UiT The Arctic University of Norway

Faculty of Health Sciences

Experiences with Capacity-based Mental Health Legislation in Norway

A qualitative interview study among patients who have come off a community treatment order, their health professionals and their family caregivers

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By

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Acknowledgements

"It goes without saying that there's a world of difference between coercion and non-coercion!"

That was what one of the study participants replied when asked if there were any differences between before and after the change in the legislation, after he had said that the health care provision, his medicines and his life were more or less the same as before his CTO (community treatment order) was revoked, when the Mental Health Care Act was amended. He did not seem to appreciate the question. He thought there was a huge difference in being able to receive the health care he needed voluntarily rather than being subjected to coercion. I hope that this study can contribute to further develop health care services in a way that respects the individual patient's integrity and human dignity, i.e. patient-centred health care.

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1 Introduction

In Western jurisdictions, including Norway, there has been a growing awareness in recent decades that people with severe mental illness should have the right to decide on their treatment (Szmukler & Kelly, 2016; NOU 2011: 9; Helsedirektoratet, 2021, 2023). On 1 September 2017, a new criterion regarding lack of capacity to consent in the use of coercion was introduced in Norwegian mental health care (Psykisk helsevernloven, 1999). This represents a comprehensive change in the legislation, involving a capacity-based model for the use of coercion. The change is an adaptation to the principles of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Capacity-based legislation emphasizes a focus on the patient's functional level rather than the diagnosis (NOU 2011: 9). If the patient is assessed to represent a serious danger to his/her own life or the life or health of others, a decision on coercion can be made, irrespective of the criterion of lack of capacity to consent (Psykisk helsevernloven, 1999, §3-3). The intention of the legislation was to increase self-determination and legal protection and to introduce reduced and appropriate use of coercion for people with a severe mental illness (NOU 2011: 9). The amendment to the legislation was expected to be particularly important in reducing the numbers of outpatients under CTOs, because it was assumed that most people capable of living at home are also capable of giving consent (NOU 2011: 9; Prop. 147 L (2015-2016)).

A capacity-based model aims to ensure a balance between a patient's right to self-determination and the right to emergency health care when the patient is unable to assert this right (NOU 2011: 9). Capacity-based legislation means that people with a severe mental illness can no longer be denied the possibility to refuse treatment, without an assessment of their capacity to consent. At the same time, it has been pointed out that severe mental illness in itself need not imply a lack of consent capacity (Szmukler, 2018; Szmukler & Kelly, 2016; Calcedo-Bara et al., 2020). The right to participate in treatment decisions is emphasized, and patients with capacity to consent have the right to decide against treatment they do not want or to end treatment that has started. The right to make one's own decisions underlines respect for patients' integrity and dignity, and it is also important for their motivation and willingness to cooperate with health care personnel (NOU 2011: 9; Szmukler, 2018). The scepticism of the change in the law in Norway mostly involved concern that patients with severe mental illness would refuse necessary treatment and care with a risk of serious deterioration, thus increasing the burden of care and responsibility for family members (NOU 2011: 9; Bruk av tvang, 2017; Larsen, 2017; Utkilen, 2017; Terjesen, 2017).

1.1 Purpose of the study

The introduction of the lack of capacity to consent as an independent criterion for the use of coercion in "Act on the Establishment and Implementation of Mental Health Care" (the Mental Health Care Act) (1999, § 3-3) is a significant change in the legislation. This study explores the experiences of the groups affected by the change in the law and aims to examine and describe the conditions necessary for enabling people with severe mental illness to receive voluntary health care as an alternative to a CTO.

This study examines the experiences of patients, family caregivers and health care personnel when CTOs were revoked as a result of the change, and consists of three sub-studies. Sub-study I explores the experiences of patients when their CTO had been revoked due to the change in the law, sub-study II investigates the experiences of the health care personnel providing treatment and care to the participants in sub-study I, while sub-study III deals with the experiences of family caregivers of the participants in sub-study I.

Sub-study I: ***Increased autonomy with capacity-based mental health legislation in Norway: a qualitative study of patient experiences of having come off a community treatment order.***

The aim was to explore patient experiences of how far the new legislation has enabled them to be involved in decisions on their treatment after they were assessed as capable of giving consent and had their CTO revoked due to the change in the legislation.

Sub-study II: ***Health professionals' experience of treatment of patients whose community treatment order was revoked under new capacity-based mental health legislation in Norway: a qualitative study.***

The aim was to explore health professionals' experiences of how capacity-based legislation affects health care services for patients whose community treatment order was revoked as a result of being assessed as having capacity to consent.

Sub-study III: ***Capacity-based legislation in Norway has so far scarcely influenced the daily life and responsibilities of patients` carers: a qualitative study.***

The aim was to explore carers` experiences of how their responsibility and daily life were affected after the patient's community treatment order was revoked based on capacity to consent.

1.1.1 Scope of the study

The patients interviewed in this study had a severe mental illness and had been under a CTO. Severe mental illness is here abbreviated to SMI, and is a collective term to cover serious and

long-lasting symptoms. These symptoms are often altered sensory experiences, distorted perceptions of reality and confusion, accompanied by anxiety and functional decline. Patients often also have concurrent drug addiction and physical illnesses (Helsedirektoratet, 2022b; Folkehelseinstituttet, 2023).

The study is primarily based on the patients and includes health care professionals and next of kin chosen by the patients. Four of the patients also had a substance abuse disorder, but substance abuse was not a prominent theme in the interviews or the data analysis, and is therefore not a central topic of this thesis.

The term health care personnel is used in this thesis to refer to any person whose job is to provide treatment or care to these patients or their family caregivers. When it is necessary for the context to mention the qualifications or responsibility of health care personnel, this is mentioned. Professionals with the main responsibility for treatment are often psychiatrists or specialist psychologists with relevant training and experience, and are here referred to as specialists. Health care personnel who provide day-to-day care have various backgrounds and qualifications, and are usually referred to as health care personnel responsible for day-to-day care.

Next of kin can be described as informal carers, relatives, family or social network (Førde et al. 2016, Weimand 2011). In this thesis, the term "next of kin" is used when discussing their rights, "family carers" about the interviewees, and sometimes "family" or "family members" are used. All participants in the study have their next of kin represented by family members.

2 Background

2.1 Historical background

The “Lov om Sindsyges Behandling og Forpleining av 1848” (Act on the Treatment and Care of the Insane) introduced the care of insane people, as those with severe mental disorders were called, as a separate field and a public responsibility in Norway (Fause, 2007). In 1935, a revision of the Act enabled voluntary admission to an asylum (Fause, 2007). This “Insanity Act” remained in force with minor changes until the introduction of the Mental Health Care Act on 28 April 1961 (Høyer & Dalgard, 2002; Nyttingnes & Pedersen, 2017). The 1961 Act did not represent a radical break with the previous one, but placed greater emphasis on the additional criteria, which then consisted of a treatment criterion, an objectionable behaviour criterion and a dangerousness criterion, at least one of which had to be present in addition to the main criterion of a severe mental disorder (Høyer & Dalgard, 2002, p. 99). The possibility of hospitalization of up to three weeks for observation was also introduced in order to determine whether the patient’s condition required involuntary admission, while the abolition of the Control Commission[1] was considered but not implemented (Høyer & Dalgard, 2002). Compulsory aftercare, the precursor to CTO, was legally introduced in 1961. There was an increasing focus on long stays in institutions. Excessive numbers of patients put great pressure on the wards. Compulsory aftercare was introduced to enable more patients to be discharged without ending their treatment (Pedersen, 2002, p. 190). The 1950s and 1960s saw revolutionary developments in pharmacology, and antipsychotics, mood stabilizers, antidepressants and tranquilizers were now used (Gerlach & Vestergaard, 1998). After a period of great optimism about the effectiveness of treatment, the mood changed (Høyer & Dalgaard, 2002). This was partly due to the Civil Rights Movement which started in the USA in the 1960s and then spread to Europe. At the same time, there was a general revolt against power structures in Europe; this included mental health care and put the spotlight on psychiatric patients as a particularly oppressed group. There was a much more critical attitude towards psychiatry in Norway and internationally in the 1970s and 1980s (Høyer & Dalgaard, 2002), with a stronger focus on rights and legal protection for people with mental disorders. The Reitgjerde scandal unfolded in 1979, where the illegal use of force and coercive

[1] The Control Commission was established by the Act of 17 August 1848 on the Treatment and Care of the Insane, and its task is to ensure legal protection for the patient in encounters with mental health care services and to ensure that the legislation is applied according to its purpose (Sinnsykeloven, 1848; Høyer, 2016).

measures, correspondence censorship and punishments was revealed, and the case led to greater awareness of patients' rights in mental health care in Norway (Høyer & Dalgard, 2002). The 1970s saw the beginning of deinstitutionalization of mental health care in Norway, which led to a reduction in the number of inpatients, mostly in hospitals, from 14 000 to 8000 in the 1980s and 1990s. Decentralized mental health care became a key goal, taking place to a greater degree in primary care settings, in people's homes, in nursing homes and in local mental health centres (Haave, 2008).

In 1984, a separate order on involuntary medication treatment was introduced. Inpatients and outpatients in involuntary care could no longer be given compulsory medication without a separate treatment order (Psykisk helsevernloven, 1961; NOU 2011: 9). In 1988, the Ministry of Social Affairs called for a review of the Mental Health Care Act to improve patients' legal protection and appointed a legislative committee which proposed the bill "Act on Mental Health Care without Consent" (NOU 1988: 8). Due to objections, the bill was not passed and the government instead decided in favour of a minor revision of the 1961 Act. The revised law, "Act on the Establishment and Implementation of Mental Health Care" (The Mental Health Care Act of 1999), came into force on 1 January 2001. This revision was part of a broader health legislation reform that also included the Patient Rights Act, the Specialist Health Care Act and the Health Personnel Act, all of which were adopted in 1999 (Høyer & Dalgaard, 2002).

The Mental Health Care Act of 1999 provides more detail in its descriptions of the use of coercion than previous acts (Høyer & Dalgaard, 2002). The Act introduced conditions for compulsory observation, involuntary mental health care for inpatients and outpatients and decisions on the use of coercive measures and seclusion. Further, there was a requirement that voluntary mental health care should be attempted and that involuntary care should only be used if it was clearly the best alternative for a patient following an overall assessment. The treatment criterion and the dangerousness criterion were continued, while an additional criterion of avoiding harm to the patient was removed from the Mental Health Care Act. The wording in the dangerousness condition was changed to "imminent serious danger to the patient's own life or the life and health of others", which could then apply to both inpatients and outpatients. The use of a CTO no longer required previous admission (NOU 2011: 9). In 2005, there was a review of the Mental Health Care Act, resulting in minor adjustments and harmonization with the Patient Rights Act (NOU 2011: 9).

Increasing service user participation has been a key trend in recent decades (Helsedirektoratet, 2015). In White Paper No. 25 “Openness and Comprehensiveness”, service user involvement is an overarching objective. Mental health patients must play an active role in the planning of their treatment and care and patient organizations should be strengthened and given a greater say in the design of mental health care services (Meld. St. 25, 1996-97). In the “Escalation Plan for Mental Health” for the period 1999-2006 (Prop. 63, (1997-2008)), specific measures were presented for people with SMI, aiming at more active participation in society, integration and citizenship. This was then followed up with the slogan “No decisions about me without me” in two white papers (Meld. St. 26 (2014-2015); Meld. St. 34 (2015-2016)). A review of research and development work on patient involvement in mental health care reveals increasing understanding of the need for more individualized care (Helsedirektoratet, 2023b).

Another important trend seen in Norway and other Western countries in recent decades has been more community-based health care services and ambulatory multidisciplinary teams in order to enhance the accessibility, continuity and quality of health care (Helsedirektoratet, 2023a). There are ongoing efforts to find balanced service models to replace “hospital beds” after the drastic reduction in inpatients and lengths of stay in hospitals (Helsedirektoratet, 2015). More low-threshold services, multidisciplinary outreach teams and health care based on recovery or specific needs are being established in primary care (Trane et al., 2021, 2022; Helsedirektoratet, 2023a; NAPHA, 2023; Landheim, 2017).

2.1.1 Next of kin

The position of next of kin in Norway has been legally strengthened in recent years. In Norway the next of kin has the right to receive information that provides a basis for influencing and safeguarding the patient’s right to appeal in cases of lack of consent capacity, cf. the Patient Rights Act (1999, § 3). Legally, a distinction is made between those who are close and other relatives or friends. A close person is chosen by the patient and can temporarily represent a patient who lacks the capacity to consent. If the patient is unable to choose someone, the clinician with the main responsibility for the patient’s health care will appoint a person who has permanent, regular contact with the patient (Helsedirektoratet, 2018b).

Health care services are now obliged to provide information and communicate with them, provide good cooperation and offer them the necessary support (Helsedirektoratet, 2018a).

Family caregivers often take on a great deal of responsibility and can be an important resource for the patient in addition to having important information for the patient's health care. The rights of next of kin are stipulated in the Patient Rights Act (1999, § 3) and are described in detail in a guideline produced by the Directorate of Health (Helsedirektoratet, 2019, 2018a).

2.2 Structure of health care services in Norway

Norwegian health care services are today divided into two levels of care: primary care, which is municipally funded, and specialist care, which is financed and run by the regional health trusts (Helse- og omsorgsdepartementet, 2023). In the Norwegian welfare state, necessary health care is publicly funded for all citizens. People with SMI may need extensive health care from various service providers at both levels of care at the same time (Helsedirektoratet, 2015). The Health Personnel Act (1999, § 3) defines health care as follows: "By health care is meant any action that has the aim of prevention, diagnosis, treatment, health maintenance, rehabilitation or nursing, which is performed by health personnel". Health care services are subject to the Patient Rights Act (1999) and the Health Personnel Act (1999), in addition to legislation relevant to each level of care.

Municipal/primary health care is subject to the Municipal Health Care Act (2011) and is responsible for meeting citizens' primary health care needs by providing medical examinations, treatment and home care. These services include general practitioners, mental health care, home nursing, staffed and unstaffed housing as well as various low-threshold services providing support, therapy and various activities. Some of the smallest municipalities cooperate with others to enable provision of some services (Helse- og omsorgsdepartementet, 2023; Helsedirektoratet, 2014). In a number of municipalities, flexible assertive community treatment teams (FACT teams) and/or assertive community treatment teams (ACT teams) have been established; these are interdisciplinary outreach teams that can provide both primary and specialist health care (Helsedirektoratet, 2023a). Several more teams are in the process of being established. These teams can create a comprehensive tailor-made intervention in collaboration with the patient, ranging from treatment of substance abuse and mental health problems to close individual follow-up care to help the patient in the areas of work, family, leisure time and housing (Helsedirektoratet, 2023a; Trane, 2023).

The specialist level of care has the main responsibility for mental health care and is obliged to provide the necessary specialist health care services stipulated in the Specialist Health Care

Act (1999) and the Mental Health Care Act (1999). Specialist health care includes hospitals and mental health centres offering assessment, treatment and care to inpatients and outpatients. The specialist level of care is also responsible for involuntary care for both groups.

2.3 Community treatment order

2.3.1 The legal basis for CTOs

In Norway, CTOs are subject to the criteria stated in the Mental Health Care Act of 1999) (Psykisk helsevernloven, 1999, § 3-3 and § 3-5), and are the same criteria as those for compulsory inpatient mental health care. A CTO decision is a legal decision taken by the specialist responsible for the patient, based on clinical facts and clinical judgement, cf. the Mental Health Care Act (1999, § 3). The specialist who makes the CTO decision must do so on the basis of available information and his/her examination of the patient. The patient must have an SMI and the CTO must be considered necessary to prevent a significant reduction in the person's prospects of recovery or significant improvement or to prevent significant deterioration, or because the patient poses a probable serious danger to his/her own life or the life or health of others.

The new criterion introduced in 2017 requires that the patient lacks consent competence, cf. the Patient Rights Act (1999, § 4-3). The exception to this is when the patient poses a probable serious danger to his/her own life or the life or health of others. As before, the Act stipulates that voluntary mental health care must be attempted without success or it must be obviously pointless to make such an attempt. An overall assessment must be made and CTO must clearly be the best solution for the patient. The assessment must include the opportunity for the patient to express his/her opinion, and the patient's wishes and previous experience of involuntary interventions must be given particular emphasis. Family members living with the patient must also be taken into consideration, cf. the Mental Health Care Act (1999, § 3-5). The CTO decision must be documented under the Mental Health Care Act (1999, § 3-3 a), which requires recording without delay how the criteria were assessed, the advantages and disadvantages of using coercion, the expected treatment effect and risks, in addition to the patient's attitude and experience of involuntary interventions and views on voluntary measures. If medication is to be given involuntarily, a separate decision is required under the Mental Health Care Act (1999, § 4-4 and § 4-4 a).

Under the Patient Rights Act, § 4a-5, first paragraph, a CTO may be valid for one year at a time, but the specialist who made the CTO decision must see the patient every three months for a conversation and an assessment of whether the criteria for the CTO still apply. If the specialist wishes to extend the CTO beyond one year, he/she must apply to the Control Commission (Høyer, 2016; Kontrollkommisjonen, 2023) for approval (Psykisk helsevernloven, 1999, § 8-3). If the CTO has not been appealed, the County Governor has a legal duty to review the case. The County Governor must also initiate a review of a CTO that has not been appealed and has been in effect for three months, cf. the Patient Rights Act (§ 4a-8, second paragraph). There is no limit to the number of extensions that may be applied for, as long as regular assessments are made, which in practice has meant that patients have been on a CTO for many years (Rugkåsa et al., 2019).

2.3.2 Clinical practice in CTOs

CTOs have often been justified as ensuring that patients do not avoid what health care providers consider to be necessary treatment following an involuntary hospital stay (Rugkåsa et al., 2019; Riley, 2016; NOU 2011: 9). The specialist responsible for the patient decides on the CTO and assesses whether it should be continued or terminated (Psykisk helsevernloven, 1999, § 1-4; Psykisk helsevernforskriften, 2011), while primary health care personnel are responsible for daily care and monitoring (Riley, 2016).

A CTO implies that a patient is required to accept the treatment and care considered necessary. This may include outpatient consultations, environmental therapy and medication treatment (Riley, 2016). Patients who do not attend appointments or refuse the treatment may be subject to involuntary readmission to hospital (Psykisk helsevernloven, 1999, § 3-5). In clinical practice, a CTO therefore means that patients can be readmitted without a new formal assessment of their condition by an independent doctor. On the other hand, an ongoing assessment of the patient's condition is required, and if the patient no longer fulfils the criteria for the CTO, it must be terminated (Riley, 2016; Psykisk helsevernloven, 1999, § 3-7).

2.3.3 Research on CTOs

CTOs have been introduced in a number of Western jurisdictions with varying criteria for treatment interventions for patients living at home (Molodynski et al., 2010, 2016; Rugkåsa, 2011). Nationally and internationally, CTOs are used to prevent relapses that require readmission, and to establish and maintain treatment collaboration (Rugkåsa et al., 2019,

2016; Riley, 2016; Churchill et al., 2007). The CTO scheme is seen as a less intrusive measure than compulsory inpatient care because patients can remain in their home environment (Rugkåsa, 2016; Churchill et al., 2007). However, several studies of patient experiences show that a CTO is felt to be an intrusion in daily life and at times very stressful (Newton-Howes, 2019; Stensrud, 2015; Riley et al., 2014).

A multi-site study from Norway (Rugkåsa et al., 2019) shows that patient characteristics in Norway are similar to those in other countries (Churchill et al., 2007; Burns et al., 2013; Kisely & Hall, 2014; Kisely et al., 2013; Lera-Calatayud et al., 2014). Males outnumber females, the typical age group is 30-50 years with a long history of mental illness, and most have been diagnosed with schizophrenia. Their medical history includes several involuntary admissions and poor cooperation on medication, and patients are often considered potentially dangerous.

Three randomized controlled trials have been conducted on the CTO scheme, two in the USA (Swarts et al., 1999; Steadman et al., 2001) and one in England and Wales (Burns et al., 2013). In addition, meta-analyses have been conducted, last updated in 2014 (Kisely & Hall, 2014) and a Cochrane review, last updated in 2017 (Kisely et al., 2017). None of these studies demonstrate that CTOs work when measured against consumption of health care services, and as early as 2014 Maughan and colleagues (Maughan et al., 2014) concluded that there was robust evidence that CTOs do not have a significant effect on admissions and other service use outcomes.

Despite the lack of evidence, CTOs have become a preferred clinical and policy solution for addressing non-adherence to treatment (Rugkåsa, 2016). The CTO rate in Norway in 2022 was 66 per 100 000 people, while in 2016 it was 61 per 100 000 (Samdata, 2023). There have been studies that question the ethical aspects of the CTO and the fact that the scheme is used extensively despite a lack of evidence that it is effective (Newton-Howes, 2019; Szmukler, 2018; Riley, 2016; Høyer & Ferris; 2001).

2.4 Introduction of capacity-based legislation

There has been an increasing focus on patient autonomy, and in this connection, Norway has introduced several reforms, escalation plans and white papers to emphasize patient self-determination (NOU 2011: 9). Self-determination or autonomy implies freedom to make one’s own decisions that affect one’s life and health, and is a fundamental human right

(European Convention on Human Rights, Art. 8, Council of Europe, 1950). Svendsen (2013, p. 93) defines autonomy by referring to Stanford Encyclopedia of Philosophy (2020) "To be autonomous is to act on the basis of reasons, reflections, characteristics, etc. which are not simply imposed upon a person, but which are part of what we may call the person's authentic self".

In 2010, the government appointed a committee to examine the ethical, professional and legal aspects of existing rules and practice, with the aim of a thorough review of provisions on coercion. Existing legislation was assessed with regard to the need for changes that could improve patients' legal protection. The concept of legal protection[2] describes the authorities' treatment of people to ensure their integrity and human rights, including providing citizens with security, equal treatment and predictability (NOU 2019: 5, p. 139). In June 2011, the committee presented the report "Increased self-determination and legal protection: Finding a balance between the right to self-determination and care responsibility in mental health care" (NOU 2011: 9). The report and subsequent consultation (NOU 2011: 9; Høring - NOU 2011: 9, 2012) formed the basis for the amendment to the Mental Health Care Act of 1 September 2017.

An important aspect of the proposed amendment was adaptation to the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations General Assembly in 2006 and implemented in 2008 (CRPD, Art. 1). The CRPD aims to ensure that people with disabilities, including people with an SMI, enjoy basic human rights on equal terms with others, and it was ratified in Norway in 2013. Two amendments to the Norwegian Constitution were also adopted and implemented in 2014 to protect the integrity and privacy of individuals in line with the provisions of the European Convention on Human Rights on

[2]Legal protection can be defined as follows: "As a general starting point, legal protection implies that the authorities' treatment of people and their decisions on cases are as correct as possible, in accordance with certain legal rules and without violating personal integrity or other human rights. Legal protection thus presupposes certain norms for what a decision should involve and for the procedure that led to the decision. Further, it must be possible to verify the procedure or the decision. Generally, the ideal of legal protection can hardly be considered as fulfilled if people do not also become confident that treatment and decisions are as correct as possible" (Meld. St. 32 (1976-77)).

the right of all people not to experience degrading treatment, the right to freedom and the right to privacy (Norwegian Constitution of 17 May 1814).

The CRPD is seen as an important instrument to implement fundamental and important changes to legislation concerning people with disabling mental illness (Szmukler, 2019), and in an ongoing international debate it is argued that all jurisdictions should introduce capacity-based legislation (Szmukler, 2018; Szmukler & Kelly 2016; Newton-Howes, 2019). Without the criterion of a lack of capacity to consent for the use of coercion in mental health care, legislation is felt to be discriminatory because it is then based on an assumption that patients with SMI are incapable of giving consent (UN, 2006; NOU 2011: 9; Szmukler, 2018).

Capacity-based legislation has been introduced in several European jurisdictions and in Australia and New Zealand (Rains et al., 2019; Szmukler & Kelly, 2016). A systematic review found that systematic assessment of consent capacity as a result of capacity-based legislation enhances patients' co-determination and increases the focus on strengthening patients' competence to make their own decisions (Curley et al., 2022). The study concludes that greater efforts should be made to optimize patients' decision-making processes irrespective of whether they are subject to coercive measures or not.

Following the introduction of capacity-based legislation in Norway, a study has been conducted to compare the use of CTOs in the periods before and after the change in the legislation (2015-2019) in two geographical areas. The study does not show the expected reduction in incidence rates and duration of new CTOs; however, the point prevalence of revoked CTOs showed a significant decrease in 2017 (Høyer et al., 2022). This suggests that a large number of patients who became assessed as capable to consent under the new legislation had their CTO revoked. There has been no research to date on how capacity-based legislation affects the use of coercion and patients' self-determination and legal protection in Norway.

2.5 Assessment of capacity to consent

Capacity to consent may be defined as follows: "Capacity refers to the functional determination of whether an individual patient has the ability to adequately make a specific decision" (Darby & Dickerson, 2017, s. 272). The key point in assessing consent capacity is whether the patient is able to understand what consent involves, cf. the Patient Rights Act (1999, § 4a). The specialist's task is to assess whether patients are capable of making meaningful decisions on specific questions about their care and treatment after receiving relevant, individualized information (Pedersen & Aarre, 2017). It must be "obvious that the

person is unable to understand" what consent entails for the person to be assessed as "lacking capacity to consent" (Helsedirektoratet, 2017b).

The Patient Rights Act (2001, § 4-1) states that a person can lose their consent capacity in whole or in part. This means that a person may lack the capacity to consent in some areas but retain that capacity in others. The law requires that the patient has received necessary individually adapted information about his/her condition and the content of the health care, and a decision about a lack of capacity to consent must be specific in relation to the relevant treatment.

When assessing capacity to consent, the specialist needs to decide whether it is obvious that the patient lacks sufficient understanding. This is called an evidentiary requirement and reflects the level of certainty in the assessment. If there is any doubt as to whether the patient is capable of giving consent, the patient must be entitled to refuse the recommended treatment, while still being entitled to emergency health care. This means that people with reduced ability to understand what care and treatment involve must be assessed as capable to consent (Helsedirektoratet, 2022a).

The capacity of people to decide on issues concerning their health may vary according to the situation and the intervention. It must be ensured that patients are in the best possible position to decide on the issues themselves. This can be done, for example, by scheduling the assessment at a time when the patient is not tired, hungry, in pain, suffering from withdrawal symptoms, or feeling upset or uncomfortable (Helsedirektoratet, 2022a). Consent must be based on provision of the necessary information and must be voluntary, see the Patient Rights Act (1999, § 4-1).

The most commonly used elements in assessment of capacity to consent are as follows: understanding of information, recognition that the information is related to one's own situation, the ability to weigh up different treatment options based on relevant information, and the ability to express a choice (Helsedirektoratet, 2022a). These elements are found in the assessment tool Aid to Capacity Evaluation (Etchells, 2010). The Aid to Capacity Evaluation is a simplification of the original tool for assessing capacity to consent, the Mac-CAT-T, which is based on empirical research, ethical evaluation and legal practice (Grisso & Appelbaum, 1998).

The assessment is of great importance to the individual patient, as the patient has the possibility to accept or refuse recommended treatment; it is also important for the patient's

legal position. When a patient lacks capacity to consent, health care personnel should try to determine what the patient wants (Pedersen & Aarre, 2017, p. 159). If a patient is unable to express his/her wishes, family carers or health care personnel who know the patient well can often provide important information (Pedersen & Aarre, 2017). If the patient has previously been in involuntary treatment, his/her wishes for future treatment can be written down during a follow-up consultation. The Mental Health Care Act (1999, § 4-2, 3rd paragraph) stipulates the right to a follow-up consultation following involuntary treatment. Further, the patient's preferences can be included in an individual plan, which patients are entitled to have in cases of long-term severe illness, cf. the Patient Rights Act (2001, § 2-5) (Pedersen & Aarre, 2017). Lack of illness insight or a different opinion on the treatment one needs does not necessarily mean a lack of consent capacity or the inability to make meaningful decisions (Samtykkeutvalget, 2023; Pedersen & Aarre, 2017; NOU 2011: 9).

Internationally, the introduction of capacity-based legislation has led to concern about the quality of assessments of consent capacity and the notion that society will be less protected against violence by SMI patients (Szmukler, 2018). An international systematic review shows that most patients in inpatient mental health care are capable of consent regarding treatment (Okai et al., 2007). A meta-analysis of literature reviews finds that most people with SMI are able to make rational decisions, including about medication (Calcedo-Bara et al., 2020). The authors find that these patients often have temporarily reduced consent capacity and believe that this demonstrates the importance of enhancing patient capacity by providing detailed information and decision-making support (Calcedo-Bara et al., 2020). A systematic review on assessment of capacity to consent from New Zealand and Australia finds low levels of skill and confidence in those who conduct the assessments (Mooney et al., 2023). They believe it is imperative that all those involved in assessing consent capacity have practice in, and feel confident about, making assessments, and understand the legal implications of an assessment. Furthermore, they point out the unclear role of other health care personnel involved in the patient's day-to-day care and find little research on how these other personnel can best contribute to this complex assessment (Mooney et al., 2023).

2.6 Contribution of the study to the research field

A capacity-based model must ensure a balance between the patient's autonomy and the right to health care. The intention of the legislation in creating a new criterion for the use of coercion is greater autonomy and legal protection and reduced and appropriate use of coercion for patients with SMI. It was assumed that the introduction of a capacity-based

model would be particularly relevant in reducing the numbers of CTOs (NOU 2011: 9; Prop.147 L (2015-2016)). In the first period following the introduction, clinicians and control commissions reported that a significant number of patients had had their CTO revoked as a result of the amended legislation.

Knowledge of the experiences of patients, family carers and health care personnel with the change in the law may be important in evaluating the legislation, and in developing better health care that patients with SMI find acceptable. This is the first qualitative study to explore the experiences of patients, family carers and health care personnel with the new legislation.

3 Theoretical background

This chapter presents concepts and theoretical background that can shed light on the study aim and clarify some of the challenges faced by health care personnel who work with patients with SMI and the competencies they require. In order to perceive changes and assess complex conditions in patients, health care personnel need a range of competencies, including biological and psychosocial knowledge and the ability to establish trust and dialogue.

3.1 Assessing the patient's condition

On the basis of their qualifications and the Health Personnel Act, health care personnel have different responsibilities in the treatment and care for patients with SMI (Helsepersonelloven, 1999). The specialists have overall responsibility for the patient's treatment and planning, in addition to evaluation, diagnosis and assessment of capacity to consent. Health care personnel responsible for providing day-to-day care and help patients to be capable of receiving the care and treatment they need. Health care personnel need knowledge about illness manifestations, life processes, diagnoses and patient rights. Life processes refer to people's natural bodily processes to sustain life, such as adequate nourishment and rest (Elstad, 2014, p. 38). The patient's condition determines the care provided, and how the care supports and is part of the treatment (Elstad, 2014; Fause et al., 2023).

