

Department of Community Medicine, Faculty of Health Sciences

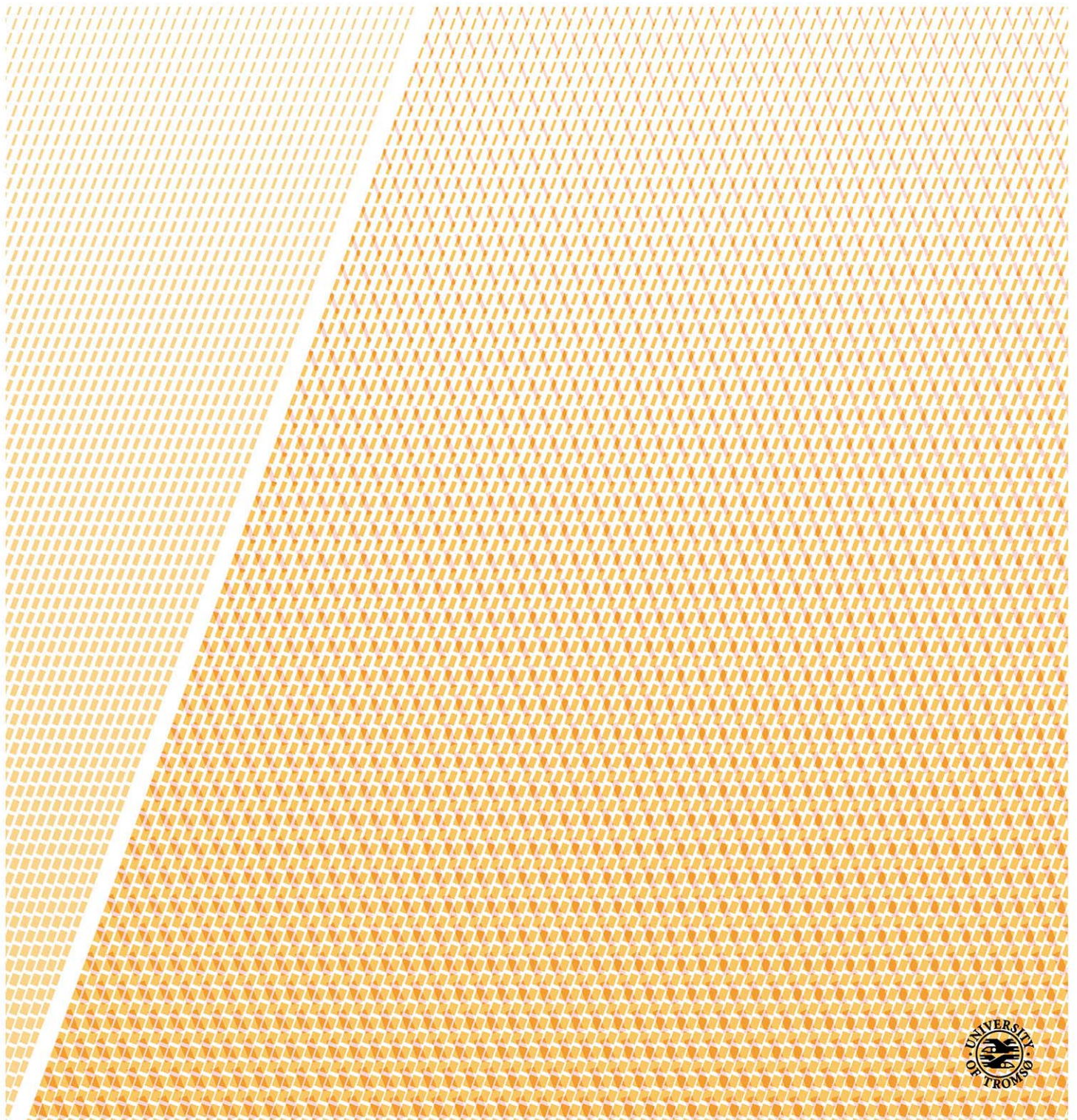
Experiences with outpatient commitment orders from the perspectives of patients, relatives and staff

A qualitative study

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Bjørn Stensrud

A dissertation for the degree of Philosophiae Doctor – May 2016



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FOREWORD

There is little research-based knowledge about the scope and content of compulsory outpatient psychiatric care in Norway, and a particular lack of knowledge of the experiences of those involved. This thesis will supplement other research on the use of coercion in mental health care being led by the Norwegian Research Network on Coercion in Mental Health Care at the University of Tromsø. As a research fellow, I have been part of this research community. This has been important to me and given me confidence.

Work on this PhD has allowed me to explore more deeply issues that have concerned me. During much of my working life, I have worked in mental health care. My interest in the field of mental health was aroused through working as an assistant in mental health facilities, and subsequently led me to take a nursing degree, continuing education, a master's degree and now towards a doctorate. I would like to thank Solveig Brekke Skard and Arve Resløyken, who gave me the opportunity to develop my professional interest at an early stage. As a clinician and later head of a hospital ward, I have always been interested in professional development. As health professionals, we are committed to ensuring that the treatment we provide represents best practice by being rooted in research and professional development. In this work, I have benefitted greatly from cooperation with the Research and Professional Development Unit of the Psychosis Department in Innlandet Hospital Trust. Thank you all, and especially Kjell Nordby for support and stimulating discussions. My cooperation with this unit brought me into contact with Hedmark University College. That was the start of a research project on milieu therapy which included my master's thesis. A special thanks goes to Professor Jan Kåre Hummelvoll for all your help and support in the work. Without you, I would not have started a PhD.

When the doctoral project “People’s Experiences with Compulsory Outpatient Care” was announced in 2012, it was natural for me to apply. All credit goes to Alf Skar (later Sylvi Nes) of the Department of Psychosis Treatment and Rehabilitation (Department of Acute Psychiatry and Psychosis Treatment), who gave me the opportunity to explore the field more deeply. Implementation of the project would not have been possible without funding. I would like to thank the Norwegian ExtraFoundation for Health and Rehabilitation, which granted the project, and to Innlandet Hospital Trust, which together with the Norwegian National Advisory Unit on Concurrent Substance Abuse and Mental Health Disorders made contributions during the research process. Since the University of Tromsø has a strong focus on research into coercion, it was natural for me to apply for admission there. Many thanks to my supervisor Georg Høyser for well-considered and systematic feedback. You have taught me much about being concise and always keeping to the empirical data. Thanks also to my co-supervisors Anne Landheim and Arild Granerud; you have helped me all the way. I am also indebted to Gro Beston, the lived experience consultant. Your input from a user perspective has been an important factor. Good help from the hospital library staff has assured the quality of important phases of the project. Finally, thanks to the research fellows at the Norwegian National Advisory Unit on Concurrent Substance Abuse and Mental Health Disorders for professional discussions, and a special thank you to Hanne Kilen Stuen for your enlightening reflections at different stages of the process.

In conclusion, I would like to thank my wife Nina for having persevered with me during these years. You have been patient. And my grandchildren Alida and Jesper, you have reminded me of what life is really about, during phases when I have been very busy with the thesis. Finally, thank you to the participants; without you there would have been no thesis.

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LIST OF PAPERS

Stensrud, B., Høyser, G., Granerud, A., & Landheim, A.S. (2015). “Life on hold”: A qualitative study of patient experiences with outpatient commitment in two Norwegian counties. *Issues in Mental Health Nursing*, 36(3), 209-216.

Stensrud, B., Høyser, G., Granerud, A., & Landheim, A.S. (2015). “Responsible, but still not a real treatment partner”: A qualitative study of the experiences of relatives of patients on outpatient commitment orders. *Issues in Mental Health Nursing*, 36(8), 583-591.

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ABBREVIATIONS

Data protection officer	Resource person who enhances an institution's knowledge and expertise on privacy
Decision maker	Psychiatrist or specialist psychologist in specialist health care with the authority to make OC decisions
DPC	District Psychiatric Centre [Specialist health care]
GT	Grounded theory [research method]
MHA	The Norwegian Mental Health Act
OC	Outpatient commitment orders. Legal regimes that give clinicians the authority to supervise patients discharged from mental health facilities
Other health professionals	Health professionals who work with patients under OC, but without decision-making authority
Ot.prp.	Parliamentary proposition to the Odelsting on legislative matters. The Odelsting was discontinued in 2009
RCT	Randomised controlled trials [research design]

REK	Regional Committees for Medical and Health Research Ethics
TvangsForsk	The Norwegian Research Network on Coercion in Mental Health Care
UIT	University of Tromsø
Rt	Norsk rettsidende. A legal publication containing judgements by the Norwegian Supreme Court and the Supreme Court Appeals Committee
St.meld.	Document from the Norwegian government to Parliament concerning matters that the government wishes to inform about or have a parliamentary debate on, without any link to a final legal or planning resolution
St.prp.	Proposition from the Norwegian government to Parliament to pass a legal or planning resolution

SUMMARY

The aim of this thesis is to gain knowledge of the experiences of the outpatient commitment (OC) scheme of patients, their relatives and health professionals, and to examine differences in the experiences of those involved. There is little research-based knowledge on the extent and content of OC in Norway, and a particular lack of knowledge of the experiences of those affected. The present thesis therefore provides insight into an area of very limited knowledge.

Over 75 jurisdictions in the Western world have legislation which provides for patients to be subjected to forced outpatient treatment. The criteria for such coercion and the coercive power of the law vary between countries, depending on national legislation. In Norway, the Mental Health Act only allows for OC patients to be taken involuntarily to hospital for examination and treatment, if necessary by physical force, if they do not attend treatment appointments. An OC decision can only be taken by a psychiatrist or a specialist psychologist employed by an institution in the specialist health services approved for the use of coercion. Prerequisites for the use of OC are that the legislative criteria have been met and that OC is considered the best option for the patient's further treatment in an overall assessment. Before a decision is taken, the patient and relatives must be consulted and cooperation with local treatment services must be established. Generally, OC begins after a prior hospital stay, but the law also allows for OC to be arranged on the basis of previous outpatient visits.

An increasing number of international studies have examined whether OC reduces the number of readmissions and hospital days, whether OC patients increasingly comply with treatment after discharge from inpatient stays and whether the scheme improves patients' quality of life in the short and long term. The three randomised studies published so far, conclude that OC does not reduce the patient's consumption of health care in terms of fewer readmissions or

fewer hospital days, and that there is insufficient evidence as to whether OC enhances patients' treatment outcomes. Systematic knowledge reviews have come to the same conclusion. Quantitative non-randomised studies show inconsistent results. Some have found that OC reduces the consumption of health care and improves patients' treatment compliance, while others have either found that OC makes no difference or that it increases the patient's consumption of health services. The results of qualitative studies are also divergent, but one consistent finding is that relatives and health professionals are more satisfied with OC than the patients under the scheme.

This thesis has a qualitative approach and a descriptive and exploratory design. The data are based on individual interviews with 16 patients and 11 relatives and on three focus group interviews with a total of 22 health professionals. The health professionals all had experience of OC patients, either as the decision maker or from working with the patients in specialist or local health services. The analysis of patient data is based on constructivist grounded theory and the analysis of data from relatives and health professionals is based on qualitative content analysis. The study was conducted in two counties in eastern Norway (Hedmark and Oppland). The results in the thesis have been published in three papers.

The results show that patients under OC want to be more involved in their own treatment and to gain acceptance for their own wishes and experiences in treatment and follow-up care. They find that the scheme keeps them in a patient role that limits their ability to take responsibility for their own recovery process. Relatives experience OC as reducing their burden. They also want to be more involved, and would like health professionals to acknowledge their expertise and experience. Both patients and their families feel they lack information on OC. This creates grey areas and uncertainty in their understanding of the

scheme. Health professionals find that OC allows them to address the patient's treatment needs, and gives them social responsibility in that the scheme allows them to intervene if the patient has a relapse and presents increasing symptoms of severe mental illness. Health professionals find the scheme to be necessary, but at the same time experience a dilemma in the combination of being responsible for therapy and managing coercion. While patients and their relatives generally had a social psychiatric perspective on the patient's treatment needs, health professionals' views were more often based on a medical understanding. OC patients found that the coercive framework hindered them in their recovery process, while clinicians considered the framework to be necessary to ensure good treatment. Relatives were in the middle ground and were more concerned with the treatment outcome than the treatment framework.

This thesis concludes that OC patients find the scheme to be more intrusive in their lives than health professionals do. The patient's relatives give little thought to the coercive aspect, being more concerned about whether the patient's functional ability will improve. Health professionals should increasingly consider whether OC is equally useful for all psychosis patients recommended for the scheme, and whether a lack of cooperation on treatment may also be because patients have other priorities for their lives. Improvement in mental illness is largely dependent on patients developing strategies and skills to cope with everyday challenges. Since OC is mainly justified by the patient's treatment needs, it must also allow for the patient to be involved in his or her own recovery process, and for resources in the patient's environment to be utilised for the benefit of the treatment. The results show that the interaction between patients, relatives and OC decision makers should be improved compared to how the scheme is practiced today.

SAMMENDRAG

Avhandlingens hensikt er å få kunnskap om hvilke erfaringer pasienter underlagt tvungen psykisk helsevern uten døgnopphold (outpatient commitment orders/OC), deres pårørende og ansvarlig helsepersonell har med ordningen. Videre å undersøke forskjellene i de involvertes erfaringer med OC. Basert på norske forhold finnes lite forskningsbasert kunnskap om omfang og innhold av OC. Særlig savnes de berørtes erfaringer. Avhandlingen bidrar derfor med kunnskap til et område med manglende kunnskapsgrunnlag.

Over 75 jurisdiksjoner i den vestlige verden har en lovgivning som hjemler å underlegge pasienter en tvungen behandlingsoppfølging uten døgnopphold i sykehus. Kriterier for tvang, og lovens «coercive power», varierer mellom land ut fra nasjonal lovgivning. I Norge hjemler Psykisk helsevernloven bare at OC pasienter kan bringes til sykehus for undersøkelse og behandling uten samtykke dersom de ikke møter til behandlingsavtaler, om nødvendig med bruk av fysisk makt. Vedtak om OC kan kun fattes av en psykiater eller psykologspesialist ansatt i en institusjon i spesialisthelsetjenesten som er godkjent for tvang. En forutsetning for bruk av OC er i tillegg at lovens kriterier er oppfylt, og at det samlet sett vurderes som det beste alternativet for pasientens videre oppfølging. Før beslutningen fattes skal pasienter og pårørende høres, og det skal etableres et samarbeid med lokalt behandlingsapparat. I hovedsak etableres OC etter et forutgående sykehusopphold, men loven åpner for å etablere OC på bakgrunn av en poliklinisk kontakt.

Et økende antall internasjonale studier har undersøkt om OC reduserer antall reinnleggelses og sykehusdøgn, om pasienter underlagt OC i større grad følger opp behandlingen etter utskrivelse fra døgnopphold og om ordningen bedrer pasienters livskvalitet på kort og på lengre sikt. De tre randomiserte studiene som er publisert så langt konkluderer med at OC

ikke reduserer pasientens forbruk av helsetjenester i form av færre reinnleggelser eller færre sykehusdøgn, og at det ikke er mulig å vise om OC er til fordel for pasientenes behandlingsutfall. Systematiske kunnskapsoppsummeringer konkluderer med det samme. Kvantitative ikke-randomiserte studier viser sprikende resultater. Noen finner at OC reduserer forbruk av helsetjenester og forbedrer pasienters behandlingsetterlevelse, mens andre enten finner at OC ikke gjør noen forskjell eller øker pasientens forbruk av helsetjenester. Resultatene i kvalitative studier spriker også, men et gjennomgående funn er at pårørende og helsepersonell er mer fornøyd med OC enn pasienter underlagt ordningen.

Avhandlingen har en kvalitativ tilnærming med et deskriptivt og eksplorativt design. Data er basert på individuelle intervjuer med 16 pasienter, 11 pårørende og tre fokusgruppeintervjuer med totalt 22 helsearbeidere. Helsearbeiderne hadde erfaring med oppfølging av pasienter underlagt OC, enten som vedtaksansvarlige eller fra oppfølging av OC pasienter i spesialist- eller kommunehelsetjenesten. Analysen av pasientdata er basert på konstruktivistisk grounded theory, og analysen av data fra pårørende og helsepersonell er basert på kvalitativ innholdsanalyse. Studien er gjennomført i to fylker øst i Norge (Hedmark og Oppland). Avhandlingens resultater er publisert i 3 vitenskapelige artikler.

Resultatene viser at pasienter underlagt OC ønsker å medvirke mer i egen behandling, og få aksept for egne ønsker og erfaringer i behandling og oppfølging. De opplever at ordningen holder dem i en pasientrolle som begrenser muligheten til å ta ansvar i egen bedringsprosess. Pårørende opplever OC som en avlastning. Samtidig ønsker de å være mer involvert, og at helsepersonell anerkjenner deres kompetanse og erfaringer. Både pasienter og pårørende opplever å mangle informasjon om OC. Dette skaper gråsoner og usikkerhet i forhold til hvordan de forstår ordningen. Helsepersonell opplever at OC gir dem mulighet til å ivareta

pasientens behandlingsbehov, og et samfunnsansvar ved at ordningen gir dem hjemmel til å intervensere hvis pasienten får tilbakefall og økende symptomer på alvorlig psykisk lidelse. Helsepersonell opplever ordningen som nødvendig, men erfarer samtidig et dilemma når de skal kombinere et terapeutisk ansvar med det å forvalte tvang. Mens pasienter og pårørende i stor grad hadde et sosialpsykiatrisk perspektiv på pasientens behandlingsbehov, la helsepersonell i større grad til grunn en medisinsk behandlingsforståelse. Pasienter underlagt OC opplevde at tvangsrammene hindret dem i egne bedringsprosesser, mens helsepersonell mente rammene var nødvendige for å sikre god behandling. Pårørende sto i en mellomposisjon og var mer opptatt av behandlingsresultatet enn behandlingsrammen.

Avhandlingens konklusjon er at OC pasienter erfarer at ordningen er mer inngripende i hverdagen enn helsepersonell gjør. Pårørende er lite opptatt av tvang, de er opptatt av om pasientens funksjonsevne blir bedret. Helsepersonell bør i større grad vurdere om OC er like nyttig for alle aktuelle pasienter med psykose, og om manglende samarbeid om behandlingen også kan skyldes at pasientene har andre prioriteringer for egen hverdag. Bedring av psykisk lidelse handler i stor grad om at pasienter utvikler strategier og ferdigheter til å takle hverdagens utfordringer. Når OC i stor grad begrunnes med pasientens behandlingsbehov, må ordningen tilrettelegges for at pasienten får medvirke til egen recovery, og at ressurser i pasientens omgivelser utnyttes til beste for pasientens behandling. Resultatene viser at samhandlingen mellom pasienter, pårørende og vedtaksansvarlige må forbedres sammenlignet med hvordan ordningen praktiseres i dag.

1.0 INTRODUCTION

There is little research-based knowledge on the extent and content of outpatient commitment orders (OC) in Norway. There is a particular lack of knowledge of the experiences of those affected. The purpose of this thesis is to contribute new knowledge about the experiences of OC of patients, their relatives and health professionals with responsibility in the scheme. The thesis will also explore how differences in the experiences of patients, families and health professionals can be understood.

1.1 Outpatient commitment orders

OCs are legal regimes that give clinicians the authority to supervise patients discharged from mental hospitals. The core elements are medication and clinical judgment calls (O'Reilly, Dawson, & Burns, 2012). The content and criteria of national laws vary with regard to coercive powers and the criteria for imposing OC (Høyer & Ferris, 2001). Common to all the schemes is that discharged patients who still need treatment will receive it even if it is not voluntary. OC in Norway is intended to be an alternative to compulsory hospitalisation, giving patients greater freedom while maintaining the stability of continued treatment (Sjöström, Zetterberg, & Markström, 2011). The use of OC seems to be increasing despite a lack of certain knowledge about the effect of coercion in mental health treatment (Bremnes et al., 2016). Proponents argue that OC reduces the need for hospitalisation, facilitates patient follow-up and is less restrictive than hospitalisation. Critics argue that OC threatens basic human rights by stigmatising people and preventing them from living their lives as they wish (Sjöström et al., 2011). Different uses of OC in different countries have led to the criticism that the scheme is based more on various needs of social control than the patient's actual treatment needs (Burns & Dawson, 2009).

OC exists in more than 75 different jurisdictions worldwide, all in Western industrialised countries (Rugkåsa, 2016). In many ways, the increase in the use of OC is in line with a trend towards more decentralised mental health care with fewer institutional places, and a strengthening of local services where people with mental illness live and are treated in the local community (Burns, 2014; Rugkåsa & Dawson, 2013). Norway was involved in this trend at an early stage, establishing a precursor to the current scheme through “compulsory aftercare” in 1961 (Lov om psykisk helsevern [The Mental Health Act], 1961). OC was introduced later in other countries, in the late 1980s and early 1990s in the United States, Australia and New Zealand, and during the 2000s in Scotland, England, Sweden and Switzerland (Sjöström et al., 2011). Denmark introduced the scheme in 2010. Churchill, Owen, Singh, & Hotopf (2007) argue that there are two main forms of compulsory care outside hospitals in use internationally. The least restrictive form has the same criteria for OC as for involuntary hospitalisation, and aims to treat a deterioration that has already occurred. This represents an alternative to continued coercion. The preventative form usually has additional criteria to forced hospitalisation, and is intended to prevent a deterioration of the mental illness that could result in dangerousness. While OC in Norway rests on an ideology whose purpose is to ensure further treatment after discharge from inpatient care, the rationale for OC in England/Wales and New York is to protect society from relapses in the patient that may result in dangerousness. Unlike in Norway, the scheme was introduced there as a consequence of serious crimes committed by people with severe mental illness (Sjöström et al., 2011). Sweden also introduced OC after serious crimes committed by persons with a severe mental disorder. However, the ideology behind the Swedish scheme is still to help the patient back to the community, in line with the thinking in Norway (ibid.). While OC is controversial in many countries, the scheme has received little attention in Norway. One

reason may be that the system has been part of Norwegian health legislation for over fifty years.

When patients are subject to an OC order, it means that they are subject to compulsory psychiatric care while living outside an inpatient facility in the specialist health services, usually in private or council housing. Compulsory mental health care may be implemented outside an inpatient facility when it is considered a better option for the patient than continued involuntary hospitalisation. In practice, OC is almost always established after forced admission to hospital, although Norwegian legislation does allow for OC without prior inpatient care. The act *Psykisk helsevernloven* [Norwegian Mental Health Act (MHA)] (1999) does not permit coercion in the patient's home, but the patient can be required to attend appointments for examination or treatment, and may if necessary be taken there by force. Additional coercive measures such as forced medication require a separate order. Decisions on coercion can only be taken by a psychiatrist or specialist psychologist from a facility approved for the use of force (Warberg, 2011). Depending on the patient's place of residence and need for follow-up care, contact in OC in addition to the decision maker may be with staff from specialist or local services, or based on collaboration between the two.

