, mobilnummer +47 90091979, e-post: christine.odegaard@helse-bergen.no.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt. Prosjektslutt er satt til 13. juli 2020.

OPPFØLGINGSPROSJEKT

Ved å delta i prosjektet samtykker du også til at prosjektleder kan kontakte deg igjen for eventuelle oppfølgingsprosjekt. Aktuelt tidsrom for dette vil være fra år 2020 til 2025.

GODKJENNING

Prosjektet er godkjent av personvernombudet i Helse Bergen, ref. 2017/8692.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato	Signatur
	Rolle i prosjektet

Intervjuguide for dybdeintervjuer

Fokus: Pasientens bakgrunn, livssituasjon, familie og venner, skole og jobb. Hvilke valg er tatt underveis?

Prosessorientert intervjuguide, få mest mulig fullstendig livsløp, hva fungerer bra, hva syns pasienten er vanskelig?Hvorfor?

Pasienthistorie – livsløp

Fortell om deg selv og livet ditt så langt.

Barndom?

Familie?

Venner?

Skole?

Jobberfaring?

Spesielle opplevelser du vil trekke frem, som har betydd noe for deg? Positive – negative?

Behandling – møter med helsevesen

Fortell om din verste opplevelse i møte med helsevesenet/helsepersonell.

Fortell om din beste opplevelse i møte med helsevesen eller personell.

Hva syns du er vanskelig med å være pasient? Hvorfor?

Er det noe som er bra med å være pasient?

Hva slags hjelp føler du at du trenger mest?

Hvilken del av behandlingen liker du best? Hvorfor?

Hvordan opplever du at din helsetilstand er?

Hva slags helsemessige utfordringer opplever du at du har?

Hva er dine sterkeste helsemessige sider?

Har du opplevd at andre tenker om deg at du er sykere eller friskere enn det du selv mener du er? Hvordan var det?

Har du fått en diagnose? Hva tenker du om den?

Hva skjer med deg når du blir dårlig?

Hva er det viktigste for deg å få hjelp til når du blir dårlig?

Opplevelse av valgfrihet

Fortell om din drømmedag på posten, når du er innlagt.

Hvis du kunne velge akkurat den behandlingen du kunne ønske deg, hva ville du velge?

Hva tror du familien din ville velge for deg, hvis de fikk bestemme? Din beste venn?

Hva tror du legen din ville valgt for deg?

Opplever du at dine tanker om valg og behov når det gjelder behandling blir tatt hensyn til av de som er behandlere?

Kan du fortelle om den behandlingen du går til nå? Hvorfor og hvordan har du valgt den behandlingen?

Hvem snakker du mest med og stoler mest på når det gjelder valg av behandling? Familie?, venner, behandlere, andre?

Hva slags opplevelser og erfaringer har du fra samtaler om valg av behandling?

Noen sier de ikke tør å fortelle alt om hvordan de har det, for da er de redd for at de ikke får velge den behandlingen de vil ha, men kanskje blir tvunget til å ta medisiner, eller til og med tvangsinnlagt. Har du hatt sånne tanker?

Kan du si litt om hva du tenker er det verste som kan skje med deg når du er dårlig?

Tanker om fremtiden

Kan du beskrive hvordan du ønsker deg at livet ditt skal være om ti år?

Hvordan tror du livet ditt vil bli i virkeligheten?

Hva tenker du at du kan gjøre for å få det livet du ønsker deg?

Hva er det viktigste for deg for at du skal være fornøyd med måten du lever på?

Hva trenger du at andre gjør for at du skal få et liv du er fornøyd med?

Intervjuguide – fokusgruppe 1 og 2

Fokus: Behandlernes erfaringer med det medikamentfrie behandlingstilbudet ved de ulike DPS-ene i Bergen.

Prosessorientert intervjuguide, hva fungerer bra, hva syns de er vanskelig? Hvorfor?

Fokus på konkrete fortellinger.

Bakgrunn – narrativ

Dere er invitert hit i dag for å dele deres erfaringer med det at pasienter med psykoselidelser nå kan velge behandling uten antipsykotika.