The nurse and philosopher Ingunn Elstad (2014) states that illness and health are forms of quality and natural aspects of the living body. Elstad refers to illness as an adjective because it is with someone; it is not the subject, but tells us something about the subject. Qualities can change, merge, or become stronger and weaker, but they cannot be measured. Quality is what makes things similar or dissimilar. One condition can therefore resemble another condition and we can recognize certain qualities. "The state of psychosis can be fleeting or manifest, last for some time, fluctuate, improve or deteriorate, and can be recognized in many variants" (Elstad, 2014, p. 127). The patient's condition tells us something about how he/she feels physically, mentally, socially and existentially. The condition can thus provide information about the current state or level of functioning of the patient (Elstad, 2014). To assess a patient's condition means to gain an overall impression. This may involve observing whether the patient has insomnia or an irregular sleep pattern, is unkempt, dirty or emaciated, has skin problems, is lethargic, inactive or restless, is disorientated or confused, etc. When the basic life processes are disturbed, health care personnel must take steps to support them; people normally take care of this themselves when they can, but they need help in times of mental and physical illness (Elstad, 2014).

The art of observing a patient's condition goes back a long way in nursing and medicine (Elstad, 2014). Health care personnel must be able to detect an important change when it is developing. They must have a clinical gaze that notices deviations from the patient's usual condition (Elstad, 2014, pp. 24-27). They must try to understand how the patient is feeling, even when they cannot converse, through observation, knowledge of the patient and experiential knowledge. Health care personnel must become familiar with the person's forms of expression and ways of acting and moving in order to understand his/her need for care and treatment and to monitor change. Theoretical knowledge is necessary to focus and structure the clinical gaze in a professionally qualified manner. However, observations must be open, otherwise we may risk not noticing what we are not looking for (Elstad, 2014). SMI can cause symptoms and problems that can overshadow signs of physical illness (Ukom, 2023; Jones et al., 2008). It can be difficult for the patient and for others to distinguish between symptoms, and patients with SMI may also have difficulty in telling others about their complaints and agreeing to an examination (Høye, 2023). It is therefore crucial that health care personnel are capable of detecting signs of illness. An experienced nurse's clinical gaze and assessments are guided by broad knowledge and experience that often enable nurses to see or sense a change in a patient's condition (Elstad, 2014). Elstad's descriptions of people's conditions display a respectful attitude and demonstrate the continuity and understanding required in working with people with severe disorders.

Professional judgement involves the ability to understand, assess and interpret a situation based on knowledge and experience. Further, observations must be made in relation to theory, specialist knowledge, procedures and ethical principles, and in the context of the patient's experiences and the clinician's experience of the condition and situation (Alvsvåg & Martinsen, 2018).

3.2 Dialogue

Language is of great importance for mutual understanding, as emphasized by the philosophers Hans Skjervheim (1996) and Hans-Georg Gadamer (2010). Skjervheim's dialogue model is still relevant to demonstrate what is needed to achieve a respectful and meaningful dialogue when serious illness challenges communication between a health care professional and a patient. According to Skjervheim (1996), encountering each other's words gives us a common world, and he argues that the decisive factor for dialogue or lack of dialogue is how we relate to each other's words. He explains how communication between two people can be changed by the attitude of one of them to the words of the other. Skjervheim's dialogue model can help

us to understand the importance of health care personnel's ways of relating to what patients and their relatives say.

Skjervheim (1996) writes that a dialogue or an exchange of opinion about a situation or a problem must be a three-part relationship. A three-part relationship will arise if we meet each other with the intention of making an effort to understand what the other person is saying about a topic. If we are interested in what the other person says, the relationship will consist of two subjects who engage in an issue or topic as an object. If, on the other hand, we simply note what the other person says without engaging in it, we soon end up with two parallel worlds. In that case, there are two subjects who relate to the topic in their own ways without exchanging views or knowledge. A third alternative is simply to note that the other person is saying something without even listening to the content, thereby reducing the other person to a purely physical object. This provides no space for two subjects around an object, such as a topic or a problem, which could, for example, be which treatment and care might be best. Thus, one party (e.g. the clinician) relates to the other party as an object (Skjervheim, 1996). An objectifying attitude can be experienced as an attack, as if the other is attacking one's autonomy. An objectifying attitude is an attempt to take control of the situation; the person adopts a simplistic, reductionist attitude, also known as a positivist approach. This is about dealing with things, finding a solution and simply seeing everything from the point of view of facts or facticity (Skjervheim, 1996).

Being engaged in what the other person says is an important part of respect and is vital in clinical work. Communication between patient and clinician is challenged when the patient is silent or when words and associations are affected by psychotic experiences and it is difficult for others to make sense of what the patient is saying. In such a case, our humanity can help us. Alvsvåg (2000) points out how the nurse and philosopher Kari Martinsen explains how subjectivity and intersubjectivity are two sides of the same coin. This means that we can understand ourselves through others and understand others through ourselves. Based on our own experiences of being ill, afraid, confused or thirsty, we can understand something of how others may have similar experiences; they need not be the same, but perhaps not completely different either (Alvsvåg, 2000). Intersubjectivity, previous knowledge of the patient, knowledge of disease processes and diagnoses and family members' knowledge can all help us at times when verbal communication is inadequate.

3.3 Trust, distrust, power, powerlessness and coercion

Trust is a pillar in all relationships (Spurkeland, 2020) and a fundamental quality of great importance for collaboration between patients and health care personnel. Trust is indispensable and has value in itself, according to Kari Martinsen (2005, pp. 142-143). We usually trust the other person; if we distrust the person, there must be a particular reason. Trust is part of our everyday life, and can be understood as daring to confide one's deepest thoughts and fears to be accepted by the other person (Martinsen, 2005). Entrusting something of value to another person or institution, either a valuable object or confidential information, implies that we show trust. We give and receive trust; we are most vulnerable when giving trust but we can also be vulnerable as recipients of trust, for example as health care personnel (Grimen, 2013). As patients, we need to trust the staff and the facilities providing care and treatment, while as health care personnel, we need patients to trust us to enable us to do our job properly (Grimen, 2013). Trust and distrust are connected; both depend on experience, which means that distrust can be an important and correct reaction (Grimen, 2013).

Trust is closely related to power, and power can create trust (Grimen, 2001). Someone with power will more readily be trusted than someone without power, and trust may be proportional to the amount or type of power. Lack of freedom to choose can force a person to trust. A patient often has no choice but to trust the competence of health care personnel and believe that they want the best for the patient (Grimen, 2001). Such knowledge is important for health care personnel, whose role implies a position of power over patients needing care and help, who are particularly vulnerable when under coercion. Powerlessness can be defined as the opposite of power. It implies a situation where a person is prevented from deciding how to act and cannot influence the situation (Slaatta & Sæbø, 1997).

Coercion implies performing an action against someone who does not want or consent to it (Frivillighet og tvang, 2023). Coercion in health care involves interventions that the patient refuses, or that are so intrusive that a person would normally refuse them. Three forms of coercion are distinguished: 1) formal coercion, where decisions have been made under the Mental Health Care Act in relation to events or actions, 2) perceived coercion, which is the patient's experience of being coerced in mental health care and 3) specific coercion, which is coercion actually used on a patient. The various forms of coercion can be difficult to record and quantify, although formal coercion is usually documented (Husum et al., 2017; NOU 2011: 9). Research shows that voluntarily admitted patients also experience the use of power

and pressure, and structures and interventions to which they have to adapt. These are forms of hidden or informal coercion that provide less legal protection for patients, because this coercion is not documented, making it difficult to complain or to lodge a formal appeal (Husum et al., 2017). Patients subject to coercion may experience it in different ways: as more or less intrusive, intimidating or offensive, and their experience will be strongly affected by the associated communication and implementation (Husum et al., 2017, p. 197; Nyttingnes et al., 2018; Newton-Howes & Mullen, 2011) and whether the intervention is perceived as useful (Husum et al., 2017).

Legislation aims to clearly distinguish between legal and illegal coercion and ensure that health care is provided correctly. Since the European Convention on Human Rights was adopted into Norwegian law in the Human Rights Act in May 1999 and incorporated into Section 113 of the Constitution in 2014, there has been a principle of legality in Norwegian law. This implies a formal requirement for legal authority regarding all interventions against individuals. Coercion is regulated by the following four acts in the health care field: 1) Section 7 of the Health Personnel Act (1999) on urgent care, 2) Chapter 4A of the Patient Rights Act (1999), which aims to ensure that patients receive the physical health care they need even if they lack capacity to consent or refuse the care, 3) Chapter 9 of the Health and Care Services Act (2011), which describes the basis for the use of coercion in health care for people with a mental disability, and 4) the Mental Health Care Act (1999) and associated regulations, which regulate coercion in mental health care. Finally, the Control Commission exercises control over the use of coercion in mental health care (Kontrollkommisjonen, 2021; Høyer, 2016).

4 Methodology and methods

This study used a hermeneutic approach to explore and understand experiences with the change to the Mental Health Care Act of three groups affected by the change. This chapter deals with the methodology of the study and describes the scientific and practical approach to the project idea and the design and implementation of the study. At the start of the study, as part of my methodological work, I made a comparison of the legal texts before and after the change in the law and familiarized myself with the associated regulations, the preparatory work for the change, relevant studies, government circulars and clarifications and the most important ruling by the Supreme Court (HR: 2018-2204-A).A hermeneutic approach

4.1 A hermeneutic approach

The German philosopher Hans-Georg Gadamer states that the meaning of the world arises through our experience, questions, interpretations and dialogue with others, and in the historical and cultural context of which we are a part (2010). The scientific-theoretical approach of the study is based in the humanities and social science in a hermeneutic interpretative paradigm. This implies an understanding of the world as we experience it, based on our pre-understanding and in dialogue with others in our particular context (Gadamer, 2010). Hermeneutics is a philosophy and methodology suitable for a research field that describes people's experiences, and enables a respectful and nuanced interpretation of data. The context of the study is the Norwegian government's reorganization of mental health care as part of the strengthening of basic human rights for people with SMI and extensive and complex care needs.

For Gadamer, dialogue is fundamental to understanding, whether verbal dialogue or dialogue with a written text. It is by listening, reading and interpreting that a person can change and achieve new understanding. Gadamer emphasizes three requirements for a genuine conversation: an open attitude to the position of the other, a desire to understand the meaning of experiences rather than merely describing them, and an awareness of opportunities that may arise (Binding & Tapp, 2008). Gadamer argues that pre-understanding is a prerequisite for all understanding and experience. Descriptions and phenomena would make no sense if the interpreter did not start with any ideas, experience or elements to look for when aiming to explore a phenomenon or relationship (2010). A person's pre-understanding involves their background, culture, beliefs, values, ideals, interests, theoretical knowledge, world view, prejudices, experiences and traditions. Pre-understanding is spontaneous and ever-present in

our encounter with the world (Moules et al., 2015). In Gadamer's thinking, interpretations always take place in a context, but are neither arbitrary nor controlled. He does not view objectivity and subjectivity as opposites, but as interrelated and as part of people's understanding. Because we are part of the world, history, culture and society, our pre-understandings are not just our own and separate from the world. Subjectivity is seen as a vital resource for insight in research; it must be available and used with care, and it is basically our pre-understanding (Moules et al., 2015). Understanding has a temporary dimension; it can always be developed further and we can constantly understand phenomena or relationships in new ways by asking questions. Gadamer calls this our horizon of understanding (2010).

The hermeneutic circle is a metaphor for the process of understanding a text, which means interacting with the text in an iterative movement between the whole and the parts. This involves reading, re-reading, reflecting, writing and talking about what one understands as in a dialogue with the text, in order to gain new understanding (Fleming et al., 2003). It is a process to capture implicit or specific elements and to find suitable ways to describe one's understanding (Moules et al., 2015). According to Gadamer (2010), however, one can never be completely sure as to whether one has understood the real meaning of a text. "Hermeneutic thinking captures the context-sensitive and situational, and takes into account the fact that a pre-understanding is just one pre-understanding, which does not need to exclude other understandings" (Bygstad-Landro, 2023, p. 73). To challenge one's pre-understanding involves first becoming aware of one's prejudices, then writing them down and allowing them to play out in the analysis process. This awareness can make the researcher let the "essence" emerge by itself and have an open attitude to being surprised; in this way, we do not let ourselves be constrained by our prejudices, only perceiving what we thought we would find. We must dare to encounter people and texts with questioning openness, wonder and listening for answers (Gadamer, 2010).

Gadamer (2010) argues that asking questions enables us to achieve understanding, and emphasizes the importance of the research question for the research process, but does not describe how to procced. It is therefore helpful that a Gadamerian-based research method has been developed by Fleming et al. (2003). Fleming et al. (2003) have described five steps to guide empirical hermeneutic research: deciding on the research question, identifying pre-understandings, gaining understanding through dialogue with participants, gaining

understanding through dialogue with the text and establishing trustworthiness through four stages of analysis. A hermeneutic approach with an openness to new understandings and ethical reflection on questions, procedures and the choices made have guided the work in all stages of the research process. Collaboration with the resource group described in section 4.4.2 and dialogue in the research team have enabled me to discuss the data and my understanding regularly throughout the research process. Here, I have attempted to be open to alternative viewpoints and other ways of understanding, which enabled me to adjust my pre-understandings (described in more detail in section 4.2).

4.2 My pre-understandings and background for the researcher role

My background for this study stems from my education as a mental health nurse, further education in relational work and networking, a higher degree in nursing science and many years of clinical experience from emergency wards and emergency outreach teams based in mental health and addiction clinics, in addition to teaching nursing bachelor's degree students. It has meant a lot to me to help provide care and treatment in crises and long-term problems as a contribution to people's recovery or sometimes as processes of finding ways to live with problems. Collaboration with patients, relatives and colleagues and being part of the health care service are important factors in the pre-understandings I have brought to the role of researcher, just as they are important for my ability to conduct this study.

In clinical practice, I have had a hermeneutic approach in working with individual patients. I have used my experience and acquired competencies to engage in dialogue, ask questions, make observations and assessments, interpret and try to understand in order to gain trust and a sound basis for collaboration on care and treatment. I have found that we as health care professionals take too many decisions for people with SMI. However, I have also experienced that the use of coercion has been necessary and I found it correct in certain situations, but the associated preparations and implementation were vital factors. Later, the approaches of "open dialogue" or "relational and network work" based on systemic thinking (Andersen, 1996; Seikkula, 2000) became an important part of my work. My clinical practice was based on the key values of relational and network thinking, such as dialogue, openness and meaningful relationships. Patients always took part in talk about their care and treatment, and the inclusion of their private and professional network was emphasized. This altered practice was decisive for my further clinical work because it implied less compromising of my professional and ethical values.

The research team I am part of has experience as nurses, a social worker, a lived experience consultant and a lawyer in similar services and contexts to the research field of this study. They have all worked with patients who have been in involuntary mental health care and with their families. In this way, in addition to our interpersonal experiences in life, we have experience from the research field and have acquired knowledge to provide a firm basis for asking relevant questions and understanding the participants' stories. When planning the study, we were keen to investigate the significance of the new legislation for those affected by it. Based on our experience from the field and our preparatory work, I feel that we as a research team had the required competencies to enter the field of the study with the research questions we developed.

Brinkmann and Kvale (2015) believe that research interviews have a certain magic about them, when participants willingly share their experiences, despite or perhaps because the researcher is a stranger who is not part of their usual environment. The role of the research interviewer feels like a privilege, but it also involves great responsibility. The goal of obtaining good data while also treating the participants well need not represent a contradiction, but it necessitates finding a balance and involves ethical challenges (Moules et al., 2015). I have found that patients may feel obliged to answer questions from health care personnel and that their patient role has made them accustomed to sharing personal and private experiences, even if this feels uncomfortable both at the moment and later. It was therefore important to me that the participants should not feel encouraged to tell me more than they wanted in the interviews, and I also strongly reassured them that nothing they said could be traced back to them.

4.3 Geographical area of the study

The study was conducted in the northernmost health region of Norway: Troms, Finnmark and Ofoten. This region has a population of about 270 000 and an area of over 75 000 km2. It contains 39 municipalities whose population varies from about 1000 to 78 000 (Statistisk sentralbyrå, 2023). Specialist care in mental health and substance use in the region is provided by the University Hospital of North Norway (UNN) and Finnmark Hospital Trust. The region has nine community mental health centres providing specialist care in an inpatient ward and an outpatient clinic. Low population density and vast distances mean that some patients live several hours' drive from the nearest mental health centre and have to take a plane to the nearest hospital.

4.4 Patient and public involvement in the study

In order to achieve patient and public involvement (Liabo et al., 2022; Røssvoll et al., 2022) and expand our insight into the field of this study, pilot focus group interviews were conducted. We also collaborated with a group of people with experience as patients or family caregivers to elicit their perspectives, and a member of the research team was a lived experience consultant. Patient and public involvement was an important aspect of the research process in order to provide a more open and democratic development of knowledge in the field, in line with professional and policy guidelines (Karlsson & Borg, 2021).

4.4.1 Pilot focus group interviews

During our work on the project description, we conducted four focus group interviews with people who would be affected by the change in the legislation. The aim was to elicit ideas on how to best explore people's experiences with the change. We asked the participants about focus areas of the study and about their expectations or possible concerns. We audio recorded the interviews, listened to them and took non-identifiable notes before deleting the recordings.

There were four participants in each group: 1) people with personal experience of being under a CTO, 2) family carers of CTO patients, 3) primary health care personnel, and 4) specialist health care personnel. The personnel who participated had various jobs in health care, but all worked with patients under a CTO. The focus group participants were recruited through the network of the research team (for information and consent form, please see Appendix No. 1).

4.4.2 The resource group

At the start of the project, we invited people with experience of being under a CTO and family caregivers to join a service user participation group (hereafter referred to as the resource group). We aimed to have a resource group that could be involved in the project from start to finish, and provide comments, thoughts and opinions from their experiential perspectives throughout the research process.

Recruitment consisted of two members of the research group inviting people with relevant experience in their network linked to the Mental Health and Addiction Clinic at UNN. Three with personal experience as a patient subject to a CTO and involuntary mental health care, and three family caregivers of patients with such experience agreed to join the resource group. The invitation clarified that their participation did not entail any obligations beyond contributing their experiential knowledge.

In the first meeting, expectations, use of time and which parts of the study the participants might like to be involved in were clarified and a collaboration plan was drawn up. Some were worried about having insufficient knowledge of research, and it was explained to them that their contribution would be based on their interest in the topic of the study and their experience of health care services, legislation and collaboration. I felt that there was a positive atmosphere and noticed that everyone present took part in the discussion. The project funds covered their payment based on the hospital rates per hour of participation, as well as expenses for refreshments at the meetings. The project plan, ideas for the sub-studies and the research questions were presented and one of the first meetings included a presentation on concepts used in research and phases in a research process. The resource group members shared experiences, took part in discussions and provided input on the research questions and the content of the interview guides, as well as ideas on how to best conduct the interviews. For example, they suggested rewording some of the questions.

Unfortunately, due to the COVID-19 pandemic, a number of meetings with the resource group had to be cancelled or postponed. Digital meetings were not an option for several of the members. The only analysis process they could be invited to join was for article three. The three members still interested in participating provided an important context for our analysis. They shared their thoughts on how they understood quotes and suggestions for themes, and spoke about similar or contrasting associations of ideas from their own experience.

4.5 Recruitment of interview participants

In sub-study I, the inclusion criterion for participation was patients who had a CTO revoked as a result of being assessed as capable to consent when the change in the law was introduced, from 01.06.2017 to 01.09.2018, in the health region under UNN. Through another study, the project manager had access to a list of all patients on CTOs and the reasons for revoking them (Høyer et al., 2022). Patients on this list who met the inclusion criterion were chosen at random and invited to participate.

Potential participants were invited by familiar health care personnel who provided care to them but was not responsible for their treatment. The project manager explained carefully to the personnel how we wanted people to be invited. It was important that no one should feel obliged to participate, but could see participation as an opportunity to share their experiences and opinions as a contribution to research. When we discovered that not all potential participants received care from health care personnel without responsibility for treatment, we

received permission from the Privacy Officer of UNN to send out invitations by letter, followed by a telephone call from the lived experience consultant in the project. The letter stated who would call and the caller's phone number, in order to make the invitation as predictable and reassuring as possible, see Appendix No 2.

Information about the project, what participation would involve, privacy and participants' rights was provided in writing (see Appendix No.3) and orally by the health care personnel who invited the participants. Information about privacy and the right to withdraw at any time without giving a reason and without any consequences was carefully explained. As the interviewer, I contacted all those who had agreed to participate by telephone to arrange a time and place for the interview and to supplement the information provided and answer questions.

In cases of doubt as to whether a participant had the capacity to consent to participate in research, the specialist responsible for the patient was asked for an assessment. However, no interviews needed to be postponed due to a lack of capacity to consent to participation in research. There were 55 patients who met the inclusion criterion, 32 were invited and 12 agreed while 18 refused. Further, we did not receive a reply to two of the letters we sent out.

In sub-studies II and III, recruitment consisted of asking the participants in sub-study I whether we could invite one of their family members and a health care professional who provided care to them. It was explained to them that an aim of the study was to gain insight into family caregivers' and health care personnel's experiences with the change in the law related to their trajectory, and that they were allowed to choose who could be interviewed. Some participants thought aloud, and considered the pros and cons of possible choices, while for others their choice needed no deliberation. The younger participants wanted us to ask their mothers. Two participants wanted me to choose between two health care professionals, and in each case I chose the one who would broaden the scope, since this person had a role and responsibility that had not been previously represented.

I contacted the chosen family caregivers and health personnel by telephone to provide project information and invite them to participate. All family caregivers and health personnel who were asked agreed to participate. They received oral information about what the interview would involve, privacy and their rights as interview participants, as well as written information sent by email, please see Appendices No. 4 and 5.

The chosen recruitment method resulted in seven triads. Each triad consisted of three participants, one with experience as a patient, one family caregiver and one health care

professional who were linked in collaboration during the patient's illness trajectory. One participant did not want family caregivers or health care personnel to be interviewed, another agreed to an interview of a family caregiver but not a health care professional, while a third agreed to the opposite.

4.5.1 Participants

In sub-study I, twelve participants from the health region of UNN were interviewed. They had all experience of SMI, had been under a CTO and had the CTO revoked as a result of being assessed as capable of consent based on the amended legislation. They were aged 20-75, there were equal numbers of men and women, most were single, two had a partner and three had children. Nine received disability benefits, while four were in employment, studying or retired. Four rented or owned their own home, seven lived in municipal sheltered housing, while the housing situation of one was unknown. One-third of the participants lived in rural areas and two-thirds lived in urban areas. They had different levels of functioning, with varying and often extensive needs for health care services. Four of the participants had a substance abuse disorder in addition to a severe psychotic disorder. There were considerable differences in their numbers and length of CTOs and other involuntary measures. Further descriptions of the participants are presented in the first article of the study.

In sub-study II, nine staff members with different health care backgrounds and areas of responsibility were interviewed. To protect their anonymity, their education and place of work cannot be stated here. There were two men and seven women; five worked in specialist health care and four in primary health care.

In sub-study III, the interviewees were seven family caregivers with considerable experience. Four were parents, while three were partners or in another close relationship with the patient; there were two men and five women and most were in employment.

4.6 Interviews

Individual interviews are a useful method to provide a personalized and comfortable interview situation and to ensure privacy (Brinkmann & Kvale, 2015). The 28 interviews were conducted at locations chosen by the participants: in their home, at work, in a hospital or in a hotel meeting room. Interviews lasted from 50 to 90 minutes.

4.6.1 The interview guides

The interview guides for each sub-study had a similar format with semi-structured questions (Justesen & Mik-Meyer, 2012) divided into three phases: introductory questions, core questions and a summing-up. Each interview guide had five main open questions with 3-11 sub-questions or cues. There were minor adjustments to the wording of the questions and the order of the sub-questions following the first interviews, please see Appendix No. 6

4.6.2 The interview procedure

As the interviewer, it was important to me to be welcoming and friendly, provide detailed information and ensure a relaxed atmosphere to help the participants feel at ease. The interview guide was generally not followed slavishly to avoid disturbing the flow of the conversation; it was used more like a reminder not to forget questions. The order and wording of the questions were adapted to the various participants and their narratives. I made attempts to help the participants to feel comfortable in the interview situation, to ensure that participation was easy for them and to show them that their participation was important. According to Moules et al. (2015), a good hermeneutic interview is conducted in a thoughtful, open and conscious manner, which will elicit understanding during the conversation. The interviewer listens intently and constantly tries to find a balance that gives the interviewee space to finish what he/she wants to say, while also drawing attention to what seems to be most meaningful. Further, the interviewer must avoid accepting invitations to give advice, and must find critical points and be curious (Moules et al., 2015).

I focused on leading the interviews, ensuring that I asked as many as possible of the questions in the interview guide, while also being sensitively present. This means being sensitive to the participant's reactions, body language and tone of voice. This is important for noticing feelings and nuances in what is said, and for taking opportunities to expand on the participant's comments or to adjust the questions to respect personal boundaries and integrity (Brinkmann & Kvale, 2015). Brinkmann and Kvale (2015) and Moules et al. (2015) write that research interviewers should choose their words carefully in their curiosity and avoid being biased and asking leading questions. I tried to be patient and to avoid providing alternative possible answers or attempting to understand too quickly. I often asked follow-up questions or expressed what I thought I understood in a questioning manner to check whether I had understood the participant's words as he wanted me to perceive them. In a hermeneutic approach, the researcher's goal is understanding, and many new questions should be asked to understand more (Moules et al., 2015). What is important here is not to reveal all the aspects

of a phenomenon or to notice every word spoken, but to understand experiences in their context (Brinkmann & Kvale, 2015).

Sub-study I

The interviews with the participants with experience as patients started in different ways. One wanted me to start by reading a long letter he had written about his experiences with health care and being subject to coercion. Most wanted some more information about the interview situation and privacy, and some wanted to know more about the aim of the project. I pointed out that they should be in no doubt that they were the ones to decide at all times what they wanted to say in response to my questions. Most of the interviews started with the participant introducing himself, while I said a little about my background as a nurse and PhD student.

Some of the interviews took place in the participants' homes. I felt that this was a particularly beneficial interview setting, giving me a broader understanding of who the participant was. When interviews were in a hospital or hotel, I ordered refreshments. One participant brought a health care worker from his sheltered housing with him for the interview.

The participants had many experiences and opinions to share with me and gave examples and detailed responses that were highly relevant to the research questions. Although the topics were often difficult to talk about, there were also amusing episodes, witty comments and well-expressed ideas. One example was when a participant spoke about his frustration with the house rules and how strictly regulated life in sheltered housing could be. He could not clearly understand what was coercion and what were house rules, but he laughed when he said: "They're pretty strict about what you can put in your sandwiches".

Strong opinions and emotions were expressed in most interviews, ranging from joy to despair and anger. Some interviews involved personal perceptions of reality/experiences of psychosis, and others revealed despair and anger towards the treatment system. This sometimes made it difficult to ask questions because I was unsure whether my questions were too personal or because too much time was being devoted to psychotic experiences. Three of the participants appeared to show variation in their level of capacity to consent during the interview. I found that for brief periods they lost track of the type of conversation they were taking part in. I was sometimes seen as a representative of the treatment system and had to be the subject of their anger and frustration, or I might be asked for help to change their treatment. When I reminded them that I was a researcher and had no contact with or influence on their health care, they might reply something like: "Yes, of course, that's not your business". Two of the participants

were affected by psychotic experiences and one seemed to be on drugs, but they still managed to answer some of the questions and seemed to be aware of the situation they were in most of the time. The atmosphere in the room could change and sometimes I needed to change the topic of conversation. Some interviews flowed well, while others were more fragmented, with short answers. Sometimes I had to ask yes/no questions to clarify the topic before I could ask more open-ended questions; an example of a yes/no question was whether the participant knew about the change in the law. Sometimes I provided an explanation or alternative answers to make myself understood. This may have resembled a leading question and required follow-up questions to try to check whether the participant's answer was what he/she really wanted to say.

In two interviews there were smoking breaks. In one of them, the participant wanted me to join her out on the steps and had a great deal on her mind that I would have liked to include in the audio recording. She was willing to repeat some of what we remembered from our chat on the steps when we came back in with the audio recorder on.

Sub-study II

The interviews with health care personnel usually started with some questions about the project, after which they introduced themselves and spoke a little about their education and experience, and I also outlined my experience in the field. The participants were used to talking about their work and were keen to answer the questions. The interviews generally flowed well. The participants answered each question in detail and often provided additional examples and descriptions to explain their experiences and opinions. I went through the points in the interview guide one by one in some interviews where I mostly had the initiative, while in others I adapted the order of questions to the participants' stories and train of thought. Several were emotionally affected and said that it could be a tough job to provide care to patients during bad periods or to be rejected and be unable to provide the care and treatment they felt were necessary. They mentioned patients who had made a deep impression on them, and with whom they had established a strong relationship after working with them for many years. Several also talked about time pressure, difficult assessments and decisions, and about poor decisions they would like to make over again.

Sub-study III

Unlike the interviews with the other two groups of participants, several family caregivers started by telling me that they had not prepared for the interview and did not know if they had

anything to contribute. I then needed to explain the aim of the interview, to assure them that they did not have to prepare in any way, and to point out that their participation was valuable for the study. I then provided more information about the project, privacy and their rights, and I tried to reassure them and make things easy for them in the interview situation. Most of them were not accustomed to talking about their responsibilities as family carers or about their life situation. Several found it difficult to remember past events, which they explained by saying that so much had happened and that they had tried to suppress difficult events or move on from them. Two participants said that they ought to have written a book to remember everything that had happened in the years since their loved one became ill. A number of them found it hard to talk about their experiences and difficult memories, but most participants still had various incidents and stories they wanted to tell me. Several felt great sadness because their loved one had such a difficult life; it was painful to talk about and some of them cried. However, they did not mind talking about it because it felt good that someone wanted to hear about their experiences. They also mentioned amusing episodes, pointed out how much they loved the person, and emphasized the person's resources and good qualities.

4.6.3 Data management

The declarations of consent signed at the start of the interviews were stored in accordance with UNN guidelines and will be deleted at the end of the project.