In order to establish and implement OC, the MHA (1999) stipulates that the decision maker must make an overall assessment that takes into account the patient's illness and his or her housing, family and social situation and individual needs as well as the possibility to establish collaboration with local treatment services. Emphasis is to be placed on the patient's own wishes. One should also take into account family members and their situation. OC can be changed to forced hospitalisation by a transfer decision if the decision maker considers it necessary. There is a simplified procedure for readmission, where the decision maker admits

the patient without the need of a new external medical examination. While the patient is subject to OC, the decision maker must conduct a control assessment every three months to determine whether the patient still meets the conditions for OC. OCs are monitored by an independent commission (the “Control Commission”), which also serves as a complaints board for patients subject to OC. Even if the patient does not complain about the coercion decision, after three months the Commission will make an independent assessment of whether the conditions for compulsory care are still present. The Control Commission must also approve the extension of OC beyond one year. Such an extension by the Commission is valid for one year at a time, but there is no limit to the number of times an OC can be extended.

1.2 The Norwegian Mental Health Act

The MHA (1999) regulates the use of coercion in both inpatient and outpatient mental health care. A basic requirement for coercive care is that the patient has a severe mental disorder. The concept of a severe mental disorder covers psychosis or certain non-psychotic abnormal conditions with the same malfunctioning as in psychosis. Prolonged psychoses are included, also in asymptomatic periods, since the lack of symptoms may be related to antipsychotic medication (Syse, 2007).

The MHA is legislation particularly aimed at people with mental illness. The Act aims to help people who need mental health care, and to protect other people if the mental illness makes a patient a danger to others. The purpose of the Act is to ensure that the establishment and implementation of mental health care takes place in a responsible manner and in accordance with fundamental legal principles (Syse, 2007). Interventions should be based on patient needs and respect for human dignity. The Act stipulates that treatment is to be provided on a voluntary and consensual basis and in accordance with the provisions of the Patients’ Rights

Act (ibid.). A severe psychotic disorder may periodically affect a person's capacity to consent, partly or wholly invalidating it (Syse, 2007). An evaluation of the patient's capacity to consent will therefore be included in any assessment of the need for coercive intervention (Helsedirektoratet [Norwegian Directorate of Health], 2009b). But the primary factor in deciding on compulsory mental health care is still whether the patient has a severe mental disorder.

The establishment of compulsory care in accordance with section 3.3 of the MHA is criteria-based, and all of the following conditions must be met:

1. *“Voluntary mental health care has been tried, to no avail, or it is obviously pointless to try this.*
2. *The patient has been examined by two physicians, one of whom shall be independent of the responsible institution*
3. *The patient is suffering from a serious mental disorder and application of compulsory mental health care is necessary to prevent the person concerned from either (§ 3-3)*
 - a. *having the prospects of his or her health being restored or significantly improved considerably reduced, or it is highly probable that the condition of the person concerned will significantly deteriorate in the very near future, or*
 - b. *constituting an obvious and serious risk to his or her own life and health or those of others on account of his or her mental disorder.*
4. *The institution is professionally and materially capable of offering the patient satisfactory treatment and care and is approved in accordance with section 3-5 [sufficient resources and expertise to use coercion in treatment]*
5. *The patient has been given the opportunity to state his or her opinion, cf. section 3-9*
6. *Even though the conditions of the Act are otherwise satisfied, compulsory mental health care may only be applied when, after an overall assessment, this clearly appears to be the best solution for the person concerned, unless he or she constitutes an obvious and serious risk to the life or health of others. When making the assessment, special emphasis shall be placed on how great a strain the compulsory intervention will entail for the person concerned.”*

The preparatory work for the MHA emphasised that the use of coercion is a powerful intrusion in a person's autonomy, and must only be used where it is clearly the best option for the patient. The exception is if the patient poses an obvious and serious risk to others' life or

health. In this case, the concern for the safety of others has priority over the patient's best interest (Ot.prp.nr.11 [Parliamentary Proposition No. 11] 1998-1999, 1998).

The Supreme Court of Norway has handed down several decisions relevant to mental health care. These show that patients with a known history of rapid relapse after discontinuing medication themselves may still be kept under a compulsory treatment order even if they are treated optimally and are not exhibiting active symptoms (Rt. [Norwegian Supreme Court Report] 1988, p. 634; Rt. 2001, p. 1481; Rt. 2014, p. 807). The Court's assessments refer to the preparatory work for the MHA, where it is stated that coercion should not be used for excessively long periods, and that patients after a time must be allowed to attempt self-mastery without coercion (Ot.prp.nr.11 [Parliamentary Proposition No.11] 1998-1999, 1998). With regard to relapse risk, the Supreme Court previously used an expected deterioration within two months as a basis for maintaining a decision on compulsion (Rt. 2001, p. 752). In a later review, this was extended to 3-4 months, related to the half-life of newer depot medications used in treatment (Rt. 2014, p. 801).

1.3 Coercion in Norway

The use of coercion in mental health care in Norway is high compared with other countries (Sosial- og helsedirektoratet [Norwegian Directorate of Health and Social Affairs], 2006a). However, differences in legislation and the organisation of health services mean that figures for coercion are not directly comparable between countries (Rugkåsa, 2011). A comparative study has shown that Norway is probably the Nordic country with the most compulsory admissions per capita (Høyer et al., 2002). Unfortunately, incomplete records lead to some uncertainty as to the extent of coercion in Norway. Records show that there were about 8000 forced admissions involving roughly 5600 people in 2014, which was a slight increase from

2013 (Bremnes et al., 2016). The number of forced admissions gave a total of 5100 persons under compulsory orders as in- or outpatients during 2014. In the same year, 17% of admissions and 32% of hospital days in mental health care for adults were based on coercion. Also in 2014, the criteria in the MHA were the sole basis for about 72% of the decisions on compulsory care [MHA, section 3.3, point 3a]. The risk criterion alone was the justification for about 3% of decisions [MHA section 3.3, point 3b]. In about 26% of cases, the decision was based on both the treatment and the risk criterion (Bremnes et al., 2016). A survey of adult mental health clinics in 2013 showed that the treatment criterion in the MHA was used for more than three out of four patients under OC (Ose, Ådnanes, & Pettersen, 2014). Records show considerable differences in the use of coercion within and between health regions in Norway. This may be due to different interpretations of the legislation, variations in morbidity and different practices (Bremnes et al., 2016).

Schizophrenia was given as the main disorder for 46% of inpatients subject to compulsory admission in 2014 (Bremnes et al., 2016). There are no reliable figures for how many patients are under OC at any given time, but it has been calculated that of the 5100 patients in 2014 subject to compulsory mental health care, 2400 had an OC order (ibid.). Estimates suggest that between one third and one half of compulsory admissions are followed by an OC decision (Bremnes et al., 2016; Bremnes, Pedersen & Hellevik, 2010). Bremnes, Hatling, & Bjørngaard (2008) reported that the use of OC in Norway increased by 50% between 2002 and 2007. A study from the same area as the data in this thesis found that the extent of OC had increased from 2008 to 2012 (Løvsletten, Haug, Granerud, Nordby, & Smaaberg, 2016).

1.4 Research questions

The aim of this thesis is to gain knowledge of the experiences of the OC scheme of patients, their relatives and health professionals, and to examine differences in the experiences of those involved. This leads to the following research questions:

1. What are the experiences of people subject to OC, and how do they feel that OC works for them?
2. How does it feel to be a relative of a person subject to OC, and what are relatives' experiences with the scheme?
3. What are the experiences of health professionals with OC?
4. How can any differences in the experiences of OC patients, relatives and health professionals be understood?

A qualitative approach was used, based on individual interviews with patients and relatives and focus group interviews with health professionals, in order to answer the research questions. Research questions 1-3 have been explored in published articles. Research question 4 is mainly discussed through the summarising of this thesis.

2.0 BACKGROUND

The oldest known laws in Norway date back to the 10th century. Already then, the laws mentioned the relationship to people with serious mental illness (insanity). Families were responsible for looking after the insane person and there was great freedom of treatment. From the 15th to the 17th centuries, society was more involved through the creation of forced labour institutions, and later hospitals. These institutions were for poor and sick people, and treated them with a mixture of work activities and care (NOU 2011:9, 2011). An increasing understanding of mental disorders as illness emerged in the late 18th century, leading to a trend towards better adapted institutions, and a shift in treatment paradigm towards a medical understanding of mental disorders (Høyer & Dalgard, 2002). Haave (2008) writes that while the Norwegian state previously had interfered little with people's welfare and health, this changed with the establishment of a new penal code in 1842, the first general poor law in 1845, the Prison Act of 1857 and the Health Act of 1860. The state became more active and started to use professional expertise to achieve social policy objectives. A review of treatment for people with mental disorders in the early 19th century contained damning criticism of the lack of professionalism in the treatment (NOU 2011:9, 2011). This criticism led to the creation of the Act, Lov av 17. august 1848 om sindsyges behandling og forpleining [the Act of 17 August 1848 concerning the treatment and care of the insane]. This legislation was later described as an epochal shift in Norwegian psychiatry because it required health personnel to be qualified and regulated various types of treatment and care, including the possibility of using coercion (Ericsson, 1974).

The Act of 1848 regulated psychiatric treatment until it was superseded by Lov om psykisk helsevern [the Mental Health Act] (1961). In the period between these laws, psychiatric treatment largely took place in total institutions with the aim of addressing all patient needs,

with an emphasis on work and social control. From the 1930s onwards, various somatic therapies were developed; these often did not lead to improvement in terms of discharge, but made patients easier to handle. Towards the end of the period, psychotropic drugs gradually became more commonly used, and eventually talk therapies, which again changed the way psychiatric treatment was provided (Haave, 2008). The Act of 1848 did not provide for voluntary admission to a psychiatric institution; not until an amendment in 1935 was the possibility of voluntary admission and treatment included (Ot.prp. 69 (1959-1960), 1960). The Act of 1961 provided for precare and aftercare of patients needing psychiatric treatment. In the new legislation, hospitals no longer had sole responsibility for hospitalised patients. Haave (2008) writes that the idea behind precare was to prevent imprisonment while the person was waiting for a hospital place, which had been an important issue until then. The purpose of aftercare was to ensure supervision of patients after discharge to prevent readmission to overcrowded hospitals (ibid.). The preparatory work for the 1961 legislation states that the reasoning for aftercare was also based on a professional perception that aftercare would help patients to gradually learn to master life outside hospital. The purpose was thus to facilitate people's return to society and to prevent readmissions and pressure on limited hospital places. Aftercare was regulated by section 13 of the Act, and could be coercive [aftercare without discharge] or voluntary [aftercare for discharged patients] (Ot.prp. 69 (1959-1960), 1960). Compulsory aftercare then evolved and was more clearly established in the MHA (1999).

2.1 Power, social control and coercion

The MHA gives health personnel the authority to perform the treatment they consider necessary to safeguard the patient's health, if necessary by coercion. Power is understood as "the possibility for one or more people to impose their own will in social relationships, even if

other members of society should resist” (Weber, 1990, p. 53, my translation). Social control is linked to how elements of society can both regulate and restrict behaviour (Øye & Norvoll, 2013). Power and social control often have a negative connotation, but will be necessary instruments in a well-functioning society in order to create predictability and security among its people. In mental health care, power and social control are often justified as being an aspect of services that helps patients and their families to use their resources (ibid.). On the other hand, the use of power and social control that limits the scope for action of people already in a vulnerable position may appear in a negative light (Vågan, Grimen, Molander, & Terum, 2008). Patients, their relatives and health professionals are in a mutual relationship. But this relationship is not an equal one, especially not when treatment is compulsory. Many patients have a problem with the power of health professionals to define their problems and prescribe treatment (Norvoll & Husum, 2011). Diagnoses can help to create understanding, but can also take the form of control where treatment is justified more by the diagnosis than by the particular context (Foucault, 2001).

Foucault critically examined the notion that social development has given people more freedom. On the contrary, he argued that people today are subject to greater demands for intellectual normalisation and institutional discipline (Foucault, 2001). The use of force has merely changed from being open, brutal and physical to become more covert and subtle. Foucault (1995) illustrated this by describing how institutions and societies are organised so that people are observed, and deviant behaviour is sanctioned. We see parallels today in hospitals and local communities where being different is sanctioned in various ways in order to ensure optimally homogeneous functioning. This form of regimentation creates social order locally. In order to control large populations, Foucault (1999) described how, for example, the state linked up with various health professions which produced knowledge about lacks and

defects in the population. Knowledge of what people had to do to maintain their health was centralised, and health care became a tool that could be used to control the population.

Foucault (1995) pointed out that the ability to resist forms part of all power relationships, and that resistance will always be directed at something or someone. The ability to resist separates power from coercion. This distinction is important in mental health care in relation to how far patients are able to resist. Issues related to power, social control and coercion may explain the relationship between OC patients, their relatives and health professionals. Patients and relatives may easily feel powerless if they do not see any possibility to change their situation (Mathiesen, 1982).

2.2 Trends in mental health care in Norway

The Norwegian health care system is based on a Nordic welfare model characterised by universal rights to health care, in contrast to more liberal models in the UK and USA, and conservative models in Germany and France, which to a greater extent relate such rights to insurance schemes and the responsibility of the employer (Mathiesen, 2003).

Norwegian health authorities have expressed concern about the extent of coercion in mental health care (Helse- og omsorgsdepartementet [Norwegian Ministry of Health and Care Services], 2012). St.meld. nr. 25 [White Paper No. 25] (1996-1997) (1997) “Openness and Comprehensiveness. Mental Health Disorders and Service Provision” shed a critical light on Norwegian mental health care. It stated that patients were not getting the help they needed, staff felt they were not doing a good enough job and the state failed to provide people with adequate services. The White Paper concluded that much needed to be changed to improve mental health care. The user perspective was more strongly emphasised than in previous mental health plans. White Paper No. 25 was followed by St.prp. nr. 63 [Parliamentary

Proposition No. 63] (1998) “Escalation Plan for Mental Health 1999-2006”. This plan aimed to promote greater independence and coping ability for people with mental illness. It also stressed the desire that society would move towards greater emphasis on cultural and human values, where family and community were more actively involved in treatment. To achieve these goals, the Escalation Plan argued for significant enhancement of services for people with mental disorders. St.meld. nr. 47 [White Paper No. 47] (2008-2009) (2009) “The Coordination Reform. The Right Treatment - in the Right Place - at the Right Time” gave local authorities the responsibility to ensure comprehensive services involving cooperation between specialist and local health care to develop good interaction models.

“Action Plan for the Reduction and Quality Assurance of the Use of Coercion in Mental Health Care” (Sosial- og helsedirektoratet [Norwegian Directorate of Health and Social Affairs], 2006a) aimed at increased voluntariness through enhanced knowledge of coercion, and improved documentation of the use of coercion in treatment. The plan was followed up by a working group with a mandate to evaluate the treatment criterion in the MHA. The group concluded that the treatment criterion should be maintained, but that professional and legal control of the use of coercion needed to be strengthened. This was particularly true of forced medication, where it was believed that better legal protection would enhance patient autonomy and prevent unnecessary and unethical use of coercion (Helsedirektoratet [Norwegian Directorate of Health], 2009b). The working group recommended the appointment of a legislative committee with a mandate to consider ethical, professional and legal aspects of current practices in mental health care. The committee was set up in 2010 and its mandate was to clarify rules for coercion in mental health care (NOU 2011:9, 2011). It suggested several changes to the MHA in order to enhance patient autonomy, such as basing the increased emphasis on the patient’s right to consent to or refuse medical care on the

patient's decision-making capacity. In addition, the decision maker should be obliged to consult with other health professionals before making a decision on coercion (ibid.). The committee continued to use the main criterion of the MHA of a serious mental disorder, together with the risk and treatment criteria. The committee was familiar with the issues related to the long-term effects of antipsychotic medication, but based their work on the assumption that such medication is crucial to the treatment of severe mental illness, and that a lack of medical treatment could have serious consequences for people with severe mental disorders.

One objective of the reforms has been to create a more open society in which people with mental illness are integrated into the community. Until the mid-1950s, psychiatry had an individual approach where patients with serious mental disorders were treated in institutions with little contact with society (Karlsson, 1997). Mental disorders were explained as a brain disease, and there was less focus on patients' own experiences. In such a framework of understanding, relatives' experiences were also of little importance in treatment decisions (NOU 2011: 9, 2011). This view has gradually been replaced by a professional recognition that patients and their relatives have experiences important to include in the planning and implementation of health services (Beston, Holte, Eriksson, & Hummelvoll, 2005). User participation has become a natural part of mental health care, with recommendations for patients on how to interact with health professionals concerning their treatment. Studies have shown that patient participation in treatment improves treatment outcomes (Borg, Karlsson, & Stenhammer, 2013; Davidson & Roe, 2007). These developments have led to health care that is now based on an understanding that everyone has the right to services tailored to their needs. In parallel with this, health services for people with mental illness have been decentralised, allowing for patients to be increasingly supervised in their own homes using

services from district psychiatric centres (DPC) and local authority health care (Sosial- og helsedirektoratet [Norwegian Directorate of Health and Social Affairs], 2006b).

A prerequisite for community-based services is that the local community has the expertise and resources to give the patient professionally sound care (Robberstad, 2002). More decentralised health services have meant that relatives are now more involved in the care of their family members (Awad & Voruganti, 2008). Relatives will often have good knowledge of the patient, be part of the patient's social network and perform caregiving functions (Engmark, Alfstadsæther, & Holte, 2006; Weimand, Hedelin, Hall-Lord, & Sällström, 2011). As relatives of people with severe mental disorders, they may be exposed to considerable strain and find themselves pressured between patient needs, clinicians' expectations and their own lives (Doornbos, 2002). Relatives may therefore be a resource but also need information, guidance and practical assistance to deal with their situation (Helsedirektoratet [Norwegian Directorate of Health], 2008). Information on patients' health and treatment is confidential, and the patient's consent is required for relatives to be informed (Pasient- og brukerrettighetsloven [Patients' Rights Act], 1999). However, the Act gives families the right to information in situations where the patient is unable to exercise his or her rights due to the severity of the disorder. Studies have shown that the involvement of relatives reduces the risk of relapse (Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001), improves patients' social functioning (Magliano, Fiorillo, Malangone, De Rosa & Maj, 2006) and enhances the experience of mastery in both patients and relatives (Lehman et al., 2004). This shows the need to involve family members in planning and implementing treatment.

These changes in health care, involving increased participation by both patients and their families, make new demands on health professionals. More than previously, they must

communicate complex knowledge in such a way that patients and their relatives are involved in treatment on an informed basis. The requirements and obligations of health personnel are described in Helsepersonelloven [the Health Personnel Act] (1999). This states that health personnel must organise health care in such a way that they can comply with their legal obligations, which implies following the intentions of the MHA and the Patients' Rights Act. The challenges in the treatment of people needing long-term, coordinated services have led to an individual plan becoming a patient right (Helse- og omsorgsdepartementet [Norwegian Ministry of Health and Care Services], 2011). The purpose of the individual plan is to put user needs at the forefront, and to ensure that people in need of long-term contact with the health services have a plan that clarifies responsibilities and highlights their need for further treatment and follow-up care.

3.0 STATUS OF KNOWLEDGE ON OUTPATIENT COMMITMENT

This chapter will review research on OC. A prerequisite for the acquisition of new knowledge is to formulate new questions on the basis of existing knowledge. The ideal is cumulative research where individual findings are linked to form theories, and where the boundaries of certain knowledge are systematically extended (Hellevik, 2003). In the present thesis, the survey of the status of knowledge was performed through literature searches in electronic databases. All the results were reviewed on the basis of the research questions (Polit & Beck, 2014). The criteria for the searches were that the articles were peer reviewed, written in English or a Scandinavian language and concerned OC. All searches were performed with the support of the library services.

As a basis for the project description, the first literature search was performed by a professional development unit at one of the hospitals in the study catchment area. Their pre-understanding was that there were few previous studies dealing with experiences of OC. The search was performed in the PsykINFO database, using the keywords “outpatient treatment”, “mental health” and “involuntary treatment”. This literature search yielded 79 articles that were then reviewed. The initial search was followed up by the first author with one search in advance of each of the sub-studies of the thesis. These searches were conducted in Medline, PsychINFO, Cinahl, SweMed and Embase, which were the databases considered most relevant to the themes of the studies. For the study on patient experiences with OC, the terms were “coercion”, “mental health”, “outpatient commitment”, “patient experiences” and “psychosis”. The literature search for the study on relatives’ experiences involved the terms “community care”, “coercion”, “family burden”, “family participation” and “outpatient commitment”. In the study of health professionals’ experiences, the terms were “insight”, “mental health professionals”, “outpatient commitment” and “psychosis”. Each search

resulted in hundreds of hits; these were reviewed but then reduced to about 100 based on their relevance to the thesis. The references in key articles led to some additional studies that the searches had not found. The literature searches revealed that research on OC has been increasing in recent years and that the literature is particularly related to research in the US, Canada, UK and Australia. The review showed that the purpose of OC was to avoid relapse and readmission, and that the target group was quite similar in different countries.

The arguments for OC are that the scheme reduces the number of readmissions and hospital days, improves patient follow-up care and is less intrusive than continued hospitalisation (Sjöström et al., 2011). Criticism of OC has pointed out that it threatens fundamental human rights, is stigmatising and prevents people from living their lives as they wish (ibid.). One danger of unilaterally emphasising individual freedom may be that this overshadows the fact that people do not exist in a relational vacuum, but live in reciprocal relationships in which they affect and are affected by interaction with others (Lepping & Raveesh, 2014). According to Dale (2010), OC would be appropriate when the goal was to enable people to interact with others on an independent basis. A more fundamental perspective is to perceive coercion on whatever grounds as a violation of human rights (Orefellen, 2011).

One argument for using coercive interventions is that coercion improves patient outcomes. Høyer (2009) concluded that in the treatment of people with mental illness there is no certain knowledge of either a positive or negative impact of the use of coercion on treatment outcome. Nevertheless, he found that many mental health patients under coercion were dissatisfied with their treatment. A complicating factor in the study of coercion is the variation in patients' perceptions of coercion. Studies have shown that patients subject to formal coercion do not always feel under coercion, while patients in voluntary treatment may have a

powerful sense of being subjected to coercion (Bindman et al., 2005; Kjellin, Hoyer, Engberg, Kaltiala-Heino, & Sigurjonsdottir, 2006). A study by Iversen, Hoyer, Sexton, & Gronli (2002) showed that patients' formal status was a poor predictor of their experience of coercion; here, 32% of voluntarily admitted patients reported a strong feeling of coercion while 41 per cent of those admitted involuntarily reported a weak feeling of coercion. Høyer & Dalgard (2002) and Norvoll & Husum (2011) pointed out that health professionals' understanding of what constitutes advice, pressure, persuasion and coercion often does not coincide with the patient's experience. Lidz et al. (2000) pointed out that relatives often have a more positive experience of coercion in treatment than patients themselves.