Temperaturen i diskusjoner i media har til tider vært høy både med hensyn til hva som er ansvarlig behandling, og hvordan samtykkekompetanse skal vurderes, men særlig i forhold til pasienters opplevelse av tvang og manglende autonomi i egen behandling, og dermed i eget liv. Vi ønsker å fokusere på de konkrete utfordringer dere som behandlere møter hver dag spesielt i forhold til implementeringen av dette behandlingstilbudet. *Tema for diskusjonen vil dermed være behandleres konkrete erfaringer med pasienter som ønsker medikamentfri behandling, enten som del av det medikamentfrie behandlingstilbudet på Kronstad, eller i løpet av «treatment as usual». Hva er vanskelig med dette? Hva er bra?*

Samvalg

Hva slags opplevelser og erfaringer har dere fra samtaler med pasienter om valg av behandling?

Opplever dere at pasientens tanker om valg og behov når det gjelder behandling blir tatt tilstrekkelig hensyn til? Hvorfor, hvorfor ikke?

Hva slags hjelp føler dere at pasientene trenger mest?

Hvilken del av behandlingen har dere mest tillit til? Hvorfor?

Behandleres behov

Hva er det verste dere opplever som behandlere i forhold til pasienter? Vil dere dele noen erfaringer?

- **selvmord**
- **drop-out**
- **forverring av tilstand**
- **samarbeid med andre behandlere**
- **samarbeid med andre etater**
- **samarbeid med pårørende**

Opplevd tilgjengelige ressurser

Er det en form for behandling som dere opplever som etterspurt, men som dere ikke kan tilby?

Hvordan ser dere for dere at (det medikamentfrie) behandlingstilbudet skulle vært i en verden der alt gikk an, og dere kunne velge å sette sammen tilbudet akkurat som dere ønsket?

Opplevd og behov for støtte

Hva er det viktigste for deg som behandler å få hjelp til når du møter på problemer i behandlingen av en pasient?

Opplever dere som behandlere at dere får den hjelp og støtte dere trenger fra arbeidsgiver for å kunne optimalisere behandlingen av pasientene?

Intervjuguide – fokusgruppe 3 (musikkterapi)

Fokus: Musikkterapeuters erfaringer med det medikamentfrie behandlingstilbudet ved de ulike DPS-ene i Bergen.

Prosessorientert intervjuguide, hva fungerer bra, hva syns de er vanskelig? Hvorfor?

Fokus på konkrete fortellinger!!

Bakgrunn – narrativ

Dere er invitert hit i dag for å dele deres erfaringer med det at pasienter med psykoselidelser kan velge behandling uten antipsykotika, og musikkterapi er en del av dette behandlingstilbudet.

Hovedfokus for diskusjonen i dag vil være:

1. **Fortellinger dere hører fra brukere som opplever at musikkterapi fungerer eller ikke fungerer?**
2. **Egne opplevelser av når og hvordan musikkterapi fungerer?**
3. **Når opplever dere at det ikke fungerer, og hva gjør dere da?**
4. **Og i hvilken grad og på hvilken måte opplever dere at brukere blir involvert i en valgprosess rundt egen behandling, kan de velge fritt musikkterapi om de**

ønsker det? Fins det begrensninger? Og i hvilken grad kan de velge form på egen terapi?

Fokus:

- *Kva forteljingar høyrer de frå brukarane om korleis musikkterapi fungerer for dei?*
- *Kva tenkjer de om og kva erfaringar har de med prosessar der brukarar er involverte i å velje musikkterapi som behandling (velje å ha det, velje innhald, velje å avslutte m.m.)?*
- *Dykkar eigne opplevingar av når og korleis musikkterapi fungerer, og av situasjonar og prosessar der musikkterapi IKKJE fungerer (korleis de handterer det, korleis de samarbeider med brukaren om det, om/korleis de søkjer støtte i fagmiljøet, osb.).*

Evt:

Behandleres behov

Hva er det verste dere opplever som behandlere i forhold til pasienter? Vil dere dele noen erfaringer?

Opplevd tilgjengelige ressurser

Er det en form for behandling som dere opplever som etterspurt, men som dere ikke kan tilby?

Opplevd og behov for støtte

Opplever dere at dere får den hjelp og støtte dere trenger fra arbeidsgiver for å kunne optimalisere behandlingen?