Interviews were recorded on a digital audio recorder. The participants were informed that their privacy would be ensured in the use and storage of the recordings, and were asked if they would consent to audio recordings of the interviews. They were told that the recordings would be stored in a secure digital location in the hospital, that only I and the project manager would have access to them, and that all recordings would be deleted on the final day of the project. More detailed information about the management of the recordings was provided to those who had questions. Some participants were somewhat apprehensive about the interviews being recorded, but they all agreed to it. They soon seemed to forget about the recorder during the interview and it did not appear to disturb the flow of the conversation. I decided not to take notes in the interviews to avoid disturbing the talk and to concentrate on the participants and what they said at all times.

Following each interview, I made notes about my experience of the interview situation, describing the background to the interview, how well it had gone, and sometimes statements or events that had made a particular impression on me.

In one interview, I found I had pressed the wrong button on the recorder, which meant that parts of the interview had not been recorded, which was annoying for me and for the participant. We then reconstructed our conversation as best we could with the audio recorder on. In another interview, a setting on the recorder had affected the sound, making it difficult to hear what was said. In that case, I reconstructed the interview to the best of my ability based on what I could hear on the recording and what I remembered from the interview.

The recordings were immediately transferred from the recorder to a secure digital location at UNN, and deleted from the recorder when the transcription was complete. The transcriber had signed the same confidentiality declaration as the project team. In the transcriptions, the participants' names were omitted and when I printed the transcriptions I removed the names of people, places and institutions and ensured that easily identifiable information was deleted or rewritten. The participants were given pseudonyms and some had their gender changed. Only I and the transcriber listened to the recordings and had access to the transcriptions before they were de-identified. The management of the audio recordings and transcriptions was in accordance with the data management principles of the Norwegian Centre for Research Data and the regulations of the Privacy Officer at UNN.

The COVID-19 pandemic prevented interviews with one health care professional and two family carers, although the interviews had already been arranged and the journeys planned. It also prevented an interview with a family caregiver whom we had been given permission to invite. If we had known that COVID-19 would close down Norway for as long as it did, we would have attempted to conduct those interviews by telephone or digitally. When face-to-face meetings were finally possible, it was too late for the interviews.

4.7 Analysis

In the first two sub-studies, the analysis was guided by Fleming and colleagues' four-step method and I attempted to achieve trustworthiness for the analysis by providing detailed descriptions. In sub-study III, the analysis drew on Braun and Clarke's (2022) descriptions of reflexive thematic analysis, and the analysis processes are therefore described in two parts.

4.7.1 Sub-studies I and II

The first step in the analysis procedure described by Fleming et al. (2003) consists of arriving at an understanding of the data as a whole. In order not to lose track or mix up different participants' statements, I decided to start by gaining an overall understanding of each interview. Here, I listened to each audio recording again, read the notes made after each

interview, and then read the transcripts several times. I jotted down ideas in the margins and wrote key words and short summaries of my overall impression. In the second step of the analysis, I read the transcripts with a focus on details, concepts, statements and passages and highlighted those that answered or shed light on the research question. I used the highlighted parts to qualify my overall understanding and tried to understand these parts in light of this understanding, as Fleming et al. (2003) recommend in the third step. Several times I noted down key words for my understanding of statements and concepts, as well as associations and suggestions for names of themes to represent them. The fourth step consists of trying to identify statements that could represent the emergent understanding. It was difficult to create categorizations, and I was worried about losing meaningful content or forgetting how I had understood statements if they were removed from their original context. Here I found it useful to follow sociologist Aksel Tjora's (2018) recommendation to keep the participants' concepts or to let whole meaning units constitute codes or categorizations. There was thus less risk of losing nuances of understanding on the way to finding useful concepts that could represent the understood meaning of the statements. The meaning units were organized by using clippings of the transcribed text that were moved around on A3 sheets of paper with different colours for the suggested themes in sub-study I and by using the mapping functions in the NVivo software in sub-study II.

In sub-study I, I "renewed my conversations" with the participants by pasting the meaning unit clippings onto large sheets of paper spread out on the floor. I sat down with each one and thought back to the interview and re-read our conversation to find out if I still understood what they said in the same way, if something new emerged, or if I wanted to go back to the transcripts or recordings again to check my understanding. I returned to some transcriptions where I was in doubt to check if I still understood them in the same way or if I needed to adjust my understanding a little. For example, I needed to re-read the statements of a participant called Arve a few times. His words gave out a deeper or clearer message when statements were put together based on a more overall understanding. "Laying out the participants on the floor" in that way was also useful for discovering further possible themes across the interviews, and new suggestions for overview maps of these themes were added.

In sub-study II, I used NVivo to gain an overview of statements and codes, sort them and create categories and to read through them a number of times to find out whether I understood them differently. Creating a map of codes and categories made it easier to have a general overview and to move them around to find out which ones fitted together.

I then presented statements and suggested themes to the other members of the research team to enable us to look at them together. My pre-understandings could also then be tested by sharing my understanding of the data; the other team members could provide input and suggest alternatives, and we could discuss various ways of interpreting participants' words. In a hermeneutic analysis, it is important to challenge one's pre-understandings and interpretation of the data (Moules et al., 2015; Fleming et al., 2003). Statements, concepts and passages can be used to challenge one's overall understanding and find out whether they agree with each other. The understanding of the whole can shed light on the parts to enable new nuances to be revealed, based on how the words and the context in which they are spoken are emphasized (Fleming et al., 2003). Our discussions helped us to find new nuances, deeper meaning and new concepts, both in individual interviews and across interviews. Gadamer believes that the understanding of a text arises from a consensus between the whole and the parts, and that this makes the process more trustworthy (Fleming et al., 2003). The statements or codes were grouped together, and then several times re-grouped and adjusted. Paricipants' statements that answered or enlightened the research question, and gave a consensus between the understanding of the parts and the whole (Fleming et al., 2003), were used to generate the themes. Here it was important to find concepts to represent our final understandings, which could give the reader insight into the experiential understandings (Fleming et al., 2003). We changed our concepts a number of times, even after we had started to discuss the results.

4.7.2 Sub-study III

In sub-study III, the analysis was guided and inspired by Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2022). Braun and Clarke (2022) describe a six-phase process and emphasize that the researcher should start the analysis through familiarization with the material. As in the previous analyses, I first read through the texts several times, focusing on an overall understanding of each interview and noting down my understandings of what was important to each participant. I then read through the texts some more times, now with a focus on statements, concepts and passages. These were highlighted in the text when they answered or illuminated the research question. Statements about the person's illness history were included to shed light on the length and content of the family caregiver role. Reflections on the meaning units were also noted down.

Braun and Clarke (2022) consider codes of statements or meaning units to be building blocks for the generation of themes. The coding, which is the second phase of their method of thematic analysis, was done in the NVivo software with the research question as the

framework. In an attempt to find precise codes for the participants' statements, the concepts were adjusted many times. I tried to follow Braun and Clarke (2022) by leaving the ideas for themes open throughout the process to make room for new ideas. In the third phase, I presented the preliminary findings, codes, categories and suggested themes to the research team and the resource group, both as text and visually using the mapping function in NVivo. That enabled me to talk about the data and be open to alternative viewpoints and ways in which they understood the statements and their suggestions for categories and themes. Their comments and suggestions provided new nuances of understanding and ideas to use in generating themes. The resource group represented a vital context for the analysis and was important for how I talked about the data. Reflections on interpretations and sorting of codes and categories using the mapping functions were helpful in removing preliminary themes that did not directly answer the research question. Phases three and four merged as they both deal with generating and refining themes. Braun and Clarke's fifth phase consists of a "theme test", where I found that three of the themes passed the test, which meant that they were clear, unique, well-defined and helped to answer the research question. We adjusted the names of the themes several times to make them more precise and informative. Braun and Clarke's sixth phase concerns the writing up and reporting (2022).

4.8 Ethical approvals

The study was conducted in accordance with the Declaration of Helsinki (De nasjonale forskningsetiske komiteene, 2014) and reported in line with the Vancouver recommendations (2023) in recognized scientific journals.

The project proposal was sent to the REK Nord Regional Committee for Medical and Health Research Ethics (Appendix No. 7) for assessment and approval. The Committee determined that the project could not be defined as a medical and health research project under the Health Research Act (2008, § 2); it was instead defined as health service research and was thus outside their mandate.

The Privacy Officer of UNN approved the privacy and data security plans of the study, provided that the project was conducted in line with the information we provided in accordance with the Personal Data Act (2018) and the Health Register Act (2014) with associated regulations (Appendix No. 8).

Data collection in the study in association with the Mental Health and Addiction Clinic of UNN was arranged and approved by the previous manager of the Clinic, Magnus Hald, and continued by the following manager Tordis Høyfødt.

5 Results

This chapter summarizes the results of the three sub-studies.

5.1 Sub-study I

Increased autonomy with capacity-based mental health legislation in Norway: a qualitative study of patient experiences of having come off a community treatment order

The participants experienced greater self-determination and more respect and trust from health care personnel after their CTO was revoked due to the change in the law. They had a different experience of coming off their CTO this time than they had had previously. Compared with the situation before the change, it was easier to be involved in a dialogue about their care and treatment, and they found that health care providers attempted to meet their wishes to a greater extent than before.

The participants were surprised to learn that their CTO was revoked, and found it difficult to understand how assessments of the need for a CTO had suddenly changed. Most had been subject to CTOs for many years, and felt that a CTO was a far-reaching decision that affected many aspects of their life. Almost all of them felt great relief at coming off the CTO, and it gave them a feeling of being free or normal. However, one participant was angry and frightened by the sudden change and worried about not getting emergency health care without a CTO.

Several participants viewed the revocation of the CTO as proof that they had been under unnecessary coercion for a long period of time. At the time of the interview, almost all had received voluntary care and treatment for over two years. Several thought that without the change in the law they would still have been on a CTO.

Some participants found it difficult to decide on matters of care and treatment. They were used to others deciding for them, and they also felt passive and with little initiative to find meaningful activities in their daily lives. For most of them, everyday life was unchanged, with little meaningful content. However, there were some who found that the change had given them a completely new life, with activities, a suitable job or studies, and more social life than before. They had gained greater insight into their lives and made their own decisions with good support from health care personnel.

Several participants had difficulty in trusting health care personnel due to their previous experiences of coercion and little opportunity to have any say in their care and treatment.

Most were afraid of becoming acutely ill again, and of being misunderstood and interpreted as being in a worse state than they were, and that they would once again be subject to coercive measures and be forced to accept more care and treatment than they wanted.

5.2 Sub-study II

Health professionals' experience of treatment of patients whose community treatment order was revoked under new capacity-based mental health legislation in Norway: a qualitative study

The participants found that capacity-based legislation increased their awareness of patients' right to self-determination, and of their own responsibility to improve patient autonomy and participation in care and treatment. They felt that the change in the law had changed the way they thought about care and treatment provision. Previously, they thought that they as health care personnel should decide what they felt was best for patients, whereas now they thought more about collaborating with patients on treatment decisions. Assessments of capacity to consent and new documentation requirements were highlighted by specialists as key factors in their increased awareness of patients' right to autonomy.

Specialists and health care personnel with a day-to-day care responsibility both felt that CTOs were necessary for the patients in the study and were surprised that they were able to accept health care after their CTO was revoked. They were unable to exercise the same control as with a CTO and therefore had to adjust their practice in order to continue to play their part in the responsibility for health care through collaboration. They were trying to improve dialogues and cooperation. Health care personnel who provide a day-to-day care felt the need for frequent assessments of the condition of patients to be able to detect changes that required rapid adjustment of treatment and care, and to prevent serious deterioration of the condition and the use of coercion. They tried to advise and support patients to make good choices for themselves.

Assessment of consent capacity was found to be challenging. Lack of competence, new requirements and changes in the condition of patients were pointed out as challenges that could hinder good quality assessments. Fluctuating health conditions that could lead to frequent changes in the level of consent competence might further compromise the validity of assessments and decisions.

Several participants felt a need for greater competence and all spoke of the need for continuity, flexibility and close cooperation between health care services and levels of care in order to provide adequate care to patients with complex and concurrent needs.

5.3 Sub-study III

Capacity-based legislation in Norway has so far scarcely influenced the daily life and responsibilities of patients' carers

The patients' family caregivers knew little or nothing about the change in the legislation at the time of the interview. Most of the family caregivers took on considerable responsibility for the patient on a daily basis, but were scarcely involved in collaboration with health care personnel. The family caregivers found varying degrees of competence, commitment and continuity among health care personnel. Their life situation was demanding due to their loved one's SMI, accompanied in two cases by substance abuse. Their responsibilities and daily life as family caregivers had not changed after revocation of the CTO. At the same time, several of them felt that their loved one had been more satisfied and independent during this period, although they had not connected this to the change in the law.

The family caregivers' experience of dealing with the person's problems made them worry about whether the change would make it more difficult to get help in a crisis and mean that coercion would not be used even if it was thought to be necessary. They believed that coercion was needed in certain situations, even though they had problems with its use.

6 Methodological reflections

The aim of the studies was to enhance understanding of how the new criterion for the use of coercion was experienced by three affected groups. A hermeneutic approach and individual in-depth interviews were suitable to gain insight into the experiences of relevant groups of participants. The researcher's pre-understandings and experience affect implementation and data generation (Brinkmann & Kvale, 2015; Moules et al., 2015; Binden & Tapp, 2008). I have little experience as a research interviewer but considerable experience as a nurse in the field. Brinkmann and Kvale (2015) write that knowledge and experience of a field are highly likely to affect the researcher's questioning and to make the researcher perceive what fits in with her/his own experiences and thoughts when listening to others. In order to counter this, I paid attention to how my background and experience could influence my questions and my interpretation of the answers. This was particularly important in the interviews with health care personnel, where I could easily identify with what they said. I took care to try to understand what the participants wanted me to understand by asking follow-up questions. The triads enabled enhanced pre-understanding of the interviews with health care personnel and family caregivers based on the first interview in each triad, which was with the patients.

As described in the method section, all of us in the research team made an attempt to become aware of our pre-understandings and tested whether the statements and their interrelationships could be understood differently. In qualitative research, it is possible to understand experiences and interrelationships in different and more or less meaningful ways (Moules et al., 2015). Hermeneutic research provides answers to research questions that cannot be overlooked, although the questions can be answered in various ways (Moules et al., 2015). Interviews represent snapshots; they do not represent "objective" truth, but one truth among many that to some extent is created while being told. Participants' narratives are affected by their relationship to the researcher and by how they feel at that point in time. The involvement of both participant and researcher is grounded in trust, which forms the basis for the data generated (Brinkmann & Kvale, 2015).

By listening to the recordings and reading the transcriptions, I realized that I was unable to follow all the advice by Brinkmann and Kvale (2015) and Moules et al. (2015) for good hermeneutic in-depth interviews in qualitative research. For example, several times I overlooked opportunities to elicit more detailed answers or did not wait long enough for a response. I could probably also have taken more control in several interviews and follow the interview guide more closely to elicit answers to several of the questions. It was difficult to

find a balance between following trains of thought and ensuring that the participant was comfortable in the interview situation, while also trying to meet the goal of detailed answers to the research questions. My reasons for not taking greater control or for postponing or eliminating certain questions were sometimes that the participant was focusing on something else or that I was unsure whether the questions were too personal. Perhaps I was most concerned that the participants should feel comfortable in the interviews, without also devoting equal attention to the data generation aspect. On the other hand, my caution and respect for the participants' experience of the interview situation may have been the reason why none of them left the interview or subsequently wanted to withdraw from participation. I was particularly pleased that the participants whose psychotic experiences affected the interview the most were able to complete it and seemed to have had a positive experience of participation.

6.1 Ethical reflections on the interviews

The strain on participants of the interview situation was the subject of ethical considerations. It was important that participants had a positive experience of the situation and did not feel that they had to reveal too much about themselves, that I was taking advantage of them, or that there might be negative consequences of participation. I tried to create a safe atmosphere with helpful information and sensitivity in my behaviour and questioning. My background as a nurse with experience of being sensitively present, expressing myself clearly and facilitating care and treatment meetings for patients, relatives and other health care personnel was helpful in my role as research interviewer. I feel that it was necessary in some of the interviews to have this type of experience, combined with familiarity with talking to people affected by their emotions, psychosis or addiction. I helped four participants to calm down. When their psychotic symptoms were intrusive or when they vented frustration and anger at previous coercive treatment and at the police, I changed the subject or reassured them and explained some reasons. In three interviews, the participants were rather loud and aggressive at times.

It was clearly stressful to be interviewed for most participants with experience as patients. Hurtful memories strongly affected the emotions of several of them. Feelings such as powerlessness, shame, fright and sadness at having lost time and opportunities in life were mentioned. In three interviews, the participant was so angry with the treatment system that I worried whether his experience of participating would be more negative than positive, and whether the interview could make things more difficult for him afterwards. However, at the

end of the interviews, all participants seemed to have had a positive view of the interview experience. Some found it demanding to be interviewed, but it also felt good to be able to talk about their experiences and opinions. All the participants with experience as patients were told that they could have a talk with an independent psychiatrist or be helped to contact their own therapist or other familiar health care personnel if necessary, but none of them were interested in that.

The level of consent capacity of four participants varied during the interview. For brief periods these four participants seemed to forget that they were in an interview. However, most of the time they were clearly aware of it, and I therefore felt that it was important to allow them to complete the interview. Several had a clear agenda for their interview; they wanted to express their opinions and talk about experiences they thought were important. They wanted to contribute to research, although it emerged that several had needed to mobilize courage and strength to agree to be interviewed. An argument for allowing them to participate despite varying consent capacity was that they had insisted that they wanted the interview ever since they were invited, which was often several days or sometimes weeks before the interview took place. No participants withdrew, either during or following the sometimes demanding interviews. However, arranging and conducting the interviews represented a process of continuous reflection and assessment of their capacity to consent. I was responsible for not subjecting anyone to an interview if they were unable to understand what it involved, and for ensuring that they felt they could withdraw from the interview if they found it too demanding or for other reasons. Josselson (2012) used two consent forms when the participant's level of consent capacity was uncertain, one before and one after the interview. I did not have two consent forms, but I asked all patients what it was like to be interviewed, following Josselson (2012). They all had a positive view and some were clearly happy and proud of their participation. I also took the opportunity to ask the others in the triads during their interviews about their impressions of the patient's experience of being interviewed. The feedback I received was entirely positive. Several family caregivers and health care personnel told me enthusiastically that the person had been highly satisfied with participation, and none of them reported that anyone regretted or was worried about what they had said during the interview.

Some of this group of participants found individual solutions to help them to participate in the interview or to get something beneficial out of it. Per reported being nervous before the interview and unsure about whether he would be able to say everything he wanted to say about his experiences of involuntary admission and release from a CTO. His solution was to

write a letter that he wanted me to read before the interview started. The interview took place around his beautifully laid coffee table where he served sandwiches and coffee. He managed to say much more than he had written in the letter, and my impression when we finished was that he was satisfied with what he had told me. For Hanna, to attend the interview required a considerable effort. She had come close to withdrawing because she did not think she could talk to an unfamiliar researcher. Her primary contact had encouraged her to maintain her desire to talk about her experiences, and during her own interview a few days later told me that Hanna had been proud and surprised at herself following the interview. She had not talked so much and managed to have such a long conversation for years. Henry had been under involuntary care for many years and had experienced a long series of admissions and CTOs. He preferred to be interviewed at the hospital because he wanted to go there voluntarily, with the option to leave again when he decided to himself. Perhaps that was a way of taking control or processing aspects of his hospital history.

It also appeared to be a strain to be interviewed for some family caregivers. They seemed unaccustomed to talking about themselves and their role as carers, and several were clearly touched and upset by their own stories. I explained that it was quite acceptable for carers to talk about the patients in their absence because the patients had given their permission. Some family caregivers may have felt almost obliged to participate because the patient had given permission and asked them to do so. At the end of the interview, they were all asked what it was like to be interviewed. Most replied that it was demanding and that they may not have had much to contribute; however, they were pleased that someone wanted to hear about their experiences and thoughts about the care and treatment provided, coercion and their own situation.

It seemed to be easier for health care personnel to participate, but some of them were also touched emotionally, and some barely had time for an interview. Two of them called the interview a debriefing session, and several said that it felt good to have an opportunity to talk about their experiences.

At the end of each interview, the importance of their participation was made clear to all participants from all groups, and they were encouraged to call or send an email if they thought of any major or minor point they wanted to add or change.

I found that the participants in all three groups referred to each other with dignity and respect, even when very difficult episodes were discussed. However, participants several times vented

great anger and despair at previous therapists, decisions on medication and coercion, the lack of care of family members, the handling of incidents by the police and the failings of "the system".

Some of what I heard moved me greatly, and I needed time afterwards to process my impressions. It was also unusual and challenging for me to have a researcher role instead of the familiar nursing role. I was in a dilemma several times because as a researcher I was not supposed to address problems that emerged in the interviews. In order to process my impressions and dilemmas, I made notes on some of my reflections and discussed some of these with my main supervisor.

The Declaration of Helsinki allows for vulnerable groups to be included as research participants in order to enhance knowledge in areas that affect their health and lives. People with SMI can be defined as a vulnerable group on the basis of the nature of their disorders and because their illness can periodically reduce their capacity to consent. The participants in sub-study I were a particularly vulnerable group, since they also had experience of being subject to coercion (De nasjonale forskningsetiske komiteene, 2014).

6.2 Timing of the study

We found it appropriate to conduct the interviews 24-30 months after the introduction of the new legislation. The change would be well established, allowing enough time for those affected to have gained some experience, while it would still be relatively recent. This proved to be true for the patients and health care personnel. They had gained experience and formed an opinion about the new legislation. Both health care personnel with a day-to day responsibility and specialists had discussed the change several times with colleagues, and could offer reflections on what it entailed and how it worked, which appears to have enriched the data. The family caregivers, on the other hand, had not been directly affected by the new legislation and several had not heard about it. It is an interesting finding in itself that close relatives knew little or nothing about the change in the law. However, it would probably have been at least as interesting to interview them at a later stage when they had more experience with the effect of the change over time. A member of the resource group who was also a family caregiver revealed that it had taken some time for her to understand the change in the law and to realize the significance it would have for her loved one, for her family and for her role and responsibilities. She called it a maturation process where she had gradually come to understand what the new legislation entailed, based on information she received and her

personal experience. This may suggest that our study took place rather early for this group of participants.

6.3 Recruitment

The procedure for the recruitment of patients for sub-study I (described in the methodology chapter, section 4.5) is a strength of the study. This is because the participants, despite being defined as a vulnerable group on the basis of their SMI and experience of coercion (De nasjonale forskningsetiske komiteene, 2014) (see section 4.8), were able to decide for themselves whether or not to accept the invitation to participate in research. They were asked directly after being randomly drawn from a list of all those who met the inclusion criteria in the study area. This method of recruitment prevented the selection of only patients with less severe disorders. However, those who declined to participate may have represented perspectives that we have not captured in this study.

The selection of family caregivers and health care personnel was entirely based on the patients' choices. This recruitment method produced triads, which is a strength of the study. The triads provided unique insight into descriptions of related experiences from three perspectives, with additional insight into incidents and episodes common to all groups and their everyday collaboration. On the other hand, the design did not enable us to expand the scope of the samples, and it would have been interesting, for example, to interview general practitioners.

The study was conducted in an area under a single health care trust. Inclusion of participants from other catchment areas could have strengthened the study, since the data may to some extent be influenced by local practice and culture in specialist health care and by geographical characteristics of the northernmost health region of Norway. Typical features of the catchment area are vast distances and low population density (described in section 4.3), although there are also some large municipalities and towns.

6.4 Patient and public involvement

The focus group interviews confirmed the relevance of the study, provided useful input for the formulation of research questions and creation of interview guides, and helped to expand our pre-understandings.

The resource group enabled us to discuss the data with people who were not health care personnel, but had experience as patients or family members. This meant that we may have

been particularly careful and precise in our choice of words when describing the study, and sensitive in the way we described the interviews and the understandings. The resource group provided interesting and useful input for the research process. Collaborating with them on the analysis meant that I had to reconsider my pre-understandings of the data, which thus expanded my understanding. We would have liked to have had further cooperation with the group, but unfortunately COVID-19 prevented several analysis meetings.

One advantage of recruiting the resource group through the research team's network was that the participants knew at least one of the team members with whom they would collaborate. This was reassuring for some members of the group. Disadvantages of this form of recruitment may be the difficulty of turning down a request from someone the participant knows very well, and only allowing people the recruiter knows to participate. However, the resource group members represented themselves and their own experiences, and were thus not responsible for representing the collective experiences and opinions of a group or an association.

The competence of the research team member who works as a lived experience consultant was important in recruitment for and conducting the focus group interviews and the resource group's work. She was a key resource in the recruitment of patients and contacted those who were recruited by letter. In addition, she contributed to the design of the interview guides and interview situations and was the person who most strongly emphasized the importance of the patient and family caregiver perspectives. She influenced our choice of words and broadened our understanding as a discussion partner and advisor throughout the research process.

6.5 Trustworthiness of the research

Trustworthiness is seen as an important concept in the assessment of the quality of qualitative research (Savin-Baden & Howel Major, 2013; Brinkmann & Kvale, 2015; Lincoln & Guba, 1985). I attempt to demonstrate the trustworthiness of the study through transparency (Brinkmann & Kvale, 2015), coherence, consistency (Justessen & Mik-Meyer, 2012) and integrity (Savin-Baden & Howell Major, 2013). By providing honest and detailed descriptions of reflections, choices, justifications and implementation of all parts of the study, my intention was to openly present the research process in order to achieve trustworthiness, in line with Brinkmann and Kvale's (2015) recommendations for assessing quality in qualitative research. The study has been a dynamic holistic process based on knowledge and experience from the field and continuous professional, ethical and methodological considerations. I have described

how we as a research team examined the relevance of the study, wrote a project proposal, research questions and interview guides, and conducted the recruitment and the interviews using a hermeneutic approach. I have briefly described my professional background and pre-understandings as well as the background of the research team. Further, I have described each step of the analysis, the theoretical choices and the reporting. This has demonstrated the development and interrelationship of all parts of the study in order to achieve trustworthiness (Justesen & Mik-Meyer, 2012). Integrity has been proposed as a quality indicator (Savin-Baden & Howell Major, 2013); it contributes to trustworthiness in association with the situatedness of the study (Rustad, 1998).

The choice of recruitment method was not made with the intention of validating the material, but functioned as a form of triangulation (Polit & Beck, 2008). The triads provided stories from their various perspectives which often confirmed each other. The different perspectives nuanced the data and broadened our understanding of trajectories and life situations, in addition to demonstrating the complexity of the episodes the participants recounted and the influence of the change in the legislation.

7 Discussion

The overall research topic of the study is to explore and describe which criteria should be used to enable people with SMI to receive voluntary health care as an alternative to a CTO. The discussion will emphasize key factors in finding a balance between this patient group's right to self-determination in care and treatment, and the right not to lose emergency health care.

7.1 The patient perspective must be taken more seriously

The new criterion for the use of coercion gives all patients with the capacity to consent, regardless of the type of disorder, the same right to decide whether to accept treatment or not and to be involved in the planning and content of the treatment (Psykisk helsevernloven, 1999; NOU 2011: 9). The fact that a person who is able to consent cannot be subject to coercion is an important step forward in terms of human rights and legal protection for mental health patients and for society in general, in accordance with Article 15 of the CRPD and Articles 3, 5 and 8 of the European Convention on Human Rights. In preliminary discussions on the change in the law, health care personnel and associations of family members expressed concerns that patients with SMI would not receive the health care they needed without a CTO (NOU 2011: 9; Bruk av tvang, 2017; Larsen, 2017; Utkilen, 2017; Terjesen, 2017). The concerns were directed at the change in the balance between patients' right to self-determination and their right to emergency health care.

The amended legislation provides guidelines for health care personnel to include patients in all decision-making processes to a greater extent than previously. This must be done even though a patient may have a fluctuating level of capacity to consent to treatment, a borderline level of functioning for living in independent housing and difficultly in accepting the health care that health care personnel consider necessary. Health care personnel must create space for variations in patients' condition and allow them to be alternately capable and incapable to consent, without being subject to coercion. A refusal by a patient to accept care or treatment must not be taken to imply lack of consent capacity. A capacity-based model thus provides new opportunities for self-determination and co-determination even for patients with SMI whose condition and capacity to consent fluctuates.

A good balance between autonomy and the right to emergency health care is important in terms of legal protection. Here we see a potential clash between two basic human rights. In an overall assessment, the patient's condition will now be emphasized more strongly, while the

diagnosis has decreased in importance in assessments of suitable care and treatment and CTO decisions following the amended legislation. We see a shift in the balance between autonomy and the responsibility of health care services to ensure that patients do not lose the right to emergency health care. The change in the law restricts the legitimacy of involuntary care for people with SMI (Syse, 2016). Voluntary alternatives must be emphasized, and it is no longer possible to use a CTO to prevent a possible relapse that requires admission to hospital (Riley, 2016). Health care personnel must make efforts to collaborate on providing health care that can improve or stabilize a patient's condition to enable the patient to retain or regain the capacity to consent. At the same time, the use of coercion must be considered if the health care personnel in collaboration with the patient are unable to find treatment and care options that the patient will accept, when the health care personnel and the patient's relatives feel that care and treatment are necessary. In the case of patients who are unable to accept, or understand their need for, health care and lack the capacity to consent, health care personnel are responsible for ensuring that they do not lose the right to emergency health care (Psykisk helsevernloven, § 3; Pasient- og brukerrettighetsloven, § 4). It is also important for patients' legal protection that health care personnel respect their care and treatment choices that differ from those recommended and demonstrate greater acceptance than previously that patients may have different goals for their treatment than professionals have.

Szmukler (2020) and Newton-Howes (2019) have argued that a change to capacity-based legislation is insufficient to meet the requirements of the CRPD. They consider it necessary to replace existing legislation with a "fusion law framework" in order to fully meet the requirements of equal non-discriminatory rights for all. They believe that particular legislation for mental health patients is stigmatizing and perpetuates the notion that they are incapable of making good decisions and can be dangerous (Szmukler, 2020; Newton-Howes, 2019). A fusion law would imply common legislation on coercion for physical and mental health care based on decision-making capacity and the patient's best interest. Northern Ireland, which is one of the few Western jurisdictions that have not introduced the use of CTOs (McDonald & O'Reilly, 2017), has a fusion law (Newton-Howes, 2019). In Norway, there is an ongoing discussion about merging all the provisions on the use of coercion for physical and mental health care into one law (NOU 2019: 4). The Consent Committee's evaluation report on the capacity-based model would then have to be included in the basis for the decision. The time frame of political discussions and a decision is unknown at the time of writing.