3.1 Studies with a quantitative design

A review by Rugkasa, Dawson, & Burns (2014) showed that the focus of research on OC has moved from human rights towards the effect of treatment. Research into OC using a quantitative approach has mainly been based on studies of OC relative to consumption of health services. The need for readmissions and the number of hospital days have been used as a measure of whether being under OC improves patients' ability to live outside care facilities. There have also been studies of the extent to which patients comply with medical treatment, and whether OC changes patients' perceived quality of life in the short and long term. There have been few randomised studies of the effect of OC. This is due to ethical and methodological problems in implementing a randomised design with patients who may be candidates for OC (Swanson & Swartz, 2014). People subject to OC have a serious mental disorder, and it may be ethically problematical to randomise patients to one group under OC and one group without the scheme. Only three randomised studies have been conducted, two in the US (Steadman et al., 2001; Swartz et al., 1999) and one in the UK (Burns et al., 2013). The US studies compared OC patients with patients discharged to voluntary follow-up care.

These studies found no effect of OC on reducing readmissions, hospital days and the need for further follow-up care or on patient treatment compliance. They also found no difference in the patients in terms of enhanced social functioning, improved mental health, better perceived quality of life, greater satisfaction with health care or less perceived compulsion. The UK study compared OC patients with a control group who were on time-limited leave from hospital, but also found no reduction in consumption of health care, readmissions or hospital days or any difference in treatment compliance in the OC group. These findings have been verified through subsequent measurements involving the same patient group with the same result (Burns et al., 2015). One criticism of the UK study was that it compared two forms of coercion, rather than comparing OC with a voluntary treatment programme (Swanson & Swartz, 2014; Szmukler, 2015).

Several non-randomised studies have examined the effect of OC by comparing patients with an OC decision at discharge with patients with the same follow-up care, but on a voluntary basis. Some studies have shown that OC reduced the number of readmissions to hospital (Hunt, da Silva, Lurie, & Goldbloom, 2007; Muirhead, Harvey, & Ingram, 2006; Nakhost, Perry, & Frank, 2012; Segal & Burgess, 2006a; Swartz et al., 2010). Three of these studies found a further decline in the number of readmissions if OC was used for more than six months (Hunt et al., 2007; Segal & Burgess, 2006a; Swartz et al., 2010). Maughan, Molodynski, Rugkåsa, & Burns (2013) discussed this finding and pointed out that in many jurisdictions, an extension of the OC is considered after six months. It may therefore be the case that patients who remain under OC beyond six months are those who benefit from the scheme. Other studies have shown more readmissions and hospital days in parallel with the patient being subject to OC (Segal & Burgess, 2006b; Zanni & Stavis, 2007). A Swedish study investigated the use of compulsory mental health care before and after the introduction

of OC. It found that the introduction of OC reduced the number of compulsory inpatient days, while compulsory follow-up outpatient care increased. Overall, the results showed that the total use of coercion increased after the introduction of OC (Kjellin & Peltö-Piri, 2014). However, the study concluded that the aim of using OC was fulfilled since the number of long compulsory hospital stays had been reduced.

Studies by Coyle et al. (2013) and Manning, Molodynski, Rugkåsa, Dawson, & Burns (2011) both showed that health professionals mainly implement OC on the basis of clinical reasoning, where the aims are to ensure medical compliance, prevent relapse and ensure that the patient maintains contact with health professionals after discharge. Studies by Busch, Wilder, Van Dorn, Swartz, & Swanson (2010) and Van Dorn et al. (2010) supported the finding that OC improved patients' medical compliance. Coyle et al. (2013) found a difference in the experience of OC between the professional groups involved in treatment. Nurses who worked with the patient were concerned that the lack of psychological interventions such as talk therapy could make OC less effective. Psychiatrists were more concerned about whether the scheme was being implemented as planned. Both nurses and psychiatrists believed that OC over time promoted therapeutic cooperation by creating stability and improving the patient's understanding of the illness. As they saw it, the benefits of the scheme outweighed the disadvantages of using coercion in the treatment.

3.2 Studies with a qualitative design

Qualitative studies have examined OC by exploring patients', relatives' and health professionals' experiences with the scheme. A consistent finding from qualitative studies has been that relatives and health professionals were more satisfied with OC than the patients subject to the scheme (Canvin, Rugkasa, Sinclair, & Burns, 2014).

Patient experiences

Gibbs, Dawson, Ansley, & Mullen (2005) interviewed patients about their experiences with OC and found that most had a positive experience and believed that OC was an important measure to help them towards stability and integration into society. O'Reilly, Keegan, Corring, Shrikhande, & Natarajan (2006) showed that patients under OC were ambivalent towards the scheme, but thought that it could help to create more structure in everyday life. Riley, Høyer & Lorem (2014) found that patients felt that OC limited their freedom, but that they adapted to it. Common to these three studies was that patients compared OC with continued compulsory hospitalisation, and did not see it as voluntary follow-up care. Stroud, Banks & Doughty (2015) showed that patients who accepted OC, and used the framework to create structure in their lives, were those who benefitted the most from OC. Brophy & Ring (2004) found that patients experienced OC as stigmatising, and felt disempowered and excluded from decisions. Gault (2009) showed similar findings, and believed that patients over time adapted to OC and accepted that they needed treatment. Ridley & Hunter (2013) found that patients experienced that the OC framework worked better when they felt that they received respect and dialogue from staff. This study also pointed out that although staff listened to patients, OC did not always make them feel more included in decision making, particularly with regard to medication. The reason why patients complied with medication anyway was because they felt threatened with readmission if they broke the agreement on medication. Most recently, Canvin et al. (2014) showed that patients felt they lacked information on OC, which led to gray areas that made everyday life appear more regimented and less flexible.

Relatives' experiences

While many studies have examined the everyday life of relatives of people with severe mental illness, fewer have explored relatives' experiences when a family member is subject to OC

(Mullen, Gibbs, & Dawson, 2006). O'Reilly et al. (2006) showed that family members were positive towards OC because it helped to stabilise the patient's life, and therefore their own lives. As Mullen et al. (2006) also found, their experience was that OC led to a better relationship between them and the patient. They found that the patient was more stable and more open to contact. But at the same time, they found that clinicians did not give much weight to their experience. They were also unsure whether the staff would follow up the treatment programme in practice. The extent to which relatives believed that coercion would improve patient outcome was an important factor in their assessment of coercive outpatient treatment (Swartz, Swanson, & Monahan, 2003). Relatives felt that medication and the possibility of readmission were the central elements of OC, and the possibility of readmission was what gave the scheme authority (Canvin et al., 2014). But they also thought that OC should cover more areas of everyday life to enhance the patient's functioning. They felt that OC supported their situation by allowing more people to be involved. They needed this reassurance to act as support for their family member (Weimand et al., 2011).

Experiences of health professionals

There are few studies of health professionals' experiences of OC. Dawson and Mullen (2008) pointed out that health professionals' assessment of the patient's illness insight and cooperation on treatment was important when they were considering OC. They found that health professionals believed that the use of OC over time improved treatment stability in that the patient gained better understanding of the treatment. As Romans, Dawson, Mullen, and Gibbs (2004) and O'Reilly et al. (2006) showed, health professionals wanted to work in a practice that provided the opportunity to use OC. But both these studies also pointed out that OC could have a negative effect on the therapeutic relationship. Mullen, Dawson, & Gibbs (2006) showed that healthcare professionals weighed up the benefits and disadvantages when considering the use of OC to support treatment. Their assessment focused on how OC would

affect the therapeutic alliance, when OC could be terminated, what threshold applied for readmission and how they should balance their professional authority with the patient's desire for participation. Stroud et al. (2015) showed that health professionals found OC to be a safety net because it gave them a structure to work in. Manning et al. (2011) and Canvin et al. (2014) reported that health professionals thought OC had the greatest effect when the patient accepted the framework involved. If patients did not comply, the usefulness of OC had to be balanced against the risk of creating mistrust that could harm the therapeutic relationship. According to these latter two studies, psychiatrists found they had to use readmission as a threat to ensure cooperation on medication. The disadvantage was that it could prevent treatment cooperation.

3.3 Knowledge reviews on OC

Systematic knowledge reviews do not lend support to the idea that OC improves treatment outcomes. Churchill et al. (2007) conducted a literature search on OC for the period 1966 to 2005 which included 72 studies from six different countries. This summary found no evidence that OC reduced the number of readmissions and hospital days, increased patients' medical compliance or improved their perceived quality of life. The study concluded that it was not possible to determine whether OC was an advantage or disadvantage for patients subject to the scheme. Maughan et al. (2013) followed Churchill's study with a summary of knowledge which included 18 studies conducted in 2006-2013. They concluded that there was still no scientific evidence that OC reduces patients' use of health services or improves their treatment outcomes. A Cochrane review found that the results of the randomised studies by Swartz et al. (1999) and Steadman et al. (2001) were valid, even when the two studies were merged to increase the number of participants (Kisely, Campbell, & Preston, 2011). The study by Burns et al. (2013) was later included in a new Cochrane review with the same result

(Kisely & Hall, 2014). Kisely (2016) reviewed studies on OC conducted in Canada and found the knowledge base underlying the use of OC to be uncertain. Rugkåsa (2016) compared the results from randomised studies and systematic literature reviews on OC in a study which also included studies published between 2013 and 2015. Rugkåsa's conclusion was that there is still no scientific basis for asserting that OC improves patients' treatment outcomes.

4.0 METHODS AND MATERIALS

The thesis has a qualitative approach, where an understanding of the features and characteristics of OC is sought through the use of qualitative methodology. Qualitative methods are based on theories of interpretation of human experience, and aim to explore meaning and complexity in everyday life through talking to people about their experiences (Silverman, 2013). The study has a descriptive and exploratory design, which is considered to be appropriate to answer the research questions. A descriptive approach will present OC as it is experienced by those involved. An exploratory approach will explore an area where there exists little prior knowledge (Polit & Beck, 2014). In all the sub-studies, informant selection was criteria-based and appropriate, and only included participants with experience relevant to the research questions (Silverman, 2013).

4.1 Theoretical standpoint

The theoretical basis of the thesis is hermeneutics, and its epistemological standpoint is symbolic interactionism (Blumer, 1969) and hermeneutic-phenomenology (Gadamer, 2004). These theories seek in different ways to clarify the ontological questions of what is in the world and what are the characteristics and true nature of things. Epistemological questions concern what we can know or recognise in these things (Thornquist, 2003). An interpretive knowledge tradition will challenge a scientific approach that understands reality as given, where the researcher in a distanced manner observes and describes characteristics of a phenomenon as independently as possible of its context. Instead, reality is conceived as created between people who interact in relation to it (Birkler, 2011).

Hermeneutics is concerned with a deeper understanding of meaning and relates knowledge acquisition to the interpretation of texts. Important concepts are the horizon of understanding,

prejudice and the hermeneutic circle (Gadamer, 1993). The horizon of understanding is the totality of a person's perceptions, experiences and expectations. Prejudice is associated with something which precedes and affects what follows. A person is never without pre-understanding when confronted with a text, but is influenced by his or her thoughts and experiences. The hermeneutic circle represents an interpretive principle where the whole is understood through the parts and the parts through the whole. These three concepts form part of the hermeneutical method. Interpretation of data takes place in a combination of empiricism, theory and experience, and in this way always contains an innovative element. This is a dynamic process whereby each new element that is understood expands the understanding of the parts and the whole (Lavery, 2003). Gadamer (1993) maintained that a complete understanding does not take place until there is a fusion of horizons where one person enters another's way of thinking, listens and in this way increases his or her own understanding.

Symbolic interactionism understands all interaction as social and explained by the importance of various situations for the people involved. Meaning is created through the interpretation of interactions with others (Blumer, 1969). Symbolic interactionism helps us to understand our social reality in explaining how experiences are created in interaction between people and their environment. While symbolic interactionism is concerned with actions in process, hermeneutic-phenomenology draws attention to people's subjective experiences. A phenomenological perspective focuses on the world as it is experienced by the subject, and relates knowledge to the context in which it occurs (Hummelvoll & da Silva, 1996). Meaning and understanding are created through an examination of lived experiences (Wilson & Hutchinson, 1991). The approach is descriptive and uses an inside perspective to attempt to explore and describe phenomena as they are experienced. It requires a naive and unprejudiced

approach where the researcher has a critical and reflective attitude towards his own standpoint (ibid.).

The scientific approach to the study of patients was based on grounded theory (GT). GT has its roots in both positivism and symbolic interactionism. The method was developed by Glaser & Strauss (1967) who understood data as objectively given. Charmaz (2014) later developed a constructivist branch of GT where meaning, concepts and theories are understood as constructed through an interaction between people, perspectives and research practices. Social constructivism entails an assumption that the world or its phenomena are the result of the operation of collectives (Nortvedt & Grimen, 2004). The constructivist approach enabled an examination of how coercion affected relationships between people. Charmaz (2014) thus loosened GT from its positivistic foundation in emphasising that the researcher was part of the research process. From another epistemological starting point, constructivist GT (hereafter synonymous with GT) is therefore understood as a method within an interpretive scientific tradition (Lind, 2013).

The studies of the experiences of relatives and health professionals were based on qualitative content analysis as described by Graneheim and Lundman (2004). The method builds on a hermeneutic-phenomenological understanding of knowledge, and gave these studies a different epistemological basis from the patient study (Hartman, 2001). Relatives and health professionals were not themselves subjected to coercion, but related to the phenomenon through their relationship to the patient. We wished to examine their experiences of the use of coercion in treatment, while maintaining a perspective on how coercion affected social relations. Graneheim and Lundman's methodological approach focuses on the individual and the context, and shows how a hermeneutical-phenomenological approach can enable good

descriptions of the experiences of participants to lead to new understanding of the totality of their experiences. Hermeneutic-phenomenological content analysis is considered a useful approach to understand people's experiences based on their understanding of various phenomena (Crist & Tanner, 2003). Graneheim and Lundmann emphasised that reality is contextual, and that knowledge is developed in a cultural and historical context in interaction between the researcher and the research field. Meaning and understanding can be changed according to the individual's subjective interpretation of situations. The data collection focused on getting good descriptions. Using an interpretative approach, the data analysis would thus be able to produce new knowledge about an underlying meaning.

Both GT and qualitative content analysis have an inductive research approach where general conclusions are drawn from individual observations (Creswell, 2013). Both approaches use a phenomenological perspective as a starting point for data collection; this perspective forms the basis for the hermeneutical interpretation. Laverly (2003) showed that a phenomenological perspective becomes hermeneutic when it shifts from being descriptive to interpreting the data. The difference in analysis and interpretation is that GT seeks relationships to develop social theories, while qualitative content analysis seeks to deepen and understand the experiences of individuals (Starks & Trinidad, 2007).

4.2 Recruitment and setting

The studies were conducted in the counties of Hedmark and Oppland, with a combined population of about 384 000 (Norges fylker [Norwegian Counties], 2016). These counties consist mainly of towns of about 30 000 inhabitants and villages in the countryside. There are specialist and local authority mental health services. Specialist health care includes two psychiatric hospitals and five district psychiatric centres (DPC). A DPC represents a level of

treatment between local health services and hospitals. A total of 48 local authorities have mental health services. OC was organised differently in the two counties. One county had transferred the responsibility for OC patients from the hospital to the DPCs. OC could be established in the hospital, but the responsibility was transferred to a DPC on discharge. The other county had organised the responsibility for OC patients in both the hospital and the DPCs. In addition to their contact with the decision maker, patients in the counties were supervised by health professionals from both local and specialist health services. This supervision overlapped in that the division of responsibility was agreed on in relation to the individual patient's history and needs.

4.2.1 Recruitment and participants, Paper 1

The inclusion criteria for the study of patient experiences of OC were that the patient had been under OC for at least six months, lived in one of the counties and was still under OC at the time of the interview. It was also required that the patient had the capacity to consent to participate, in the decision maker's assessment. The minimum period of six months was set to ensure that patients had an adequate basis to express an opinion on OC. It was important that patients were under OC at the time of the interview to ensure that OC was a current issue, not an intervention they viewed retrospectively. The age range of 18-67 years was based on a desire to study OC in an adult psychiatric population. Only Norwegian-speaking participants were chosen in order to provide good interview data.

Recruitment to the study was based on an overview in each hospital of all patients subject to OC; this showed that 33 patients met the inclusion criteria when the study commenced in December 2012. The decision maker gave patients an invitation to participate, supported by an information sheet. Clinicians in the specialist and local services followed up the requests

and confirmation of participation usually came from these. Based on the hospital overview, 16 interviews were conducted until October 2013. The number of patients meeting the inclusion criteria varied somewhat during the inclusion period, as OC was terminated for some patients while others joined the scheme. We chose to end recruitment after 16 interviews, because the last interviews had confirmed the content of the previous ones without contributing anything new [described by Charmaz (2014) as saturation], and because there were no new potential interviewees at that point. We therefore did not find it appropriate to wait for new participants. The characteristics of the participants are shown in Table 1:

Table 1: Characteristics of patients included in the study on the basis of selected variables by ten-year age groups

Participants	N	Age:					Median
		20-30	31-40	41-50	51-60	61-70	
Male	8		3	4		1	43
Female	8	3	1	1	1	2	41
Diagnosis							
Schizophrenia	12	2	2	4	1	3	
Mood disorder	3		2	1			
Other psychotic disorder	1	1					
Housing							
Lives alone in staffed sheltered housing	6	3		2		1	
Lives alone in own or rented accommodation	10		4	3	1	2	
Income							
Disability benefits	16	3	4	5	1	3	
Forced medication decision							
Current	2		1			1	
Previous	7	2	2	1	1	1	
Never	7	1	1	4		1	
Substance abuse							
Yes	9	2	3	3	1		
No	7	1	1	2		3	

An overview of the use of OC in Norway shows that most patients are male. They are usually aged 30-50, seven out of ten have a schizophrenic disorder, a large proportion live alone and most receive disability benefits (NOU 2011: 9, 2011). There is considerable concurrence

between severe mental illness and substance abuse (Helsedirektoratet [Norwegian Directorate of Health], 2012). Apart from a higher proportion of women in the present study, our selection coincides well with the general Norwegian OC population. Only two (12 percent) of the participants had a current forced medication order in parallel with OC. This is lower than reported by Drivenes (2014), who found a proportion of 39 percent. Two-thirds of the participants in our study had experience of a forced medication order.

4.2.2 Recruitment and participants, Paper 2

The inclusion criteria in the study of relatives' experiences of OC were that the participants were relatives over 18 of patients in the first study, and that they were Norwegian speakers, to ensure good interview data. The aim was to shed light on the relatives' situation. Participants were those whom the patients had indicated as their close relatives (Pasient- og brukerrettighetsloven [Patients' Rights Act], 1999). Patients were asked on inclusion in the study whether they consented to their relatives being approached. Only three agreed to this. Relatives of two of these patients agreed to participate. The original plan was to interview patients and relatives in pairs, but since only two such interviews were possible, we rejected this procedure. Our assessment was that only two relatives was too small a sample to adequately represent their situation. Recruitment was therefore expanded to include relatives of patients who lived in the catchment area but who had refused to participate. This change was approved by the Data Protection Officer on condition that the patients consented to their relatives being approached. The team disagreed with this assessment on the grounds that it deprived relatives as a group of the opportunity to express their own experiences, and secondarily that the requirement of patient consent could result in a specially selected group of relatives with a risk of bias in the data. However, for pragmatic reasons we chose to follow the recommendations of the Data Protection Officer.

In the second round of inclusion, 8 patients consented to their relatives being approached. One of the relatives did not want to participate. Ten interviews with 11 relatives of 9 patients were conducted. Two relatives of the same patient lived separately and were interviewed individually. Another two relatives of one patient were interviewed together. Table 2 shows characteristics reported by relatives:

Table 2: Characteristics of relatives in terms of gender, age range, relationship and main activity

Participants (n = 11)		Relationship to patient		Main activity	
Male	3	Parent	4	Student	2
Female	8	Sibling	4	Employed	2
Age range	20-83	Spouse	1	Old age pensioner	6
		Child	1	Disability pensioner	1
		Other	1		

All interviews were conducted from September 2013 to August 2014.

4.2.3 Recruitment and participants, Paper 3

The study of clinicians' experiences with OC recruited health professionals responsible for decision making or for work with patients during OC. The inclusion criteria were that they worked in the study catchment area, had at least a 75% position and clinical experience of working with OC patients for at least a year. The inclusion was strategic in that the aim was to recruit as many clinicians as possible with experience of working with patients on OC orders. Based on the same hospital overview of OC patients as in the patient study, those invited to participate were health professionals working at one hospital, four DPCs and in four local authorities, two urban and two rural. The written invitation was sent to the director of each facility. Due to lack of time, one rural local authority declined to participate. Profession, place of work and responsibilities reported by the participants are shown in Table 3:

Table 3: Profession, place of work and responsibilities of participants

Participants (n = 22)	Hospital	DPC	Local authority health services	Decision maker	Follow-up work in OC
Psychiatrist	1	5		6	
Psychologist		2		2	
Mental health nurse		5	4		9
Nurse	2				2
Assistant nurse			3		3

The follow-up work with OC patients was organised in collaboration between the decision maker and other health professionals in hospitals, DPCs and local authority health services. The other health professionals had overlapping functions related to following up the OC decision and practical everyday supervision of the patient adapted to the patient's history and needs.

4.3 The interviews

A qualitative research interview is neither a free conversation nor based on a structured questionnaire. In order to create a meaningful conversation, the researcher is required to have some knowledge of the topic being researched. As a form of conversation, such an interview allows for an in-depth exploration of a topic with a person or group with experience of the phenomenon (Kvale, 2006). For our data collection method, we chose individual interviews with patients and relatives (ibid.) and focus group interviews with health professionals (Malterud, 2012). The main structure in both approaches was based on the qualitative research interview described by Kvale (2006). The purpose was to reveal descriptions of participants' everyday lives, especially with regard to their understanding of the phenomenon of OC. The focus was not on general opinions but on specific experiences. An individual approach was chosen on the assumption that both patients and relatives would be vulnerable if expected to share their stories in a group. We assumed that it would be easier to obtain nuanced stories

about personal experiences through individual interviews (Hummelvoll, Andvig, & Lyberg, 2010). Data from the individual interviews provided the basis for articles one and two. For the study of health professionals' experiences, the data collection method was focus group interviews. The use of focus groups is considered a useful approach for exploring experiences, attitudes and views in an environment where people interact, and is therefore suitable to study health professionals' views and experiences (Malterud, 2012). The group dynamics could help to create new stories by encouraging participants to deepen and clarify their views in a way that would not be possible in an individual interview (Granerud, 2008). Data from the focus group interviews formed the basis of article three.