HELSE BERGEN
Haukeland universitetssjukehus

Personvernombudet

Christine Henriksen Ødegaard
Haukeland universitetssykehus/Divisjon psykisk helsevern
christine.odegaard@helse-bergen.no

Deres ref:	Vår ref:	Saksbehandler	Bergen,
	2017/8692	Christer Kleppe, tlf. 55975558	13.07.2017

Tilrådning fra personvernombudet

Viser til innsendt melding om behandling av personopplysninger. Meldingen gjelder prosjektet *«Betydningen av å kunne velge medikamentfri behandling for pasienter med psykoselidelser- en kvalitativ utforskningsstudie»*. Databehandlingsansvarlig for studien er Helse Bergen HF.

Det følgende er en formell tilråding fra personvernombudet. Forutsetningene nedenfor må være oppfylt før innsamlingen av opplysningene / databehandlingen kan begynne.

Formålsangivelse:
Formålet med studien er å undersøke personalets og brukernes erfaringer med et nytt medikamentfritt behandlingstilbud ved Kronstad DPS.

Studien har vært forelagt REK for vurdering, ref. REK nr. 2017/736. REK har i sin tilbakemelding gitt uttrykk for at studien vil kunne gi nyttig informasjon om et nytt behandlingstilbud for psykosepasienter, og at den vil være forsvarlig å gjennomføre. Komiteen har imidlertid lagt til grunn at studien ikke omfattes av helseforskningsloven.

På bakgrunn av de innsendte dokumenter og samtale med prosjektleder legger personvernombudet til grunn at studien skal gjennomføres i tråd med de forutsetningene REK oppstiller i sitt vedtak datert 19.05.2017. Personvernombudet legger til grunn at studien ikke omfattes av helseforskningsloven, men kan anses som helsetjenesteforskning

Rekruttering:
Deltakere til studien vil bli rekruttert fra divisjon psykisk helsevern i Helse Bergen HF. Det skal rekrutteres 8-10 pasienter som har valgt behandling uten medikamenter, 8-10 pasienter som har valgt behandling med medikamenter og to fokusgrupper med 8-12 behandlere involvert i det medikamentfrie tilbudet. Det innhentes skriftlig samtykke fra all deltakerne.

I protokollen angis at pasienter også skal rekrutteres fra andre virksomheter. På bakgrunn av tilbakemelding fra prosjektleder legger personvernombudet til grunn at dette likevel ikke er aktuelt på nåværende tidspunkt. Prosjektleder er informert om at en evt. inklusjon av pasienter fra andre virksomheter vil være gjenstand for en endringssøknad til personvernombudet.

Samtykke-/informasjonsskriv:
Det forutsettes at det skal innhentes et informert, frivillig, og uttrykkelig samtykke fra deltakerne i studien.

Det er utformet samtykke-/informasjonsskriv til hver av gruppene som skal inkluderes i studien. Før deltakere kan rekrutteres til studien, må det gjøres noen endringer til samtykke-/informasjonsskrivet som beskrevet herunder.
Det angis i informasjonsskrivet: *«I tillegg vil vi transkribere og lagre informasjon gitt i terapigruppen, og bruke* ***anonymisert*** *informasjon du der gir i videre analyser i prosjektet.»*. I meldeskjemaet går det imidlertid frem at koblingsnøkkelen vil bli lagret inntil 30.06.2025. en koblingsnøkkel medfører at tilknyttede data ikke kan anses som **anonyme**. Dvs. dersom analysen det her refereres til skjer på avidentifiserte data, kan ikke prosjektleder her omtale dataene som anonyme.

Prosjekts sluttdato må fremgår av samtykke-/informasjonsskrivet. Det må fremgå at prosjektslutt er 13.07.2020, ref. telefonsamtale med prosjektleder.

I avsnittet «Frivillig deltakelse og mulighet for å trekke sitt samtykke» må det komme tydelig frem at det ikke vil få noen innvirkning for den videre behandlingen av pasienten, dersom vedkommende ønsker å trekke seg fra studien.

I avsnittet «Hva skjer med informasjonen om deg?» bør det fremgå at opplysninger innsamlet til bruk for studien vil bli lagret på et eget område på Helse Bergen HF sin Forskningsserver hvor bare personer tilknyttet prosjektet har tilgang. Det bør videre komme frem at koden som kan knytte deltakeren til person-/helseopplysninger lagres separat fra de øvrige opplysningene.