7.2 The numbers of CTOs have not decreased

The findings of this study reveal that patients with SMI and extensive health care provision managed without a new CTO for more than two years after the change in the law, although the total number of CTOs has not decreased (Høyer et al., 2022). When the new criterion was introduced in 2017, there was a marked reduction (Høyer et al., 2022), but the number of CTOs has increased since 2019 and was higher in 2022 than in 2016 (Samdata, 2022). There are several possible explanations for this trend. It may partly be due to problems of capacity, including a decrease in inpatient beds without a corresponding increase in alternatives in primary health care. Further, clinical practice has changed in terms of when CTO decisions are made for patients who lack capacity to consent and do not object to involuntary inpatient care (Hellesvik et al., 2019; Samtykkeutvalget, 2023). One explanation for the reduction in the number of CTOs when the new legislation took effect in 2017 could have been that the proposed change led the decision-makers to end long-term CTOs for patients they considered capable to consent (Høyer et al., 2022).

A study from Australia also shows that the number of CTOs has increased following adaptation of the legislation to the CRPD (Gill et al., 2020). A lack of alternatives to CTOs, coupled with a paternalistic culture in mental health care and concern about reduced protection for society with decreased use of coercion have been mentioned as possible reasons (Gill et al., 2020), which may also be true of Norway. There are considerable geographical differences in the use of coercion in Norway, but the reason for this is unclear (Hofstad, 2022). Two studies from before the change in the law suggest that cultural differences may partly explain local differences in the use of coercion (Husum, 2011; Bowers, 2004). An Australian study suggests that the number of CTOs may be associated with failings in the mental health care system, where a CTO compensates for under-resourced services and little attention to and prioritization of mental health resources (Light et al., 2017). The results of the present study and in the report of the Consent Committee (2023) suggest that the new criterion was introduced with inadequate preparation, and that there is a need to improve training and structures for discussion and reflection on what a lack of capacity to consent to the use of coercion actually involves. A further factor for consideration is to assess the possible voluntary treatment and care alternatives to a CTO.

7.3 Prerequisites for a capacity-based model

High-quality primary health care services are essential to prevent admission to involuntary care (Wormdal et al., 2020), and can be understood as a prerequisite for the capacity-based

model to work well. Broad-based knowledge, dialogue and cooperation, collaboration with the patient's family and structures that provide flexibility and continuity will be important areas to develop further.

7.3.1 The importance of dialogue for autonomy and good quality health care when consent capacity fluctuates

SMI can make communication and interaction difficult, with the result that patients are unable to insist on their health care preferences. Patients whose CTO has been revoked can refuse the health care offered and break off contact with health care personnel. Therefore, in order to monitor a patient's condition and provide individualized care and treatment that the patient accepts, health care personnel need to be in contact with the patient, which includes dialogue and collaboration over time. Collaboration on health care is a complex matter (Forenkle og forbedre, 2023), and it can be difficult to reach a common understanding of care and treatment needs and to find alternatives that the patient is willing to accept. Here, good dialogue is of vital importance.

Dialogue can be improved with an attitude of trying to understand one another and engaging in an exchange of views (Skjervheim, 1996). The opposite case would be not listening or not taking seriously what the other person says. If people are not taken seriously and respected for their opinions and experiences, they may experience this as a form of attack or control by being overlooked in decision-making so that solutions are found for them without consulting them (Skjervheim, 1996). This is how patients can feel when health care personnel act and decide on their behalf instead of inviting them for dialogue and cooperation. If a patient's diagnosis is the main concern, it may be difficult to see the patient as a whole person with experience and an active creator of personal meaning in life (Pedersen et al., 2017). If the professional does not make room for the patient as a fellow human being and as a partner in health care, this may result in distancing. Professor of psychology Tor-Johan Ekeland (2020) warns against distancing, and argues that it must be avoided by health care personnel in order to protect themselves from their own potential inhumanity and mitigate the risk of manipulation and control. This applies particularly to those who work with vulnerable groups who find it more difficult to express themselves and stand up for themselves. SMI can often affect how a person communicates. People in a psychotic state may have forms of expression and behaviour that appear incoherent and incomprehensible to others, and which therefore create distancing. Without sufficient knowledge of SMI and competence to assess a patient's condition, health care personnel may be less likely to make efforts to establish a dialogue with

the patient. The nature of psychotic disorders, with variations in a patient's condition and capacity to consent, make the patient vulnerable, especially in periods when the condition makes it difficult to understand or express one's need for health care. Despite this, health care personnel must always see the patient as someone they can talk to, as someone who has opinions and experiences, who needs information and with whom they can collaborate. An essential skill in respecting another person is to listen attentively and to show that one considers the other person's opinions to be important and worth listening to (Skjervheim, 1996; Ekeland, 2014, 2021). The many dilemmas and complex challenges that arise in daily care and treatment of people with SMI, and in assessments of their capacity to consent, call for competence and resources.

7.3.2 The competence of health care personnel

The findings of this study suggest that it is possible for clinical practice to involve fewer involuntary measures for patients with SMI and fluctuating conditions and consent capacity, but that this can be challenging for health care personnel. Health care personnel must use their professional, interpersonal, practical and ethical competencies to ensure that good quality care and treatment are provided in a voluntary, non-coercive manner. This is nothing new, but is probably more challenging after the change in the law because health care personnel are now more dependent on establishing and maintaining good contact and cooperation with patients in order to help them. Patients with SMI can change their minds and be unstable in their desire to receive health care. Care provision in a stable and secure relationship can improve everyday mental and physical health, where the moments, tasks and activities of each day can be part of something meaningful and purposeful, and help patients to experience support, acknowledgement and greater self-worth (Beyene et al., 2023). Patients with SMI may need help to live independently, to keep to appointments with doctors and public services and will sometimes need support with such basic needs as healthy food and drink, personal hygiene and adequate sleep (Elstad, 2014). Several need help with managing their medications, keeping their accommodation clean and tidy, looking after their finances, taking part in meaningful activities and socializing. Everyday help and support are vital to improve the patient's health, and to reduce the risk of physical illness and worsening of the mental illness (Lauveng, 2020; Karlsson & Kim, 2015).

Primary care personnel must try to find the best way to deal with situations where the patient needs to be encouraged or convinced to make constructive choices, in addition to the many large and small everyday tasks and decisions. A key responsibility for primary care personnel

is to monitor the patient's condition, look for changes in symptoms and health problems, and cooperate with the patient to take appropriate steps at the first signs of psychosis or deterioration (Johannesen & Sebergsen, 2023; Elstad, 2014). Patients can recognize their own signs of deterioration and the development of psychosis and they have their own ways of dealing with this to mitigate the deterioration (Sebergsen et al., 2014). However, they may still often need support to use their resources to deal with the symptoms and problems involved in deterioration. Health personnel need the competence to recognize signs of deterioration and improvement (Fause et al., 2023), or signs of physical illness and side effects of medication, and to help to prevent lifestyle diseases (Høye, 2023). Patients with SMI are susceptible to physical illnesses, particularly when the mental illness is combined with substance abuse (Plana-Ripoll, 2020; Corell, 2022). Lifestyle diseases, due to poor diet, little exercise and smoking are common in this group (Høye, 2023; Firth et al., 2019; Chesney et al., 2021). Mental health problems can overshadow physical illness (Ukom, 2023; Jones et al., 2008), while research shows that patients with SMI receive a physical examination and diagnosis less often than others (Heiberg et al., 2019; Solmi et al., 2021). It is not uncommon for cardiovascular diseases to remain undiagnosed (Heiberg et al., 2019). Physical illnesses, in addition to a higher suicide rate, shorten the average life expectancy of patients with SMI by 15-20 years (Correll et al., 2022; Plana-Ripoll et al., 2020). This is a serious problem which is difficult to handle in clinical practice and which requires competence and extensive care and monitoring (Høye, 2023).

Patients' wishes must be heard and their opinions should often be taken into account even when consent capacity is lacking, with the patient's best interest in mind (Szmukler, 2018). Mike Slade, Professor in Mental Health Recovery and Social Inclusion argues that recovery processes and support for well-being should receive as much emphasis as traditional assessment and treatment thinking (2010). Slade describes recovery as the patient's personal process of recovery or of finding a way to live with the problems (2010). Involuntary treatment should be avoided, but it is not always easy to know the right thing to do. There may be nuances and different perceptions of situations, but also more serious situations where health care personnel try to help a patient with a physical illness to avoid serious consequences. Everyday situations present various difficult dilemmas for health care personnel, where they must pay close attention to how they interact with the patient and to ethical issues in their work (Hem et al., 2018a, 2018b, 2014).

Dilemmas between ideals, guidelines and legislation for minimal use of coercion on the one hand and realities in clinical work, organization and resources on the other hand, may make health care personnel feel squeezed between the health care system and their moral values and loyalty to patients. This can lead to moral stress and concern about the working environment and thus negatively affect care quality (Jansen, 2022a, 2022b). Health care personnel often feel great personal and ethical responsibility for providing good care, which may also cause moral stress (Jansen et al., 2017). The possibility to receive professional advice is an important safeguard for health care personnel and care quality (Vråle, 2023; Hem et al., 2018a). A systematic review finds that professional advice and guidance are essential to prevent paternalistic practices and enhance the quality of and confidence in assessments in difficult situations and in matters of coercion. Health care personnel need to develop their awareness of ethical challenges and to use rich and precise language to describe ethical aspects of the situations they encounter and are part of (Hem et al., 2018 b). Primary care management must provide clinical ethics support activities, including education sessions (Magelssen et al., 2018).

7.3.3 New opportunities for dialogue and shared decision-making

The overall results of the study suggest that capacity-based legislation leads to better dialogue and new forms of collaboration between patients with SMI and their health care personnel. However, it may be difficult to build a trusting relationship between the parties when the patient has previously been under coercion (McMillan et al., 2019). Patients who have been subject to coercion may still have the feeling that they are being coerced (Vandekerkhove et al., 2023). The dialogue and relationship between health care personnel and patient must be able to accommodate and tolerate variations in behaviour and responsibility. In this way, health care personnel can use their contact with the patient, and their power, to ensure the patient's trust and respect the patient's integrity. "A morally responsible exercise of power is to act in such a way that the other's room for action is expanded" (Delmar, 2012, p. 238). Shared decision-making and supported decision-making can be ways of providing a high degree of self-determination in line with the patient's condition (Beyene et al., 2018; Jeste et al., 2018; Slade, 2017) and may be seen as a clinical adaptation of the CRPD.

In mental health care, shared decision-making can be defined as an approach to planning and providing care that focuses on decision-making processes in the relationship between the patient, health care personnel and sometimes the patient's family members (Davidson et al.,

2017). Shared or supported decision-making can increase patients' influence by ensuring that their preferences, experiences and opinions are included in decision-making processes in addition to the professional knowledge of the health care personnel (Beyene, 2018). Shared decision-making in mental health care is intended to be part of a patient participation process, where health personnel in their relationship with the patient can have existential responsibility and be a close partner (Beyene, 2020). From the patient's perspective, it is always important to be heard, but patients must not be expected to know at all times what they want or what is best for them. It must be a safe process in complementary collaboration, a safe relationship characterized by dialogue and a fair distribution of power, where the patient is in the centre as an active participant (Beyene, 2023, 2018a). Shared decision-making is complex and health care personnel may feel that it is difficult to find a balance between power and responsibility in this context, and there is a need for education sessions and to establish safe procedures between the parties in the clinical environment (Beyene et al., 2019). Studies have revealed limited understanding of shared decision-making and of how to provide patients with informed and supported choices in line with their preferences (Haugom et al., 2020; Slade, 2017).

Patients with SMI may periodically be unable to understand information or express their wishes. Care and treatment decisions must then be postponed or made on behalf of the patient, but supported decision-making is also an alternative. Supported decision-making is mostly used in the care of people with permanently limited capacity to consent and can be seen as an additional support measure in the context of shared decision-making and patient participation (Szmukler, 2018). For people who have difficulty in understanding information and expressing choices, supported decision-making can be an aid that can be compared to a ramp for a wheelchair user, according to Szmukler (2018). Supported decision-making can be seen as an alternative to coercion (Szmukler, 2018).

7.3.4 Enhancing cooperation with the patient's family

Studies have found that family involvement can have a positive effect on a patient's care and treatment and on the work of health care personnel, and can alleviate the burden on family members (Hestmark et al., 2023; Mayberry et al., 2021; Førde et al., 2016; Weimand, 2012). Despite this, health care personnel do not involve family caregivers to any great extent (Hansson et al., 2022; Aslerin & Tingleff, 2021; Bucci et al., 2016; Rowe et al., 2012) and they often have little opportunity to share important information or to receive support from

health care providers to cope with their responsibilities (Rugkåsa & Canvin, 2017; Stensrud et al., 2015; Aslerin & Tingleff, 2021; Mayberry et al., 2021; Hestmark et al., 2021; Schaffer, 2021; Weimand et al., 2011). This is despite the fact that family caregivers are the patient's closest and sometimes only private network, who often take on considerable responsibility to meet the patient's everyday care needs. Family members (sometimes friends) close to patients with SMI have the right to be included in collaboration, an independent right to information and the right to appeal against an assessment of lack of consent capacity, if there are no other factors involved and the patient does not disagree (Psykisk helsevernloven, § 4a-7, first paragraph; Pasient- og brukerrettighetsloven, § 3-3a).

Family members' engagement and efforts in caring for their loved one often mean a great deal to a patient with SMI in everyday practical and social life, but also in terms of a feeling of belonging and connection to the family and the local environment (Elphinstone & Terjesen, 2023). In line with the previously mentioned model of good dialogue of Skjervheim (1996), family caregivers need health care personnel who show interest in their opinions, try to understand their experiences and give them room for a safe dialogue (Hestmark et al., 2023). Family caregivers can provide knowledge and continuity and be more familiar with the illness trajectory and many aspects of the care and treatment history than anyone else. Health care personnel often come and go, while the family caregivers will have been there the whole time. They may therefore have important information that can help health care personnel to understand the patient's problems, history and current situation, which the patient, due to the nature of the disorder, is not always able to grasp or explain (Elphinstone & Terjesen, 2023). Family members' knowledge can therefore improve the quality of patient care (Hansson et al., 2023) and enhance patients' ability to accept health care and avoid relapse (Rodolico et al., 2022; Bighelli et al., 2021; Pharoah et al., 2010; Pitschel-Walz et al. 2001; Dixon et al. 2001; Ukom, 2023).

Family involvement is important in view of the increasing provision of care and treatment in patients with SMI' homes. Fewer inpatient beds, an expansion of primary care and a shortage of qualified health care personnel in certain areas all increase the importance of the efforts of family caregivers (Ukom, 2023; Samtykkeutvalget, 2023). The Consent Committee points out that the care burden of family members has increased over time due to a higher threshold for admission to inpatient care and capacity problems (2023). A further factor, according to the Committee (2023), may be that the threshold for involuntary health care has risen because of unclear assessments of capacity to consent and the fact that several people with fluctuating

consent capacity have to cope in their own accommodation with varying levels of care and treatment. In a recent report, Ukom (the Norwegian Health Care Investigation Board) argues that the burden and well-being of family members must be taken into account and it must be ensured that they are able to provide care and support to the patient and function as a resource for the health care services (2023). Studies show that health care personnel lack competence in how to include family members and have poor knowledge of their rights, and that health care services often have inadequate structures and procedures for collaboration with them (Hansson et al., 2022a, 2022b; Førde et al., 2016).

The family caregivers in this study wanted to have contact with the same health care personnel over a long period of time. They also felt that greater continuity, availability and expertise would facilitate discussion of major and minor concerns and individualization of care, provide reassurance and make it easier to find solutions that would satisfy all parties involved. Closer cooperation may also help in finding others who can provide care to the patient, thus lightening the burden on family caregivers. It may also make it easier for family members to hand over more responsibility to health care personnel to ensure that the patient receives the necessary health care.

However, family members may not be included by the patient as next of kin and may not be involved in collaboration. In such situations, it is important to clarify how health care personnel and the patient should relate to them, and in some cases how to protect the patient. If a patient wants nothing to do with the relatives, it can be difficult to give them the support they need, and it will lead to challenges in trust, confidentiality and loyalty between the parties in the triad (Hansson et al., 2022b; Chen, 2008). Health care personnel find confidentiality to be a problem in their contact with family members (Hansson et al., 2022 b; Wilson et al., 2015). There is a need for knowledge, reflection and guidance to deal with the issue of confidentiality and to avoid unnecessary exclusion or dismissal of family members (Hansson et al., 2022b; Marshall & Solomon, 2003).

Family relationships can be negatively affected when a family member has SMI. The problems can lead to various difficult situations in the family's life, especially in connection with crises and admissions to inpatient care. Both patient and family need to deal with the consequences of the SMI. For this reason, psychoeducation for family members is important, because it will be easier for them to provide emotional and practical support when they have enhanced knowledge of the disorder and the most helpful forms of care and support in different phases or situations (Hansson, 2023). Mutual expectations, family communication,

family secrets, problematic relationships, and what can and cannot be talked about must be clarified and will affect the degree of inclusion of family members by health care personnel (Elphinstone & Terjesen, 2023; Andersen, 1996; Seikkula, 2000). It may be important to clarify how the parties can communicate; the patient, the family members and others in the close network may need to find ways to express what is important to them and to share experiences. Family caregivers must be allowed to indicate how much or in what ways they can or want to be involved, just as the patient must be allowed to indicate how much he/she wants them to be involved. Increased knowledge can help the parties to understand each other's differences and lead to satisfactory collaboration (Andersen, 1996; Seikkula, 2000).

There is a clear need to focus more strongly on collaboration with family caregivers in all services involved in patient care and treatment at both levels of care (Samtykkeutvalget, 2023; Hansson, 2023; Ukom, 2023). The guidelines for next of kin and studies call for measures such as providing knowledge of relevant regulations, the implementation of ethical reflection models and the establishment of ethical reflection groups (Helsedirektoratet, 2017a; Karlsen et al., 2018; Førde et al., 2016).

7.3.5 Structural changes

Patients with SMI often find meaningful relationships with health care personnel to be beneficial to them (Aarre & Hem, 2023; Lauveng, 2020). However, many patients with extensive and complex care needs find mental health care services to be fragmented and difficult to navigate, with poor coordination and continuity in transitions between different services and levels of care, and in collaboration over time (Trane et al., 2021; Bjørkquist & Hansen, 2018; Ådnanes & Steihaug, 2016). The organization of health care services may be perceived as a rigid service system, rather than patient-oriented, flexible care provision. When a patient needs various services from both levels of care, holistic and coordinated care is challenged by different legislation, different digital systems for reporting and keeping patient records, a different bureaucratic organization and limited opening hours (Trane et al., 2022).

The present study finds that health care services are able to provide comprehensive high-quality care to patients with SMI in some municipalities, but municipalities are organized differently and have unequal access to qualified health care personnel. There appears to be room for improvement in organization and structures within and between health care services and levels of care for patients with SMI, as found by Wormdal et al. (2021). Increased competence and more flexibility will also be important in developing more voluntary

treatment options, as pointed out in several reports and white papers (Samtykkeutvalgets rapport, 2023; Ukom, 2023; Meld. St. 7 (2020-2023); Forenkle og forbedre, 2023; Meld. St. 23 (2023-2033)). ReCon is an ongoing study with the aim of developing services for patients with SMI, which includes an extensive intervention for primary care in Norway to prevent the use of coercion (Wormdal et al., 2022). ACT and FACT teams have become important players in health care provision for patients with SMI in several municipalities in recent years (Trane et al., 2021; Landheim et al., 2017). ACT and FACT teams have the advantage that they include both primary and specialist health care personnel in their interdisciplinary outreach service, which may make it easier for patients with SMI and extensive care needs to accept the care and treatment offered (Trane, 2021). The teams can adapt care and treatment to the person's needs and condition, coordinate different health care services and reduce some of the gaps in care that often occur with fragmented services (Trane, 2023; Trane et al., 2021).

There is a shortage of qualified health care personnel; 22% of mental health care workers have no qualifications in health and social care (SSB, 2021). Qualified staff are thus referred to as a "luxury" in the new escalation plan for mental health (Meld. St. 23 (2023-2033)). It would thus seem to be important to share specialist knowledge and be discussion partners across health care services and levels of care. The report "Time for action" (NOU 2023: 4, p. 17) suggests measures to increase flexibility and quality in health care. It is proposed that some staff could have their main job in one area of health care but also smaller part-time positions in other areas in the same or a different level of care. The benefits might be that special expertise may be useful in different health care services and that it will increase flexibility for staffing when needed and to provide a flow of expertise (NOU 2023: 4).

For patients with SMI and their primary health care personnel, the availability of more expertise from specialist health care would make a significant difference. Descriptions by patients and primary and specialist health care personnel in this study show that it can provide reassurance if patients and primary care staff can easily call the patient's previous health care personnel in a hospital or a mental health centre. Contact by phone would enable discussion and clarification of issues with a specialist who knows the patient and the situation. Variations in condition and health care needs should not lead to patients with SMI constantly having to end relationships with staff, especially a stable therapeutic relationship; they need stable and secure contact with health care personnel. Health care personnel providing day-to day care should also be given enough flexibility in their jobs to be able to follow up patients with

whom they have a close relationship when their patients periodically need other health care services. This could provide continuity in important relationships, which we know can make patients feel secure, mitigate their symptoms, and improve their functioning and quality of life (Aarre, 2023; Fortin et al., 2018). The goal for improving health care services should be "...to create a patient-centered health care service where all patients should feel sure of receiving care when they need it, being looked after and informed, and having influence and power over their choices and decisions" (Meld. St. 34 (2015-2016), p. 3).

7.4 Implications for practice

This study has revealed several factors of importance for practice. Firstly, patients with SMI can receive health care without a CTO, which health care personnel had not expected. Secondly, it often proves difficult to provide comprehensive, flexible and coordinated health care to patients with SMI, due to variations in the quality of and access to health care services. A third implication is an important untapped potential for collaboration with family caregivers.

If patients with SMI and extensive health care needs are to be involved in their care and treatment, flexibility, continuity and a high level of professional expertise are necessary. Patients and health care personnel must know each other well and have close communication to enable the personnel to adjust health care in cooperation with the patient based on variations in the patient's condition. This requires coordination and continuity in care and treatment and highly qualified health care personnel.

The potential for collaboration with the patient's family has yet to be exploited. SMI is difficult to live with and there may be extensive health care needs; here, family members are often particularly important for this patient group. Closer cooperation with family caregivers can improve care and quality of life for both patient and family. Health care personnel need to involve and collaborate with the patient's family to a greater extent. Good collaboration is important for the family caregivers' own health, and it can lead to better care for the patient and enable the carers to become more involved in the care and treatment provided by health care personnel. Expectations for involvement and support needs must be clarified with the individual patient and family.

7.5 Further research

It would be interesting to explore what the increased focus on capacity to consent means in the lives of patients with SMI and their family carers, and for the work of health care

personnel, after the new legislation has been in effect for a few more years. It could be useful to interview the participants in this study again to find out how things have developed and how they experience the new legislation after several years. It would also be interesting to conduct a similar study to this one on a larger scale and in a number of health regions. Both studies suggested here should lead to important insights to form a basis for further development of health care services, collaboration in the triads and the legislation.

There is a need to explore the skills and structures health care personnel feel are needed in the various primary health care services for this group of patients to assess their condition, adjust the health care provided and accommodate variations in condition and capacity to consent. There is further a need to explore experiences of consent capacity assessments and of which forms of training, tools and interdisciplinary collaboration are seen as successful and what is found to be lacking.

Also important in improving health care services will be knowledge of possible alternatives to CTOs and of the perceived needs of patients with SMI, family caregivers and health care personnel in terms of voluntary care and treatment alternatives.

There is a need to examine how the various jobs across health care services and levels of care can be organized to improve flexibility, continuity in relationships and sharing of expertise in health care.

8 Conclusion

A triadic approach was used in this study, where the patients chose which next of kin and health care personnel would participate. This provided unique insight into the experiences of three groups affected by the change in the law.

The capacity-based model has improved dialogue and interaction between patients with SMI and health care personnel. Patients experience enhanced self-determination, participation and freedom in collaboration with health care personnel on their care and treatment, which is also confirmed by health care personnel and family caregivers. The study shows that health care personnel have become more interested in establishing a dialogue with patients with SMI to provide health care that patients want and find useful. However, inclusion of patients' family members in the collaboration has not improved since the change in the law, and this is therefore an area with considerable room for improvement.

The amended legislation has led to a new practice in assessing patients' condition and capacity to consent. Specialists now focus more on the patient's current condition and preferences and less on the diagnosis when assessing treatment and the possible use of coercion. Health care personnel providing day-to-day care are now more consciously providing support to patients to help them retain or regain consent capacity. In order to stabilize or improve the level of functioning, they need to have close communication and collaboration with patients in order to mutually adapt care provision to changes in their condition. The study demonstrates a need for health care services to be organized in ways that provide more flexibility in care provision. Patients with SMI and their family need more continuity in relationships with health care personnel, while more voluntary care and treatment options that patients find helpful need to be established.

In order to ensure legal protection for patients, high-quality assessments and care are essential, and detailed justifications for decisions and supporting documentation must be provided, which can then be verified. Reacting to changes in the condition and capacity to consent of patients with SMI, while ensuring their autonomy, requires high levels of competence and collaboration among and between health care personnel in specialists care and primary care. There is a need for structures that encourage greater collaboration between health care services, and professional development and training for all health care personnel. Greater competence in assessments of patients' condition and individualization of care and

treatment is also needed, in addition to opportunities for reflection on decisions and ethical issues.

This study demonstrates that the change in the law can be seen as a key step towards more humane mental health care. The patient's preferences and level of functioning are now more strongly emphasized. The study shows that aim of the legislation to increase self-determination and reduce coercion is possible for patients with SMI, without serious consequences for the health and daily life of patients and their families. However, it is becoming clear that health care must be organized in a way that provides flexibility, continuity and professional development to enable patients to benefit greatly from capacity-based legislation, while also ensuring their legal protection. Improved competence among health care personnel and legal enforcement of the consent criterion will eventually lead to a more uniform practice in the application of the new legislation.

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RESEARCH

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Increased autonomy with capacity-based mental health legislation in Norway: a qualitative study of patient experiences of having come off a community treatment order

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Abstract

Background: Capacity-based mental health legislation was introduced in Norway on 1 September 2017. The aim was to increase the autonomy of patients with severe mental illness and to bring mental health care in line with human rights.

The aim of this study is to explore patient experiences of how far the new legislation has enabled them to be involved in decisions on their treatment after they were assessed as capable of giving consent and had their community treatment order (CTO) revoked due to the change in the legislation.

Method: Individual in-depth interviews were conducted from September 2019 to March 2020 with twelve people with experience as CTO patients. Interviews were transcribed and analysed using thematic analysis inspired by hermeneutics.

Results: Almost all interviewees were receiving the same health care over two years after their CTO was terminated. Following the new legislation, they found it easier to be involved in treatment decisions when off a CTO than they had done in periods without a CTO before the amendment. Being assessed as having capacity to consent had enhanced their autonomy, their dialogues and their feeling of being respected in encounters with health care personnel. However, several participants felt insecure in such encounters and some still felt passive and lacking in initiative due to their previous experiences of coercion. They were worried about becoming acutely ill and again being subjected to involuntary treatment.

Conclusion: The introduction of capacity-based mental health legislation seems to have fulfilled the intention that treatment and care should, as far as possible, be provided in accordance with patients' wishes. Systematic assessment of capacity to consent seems to increase the focus on patients' condition, level of functioning and opinions in care and treatment. Stricter requirements for health care providers to find solutions in cooperation with patients seem to

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lead to new forms of collaboration between patients and health care personnel, where patients have become more active participants in their own treatment and receive help to make more informed choices.

Keywords: Coercion, Community treatment order, Outpatient commitment, Capacity to consent, The Mental Health Care Act, Patient experiences, Self-determination, Autonomy

Background

There is growing awareness of mental health patients' right to self-determination. The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly in 2006 and implemented in 2008 [1]. The CRPD aims to ensure that people with disabilities, such as severe mental illness, have the same basic human rights as other people. In an ongoing international debate, it is argued that mental health care legislation without conditions for the lack of capacity to consent to the use of coercion is discriminatory, because without such conditions it is assumed that patients with severe mental illness lack the capacity to consent [2, 3].

In Norway, there have been efforts for several decades to enhance the freedom and autonomy of mental health patients [4, 5]. In 2013 the CRPD was ratified in Norway [6] and in 2014 two amendments to the Norwegian constitution were adopted that protect the integrity and privacy of individuals [7]. The lack of any reduction in the use of coercion, as well as strong pressure from service user organizations, led to an amendment to the legislation in 2017 where lack of capacity to consent was introduced as an independent condition for the use of coercion under the Mental Health Care Act [8]. This change is an adaptation to the principles of the CRPD, and is intended to strengthen patients' right to self-determination and legal protection [9]. The change to capacity-based legislation is also aimed at decreasing the importance of a patient's diagnosis. Patients should be able to refuse treatment they do not want, or end treatment they have started, provided that they are capable of weighing up alternatives and understanding the consequences of their choices. Patients are still entitled to health care, and must be allowed to choose between different suitable forms of treatment. Only patients who are assessed to represent a danger to their own life, or the health or life of others are exempt from the condition of lack of capacity to consent [8]. The patient's capacity to consent is assessed by the responsible psychiatrist or specialist clinical psychologist.

When introducing the change in the legislation, the government focused on these four areas in assessing patients' capacity to consent: 1) the ability to understand information relevant to health care decisions, 2) the ability to apply the information to their own situation, especially in relation to their particular mental health problems and possible consequences of different treatment options, 3) the ability to use relevant information to weigh up treatment options, and 4) the ability to express a choice [10]. If there is any doubt as to whether the patient understands what consent entails, the patient must be allowed to refuse recommended treatment, while still being entitled to necessary health care [11]. Before the introduction of the new criterion in the legislation, there was little focus in Norway on structured assessment of patients` capacity to consent to treatment in mental health care. Following the amendment to the legislation, health care professionals have been given greater responsibility to assess a patient`s condition. They have to attend more closely to the patient's precise condition to be able to collaborate more fully with the patient and to make additional efforts for the patient to voluntarily engage in their care. Health care professionals need to look for signs and symptoms, and listen to the patient`s preferences to acquire knowledge of the patient's condition in order to provide suitable treatment and care, and to adapt the care in the event of improvement or immediately take necessary steps in the event of deterioration. The term condition indicates a temporary state of illness or health, and provides information about a patient's physical, mental and cognitive capacity at a specific point in time [12].