In all the interviews, it was important to be open to allow the participants to come up with new and unexpected views. As an interviewer, I concentrated on being attentive and supporting the participants' reflections with comments and clarifying questions. There was a continual focus on understanding the participants' experiences of OC. Ambiguous statements were examined to determine whether they were due to communication difficulties or whether they represented the participants' unclear views. My experience was that the conversation in the interviews helped to raise the participants' awareness and deepen their understanding of their situation. The interviews were adapted according to how direct and probing questions the participants seemed comfortable with. My own experiences enabled me to ask targeted questions, while it was also important to remain aware of my experience of mental health care. Without such a reflective attitude, there would have been a danger that my questions sought confirmation or defended my own experiences rather than being exploratory (Coghlan & Casey, 2001).

In accordance with a hermeneutical understanding, the experiences from earlier interviews influenced later ones, as the interviews built on each other and followed each other towards a comprehensive understanding. In the patient study, this particularly took place as part of the methodological approach (Charmaz, 2014). In GT, the interview guide develops during the process in order to follow up and deepen earlier themes in later interviews. The hermeneutic-phenomenological approach also sought to achieve in-depth understanding. Here, all interviews were completed before the analysis started.

Of a total of 30 interviews, 27 were sound-recorded and supported by brief written notes. In the other three, notes were taken during the interviews. After each interview, the first author noted down his reflections from the interview. In GT, such reflections are part of the method and the memos are included in the analysis (Charmaz, 2014). In the qualitative content analysis, such notes were also useful with their descriptions of context and the interviewer's thoughts immediately after the interview. The digital recordings were transcribed verbatim by the first author, except for two patient interviews and two relatives' interviews which were transcribed by a medical secretary. The recordings, notes and transcripts were the empirical data of the study.

4.3.1 The interview guides

In all the studies, the interviews were based on a thematic interview guide developed on the basis of the research group's theoretical understanding and practical experience of OC. A staff member with user experience participated in the design of the interview guides. The research group consisted of the first author, with clinical experience of working with patients subject to OC, and three experienced researchers, one of whom had experience from research on coercion. A focus on the user perspective in the planning of the studies of patients and

relatives was important to ensure that this perspective was visible in the interviews, and that the questions were comprehensible and not felt to be offensive. In the study of health professionals' experiences, user participation provided breadth in the interview guide in that user experience complemented the research group's pre-understanding.

Thematic interview guides were developed for each of the studies. The interview themes were flexible, allowing the researcher to explore the participants' experiences. At the same time, the guide structured the interviews and served as a checklist to ensure that all the themes were included (Hummelvoll & da Silva, 1996). The interview guide for the patient study was tested in a pilot interview with a user with experience of being under OC. The pilot interview showed that it might be difficult to distinguish between experiences of mental health care in general and OC in particular. It also revealed that forced medication received great attention at the expense of other areas we considered important in relation to life under OC. The final interview guide therefore had an overall structure consisting of an initial open question about OC followed by sub-themes that sought to explore a variety of everyday life experiences: treatment and follow-up care, autonomy and perceived restrictions, activities and relationships with family and friends. The interviews with relatives focused on their everyday lives, their understanding of coercive treatment, their experiences with specialist and local health services and their experiences with the patient's follow-up care. The interviews with health professionals were related thematically to the use of coercion, OC as a treatment framework and the organisation of OC in practice. All the interview guides are attached in an appendix to this thesis.

4.3.2 The individual interviews

The individual interviews were conducted by the first author alone. Of the 16 patient interviews, 14 were conducted in the participant's home and two in hospital premises. All participants seemed prepared for the interview and most had made coffee. In the interviews in the hospital, I served coffee. My experience from the interviews was that the participants showed great trust in me by revealing in some detail their experiences of living under OC. I found that they did not view me as a representative of the hospital, but as someone from outside who was interested in their history. Several said they had decided to participate because this was a research study, and because they felt it useful to share their experiences when the goal was new knowledge and improved services. Thirteen patients consented to digital recording; in the remaining three interviews notes were taken. All the interviews were included in the analysis, but only quotes supported by a recording have been used. As mentioned, the interview guide was adjusted during the sequence of interviews. This took place after interviews eight and twelve in order to expand on key themes in the participants' stories about forced medication, the lack of a sense of freedom and relational obstacles.

Five of the interviews with relatives took place in their homes, three in hospital premises and two in local health care premises. All the relatives agreed to digital recording. I found that the relatives showed great trust in me in the interviews by providing nuanced descriptions and sharing their personal experiences. They said that they saw the interviewer as a person outside mental health care and that they were pleased to share their experiences and that interest was being shown in OC.

4.3.3 The focus group interviews

The focus group interviews were led by the first author as moderator and a lived experience consultant as co-moderator (Malterud, 2012). Three focus group interviews were conducted in hospital premises in November and December 2014. The interviews began by the participants briefly introducing themselves, their workplace and their experience of working with OC patients. This was done to establish a basis for further discussion in the group, and in the perception that it was important for everyone to “get started” by having said something to the group. The interviews continued with an open question on the participants’ experience with OC, followed by more detailed questioning. The questions differed slightly according to the roles and responsibilities of the decision makers and of those involved in follow-up supervision. The third focus group interview focused on cooperation between decision makers and other health professionals. As the researcher, I took notes to sum up the main themes to ensure that no key points were missed. The co-moderator also noted down her reflections from her position as a listener. The co-moderator was also invited to join in to share her reflections and ask more detailed questions.

4.4 Pre-understanding

Within the theoretical perspective of the thesis, the researcher’s pre-understanding is an important factor (Charmaz, 2014; Graneheim & Lundman, 2004). I shall therefore briefly outline my professional standpoint. My work experience is mostly from specialist health services, more specifically from work in an emergency department, substance abuse treatment and facilities for people with severe mental disorders. Treatment of psychotic disorders has been my special interest. I understand psychoses as dynamic processes where the disorder develops in phases, with simultaneous elements of other emotional problems such as depression and anxiety (McGuire & Dixon, 2000). Psychodynamic theory has been

meaningful for me to understand psychoses. Central to my understanding is how psychosis represents a breakdown of people's psychological coping strategies, which then leads to a withdrawal from common reality as a strategy to cope with stress and strain. Acute psychosis constitutes a breakdown of the person's ability to maintain continuity and coherence in his or her understanding of the world. The requirement of coherence and meaning in a psychosis thus supersedes the requirement of logic and rationality. The result is misinterpretations which provide a fragile internal stability but threaten the person's participation in a common reality. Long-term psychosis involves an adjustment to everyday life which is often dysfunctional and leads to the functional obstacles typical of protracted psychoses (Cullberg, 2005).

Over the years, I have met many patients in a variety of treatment units. A turning point for my professional interest came 25 years ago, when I was working in a unit with two young psychotic patients. In working with these two, it struck me that we as staff were failing to establish a good dialogue and long-term treatment cooperation. Our attention was instead focused on the patient's large and small everyday conflicts. These conflicts prevented the development of a partnership where the goal was the patient's independent existence outside the hospital. That was the start of my efforts to explore how milieu therapy could be developed to improve treatment for the sickest patients. I was particularly interested in how milieu therapy could form a framework for other types of treatment, while also being an independent approach to allow people to develop their skills within a secure structure (Stensrud, 1999; Stensrud, 2007).

As a mental health nurse, I have given a great deal of thought to how various health professions can benefit from each other's expertise in interdisciplinary cooperation. My professional approach has always been eclectic, anchored in a psychodynamic and existential

understanding where people are perceived in terms of their history and everyday lives. The stress-vulnerability model integrates a psychological understanding with possible biological explanatory models, and this has been a meaningful model for me to understand how mental disorders develop and can be treated (Gispen-de Wied & Jansen, 2002; Zubin & Spring, 1977). My interest in psychosis has also brought me closer to the issues surrounding compulsory psychiatric care. My understanding has been that coercive treatment is a necessary framework in periods when patients lack the capacity to make positive decisions in their own lives. At the same time, I have been concerned with patient participation and cooperative solutions. A focus on recovery processes has been an important part of my professional approach, although I have not always defined this within the concept of recovery. I have considered antipsychotic medication as necessary, in spite of often feeling that it is too easy to start pharmacological treatment without first trying to find out what caused the changes in the patient's life, and whether there were other ways to address these changes.

As a leader, I have been interested in OC in recent years. I have focused on a perception that patients subject to OC must be provided with more treatment than medication supervision and controls every three months. To a lesser extent, I have also questioned the effect of OC for patients, relatives and healthcare professionals. This issue has become more apparent to me during my work on this thesis.

4.5 The analysis

The aim of the analysis was to allow for interpretation of the data. Through open and critical reflection, I wished to highlight themes, patterns and relationships in the data (Malterud, 2011). To allow the participants' experiences to be revealed as freely as possible, I was aware of my pre-understanding throughout the analysis. Charmaz (2014) argued that the researcher

should be aware of his or her position, but that an analysis free of theory is impossible; one sees what one sees on the basis of one's own experience. A hermeneutic view of science emphasises precisely the interpretation of experiences where reality is seen as constructed through interaction between people (Laverty, 2003).

The qualitative analysis entailed reorganising the data into internally homogeneous and externally heterogeneous categories that were mutually exclusive. The aim was to highlight the meaning content of the data (Starks & Trinidad, 2007). That implied a focus on the transcribed text, not on who said what (Ricœur, 1979). The first author worked on the different steps of the analysis. The implementation and results of the analysis were then discussed with the research group to validate the understanding. These processes were dynamic; concepts and new understanding were clarified and developed in an interchange between the first author and the research group. In addition, the research group read some of the interviews to assess the first author's understanding in comparison with their own understanding. In the third study, the lived experience consultant took part in the analysis through a dialogue with the first author. The unit of analysis in all the studies was the individual interview, and the analysis was supported by the NVivo 10 electronic analytical tool (Alfasoft, Sweden). This tool provided structure and an overview when the meaning content was reorganised across interviews. NVivo 10 was also used to ensure that the categories developed covered all the empirical data.

4.5.1 Analysis and interpretation - Paper 1

The analysis was based on GT. The interviews were transcribed and analysed between one interview and the next. The analysis was an ongoing process and focused on what happened and the consequences for those involved. Later interviews continued the open approach, but

focused on following up and elaborating on themes that had emerged in the preliminary analysis. Thoughts and reflections noted down from the interviews (memos) were included in the analysis. The goal was to employ an inductive approach to develop new concepts and knowledge of theoretical relationships in connection with life under OC.

The analytical process consisted of several steps. Based on Charmaz (2014), the steps followed were initial coding, focused coding and theoretical coding. In the initial coding, the data were first transcribed verbatim and then read through several times. The overriding question was what the text was about. Meaning units were isolated by questioning the text to ascertain what the participants had experienced, what caused these experiences, what strategies they used to deal with the experiences and what the consequences of the chosen strategies were (Creswell, 2013). The meaning elements were marked with a code, resulting in a table providing an overview of the preliminary findings.

In the focused coding, more overarching codes were developed to describe the content and to help to explain much of the textual material and how the parts related to each other. This took place through a concentration of the material and the construction of a story. In this phase, efforts were made to select the most significant codes based on their regular occurrence in the material. An important strategy was to examine how the codes related to each other, and whether there were overlapping areas. It was also studied whether it was possible to establish a hierarchy where some areas were superior to others. In this way, six sub-categories were drawn up, describing different experiences of living under OC. These experiences were interrelated and together resulted in an understanding divided into three categories. Table 4 shows the sub-categories and categories derived from a quote from one patient:

Table 4: Exemplification of how sub-categories and categories were derived from patient experiences

Patients' experiences	Sub-categories	Categories
<p><i>“My friends are really annoyed with the whole arrangement. I go fishing a lot in the summer. At five o'clock I have to come and take tablets. I can't spend the night anywhere, because at seven a.m. they bring the tablets to my home. Three days a week I have to take a urine test at the doctor's. So everything's split up all the time, I never kind of get a whole day.”</i></p>	<p>Being different Being punished Insecurity in relationships Being devalued Freedom with restrictions</p>	<p>Perceived coercion Dependence on health care providers Constrained social interaction</p>

Theoretical coding consisted of exploring and specifying possible relationships between the categories developed in the focused coding (Glaser, 1978). Here, the focus was on establishing conceptual (theoretical) relationships to reach a main category which provided a description of the data. In this phase, it was important not to stop the analysis at a thematic level because the data would then only be descriptive without a new understanding of OC being developed. This analysis led to the main theme of “Life on hold”, which referred to experiences of living under OC.

The analysis used the constant comparative method approach described by Glaser and Strauss (1967). This method shows how categories are constructed in an interaction between data collection, analysis and interpretation. Throughout the analysis, the data was interpreted in the light of pre-understanding, context, memos and theory. In developing sub-categories and categories, I compared data to find similarities and differences. The analysis alternated between the whole and the parts in a process that ensured that the categories and conceptual relationships had an empirical basis. Meanwhile, the analysis between the interviews provided new lines of thought to follow in later interviews. This procedure is similar to what Gadamer (1993) called the circularity of understanding; here, he pointed out that we can only understand something on the basis of what we have already understood.

4.5.2 Analysis and interpretation - Papers 2 and 3

The analysis of the data for the second and third articles was based on qualitative content analysis. This analytical method is suitable for a descriptive and crosswise analysis, and was performed stepwise. The first step involved achieving an overview of all the interviews by listening to and transcribing the audio files. The transcribed text was then read through several times to gain a clearer impression of what the interviews were about. Each interview was summarised to a page of text. From this concentrated text, 6 to 8 themes were derived that gave a general idea of the subject matter. The overriding themes were entered into a table with key words that underpinned each theme. In the second step of the analysis, all the text from each interview was reorganised so that each text was concerned with a different theme. The source material was now no longer the interviews, but different themes underpinned by empirical data. The third step of the analysis was a review of the themes to encode text with similar meaning content into meaningful units. In this stage, the text was concentrated in that only those parts related to the themes were studied further. The various codes were then compared to find similarities and differences and how they related contextually to each other. Through analysis and interpretation, a hierarchy of unifying sub-categories and categories was constructed. The meaning content of the sub-categories and categories was then rewritten to create what Malterud (2011) calls an analytical text. This phase involved a new concentration of the material, involving a summarisation of similar and overlapping meanings. The analytical text generated the results of the study. Table 5 exemplifies the steps (from article two):

Table 5: Exemplification of the development of a category from relatives' experiences via an indicator and a sub-category

Relatives' experiences	Indicator	Sub-category	Category
<i>I do feel OC as a relief, I must say. That is the right word, I think. There are more people to support us now. Because my sister is functioning so poorly. I mean, all the time you want – you hope it'll work. But it's not like that, I just have to face up to it"</i>	OC supports us, we feel more freedom through less responsibility	OC gives relatives others to share the responsibility with	Improved predictability through increased patient stability

At this stage of the analysis, a descriptive understanding of the material was developed; this is what Graneheim and Lundman call the manifest content. The fourth and final step in the analysis was an interpretative process; on the basis of the manifest content, the researcher's own understanding and theory, the data were interpreted and a main category was developed which shed light on the participants' experiences with OC. Graneheim and Lundman call this the latent content or underlying meaning of the text. The interpretation took place through an approach based on self-understanding, critical common-sense understanding and theoretical understanding (Kvale, 2006). Self-understanding is related to the participants' own understanding and took place when the participants themselves discovered new connections in the interviews. The researcher's summarisations are related to critical common-sense understanding and could broaden the perspective by allowing the participants to correct the researcher's perception of the interviews. The hermeneutic interpretation took place in the context of the research group's pre-understanding, findings in literature searches and the theoretical framework. In this way, the theoretical framework of the study was a delimiting factor, providing a perspective that steered the interpretation by correcting it while also allowing the empirical data to be expressed (Kristoffersen, 1998).

4.6 Ethical considerations

Ethical approval for the study was sought from the Regional Ethics Committee (REK). REK concluded that the study was not covered by Helseforskningsloven [the Health Research Act] (2008) (Case 2012/1667/REK nord). The project was then reported to the Data Protection Officer and was approved (Case 2012/14889). The study was conducted according to the ethical guidelines of the Declaration of Helsinki (1964), as subsequently amended (World Medical Association, 2013). Ethical considerations were included in all phases of the study and were based on the four ethical principles of Beauchamp and Childress (2013): the study should respect the participants' autonomy and be beneficial, non-maleficent and just.

As a researcher, I had a responsibility to establish a good relationship with the participants while at the same time ensuring my independence as a researcher (Kvale, 2006). Participation in the study was voluntary and based on informed consent. Participants were informed that refusing to participate would have no consequences for them and that they could withdraw from the study at any time if they wished to do so. They had the right to access information recorded about them, and the right to correct errors in the records. If they wished to withdraw from the study, they were entitled to have all information about themselves deleted unless this information already formed part of a scientific analysis and scientific work. This did not in fact arise. All the interview data were treated confidentially. The name lists were stored separately from the interview data. A code connected the interviews to the list of names. Only the researcher and supervisors of the study have had access to the transcripts. Audio files and transcripts were stored on the hospital research server, to which only the researcher had access. The data in all publications is anonymous and non-identifiable.

People with a severe mental disorder subject to coercive measures are a vulnerable group.

However, vulnerability cannot be sufficient reason to deprive an entire group of people of the

opportunity to present their own views; they cannot collectively be considered as a group of people who must be isolated to the extent that they are prevented from sharing their experiences with others (Hummelvoll et al., 2010). It was reasonable to assume that patients suitable for the study would have reduced capacity to consent, since they all fulfilled the requirements for compulsory psychiatric care. But at the same time, all the patients lived outside specialist mental health facilities, and were considered to have the skills to cope with everyday life. Therefore, the way the requirement for consent was practised was that the patient would only be excluded from the study if it was obvious that he or she did not understand what participation would involve. This assessment was made by the decision maker before the patient was approached. We also added a condition that if the interview revealed that the patient did not understand what he or she was involved in, the interview was to be terminated. This situation did not arise, and all interviews were conducted as planned.

Tee and Lathlean (2004) discussed psychotic disorders in terms of the ability to make autonomous decisions and argued that although patients periodically may have decreased capabilities, they are essentially cognitively intact with full capacity to consent. Therefore, although the psychotic disorder may have quite a strong effect on patients, they are usually able to assess whether they want to participate in various contexts. Their capability may be briefly impaired in an acute phase of the disease but is soon recovered when the situation stabilises (ibid.). My own clinical experience supports this. To prevent patients from relating their experiences with OC represents a paternalistic attitude I find overprotective and difficult to justify ethically. At the same time, it must be ensured that consent is given on the basis of sufficient information and voluntarily. The boundary between a voluntary decision and one due to external pressure may sometimes be difficult to draw. The patient's voluntariness may for example be undermined by distorted information or by people in authority recommending

too strongly (Pedersen, Hofmann, & Mangset, 2007). NOU 2011: 9 (2011) discussed the capacity to consent and argued that the requirements for valid consent were relative and interdependent. The less capacity a person had, the more seriously the context of the consent had to be considered. The requirements for a valid consent could vary according to aspects of the clinical activity such as the type of treatment, its purpose and the severity of the condition. The conclusion was to recommend a high threshold for denying consent, where the person was clearly unable to understand what consent involved (ibid.).

The relatives in the study were adults capable of consent. The purpose of the interviews with relatives was to reveal their experiences with OC, not to ascertain their information about the patient. A new situation arose with the requirement by the Data Protection Officer that relatives could only participate with the consent of the patient. This issue is ethically relevant, since the decision deprived relatives of the opportunity to independently consider their participation in the study. In those cases where the patient did not consent, the decision by the Data Protection Officer meant that the relatives were not asked to participate. In one case, a relative had to leave the study because the patient withdrew consent. For the health professionals, the interviews provided an opportunity for professional development by encouraging reflection on practices related to OC. Several of the participants knew the interviewer from previous work. The purpose of the focus group interview as data collection for research was therefore clarified.

On an individual, group and societal level, the project was considered useful in that it generated knowledge of importance to patients under OC, their relatives and the health professionals involved. It was important to ensure that the project did not have unintended negative consequences for the participants. Interviews with patients and their relatives mainly

took place in familiar surroundings at home, in hospital or in community health care. Emphasis was placed on creating a reassuring atmosphere by taking time, clarifying the background for the interview and taking breaks as needed. The interviewer had considerable experience of mental health care and was prepared for potential difficulties in conversing about mental illness and coercive treatment. When planning, we had considered that individual interviews might present a small risk in themselves. Our experience from the interviews was that patients and their relatives showed confidence and related their experiences in detail. A certain risk was that patients and their relatives, after long experience of mental health services, might easily slip into a “treatment relationship” with me as the interviewer. However, I found that the participants were pleased to share their experiences, and were glad that someone was interested in their situation outside of the treatment context. Arman & Rehnsfeldt (2006) showed that people in a difficult situation often want to talk about it, and that a conversation can be a way to work through their experiences. They found that patients only raised issues they were able to continue to work on themselves. My experience was that both patients and relatives felt that the interviews acknowledged their experiences as important. Despite the risk being assessed as low, an agreement was made that the participants could contact a psychiatrist at the hospital after an interview, if necessary. But I have no information that this occurred.

5.0 RESULTS

This thesis includes three qualitative research articles. The articles answer research questions one, two and three, respectively [page 8]. The fourth research question deals with how differences in the experiences of those involved can be understood. This question is hardly touched upon in the articles and is emphasised in the discussion section of the thesis.

5.1 Paper one: “Life on hold”: a qualitative study of patient experiences with outpatient commitment in two Norwegian counties

The main category in this study, “Life on hold” indicates how the participants found OC to be an obstacle to taking responsibility for their lives. They hesitated to do so as long as they were made dependent on others’ assessments. The analysis of the data led to six sub-categories showing different experiences of everyday life under OC: being different, being devalued, freedom with restrictions, being punished, trapped by history and insecurity in relationships. The participants felt different because most people do not live under OC. They felt devalued in that their responsibility for their own lives was taken from them. Although they experienced greater freedom under OC than in compulsory hospitalisation, they felt that this freedom came with restrictions. OC felt like a punishment, because the participants did not see any connection between the follow-up care they had to agree to and the kind of everyday life they wanted. They often felt that clinicians used their previous history more than the current situation as justification for OC decisions. The lack of control over their lives meant that many felt insecure in social situations. Although few had experienced physical coercion, they all felt that they were within a coercive framework.

Three categories were developed from the six sub-categories, namely perceived coercion, dependence on health care providers and constrained social interaction. The participants felt

that the medication was compulsory, and that OC was largely about ensuring their adherence to the medical treatment. Only two had a separate decision on forced medication. Many of the participants were critical of medicines. They accepted medication in emergencies, but found it to be static and independent of their functioning. The participants did not find that their experiences were taken into account when medication was being considered. They had no feeling of participation or cooperation, partly because they only rarely met the decision maker. Instead, the medical context was experienced as an obstacle to recovery and the transition to a normal life.