I avsnittet «Utlevering av opplysninger til andre» fremgår det at anonymiserte opplysninger kan utleveres til utlandet, men at koden som knytter opplysningene til den registrerte ikke vil bli utlevert. All den tid prosjektleder har opplyst at person-/helseopplysninger likevel ikke skal utleveres, kan avsnittet fjernes. Det bemerkes forøvrig at opplysningene ikke er å anse som anonyme så lenge en koblingsnøkkel finnes. For det tilfellet at opplysninger skulle blitt utlevert, ville dette vært en mangel ved samtykke-/informasjonsskrivet.

Samtykke-/informasjonsskrivet er tilpasset protokollen som var forelagt REK, men er ikke endret etter at REK avviste prosjektet pga. manglende mandat. Bl.a. medfører dette at punktet om at prosjektet er godkjent av REK må fjernes.

Personvern og informasjonssikkerhet:
Som ledd i studien vil det bli innhentet identifiserbare helseopplysninger om pasienter og identifiserbare personopplysninger om behandlere som deltar i fokusgruppene. På bakgrunn av korrespondanse med prosjektleder legges det til grunn at opplysningene som samles inn er relevante og nødvendige for det angitte formålet.

Personvernombudet har stilt spørsmål til prosjektleder om studien kan gjennomføres uten bruk av lyd-/videoopptak. Bruk av lyd/videoopptak medfører en risiko for at det samles inn opplysninger utover det som er nødvendig for gjennomføringen av studien. Bl.a. oppstår en risiko for at det samles inn opplysninger om 3. person som ikke har gitt samtykke til behandling av egne personopplysninger. Denne risikoen øker når spørsmålene i intervjuguiden er så vidt utformet som er tilfellet her. Bruk av lyd-/videoopptak medfører også at personvernkonsekvensene blir større dersom informasjonen skulle komme på avveie.

Prosjektleder har gitt tilbakemelding om at studien vanskelig kan gjennomføres uten at det gjøres opptak. Personvernombudet legger til grunn at dette er tilfellet, men bemerker at prosjektleder og ansvarlig avdeling må iverksette tiltak som kan redusere risikoen for at personopplysninger kommer på avveie, og evt. konsekvensen for den registrerte dersom dette skulle skje.

Personvernombudet forutsetter at lyd-/videoopptak skal bare brukes i den utstrekning dette er nødvendig for gjennomføringen av studien. Det skal gis tydelig informasjon til den registrerte om at det gjøres opptak, og evt. hva slags opptak det gjøres før intervjuene starter. Informasjonen i samtykke-/informasjonsskrivet er ikke i seg selv tilstrekkelig. Dersom pasienten motsetter seg at det gjøres opptak, skal dette respekteres. Dersom datainnsamlingen heller ikke kan skje gjennom bruk av mindre inngripende midler, f.eks. gjennom bruk av notater, bør den registrerte informeres om at de kan trekke sitt samtykke uten at det får betydning for den videre behandlingen.

Det er ikke beskrevet i meldeskjemaet hva slags utstyr som skal benyttes for datainnsamlingen. Personvernombudet forutsetter at det bruk utstyr som er godkjent for bruk av Helse Bergen HF. Det skal ikke brukes opptaksutstyr som kan kobles til internett og lyd-/videoopptak bør overføres til sikkert lagringsområde uten ugrunnet opphold. Inntil data er overført til sikkert lagringsområde, skal data lagres nedlåst på prosjektleders kontor. Når lyd-/videoopptak er overført til sikkert lagringsområde og dataintegriteten er bekreftet, bør data slettes fra opptaksenheten på en slik måte at det ikke er mulig å gjenopprette. Innsamlede data skal ikke lagres for en lengre periode enn hva som er nødvendig for formålet. Når det ikke lengre er nødvendig å lagre identifiserbare data, skal disse anonymiseres. Det legges videre til grunn at innsamlede person-/helseopplysninger bare skal være tilgjengelig for personer i prosjektgruppen som er underlagt taushetsplikt og Helse Bergen HF sin styringsrett gjennom ansettelsesforhold eller databehandleravtale.