Community treatment orders (CTOs) have been introduced in most Western jurisdictions [13] with different options for intervening and treating patients under coercion [14]. Most CTOs stipulate that the patient must comply with what the health care provider considers to be necessary care and treatment, in order to avoid a relapse that requires re-admission to hospital [14–16]. The change to a model based on capacity to consent was considered particularly relevant in order to reduce the number of patients on CTOs. In discussions and consultations before the amendment, sceptics expressed concern about its consequences. They feared that patients with severe mental disorders and complex needs would avoid treatment, with serious implications for the health and welfare of patients and their families [17]. The Norwegian CTO scheme is summarized in Table 1.

The aim of this study is to explore patient experiences of how far the new legislation has enabled them to be involved in decisions on their treatment after they were assessed as capable of giving consent and had their CTO

Table 1 Norwegian CTO scheme

Norwegian CTO Scheme:
The CTO scheme was introduced in Norway with the Mental Health Care Act in 1961, and was continued based on an amendment to the Act in 2001. The scheme is based on clinical practice and each CTO is decided by the responsible psychiatrist or specialist psychologist. The conditions for implementing a CTO are the same as for involuntary inpatient treatment: patients must have a severe mental illness and either have an evident need for treatment or represent an imminent danger to their own life, or the life or health of others. A study of Norwegian CTOs has shown that they are solely based on patients` clear need for treatment (treatment criterion), with the addition in a few cases (18%) of the risk of posing a danger to themselves or others (harm criterion) [18]. In the case of involuntary medication treatment, a separate treatment decision is required. The legislation requires that coercion is considered necessary and a CTO presupposes that voluntary treatment has been unsuccessfully attempted, or it would be clearly futile to attempt this. Patients must also be offered adequate treatment and care that meet their needs. The CTO decision must be made on the basis of available information and a medical examination of the patient. An overall assessment must also be made as to whether a CTO is the best solution for the patient. In this assessment, patients must be allowed to express their opinion and particular emphasis must be placed on patients' wishes, and how they feel about involuntary treatment. A CTO decision is valid for 12 months, but it must be re-assessed by the responsible professional at least every three months to determine whether the conditions are still met. If the CTO continues for more than 12 months, it must be approved by an independent review board (the Control Commission). In practice, this means that a patient may be under a CTO indefinitely. The CTO population in Norway has been shown to have the same patient characteristics as seen in studies from other jurisdictions [15, 18, 19]. There is no complete information on the numbers of CTOs in Norway, but in a study from 2012 that included a third of the population, the incidence rate was 23.8 and the prevalence rate was 47.4 per 100 000 inhabitants over the age of 18 [20].

revoked due to the change in the legislation. The results are discussed in light of the intentions behind the new condition in the legislation.

Method

Design

The study used qualitative in-depth interviews to explore participants' experiences and opinions. The interview and analysis processes were inspired by hermeneutics and a dialogical approach [21, 22]. The data were developed through dialogue between participants and researchers, where the researcher focuses on not seeking to confirm what she already knows, but instead attempts to be open to potential new understandings [21]. The study was conducted in specialist and primary health care in a region of Norway. The present article forms part of a larger study that examines the experiences of the new legislation of health care professionals, patients and their relatives.

Involvement of service users

In order to design a study with a high degree of relevance and clinical benefit, four focus group interviews were conducted with distinct groups during the planning stage. The participants were 1) patients with experience of involuntary admission and CTO, 2) relatives of patients with experiences of involuntary admission and CTO, 3) health care professionals working in the community and 4) health care professionals working at a psychiatric hospital. Groups 3 and 4 both worked with patients who had experience of involuntary admission and CTO. The focus group interviews contributed to the development of the interview guides and gave the research team insight into what the various groups considered important to consider and explore in conducting the study.

At the start of the study, collaboration was established with a peer group of six people with personal experience of involuntary mental health care and CTOs as patients or relatives. This group of experts by experience contributed to discussions and made suggestions for the interview guide and the implementation of the interviews. This cooperation enhanced our understanding of what the amendment meant from their perspectives. A lived experience consultant was also engaged in the study.

Recruitment

The participants were recruited from patients who had been on a CTO at the university hospital in the catchment area of the study. The inclusion criterion was patients who had their CTO revoked between 01.06.2017 and 01.09.2018, being assessed as competent to give consent. Fifty-five patients met the inclusion criterion during the study period. Random sampling was conducted among these patients. The last author had access to patient records to find out the patient's age and the names of clinicians who had provided care to the patient. Those who knew the patient, but were not in charge of treatment, were contacted and given written and oral information to invite the patient to participate. Potential participants who no longer received care from the specialist health service were invited to participate by letter, followed by a telephone call from a lived experience consultant. Eighteen persons declined to be interviewed. When participants agreed orally to participate, the first author contacted them to clarify any questions and agree on the interview location. No participants withdrew during the study.

Participants

The data consist of interviews with twelve participants aged 20–75 years, six women and six men. Four of them had a job, were studying or retired, and nine had disability benefits. Ten participants were single, two had

partners and three had children. Two-thirds of them lived in urban areas and one-third in rural areas. Four participants rented or owned their homes, seven lived in supported council housing, while the accommodation of one was unknown. Participants had different levels of functioning. Several needed help with self-care, medication and practical tasks such as cooking and cleaning, while others only needed counselling. They received this support from the housing staff, mental health care staff or their doctor. One participant had regular voluntary hospital admissions and a few had treatment in an outpatient clinic. Eleven participants revealed their diagnosis, while one did not want to talk about his diagnosis. Nine had been diagnosed with schizophrenia spectrum disorders (ICD-10 F20-29), one with mood (affective) disorder (ICD-10 F30-39) and one within the category of disorders of adult personality and behaviour (ICD-10 F60-69). In addition, four were addicted to alcohol/drugs. One participant had been under a CTO once, seven had been under a CTO several times, while for one, the number of CTOs was unknown. The length of the CTOs had varied from three months to several decades. At the time of the interview, two of the participants were back on a new CTO.

Interviews

Interviews were conducted by the first author from September 2019 to March 2020. Participants chose the location, and interviews took place in their homes or in the hospital. During the interviews, efforts were made to make participants feel comfortable and secure and to provide them with information suitable to their level of functioning.

The interviews lasted from 45–90 min; they were audio recorded and subsequently transcribed in their entirety and anonymized. Following each interview, field notes were written about the interview situation and the interviewer's experience of the session.

The interview guide consisted of open questions and accompanying sub-questions based on the following topics: 1) Presenting oneself, one's everyday life and one's collaboration with health care professionals, 2) Experience of being under a CTO, and 3) Experiences of the change in the law and no longer being under a CTO. At the end of the interviews, the interviewer asked the participants about their experience of the interview situation.

Analysis

A thematic analysis was conducted, with a hermeneutic approach inspired by Fleming et al. [21]. In hermeneutic analysis, researchers identify their horizon of understanding, understood as pre-understanding based on their background and experience and the context of the interviews and analysis. This approach presupposes critical reflection, dialogue and the capacity of researchers to see the significance of their own role in dialogue with participants and in interpretation of the data [21]. The authors have extensive experience of treatment and follow-up care of patients in involuntary mental health treatment and CTOs from their clinical work, counselling, advocacy or legal assistance. In a qualitative study with a hermeneutical approach, the researchers' pre-understandings and experiences from the field are seen as a necessary basis for new understanding, although it is also vital to challenge one's pre-understanding in order to understand in new ways. A movement back and forth between the whole and parts of the material, questions posed to the text and dialogue between the researchers are all necessary to achieve a new understanding [21].

The audio recordings were listened to and the transcripts read many times. Inspired by the analytical steps recommended by Fleming et al. [21], efforts initially concentrated on gaining an understanding of each interview as a whole, and as a context and condition for understanding the parts. In the next step, each sentence or passage was studied to grasp its meaning and enhance understanding. Particularly interesting statements or passages were highlighted in the text and questions, reflections and ideas were noted down in the margin and discussed by the researchers. The meaning units ranged from a few words to whole sentences and paragraphs, to ensure that the participants' concepts were retained [23, 24]. The meaning units were discussed and preliminary topics were identified. We used the research question as a basis for deciding on the topics to continue with. Further rounds of reading were conducted. Questions were posed to the text about how to understand the various parts or statements, alternating with considering them in relation to the whole. The first understanding of the whole was challenged and revised by working on the parts. The movement from the parts back to the whole constituted the third step of the analysis. Themes changed and were continuously assessed in relation to participants' statements, then retained or rejected, or new analytical concepts were identified. Quotes that represented the various themes were selected and sorted on large pieces of paper to gain an overall visual impression of themes and sub-themes. Some themes were interwoven and some new ones emerged. In order to understand the latent descriptions of participants' experience, it was important that the first author had conducted the interviews. Through dialogue, the researchers challenged each other's understandings based on their different backgrounds and experiences from the field, misunderstandings were eliminated and an effort was made to achieve

a common understanding of the data. Dialogue with the text and relevant research literature helped to challenge the researchers' pre-understandings and to develop the analysis. The analysis finally resulted in three main themes: 1) a feeling of greater autonomy and respect, 2) no change in condition and treatment, and 3) past experiences are not erased.

Ethics

This study has been assessed by the Regional Ethics Committee (REK Nord) REK No. 2018/1659, and approved by the data protection officer of the University Hospital of North Norway.

In conducting this study, the researchers were aware that the participants' mental health disorders could lead to changes in their condition and capacity to consent. During some interviews, it was necessary to assess participants' understanding of what participation in research involved. To ensure that patients who were on CTOs at the time of the interview ($N=2$) were able to make an autonomous assessment of their participation in the study, the clinicians treating them were asked to assess their capacity to consent to participation in the research.

All participants received oral and written information about the study, and were informed that participation was voluntary. They were also told that they could withdraw from the study at any time before the data had been included in the analysis, without giving a reason and with no negative consequences for them.

Results

The analysis revealed three themes that show how the participants experienced having come off their CTO on the basis of capacity to consent.

A feeling of greater autonomy and respect

Having their CTO revoked under the new legislation had a considerable impact on the participants. Several of them stated that coming off the CTO this time was a different experience from before. They experienced greater autonomy, freedom and respect. They also stated that it was the right decision to terminate the CTO, although they were very surprised because they did not feel that there was any change in their state of health. Several participants did not understand how it was possible to keep them in involuntary treatment for many years and then remove the coercive measures without any change in their condition. Some had received little information when the new legislation came into force and wondered to what extent changes in their level of functioning had played a part in the assessment of whether or not to continue the CTO.

Several participants found it difficult to make decisions about their own treatment after having been on a CTO for a long time. For some it was a great relief, while for others it was frightening. Klara was angry at first when her CTO was revoked because she was afraid of not receiving the same care and treatment without a CTO. It was difficult for her to understand how the change could have come so suddenly:

> *"It all went so damn fast when the new law came, because I was used to being on a CTO all the time, then suddenly I was going to come off it. And then you think, well, bloody hell, now they've been giving me involuntary treatment for years and years, and then suddenly they want it to be voluntary... What was the point of having me on a CTO for so many years? And then suddenly, after the law was changed, did they change? … So, like, it doesn't apply any longer?"*

After coming off the CTO, the participants were in a different position when collaborating with health care professionals. They found that the professionals were more likely to involve them in discussions and listen to their opinions, and they experienced respect. Several said that they participated more actively in collaboration; they offered their own opinion and were not afraid to disagree. No longer being under a CTO had a positive effect on their self-image, their dignity and their feeling of being more normal. Hans put it this way:

> *"I don't want to talk about the way it was before. … Now people don't think there's something strange about me. …I don't think they see anything wrong with me. …they respect me properly."*

The CTOs had been revoked over two years previously, and two of the participants were back in involuntary treatment again. Most participants said that they had not needed voluntary admissions to community mental health centres or hospitals. None had lost any treatment or care since their CTO was revoked, and they cooperated on treatment. Most participants believed that they would still be under a CTO if the legislation had not changed.

No change in condition and treatment

Participants' treatment and care had not changed as a result of the new legislation. The majority were offered and wanted to continue with the same care with some adjustments, e.g. their care provider changed from an outpatient clinic to primary health services. Some participants could still contact therapists at the community mental health centre or the regional psychiatric hospital as required, which was felt to be reassuring.

For most participants, their housing and everyday lives were unchanged. Those who previously lived in supported housing continued to live there. They were happy with the services offered, but wanted a more meaningful life with work and hobbies. Several stated that having had others decide things for them for many years had made them passive and lacking in initiative, and that they found it difficult to live meaningful lives. Several participants also had problems with irregular sleep patterns and with socializing. Many were distressed because of their disorder and medication; they felt lonely and found life monotonous.

A few participants wanted a different kind of accommodation because they found it challenging to have to constantly relate to staff and other residents with whom they had little in common. One participant felt that the staff focused too much on his illness and gave him too much advice about diet and cutting down on tobacco, alcohol and drugs. Pål, who was addicted to drugs and had considerable experience of involuntary treatment, said the following about the supported housing:

> *"It's not obvious to me what are rules and what's the involuntary stuff."*

Some participants found the regulations in council housing difficult to comply with. This was because their lives and disorders were often challenging enough in themselves, and because it seemed unreasonable or meaningless to have some of the rules in one's own home. Problems with the regulations made one participant worry about being evicted and losing her right to council housing since the council no longer had the same responsibility since her CTO was revoked.

Participants who owned or rented their own home described a different structure to their lives, with work, education or various enjoyable activities. These participants also had severe mental disorders, but described improved mental health and greater independence to take control of their lives. Two who lived in their own homes felt that their life had greatly improved after coming off the CTO. They described enthusiastically how much it meant to regain their autonomy and have more freedom. They talked about reducing and adjusting their medication to make them feel better physically and have fewer side effects. Hedda said:

> *"You get quite ... apathetic from taking medicines, they kind of dull your feelings. Now I'm taking Haldol. Haldol has a lot of side effects, maybe you can see the side effects in my mouth and eyes, they move a lot? … Haldol gives me such a chemical feeling in my body so it's just awful! When I take it and it has a powerful effect on me. I used to take 12 milligrams, but now I'm on 3.5."*

Hedda had never had a say in her medication for several years, but she described completely different cooperation after the CTO was revoked. Several other participants had similar experiences.

Past experiences are not erased

In addition to having been on CTOs, all participants had experienced involuntary admission to hospital. They all described having been subject to various coercive measures, both during the process of being admitted and after admission. They talked about how it felt to be taken by force from their home for a compulsory examination, and to be forcibly medicated and restrained with belts. Their experiences of coercion also involved being prevented from making decisions on their own treatment, and being subject to various forms of compulsion over a long period of time. The participants' stories of their experiences of coercion did not distinguish between a CTO and involuntary inpatient treatment. Their previous experiences of both inpatient and outpatient compulsory treatment were important factors in their current treatment, their sense of autonomy and their everyday life without coercion.

The participants' many years of experience of various forms of coercion had made a lasting impression that affected their view of seeking help if their condition deteriorated. Although they now experienced greater trust and kindness among health care personnel, several had lost confidence in certain individual professionals. They felt vulnerable, being afraid of becoming acutely ill again and unsure whether they could be subject to coercion again if their condition worsened. Negative experiences of coercion made some participants afraid that it could happen again if there was a new crisis. Several participants had previously asked for help when their illness seemed to be deteriorating, but did not receive what they asked for. They received far more intrusive care than they requested and felt misunderstood or mistrusted. Anne explained:

> *"I'd been to my doctor to get a sick note. And then I'd told him how I was feeling. For a long time I'd felt that someone was watching what I was doing. A few days later, a lady… who was a substitute for my GP… came to my house and said that I had to go to a psychiatric hospital. I couldn't believe it was true! I thought she was joking! I was terrified!"*

Several participants mentioned how meetings with health care staff had been important to them, for better or for worse. Ole said that it made a difference whom he got to talk to when he rang the hospital, and added that it

was not right that the treatment you are offered depends on which clinician you happen to talk to when you need help. Another participant, Pål, wanted to be inconspicuous and therefore mostly talked about everyday matters with the health care staff working in his supported accommodation. If they viewed him as psychotic, he was uncertain about the reactions and measures he could expect. He explained:

> *"I try to keep to my senses... otherwise I may get some unwelcome reactions."*

As they were unsure about the types of treatment and care offered, the participants found it difficult to tell clinicians about problems or experiences that could be interpreted as signs of illness; it could be difficult to be oneself and to ask for help at the same time.

Discussion

The aim of this study was to explore patient experiences of having come off a CTO due to their capacity to consent. The study shows that the participants experienced greater autonomy as a result of the new legislation. They also found that their care, treatment and accommodation remained largely unchanged. However, they were concerned that they could be subject to coercive measures again if their condition worsened.

The intention of the capacity-based mental health legislation in Norway was to achieve greater alignment between human rights and mental health care. In connection with the prevention and restriction of coercion and patient participation in health care decisions, mental health care services are now expected to cooperate with patients to find suitable solutions for treatment and care.

The capacity-based mental health legislation means that it is no longer possible to justify the use of coercion on patients needing maintenance treatment. This also applies to patients who have had successful medication treatment and thus regained their capacity to consent, but who are assumed likely to stop taking the medication when it becomes voluntary, leading to rapid deterioration. A feared consequence of the change in the legislation was that patients with severe mental disorders and complex needs would avoid treatment, with serious consequences for their health and welfare [17]. At the same time, it has previously been argued that patients under a CTO generally appear to have a level of functioning that indicates capacity to consent as long as they live and function outside an inpatient facility [25]. Our study shows that the participants still wanted care and treatment after their CTO was revoked. Almost all the participants had collaborated on voluntary medication and follow-up care for over two years following the termination of their CTO. Only two participants had needed involuntary admission or a new CTO, two years after their CTO was revoked.

This contrasts with the participants' previous experience of periods when they were not on a CTO. When CTOs were revoked previously, they were not listened to or consulted regarding their treatment and care even though this was voluntary. This suggests that being considered as having capacity to consent meant that participants were now more valued and respected, with a new status and position with regard to their treatment and collaboration with health care personnel, involving dialogue and more information. Increased self-determination as described by the participants is in line with the aim of the amended legislation [9]. Several participants pointed out that they still found it difficult to relate to their housing regulations and advice from staff on diet and abuse of alcohol or drugs. Supported housing can provide security and protection, but can also be perceived as invasive or overprotective, which affects quality of life and whether the housing feels like a home [26].

The amendment to the legislation stipulates that a systematic assessment of the patient's condition must be performed by a professional responsible for the patient. All study participants had a severe mental disorder, which meant that they were dependent on everyday help to varying degrees. The nature of such disorders often includes periods of deterioration which may reduce patients' ability to assess their own situation and to make decisions [27]. The shift from a diagnostic focus to a focus on functioning means that changes in patients' condition must be taken into account to a greater extent. It has been argued that this calls for changes in health care professionals' attitudes and their views on which patients need to be subject to involuntary treatment [28]. The results from our study show that patients experienced a change in how health care personnel interacted with them after the change in the law, being more often included in dialogue and decision-making. This indicates that the new legislation has opened a new window of opportunity and new forms of cooperation in the treatment of severe mental disorders.

The amendment to the Norwegian Mental Health Care Act provides assessment guidelines for those responsible for decisions on the use of coercion. A Norwegian supreme court ruling from 2018 regarding a patient discharged from a CTO raised the question of what was required for lack of capacity to consent to be a condition for the use of coercion [29]. The ruling confirms that the decisive factor must be the extent to which the illness affects patients' ability to make realistic assessments of their condition and the consequences of treatment decisions. The ruling states: "*Patients with a fair degree of realistic insight into their own situation should be able to*

decide for themselves whether they want to receive health care. This also applies when there is a question of whether long-term medication has given them back the ability to understand. Unlike in the past, they can now decide to end their treatment even if health care personnel think this is unfortunate" [29]. This demonstrates legal practice that follows the intention of the legislation, i.e. the patient's right to self-determination shall be decisive as long as the capacity to consent is present.

The majority of the participants in our study were living stable lives with a disorder that was manageable at the time of the interview. Nevertheless, several were afraid that their condition could deteriorate, leading to loss of control and involuntary treatment again. This fear was quite marked in a number of participants, but seemed to be less so in those who had trusting relationships with health care professionals. A trusting relationship is key to patient-clinician collaboration, but is often challenged when treatment is involuntary. Several of the participants in this study described trusting relationships with health care professionals despite the power imbalance in a CTO. This is also emphasized in a study that finds that trusting relationships can be achieved by health care professionals who show confidence in patients, are seen as sincerely concerned about their best interests, and are honest, reliable and good listeners [30]. It is also important that professionals have sufficient knowledge to interpret early signs of a negative development in the disorder to enable them to provide the necessary treatment and care to avoid loss of control and acute admission to hospital. This is clearly vital to maintain patient autonomy [27]. To understand the nature of a disorder, it is not sufficient to know how the patient is feeling, but also how the disorder, e.g. psychosis, may develop [31]. This requires knowledge of how illnesses and disorders arise and how to proactively anticipate a flare-up to prevent exacerbation and the development of severe illness [32]. Also important here are good insight and the capacity to understand how patients experience their illness and what is helpful.

Previous studies have shown that patients on CTOs in Norway felt that their mental health care was a far-reaching intrusion in their lives that hindered their self-expression [33, 34]. Efforts to increase participation of seriously ill mental health patients in their treatment and care have been proceeding for many years. However, it was not until the introduction of the condition of lack of capacity to consent that mental health patients with such capacity became legally entitled to refuse treatment they did not want in the same way as patients in physical health care. The amendment to the Mental Health Care Act may thus represent part of an ongoing paradigm shift in the treatment and care of seriously ill mental health patients with complex needs in Norway.

Strengths and limitations

This study focuses on patients' perspectives and experiences, and aims to provide first-hand knowledge of the experience of having come off a CTO based on capacity to consent. Therefore, the study has not included any other perspectives on the change in the legislation, such as those of health care personnel and patients' relatives. The changes and experiences described by participants may have been influenced by various factors in their lives, and cannot be traced back to the amendment alone. Some participants reported not having received information about the change, but it may be said to strengthen the results that these patients also experienced a marked improvement in their autonomy and involvement in their treatment and care.

The participants were recruited from lists of patients in the catchment area whose CTO had been revoked during the study period, based on strategic sampling. Treatment personnel have thus had no influence on recruitment. In this way, we have aimed at a varied sample of participants. The study had a small number of participants, while a larger number would have been able to provide a greater variety of opinions and experiences.

The project group collaborated with a peer group of people with experience of CTOs as patients or family members. This collaboration gave the research team valuable insights into conducting recruitment and interviews. The original plan was to include the peer group in the data analysis, but this was not feasible due to the COVID-19 pandemic.

Conclusion

For patients in this study with previous experience of a CTO, it would seem that the changed legislation has worked as intended. The study shows that health care is largely provided in accordance with the patient's wishes. A systematic assessment of capacity to consent seems to lead to a greater emphasis on patients' opinions, state of health and level of functioning in their treatment and care. The participants experienced improved dialogue, information and assistance in collaboration with health care professionals. This helped them to make more informed choices and to be more actively involved in decisions on their treatment. The change in the legislation may indicate that new forms of patient-clinician collaboration are emerging in mental health care, where patients are trusted and their views taken seriously. The participants experienced a notable reduction in both formal and informal coercion.

As a step in improving treatment and care for people with severe mental illness and reducing the use of coercion, there is a need for studies that include the perspectives of health care professionals and patients' relatives. Knowledge is needed on how relatives experience the new situation, and on whether their role and responsibilities have changed since their family member came off the CTO and gained more autonomy. A further area for exploration is health care professionals' experiences of providing care and treatment with and without a CTO, and how far they feel they should accommodate patient wishes.

Abbreviations

CRPD: The Convention on the Rights of Persons with Disabilities; CTO: Community treatment order.

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Authors' contributions

NCW designed the study, recruited participants, conducted the interviews, analysed the interviews, drafted, revised and approved the manuscript. ÅS analysed the interviews, revised and approved the manuscript. AKW designed the study, recruited participants, revised and approved the manuscript. ABOF provided legal expertise, revised and approved the manuscript. HR designed the study, recruited participants, analysed the interviews, revised and approved the manuscript.

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Availability of data and materials

In order to protect the anonymity of the participants, the data on which this manuscript is based will not be made generally available, with the exception of the data that has been carefully selected for presentation in the manuscript.

Declarations

Ethics approval and consent to participate

All methods were performed in accordance with the relevant guidelines and regulations. The study has been assessed by the Regional Ethics Committee (REK Nord) REK No. 2018/1659, and approved by the data protection officer of the University Hospital of North Norway. The participants gave written informed consent to take part in the study. Participation in the interviews was voluntary.

Consent to publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Paper 2

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Health professionals' experience of treatment of patients whose community treatment order was revoked under new capacity-based mental health legislation in Norway: qualitative study

Nina Camilla Wergeland, Åshild Fause, Astrid Karine Weber, Anett Beatrix Osnes Fause and Henriette Riley

Background

Norway introduced capacity-based legislation in mental healthcare on 1 September 2017 with the aim of increasing patient autonomy and legal protection and reducing the use of coercion. The new legislation was expected to be particularly important for patients under community treatment orders (CTOs).

Aims

To explore health professionals' experiences of how capacity-based legislation affects healthcare services for patients whose compulsory treatment order was revoked as a result of being assessed as having capacity to consent.

Method

Nine health professionals responsible for treatment and care of patients whose CTO was revoked owing to the new legislation were interviewed in depth from September 2019 to March 2020. We used a hermeneutic approach to the interviews and analysis of the transcripts.

Results

The participants found that capacity-based legislation raised their awareness of their responsibility for patient autonomy and involvement in treatment and care. They also felt a need for more frequent assessments of patients' condition and capacity to consent and more flexibility between levels of care.

Conclusions

The study shows that health professionals found that capacity-based legislation raised their awareness of their responsibility for patient autonomy and involvement in treatment and care. They sought closer dialogue with patients, providing information and advice, and more frequently assessing patients' condition to adjust treatment and care to enable them to retain their capacity to consent. This could be challenging and required competence, continuity and close collaboration between personnel in different healthcare services at primary and specialist level.

Keywords

Capacity-based legislation; capacity to consent; autonomy; coercion; community treatment order.

Capacity-based legislation has been introduced in several Western jurisdictions[1] to enable healthcare for people with severe mental illness to comply with the Convention on the Rights of Persons with Disabilities.[2,3] Norway introduced the legislation on 1 September 2017 to enhance patient autonomy and legal protection and reduce the use of coercion, particularly community treatment orders (CTOs).[4]

The Norwegian Mental Health Act now includes a requirement that a patient must clearly lack the capacity to consent, unless there is an imminent risk to the patient's life or the life and health of others (the harm criterion). [5,6] An assessment must be made of the patient's capacity to consent to voluntary admission and treatment. If the patient is considered to lack capacity to consent, involuntary admission and treatment must be implemented, regardless of whether the patient refuses or not.[5] Four factors are emphasised in assessing capacity to consent: (a) the ability to understand information relevant to healthcare decisions, (b) the ability to apply the information to their own situation, especially in relation to their particular mental health problems and possible consequences of different treatment options, (c) the ability to use relevant information to weigh up treatment options and (d) the ability to express a choice.[7–9] When patients have the capacity to consent, they have the right to refuse recommended treatment, but still have the right to receive the healthcare they need.[10] Further, they are entitled to receive personalised information that provides greater insight into their condition and treatment options, which will enable them to be more involved in their own care and treatment.[10]

CTOs have been used in mental healthcare in Norway since 1961.[11] They have been established following involuntary in-patient care when patients are considered to still need compulsory care and treatment, but as out-patients.[5,12] A study from 2016 shows that CTOs were previously justified as ensuring maintenance treatment and preventing relapse,[12] which is no longer possible when patients are considered capable to consent. In 2019, the prevalence rate of CTOs in Norway was 43/100 000 population.[13]

Before the new legislation, health professionals and family carers expressed concern that patients would refuse the treatment and care they needed and were worried about increased use of the harm criterion to justify CTO decisions.[4] However, a study shows that 4 years after the change in the law, incidence rates and duration have not changed significantly, while prevalence rates have declined significantly and the use of the harm criterion has only shown a marginal increase.[13]

Organisation of CTOs and regulations on who may impose them vary between jurisdictions.[14] The CTO regime in Norway is described in Rugkåsa et al[15] and Wergeland et al.[16] Norway has two levels of care: primary and specialist care. The person responsible for treatment, either a psychiatrist or a specialist clinical psychologist, makes CTO decisions under the Mental Health Act 1999.[5] If this person considers medication to be necessary and the patient refuses, a separate decision is required for compulsory medication.[5] Primary care staff are often responsible for implementation and daily care in connection with a CTO; this involves a general practitioner, mental healthcare, home care, staffed or unstaffed housing

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and various low-threshold services.[16] Individuals with severe mental illness often need close monitoring to meet their basic needs and adjust treatment to their condition. The term condition indicates a temporary state of illness or health, and provides information about a patient's physical, mental and cognitive capacity at a specific point in time.[17]

The purpose of this study is to explore health professionals' experiences of how capacity-based legislation affects healthcare provision for patients whose CTO was revoked after being assessed as capable of consent. The research question is: How do health professionals find that the new legislation affects treatment and care of patients whose CTO was revoked?

Method

Design

The study has a qualitative design, using in-depth interviews to explore health professionals' experiences of the significance of capacity-based legislation for care of patients whose CTO has been revoked. The interviews and data analysis were inspired by a dialogical hermeneutic approach described by Fleming et al.[18] This paper is part of a larger study which also explores patients'[16] and family carers' experiences.

Study setting

This study took place in the sparsely populated northernmost region of Norway. Primary (municipal) healthcare includes general practitioners, home nursing and housing. The University Hospital of Northern Norway and Finnmark Hospital Trust provide specialist care in mental health and substance misuse in the region. The region has nine community mental health centres offering specialist care in an in-patient ward and an out-patient clinic. Outreach services are also available. Low population density and vast distances mean that some patients live several hours' drive from the nearest mental health centre and have to fly to the nearest hospital.

Patient and family carer involvement

As part of the larger study, four focus group interviews had been conducted with various groups affected by the change in legislation to gain insight into their expectations and opinions. These interviews were divided into distinct groups to explore participants' opinions on what the change would mean for practice and what they thought the study should investigate. The participants in the four focus groups were divided as follows: Group 1 had personal experience of having been under a CTO and coercion, Group 2 consisted of relatives of former or current CTO patients, Group 3 consisted of specialist care staff with experience of CTO patients, and Group 4 contained primary care staff with experience of CTO patients. The focus group interviews were analysed with the aim of formulating the research questions and preparing interview guides.