When under OC, the participants felt that they lacked information on what was voluntary and what was not. Insufficient information gave them a poor understanding of the distinction between areas of autonomy and areas covered by OC. They had a feeling of a lack of control over their own lives. OC gives health professionals a limited possibility to use coercion in treatment, yet the participants experienced a high degree of coercion in their everyday lives. Coercion was not tied to particular situations, but coloured everyday life and was perceived as an obstacle to establishing normal relations with family and friends. Health professionals played a key role in the participants' social network as helpers, friends and supervisors. Many participants perceived all contact with health professionals as obligatory when they were subject to OC. They experienced that their activities were often established and managed by the staff. Many participants felt lonely and missed supportive relationships outside health care. They particularly found that clinicians considered them as sick people to be judged on the basis of symptoms and behaviour. As they saw it, the healthy aspects, and life before their mental health problems, received less attention.

The study concludes that people subject to OC find that the scheme keeps them in a patient role that prevents them from starting their own recovery process. The participants' experience shows that health professionals must be strongly aware of how OC is implemented in order to provide the kind of treatment that best safeguards patient autonomy, where patients are allowed to use their own resources to develop everyday coping skills.

5.2 Paper two: “Responsible, but still not a real treatment partner”: a qualitative study of the experiences of relatives of patients on outpatient commitment orders

The main category of this study “Responsible, but still not a real treatment partner” refers to the great responsibility still felt by relatives for the patient's life even when the patient was under an OC order. Relatives played a key role in the patient's life, but felt sidelined when their experiences were given little weight by health professionals. The analysis identified five categories indicating relatives' experiences: improved predictability through increased patient stability, focus on medication experienced as of limited help in everyday life, inadequate communication as a barrier to cooperation, impact on relatives' everyday life and still feeling responsible.

Relatives gave little thought to coercion; what concerned them most was that the patient received the best possible treatment. They accepted coercion, especially during periods when the patient's disorder led to greatly reduced functioning. They found that their situation improved when the patient was under OC, because more people were involved in the care of the patient, and because OC stabilised the patient's functioning. This resulted in greater predictability in the relatives' lives. However, the relatives found that medical treatment did not solve the patient's problems. The clinicians' emphasis on the patient's adherence to the medication was experienced as alienating and exclusionary in comparison with the areas the

relatives emphasised, such as the patient's ability to interact socially and master practical everyday challenges. Relatives were concerned about the lack of meaningful activities, and thought that OC should encompass a broader approach to the patient's situation. They found themselves in an intermediate position, torn between the patient's wish for support for his point of view and the health professionals' expectations for support for the treatment initiated. They also found the lack of information from clinicians to be an additional burden. They felt their situation to be especially difficult if the patient and health professionals were in conflict about the implementation of the treatment. Overall, the relatives' experiences showed that they considered themselves as the element of continuity in the treatment. They could not entirely rely on the clinicians keeping to their obligations, as they had had too many experiences of discontinuity in treatment and follow-up care. They had to rely on themselves.

The conclusion of the study is that the relatives of patients subject to OC should be given more consideration. Patients are vulnerable and their families are a key resource in their network. Health professionals should involve relatives in a way that takes account of their experiences, and their need for support and guidance. Not until health professionals acknowledge relatives' experience will relatives become a resource to enhance the patient's treatment outcome.

5.3 Paper three; "Care or control": a qualitative study of staff experiences with outpatient commitment orders

The main category "Care or control" refers to the fact that health professionals found it challenging to balance the role of therapist with the administration of coercion. They considered OC to be a necessary treatment framework for some patients. But they found it difficult to combine control with other therapeutic work. The study included decision makers

and clinicians who work with patients under OC, but without decision-making authority. The analysis identified three themes: responsibility and OC, therapeutic cooperation and OC and difficult decisions and OC.

Health professionals experienced the responsibility for OC as a social responsibility; they considered themselves to be responsible for providing the treatment they thought would best address the patient's health needs over time. Health professionals had a positive view of OC, and saw it as a necessary scheme for patients who lacked the insight to assess their own treatment needs. They felt that OC was a minor intrusion in the patient's autonomy and that they had good relationships with patients, apart from conflicts around medication. Because patients had the same psychiatrist as an inpatient and as an outpatient, it was particularly psychiatrists who thought that OC improved the medication treatment. Decision makers felt that an OC decision was easier when they considered the patient to be a danger to himself or others. It was more difficult when OC was justified by a need for treatment and the patient did not want treatment, or when they were unsure whether the treatment would improve the patient's condition.

Health professionals who supervised patients under OC felt themselves to be a link between the patient and the decision maker. They tried to downplay the coercive aspect of the scheme, preferring to focus on the milieu therapeutic aspect. The study showed a large consensus between the health professionals involved regarding roles and responsibilities in OC. One problem experienced by decision makers was the lack of alternatives to using OC in treatment. Other health professionals also felt this to be an issue, but it was less of a challenge for them, as they could refer to the decision already made. The decision makers experienced pressure from others to expand OC to include more areas of a patient's life in order to

improve patient functioning. However, this pressure had decreased now that more council health workers had knowledge of OC. One common experience was that a growing number of young patients were under OC orders. Health professionals felt that the young patients made them more ambitious in terms of working towards full recovery.

The study concludes that health professionals have a paternalistic approach towards OC patients, justified by patients' lack of insight into their condition and treatment needs. At the same time, they experience a therapeutic dilemma in that OC leads to conflict and breaks with an approach that emphasises the patient's own resources and mastery. There is therefore a need to discuss whether an emphasis by clinicians on patients' autonomy rather than insight into their illness would lead to improved patient cooperation and fewer dilemmas by reducing the use of coercion.

5.4 Three perspectives on OC

Overall, the results show that those involved had varied experiences with OC. Antipsychotic medication was a key theme for everyone. Patients wanted more cooperation on medication, and were worried about side effects. Relatives found that the medicines stabilised the patient's everyday situation, but were concerned about the lack of recovery. Health professionals believed the medications were often necessary, but acknowledged that they might have little or no effect. Patients and their families found that they lacked information, and believed that this hindered cooperation. Table 6 shows the different experiences of OC of those involved:

Table 6: Perspectives on OC from patients, relatives and staff

Patients' experiences with OC	Relatives' experiences with OC	Staff experiences with OC
«Life on hold»	“Responsible, but still not a real treatment partner”	“Care or control”
They want to be involved and gain recognition for their wishes and experiences. They want more autonomy through increased responsibility for their own lives.	They want to share responsibility for the patient with the clinicians by being involved. They miss being able to participate and to gain recognition of their experiences.	Individual treatment responsibility and social responsibility. Necessary for patients who lack insight. Difficult to combine therapeutic responsibility with managing coercion.

The perception of the coercion potential of OC ranged from the patients' experience that coercion in OC coloured their lives to the health professionals' notion that coercion was limited and not very intrusive. The patients found support in OC for a limited period, but that over time it kept them in a patient role and prevented them from taking responsibility for their own lives. They found the scheme was unclear and did not meet their expectations of an independent life outside the hospital. They wanted more responsibility to start their own recovery process. Relatives found that OC relieved them, but that it was not effective enough. They felt unsure as to whether there was a holistic approach to the patient's situation. Instead they found that the health professionals' understanding of illness invalidated their own and the patient's experiences, and that there was too little focus on activities and work in the treatment. Health professionals found that they had to balance their therapeutic responsibility with their social responsibility as health care workers. They felt that OC was necessary to create a framework to treat the sickest patients. At the same time, they found that OC challenged their relationship with patients and relatives.

6.0 DISCUSSION

6.1 Methodological considerations

The aim of this thesis was to enhance insight and understanding of the phenomenon of OC on the basis of the experiences of those involved. This was done through three studies based on descriptions from practice. The empirical data combined with theory and research literature form the basis for the analysis. My assessment is that a qualitative approach was suitable for the analysis and interpretation of features and qualities of the phenomenon of OC (Malterud, 2011). The methods of GT and qualitative content analysis have been explained and are understood from an overarching hermeneutical perspective that emphasises that all understanding is contextual and formed in a cultural and historical context (Nortvedt & Grimen, 2004). With different ontological and epistemological starting points, constructivist GT and qualitative content analysis have common features within an interpretative scientific tradition where everyday life is understood as constructed through interaction between people (Alvesson & Sköldbberg, 2008). The difference is that while an analysis in GT seeks to develop concepts and a theoretical understanding of social interactions, qualitative content analysis attempts to delve into the meaning of concepts for the individual participant (Wimpenny & Gass, 2000).

GT was the method chosen, as it is well suited for the study of phenomena where there is little knowledge (Charmaz, 2014; Glaser & Strauss, 1967). This approach aimed to shed light on how OC affected social relationships. This perspective was deliberately chosen, and its consequence was a greater awareness of relationships and interaction, rather than exploring the depth of individual experiences. One danger of GT is that the phenomenon under study is not explored broadly enough, because topics arising in early interviews may divert the

researcher's focus towards those topics in later interviews. As mentioned, this was addressed by ensuring that all the interviews had a broad introduction which allowed for new topics to arise. I found that the category "Life on hold" adequately covered the patients' perception of their social situation, and simultaneously revealed their individual experiences with OC.

The qualitative content analysis sought to examine the participants' everyday lives on the basis of their descriptions of their own reality (Hummelvoll & da Silva, 1996). This approach was chosen out of a desire to examine and elaborate on participants' individual experiences. For the relatives, this applied to their need to relate to coercion as part of the care of their family member. For the health professionals, this was about managing coercion while being in a treatment relationship with patients and relatives. I considered it important to continue to focus my attention on social interaction. The approach described by Graneheim & Lundman (2004) was chosen, because this method maintains breadth and depth by focusing on the individual in a social context. There was also a danger here in that the depth of the individual experience might be lost through excessive attention to relationships. However, I considered that I was sufficiently aware of this, and that individual experiences were addressed while the themes that emerged in articles two and three also addressed the perspective on social relationships.

One problem in qualitative research is when to stop the data collection. Glaser and Strauss (1967) stated that data were saturated when new interviews confirmed previous findings and did not introduce new elements. Malterud (2011) criticised the term saturation since it referred to a perception that there was a finite amount of facts that could be collected. That runs contrary to social constructivist thinking, which understands knowledge as being

constantly developed in the interaction between those involved. There will always be new people and new relationships that can give rise to new knowledge. In terms of the number of participants (N), Sandelowski (1995) says that the number in a qualitative study must not be too large, and that N = 1 may be enough when the purpose of the study is to shed new light on a phenomenon. In my understanding, it is more important to have a selection that provides rich descriptions through good knowledge of relevant themes than it is to have a large number of participants (Malterud, 2011). The selection in this thesis was therefore made to ensure good descriptions while also being small enough to enable a sound analysis. In my opinion, the number and selection in the sub-studies balanced these considerations.

In the study of relatives' experiences, the original design was to include the relatives of the patients who participated in the first study. Only three patients consented to the researcher approaching their relatives. The reason given by those who refused was that they felt that including their family members would represent interference with their private life that they did not want. In retrospect, my understanding is that patients should have been asked about the participation of their relatives after their interviews. That might have increased the number of participants, because the patients would then have been more familiar with the interviewer and the studies on the basis of the first meeting. The change in the way of including relatives had little bearing on the possibility to answer the research question. They were still relatives of OC patients who lived in the catchment area of the study.

The purpose of the focus groups in study three was to describe the phenomenon of OC from the point of view of health professionals with experience of working with OC patients. Based on the arguments of Malterud (2012), I believe that focus group interviews with 22 participants divided into three groups of four to ten provided rich data for subsequent analysis.

In the group with four participants, I focused on facilitating group dynamics that led to a group interview, rather than four individual interviews conducted in a group (ibid.). The original plan was to have one focus group interview with health professionals with the authority to make OC decisions and another interview with those without such authority. This division was based on my understanding that the decision makers as the people with overall responsibility for treatment could easily dominate the focus groups, and prevent the staff who worked with the patients during OC from freely expressing their experiences. The plan was to have a third joint interview with participants from the first two interviews in order to elaborate on the experiences and focus more strongly on cooperation. But this was difficult to organise because the decision makers did not set aside time for two interviews. The design was then amended, with the same structure in the first two groups, but with a third mixed group of new participants. This group consisted of those who were unable to attend one of the first two interviews. One consequence of the change was a lost opportunity to deepen the experiences from the first two interviews through a third interview with the same participants. Instead, I gained a broader perspective on OC through experiences from two homogeneous interviews and one more heterogeneous interview. I found that this design provided good descriptions of health professionals' experiences with OC.

6.1.1 Generalisability, reliability and validity

The methodology literature contains various approaches to examine the generalisability, reliability and validity of qualitative studies. In this thesis, I have used Kvale's (2006) descriptions to assess its generalisability, reliability and validity.

Generalisability concerns the universality of the findings in a study. Unlike the requirements for quantitative methods, the sample in a qualitative study is not intended to be representative

of the population in question. Furthermore, that is not possible since a qualitative study is based on a limited number of informants (Malterud, 2011). Kvale (2006) believes it is a good method to deeply explore a theme with a small number of participants if the researcher wishes to gain a sound understanding of a phenomenon. Good reliability implies that the quality of the implementation of the study is sufficient to provide answers one can rely on. The ideal is for a number of studies of the same phenomenon to produce the same result. Since qualitative research has less standardised methods, it is important to describe the methodology clearly to show the basis on which the results were obtained (Kristoffersen, 1998). Reliability will rest on the researcher's preparation, execution and follow-up work. The present studies were clearly explained in the project description and research protocol. These were prepared on the basis of experiential knowledge, theory and research literature. The interview guides were developed in the research group with input from a researcher with experience as a user. A pilot interview tested the interview guide before the patient study. Throughout the interviews, the technical equipment worked well and the recording equipment did not seem to distract the participants. My experience from the interviews was that patients, relatives and staff all provided good and reflective feedback about their experiences with OC. I noticed that I adhered too closely to the interview guide in the first interviews, but that I later managed to have more open conversations. Following the main structure of the qualitative research interview as described helped to provide a framework to conduct the interviews. Together with my clinical experience as a psychiatric nurse, this afforded a good basis for the implementation of the interviews.

While conducting the interviews, I was keenly aware of not allowing myself to be directed by my pre-understanding, but instead encouraged the informants to provide their own reflections through short follow-up questions. My input was thus mostly to clarify, provide structure and

ensure progress in the interview. My own voice was not obvious until the final summing up. Kvale (2006) believed that this procedure could enhance reliability in that the researcher's knowledge of the topic could provide more depth. In being aware of my own position, I found that the summary did work in this way. The interviews were transcribed verbatim. When working with the transcribed material, I found that everyday speech had to be worked on to provide an overview and context. In the analysis I followed the analytical steps as described. I found the analytical process time-consuming and it was difficult to maintain an overview. Here, the NVivo10 analytical tool was of great help. My experience was that the analysis could be conducted as planned. I consider this to be due to good preparation backed by methodology literature, experience of qualitative analysis from past projects and good support from supervisors. The study findings have been presented in three articles containing the usual elements of research papers.

The validity of the thesis concerns whether the studies measure what they are intended to measure, i.e. whether the method is relevant to the research questions (Creswell, 2013). The selection was made with a view to ensuring that the participants had experiences which indicated suitable knowledge to answer the research questions. The validity of the studies will be linked to the extent to which the results presented in the thesis reflect people's experiences with OC. The internal validity of the thesis rests on the extent to which the results are valid for the participants involved. The external validity (generalisability) has already been mentioned; this will depend how far the results can be generalised to patients under OC, their relatives and health professionals outside the catchment area of the study (Malterud, 2011). Kvale (2006) linked assessments of validity to the concepts of intersubjective and communicative validity. He states that all of the following have an impact on validity: theoretical understanding, choice of methods, the participants' credibility, the skill of the

interviewer, the quality of the transcribed material, the quality of the analysis, how the researcher's conclusions are tested on the participants and whether the final report provides a valid description of the study findings. Intersubjective validation involves assessing the extent to which there is a consensus between the participants and the interviewer on how the descriptions from the interviews emerged. This validity depends on whether the presentation is correct, accurate and objective in an epistemological context (Hummelvoll & da Silva, 1996). I addressed this in the interviews by asking questions such as: "Did I understand you correctly when you said...?" and also by allowing the participants to give me corrective feedback when the interviews were being summarised. Communicative validation involved checking the required knowledge in a dialogue. Kvale (2006) argued that valid knowledge occurs when conflicting statements are discussed in a dialogue. This took place specifically in the dialogues in the interviews. The assessment of whether the interviewer's interpretation was valid took place in a dialogue with the same people who participated in the interviews. The interpretations could thus reveal themes derived from the interviews, but also include interrelationships that went beyond the informants' understanding of the interviews. The transcripts showed that intersubjective and communicative validation helped to elaborate on the themes. Although my intention was to allow the participants to speak freely, the transcripts show that I sometimes asked new questions too soon. However, my overall experience was that the informants were given enough space to express themselves, the conversation flowed well, and the data gave a satisfactory picture of the participants' experiences of OC.

Repstad (1998) described how research in one's own field of work requires conscious reflection on one's pre-understanding, view of the organisation and role as a researcher and professional. Good knowledge of the research field represents a risk of considering quality

more than producing precise descriptions, and of taking certain things for granted without questioning them. My point of departure was an awareness of the problems of being involved in the research field. In implementing the studies, I was very conscious of my role as a researcher, and emphasised this when meeting the participants. The researcher role was also clearly stated in the information letter. I found that the participants saw me as a researcher, and that the interviews had a continual focus on the participants' experience with OC. The participants seemed comfortable in the interview situation, and told me they were pleased that someone outside the clinical treatment environment was interested in OC. I cannot rule out the possibility that my previous clinical work influenced the responses in that participants wished to appear better than they were, but I found the informants to be honest and direct in the way they responded. Following Hammersley and Atkinson (1996) and Coghlan and Casey (2001), I therefore believe that I exploited the potential of having knowledge of the field while avoiding the associated pitfalls.

The studies were conducted in a limited geographical area with the inherent risk that the findings represent local more than general issues. The purpose of the thesis was not to generalise the findings, but to describe and understand some key experiences with OC. The studies followed accepted scientific methods of analysis and interpretation. Through a phenomenological perspective and a hermeneutic interpretation, the findings reached a theoretical level of reflection. The fact that the results are consistent with findings from other studies makes it probable that they are valid beyond the participants involved (Creswell, 2013). My understanding is therefore that the results presented in this thesis discuss, highlight and provide nuances of the experiences with OC of patients, relatives and health professionals, and offer a new and broader understanding of the scheme.

6.2 Discussion of the results

The findings show that patients subject to OC, their family members and the health professionals involved had varied experiences and expectations of OC as a treatment framework. This demonstrates the importance of clarifying each other's perspectives when OC is discussed. Without this clarification, there is a risk that patients, relatives and health professionals will be on different wavelengths and end up in conflict, instead of using their experiences to promote autonomy and collaborative solutions wherever possible. The present thesis helps to provide a more comprehensive understanding of how the scheme works in practice. The results showed overall that OC was used to ensure treatment of the patient, and to a lesser extent to control dangerousness. The justification of OC as a treatment intervention therefore provides the framework for the discussion.

Findings by Bremnes et al. (2016) and Løvsletten et al. (2016) suggest that the use of OC in Norway is increasing. The number of patients under a compulsory care order for more than a year increased from 2013 to 2014, and much of this increase applied to the group of OC patients (Bremnes et al., 2016). This increase in the use of OC is taking place in spite of an uncertain knowledge base for the scheme. There is also no research evidence to show that coercion has a positive effect on treatment outcome (Høyer, 2009). Norvoll (2011) pointed out that coercion can harm the therapeutic relationship, and diminish patients' experience of mental health care. This thesis shows how OC is experienced in practice, and points to a need to develop a common understanding of OC among patients, relatives and health professionals with the goal of improved cooperation and decreased use of coercion. The thesis indicates that coercion should not only be understood as formal coercion related to legislation, but also as patients' actual experience of their situation. As shown by Canvin, Rugkåsa, Sinclair, & Burns (2013) and Vatne (2006), coercion may include informal measures such as strong

pressure and the withholding of benefits. This broader understanding of coercion becomes evident in conversations with users of mental health services (Kogstad, Hummelvoll, & Eriksson, 2009). The findings in this thesis do not provide a clear argument for or against the use of OC. Instead the three studies highlight three experiential perspectives, and seek to understand how the scheme functions.

6.2.1 Experiences of patients and their relatives

Patients preferred being under OC to continued compulsory hospitalisation. They were less satisfied with OC in comparison with voluntary follow-up care. Relatives had varied experiences. One may ask what constitutes necessary treatment, and what latitude people should have to define their everyday lives. The treatment criterion in the MHA has been debated in Norway (Helsedirektoratet [Norwegian Directorate of Health], 2009b; NOU 2011:9, 2011). The issues have centred on treatment needs versus the right to self-determination. These dilemmas can be seen in the studies of the experiences of patients and their relatives, and have also been highlighted in other patient stories about serious abuse through the use of coercion in treatment (Lauveng, 2005; Thune, 2008). The challenge in the use of the treatment criterion lies precisely in the tension between abuse and human rights. The treatment criterion has in recent years been reviewed by a working group appointed by Helsedirektoratet [Norwegian Directorate of Health] (2009b), and by a government-appointed legislative committee (NOU 2011:9, 2011). In both cases, the recommendation was for the criterion to continue out of a concern that its removal would raise the threshold of intervention with severely mentally ill patients and place a considerable burden on patients, families and society. At the same time, concern was expressed that the rules on coercion as expressed in the legislation may preclude the development of alternative forms of treatment based on voluntariness (ibid.). One concern raised is that coercive medication treatment may diminish

the importance of patients developing alternative coping strategies that are more suited to their situation. The results of our studies support this concern.

Patients and their relatives accepted that there may be phases of the treatment where it is necessary to use coercion: patients accepted this if they felt they could be a danger to themselves or others, and relatives accepted it if the disorder meant that the patient had a low level of functioning. A decisive factor in patients' and relatives' perception of coercion was whether they felt they were listened to, and whether the coercion was implemented in a way that took account of their experiences. Patients had a stronger feeling of coercion if they found they were not given back responsibility after a critical period. Relatives were concerned about whether the patient was receiving good treatment. The question here is whether coercion is necessary to provide suitable care for the individual patient, or whether care can be organised to accommodate the needs of patients and their families with less coercion. Studies by Swartz et al. (1999) and Steadman et al. (2001) have precisely pointed out that additional resources improved patient care outcomes more than coercion did.