Det gjøres oppmerksom på at prosjektperioden er relevant for vurderingen av personvernet. Person-/helseopplysninger kan ikke lagres lengre enn hva som er absolutt nødvendig for formålet med studien. I meldeskjemaet fremgår det at prosjektslutt er 30.06.2025, og at data skal anonymiseres samme dag. I samtykke-/informasjonsskrivet er det imidlertid oppgitt at data skal lagres inntil 5 år etter prosjektslutt. Det er dermed noe uklart når data er tenkt slettet/anonymisert. Etter samtale med prosjektleder legger personvernombudet til grunn at ***prosjektslutt*** er 3 år fra d.d. dvs. 13.07.2020 og at data skal lagres for kontrollformål inntil 30.06.2025. Skulle det senere vise seg at det blir nødvendig med å legge ***prosjektslutt*** til en senere dato, må det sendes endringsmelding om dette i god tid før 13.07.2020. Etter forholdene kan en slik endring medføre krav til nytt samtykke fra de registrerte.

Tilrådning:
Med hjemmel i personopplysningsforskriften § 7-12 og personopplysningsloven § 31 har Datatilsynet fritatt Helse Bergen HF for meldeplikten til Datatilsynet når prosjektet er meldt til personvernombudet.

Personvernombudet har vurdert det til at den planlagte databehandlingen omfatter annen forskning, og er meldepliktig til personvernombudet i henhold til personopplysningsloven § 33 og personopplysningsforskriften § 7-27.

Personvernombudet tilrår at prosjektet gjennomføres under forutsetning av følgende:

1. Helse Bergen HF er databehandlingsansvarlig for studien.
2. Prosjektet er forelagt og godkjent av ansvarlig leder.
3. Behandling av helse- og personopplysningene skjer i samsvar med og innenfor det formål som er oppgitt i meldingen og i telefonsamtale og korrespondanse med personvernombudet.
4. Det gjøres endringer til samtykke-/informasjonsskrivet som beskrevet herover
5. Tilgangen til registeret skjer i overensstemmelse med taushetspliktbestemmelsene.
6. Data lagres avidentifisert på helseforetakets Forskningsserver. For å få tildelt plass på Forskningsserveren må saksnummer på REK-vedtak (under Vår ref) fylles ut i søknadsskjemaet. Tilrådingsbrevet skal også legges ved. Annen elektronisk lagringsform forutsetter gjennomføring av en risikovurdering som må godkjennes av foretakets IKT-sikkerhetsleder/personvernombud.
7. Kryssliste som kobler avidentifiserte data med personopplysninger lagres enten elektronisk på tildelt område på Forskningsserveren eller nedlåst på prosjektleders kontor.
8. Data slettes eller anonymiseres (ved at krysslisten slettes) senest 30.06.2025. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.
9. Prosjektet kvalifiserer ikke som medisinsk- og helsefaglig forskning slik det er definert i helseforskningsloven. Du kan benytte bekreftelsen fra REK om at prosjektet ikke er fremleggingspliktig, dersom dette kreves av tidsskrift.
10. Dersom formålet eller databehandlingen endres må personvernombudet informeres om dette.
11. Kontaktperson for prosjektet skal hvert tredje år sende personvernombudet ny melding som bekrefter at databehandlingen skjer i overensstemmelse med opprinnelig formål og helseregisterlovens regler.

Med vennlig hilsen

Christer Kleppe
Personvernombud
Helse Bergen HF

Kopi til:
Hans Olav Instefjord
Randi-Luise Møgster

Dokumentet er elektronisk signert

HELSE VEST

Stavanger, februar 2016

Protokoll

mellom

Helse Vest RHF og Regionalt brukerutvalg

om medikamentfri behandling i psykisk helsevern

Bakgrunn for saken

I oppdragsdokumentet for 2015 ble det satt følgende mål:

> Pasienter i psykisk helsevern skal så langt det er forsvarlig kunne velge mellom ulike behandlingstiltak, herunder behandlingstiltak uten medikamenter. Tilbudet skal utformes i nært samarbeid med brukerorganisasjonene.

Styringskravet er fulgt opp i samarbeid med helseforetakene og brukerrepresentanter og gjennom rapportering til Helse- og omsorgsdepartementet i løpet av 2015.