At the start of the larger study, a peer group of six persons was also established; some members had been CTO patients, while others had experience as family carers of CTO patients. The peer group made suggestions for the research questions, interview guides and data collection. Owing to the COVID-19 pandemic, this group was not included in the analysis as originally planned.

Recruitment

Participants in the present study were therapists or staff involved in the daily care of patients who had come off a CTO, having been assessed as capable of consent. Recruitment was conducted in a substudy that dealt with patients' experiences of the new legislation;[16] patients were asked whether one of their therapists or care workers could be invited to participate in the study. Ten out of twelve patients agreed to this. Following the patient's consent, the first author (N.C.W.) phoned the person to provide study information and invite the person to participate. All agreed to participate, and no participants later withdrew. COVID-19 prevented the interview of one participant who had agreed to be interviewed.

Participants

Nine health professionals were interviewed in the study – seven women and two men – and the age range was from about 30 to 60 years. Four worked on a daily basis with mental health and substance misuse patients in primary care, either in home care or in sheltered housing. Five were therapists in in-patient or out-patient specialist healthcare. They were qualified as psychiatrists, social workers, healthcare assistants, environmental therapists and nurses with various specialisations. Most had extensive experience of working with people with severe mental illness under a CTO.

Interviews

The first author (N.C.W.) conducted the interviews at the participants' workplaces between September 2019 and March 2020. The 50–90 min interviews were audiotaped and later transcribed and anonymised. After each interview, the interviewer made notes about the interview situation and her perception of the interview.

The interview guide contained three main parts, with different subquestions and keywords. The first part was introductory questions concerning the presentation of the participant and the connection to the patient that was the inclusion criterion for participation. The main part contained questions about the participants' experience of the change in the legislation and its impact on patient treatment, particularly regarding the patient who gave permission for their participation. The last part contained rounding off questions, including how the participants felt about the interview.

Analysis

The empirical data were developed in dialogue between the participants' descriptions of their experiences and the researchers' understandings. A hermeneutically inspired process with repeated movement between the whole and parts was used to analyse the data and enhance understanding.[18] The first author (N.C.W.) became well acquainted with the data by conducting, transcribing and anonymising all the interviews. The interviews were listened to and read based on the research question. Notes on a holistic understanding were written. Each interview was then read with a focus on concepts, sentences and passages, and on viewing these in light of the holistic understanding. Parts that answered or illuminated the research question were marked. We could then challenge and correct the first holistic understandings of the interviews to gain new understanding. Keywords for how the descriptions were understood and ideas, associations and possible themes were noted in the margin. This was repeated several times and the software program NVivo was used to organise the data. The meaning units were coded in NVivo, using the participants' words and phrases as far as possible.[19,20] NVivo mind maps were used for the visualisation of codes and categories.

In a hermeneutically inspired approach, researchers discuss their understandings of the findings and are open to different understandings of participants' statements, which they try out in order to capture possible misunderstandings.[18] Our extensive experience of similar work to that of the participants influenced how we as researchers were involved in interviews, transcriptions,

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analysis and presentation, and formed a sound basis for our understanding,[18,21] since we have experience from clinical work, counselling, advocacy and legal assistance for patients in involuntary mental health treatment and CTOs.

Preliminary findings were sorted and categorised, and then discussed and interpreted by the research team in several rounds. Themes and concepts were tested to determine whether they could be understood differently and whether they were appropriate to the statements or categories, thus challenging our preunderstandings. The first author (N.C.W.) read the interviews several times to ensure that important statements and nuances were not overlooked. Quotes that best represented the themes were selected.

Ethics

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects were assessed by the Regional Ethics Committee (REK Nord), REK No. 2018/1659, and approved by the data protection officer of the University Hospital of North Norway.

All participants received oral and written information about the study. They also received information on voluntary participation and the opportunity to withdraw from the study at any time before the data were included in the analysis, without giving any reason. The participants gave written informed consent to take part in the study. The participants' names and sometimes also their gender have been changed for confidentiality.

The design and recruitment of the study meant that the participants were encouraged to talk about the patient who agreed to their participation. This necessitated a particularly respectful description of the patient.

Presentation of results

The results consist of three main themes: (a) increased awareness of one's responsibility, (b) more frequent assessments of condition and capacity to consent and (c) the need for flexibility and continuity.

In the presentation of the results, participants are divided into two groups of health personnel based on their different duties, overall treatment responsibility or daily care provision.

Results

Increased awareness of one's responsibility

The participants providing daily care were positively surprised that most patients who had come off a CTO did not refuse the necessary healthcare, including medication. With some patients, there was a transition period where collaboration was challenging; these patients made choices that the health personnel disagreed with but had to accept. Anna, who had a patient who had been in involuntary treatment for several decades, put it this way:

> 'We were all very worried! But things actually went very well. And it's still going well. We're very pleasantly surprised. I remember we were very … I thought this won't work, now he'll get ill, now he won't take his medicine. That was our main thought, that he wouldn't take the medication and how could he live in the housing then.'

The participants felt that it was right that patients with severe mental disorders should decide as much as possible about their lives and their treatment. Ina, a therapist, said:

> 'I think it's important to realise that however ill people are, they're masters of their own lives. You shouldn't just come along [as a health professional] and tell them what they need and decide everything for them. It's important for them to decide for themselves as far as possible.'

A few patients refused all healthcare because they perceived the revocation of the CTO as meaning that they no longer needed medication or further care. Two of these patients had a severe relapse and were unable to receive help, which led to a new CTO for them.

All participants found it difficult to collaborate with patients whose severe mental illness sometimes made their symptoms increase and their capacity to consent decrease. Several participants stated that to improve collaboration, patients needed to feel that the treatment was useful and meaningful. Gry, a therapist, mentioned a patient who wanted help, but when she asked for it, she felt that health personnel misunderstood her or did not listen to her. The patient lost confidence in the healthcare services because she did not receive what she asked for, but had to accept treatment she did not agree with. Gry summed up the story as follows:

> 'We have to be useful to people, offer them something meaningful, something they need.'

Detailed documentation requirements introduced with the new legislation were found to raise awareness of what decisions health personnel can make without strong justification. Tim, a therapist, said:

> ' … If you read old medical records, let's say the last 10 to 20 years, then I think, as an oversimplification, it might say: "The patient is ill. In my opinion, he needs medication. A CTO is needed". But today we have to present the pros and cons (whether or not the patient has capacity to consent), what the patient wants, side-effects of medication and so on. The documentation requirements today obviously emphasise autonomy more. We don't treat them in such a patronising way now.'

Although several participants found that the documentation required much more of them, two pointed out the problem that patients receive the same written information on the decision. The decisions are difficult for patients to understand because the documentation requirements mean that the text is quite extensive and couched in legal and medical terminology.

Tim, a therapist, felt that managing involuntary treatment was a difficult task for society; following capacity-based legislation, a change in attitude was needed:

> 'It's important to accept the change and not stick to a "take care of" attitude towards patients.'

Tim added that the shift from deciding what is best for patients to collaborating with them could be challenging for experienced professionals. He thought that the rules could be bent in line with therapists' beliefs and attitudes, which would then colour their assessments.

More frequent assessments of condition and capacity to consent

The participants providing daily care described how they assessed patients' condition and helped them to make constructive choices about their treatment in order to maintain their capacity to consent. Anna systematically adapted daily care to facilitate collaboration. Her patient had lived in municipal housing for several years and had various physical conditions in addition to mental illness. Anna said that this meant that staff sometimes needed to be determined and help the patient to make decisions, regarding for

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example diet, personal hygiene and social skills. She said that the care she provided now was similar to the care she provided during the CTO, because they had known each other for many years:

> ' … he knows me very well. I may be a bit strict, I mean, I look after him properly, but I have such a good relationship with him. I make sure he's ok, like he gets the help he needs and I try to get my colleagues to give him the same care and … '

The staff focused on providing personalised, repeated information to patients about their health, their rights and care and treatment options, to help them make sound choices to improve their health and maintain their capacity to consent.

Several participants found it difficult to determine whether patients understood the difference between compulsory and voluntary treatment. Siri, who provided daily care, mentioned a case where she became unsure of the patient's feelings about the situation:

> 'She really wants to come off the medicine. But if she cuts it out too fast, she gets in such a state that she doesn't know how to live. And we got to a point where I had to intervene and say … her choice was between ending up on a CTO again and deciding to take the medicine after all. That was a critical point and I had to say, look, you've got to change your mind, or things won't be looking good for you! I didn't force her, but I spoke firmly … and I was a bit unsure about how much I could insist without forcing her. But that conversation boosted her trust again, and she listened to my advice. In her case, strong persuasion was needed and it wasn't about me or us wanting to force her to take the medication, but to help her to carry on. Take a bit more medicine now, so you can keep your freedom and your desire to come off it one day.'

Gry, a therapist, said the following about finding a balance between forcing patients and letting them decide for themselves:

> 'It's a delicate balancing act. Especially with clients with bipolar disorder, where it can fluctuate a lot and if we discharge them too soon, they can mess things up for themselves, because I've seen several examples of that, which is very sad. Where they didn't get the care they needed and had to bear all the consequences themselves. It's important to see this from different angles. Even though we should have all respect for this [use of coercion], what we actually inflict on people.'

Gry found it demanding to be in situations where patients did not receive the necessary healthcare because they refused it.

All the therapists found it challenging to assess capacity to consent. The time frame and the assessment situation itself could jeopardise a thorough assessment, especially when the patient's condition could change rapidly. John said:

> 'It's incredibly difficult! I have to try to find out what patients understand about their situation and their illness, and about what it means to consent … capacity to consent doesn't mean that you choose the same treatment as I recommend. … I think it's absolutely awful to have to write a good assessment in a short text, because it's really completely impossible. I think we often use our gut feeling about what's best, but we present all the arguments and write them in our assessments, but we can't really make brilliant assessments in such a short time.'

John described assessments as even more challenging when patients were taking drugs:

> 'The ones who take drugs can often go in and out of capacity to consent and psychosis, and then you really have to change that text. You can't keep assessing every hour, that doesn't work.'

Birgitte, a therapist, was often dependent on clarifying a patient's condition with others who knew the patient well. However, this was not always possible in the limited time available. She explained:

> 'You get a snapshot as a doctor. The patient may seem fine and doesn't need to be admitted to hospital. Then later home care gives you a completely different picture. Some of my patients may pull themselves together when they go to the doctor and they look very nice and proper. But if you're with them for more than 10 or 15 min, you see the delusions starting. These snapshots and capacity to consent don't match up. They should get information from people who know the patient, so that they can assess capacity to consent.'

The need for flexibility and continuity

Both groups of participants pointed out the need for close collaboration between levels of care for patients whose CTO had been revoked. They found that collaboration was satisfactory for some patients. For others, resources were inadequate and they received poor-quality treatment and care. Participants from both groups wanted to be more accessible to patients. They called for more flexible use of health personnel in order to adapt treatment to patients' condition and maintain their capacity to consent. Several mentioned the assertive community treatment (ACT) team, which has members from both primary and specialist care, and provides flexible care that the participants thought was suitable for the target group. Birgitte, a therapist, explained:

> 'Most patients are offered care and treatment, and we [in specialist healthcare] can provide this, but they refuse it. In a busy day, it's easy to feel rejected. But this rejection is linked to paranoia and isolation. But you can also do what the ACT team does, they do a fantastic job. They keep on knocking at the door, maybe eighteen times until they see the curtains move. And the patient gets to know the voice and those are the kind of resources I think … Flexibility and the way they work … that's what I miss so much … I think we could ensure care quality and improve our patients' quality of life.'

The participants were concerned that the vast distances in the region made it difficult to assess and treat patients whose CTO had been terminated. Several of the therapists found that the long distances limited their ability to take an active part in daily care and treatment, and that it was challenging to achieve good collaboration with patients who lived far from the hospital. The distances made it difficult to know whether treatment and care were being followed up in a satisfactory manner, and to know when the CTO should be continued or revoked. Gry felt that the therapeutic relationship was a vital factor in any decision to revoke a CTO:

> 'I think it [a CTO] has been necessary in one phase at least. But I may well have been a bit too afraid to revoke it too soon, I mean, it may have been … perhaps looking back at it, I might have dared to cancel it sooner. But experience is also important here … assuming you've had good collaboration and a good relationship and so on, where both sides could clearly see that the CTO was no longer necessary.'

Discussion

The aim of this study is to explore health professionals' experiences of how capacity-based legislation affects healthcare services for patients whose CTO was revoked after being assessed as capable of consent. The results are discussed in light of the aim of the legislation to strengthen patient autonomy and legal protection, and reduce the use of coercion.

The study shows that health professionals have become more aware of how to ensure patients' right to autonomy and involvement

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in their treatment. This is in line with government expectations and the aim of the legislation.[4] When patients have the capacity to consent, health professionals see that a patient may choose treatment that differs from what is recommended, which they have to respect. They described a more equal dialogue with patients about treatment and care, which is in line with patients' own experience.[16] The participants were very keen, on a professional and personal level, for patients to manage without compulsory treatment, and saw the need for new forms of collaboration to make this possible.

Both groups of health personnel made efforts to achieve close communication with patients. To facilitate participation, they placed greater emphasis on providing patients with personalised information about their condition and treatment options. The more equal relationship resulted in more discussion and negotiation, which meant that the health professionals listened to what patients considered useful. They tried to respond to their wishes by presenting the advantages and disadvantages of different treatment options, while also making recommendations. Patient participation in dialogues about their treatment and care presupposes personalised information, which is mandated by law.[10,22] Shared decision-making is emphasised by the Norwegian Directorate of Health as an important way of helping patients to make informed choices.[23] However, one study finds that shared decision-making can be difficult to apply in practice; it is time-consuming and health professionals are unsure as to whether patients with psychotic disorders can understand information sufficiently well to make informed choices.[24]

Health professionals often find it difficult to balance care and control when treating patients under CTOs.[12] If a patient has come off a CTO but still has a serious mental illness, health professionals try to find flexible ways to help the patient receive the same treatment and care without being too strict or controlling. They try to help patients to retain their autonomy through 'compassionate interference'.[25] Active and committed health professionals who would not leave patients to make their choices alone do not need to threaten autonomy with their interference. They might in fact be helping patients to retain or achieve autonomy. If patients have a firm conviction about their illness or their environment that is completely different from the therapist's understanding, communication and interaction can be challenging.[26] The requirement in capacity-based legislation for increased patient autonomy represents an even greater challenge to health professionals when the patient's capacity to consent fluctuates in line with the illness.

This study shows that more frequent assessments of patients' condition and capacity to consent are needed. Health personnel who provide daily care must handle complex and demanding care work over time. They described how care and treatment were adjusted according to the patient's condition. Because many patients are unable to ask for help when their condition worsens, care workers must monitor their condition and make daily assessments.[27] Close monitoring and continuity are necessary to detect deterioration and intervene before the patient becomes so ill that coercion is needed. This requires close cooperation between health professionals. Interventions often involve negotiations with the patient and require a good relationship, which can be problematic when the patient has experienced coercion.[28]

Therapists responsible for assessing patients' capacity to consent expressed concern about whether the assessments were thorough enough. They found that the assessment situation was often complicated by time pressure, fluctuations in the patient's condition, drug or alcohol addiction and poor knowledge of the patient coupled with lack of contact with someone more familiar with the patient. Previous studies show that therapists have attached great importance to CTOs to improve patients' health, and have therefore maintained the CTO in order to ensure stability and avoid relapse.[12] Capacity-based legislation requires therapists to recognise the patient's right to self-determination and facilitate a more equal dialogue. Since the Mental Health Act 1999 has now established the right of patients to decide on their treatment and daily life,[5] the quality of the assessment of capacity to consent is of vital importance for the patient's legal protection.[29] The assessment is discretionary[30] despite the availability of assessment tools.[7,8]

Patients have a legal right to receive necessary healthcare at both primary and specialist levels.[10] Studies conducted before capacity-based legislation was introduced show that the range of services decreased at both levels when a CTO was revoked.[31,32] The finding in the present study that the daily care provided today is similar to that previously provided to the same patient under a CTO may suggest that the new legislation has led to a change in clinical practice. Based on their experiences following the legislation, both groups of health personnel called for more flexibility in the organisation of staff resources in order to adapt treatment to patient needs in ways that promote autonomy. This is in line with studies that show that lack of resources and flexibility in healthcare can increase the risk of involuntary hospital admission[33] and that there is a need for easy access to healthcare in the early stages of deterioration.[34] In the present study, both groups underlined the importance of maintaining significant relationships and called for frameworks that allow for continued contact with patients even when they need treatment and care from other health service providers for shorter or longer periods.

The study shows that the participants considered it important to be able to offer healthcare on the patient's terms with more flexible working methods across levels of care. However, this presupposes a safe and stable working environment to enable health personnel to maintain their commitment and cope with challenging situations.

Strengths and limitations

The interviews were conducted 24–30 months after capacity-based legislation was introduced. The participants had therefore gained experience of the new scheme, but had not had sufficient time to establish it as a well-tried practice. The interviews were conducted at a time when the change was the subject of much reflection and discussion in both groups of health personnel. This probably enriched the descriptions of experience for the study.

The study had a small number of participants, but they provided different healthcare services and were from urban and rural areas, which gave a variety of descriptions of experience, but from a single region. It is a weakness that no general practitioners participated in the study because they are part of the care team for all patients, and make assessments of capacity to consent.

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Data availability

To protect the anonymity of the participants, the data on which this paper is based will not be made generally available, with the exception of the data that have been carefully selected for presentation in the paper.

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Author contributions

N.C.W. designed the study, recruited participants, conducted the interviews, analysed the interviews, drafted, revised and approved the manuscript. Å.S. analysed the interviews, revised and approved the manuscript. A.K.W. designed the study, revised and approved the manuscript. A.B.O.F. provided legal expertise, revised and approved the manuscript. H.R. designed the study, analysed the interviews, revised and approved the manuscript.

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Declaration of interest

None.

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Paper 3

BMC Psychiatry

RESEARCH

Open Access

Capacity-based legislation in Norway has so far scarcely influenced the daily life and responsibilities of patients' carers: a qualitative study

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Abstract

Background When capacity-based mental health legislation was introduced in Norway in 2017, there was concern about the consequences of change in the law for patients'carer whose community treatment order was revoked as a result of being assessed as having capacity to consent. The concern was that the lack of a community treatment order would increase carers' responsibilities in an already challenging life situation.

The aim of this study is to explore carers' experiences of how their responsibility and daily life were affected after the patient's community treatment order was revoked based on capacity to consent.

Method We conducted individual in-depth interviews from September 2019 to March 2020 with seven carers of patients whose community treatment order was revoked following assessment of capacity to consent, based on the change in the legislation. The transcripts were analysed with inspiration from reflexive thematic analysis.

Results The participants had little knowledge about the amended legislation, and three out of seven did not know about the change at the time of the interview. Their responsibility and daily life were as before, but they felt that the patient was more content, without relating this to the change in the law. They had found that coercion was necessary in certain situations, which made them worry whether the new legislation would make it more difficult to use coercion.

Conclusion The participating carers had little or no knowledge of the change in the law. They were involved in the patient's everyday life as before. The concerns prior to the change about a worse situation for carers had not affected them. On the contrary, they found that their family member was more satisfied with life and the care and treatment provided. This may suggest that the intention of the legislation to reduce coercion and increase autonomy was fulfilled for these patients, without resulting in any significant change in carers' lives and responsibilities.

Keywords Carer, Family-carer, Capacity-based legislation, Coercion, Community treatment order, Patient autonomy, The Norwegian mental health act

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Background

The introduction of capacity-based legislation in mental healthcare in Norway on 1 September 2017, see Table 1, was extensively debated. The new legislation was expected to reduce the number of Community treatment orders (CTOs) [3], because compulsory maintenance treatment for patients with severe mental illness could not now be continued if they had capacity to consent [1, 3]. Previous studies have shown that carers found that CTOs provided stability for both patient and family, ensuring follow-up treatment from healthcare services [8, 9].

When the new legislation was introduced, carer associations and healthcare personnel were concerned about possible consequences for patients and carers [3, 10–13]. Without a CTO, the concern was that patients would refuse treatment and follow-up care, or any healthcare services. During initial work on the legislation and in the media, fears emerged that patients would deteriorate and that carers' responsibilities would increase in an already challenging situation [3, 10–13]. However, carer associations supported the new legislation because they believed that a reduction in coercion was necessary, but they also pointed out that for the legislation to work as intended, more flexible healthcare for patients and separate support for carers were necessary [13].

Carers of people with co-occurring severe mental illness and substance abuse are not a uniform group. Under Norwegian law, the person designated by the patient as the "closest carer" is entitled to receive specific information about the patient's condition and health care if the patient consents to this [14]. When the patient is unable to decide on the closest carer, the person with the most stable contact with the patient will receive these rights [14]. If the patient lacks capacity to consent, the closest carer is entitled to be involved with the patient in treatment decisions and to receive the same information about the patient's condition as the patient, unless otherwise determined [7].

The Mental Health Action Plan 2013–2020 of the World Health Organization calls for increased cooperation with carers [15], and several nations have made efforts to strengthen carers' position and rights through health policy guidelines [16]. Studies show that family involvement can have positive effects for patients, clinicians and carers [16, 17]. However, studies from several Western countries show that carers are still little involved in collaboration [18, 19] they do not often have the opportunity to share important information and receive scant support from the healthcare system to handle their responsibilities [8, 16, 20–22].

No studies on carers' experiences of the introduction of capacity-based legislation have been published in Norway. The aim of this study is to explore carers' experiences following the revocation of a patient's CTO based on capacity to consent.

Method

Design

This study has a qualitative design using in-depth interviews to explore carers' experiences following the introduction of capacity-based mental health legislation. It is sub-study three in a larger study that examined the experiences of patients [23] and healthcare personnel [24] with the change in the legislation. The research question of the present study is *What are the experiences of patients' carers following the change in the legislation and how has the change affected their daily life and perceived responsibility as carers?*

The participants in the various sub-studies formed triads, where patients in the first sub-study chose which relatives would be invited to participate in the present study. The study was conducted in the northernmost health region of Norway.

Carer's involvement

When preparing the project proposal, three members of the research team (NCW, AW and HR) conducted four focus group interviews to gain insight into different

Table 1 Capacity-based legislation in Norway

Capacity-based legislation in Norway
Capacity-based legislation was introduced on 1 September 2017 as an amendment to the Norwegian Mental Health Act [1] in order to strengthen patient autonomy in accordance with the United Nations Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities [2, 3]. Several European countries and Australia have also introduced various forms of capacity-based legislation [3–5]. The change in the law represents a shift from decisions to use coercion based on diagnosis to a focus on the patient's autonomy, i.e. a capacity-based criterion [3, 5, 6]. A new condition in Section 3–3 of the Mental Health Act §3–3 [1] is: The patient lacks capacity to consent, cf. the Patient Rights Act §4–3 [7], which states that capacity to consent may be partly or wholly invalidated if the patient, due to a physical or mental disorder, dementia or an intellectual disability, is clearly unable to understand what the consent implies. The new condition shall not apply in cases of imminent and serious danger to the patient's own life or the life or health of others [1]. A decision to use coercion is based on a clinical assessment; the patient's capacity to consent is assessed by the patient's therapist, who must be a psychiatrist or specialist clinical psychologist [1]. Decisions on the use of coercion can be reviewed by a control commission, and the commission's decision may be submitted for judicial review [1].

perspectives, expectations and opinions about the change in the law. One of the focus groups consisted of carers of patients who were or had been under a CTO. The participants were asked what they thought was important to explore in the study, with the aim of including their views in the design of the research questions and the interview guide.

At the beginning of the study, a peer group was established; of the six members, three had experience as carers of a patient under a CTO. In the first two meetings, we discussed the implementation of the study; the members made suggestions on recruitment, conducting interviews and the interview guide. Two members of the group participated in the analysis.

Recruitment

Inclusion criteria for the participants was: Carers of patients with severe mental illness whose CTO was revoked following assessment of capacity to consent when capacity-based legislation was introduced in 2017. Ten of the patients who participated in the first sub-study [23] gave consent for one of their carers to be interviewed in the present study. Nine of these carers were contacted by telephone by the interviewer (NCW), given information about the study and recruitment, and invited to participate. The tenth carer could not be invited and two interviews that had been agreed on could not be conducted due to COVID-19 and the long time of "shutdown" in Norway. All those invited agreed to participate and were sent written information and a consent form by e-mail. None withdrew from the study.

Participants

Seven participants were interviewed in this study; they were all carers of patients with severe mental illness, and in two cases concurrent substance abuse. All participants had been in a close relationship with the patient for a long time, four as parents and three as partners or in another close relationship. Most lived near the patient, one lived with the patient, while one lived fare away. They were in the age group 40–70 years, two of the seven were men, while two were retired and five were in full-time employment.

Interviews

Interviews took place in a hospital, a hotel, and the participants' home or workplace from September 2019 to March 2020, i.e. at least 2 years since the change in the law. They lasted from 60 to 90 minutes and were audio recorded and subsequently transcribed and anonymized. The first author conducted all the interviews and after each interview made notes about her experience of the interview and the context.

The interview guide consisted of three main parts with questions and cues. The introductory questions dealt with the presentation of the participant, relationship to the patient and the illness trajectory. In the main part of the guide, participants were asked about their knowledge and experience of the change in the law and its significance for the patient's treatment and follow-up care. They were also asked about any changes to their lives and their cooperation with the patient and clinicians after the CTO was revoked. The last part of the interview guide contained rounding off questions and questions about how they felt about being interviewed.

Analysis

The approach is hermeneutically inspired. This implies that the data were generated in a dialogue between the participants' narratives and the researchers' understandings [25, 26]. The analysis of the interview data was also inspired by reflexive thematic analysis as developed by Braun and Clarke [27, 28]. The fact that this is the third part of the larger study was of vital importance to the research team's reflections on the participants' narratives during the analysis. The knowledge gained from the first two sub-studies on experiences of patients and healthcare personnel was included in much of the interviews and in the data analysis and interpretation in this study.

The first phase of analysis as described by Braun and Clarke [28] consists of the researcher's familiarization with the data. The first author conducted all the interviews, participated in parts of the transcription and listened to the audio recordings several times. When reading the interviews, she focused on each one as a whole, aiming to gain insight into the main issues for the participants. She noted ideas, comments and questions to the data in the margins while reading. This was also done in the next reading, where the focus was on individual statements or passages, and how these could be understood in the light of an overall understanding. A number of statements were highlighted. Reflections were written down on how the statements were understood and associations with other participants' statements, in addition to brief notes on what the first author felt was the essence of the participants' narratives.

Once the first author was well acquainted with the data, the second phase of coding commenced [28]. The NVivo software was used for the coding. The statements coded were those that could provide insight into the participants' life situation, daily life and history with the patient, as well as those that more directly answered the research question. The coding was thus not clearly defined by the research question, but included e.g. the onset of the illness in order to enhance understanding of the duration and progression of the role of the carers.

Coding took place in several rounds in order to find precise labels for the codes. It was also necessary to adjust the content of the codes when they were too general, too narrow or too specific. Several attempts were made to sort the codes into groups that seemed to contain related elements. Braun and Clarke [28] point out that preliminary ideas for themes should be kept open to make room for new ideas. However, one theme (little or no knowledge of the change in the law) took shape at an early stage through various codes that nuanced the content such as *not knowing about* and *lacking information*. Preliminary ideas for themes and overviews of codes were presented to the other researchers in the team and later to two of the members of peer group to provide a broader basis for reflections and understandings of the data. In the third phase, the preliminary themes and code groups were visualized in an NVivo map to provide an overview and to assist in finding patterns and meaning across the interviews. Some of the preliminary themes did not answer the research question and some were merged.

Phase three merged with phase four, as they both consisted of developing themes. Three of the resulting themes passed the quality test in Braun and Clarke's fifth phase [28], which showed that the themes were clear, well defined and unique, and contributed to the study's overall analysis related to the research question. The names of the themes were changed a number of times even after the results section had been written and the writing of the discussion had started in an attempt to find suitable, precise and informative names. The final themes were as follows: 1) little or no knowledge of the change in the law, 2) responsibility, cooperation and daily life are unchanged, and 3) coercion is felt to be necessary.

Ethics

This study was assessed by the Northern Norway Regional Ethics Committee (REK Nord), REK No. 2018/1659, and approved by the data protection officer of the University Hospital of North Norway.

All participants received oral and written information about the study. They were also informed about voluntary participation and the possibility to withdraw from the study at any time before the data were included in the analysis, without giving any reason.

The participants were given pseudonyms and their gender and characteristics may have been changed for the purpose of anonymization without any effect on the content of the study.

The interview topics may have been difficult to talk about. The participants were asked to talk about their family member's often long and challenging illness, which meant a difficult situation for the whole family. Several of the participants were fatigued and some may have agreed to participate because they felt obliged to do so. The interview may have been perceived as intrusive and was therefore conducted with consideration and empathy. The interviewer provided a safe space for the participants to talk about their experiences of responsibility. Several started by saying that they maybe should have come better prepared to the interview. They were assured that good preparation was not relevant to the purpose of the interview, and that they should only talk about what they wanted to share. However, several found it difficult to talk about their challenging life situation and memories they had tried to forget. Some cried, but were pleased to be able to talk about their experiences and to contribute to research.

Results

The results presented below must be seen in the light of the participants' challenging life situation.

The participants said that having a close family member with a severe mental illness who had been under a CTO had been very demanding and had affected the daily life of the entire family. They constantly worried about the patient and what the future would bring. Heidi put it this way:

> *"It's a really really big role being Simon's mother. I haven't had a holiday for many, many years, I'm so afraid of being away from him if something happens to him."*

Heidi and Berit had mostly had sole responsibility for their sick children. Berit said that she was in a new and less demanding phase as a carer at the time of the interview, but described her responsibility over many years as follows:

> *"Well, it hasn't exactly been a walk in the park, I can tell you. But I've kept going. I've coped, but it's been pretty tough at times. To be a mother in this situation."*

Little or no knowledge of the change in the law

The participants had limited or no knowledge of the change in the legislation at the time of the interview. Three of them said that healthcare personnel had spoken to them about the change. They were not sure about who had informed them, but thought it was the patient's therapist or the staff who provided daily care. Several had been told that the patient's CTO had ended, but did not realize that it was due to a change in the law. Two of the participants had heard about the change on television or radio. Berit explained:

> *"I love watching TV and it was on the news about*

the new law that had come."

The two remaining participants were not aware of the change at the time of the interview, and when asked if she had received information about it, Ella replied:

"No, this is the first time I've heard about it (in the interview)."