6.2.2 OC as a treatment framework

Health professionals justified OC by referring to the patient's lack of insight, and gave varying degrees of weight to patients' capacity to make independent decisions. Justification of coercion by the patient's mental state more than by emphasising the patient's autonomy and opinions raises ethical and professional issues that can be found in the main themes of the thesis (Life on hold, Responsible - but still not a real treatment partner and Care or control). Likestillings- og diskrimineringsombudet [The Equality and Anti-Discrimination Ombud] (2015) has pointed out that psychiatric patients in Norway run a particular risk of being subjected to coercion. The report discusses the problem that society too often considers a

mental health disorder to be a characteristic of the individual rather than a consequence of social factors and lack of suitable care. The present thesis finds that health professionals' emphasis on illness and insight into the illness leads to a focus on correcting what is wrong rather than providing follow-up care to enhance everyday coping on the patient's own terms. The medical treatment-based approach of health professionals may tend to define them as experts and patients as passive recipients of treatment (Hummelvoll, 2012). OC leads to a focus on the individual's disease rather than on the patient's coping skills and interaction with others. Lack of cooperation is interpreted as lack of insight, and the MHA (1999) does not stipulate that clinicians should assess the degree of decision-making competence of the patient (Helsedirektoratet [Norwegian Directorate of Health], 2009b). This contrasts with the fact that psychotic patients, except in periods of crisis, are usually quite capable of participating in an assessment of their situation (NOU 2011:9, 2011; Tee & Lathlean, 2004). An excessively one-sided emphasis on disease and insight may therefore be problematic.

The studies showed that patients, relatives and health professionals emphasised different aspects of the consequences of the patient's disorder, and that patients and relatives missed alternative approaches. Patients and their relatives had an existential and social psychiatric perspective on everyday functioning and coping. Health professionals also emphasised these perspectives, but saw them as secondary to medication. A medical understanding views mental disorders as a result of disease processes in the central nervous system. The patient's symptoms lead to one or more diagnoses that result in a certain type of treatment (Stuart, 2005). This understanding creates a hierarchy of responsibility between clinicians, where psychiatrists and specialist psychologists take decisions, and other health professionals follow up the treatment. The same hierarchy is seen in the implementation of OC. In a biomedical understanding, psychosocial factors are considered to predispose to or potentially trigger an

episode of illness, but the patient's existential situation, such as relations with family and friends, is not considered to be a vital factor (Kringlen, Mjelle, Øgar, Selle & Høglend, 2008). The findings of this thesis show how this understanding affects the priorities of health professionals. They do consider existential and social psychiatric measures as important, but often under the assumption that a medical intervention is in place. A study from the same area as patients included in the actual study supports such an understanding, since all the OC patients in the study were taking antipsychotic medication (Løvsletten et al., 2016).

Eriksson and Lindholm (1993) have described different dimensions of living with mental illness. What they call the suffering of illness shows how psychosis affects people physically and mentally, while what is termed the suffering of life points toward grief that life may often turn out differently, and how this can make patients and their families set new goals. A third suffering, the suffering of care, shows how treatment can also increase the patient's suffering, such as in the form of restricted freedom or the side effects of medications. The consequences of living with OC may partly be understood as an example of suffering of care. In addition, patients and their relatives may find that social constraints and reduced opportunities for socialising are reinforced by the often stigmatising attitudes in society towards people with psychotic disorders (Hummelvoll, 2012). Health professionals justified the need for stable medication by stating that it was necessary to improve the patient's health in a long-term perspective; an improvement in the patient's suffering of illness would mitigate the suffering of life and the resulting social problems. They considered the patient's stability more important than current inconveniences. By contrast, patients and their relatives had a "here and now" perspective, and assessed the current situation on the basis of whether OC promoted or inhibited the patient's coping and functioning. Patients especially stressed that the medication had side effects that prevented them from living the kind of life they wanted. An

important distinction in the experiences of the groups involved in OC was therefore that the subjective experience of the illness was important to patients and relatives, whereas health professionals tended to view the patient's behaviour objectively as a disease that could be treated (Eisenberg, 1977).

Health professionals' emphasis on medication is in line with the guidelines for the treatment of psychotic disorders that recommend drug treatment for acute psychosis, and as relapse prevention for two years from the initial psychosis and up to five years if a relapse occurs (Helsedirektoratet [Norwegian Directorate of Health], 2013). These recommendations were reviewed by Orre (2014), who concluded that antipsychotic medication is justified in the acute treatment of psychosis, but that its effect over time is less certain. A study by Leucht et al. (2012) pointed out that studies showing that antipsychotic drugs reduce relapses have a short observation time, and that there is a lack of knowledge of the effects of antipsychotic medication versus placebo beyond three years of treatment. Harrow & Jobe (2013) showed that most relapses occur six to ten months after discontinuation of medication, and that patients after that time have a lower risk of recurrence than those still on medication. A study evaluating patients' recovery after seven years found that the patients who managed best were those who had taken the least medication, particularly in relation to independent living and meaningful activities (Wunderink, Nieboer, Wiersma, Sytma, & Nienhuis, 2013). Although one should not put too much faith in individual studies, these results do lend support to the experiences of patients and their relatives that medication should be used for a limited period with a high disease burden as support for alternative care, but not as a continuous treatment approach based on a fear of relapse. For decision makers, the studies raise the question of whether it is justifiable to treat people with antipsychotic medication for a long time without

attempting reduced doses or medication-free periods if they assess the efficacy of the treatment to be uncertain.

The results of our studies emphasised medication as a central theme, together with uncertainty about its advantages and disadvantages, although experiences varied among the participants. It is important to understand these findings in relation to a growing number of studies that are critical of the use of antipsychotic medication, due to both unpleasant side effects and insufficient help with patients' problems. Gøtzsche (2015) considered that psychiatry has shifted from a bio-psycho-social model to a biomodel where medication is seen as the solution to all problems. In his view, the problem is that the solution is often inconsistent with the patient's wishes, and that a limited effect of medication often generates new medicines and increased doses rather than alternative approaches. Whitaker (2014) argue that antipsychotic medication is the problem more than the solution, and that the effect of medicines perpetuated the patient's problems. Priebe, Burns, & Craig (2013) gave partial support to the criticism of the current use of medication. Their understanding was that mental disorders arise in relationships between people, and that treatment must include social explanations to a greater extent. These papers referred to above discuss different aspects of medication treatment. Antipsychotic medication can help, but not always and not for everyone. Our results reveal a need for health professionals to take these issues into account and improve the inclusion of patients and their relatives in discussions on the advantages, disadvantages and limitations in treatment regulated by OC. Although clinicians have overall responsibility for decisions, a better common understanding will encourage cooperation rather than coercion in the patient's treatment.

The results showed that the organisation of follow-up care of OC patients gave the decision maker little insight into the everyday life of the patient and relatives. At the same time, the relatives could easily find themselves pressurised between the patient's expectations and those of the health professionals. The lack of sufficient and regular contact between patients, relatives and decision makers helped to maintain a conservative practice, since the inadequate follow-up care meant that the justification for OC lay more in the patient's history than in the current situation. Health professionals seemed more aware of this issue when young patients with a shorter history of treatment were subject to OC than in cases where patients had been under mental health care for many years. Yet feedback from patients and relatives was still that they found OC to be repetitive and conservative, rather than encouraging flexibility and innovation. For their part, health professionals justified the use of OC by a fear that patients would otherwise have relapses and poorer functioning. It is therefore challenging to envisage how patients can use their capabilities to work on their coping skills if they are forced into a framework of understanding that they find of little relevance to their own understanding of their situation (Solbjør, Rise, Westerlund, & Steinsbekk, 2013; Stensrud, 2007).

The follow-up of OC by the decision maker often resembled supervision; it did not promote active cooperation where patients' and relatives' experiences were heard. Health professionals often had a paternalistic approach to the sickest patients. Such an approach can be due to the emphasis on disease understanding, which generally requires the patient's choice to accord with the explanatory models that health professionals believe are correct (NOU 2011:9, 2011). The thesis shows how health professionals' focus on disease and lack of insight created conflicts because patients and relatives felt that their own experiences were marginalised. This situation created a crisis of confidence between OC patients and clinicians, where relatives were oscillating as to whom they should listen to. Stratford, Brophy, Beaton, & Castle (2013)

pointed out that partnerships could be difficult where the parties believed they had a common understanding, but in fact were working on the basis of different understandings and experience. This thesis shows that a coercive framework could disturb the relationship between patients and their families, because patients felt insecure as to whether they could count on support from family members in conflict situations. The fact that only three of 16 patients wanted to include their relatives in the study may be an expression of this uncertainty. The relationship between patients, relatives and health professionals was also influenced by the fact that the professionals had the authority to override the patient's decisions and wishes.

6.2.3 Other studies

Other studies mirror the findings of this thesis. O'Reilly et al. (2006) and Canvin et al. (2014) both examined OC from the perspectives of patients, relatives and health care staff simultaneously. The patients in O'Reilly's study reported that OC provided more structure in their lives, but also felt that it lasted too long. They experienced the presence of coercion in OC in various contexts, and were worried about the side effects of medications. The fact that the patients in our study found that OC bore little relation to their particular problems points towards the same problem areas. O'Reilly's study showed that relatives believed that OC helped to control a previously chaotic situation. A further finding was that relatives experienced a lack of cooperation with health professionals, and a lack of common understanding of what OC should include. Our study confirmed similar dilemmas in that relatives found OC to be a relief for them, but also felt uncertain about whether the content of OC addressed all of the patient's problems. An important lesson from our study is that relatives felt responsible, but not involved and appreciated, in the patient's follow-up care. O'Reilly's study showed that health professionals had a positive view of OC, and felt that the scheme had a greater impact if it was maintained over time. But they also found that OC

challenged patient autonomy, and could threaten their therapeutic relationship with the patient. Themes in our study related to care or control are therefore also found in O'Reilly's study. Canvin et al. (2014) pointed out many of the same phenomena, and found that the main purpose of OC was to ensure medication compliance.

The findings in this thesis show that health professionals have considerable power in health-related issues when patients are subject to OC. This power lies in their authority to implement treatment against the patient's will, when the health professional considers it to be in the patient's best interest. Patients' and relatives' lack of understanding of OC reinforced the power of the health professionals, because a lack of knowledge of the content and scope of the scheme could lead to grey areas in patients' and relatives' understanding of its consequences. Canvin et al. (2014) also showed that patients and relatives were unsure about what being under OC entailed. Gault (2009) pointed out how a lack of information and time for cooperation reinforced patients' experience of being subject to coercion. In our studies, patients and relatives felt alienated in the decision-making process. For them, OC represented a scheme where they did not know the rules. It was especially patients who experienced uncertainty; this may help to explain why they felt that coercion coloured their whole life under OC. Canvin et al. (2014) and Sjöström (2012) pointed out the same problem, where patients are made dependent on others' assessments because they lack information about the content and scope of the scheme they are subject to. The present thesis shows that this situation was exacerbated by the fact that both patients and relatives felt that they had insufficient contact with the decision maker. More regular contact with other health professionals who provided practical support and guidance did not compensate for this, because patients and relatives sought contact with the person responsible for the decisions concerning OC.

Several studies have shown that mental health care, despite reforms and a changing knowledge base, is still characterised by tension between the responsibility for providing treatment and the regulation of the patient's life through social control (Terkelsen, 2010; Vatne, 2006). In this thesis, the continuation of OC by decision makers despite its uncertain treatment effect may be understood in this context. The fear of making faulty assessments that led to relapses was greater than the will to let the patient take responsibility to attempt self-mastery, and to find good ways of cooperating with relatives. Medication mitigated the patient's symptoms so that they "fitted in", but without necessarily enhancing the patient's experience of coping.

6.2.4 Participation and co-determination

The results of the present study raise questions about whether health professionals inform patients and relatives about treatment in a way they find meaningful. To what extent are health professionals willing to transfer decision making to the patients they treat? Would better information from clinicians about alternative treatment, the scope of OC and patients' rights lead to improved cooperation and a voluntary treatment relationship for patients? Recovery can be described as a personal experience in which people through their own efforts, using their own experiences and supported by others undergo personal development towards improved everyday coping (Anthony, 1993). The concept of recovery implies that the patient establishes hope and optimism and sees the meaning of life despite the limitations of the disorder (Stickley & Wright, 2011). In a social perspective, recovery will imply that patients develop strategies to cope with everyday life and their local environment (Karlsson, Borg, Revheim, & Jonassen, 2013). Borg and Topor (2014) showed that relational qualities are a decisive factor in determining whether the patient is motivated to change, and whether any measures taken have a positive effect on the recovery process. The studies in this thesis of

patients' and relatives' experience show how OC hampers such recovery processes by placing the patient in a dependent relationship, and by providing a treatment framework in which relatives do not feel involved. The way health professionals practise the implementation of OC can complicate cooperation with patients and their families, and does not promote patients' recovery processes.

One may question whether patients are recovering even with fewer objective symptoms if they do not feel better (Topor, 2004). An approach that increasingly emphasises patients' recovery would break with a focus on medical expertise by paying attention to patients' and relatives' resources, wishes and needs. An emphasis on medical interventions may support the recovery process if these reduce the patient's symptoms. Recovery is therefore not incompatible with a justification of the use of coercion in some situations. But this must be on condition that clinicians work towards including involuntary interventions in order to achieve recovery goals (Geller, 2012). In such an understanding, medicines will form part of a recovery-based thinking where medication supports patient recovery. A recovery-based approach would still require health professionals to emphasise the experience and knowledge of patients and their relatives in conjunction with professional knowledge in the implementation of treatment and follow-up care (Stratford et al., 2013). This thesis shows that this did not happen sufficiently.

The thesis raises the question of whether OC patients get the opportunity to try out voluntary solutions after a period subject to coercion. The results suggest that health professionals were not always willing to terminate OC even though the patient's functioning was stable. The stability was instead used as a reason to continue OC rather than as a justification for allowing the patient to try to function without OC. Rowe (2013) argued that mental health outreach

teams, peer engagement and citizenship interventions were alternatives to using OC. These models represent ways of organising services that could lead to a better dialogue and reduce the need to use coercion in treatment. In a Norwegian study, Stuen, Rugkåsa, Landheim, & Wynn (2015) showed that mobile teams that included the decision maker provided enhanced follow-up care in ensuring more regular interdisciplinary discussions within the team and with the patient. I consider that such an arrangement would enable patients and their relatives to feel that health care was more comprehensive. Instead, the thesis shows that the lack of continuity in contact with the decision maker left patients and their families locked in a situation of reduced opportunities to participate. They often found health professionals' involvement to be paternalistic and to lead to conflict, and as an obstacle for them to participate with their own experiences. There is a risk that coercion that patients and their families find meaningless over time can undermine the trust needed to create a therapeutic relationship with clinicians. Health professionals must therefore acknowledge the fact that patients find OC to be a restrictive arrangement that scarcely promotes the patient's integration into society.

6.2.5 OC and society

As a society, Norway emphasises integration and individual freedom. People with severe mental disorders may be vulnerable to developments in society that emphasise individual liberty and at the same time set requirements for behavioural norms (Eriksson & Hummelvoll, 2008). On the other hand, society can be vulnerable to situations where people behave differently than the social structure requires (ibid.). A society that emphasises individual rights and freedoms may also involve increased awareness of controlling a potential risk from people who are considered to pose a danger to themselves or others if untreated (Sjöström et al., 2011). Such a society may lead to alienation and insecurity and increase the number of

marginalised people (Drevdahl, 2002; Eriksson & Hummelvoll, 2012). The first sub-study, concerning patient experiences with OC, points in this direction. Foucault (1995, 1999) shows how health professionals play a role in societal implementation of social control, and how psychiatry, in addition to providing treatment, can be responsible for controlling people who are different (Roberts, 2005). As in Sjöström (2012), this thesis shows that control is still present when OC patients experience diffuse coercive frameworks, surveillance and the threat of hospitalisation if they do not comply with the expectations of health professionals. The results of the thesis demonstrate that health professionals use OC to ensure that the patient receives treatment. But the social mission is also made clear in that OC allows clinicians to intervene if discharged patients do not behave rationally in relation to accepted societal norms.

Norwegian health authorities are concerned about the extent of coercion in mental health care (Helse- og omsorgsdepartementet [Norwegian Ministry of Health and Care Services], 2012). These concerns are related to human rights and to the effect of coercion in treatment (Hatling, 2013). The major user organisation Mental Helse is against coercion in principle, believing that it violates patient autonomy and does not lead to improvement (Mental Helse, undated). OC in Norway is intended to be a less restrictive alternative to continued compulsory hospitalisation (Sjöström et al., 2011). Is that how the scheme works, or has OC become a supplement to inpatient care which has expanded the scope for coercion? National surveys show that the use of coercion remains at a high level with little variation from year to year, in spite of national efforts to increase autonomy in mental health care (Bremnes et al., 2016). Burns (2014) argues that the answer to reduced inpatient care has largely been an increased use of OC. O'Brien, McKenna, & Kydd (2009) pointed out the danger in using OC because of a lack of inpatient beds rather than because the scheme improves treatment. In a study from

Norway, Løvsletten et al. (2016) also discuss whether the increased use of OC is due to fewer inpatient beds and earlier discharge of patients. Experience from Sweden showed that the overall number of days of compulsory hospitalisation decreased after the introduction of OC, but that the extent of compulsory outpatient treatment increased during the same period. This amounted to a slight increase in the overall use of coercion (Kjellin & Pelto-Piri, 2014). When the use of coercion in treatment is questioned in all the sub-studies of this thesis, there is reason to reflect on the use of OC in these perspectives, because reduced inpatient care does not necessarily run parallel with increased tolerance in society for mental disorders.

Patients under OC need continuous and intensive monitoring (Burns & Molodynski, 2014). The distance between decision maker and relatives and especially patients, as the sub-studies show, is therefore problematic. Torrey & Drake (2010) argue that developments in health care create such situations because health care systems today focus largely on acute interventions, with less opportunity for clinicians to follow up patients in long-term treatment. Service provision concentrates on acute problems, and not on preventing health problems from occurring or continuing. A related issue is discussed by Lorem, Frafjord, Steffensen, & Wang (2014), who showed that health professionals have insufficient time to create alliances that could enable discussions of advantages and disadvantages of different treatment options with patients and relatives. This thesis shows that patients and their relatives found they received inadequate information about OC from health professionals. Inadequate information in conjunction with changes in the organisation of health services may explain patients' and relatives' experience of grey areas, lack of participation, and coercion, as shown in the sub-studies.

7.0 CONCLUSION AND IMPLICATIONS

7.1 Conclusions

The first study examined patients' experiences of being subjected to OC, emphasising how the scheme worked for them. The main finding was that OC patients experienced their lives as being on hold. All patients reported a high level of perceived coercion in their daily lives as OC patients. Their understanding was that OC kept them in a role as patients and made them hesitant and dependent on health professionals' decisions. The medical context was perceived as an obstacle to recovery and transition to a more normal life. Few patients had experienced physical coercion, but all felt subject to a coercive regime. Inadequate information and poor understanding of the boundary between personal autonomy and clinical decisions gave patients a sense of lacking control over their own lives. The feeling of coercion was thus not only linked to specific situations but it also coloured their whole world. This prevented the patients from developing normal relations with friends and civil society.

The second study examined relatives' experiences as relatives of a family member subjected to OC. The main finding was that relatives of OC patients felt that they were responsible, but still not a real treatment partner. The OC framework gave them a sense of security. They felt that OC ensured the medical treatment and stabilised the patient's life. At the same time they felt sidelined because their experience was not taken into account in the implementation of the OC. Relatives were little concerned about coercion, but focused instead on everyday functioning. They accepted coercion in periods when the patient's functioning was severely impaired. However, the relatives' experience was that medical treatment did not solve the problems they lived with. They worried about the lack of meaningful activities in the patient's life, and therefore believed that OC should encompass a broader approach to the patient's situation. Relatives faced contradictory expectations,

being torn between the patient's desire for support of his/her choices and the clinicians' desire for support of the medical treatment. Such divergent expectations were experienced as stressful, especially when patient and staff were in conflict about OC. The relatives' situation was challenged in that they still represented the main continuity in the patient's life even in OC. At the same time they could not completely rely on the staff keeping to agreements as they wanted. They had to rely on themselves.

The third study examined health professionals' experiences with OC orders. The main finding was that health professionals found difficulty in balancing the role of therapist with the management of coercion. Health professionals had a positive view of OC, believing it was necessary to safeguard the patient's health in a long-term perspective. They justified OC with patients' lack of insight to assess their own treatment needs. Health professionals judged that OC limited patients' autonomy to a minor extent and felt they had a good relationship with patients. However, focus on the patient's lack of insight led to a paternalistic approach more than measures to enhance patient autonomy. There was general consensus on roles and responsibilities in OC between the clinicians involved. But they found the management of coercion to be burdensome in that OC challenged their therapeutic relationship and treatment ideology.

If the studies are viewed as a whole, the results show that patients, relatives and health professionals experienced OC differently. Patients found that the coercion in OC coloured their everyday lives, and they wanted more autonomy and greater responsibility for their own lives. Relatives emphasised that OC provided relief for them, and created greater security through increased stability during follow-up care. But they found they had little opportunity to participate. Health professionals considered OC to be necessary. They felt the coercion to be

limited and not particularly invasive, but also experienced difficulty in combining their therapeutic responsibility with the management of coercion. Patients and relatives felt that health professionals' focus on medical treatment led to an individual disease focus instead of directing attention to the patient's coping skills and interaction with others. Patients and relatives found that the disease understanding invalidated their experiences. They wanted a more holistic approach that emphasised activities and work. Patients and their relatives accepted that there could be a need for drug treatment, but put more emphasis on a treatment understanding based on a social psychiatric perspective which focused on meaningful everyday life. The thesis shows that particularly decision makers had insufficient insight into the lives of patients and their relatives, and that their fear of making wrong assessments that led to relapses was greater than the consideration to let the patient take responsibility to attempt self-mastery. This led health professionals to take a paternalistic approach with a risk of conflict, rather than developing cooperation with patients and relatives.

7.2 Implications for practice

Having studied patients', relatives' and health professionals' experiences with OC, my understanding is that health professionals need to have a more nuanced approach to how OC is used and to challenge certain elements of OC as it is practised in Norway. The importance of patients and their relatives being involved in decisions that affect their lives must have implications for the content and implementation of OC. One question is whether OC is equally useful for all patients with psychosis disorders that do not cooperate on treatment. Another question is whether patients' lack of treatment cooperation is due to lack of insight, or whether they have other priorities for their everyday lives.

With the results of the studies in mind, it is worrying that use of OC is increasing, despite health policies to reduce the use of coercion in treatment, and in contrast to a society that emphasises increased autonomy and participation of patients with mental disorders. There is much in the study findings to suggest that the feeling of coercion could be reduced by providing better information on the content, basis and purpose of OC through closer interaction between patients, relatives and health professionals. Although decisions in the patient record are available to patients and their families, the thesis shows that this does not work well enough today to address the information needs and rights of patients and their families.

Despite the very limited coercive powers of OC orders and their infrequent application in practice, clinicians involved in the procedures and implementation of OC need to be aware of patients' experiences with the scheme in order to enhance their autonomy. Increased attention to OC patients' perceived lack of autonomy rather than their assumed lack of insight into their illness could improve treatment cooperation and reduce the use of coercion. Health professionals' recognition of relatives' need for involvement, support and guidance is a prerequisite for good cooperation in OC planning and implementation. Health professionals must take better account of the situation of patients' relatives; they represent an untapped resource in the patient's otherwise vulnerable network. Including their expertise and experience can enhance treatment.