I tilbakemelding i brev av 11/2015 spesifiserer departementet oppdraget med frister.

Det presiseres at de regionale helseforetakene skal:

- Etablere et reelt tilbud til de som ønsker det om valg av alternativer til legemidler, herunder hjelp til nedtrapping og avslutning og igangsetting av andre terapeutiske støtte- og behandlingstiltak.
- Tilbudet skal utformes i en dialog med brukerorganisasjonene. Det innebærer at målet er å etablere tilbudet på en måte som brukerorganisasjonene er tilfreds med.
- Departementet ber om at en omforent løsning kommer til uttrykk i en protokoll underskrevet av begge parter, dvs RHF og berørte brukerorganisasjoner.
- Protokollen skal være en ramme for lokalt arbeid.
- Protokollen skal være undertegnet til 01.03.16 og sendes departementet til orientering.

Som ledd i arbeidet og for å vinne erfaring skal:

> Helse Vest etablere minst en enhet/post i DPS øremerket for medikamentfri behandling/nedtrapping av medikamentell behandling.

Vurdering av dagens situasjon

Helseforetakene tilbyr i dag en rekke behandlingstilbud som er medikamentfrie. Det kan likevel stilles spørsmål ved hvor reelt tilbudet framstår for pasientene. I den grad medikamentfri behandling ikke oppleves som et reelt valg for pasientene kan det bl.a. skyldes:

- at pasientene ikke får tilstrekkelig informasjon om behandlingstilbudet og om muligheten til å velge behandling uten bruk av medikamenter,
- at det ved noen avdelinger mangler alternative tilbud og
- at det fortsatt kan være en «medikamentkultur» enkelte steder som gjør at medikamenter blir valgt selv når det ville vært forsvarlig å tilby et medikamentfritt tilbud

Denne forståelsen er lagt til grunn for videre oppfølging.

Plan for videre oppfølging

I samarbeid med helseforetakene og representanter for brukerne er det utarbeidet en tiltaksplan for arbeidet med å videreutvikle medikamentfrie behandlingsalternativ i Helse Vest.

Det er her lagt til grunn:

- I Helse Vest skal tilbud om medikamentfri behandling prege hele virksomheten i psykisk helsevern. Pasienter som ønsker det, skal så langt det er forsvarlig, få tilbud om medikamentfri behandling ved sitt lokale DPS, på sykehusavdelinger, i poliklinikker og på sengeposter. Det er ikke ønskelig å begrense tilbudet til egne enheter i helseforetakene.

- For å sikre at tilbudet om medikamentfri behandling framstår som reelt for pasientene, skal pasientene informeres om retten til å velge, og få informasjon om behandlingstilbud som er medikamentfrie. Helse Vest vil i løpet av våren 2016, sammen med brukerorganisasjonene/brukerutvalgene og helseforetakene, utarbeide felles informasjonsmateriell til pasientene.

- Den enkelte pasient skal rutinemessig informeres om ulike typer behandling tidlig i behandlingsforløpet. Pasienten skal få informasjon om tilgjengelige og forsvarlige behandlingsformer som pasienten kan velge mellom. Valget til pasienten skal dokumenteres i journal og komme til uttrykk i behandlingsplan/kriseplan. Alle avdelinger skal ha dette på plass i løpet av 2016.

- På kort sikt skal det i helseforetakene utvikles flere nye medikamentfrie behandlingstilbud. Målet er at medikamenter gis i «samvalg» med pasienten, primært fordi det er det beste alternativet og ikke i mangel av medikamentfritt behandlingstilbud.

- På lengre sikt skal det fortsatt jobbes med kultur, kunnskapsutvikling og forskning på medikamentfri behandling.

Som ledd i å styrke, konkretisere og realisere et reelt medikamentfritt tilbud i regionen vil det være ønskelig å utvikle verktøy for samvalg og beslutningsstøtte. Slike konkrete hjelpemidler vil være til hjelp for både pasient og behandler.

Pilotprosjekt

For å oppfylle kravet om at Helse Vest skal etablere minst en enhet/post i DPS øremerket for medikamentfri behandling/nedtrapping av medikamentell behandling, er alle helseforetakene forespurt om forslag. Forslagene er drøftet i fellesmøte med alle helseforetakene og representanter for brukerorganisasjonene. Det var her bred oppslutning om å gå videre med forslaget fra Helse Bergen med utgangspunkt i Kronstad DPS.