Several participants were surprised that the patient's CTO had been revoked because they had not noticed any improvement in the patient's condition or functioning. They had not understood that the patient had been assessed as having capacity to consent and could therefore no longer be under a CTO. Before the CTO was revoked, two participants had been asked if they agreed, which they both did. However, one of them felt that her daughter's CTO should have been revoked at a much earlier stage.

Berit felt that her daughter was happier and trusted her therapists more over the past 2 years. She had thought that these changes were because her daughter had gained more experience with the disorder and had accepted the need for treatment. Berit had heard about the change in the law on the TV news, but had not thought that the new legislation and greater autonomy could be linked to her daughter's increased satisfaction until during the interview. When we talked about the change, Berit reasoned as follows:

"I haven't thought about it. But it might be because of that (the change in the law)… that she trusts the therapists much more now. Perhaps it's the change in the law, she's felt like she has more influence, she's got the right to decide her own treatment and her own life in all this. It could be. I hadn't thought much about that until you… But it may well be true. Because she's much happier and well, all in all…."

Two other participants also said that their children were more satisfied with the treatment they had received in the past 2 years since the CTO was revoked.

Responsibility, cooperation and daily life are unchanged

The treatment and care provided by primary healthcare services were much the same as before the CTO was revoked. All patients received medication treatment, two had outpatient treatment and most received daily follow-up care. Two of the participants were surprised that their family member accepted the same treatment and care as under the CTO. Five of the participants' family members accepted the treatment and care voluntarily, while two were under a new CTO at the time of the interview. The participants said that they found it necessary to take the same responsibility for the patient as before.

Several participants stated that their burden of responsibility varied according to the patient's condition and their perception of how well the healthcare services were functioning. As an example of their responsibilities, several participants found it necessary to clear out rubbish and used needles from their child's room or make sure that he or she took a shower more often. The participants' perception of the commitment, competence and continuity of the healthcare staff determined how much responsibility they needed to take. Heidi, whose son lived in staffed housing, felt that many staff could be better at communicating with residents in order to provide help. She said:

"He's supposed to get the help he needs to tidy up his room in housing with 24-hour staffing, but I can see he's not getting it. He's been given over 30 hours a week by the social services, they should help him to tidy up and... but there's quite a big conflict between me and this housing. I've told them, 'You're not doing your job', and they say, 'But he doesn't want to'… So I say, 'Well, how do you ask him then?', and then I say, 'If you get to know Per properly, you can ask him in a way that makes him say yes.' And it's also about building relationships... if he gets a good relationship with someone there, it's often with people who disappear again."

However, four participants reported that both they and the patient thought that healthcare services had improved, but this was against a background of many years of different kinds of treatment from the hospital, the mental health centre and primary health care within a CTO framework. Despite this, the participants were unable to link these experiences to the change in the law. Evy said:

"Now I feel that the system around him is working. So that... I can sort of just be his mother and I don't have to be a kind of helper as well."

One participant felt that the care provided was still inadequate; there was a large turnover of staff in the housing and a reduction in the hours allotted to care after the CTO was revoked.

Coercion is felt to be necessary

Three of the participants who were sceptical of the change in the law when they heard about it were now worried about whether it would be more difficult to intervene using coercion if necessary. Heidi, whose son was under a CTO at the time of the interview, felt that it was right to terminate the CTO for her son when the law was changed. She wanted her son to have the chance to take on more responsibility when he was able to.

However, she had also felt that a CTO was a necessary framework for treatment and follow-up care that would improve the lives of both patient and family. She said:

> *"I think in relation to... well, you know, there are all these admissions and there's much less of that since he was put on a CTO and getting involuntary medication... When he's on a CTO and he's medicated, things are more stable for all of us."*

Several participants found that a CTO had led to a stable situation for themselves and their family member. They pointed out that a CTO prevented the sudden discontinuation of medication, and reduced admissions to hospital and the unpleasant situations that involuntary admission often involved.

All the participants felt that coercion was necessary to ensure adequate help in certain conditions and situations. They had experience of situations where it was necessary to use force to intervene to prevent serious consequences for the patient and the family as a whole, especially in the early stages of the illness. The participants described living in great uncertainty at times, and several had been threatened by the patient while they were waiting for help to arrive. In such situations, the CTO reassured them that their family member had easier access to treatment from a specialist at the hospital.

One participant, Thomas, was sceptical when the CTO was revoked, because he felt that his relative had limited insight into his illness, and was incapable of taking responsibility for his own health and accepting help. When in fact things turned out well, Thomas suggested two reasons for this. Firstly, his relative had a safe and stable environment in which he received the same healthcare as before from competent professionals. Thomas put it like this:

> *"I'd say he's doing fine now.... as soon as his world is unstable, either he gets less medication, or things change... well, then he gets worse and more unstable again. But as long as he knows what's going to happen every day, he functions very well. As long as he has a secure framework, and he gets to keep Anna (as his primary contact), I think that's really important for him to feel ok, she knows him very well and handles him incredibly well, it's good to see."*

Secondly, Thomas thought that his realtive was easier to help now that he had grown older with a weaker body and reduced health as a result of his illness and long-term use of psychotropic medications.

The participants expressed a need for a safe and stable situation for the patient and themselves, but they were also interested in voluntary care and treatment when the patient's condition allowed it.

Discussion

This study explores carers' experiences of how the introduction of new legislation on lack of capacity to consent regarding the use of coercion affected their lives and responsibilities as carers. The results show that the participants' responsibilities and daily life had not changed significantly, but they found that the patient's condition had improved. The participants had little or no knowledge of the change in the law and its significance. They wished to point out that coercion had been necessary in certain situations.

The significance of the change in the law

The participants had varying knowledge of the CTO scheme, even though their family member had previously been under a CTO for a long time. Their poor knowledge of the change in the law suggests that they did not know much about the Mental Health Act either before or after the change. Stensrud [9] found in his study that carers of patients under a CTO focused on practical everyday life and effects of the treatment, and were less concerned about coercion. The particular legal terminology and logic made the change difficult to understand, and it may well be natural for carers to feel that the legal aspects are the responsibility of the healthcare services. Carers' lack of awareness of the change in the law may have been due to the prolonged and complex burden of being close relatives of a patient with severe mental illness, making their lives difficult and leaving them exhausted. Several other carers' stories in the Norwegian media [10, 11, 29] and in research [22, 30] confirm the participants' narratives about their burden of responsibility. Having a family member with severe mental illness leaves little energy to study legislation.

Healthcare personnel are responsible for providing advice and information to carers in a clear and comprehensible form [14]. It was probably difficult for clinicians to provide clear information to carers, given the uncertainty in the period following the new law as to how it should be interpreted and practised [24]. However, several studies have shown that poor information, training and involvement of carers are not unusual [17–19, 30]. Healthcare services often lack adequate procedures for the involvement of family members, and leave such work to the personal initiative and competence of individual health workers [17, 20, 30]. This is despite the fact that studies show that involving and supporting carers has a positive effect on treatment quality [17], can reduce the risk of relapse [31–34] and can improve carers' own health [35, 36].

The new legislation had changed little in the lives of the participants. They had continued their engagement and great responsibility in the life of their family member.

The participants found that the patient was more stable with well-established healthcare services at the time of the interview, unlike the first years of the illness. Nevertheless, they still worried about their family member's future. The participants had previously felt a need for more continuity and competence among healthcare providers because of the event of changes in the patient's condition and need of a reassured living situation. Some of them had experienced reduced healthcare services and that it became more difficult to admit the patient to hospital, without the framework of a CTO. A decrease in help from the healthcare system after a CTO has ended has been confirmed in other studies [8, 9], and this may have made the participants worry that the change in the law would make the threshold for coercion too high if the patient's condition deteriorated. One study found that healthcare personnel believe that CTOs makes a difference for patients' rights and facilitate adequate care provision [37].

In contrast to this, studies of the experiences of patients and clinicians with the change in the law and termination of a CTO show that patients were offered and accepted the same healthcare services [23], and that healthcare staff to a greater extent than previously adapted treatment and care to the patient's preferences with a focus on the patient maintaining or regaining autonomy [24]. The amendment to the Mental Health Act still allows for involuntary treatment when patients lack capacity to consent and to receive necessary healthcare, or when patients are considered to represent a risk to their own life or the life and health of others [1].

The concerns expressed prior to the change in the law about a worse situation for relatives had not affected the participants in this study at the time of the interview. Most of them, on the contrary, had found that their family member seemed to be more satisfied with life and healthcare services. This suggests that the aim of the legislation to reduce coercion and increase autonomy was fulfilled for the patients, but without significantly changing the carers' daily life and responsibilities.

Our findings support there is a need for more studies on implementation of research on family involvement for patients with severe mental illness to prevent and reduce use of coercion. There is a lot of knowledge which we need to put to use to improve family involvement practices.

Strengths and weaknesses

This study forms part of a larger study in which we explore experiences from different perspectives in connection with the assessment of patients as capable to consent leading to the revocation of CTOs [23, 24]. This design gave us a variety of perspectives on the same treatment path and on the change in the law. The interviews and analyses in the present study were influenced by the research team's experience from the first and second parts of the larger study. This experience has expanded our understanding and enabled us to see connections and coherence in a way that would have been impossible without a triad design. At the same time this required us to be aware of the influence the knowledge from sub-studies one and two possible had on our preconception. We have listened to and read the participants statements carefully in this third sub-study, with an aim to let them present themselves and to perceive their stories and their versions of the situation.

The interviews were conducted in 2019 and 2020. At that time, the participants had limited knowledge of the change in the law and the results might have been different if the new legislation had been implemented for several years. Feedback from carers in the peer group suggests that it took time to understand the significance of the content of the amended legislation.

This study had a limited number of participants. A greater number would probably have enhanced the diversity of the study. A further three interviews were planned but had to be cancelled due to the ongoing COVID-19 pandemic. The study was conducted in a limited geographical area where one hospital is responsible for all involuntary mental health care, which may mean that the findings are influenced by local practice.

Conclusion

The study participants were carers of patients with severe mental illness whose CTO was revoked following assessment of capacity to consent when capacity-based legislation was introduced in 2017. They had little or no knowledge of the change in the law at the time of the interview. We found that only a minority had heard of the change, and that these had little understanding of its significance. A further finding was that the change in the law had no great influence on relatives' responsibilities. The participants were just as involved in the life of their family member and their daily life was little changed. At the same time, several participants found that the patient was more satisfied and independent, but did not relate this to the legislation. Based on their experience of the patient's severe mental illness and fluctuating condition, the participants felt that coercive intervention could be necessary in certain situations, and were therefore worried that the change in the law would make this more difficult to implement.

Abbreviation

CTO Community treatment order

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Authors' contributions
NCW designed the study, recruited participants, conducted the interviews, analysed the interviews, and drafted, revised and approved the manuscript. ÅF analysed the interviews, and revised and approved the manuscript, AKW designed the study, recruited participants, and revised and approved the manuscript. ABOF provided legal expertise, and revised and approved the manuscript. HR designed the study, recruited participants, analysed the interviews, and revised and approved the manuscript.

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Availability of data and materials
The datasets generated and analysed during the current study are not publicly available in order to protect the anonymity of the participants, but are available from corresponding author on reasonable request.

Declarations

Ethics approval and concent to participate
All methods were conducted in accordance with the relevant guidelines and regulations. The study has been assessed by the Northern Norway Regional Ethics Committee (REK Nord No.2018/1659) and they rated the study to be health service research meaning it should not be approved by the Ethics Committee. The data protection officer responsible for assessing research projects at the University Hospital of North Norway did the assessment and approved the study, considering safeguarding of anonymity for participants and the empirical data. The participants gave written informed consent to take part in the study. Participation in the interviews was voluntary.

Consent to publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

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Publisher's Note

Appendix 1-8

UNIVERSITETSSYKEHUSET NORD-NORGE
DAVVI-NORGGA UNIVERSITEHTABUOHCCEVIESSU

PSYKISK HELSE- OG RUSKLINIKKEN
PSYKALAŠ DEARVVAŠVUOĐA- JA GÁRRENKLINIHKKA

Forespørsel og informasjon om deltakelse i fokusgruppe til studien

Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017

Innledning

Dette er en forespørsel til deg i forbindelse med en forskningsstudie om tvunget psykisk helsevern uten døgnopphold (TUD) og endringen i psykisk helsevernloven som trådet i kraft 1 september 2017. I studien skal vi intervjue pasienter som har fått opphevet vedtak om TUD, pasientens pårørende og helsepersonell.

Vi ønsker å spørre deg om du vil delta i en fokusgruppe for å diskutere og kvalitetssikre hvordan innholdet i disse intervjuene (intervjuguidene) skal være. I tillegg vil en til to av dere bli spurt i etterkant om å være med i en pilotundersøkelse hvor intervjuguiden blir testet. Hensikten med pilotundersøkelsen er at vi gjennomfører et prøveintervju for å se hvordan intervjuguiden fungerer. Dette gir oss mulighet til å justere intervjuguiden ytterligere. Det kan også bli aktuelt å publisere resultatene fra fokusgruppen i form av vitenskapelige artikkel.

Bakgrunnen og formålet med studien

Den 1 september 2017 innførte Norge manglende samtykke som selvstendig vilkår for å kunne bruke tvang i psykisk helsevern. Dette betyr at pasienter med alvorlig psykisk lidelse selv kan bestemme om de vil ta imot behandling dersom de er samtykkekompetent. Unntaket fra vilkåret om manglende samtykkekompetanse er dersom pasienten er til fare for eget liv, eller andres liv eller helse. Dette er en overgang til en kompetansemodell, hvor en går bort fra fokus på diagnose, til fokus på funksjon. Det er uttalt at en mulig ulempe kan være at pasienter med stort hjelpebehov kan unndra seg helsehjelp, med økt helsemessig og sosial belastning for pasienten selv og deres pårørende. Tvunget psykisk helsevern uten døgnopphold (TUD) vil si at pasienten er underlagt tvang, men bor hjemme. Pasienter under TUD kan påtvinges oppfølging og behandling som de helt eller delvis ikke ønsker, og formålet er ofte å opprettholde eller bedre pasientens funksjonsnivå.

Innføringen av manglende samtykke som selvstendig vilkår for å bruke tvang gir ikke lenger mulighet for å vedlikeholdsbehandle pasienter under tvang i psykisk helsevern, og endringen antas å være særlig aktuell for å redusere bruk av tvang overfor pasienter under TUD. Helsepersonell og kontrollkommisjoner rapporterer at et stort antall pasienter får opphevet vedtak om TUD som følge av lovendringen.

Formålet med studien er å få kunnskap om hvordan pasienter som har erfaring med TUD opplever at lovendringen har påvirket deres liv, og hvordan deres pårørende og helsepersonell erfarer lovendringen. Ved å ta utgangspunkt i pasienter som fikk opphevet vedtak om TUD, vil studien fokusere på erfaringer og forandringer som følge av opphevet vedtak, og hvordan deres dagligliv påvirkes.

Organisering av fokusgruppeintervju

Et fokusgruppeintervju er et gruppeintervju og vil i dette tilfellet bli ledet av to til tre personer. Fokusgruppen vil bestå av 4-6 deltakere, og alle er helsepersonell som jobber i spesialist- eller kommunehelsetjenesten. Gjennom gruppediskusjon ønsker vi at dere skal utveksle meninger om hva som er av betydning å spørre pasienter, pårørende og helsepersonell i studiens intervjuer. Meninger og synspunkter som kommer fram i diskusjonen vil bidra til at intervjuguidene i studien blir mer relevant. Dette er en viktig del i forskningsprosjektet for å kvalitetssikre spørsmålene som skal brukes under intervjuene. Vi vil på forhånd ha formulert noen spørsmål, men ønsker og at dere skal komme med egne tema som er viktige.

Mulige fordeler og ulemper med å delta

Mulige fordeler med å delta i fokusgruppen er at du vil kunne bidra til å øke kunnskapen om forhold som vedrører TUD og hvordan lovendringen som gjør at bare pasienter som ikke er samtykkekompetant kan underlegges tvang erfares. Det er ikke gjort noen studier i Norge om hvordan lovendringen erfares, og vi ønsker å få kunnskap om hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i fokusgruppen.

Personvern

Et grunnprinsipp ved all forskning av denne typen er at du som er deltakerne har krav på at det som blir sagt ikke skal gjengis slik at det er mulig å vite hvem som har sagt det. Dette vil si at all informasjon som fremkommer i fokusgruppen vil bli behandlet konfidensielt. Det betyr at alt du sier er fortrolig og det vil ikke bli brakt opplysninger videre til andre som kan knyttes til deg. I gruppen vil det være en gjensidig taushetsplikt som gjør at dere ikke kan snakke om hva andre i fokusgruppen har sagt. Det vil ikke bli registrert navn eller andre personlige kjennetegn om deg som deltaker i fokusgruppen. Personene som leder fokusgruppen har lovpålagt taushetsplikt. All informasjon vil bli slettet når studien er fullført.

Hva skjer med informasjonen fra fokusgruppen?

Hensikten med fokusgruppen er å utvikle intervjuguider til studien, men det kan også bli aktuelt å publisere resultatene fra fokusgruppen i form av vitenskapelig artikkel. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dere som har deltatt i fokusgruppen. Som deltaker vil du få tilsendt artiklene dersom du ønsker dette.

Organisering
Fokusgruppen vil vare rundt 1- 2 timer alt etter hvor mye gruppen har å formidle og vil bli tatt opp på lydbånd. Lydbåndet vil bli slettet når studien avsluttes. Fokusgruppen vil bli ledet av forsker Nina Camilla Wergeland, erfaringskonsulent Astrid Weber og prosjektleder Henriette Riley.

Frivillig deltakelse
Det er frivillig å delta i fokusgruppen. Du kan når som helst og uten å oppgi noen grunn trekke deg fra å delta. Dersom du under fokusgruppen ønsker å trekke deg fra deltakelse kan du forlate gruppen uten at du trenger å oppgi noen grunn.

Om du har spørsmål til studien, kan du kontakte forsker Nina Camilla Wergeland telefon 97046263, Erfaringskonsulent Astrid Weber telefon 99505831 eller prosjektleder Henriette Riley telefon 94327012.

Samtykkeerklæring

Jeg er blitt informert om hva deltakelse i en fokusgruppe knyttet til studien *Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017,* innebærer, og samtykker med dette til å delta i fokusgruppen.

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Økonomi
Som deltaker i fokusgruppeintervjuet vil du bli honorert etter gjeldende sats i Helse Nord og underliggende organer for honorering av brukere.

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Vi ønsker å spørre deg om du vil delta i en fokusgruppe for å diskutere og kvalitetssikre hvordan innholdet i disse intervjuene (intervjuguidene) skal være. I tillegg vil en til to av dere bli spurt i etterkant om å være med i en pilotundersøkelse hvor intervjuguiden blir testet. Hensikten med pilotundersøkelsen er at vi gjennomfører et prøveintervju for å se hvordan intervjuguiden fungerer. Dette gir oss mulighet til å justere intervjuguiden ytterligere. Det kan også bli aktuelt å publisere resultatene fra fokusgruppen i form av vitenskapelige artikkel.

Bakgrunnen og formålet med studien

Den 1 september 2017 innførte Norge manglende samtykke som selvstendig vilkår for å kunne bruke tvang i psykisk helsevern. Dette betyr at pasienter med alvorlig psykisk lidelse selv kan bestemme om de vil ta imot behandling dersom de er samtykkekompetent. Unntaket fra vilkåret om manglende samtykkekompetanse er dersom pasienten er til fare for eget liv, eller andres liv eller helse. Dette er en overgang til en kompetansemodell, hvor en går bort fra fokus på diagnose, til fokus på funksjon. Det er en mulig ulempe at pasienter med stort hjelpebehov kan motsette seg helsehjelp, med økt helsemessig og sosial belastning for pasienten selv og deres pårørende. Tvunget psykisk helsevern uten døgnopphold (TUD) vil si at pasienten er underlagt tvang, men bor hjemme. Pasienter under TUD kan påtvinges oppfølging og behandling som de helt eller delvis ikke ønsker, og formålet med ordningen er ofte å opprettholde eller bedre pasientens funksjonsnivå.

Innføringen av manglende samtykke som selvstendig vilkår for å bruke tvang gir ikke lenger mulighet for å vedlikeholdsbehandle pasienter under tvang i psykisk helsevern, og endringen antas å være særlig aktuell for å redusere bruk av tvang overfor pasienter under TUD. Helsepersonell og kontrollkommisjoner rapporterer at et stort antall pasienter får opphevet vedtak om TUD som følge av lovendringen.

Formålet med studien er å få kunnskap om hvordan pasienter som har erfaring med TUD opplever at lovendringen har påvirket deres liv, og hvordan deres pårørende og helsepersonell erfarer lovendringen. Ved å ta utgangspunkt i pasienter som fikk opphevet vedtak om TUD, vil studien fokusere på erfaringer og forandringer som følge av opphevet vedtak, og hvordan deres dagligliv påvirkes.

Organisering av fokusgruppeintervju

Et fokusgruppeintervju er et gruppeintervju og vil i dette tilfellet bli ledet tre personer, og det vil være 4-6 deltakere. De andre deltakerne i fokusgruppen vil også ha egenerfaring som pasient i psykisk helsevern. Gjennom gruppediskusjon ønsker vi at dere skal utveksle erfaringer og meninger om hva som er av betydning å spørre pasienter, pårørende og helsepersonell i studiens intervjuer. Meninger og synspunkter som kommer fram i diskusjonen vil bidra til at intervjuguidene i studien blir mer relevant. Dette er en viktig del i forskningsprosjektet for å kvalitetssikre spørsmålene som skal brukes under intervjuene. Vi vil på forhånd ha formulert noen spørsmål, men ønsker og at dere skal komme med egne tema som er viktige.

Mulige fordeler og ulemper med å delta

Mulige fordeler med å delta i fokusgruppen er at du vil kunne bidra til å øke kunnskapen om forhold som handler om TUD og hvordan lovendringen som gjør at bare pasienter som ikke er samtykkekompetant kan underlegges tvang erfares. Det er ikke gjort noen studier i Norge om hvordan lovendringen erfares, og vi ønsker å få kunnskap om hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i fokusgruppen.

Personvern

Et grunnprinsipp ved all forskning av denne typen er at du som er deltaker har krav på at det som blir sagt ikke skal gjengis slik at det er mulig å vite hvem som har sagt det. Dette vil si at all informasjon som fremkommer i fokusgruppen vil bli behandlet konfidensielt. Det betyr at alt du sier er fortrolig og det vil ikke bli brakt opplysninger videre til andre som kan knyttes til deg. I gruppen vil det være en gjensidig taushetsplikt som gjør at dere ikke kan snakke om hva andre i fokusgruppen har sagt. Det vil ikke bli registrert navn eller andre personlige kjennetegn om deg som deltaker i fokusgruppen. Personene som leder fokusgruppen har lovpålagt taushetsplikt.

Hva skjer med informasjonen fra fokusgruppen?

Hensikten med fokusgruppen er å utvikle intervjuguider til studien, men det kan også bli aktuelt å publisere resultatene fra fokusgruppen i form av vitenskapelig artikkel. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dere som har deltatt i fokusgruppen. Som deltaker vil du få tilsendt artiklene dersom du ønsker dette.

Organisering
Fokusgruppen vil vare rundt 1- 2 timer alt etter hvor mye gruppen har å formidle og vil bli tatt opp på lydbånd. Lydbåndet vil bli slettet når studien avsluttes. Fokusgruppen vil bli ledet av forsker Nina Camilla Wergeland, erfaringskonsulent Astrid Weber og prosjektleder Henriette Riley.

Økonomi
Som deltaker i fokusgruppeintervjuet vil du bli honorert etter gjeldende sats i Helse Nord og underliggende organer for honorering av brukere.

Frivillig deltakelse
Det er frivillig å delta i fokusgruppen. Du kan når som helst og uten å oppgi noen grunn trekke deg fra å delta. Dersom du under fokusgruppen ønsker å trekke deg fra deltakelse kan du forlate gruppen uten at du trenger å oppgi noen grunn.

Om du har spørsmål til studien, kan du kontakte forsker Nina Camilla Wergeland telefon 97046263, Erfaringskonsulent Astrid Weber telefon 99505831 eller prosjektleder Henriette Riley telefon 94327012.

Samtykkeerklæring

Jeg er blitt informert om hva deltakelse i en fokusgruppe knyttet til studien *Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017,* innebærer, og samtykker med dette til å delta i fokusgruppen.

Dato: **Underskrift:**

UNIVERSITETSSYKEHUSET NORD-NORGE
DAVVI-NORGGA UNIVERSITEHTABUOHCCEVIESSU
PSYKISK HELSE- OG RUSKLINIKKEN
PSYKALAŠ DEARVVAŠVUOĐA- JA GÁRRENKLINIHKKA

UNIVERSITETET I TROMSØ

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKT

Dette er en forespørsel til deg om å delta i et forskningsprosjekt om erfaringer med tvang i psykisk helsevern. Vi ønsker å høre om hvordan du har erfart å være underlagt tvang og om hvordan du har erfart å få opphevet vedtak om tvang. Dersom du ønsker å delta vil du bli intervjuet av forsker Nina Camilla Wergeland. Det du forteller vil bli anonymisert og gjort ikke identifiserbart for andre.

I intervjuet ønsker vi å høre om dagliglivet ditt, dine erfaringer med behandling og oppfølging med og uten tvang, og dine meninger om alternativer til tvang. Du vil også få anledning til å fortelle om det som opptar deg.

Dersom du vil delta kan du bestemme hvor intervjuet gjennomføres. Forsker kan komme hjem til deg, eller du kan komme til Universitetet i Tromsø eller til UNN. Alle eventuelle utgifter til reise, mat og lignende vil bli dekket. Intervjuet vil vare i ca 1 time, alt etter hvor mye du ønsker å fortelle.

Omtrent en uke etter at du har mottatt dette brevet vil prosjektmedarbeider og erfaringskonsulent Astrid Weber ringe deg for å høre om du ønsker å delta, eller har noen spørsmål. Astrid Weber vil ringe fra telefon 902 46 649.

Det er vedlagt et utfyllende informasjonsskriv som forteller mer om forskningsprosjektet og hva det innebærer å delta.

Dersom du ønsker mer informasjon før du bestemmer deg og før Astrid Weber ringer, kan du gjerne ta kontakt på telefon eller e-post til forsker Nina Camilla Wergeland telefon 97046263/e-post: nina.camilla.wergeland@unn.no eller prosjektleder Henriette Riley telefon 93427012/e-post: henriette.riley@unn.no.

Med vennlig hilsen

Forsker Nina Camilla Wergeland
Prosjektmedarbeider Astrid Weber
Prosjektleder Henriette Riley

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

" Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringer i psykisk helsevernloven av 1.september 2017"

Undertegnede har fått både muntlig og skriftlig informasjon om studien.

Sett et kryss for hver enkelt del du samtykker til:

___ Jeg er villig til å delta i intervjustudien.

___ Jeg er villig til at den jeg velger er min pårørende kan forespørres om å bli intervjuet om sine erfaringer med å være min pårørende.

___ Jeg er villig til at et helsepersonell som jeg får oppfølging fra, og som jeg bestemmer hvem er, kan delta i intervjustudien.

___ Jeg er villig til at forsker og prosjektleder får innsyn i min journal.

___ Jeg er villig til at forsker kan kontakte meg på nytt for eventuelle oppklarende eller utdypende spørsmål i etterkant av intervjuet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

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Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017.

Dette er et spørsmål til deg om å delta i et forskningsprosjekt om hvordan du har erfart å få opphevet vedtak om tvunget psykisk helsevern uten døgnopphold (TUD). Nedenfor vil du finne informasjon om hva prosjektet går ut på og hva det vil innebære for deg om du deltar.

HVA INNEBÆRER STUDIEN?

Studien undersøker pasienters, pårørendes og helsepersonells erfaringer når vedtak om TUD blir opphevet som følge av lovendringen om manglende samtykke som selvstendig vilkår for å bruke tvang. Vi ønsker å intervjue pasienter, pårørende og helsepersonell, og spørre om deres erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan dagligliv og arbeidshverdag påvirkes av lovendringen. Studien er et samarbeid mellom Psykisk helse- og rusklinikken ved Universitetssykehuset Nord-Norge og UIT Norges Arktiske Universitetet.

HVA INNEBÆRER DET FOR DEG Å DELTA?

Deltakelse i studien gir deg mulighet til å fortelle om dine erfaringer med behandling og oppfølging både når du var underlagt TUD vedtak og uten TUD vedtak. Kunnskapen du har gjennom erfaringer med behandling og oppfølgingen innenfor psykisk helsevern er viktig og vil kunne bidra til å utvikle og tilrettelegge helsetjenesten. I studien vil omtrent 20 personer som har fått opphevet vedtak om TUD bli intervjuet.

For deg vil det å delta innebære at du stiller opp til et intervju som varer ca 1 time, alt etter hvor mye du ønsker å fortelle. I intervjuet ønsker vi at du deler dine erfaringer om hvordan du opplever din egen situasjon, hvordan du har erfart behandling og oppfølging før og etter at vedtak om TUD ble opphevet, og hvordan du erfarer muligheten til selvbestemmelse i egen behandling. Vi er også interessert i å høre om din vurdering av egen helse og i hvilken grad du opplever å være i stand til selv å fatte beslutninger om din egen behandling.

Du bestemmer selv hvor intervjuene skal gjennomføres dersom du vil delta. Det kan enten skje hjemme hos deg, på UNN i Tromsø, Universitetet i Tromsø eller et annet sted du foretrekker. Dersom du hat utgifter til reise, mat og lignende vil de bli dekket.

Vi ønsker også å intervjue den du mener er din nærmeste pårørende og den du mener er det helsepersonellet som følger deg tettest opp, men bare om du gir tillatelse til at vi kan gjøre det. Om du tillater det vil den som er din pårørende og ditt helsepersonell også få forespørsel om å delta i studien på lik linje med deg.

Intervjuene vil bli tatt opp på lydbånd. Bare forskeren som intervjuer deg, veileder og prosjektmedarbeider vil ha adgang til lydbåndene. Lydbåndene vil bli ødelagt når prosjektet er fullført (01.07.2022).

Etter at forskeren har analysert intervjuene ønsker vi å se i din pasientjournal dersom du samtykker til dette. Vi vil særlig se på hva som står i journalnotatene når vedtaket om TUD ble opphevet, og eventuelt nye vedtak om tvang/TUD. Vi ønsker innsyn i din journal for å se hvordan helsepersonell har vurdert din situasjon og din helse.

Om du er i tvil eller ønsker mer informasjon, kan du enten vente lenger før du bestemmer deg, eller du kan få møte forskeren som senere eventuelt intervjuer deg, for å snakke om prosjektet før du bestemmer deg.