7.3 Implications for further research on OC

As a research field, coercion is difficult to define and operationalise. It is not easy to measure coercion or to isolate its effect, because many interventions in psychiatric treatment, individually or collectively, may affect patient outcomes. Increased knowledge of the

consequences of coercion will therefore require further studies on what is perceived as coercive, and also the development of methodology to isolate the effect of coercion. Variables must be developed to better measure the effect of coercion, and to examine how coercion influences other interventions in medical, psychological or social psychiatric treatment (Helsedirektoratet [Norwegian Directorate of Health], 2009). Since international scientific publications on OC cannot automatically be applied to Norway, there is a need for more studies on the specific way OC is practised in Norwegian mental health care.

Randomised studies on the effects of OC have not been able to demonstrate any positive effect of OC on consumption of health services or patient treatment outcomes (Rugkåsa, 2016). The low number of randomised trials is largely due to methodological challenges (Swanson & Swartz, 2014). There are more non-randomised studies with a quantitative design. These studies show inconsistent results, ranging from positive to negative experiences of OC. One weakness of these studies is that they use different variables in their analysis of OC (Rugkasa et al., 2014). In planning new research, it is important to find a common set of effect variables, since different outcome measures make it difficult to compare the studies available (ibid). Studies with a qualitative design may help to find outcome measures which provide a better description of the effects of OC. One may question whether the effect of OC can only be assessed on the basis of health and health-economic variables, or whether an individual assessment of the efficacy and usefulness of OC must be made in each case (Hiday, 2003). Although relapses, readmissions and hospital days are measures frequently used to evaluate the effect of OC, this does not mean that these are the areas that best describe its effect. There is therefore a need for more studies which examine patients', relatives' and health professionals' experiences with the scheme. An increase in readmissions and hospital days may mean that OC does not work as intended, but it may also mean that patients are

offered shorter periods of hospitalisation for stabilisation in order to prevent deterioration and the risk of more prolonged hospital stays.

The current knowledge base raises doubts about whether OC improves patients' treatment outcomes in a way that compensates for the disadvantages it implies for patients and their families. There is a need for further qualitative studies to enhance our understanding of what life with OC is actually like. These can be combined with studies that look into what patients and relatives find helpful. Qualitative studies will shed light on what patients, relatives and health professionals consider important when involved in OC. One tool to improve understanding of the experiences of those involved could be to involve patients and relatives more directly in research. One of sub-studies of this thesis was conducted with a co-researcher with user experience of mental health care. This research approach represents a new form of knowledge acquisition where the professional researcher no longer has absolute control of the research, and where user groups themselves can help to decide the questions to be asked and how the results can be understood and used (Kristiansen et al., 2009). The development of knowledge from such studies will supplement that of more "traditional" studies.

In view of present knowledge of OC, Rugkasa et al. (2014) questioned whether it is professionally sound practice to continue the current use of OC when it has no scientifically proven effect. They argued that health professionals who wished to work within evidence-based practice could not continue to use OC in its current form. On the basis of existing knowledge, Dawson (2016) finds no robust evidence that coercive treatment gives better results than offering the same treatment on a voluntary basis. My understanding is that the scheme still needs to be explored further, and that empirical studies must be contextualised. One cannot merely justify decisions on the basis of such complex ethical and professional

issues as those involved in OC. OC must be considered in a synthesis of scientific documentation, historical developments, political and social context and in relation to ethical arguments (O'Brien et al., 2009; Segal & Tauber, 2007). Meanwhile, it must be ensured that knowledge of OC is integrated into practice and influences the way OC is implemented. One issue pointed out by Swanson & Swartz (2014) was that the use of OC is so complex and varied that we may never get individual studies that can draw conclusions about the advantages and drawbacks of OC. Perhaps new studies should rather seek to answer questions such as how long, and for whom, OC is useful. The results of this thesis support such an approach. A further research strategy could then be to examine under what conditions, and for whom, OC is an effective intervention.

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Appendix 1



Forskningsprosjekt om tvunget psykisk helsevern uten døgnopphold (TUD)

Dette er et svært viktig område å få forskningsbasert kunnskap om, noe som vi i stor grad mangler, både lokalt, nasjonalt og internasjonalt. I Sykehuset Innlandet, Divisjon psykisk helsevern er det flere pasienter som er underlagt TUD. De langt fleste av disse pasientene er knyttet til Avdeling for Psykosebehandling og Rehabilitering.

Som avdelingssjef støtter jeg at vår FoU enhet deltar i et forskningsprosjekt om TUD hvor koordineringen ligger hos professor Georg Høyen ved Universitetet i Tromsø. Prosjektansvarlig lokalt vil være 1. amanuensis ved Høgskolen i Hedmark og forskningsrådgiver ved Avdeling for Psykosebehandling og rehabilitering, Arild Granerud.


Alf Skar
Avdelingssjef

Stange, den 16.09.2011

BESØKSADRESSE:

Avdeling for psykosebehandling
og rehabilitering
Petter Skreddersvei 34
2312 Ottestad

POSTADRESSE:

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E-post: postmottak@sykehuset-innlandet.no
www.sykehuset-innlandet.no

Org.nr. 983 971 709

Region:
REK nord

Saksbehandler:

Telefon:

Vår dato:
09.11.2012
Deres dato:
25.09.2012

Vår referanse:
2012/1667/REK nord
Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Georg Høyer
ISM

2012/1667 Menneskers erfaring med tvunget psykisk helsevern uten døgnopphold.

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 25.10.2012.

Forskningsansvarlig institusjon: Universitetet i Tromsø ved Bjørn Straume
Prosjektleder: Georg Høyer

Prosjektleders prosjekttomtale:

Studiens hensikt er å beskrive og få en dypere forståelse av erfaringer og opplevelser som pasienter, pårørende og helsepersonell har med bruk av tvungen psykisk helsevern uten døgnopphold (TUD). Studien gjennomføres i Hedmark og Oppland fylker, og problemstillingene belyses gjennom kvalitative intervjuer med pasienter og pårørende. I tillegg skal det gjennomføres fokusgruppeintervjuer med helsepersonell i spesialist – og kommunehelsetjenesten. Studien vil gi kunnskaper innen et område som til nå ikke er undersøkt i Norge, og som er viktig for å kunne redusere bruk av tvang i behandlingen i det psykiske helsevernet. Studien supplerer tilsvarende studier om TUD som for tiden gjennomføres under ledelse av Nettverk for forskning og kunnskapsutvikling om bruk av tvang innen psykisk helsevern - Universitetet i Tromsø (TvangsForsk), jamfør REK 2010/2286.

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 (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 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.

Komiteens vurdering

Slik komiteen forstår søknaden skal prosjektet ikke behandle temaet om hvordan tvang har påvirket sykdommen til pasienten. Slik det er beskrevet skal man hovedsakelig fokusere på hvordan pasientene har opplevd bruken av tvang, og at man kan bruke denne kunnskapen til å forbedre klinisk praksis.

Komiteen er av den oppfatning at prosjektet ikke vil fremskaffe ny kunnskap om helse eller sykdom, men skal undersøke en bestemt type helsetjeneste og har kommet til at prosjektet ikke skal vurderes etter helseforskningsloven.

Dersom prosjektleder har ment at prosjektet skal fremskaffe ny kunnskap om sykdom eller helse, må dette

fremstilles klarere og søknaden og forskningsprotokollen må omformuleres.

Vedtak

Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke fremleggingspliktig, jf. helseforskningslovens § 10, jf. forskningsetikkloven § 4, 2. ledd.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK nord. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Vi ber om at eventuell klage sendes inn via vår saksportal: <http://helseforskning.etikkom.no>

Med vennlig hilsen

May Britt Rossvoll
Sekretariatsleder

Kopi til: bjorn.straume@uit.no



Personvernombudet for forskning og kvalitetssikring
Kompetansesenter for personvern og
informasjonssikkerhet
Oslo universitetssykehus HF

PERSONVERNOMBUDETS TILRÅDING

Til: Bjørn Stensrud,
Georg Høyser

Kopi: Forskningsansvarlig

Fra: Personvernombudet for forskning og kvalitetssikring

Saksbehandler: Helge Grimnes

Dato: 27.11.2012

Offentlighet: Ikke unntatt offentlighet

Sak: Personvernombudets tilråding til innsamling og
behandling av personopplysninger

Saksnummer/
Personvernnummer: 2012/14889

Personvernombudets tilråding til innsamling og behandling av personopplysninger for prosjektet ”Menneskers erfaring med tvunget psykisk helsevern uten døgnopphold i institusjon fra tre perspektiver - en kvalitativ studie”

Viser til innsendt melding om behandling av personopplysninger / helseopplysninger. Det følgende er personvernombudets tilråding av prosjektet.

Med hjemmel i Personopplysningsforskriftens § 7-12 jf. Helseregisterlovens § 36 har Datatilsynet, ved oppnevning av personvernombud, fritatt sykehuset fra meldeplikten til Datatilsynet. Behandling og utlevering av person-/helseopplysninger meldes derfor til sykehusets personvernombud.

Databehandlingen tilfredsstillende forutsetningene for melding gitt i personopplysningsforskriften § 7-27 og er derfor unntatt konsesjon.

Personvernombudet tilrår at prosjektet gjennomføres under forutsetning av følgende:

1. Databehandlingsansvarlig er Sykehuset Innlandet HF ved adm. dir.
2. Behandling av personopplysningene / helseopplysninger i prosjektet skjer i samsvar med og innenfor det formål som er oppgitt i meldingen.
3. Data lagres som oppgitt i meldingen. Annen lagringsform forutsetter gjennomføring av en risikovurdering som må godkjennes av Personvernombudet.
4. Deltagerne samtykker skriftlig. Informasjonsskrivet må suppleres med informasjon som fremgår av vedlagte mal (informasjon som ikke er markert med gult). Eventuelle fremtidige endringer som berører formålet, utvalget inkluderte eller databehandlingen må forevises personvernombudet før de tas i bruk.
5. Kryssliste som kobler aidentifiserte data med personopplysninger lagres som angitt i meldingen og oppbevares separat på prosjektleders avlåste kontor.
6. Dersom formålet eller databehandlingen endres må personvernombudet informeres om dette.
7. Kontaktperson for prosjektet skal hvert tredje år sende personvernombudet ny melding som bekrefter at databehandlingen skjer i overensstemmelse med opprinnelig formål og helseregisterlovens regler.
8. Data slettes eller anonymiseres ved prosjektslutt 31.12.2015 ved at krysslisten slettes og eventuelle andre identifikasjonsmuligheter i databasen fjernes. Når formålet med registeret er oppfylt sendes melding om bekreftet sletting til personvernombudet.

Prosjektet er registrert i oversikten over tilrådinger og uttalelser til forskning som Personvernombudet fører for sykehuset. Oversikten er offentlig tilgjengelig.

Lykke til med prosjektet!

Med vennlig hilsen
for Personvernombudet for forskning og kvalitetssikring

Helge Grimnes
Personvernrådsgiver
Kompetansesenter for personvern og informasjonssikkerhet
Stab pasientsikkerhet og kvalitet
Oslo universitetssykehus HF

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Web: www.oslo-universitetssykehus.no/personvern



Til: Deg som har erfaring med tvunget psykisk helsevern uten døgnoophold i institusjon

FORESPØRSEL OM Å DELTA I EN STUDIE OM TVUNGET PSYKISK HELSEVERN UTEN SYKEHUSOPPHOLD.

Bakgrunn

Dette er et spørsmål til deg om å delta i en forskningsstudie om tvunget psykisk helsevern uten døgnoophold i Norge (TUD). Til nå har det ikke vært gjennomført forskningsprosjekt om bruk av TUD i Norge, og vi mangler derfor kunnskap om hvordan ordningen fungerer.

Vi ønsker derfor å gjennomføre en studie der vi intervjuer pasienter, pårørende og helsepersonell om erfaringer de har med TUD. At akkurat du blir spurt om å delta er fordi vi har fått en oversikt fra Sykehuset Innlandet over alle som enten er, eller nylig har vært på TUD. Vi ser at dette gjelder for deg. I alt vil vi intervjuer rundt 15 personer som er i samme situasjon som deg.

Hva innebærer studien?

Om du velger å være med i undersøkelsen innebærer dette at du vil bli innkalt til en samtale (intervju) om dine erfaringer med tvunget psykisk helsevern utenfor sykehuset. Samtalen vil dreie seg om hverdagen din, din kontakt med sykehuset, kontakten med psykisk helsetjeneste i kommunen og hvordan du opplever det å være på TUD. Intervjuet vil bli gjennomført av Bjørn Stensrud og vil ta ca. en time. Intervjuene vil bli tatt opp på lydbånd dersom du tillater dette. Intervjuet kan enten finne sted hjemme hos deg, på Sykehuset Innlandet eller et annet sted du selv foretrekker. Om du velger å møtes andre steder enn der du bor, vil du få dekket reisekostnaden. Om du ønsker å ha med deg en person du kjenner til samtalen er det helt greit. Vi ønsker også å intervjuer en av dine pårørende på et senere tidspunkt dersom du gir oss tillatelse til at vi spør dem. Med pårørende mener vi den personen du selv ser på som din nærmeste pårørende. Det trenger ikke være en du er i slekt med, men det må være en person som kjenner deg og som du har kontakt med.

Undersøkelsen er et samarbeidsprosjekt mellom Universitet i Tromsø, Høgskolen i Hedmark og Sykehuset Innlandet. Resultatene vil inngå i Bjørn Stensruds doktorgradsavhandling. Stensrud er psykiatrisk sykepleier og har lang erfaring fra arbeid innenfor psykisk helsevern. Undersøkelsen er vurdert av Regional etisk komité for Helse nord og godkjent av personvernombudet ved Sykehuset Innlandet.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg vil behandles konfidensielt og kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Bare Stensrud og hans to veiledere vil ha adgang til navneliste og intervju. Alle involverte har taushetsplikt. Når resultatene publiseres vil alle opplysninger være anonymisert slik at det ikke vil være mulig å kjenne igjen enkeltpersoner. 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 korrigere eventuelle feil i registrerte opplysninger. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger så sant de ikke allerede inngår i

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www.sykehuset-innlandet.no

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HELSE SØR-ØST



vitenskapelig analyse og vitenskapelig arbeid. Navnelister vil slettes ved prosjektets slutt i 2015. Lydfiler (intervju) oppbevares 2 år etter prosjektslutt for så å slettes.

Frivillig deltagelse

Deltagelse i studien er frivillig, og du kan når som helst trekke deg hvis du skulle ombestemme deg underveis. Om du ikke vil være med i undersøkelsen, eller velger å trekke deg underveis, har dette ingen betydning for annen type hjelp du mottar.

Du har fått denne informasjonen av en i helsevesenet du har kontakt med. Dersom du vil delta, eller ønsker å vite mer om undersøkelsen, kan du gi tilbakemelding til den du mottok informasjonen fra. Du vil da bli kontaktet av Bjørn Stensrud for å gjøre en avtale om intervju eller få mer informasjon før du bestemmer deg om å delta eller ikke. Du kan også ta direkte kontakt på telefon med en eller flere av de som er ansvarlig for undersøkelsen (de samme som har undertegnet denne invitasjonen til å delta).

Med vennlig hilsen

Bjørn Stensrud
Doktorgradsstudent

Sykehuset Innlandet HF
Tlf. 62581636/90742943

Arild Granerud
Biveileder
I. ammanuensis
Høgskolen i Hedmark
Tlf. 97067220

Georg Høyer
Hovedveileder
Professor dr. med.
Universitetet i Tromsø
Tlf. 77644829/95195042

--(klipp)-----

Ottestad, 30.11.12

Samtykke til deltagelse i studie om erfaringer med tvunget psykisk helsevern utenfor sykehus

Jeg er villig til å delta i studien og samtykker til (sett et kryss foran det du samtykker til):

Å være med på en samtale (intervju) med Bjørn Stensrud.

At denne samtalen tas opp på lydbånd

At Bjørn Stensrud kan ta kontakt med min nærmeste pårørende for å spørre om han/hun vil være med i undersøkelsen:

Navn: _____



Dato: _____

Signatur: _____
(Prosjektdeltager)

Jeg bekrefter å ha gitt informasjon om studien

Dato: _____

Signatur: _____
(Dokto:gradsstudent)



Til: Deg som har erfaring med tvunget psykisk helsevern uten døgnopphold i institusjon

FORESPØRSEL OM SAMTYKKE TIL AT DIN NÆRMESTE PÅRØRENDE KAN DELTA I EN STUDIE OM TVUNGET PSYKISK HELSEVERN UTEN SYKEHUSOPPHOLD.

Bakgrunn

Dette er et spørsmål om ditt samtykke til at din nærmeste pårørende forespørres om deltagelse i en forskningsstudie om tvunget psykisk helsevern uten døgnopphold i Norge (TUD). Til nå har det ikke vært gjennomført forskningsprosjekt om bruk av TUD i Norge, og vi mangler derfor kunnskap om hvordan ordningen fungerer. Årsaken til at vi spør deg er at det i intervjuet kan komme frem informasjon om deg og din sykdom.

Vi ønsker å gjennomføre en studie der vi intervjuer pasienter, pårørende og helsepersonell om erfaringer de har med TUD. Intervjustudien med pasienter er avsluttet. At akkurat du blir spurt om samtykke til at din nærmeste pårørende deltar er fordi din psykiater i sykehuset har deg på sin oversikt over pasienter på TUD. Din nærmeste pårørende er derfor aktuell for studien.

Hva innebærer studien?

Om du velger å samtykke innebærer dette at din nærmeste pårørende vil bli forespurt om å delta i en samtale (intervju) om sine erfaringer med tvunget psykisk helsevern utenfor sykehuset. Med nærmeste pårørende mener vi den personen du selv ser på som din nærmeste. Det trenger ikke være en du er i slekt med, men det må være en person som kjenner deg og som du har kontakt med.

Samtalen vil dreie seg om din nærmestes pårørendes hverdag: kontakt med sykehuset, kontakten med psykisk helsetjeneste i kommunen og hvordan den opplever det å være nærmeste pårørende til en pasient underlagt TUD. Dette innebærer at informasjon om deg og din sykdom vil kunne bli omtalt selv om det ikke er fokuset med studien. Intervjuet vil bli gjennomført av Bjørn Stensrud og vil ta ca. en time. Intervjuene vil bli tatt opp på lydbånd dersom det tillates og finne sted enten hjemme hos din pårørende, på Sykehuset Innlandet eller et annet sted som foretrekkes.

Undersøkelsen er et samarbeidsprosjekt mellom Universitetet i Tromsø, Høgskolen i Hedmark og Sykehuset Innlandet. Resultatene vil inngå i Bjørn Stensruds doktorgradsavhandling. Stensrud er psykiatrisk sykepleier og har lang erfaring fra arbeid innenfor psykisk helsevern. Undersøkelsen er vurdert av Regional etisk komité for Helse nord og godkjent av personvernombudet ved Sykehuset Innlandet.

Hva skjer med informasjonen om deg?

Det er bare informasjon som indirekte kan knyttes til deg som kan bli registrert eller fremgå av lydopptak. Det er relasjonen mellom din pårørende og deg som indirekte kan knyttes til deg og din sykdom. På lydopptaket kan det hende ditt navn fremkommer, men det vil vi forsøke å unngå. Alle opplysninger som skrives ned vil bli behandlet uten navn eller andre

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direkte gjenkjennende opplysninger. En kode knytter pårørende til sine opplysninger gjennom en navneliste. Alle involverte har taushetsplikt. Når resultatene publiseres vil alle opplysninger være anonymisert slik at det ikke vil være mulig å kjenne igjen enkeltpersoner. Du har rett til innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å korrigere eventuelle feil i registrerte opplysninger. Dersom du trekker ditt samtykke, kan du kreve å få slettet opplysninger som angår deg så sant de ikke allerede inngår i vitenskapelig analyse og vitenskapelig arbeid. Navnelister vil slettes ved prosjektets slutt i 2015. Lydfiler (intervju) oppbevares 2 år etter prosjektslutt for så å slettes.

Frivillig deltagelse

Dette er frivillig. Om du ikke ønsker at informasjon om deg inngår i studien vil det bli respektert, og vi vil ikke spørre din pårørende om å delta. Dette vil ikke få noen konsekvenser for deg eller din pårørende.

Du har fått denne informasjonen av en i helsevesenet du har kontakt med. Dersom du samtykker til at din nærmeste pårørende forespørres, eller ønsker å vite mer om undersøkelsen, kan du gi tilbakemelding til den du mottok informasjonen fra. Ved samtykke vil Bjørn Stensrud kontakte din pårørende og forespørre om intervju.

Med vennlig hilsen

Bjørn Stensrud
Doktorgradsstudent

Sykehuset Innlandet HF
Tlf. 90742943

Arild Granerud
Biveileder
I. ammanuensis
Høgskolen i Hedmark
Tlf. 97067220

Georg Høyer
Hovedveileder
Professor dr. med.
Universitetet i Tromsø
Tlf. 77644829/95195042

--(klipp)-----

Ottestad, 03.01.14

Samtykke til at min nærmeste pårørende forespørres om deltagelse i studie om sin erfaring med tvunget psykisk helsevern utenfor sykehus

_____ Jeg samtykker til at Bjørn Stensrud kan ta kontakt med min nærmeste pårørende for å spørre om han/hun vil være med i undersøkelsen (sett et kryss).

Pårørendes navn: _____

Dato: _____

Signatur: _____
(Egenerfaring med TUD)

_____ Jeg bekrefter å ha gitt informasjon og at pasienten muntlig har samtykket (Sett kryss).



Til: Deg som er pårørende til et familiemedlem med erfaring fra tvunget psykisk helsevern utenfor sykehus.

FORESPØRSEL OM Å DELTA I EN STUDIE OM TVUNGET PSYKISK HELSEVERN UTEN SYKEHUSOPPHOLD.

Bakgrunn:

Dette er et spørsmål til deg om å delta i en forskningsstudie om tvunget psykisk helsevern uten døgnopphold i Norge (TUD). Til nå har det ikke vært gjennomført forskningsprosjekt om bruk av TUD i Norge, og vi mangler derfor kunnskap om hvordan ordningen fungerer.

Vi ønsker derfor å gjennomføre en studie der vi intervjuer pasienter, pårørende og helsepersonell om erfaringer de har med TUD. At akkurat du blir spurt om å delta er fordi en av deltagerne inkludert i studien har oppgitt deg som sin pårørende, og gitt sitt samtykke til at jeg spør deg om å delta i studien. I alt vil vi intervju ca. 10 personer som er i samme situasjon som deg.

Hva innebærer studien?