Pilotprosjektet i Helse Bergen tar utgangspunkt i et etablert psykoseforløp/pakkeløp og en egen enhet ved Kronstad DPS for nysyke der pasientene kan velge medisinfri behandling. Det skal utvikles til å omfatte de andre DPSene i foretaksområdet.

Opplegget kan illustreres ved nedenfor stående klipp fra nettsiden i Helse Bergen:

> **Medikamentfritt behandlingsalternativ som forløp for nysyke ved Kronstad DPS**
>
> Det vektlegges samarbeid mellom pasient og behandler. Behandlingen tilrettelegges for pasientens egne valg og prioriteringer. Målet er å bidra til økt mestring og deltakelse i samfunnet.
>
> En vektlegger at tilbudet i størst mulig grad skal være kunnskapsbasert og oppdatert etter aktuelle faglige retningslinjer. Forløpet skal være faglig forsvarlig, og det gjøres fortløpende evalueringer.
>
> En tilstreber å bruke «shared desicion making» som samarbeidsmetode i utforming av pasientens behandlingsplan/ individuell plan. Alle pasienter får tilbud om et eget tverrfaglig team. Evaluering av hva som kan være nyttig tilbud gjøres regelmessig sammen med pasienten.
>
> Innholdet i et medikamentfritt behandlingsforløp kan være:
>
> - Flerfamiliegruppe og pårørende kvelder
> - Terapi, som kognitiv atferdsterapi og psykodynamisk psykoterapi
> - Kunst og musikkterapi
> - Fysisk aktivitet, trening og fysioterapi
> - Levevaner, som kurs om levevaner som forebygging til livsstilsrelatert sykdom
> - Tilfriskningsgruppe (IMR)
> - Individuell jobbstøtte (IPS)
>
> Les mer: http://www.helse-bergen.no/no/OmOss/Avdelinger/kronstad-dps/Sider/psykosedagbehandling-gruppepoliklinikk.aspx

Det betyr at det skal legges til rette for et pakkeløp:

- for medisinfri behandling av pasienter med psykosespekter lidelser,
- et forløp hvor pasientene innledningsvis blir godt informert om de ulike behandlingstilbudene og
- kan gjøre et reelt valg i samarbeid mellom pasient og behandler.

Det må sikres at pasientene tilbys et forsvarlig behandlingstilbud som systematisk og tett følges opp, også med monitorering av symptomuttrykk og funksjonsnivå. Behandlingsplan/individuell plan må nyttes i tråd med nasjonale retningslinjer for psykosebehandling.

Pilotprosjektet må organiseres som et eget prosjekt og gi grunnlag for å vinne erfaring med medikamentfri behandling. Det betyr bl.a. at det forløpene må dokumenteres, data systematiseres og danne grunnlag for evaluering og forbedring.

I etterkant vil kunnskapen og erfaringene fra piloten kunne brukes til å utarbeide rammer for tilbud om medikamentfri behandling innen alle diagnoser hvor dette vurderes forsvarlig.

Pilotprosjektet organiseres med en styringsgruppe bestående av representanter fra Regionalt Brukerutvalg i Helse Vest, Helse Vest RHF, Helse Bergen, Helse Fonna, Helse Stavanger og Helse Førde.

I prosjektgruppen vil representanter for alle DPSene i Helse Bergen, representanter fra lokalt brukerutvalg og erfaringspanelet delta. For å sikre etterfølgelse av pakkeforløp innen faglig forsvarlige rammer skal det være en egen koordinator, knyttet til Kronstad DPS.

Pilotprosjektet skal nærmere utformes i samarbeid mellom Helse Bergen og Helse Vest og brukerrepresentanter i Helse Bergen og Regionalt brukerutvalg i Helse Vest.

Pilotprosjektet skal startes senest 1. juni 2016.

Arbeidet med utvikling av medikamentfrie behandlingstilbud i Helse Vest skal skje i nært samarbeid med brukerne og brukerorganisasjonene.

Stavanger: 25.02 2016

Herlof Nilssen
adm. direktør

Linn Bæra
leder Regionalt brukerutvalg

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