MULIGE FORDELER OG ULEMPER

Mulige fordeler med å delta i studien er at du vil kunne bidra til å øke kunnskapen om forhold som berører lovendringen og hvordan det erfares for de som er direkte berørt. Det er ikke gjort noen studier i Norge på dette, og vi ønsker derfor å få kunnskap om hva som er dårlig, hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i studien, men du som har erfaring med å være på TUD vil bli spurt om en del personlige spørsmål. Skulle du ha behov for å snakke med din behandler, annet helsepersonell eller en uavhengig psykiater etterpå, vil du få det.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i studien. Om du ikke vil svare på enkelte spørsmål eller deler av intervjuet er det også helt i orden. Du kan også avbryte intervjuet når du vil dersom du ikke ønsker å fortsette. Du kan også velge å si ja til bare intervjuene og nei til innsyn i journalen eller intervju med pårørende og helsepersonell, eller omvendt.

Dersom du ønsker å delta, kan vi sammen se på samtykkeerklæringen på siste side av dette skrivet når vi møtes til intervju. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få noen konsekvenser.

Dersom du har spørsmål til studien kan du kontakte forsker Nina Camilla Wergeland på telefon 97046263 / e-post: nina.camilla.wergeland@unn.no eller prosjektleder Henriette Riley på telefon 93427012 / e-post: Henriette.riley@unn.no.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Forsker og prosjektleder har lovpålagt taushetsplikt. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Selv om det er et lavt antall pasienter som blir bedt om å være med (20 stykk) vil det ikke la seg gjøre å gjenkjenne deg på noen måte.

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede data og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Resultatene av studien vil bli offentliggjort i form av vitenskapelige artikler. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt i studien. Som deltaker vil du få tilsendt artiklene dersom du ønsker det.

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.

ØKONOMI

Som deltaker i studien vil du ikke ha noen former for økonomiske utgifter. Eventuelle reise- og oppholdsutgifter dekkes av prosjektet. Det betales ikke godtgjørelse for deltakelse i intervjuene.

GODKJENNING

Prosjektet er vurdert av Regional komite for medisinsk og helsefaglig forskningsetikk, 2018/1659, 02.10.2018, og godkjent av Personvernombudet ved Universitetssykehuset Nord-Norge.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

" Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringer i psykisk helsevernloven av 1.september 2017"

Undertegnede har fått både muntlig og skriftlig informasjon om studien.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Dersom du har spørsmål til studien kan du kontakte:
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Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017.

Dette er et spørsmål til deg om å delta i en forskningsprosjekt om hvordan du erfarer å være pårørende til en nær etter vedtaket om tvunget psykisk helsevern uten døgnopphold (TUD) ble opphevet. Nedenfor vi du finne informasjon om hva studien går ut på, og hva det vil innebære for deg om du deltar

HVA INNEBÆRER STUDIEN?

Studien undersøker pasienters, pårørendes og helsepersonells erfaringer når vedtak om TUD blir opphevet som følge av lovendringen om manglende samtykke som selvstendig vilkår for å bruke tvang. Vi ønsker å intervjue pasienter, pårørende og helsepersonell, og spørre om deres erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan dagligliv og arbeidshverdag påvirkes av lovendringen. Studien er et samarbeid mellom Psykisk helse- og rusklinikken, Universitetssykehuset Nord-Norge og UIT Norges Arktiske Universitetet.

HVA INNEBÆRER DET FOR DEG Å DELTA?

I studien vil 20 personer som har fått opphevet vedtak om TUD bli intervjuet, og deres pårørende og helsepersonell. Du forespørres om å delta i egenskap av at du er pårørende til en pasient som er intervjuet, og pasienten har gitt skriftlig samtykke til at du kan forespørres. For deg vil det å delta innebære at du stiller opp til et intervju som vil vare fra 1-2 timer, alt etter hvor mye du ønsker å fortelle. I intervjuet ønsker vi at du deler dine erfaringer om hvordan du opplever å være pårørende. Vi ønsker å høre om hvordan du erfarer din situasjon, og om det er endringer i ditt ansvaret og rollen som pårørende før og etter at vedtak om TUD ble opphevet.

Du bestemmer selv hvor intervjuene skal gjennomføres dersom du vil delta. Det kan enten skje hjemme hos deg, på UNN i Tromsø, Universitetet eller et annet sted du foretrekker. Alle utgifter til reise, mat og lignende vil bli dekket.

Intervjuene vil bli tatt opp på lydbånd. Bare forskeren som intervjuer deg, veileder og prosjektmedarbeider vil ha adgang til lydbåndene. Lydbåndene vil bli ødelagt når prosjektet er fullført (01.07.2022).

Om du er i tvil eller ønsker mer informasjon, kan du enten vente lenger før du bestemmer deg, eller du kan få møte forskeren som senere eventuelt intervjuer deg, for å snakke om prosjektet før du bestemmer deg.

MULIGE FORDELER OG ULEMPER

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Det er ingen sikre ulemper med å delta i studien for deg som er pårørende.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i studien. Om du ikke vil svare på enkelte spørsmål eller deler av intervjuet er det også helt i orden. Du kan også avbryte intervjuet når du vil dersom du ikke ønsker å fortsette.

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 har spørsmål til studien kan du kontakte forsker Nina Camilla Wergeland på telefon 97046263 /e-post: nina.camilla.wergeland@unn.no eller prosjektleder Henriette Riley på telefon 93427012 / e-post: Henriette.riley@unn.no.

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Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede data og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Resultatene av studien vil bli offentliggjort i form av vitenskapelige artikler. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt i studien. Som deltaker vil du få tilsendt artiklene dersom du ønsker det.

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.

ØKONOMI

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GODKJENNING

Prosjektet er vurdert av Regional komite for medisinsk og helsefaglig forskningsetikk, 2018/1659, 02.10.2018, og godkjent av Personvernombudet ved Universitetssykehuset Nors-Norge.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

" Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringer i psykisk helsevernloven av 1.september 2017"

Undertegnede har fått både muntlig og skriftlig informasjon om studien.

___ Jeg er villig til å delta i intervjustudien.

___ Jeg er villig til at forsker kan kontakte meg på nytt for eventuelle oppklarende eller utdypende spørsmål i etterkant av intervjuet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

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UNIVERSITETET I TROMSØ

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017.

Dette er et spørsmål til deg om å delta i et forskningsprosjekt om hvordan du erfarer å være helsepersonell til en pasient som har fått opphevet vedtak om tvunget psykisk helsevern uten døgnopphold (TUD) etter lovendringen av 1.september 2017. Nedenfor vil du finne informasjon om hva studien går ut på, og hva det vil innebære for deg om du deltar.

HVA INNEBÆRER STUDIEN?

Studien undersøker pasienters, pårørendes og helsepersonells erfaringer når vedtak om TUD blir opphevet som følge av lovendringen om manglende samtykke som selvstendig vilkår for å bruke tvang. Vi ønsker å intervjue pasienter, pårørende og helsepersonell, og spørre om deres erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan dagligliv og arbeidshverdag påvirkes av lovendringen. Studien er et samarbeid mellom Psykisk helse- og rusklinikken, Universitetssykehuset Nord-Norge og UIT Norges Arktiske Universitetet.

HVA INNEBÆRER DET FOR DEG Å DELTA?

I studien vil 20 personer som har fått opphevet vedtak om TUD bli intervjuet, og deres pårørende og helsepersonell. Du forespørres om å deltakelse i egenskap av at du er helsepersonell, og en pasient som har blitt intervjuet har samtykke til at du kan forespørres om å bli intervjuet. For deg vil det å delta innebære at du stiller opp til et intervju som vil vare ca 1 time. I intervjuet ønsker vi at du deler dine erfaringer om hvordan det er å gi oppfølging og behandling i rammene med og uten TUD, og hva du mener er handlingsrommet til å imøtekomme pasientens ønsker. Det understrekes at pasienten er informert om hensikten med å intervjue deg, og at pasienten har samtykket i at vi spør deg om å delta.

Om du samtykker til å delta vil phd kandidat Nina Camilla Wergeland kontakte deg for å avtale tid og sted for intervjuet. Intervjuene vil bli tatt opp på lydbånd. Bare forskeren som intervjuer deg, veileder og prosjektmedarbeider vil ha adgang til lydbåndene. Lydbåndene vil bli ødelagt når prosjektet er fullført (01.07.2022).

Om du er i tvil eller ønsker mer informasjon, kan du enten vente lenger før du bestemmer deg, eller du kan få møte forskeren som senere eventuelt intervjuer deg, for å snakke om prosjektet før du bestemmer deg.

MULIGE FORDELER OG ULEMPER

Mulige fordeler med å delta i studien er at du vil kunne bidra til å øke kunnskapen om forhold som berører lovendringen og hvordan det erfares for helsepersonell. Det er ikke gjort noen studier i Norge på dette, og vi ønsker derfor å få kunnskap om hva som er dårlig, hva som er bra og hva som kan bli gjort bedre.

Det er ingen sikre ulemper med å delta i studien for deg som er helsepersonell.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i studien. Om du ikke vil svare på enkelte spørsmål eller deler av intervjuet er det også helt i orden. Du kan også avbryte intervjuet når du vil dersom du ikke ønsker å fortsette.

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 har spørsmål til studien kan du kontakte forsker Nina Camilla Wergeland på telefon 97046263 /e-post: nina.camilla.wergeland@unn.no eller prosjektleder Henriette Riley på telefon 93427012 / e-post: Henriette.riley@unn.no.

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Forsker og prosjektleder har lovpålagt taushetsplikt. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres. Selv om det er et lavt antall helsepersonell som blir bedt om å være med vil det ikke la seg gjøre å gjenkjenne deg på noen måte.

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede data og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Resultatene av studien vil bli offentliggjort i form av vitenskapelige artikler. I disse artiklene vil det ikke være mulig å gjenkjenne noen av dem som har deltatt i studien. Som deltaker vil du få tilsendt artiklene dersom du ønsker det.

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.

ØKONOMI

Som deltaker i studien vil du ikke ha noen former for økonomiske utgifter. Eventuelle reise- og oppholdsutgifter dekkes av prosjektet. Det betales ikke godtgjørelse for deltakelse i intervjuene.

GODKJENNING

Prosjektet er vurdert av Regional komite for medisinsk og helsefaglig forskningsetikk, 2018/1659, 02.102018, og godkjent av Personvernombudet ved Universitetssykehuset Nord-Norge.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

" Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringer i psykisk helsevernloven av 1.september 2017"

Undertegnede har fått både muntlig og skriftlig informasjon om studien.

___ Jeg er villig til å delta i intervjustudien.

___ Jeg er villig til at forsker kan kontakte meg på nytt for eventuelle oppklarende eller utdypende spørsmål i etterkant av intervjuet.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Dersom du har spørsmål til studien kan du kontakte:
Forsker Nina Camilla Wergeland 97046263 eller
Prosjektleder dr. Henriette Riley 93427012

INTERJUGUIDE TIL PERSONER MED PÅRØRENDEERFARING (TUD)

INNLEDNINGSSPØRSMÅL	Vil du fortelle meg litt om deg selv?	
Er du vant med TUD forkortelsen?	• Jobb, familie, hverdagen din? • Relasjon til den med TUD-erfaring • Hvordan opplever du behandlingen og oppfølgingen din nære får? • Samarbeid og kontakt med hjelpeapparatet? For deg? For din nære? • Oppgaver som familiemedlem/pårørende? • Ansvar? • Bekymring? • Pårørendegruppe? • Din opplevelse av tvangsbruk? • Hva betyr tvangsbruken for deg? • Hva betyr tvangsbruken for din nære? • Ble frivillighet forsøk? Hva ble forsøkt? • Hva har du fått av informasjon om TUD? Hvordan har du fått informasjon? (tidsaspekt? innebærer? rettigheter?) • Hvor godt er din nære informert om TUD? Hvordan har vedkommende fått informasjon?	
LOVENDRINGEN	Kan du fortelle om hva lovendringen har betydd for deg som pårørende?	
	• Endringer i hverdagen du kan peke på? • Ansvar? • Bekymring? • Utfordringer • Fordeler?	

	• Hvordan har informasjonen om endringen vært? Er endringene tydelig forklart for deg og din nære? • Hva har lovendringen betydd for den du er pårørende til? • Samarbeid? / Kommunikasjon? • Hva gjør dere sammen? • Hva mener du om lovendringen? • Sammenligne før og etter? -Din nære sin situasjon -Deres relasjon -Samarbeid med helsepersonell -Bestemmer din nære mer? -For mye? • Hvordan ble TUD avsluttet? Plan? Samarbeid? Videre oppfølging og behandling? • Opplever du at avslutning av TUD var riktig?	
FOREBYGGING AV TUD	Har du gjort deg noen tanker om hva som kan gjøres for å forebygge TUD	
	• Forslag til tiltak eller ordninger som kan bidra til at din nære ikke hadde trengt TUD vedtak? • Opplever du TUD positivt eller negativ? • Kriseplan?	
AVSLUTNINGSSPØRSMÅL	Er det noe jeg ikke har spurt om som du har lyst til å fortelle?	
	• Hvordan kjennes det å snakke om dette? • Vil du høre litt om hva jeg har oppfatta av det du har fortalt? • Noe du vil kommentere?	

	• Ta gjerne kontakt hvis det noe mer du kommer på som du gjerne vil fortelle.	Mai 2019

INTERVJUGUIDE TIL HELSEPERSONELL
FOR PASIENTER MED TUD ERFARING

INNLEDNINGS-SPØRSMÅL	**Vil du starte med å fortelle litt om deg selv og din helsefaglige bakgrunn?**	
	• Kan du fortelle om dine erfaringer med pasienter som har TUD vedtak? • Eksempel på TUD-samarbeid som du opplevde som godt? • Eksempel på TUD-samarbeid som du mener ikke var til det beste for pasienten? • Eksempler på TUD-samarbeid som var vanskelig å få til /utføre? • Samarbeid/kommunikasjon med andre tjenestenivå, hvordan har det fungert? Eksempler? • Hva ble forsøkt av frivillige tilbud og hvordan ble det forsøkt før TUD? • Hvordan opplever du at behovet for informasjon om TUD vedtak er hos pasienter og pårørende? • Hvordan ser du på ansvar for å gi informasjon om TUD vedtak? • I hvilken grad har du tenkt at TUD vedtak har vært nødvendig hos de du har jobbet med?	
LOVENDRINGEN	**Hvordan opplever du at lovendringen har betydning for deg i ditt arbeid?**	
	• Opplever du å ha nok informasjon om lovendringen? • **Hva er dine erfaringer ift lovendringens betydning for ditt samarbeid med pasientene?** **-pårørende?** **-andre tjenestenivå/instanser?** • Hva tenker du om lovendringens intensjon og hvordan du erfarer at den fungerer? Svarer endringen til intensjonene? • **Hvilke informasjon og hvordan blir informasjon gitt** til pasienter og pårørende om lovendringen og dens betydning? • **På hvilken måte har lovendringen hatt betydning for pasientens medbestemmelse i egen behandling?** • **Hva er din erfaring med samtykkekompetanse vurdering** – hvordan opplever du at det fungerer? Hvordan gjennomføres vurderingen? Hva er viktig i en slik vurdering? Hvordan fungerer lovtekst og hvilke verktøy brukes i vurderingen? Hvordan er pasientene ivaretatt i vurderingssituasjonen? Din tillit til vurderingene? Eksempler?	

	• **Hvordan er din erfaring med avvikling av TUD?** Hvordan foregår det? Hva betyr det for oppfølging og tilbud? Medisiner? Samarbeid? Plan? Er det noen endringer i ressurser og muligheter, **ditt handlingsrom til å imøtekomme pasienters ønsker** for behandling og oppfølging? • **Hvilke fordeler og ulemper har lovendringen for pasienten? For ditt arbeid? For pårørende? Eksempler?** • Hvis du kunne ønske deg ordninger eller tiltak uten å tenke på ressurser eller hva som er vanlig oppfølging, hva kunne du ønske deg for dine pasienter? For **optimal oppfølging?** • Hvordan stiller du deg til avviklingen av TUD? Er det flere eller færre som skulle vært på TUD av de du jobber med?	
FOREBYGGING AV TUD	**Hvilke tanker har du om forebygging av TUD?**	
	• Erfarer du at lovendringen forebygger TUD? • Hva tenker du kan være gode alternativer til TUD? • Kan du fortelle om dine tanker om bruk av kriseplan?	
AVSLUTNINGS-SPØRSMÅL	**Er det noe jeg ikke har spurt deg om som du har lyst til å fortelle?**	
	• Hvordan har det vært for deg å snakke om dette? • Hvis du kommer på noe mer du vil fortelle må du gjerne ta kontakt på telefon eller e-post	
		August 2019

INTERJUGUIDE FOR PERSONER MED TUD ERFARING

INNLEDINGS SPØRSMÅL	**Vil du begynne med fortelle meg litt om deg selv og hverdagen din?** (f.eks. om dagen i går)	
	• Opplevelse av hverdagen • Hva liker du å bruke tiden din på? aktiviteter, familie, venner, jobb • Kan du fortelle om tilbudet du har fra helsevesenet nå? Hva trenger du fra helsevesenet? Hva er du fornøyd med /ikke fornøyd med? Hvem har du kontakt med? Hvordan opplever du kontakten? Hvordan vil du beskrive samarbeidet?	
TVANG/ HJELPEAPPARATET	**Kan du fortelle meg om din erfaring med tvunget vern hjemme (TUD)?**	
Er du vant til TUD-begrepet?	• Første gang – hva betydde det for deg? Praktisk? Følelsesmessig? • Hvilke informasjon har du fått om TUD? Opplever du å ha oversikt på hva det innebærer? Rettigheter? Tidsperiode? • **Har du erfaring med at dine ønsker for behandling og oppfølging er etterspurt? Hva var tilbudt og forsøkt før TUD vedtak ble fatta?** • Hva var eller er dine behov og ønsker for behandling og oppfølging? • Vil du fortelle om dine erfaringer fra møter og samarbeid med helsepersonell? • Negative og positive sider ved TUD? • Hva består tilbudet ditt av nå? Hvordan opplever du at samarbeidet og kontakten med helsepersonell og evt vedtaksansvarlig er nå? Tillit? Nære relasjoner?	
LOVENDRINGEN	**Hvis du merker noen forskjell etter at psykisk helsevernloven ble endret for to år siden, kan du fortelle meg om hvordan du merker det?**	
	• Hva har du fått av **informasjon om lovendringen?** Av hvem og hvordan ble informasjonen gitt? • **Har du opplevd å bli samtykkekompetansevurdert?** Kan du fortelle hvordan du opplevde vurderingssituasjonen? Hvordan kjente du deg respektert og ivaretatt? Hvordan er din tillit til vurderingene? • **Erfarer du noen endring i medbestemmelse**? Evt på hvilke måte og på hvilke områder? (Frihet? Verdighet? Tillit? Åpenhet/kommunikasjon?) • **Opplever du noen forskjeller i oppfølging/behandling med eller uten TUD? Endrer helsepersonell eller pårørende seg noe?** • Plan, ved evt ny sykdomsepisode hva skal skje? **Kriseplan?**	

	• **Fordeler og bakdeler ved lovendringen?** • **Hvordan ble TUD avvikla?** Hvem sin ide var det å avvikle TUD? Var du enig? Plan? Samarbeid? Medisiner? **Bekymringer? Redd for å miste tilbud?** • Betydning for økonomi? • **På TUD igjen, hva skjedde? Ba du om noe/hjelp? Hvordan opplevde du møtet med helsevesenet i denne situasjonen?** • **Hva kunne vært gjort for å unngå TUD i denne situasjonen?** Medisiner? Bestemme selv? Samarbeid? Type hjelp/oppfølging?	
FOREBYGGING AV TUD	**Kan du fortelle om hva det betyr for deg å ikke lenger være på TUD?**	
	• **Hva kan forebygge TUD? Hvilke tilbud mangler?** • Trenger vi TUD? • Kan du fortelle hvordan TUD-erfaringene dine har hatt betydning for deg? Hvordan har TUD erfaringene påvirket deg? Har TUD-erfaringene gjort noe med hvordan du ser på deg selv? • Kriseplan? • Hvis du kunne ønske helt fritt, uten å tenke på hva som er mulig eller vanlig, hva kunne du ønske deg av oppfølging/behandlingstilbud og muligheter da? • Er det noe i måten vi tenker på i dagens samfunn om psykisk sykdom, behandling og hjelp som etter ditt syn burde være annerledes?	
AVSLUTTENDE SPØRSMÅL	**Er det noe jeg ikke har spurt om som du har tenkt du ville fortelle om?**	
	• Hvordan kjennes det å ha snakket om dette? • Vil du høre litt om hva jeg har oppfatta av det du har sagt? • Er det noe av dette du vil kommentere? • Ta gjerne kontakt hvis du kommer på mer du har lyst til å si, du kan ringe meg eller sende e-post • Får jeg lov til å snakke med en av dine pårørende? Og eller et helsepersonell som du forholder deg til. (Gå gjennom kryssene på skjema) • Hva skal du gjøre nå?	
Kan du si litt mer om det? Forstår jeg deg rett….	Kan du gi et eksempel? Kan du fortelle meg om? Hvordan opplevde du det? Hvordan var det for deg?	AUG. 2019

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			02.10.2018	2018/1659/REK nord
			Deres dato:	Deres referanse:
			14.08.2018	

Vår referanse må oppgis ved alle henvendelser

Henriette Riley
Psykisk helse og rusklinikken

2018/1659 Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 13.09.2018. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig institusjon: Universitetssykehuset Nord-Norge HF
Prosjektleder: Henriette Riley

Prosjektleders prosjektomtale (original):
Den 1 september 2017 innførte Norge manglende samtykke som selvstendig vilkår for bruk av tvang i psykisk helsevern. Dette betyr at pasienter med alvorlig psykisk lidelse selv kan bestemme om de vil ta imot behandling dersom de er samtykkekompetente. Unntaket fra vilkåret om manglende samtykkekompetanse er dersom pasienten er til fare for eget liv, eller andres liv eller helse. Lovendringen skal styrke pasientens selvbestemmelsesrett, og antas å være særlig aktuell for å redusere bruk av tvang overfor pasienter under tvunget psykisk helsevern uten døgnopphold (TUD). Den aktuelle studien skal undersøke pasienters, pårørendes og helsepersonells erfaringer når vedtak om TUD blir opphevet som følge av lovendringen. Studien fokusere på erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan informantenes dagligliv og arbeidshverdag påvirkes av lovendringen. Data vil bli samlet inn gjennom individuelle intervju med pasienter, deres pårørende og helsepersonell, og journalinnsyn.

Data
Data skal samles inn gjennom individuelle intervju med pasienter, deres pårørende og helsepersonell, samt ved journalinnsyn.

Studien skal fokusere på erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan informantenes dagligliv og arbeidshverdag påvirkes av lovendringen.

Framleggingsplikt
De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven § 2. "Medisinsk og helsefaglig forskning" er i helseforskningsloven § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet er formålet å finne pasientens, pårørendes og helsepersonells opplevelse og erfaringer om egen situasjon i forbindelse med tvunget helsevern, før og etter lovendring.

Selv om dette er en helsefaglig studie og funnene i studien indirekte vil kunne gi en helsemessig gevinst faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Ettersom studien omhandler en sårbar gruppe vil REK gjøre oppmerksom på at Den nasjonale forskningsetiske komité for samfunnsvitenskap og humaniora kan kontaktes. Denne komiteen har også utgitt retningslinjer for forskning.

Godkjenning fra andre instanser
Det påhviler prosjektleder å undersøke hvilke godkjenninger som er nødvendige fra eksempelvis personvernombudet ved egen institusjon.

Vedtak
Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke framleggingspliktig, jf. helseforskningsloven § *2.*

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til:henriette.riley@unn.no;rek-svar@unn.no

UNIVERSITETSSYKEHUSET NORD-NORGE
DAVVI-NORGGA UNIVERSITEHTABUOHCCEVIESSU

Henriette Riley
Psykisk helse- og rusklinikken

Deres ref.:	Vår ref.:	Saksbehandler/dir.tlf.:	Dato:
	2019/934	Kristin Andersen/77626506	8.2.2019

ANBEFALING – BEHANDLING AV PERSONOPPLYSNINGER

Det vises til Meldeskjema for forsknings- og kvalitetsprosjekt og annen aktivitet som medfører behandling av personopplysninger, mottatt 10.12.2018

Meldingen gjelder prosjektet:

> ***Nr. 02218***
> ***Navn på prosjektet:*** *Økt selvbestemmelse? Erfaringer med tvunget psykisk helsevern uten døgnopphold og pasienters medbestemmelse etter endringen av psykisk helsevernloven av 1. september 2017.*

Prosjektet er et ***forskningsprosjekt*** hvor Universitetssykehuset Nord-Norge HF er dataansvarlig.

> ***Formål:*** *«Den aktuelle studien skal undersøke pasienters, pårørendes og helsepersonells erfaringer når vedtak om TUD blir opphevet som følge av lovendringen. Studien fokusere på erfaringer før og etter at vedtak om TUD ble opphevet, og hvordan informantenes dagligliv og arbeidshverdag påvirkes av lovendringen. Data vil bli samlet inn gjennom individuelle intervju med pasienter, deres pårørende og helsepersonell, og journalinnsyn.*
> *Studiens forskningsspørsmål er:*
> *1. Hvordan erfarer pasienter å få opphevet vedtak om TUD som følge av at de ikke oppfyller vilkåret om manglende samtykkekompetanse, og hvordan opplever de muligheten for selvbestemmelse i egen oppfølging og behandling?*
> *2. Hvordan erfarer pasientens pårørende lovendringen, og har endringen påvirket opplevd ansvar og rolle som pårørende?*
> *3. Hvordan erfarer helsepersonell at lovendringen har påvirket oppfølging og behandling, og hvordan erfares mulighetene for å imøtekomme pasientens egne ønsker om behandling og oppfølging utenfor TUD?*
> *4. Hva mener pasienter, pårørende og helsepersonell er gode alternativer for å forebygge TUD?»*

REK har vurdert prosjektet, og finner at behandlingen av personopplysningene ***ikke faller inn under medisinsk- og helsefaglig forskning etter Helseforskningsloven.*** Prosjektet

Postadresse: UNN HF 9038 TROMSØ
Personvernombudet
Avdeling: Kvalitets- og utviklingssenteret
Besøksadr.: G-fløya (PET-senteret) 10. et.
Telefon: 77 62 60 00
Internett: www.unn.no
E-post: personvernombudet@unn.no

trenger ikke REK godkjenning. Behandlingen vil være hjemlet etter Helseregisterloven § 6, jf. Personvernforordningen artikkel 6.1.a) og artikkel 9.2.j).

Forskningsprosjektet er basert på samtykke og prosjektleder har i meldeskjemaet kommentert: «*Dette reiser spørsmålet om pasienter som i utgangspunktet er vurdert til ikke å være samtykkekompetent allikevel kan samtykke til deltakelse i studie som innebærer intervju om sin egen situasjon og erfaring.*
...
For å sikre at pasienter underlagt tvang som forespørres om deltakelse i studien er i stand til å foreta en autonom vurdering av deltakelse vil den som er faglig ansvarlig for pasienten (psykiater eller psykologspesialist) bli forespurt om sin vurdering.»

PVOs anbefaling forutsetter at prosjektet gjennomføres i tråd med de opplysningene som er gitt, samt i henhold til Personopplysningsloven og Helseregisterloven med forskrifter.

PVO har på bakgrunn av tilsendte meldeskjema med vedlegg registrert prosjektet og opprettet et eget område (mappe) på **\\hn.helsenord.no\UNN-Avdelinger\felles.avd\forskning** (O:\) med navn **02218** hvor all data i forbindelse med prosjektet skal lagres.
I tillegg er det opprettet et område på **\\hn.helsenord.no\UNN-Avdelinger\felles.avd\forskning\key** med navn **02218N** hvor nøkkelfil skal oppbevares. Tilgang til dette området er begrenset til kun å omfatte prosjektleder og den/de som prosjektleder oppgir. PVO vil ha tilgang til området.

PVO gjør oppmerksom på at dersom registeret (data lagret på O:) skal brukes til annet formål enn det som er nevnt i meldingen, må dette meldes særskilt.

PVO skal ha melding når registeret er slettet. PVO skal ha melding hvert 3. år inntil registeret er slettet.

Med hjemmel i Personvernforordningens artikkel 39, anbefaler PVO at behandlingen kan iverksettes.

Med vennlig hilsen

UNIVERSITETSSYKEHUSET NORD-NORGE HF

for Personvernombudet

Kristin Andersen

Kopi: klinikksjef Tordis Sørensen Høifødt

Om personvernombud

Personvernombudet er utpekt av Universitetssykehuset Nord-Norge HF (UNN) og meldt til Datatilsynet. Personvernombudet har som oppgave å bidra til at UNN følger gjeldende regelverk for behandling av personopplysninger. Oppgaven innebærer blant annet å kontrollere overholdelsen av regelverket, informere og gi råd til virksomheten og de ansatte, og gi råd i vurdering av personverskonsekvenser. Personvernombudet er uavhengig og kan ikke instrueres av UNN i gjennomføring av sine oppgaver.

Om uttalelsen

Personvernombudets uttalelse er ikke selvstendig juridisk bindende og du kan selv velge hvordan du ønsker å forholde deg til denne. Du er imidlertid selv ansvarlig for at du følger gjeldende personvernregler innenfor ditt ansvarsområde. Velger du å avvike fra personvernombudets uttalelse bør du begrunne dette skriftlig i ditt arbeid.

Klageadgang

Personvernombudets uttalelse er har ingen selvstendig juridisk virkning og det finnes ingen adgang til å klage på uttalelsen. Dersom uttalelsen konkluderte på annen måte enn du ønsket kan personvernombudet bistå.

Taushetsplikt

Personvernombudet har taushetsplikt ovenfor opplysninger om personlige forhold, enkeltpersoners varsling om mulige brudd på personvernlovgivningen, forretningshemmeligheter eller sikkerhetstiltak som det får kjennskap til i utførelsen av sitt arbeid. Dersom slike opplysninger er nødvendig for å gjennomføre lovpålagte oppgaver kan den registrerte bli bedd om samtykke til å gi nødvendige opplysninger videre.

For mer informasjon om personvernombud se Datatilsynets sider om personvernombud
For mer informasjon om pasientens rettigheter se Dine rettigheter på Datatilsynets sider
For mer informasjon om virksomheten (UNN) sine plikter se Virksomhetenes plikter