Om du velger å være med i undersøkelsen innebærer dette at du vil bli innkalt til en samtale (intervju) om dine erfaringer som pårørende med tvunget psykisk helsevern utenfor sykehuset. Samtalen vil dreie seg om pasientens hverdag, kontakt med sykehuset, kontakten med psykisk helsetjeneste i kommunen og hvordan du opplever det å være pårørende til en pasient underlagt TUD? Intervjuet vil bli gjennomført av Bjørn Stensrud og vil ta ca. en time. Intervjuene vil bli tatt opp på lydbånd dersom du tillater dette. Intervjuet kan enten finne sted hjemme hos deg, på Sykehuset Innlandet eller et annet sted du selv foretrekker. Om du velger å møtes andre steder enn der du bor, vil du få dekket reisekostnaden.

Undersøkelsen er et samarbeidsprosjekt mellom Universitet i Tromsø, Høgskolen i Hedmark og Sykehuset Innlandet. Resultatene vil inngå i Bjørn Stensruds doktorgradsavhandling. Stensrud er psykiatrisk sykepleier og har lang erfaring fra arbeid innenfor psykisk helsevern. Undersøkelsen er vurdert av Regional etisk komité for Helse nord og godkjent av personvernombudet ved Sykehuset Innlandet.

Hva skjer med informasjonen om deg?

Informasjonen som registreres gjennom intervjuet vil behandles konfidensielt og kun brukes slik som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Bare Stensrud og hans to veiledere vil ha adgang til navnelister og intervju. Alle involverte har taushetsplikt. Når resultatene publiseres vil alle opplysninger være anonymisert slik at det ikke vil være mulig å kjenne igjen enkeltpersoner. Hvis du sier ja til å delta i studien har du rett til innsyn i hvilke opplysninger som er registrert fra deg. Du har videre rett til å korrigere eventuelle feil i registrerte opplysninger. Dersom du trekker deg fra studien kan du kreve å få slettet innsamlede opplysninger så sant det ikke allerede inngår i vitenskapelig analyse og vitenskapelig arbeid. Navneliste vil slettes ved prosjektslutt i 2015. Lydfiler (intervju) oppbevares i 2 år etter prosjektslutt for så å slettes.

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HELSE  SØR-ØST



Frivillig deltagelse

Deltagelse i studien er frivillig, og du kan når som helst trekke deg hvis du skulle ombestemme deg underveis. Om du ikke ville være med i undersøkelsen, eller velger å trekke deg underveis, har dette ingen betydning for deg eller den du er pårørende for.

Du mottar denne forespørselen per brev. Dersom du ønsker å delta, eller ønsker mer informasjon før du bestemmer deg, kan du kontakte Bjørn Stensrud - tlf. 907 42943, eventuelt en av de to andre som har medsignert dette brevet. Hvis vi ikke har hørt noe fra deg innen 14 dager vil du bli kontaktet på telefon en gang for å forsikre oss om at du har mottatt denne henvendelsen.

Med vennlig hilsen

Bjørn Stensrud
Doktorgradsstudent

Sykehuset Innlandet HF
Tlf. 62581636/90742943

Arild Granerud
Biveileder
1. ammanuensis
Høgskolen i Hedmark
Tlf. 97067220

Georg Høyner
Hovedveileder
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Universitetet i Tromsø
Tlf. 77644829/95195042

--(klipp)-----

Ottestad, 1. august 2013

Samtykke til deltagelse i studie om erfaringer med tvunget psykisk helsevern utenfor sykehus

Jeg er villig til å delta i studien og samtykker til (sett et kryss foran det du samtykker til):

Å være med på en samtale (intervju) med Bjørn Stensrud.

At denne samtalen tas opp på lydbånd

Dato: _____ Signatur: _____

(Prosjektdeltager)

Jeg bekrefter å ha gitt informasjon om studien

Dato: _____ Signatur: _____

(Doktorgradsstudent)



Til: Deg som vedtar og/eller har erfaring med oppfølging av mennesker underlagt tvungent psykisk helsevern uten døgnopphold i institusjon: helsepersonell i spesialist- og kommunehelsetjenesten.

FORESPØRSEL OM Å DELTA I EN STUDIE OM TVUNGENT PSYKISK HELSEVERN UTEN DØGNOPPHOLD I INSTITUSJON.

Bakgrunn

Dette er et spørsmål til deg om å delta i en forskningsstudie om tvungent psykisk helsevern uten døgnopphold i Norge (TUD). Til nå har det ikke vært gjennomført forskningsprosjekt om bruk av TUD i Norge, og vi mangler derfor kunnskap om hvordan ordningen fungerer.

Vi ønsker å gjennomføre en studie hvor vi intervjuer mennesker underlagt TUD, deres pårørende og involvert helsepersonell om erfaringer de har med TUD. Du blir forespurt fordi du har arbeids- og ansvarsoppgaver innenfor dette fagområdet. Intervjuene med helsepersonell skjer ved fokusgruppeintervju.

Hva innebærer studien?

Din deltagelse innebærer at du deltar i to fokusgruppeintervju med 3 - 4 ukers mellomrom. Temaene vil være TUD slik den fungerer i din praksis. Intervjuene vil bli ledet av Gro Beston (erfaringskonsulent i SI) og Bjørn Stensrud. De vil ta ca. 1,5-2 timer hver gang. Intervjuene tas opp digitalt. Det ene intervjuet gjennomføres ved SIHF Sanderud, det andre ved SIHF Reinsvoll. Du vil få dekket reisekostnader til intervju hvis disse ikke dekkes av arbeidsgiver.

Undersøkelsen er et samarbeidsprosjekt mellom Universitet i Tromsø, Høgskolen i Hedmark og Sykehuset Innlandet. Resultatene vil inngå i Bjørn Stensruds doktorgradsavhandling. Stensrud er psykiatrisk sykepleier og har lang erfaring fra arbeid innenfor psykisk helsevern. Undersøkelsen er vurdert av Regional etisk komité for Helse nord og godkjent av personvernombudet ved Sykehuset Innlandet.

Hva skjer med informasjonen som registreres?

Informasjonen som registreres vil behandles konfidensielt og kun brukes som beskrevet i hensikten med studien. Alle opplysninger vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til din fokusgruppe gjennom en navneliste. Bare Stensrud, Beston og veiledere vil ha adgang til navneliste og intervju. Alle involverte har taushetsplikt. Når resultatene publiseres vil alle opplysninger være anonymisert slik at det ikke vil være mulig å kjenne igjen enkeltpersoner. Hvis du sier ja til å delta i studien har du rett til å få innsyn i opplysninger registrert fra ditt fokusgruppeintervju. Du har videre rett til å korrigere eventuelle feil i registrerte opplysninger. Dersom du trekker deg fra studien kan du kreve å få slettet opplysninger gitt av deg så sant de ikke allerede inngår i vitenskapelig analyse og vitenskapelig arbeid. Navnelister vil slettes ved prosjektslutt i 2015. Lydfiler (intervju) oppbevares 2 år etter prosjektslutt for så å slettes.

Frivillig deltagelse

Deltagelse i studien er frivillig, og du kan når som helst trekke deg hvis du ombestemmer deg underveis. Dette får ingen betydning for din arbeidssituasjon. Du mottar denne forespørselen

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via din leder. Beskjed om du ønsker å delta gis tilbake til samme leder. Om du ønsker mer informasjon før du bestemmer deg kan du kontakte Bjørn Stensrud, eventuelt Georg Høyer som er hovedveileder i prosjektet.

Leder vil formidle deltagere i fokusgruppen tilbake til undertegnede.

Med vennlig hilsen

Bjørn Stensrud
Doktorgradsstudent

Sykehuset Innlandet HF
Tlf. 62581636/90742943

Georg Høyer
Hovedveileder
Professor dr. med.
Universitetet i Tromsø
Tlf. 77644829/95195042

--(klipp)-----

Ottestad, 28. oktober 2014

Samtykke til deltagelse i studie om helsepersonells erfaringer med tvunget psykisk helsevern uten døgnopphold i institusjon.

___ Jeg samtykker til å delta i fokusgruppeintervju ledet av Gro Beston og Bjørn Stensrud.

Dato: _____

Signatur _____

Menneskers opplevelser og erfaringer med TUD: Temaguide-pasienter (1-8).

Intervjuguiden viser hvilke hovedtema intervjuet vil dekke.

Innledning: presentasjon, avklare spørsmål og signere samtykke.

Demografiske data: kjønn og alder.

Hovedtema:

Hvilke opplevelser og erfaringer har du med å være underlagt vedtak om tvunget psykisk helsevern uten døgnopphold i institusjon, og hvordan vurderer du at TUD fungerer for deg?

Undertema:

Med utgangspunkt i vedtak om TUD:

- Dine erfaringer med kontakt til sykehus og kommune?
- Dine erfaringer med kontakt til familie og venner?
- Dine erfaringer med bruk av medikamenter?

Avslutningsvis:

- Oppsummert: Hva er mest bra i livet ditt slik du har det nå?
- Oppsummert: Hva er mest dårlig i livet ditt slik du har det nå?
- Andre ting som vi ikke har pratet om?

Oppsummering av intervjuet med rom for tilleggskommentarer.

Menneskers opplevelser og erfaringer med TUD: Temaguide-pasienter (9 – 12).

Intervjuguiden viser hvilke hovedtema intervjuet vil dekke.

Innledning: presentasjon, avklare spørsmål og signere samtykke.

Demografiske data: bosituasjon, kjønn og alder.

Hovedtema:

- Hvilke opplevelser og erfaringer har du med å være underlagt vedtak om tvunget psykisk helsevern uten døgnopphold i institusjon?
- Hvordan vurderer du at TUD fungerer for deg i dag?
- Hvilke tanker gjør du fremover i forhold til TUD?

Undertema:

1. Frihet (hva er tvangen i TUD?)
 - handlingsrom i hverdagen (aktiviteter / sosialt nettverk / bolig)
 - opplevelsen av å være fri (følelse / tanke). Fremmere og hemmere.
2. Medikamentell behandling
 - erfaringer med bruk (effekt / bivirkning / tvang)
 - relasjonen til hjelper (innsikt / informasjon / tillitt)
3. Nettverk og relasjon
 - betydningsfulle andre: hverdagsrelasjon i kommunen / sykehuset som kontrollør. Oppfattelse av sine hjelpere?
 - erfaringer som peker mot myndiggjøring i eget liv
 - TUD som middel til integrasjon eller desintegrasjon?

Avslutningsvis:

- Oppsummert: Hva er mest bra i livet ditt slik du har det nå?
- Oppsummert: Hva er mest dårlig i livet ditt slik du har det nå?
- Andre ting som vi ikke har pratet om?

Oppsummering av intervjuet med rom for tilleggskommentarer.

Menneskers opplevelser og erfaringer med TUD: Temaguide: pasienter (13-16)

Intervjuguiden viser hvilke hovedtema intervjuet vil dekke.

Innledning: presentasjon, avklare spørsmål og signere samtykke.

Demografiske data: kjønn og alder.

Hovedtema:

Hvilke opplevelser og erfaringer har du med å være underlagt vedtak om tvunget psykisk helsevern uten døgnopphold i institusjon, og hvordan vurderer du at TUD fungerer for deg?

Undertema:

Med utgangspunkt i vedtak om TUD:

- Dine erfaringer med kontakt til sykehus og kommune?
- Dine erfaringer med kontakt til familie og venner?
- Dine erfaringer med bruk av medikamenter?

- Låst av historien
- Frihet til selv å forme beslutninger
- Strukturens dilemma
- En opplevelse av å være annerledes
- Helsepersonells meninger teller mer enn egne
- Opplevelse av å straffes uten grunn
- Kan jeg stole på mine støttespillere?

Avslutningsvis:

- Oppsummert: Hva er mest bra i livet ditt slik du har det nå?
- Oppsummert: Hva er mest dårlig i livet ditt slik du har det nå?
- Andre ting som vi ikke har pratet om?

Oppsummering av intervjuet med rom for tilleggskommentarer.

Forskers hjelpetekst/huskeliste pasientintervju:

Erfaringer med tvunget ettervern

- Hvordan ser en vanlig dag og en vanlig uke ut for deg i dag?
- Hvilke tanker gjør du deg om tvunget psykisk ettervern?
- Hvordan hadde du det tidligere – før tvunget ettervern ble etablert?
- Synes du at ting har endret seg etter at tvunget ettervern ble etablert? Hvis ja, hva har endret seg?
- Hvordan tror du at livet ditt ville sett ut i dag om du ikke var på tvunget ettervern?

Erfaringer med sykehuset og kommunen

- Hva er innholdet i din kontakt med sykehuset, og hvordan opplever du denne kontakten?
- I din kontakt med sykehuset, hvem er de viktigste personene for deg?
- Har du noen kontakt med det kommunale tjenestetilbudet? Hvis ja: kan du fortelle litt om tilbudet du har?
- Hvorfor tror du det er bestemt at du skal være underlagt tvunget ettervern?

Erfaringer med medikamentell behandling

- Hvilke tanker gjør du deg med å bruke medisiner i forhold til din psykiske lidelse?
- Hvordan tenker du at tvunget ettervern påvirker din medisinerings? Hva ville skjedd hvis du ikke brukte foreskrevne medisiner?
- Hvis du har erfaringer med en situasjon hvor du var uenig i medisineringsen, kan du fortelle meg litt om den situasjonen?
- Hvis du bruker medisiner regelmessig, hva er dine grunner til å fortsette med det?

Erfaringer med relasjoner

- Påvirker tvunget ettervern dine relasjoner til mennesker du omgås daglig?
- Hvilke tanker tror du mennesker du omgås daglig har til at du er på tvunget ettervern?

Menneskers opplevelser og erfaringer med TUD – Temaguide: pårørende intervju

Temaguiden er stikkordsmessig for å vise hvilke hoved-emner intervjuet vil dekke.. I spørsmålsstillinger brukes *tvunget ettervern* da dette begrepet er det vanligste i dagligtale.

Innledning: presentasjon, avklare eventuelle spørsmål og signere samtykke.

Demografiske data: Familierelasjon, aldersrelasjon (eldre/ynge/jevngammel) og kjønn.

Generelt tema: hverdagsliv

- Hvordan opplever du det er å være pårørende til en slektning med en alvorlig psykisk lidelse (hvordan påvirker det deg og din hverdag)?
- Hvor ofte er det kontakt mellom pasienten og deg som pårørende? Hvordan synes du denne kontakten fungerer?
- Etter din vurdering, hvem er sentrale personer i pasientens hverdag?
- Hvordan vurderer du at det fungerer i pasientens hverdag (bosituasjon, økonomi, aktiviteter)? Er hjelpetilbudet tilpasset og tilstrekkelig?

Spesielt tema: tvunget ettervern

- Hvordan var situasjon for pasienten og deg som pårørende før TUD ble etablert?
- Hva er annerledes nå (positivt og negativt)?
- Hvordan tror du pasientens og din situasjon ville vært nå uten vedtak om TUD – ville noe vært annerledes?
- Hvilke tanker gjør du deg om tvunget ettervern – er det nødvendig eller unødvendig (begrensninger, frihetsberøvelse, alternativer)?
- Hvilke tanker gjør du deg om tvunget ettervern i forhold til din rolle som pårørende?

Spesielt tema: kontakt med sykehuset

- Hvem er sentrale personer i sykehuset? Har du noen kontakt med disse?
- Slik du ser det, hva er innholdet i pasientens kontakt med sykehuset?
- Har du fått tilbud om eller mottatt informasjon knyttet til tvunget ettervern?
- Opplever du at du har tilstrekkelig kunnskap om hva tvunget ettervern innebærer?
- Føler du at du har et sted å henvende deg hvis det skulle være behov for det?

Spesielt tema: kommunalt tjenestetilbud og brukersenter

- Er du kjent med hvilke tilbud og muligheter som foreligger i det kommunale tjenestetilbudet og ved brukersenter?
- Har du noen erfaring med hvordan dette fungerer for pasienten? Kan noe gjøres for å tilpasse tilbudet bedre?

Spesielt tema: medisiner

- Hvilke tanker gjør du deg om bruk av medisiner ved psykiske lidelser (virkninger/bivirkninger)?
- Hvilke tanker gjør du deg om at noen mennesker med psykiske lidelser må bruke psykofarmaka mot sin vilje?

Andre ting vi ikke har pratet om, men som du synes det er viktig å få sagt?

Oppsummering av intervjuet ved intervjuer med rom for tilleggskommentarer fra informant.

Menneskers opplevelser og erfaringer med TUD – Temaguide: intervju av helsepersonell som følger opp pasienter underlagt TUD.

Tema 1: Hvordan er arbeidet rundt TUD organisert? [praksissituasjon]

- Hvem inngår i oppfølgingen av TUD pasienten?
- Hvordan er samarbeidet med vedtaksansvarlig og sykehuset [arenaer]?
- Hvorfor brukes TUD som en del av ettervernet til disse pasientene?
- Hvordan informeres pasienten om krav og rettigheter under TUD?

Tema 2: Hvordan påvirker TUD samarbeidet med pasienten?

- Hva kjennetegner pasienter som er underlagt TUD?
- Hva er innholdet i TUD slik du ser det [Hva er pasienten forpliktet til]?
- Har pasientene i din praksis et behovstilpasset tilbud [mulighet frie valg]?
- Hvordan påvirker TUD relasjonen til pasienten?
- Hvordan virker TUD inn på pasientens bedringsprosesser?
- Erfarer du spesielle konfliktområder knyttet til TUD?

Tema 3: Hvordan er samarbeidet med de involverte (konkret)?

- Hvordan opplever du samarbeidet med vedtaksansvarlig?
- Er du informert om innhold og målsetting m/TUD for ”dine” pasienter?
- Hvilken rolle og ansvar har pårørende [involvert, informert og fulgt opp]?
- Erfarer du spesielle samarbeidsutfordringer [pas/pår/internt]?

Tema 4: Hvordan opplever du å arbeide med pasienter underlagt tvungen behandling?

- Hvordan opplever du å arbeide med pasienter på tvungen vern? Skiller det seg ut med frivillig oppfølging?
- Redusert og riktig bruk av tvang: hva er deres erfaringer fra egen praksis?
- Hvorfor øker bruken av TUD i Norge?
- Hva skulle alternativene til tvunget ettervern være [Med.frie tilbud]?

Tema 5: Oppsummering / validering

- Hva er fordelene med å bruke TUD slik du ser det?
- Hva er ulempene?

Tema 6: Tema som ikke er berørt?

Menneskers opplevelser og erfaringer med TUD – Temaguide: intervju av helsepersonell med TUD vedtaksansvar.

Tema 1: Hvordan er arbeidet rundt TUD organisert? [Klinisk erfaring]

- Hvem inngår i oppfølgingen av TUD pasienten?
- Hvordan foregår samarbeidet mellom sykehuset og DPS, og samarbeidet mellom Sykehus/DPS og kommunehelsetjenesten?
- Hva er hensikten med å bruke TUD [Behandling eller beskyttelse]?
- Hvordan informeres pasienten om krav og rettigheter under TUD?

Tema 2: Hvordan virker TUD på ditt samarbeid med pasienten?

- Hva kjennetegner pasienter som er underlagt TUD?
- Hva er innholdet i TUD [Hva er det pasienten er forpliktet til]?
- Hvor lang er dere villig til å følge pasientens egne ønsker [vurderinger ved etablering. Når tas pasienten av TUD: 'frisk'/prøve ut stabilitet]?
- Hvordan påvirker TUD deres relasjon til pasienten?
- Hvordan virker TUD inn på pasientens bedringsprosess?
- Erfarer du spesielle konfliktområder knyttet til TUD?

Tema 3: Hvordan er samarbeidet med de involverte (konkret)?

- Hvordan opplever dere samarbeidet med kommunehelsetjenesten?
- Hvilken rolle og ansvar har pårørende til pasienter på TUD?
- Hvordan blir pårørende involvert, informert og fulgt opp?
- Erfarer du spesielle samarbeidsutfordringer [pas/pår/sykeh/kom]?

Tema 4: Hvordan opplever du å arbeide med pasienter underlagt tvungen behandling?

- Hvordan opplever du å arbeide med pasienter på tvungent vern? Skiller det seg fra kontakten med pasienter som har frivillig oppfølging?
- Redusert og riktig bruk av tvang - hva er deres erfaringer fra praksis?
- Hva er dine problemstillinger som vedtaksansvarlig i egen praksis?
- Hvorfor øker bruken av TUD i Norge?
- Hva skulle alternativene til tvungent ettervern være [Med.frie tilbud]?

Tema 5: Oppsummering / validering

- Hva er fordelene med å bruke TUD slik du ser det? Og ulempene?

Tema 6: Tema som ikke er berørt?

Menneskers opplevelser og erfaringer med TUD – Temaguide: intervju av helsepersonell som vedtar og følger opp pasienter underlagt TUD (blandet gruppe).

Tema 1: Hvordan er arbeidet rundt TUD organisert? [praksissituasjon]

- Hvem inngår i oppfølgingen av TUD pasienten?
- Hvordan er samarbeidet mellom sykehus/DPS, kommune og fastlege?
- Hvorfor brukes TUD som en del av ettervernet til disse pasientene?
- Hvordan informeres pasienten om krav og rettigheter under TUD?

Tema 2: Hvordan påvirker TUD samarbeidet med pasienten?

- Hva kjennetegner pasienter som er underlagt TUD?
- Hva er innholdet i TUD slik du ser det [Hva er pasienten forpliktet til]?
- Pasientens handlingsrom – hvor langt er dere villige til å følge pasientens ønsker [mulighet for frie valg]?
- Hvordan påvirker TUD relasjonen til pasienten?
- Hvordan virker TUD inn på pasientens bedringsprosesser?
- Erfarer du spesielle konfliktområder knyttet til TUD?

Tema 3: Hvordan er samarbeidet med de involverte (konkret)?

- Hvordan opplever du samarbeidet mellom de involverte?
- Er du informert om innhold og målsetting m/TUD for ”dine” pasienter?
- Hvilken rolle og ansvar har pårørende [involvert, informert og fulgt opp]?
- Erfarer du spesielle samarbeidsutfordringer [pas/pår/internt]?

Tema 4: Hvordan opplever du å arbeide med pasienter underlagt tvungen behandling?

- Hvordan opplever du å arbeide med pasienter på tvungen vern? Hvordan skiller TUD seg fra frivillig oppfølging?
- Redusert og riktig bruk av tvang: hva er deres erfaringer fra egen praksis?
- Hvorfor øker bruken av TUD i Norge?
- Hva skulle alternativene til tvungen ettervern være [Med.frie tilbud]?

Tema 5: Oppsummering / validering

- Hva er fordelene med å bruke TUD slik du ser det?
- Hva er ulempene?

Tema 6: Tema som ikke er berørt?

Momenter 18 + 25/11

Hvor tidlig involveres kommunen?
Hvordan styrke pasientens medvirkning?
Hvordan etablere innsikt?
Bivirkningsfri behandling?
Aksept ”annerledeshet”?
Hierarki i helsevesen
Språk definerer virkeligheten (impulsiv/kreativ)
Hvorfor vil ikke pas. ha IP?
Stabilisering – normalitet – disiplinering
”Tåler pas. informasjon”?
Hvordan bruke og utnytte hverandres kompetanse?

