UiO University of Oslo			
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Patients' Experience of Coercion in Mental Health Care			
Dissertation			

**Faculty of Medicine** 

### © Olav Nyttingnes, 2018

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## **Acknowledgements**

Freedom and restrictions are important dimensions in most people's lives, and freedom and predictability are important for well-being and sanity. Maybe that was why the coercion theme interested me so strongly, when it appeared during interviews and conversations with user representatives during my work at the Norwegian Council for Mental Health in 2002. Important questions soon came to mind: Is coercion really necessary, how frequently is it used, are there alternatives, how is it experienced, and does it achieve its aims, and if so, at what cost?

I learned that there was a dearth of knowledge and well-designed quantitative studies. I saw the lack of consensus, and even encountered strongly opposing views between and within stakeholder groups. When a report showed that point prevalence rates of involuntary admitted patients by catchment area varied with a factor of 12 within Norway (Statens helsetilsyn, 2006), I became very curious: How could it be that the high-status, affluent, attractive neighboring health trust of Norway's capital Oslo had the highest rates, and that a small coastal backcountry decentralized trust in northern Norway had the lowest? While coercion rates and predictors are interesting in their own right, my interest was also frequently fueled by the apparent disagreement within and between patients, carers, and professionals. I was therefore both excited and concerned when I started working on the development of a measurement scale of experienced coercion, with the possible prospect of a future PhD on the subject, at Akershus University Hospital.

I am very thankful for the opportunity to study experienced coercion. The development of the Experienced Coercion Scale was funded by the Norwegian Directorate of Health (Helsedirektoratet), which was necessary for this project. Likewise, Akershus University Hospital's R&D Department of the Division of Mental Health funded an expansion of the data foundation, my PhD work, and gave me all opportunities to finish this thesis.

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Thanks to my parents, Bodil and Gunnar, for care, support, and freedom to go my own way. Finally, the safe haven at home has been an invaluable secure and supportive base during this work. To my supporting and caring wife Beatrix, and my fun, frank and sweet daughters Frøya and Aurora: You matter most, and you're the best!

Akershus, September 2017 Olav Nyttingnes

## **Abbreviations**

ACT Assertive Community Treatment

CES Coercion Experience Scale

CL Coercion Ladder

CTO Community treatment order ECS Experienced Coercion Scale

MPCS MacArthur Perceived Coercion Scale

## **Summary**

Coercion in mental health care can be divided into compulsion, informal coercion and experienced or perceived coercion. The focus in this thesis is on the third of these categories: coercion according to the patients' own experiences.

The research questions in the thesis are: 1) How do patients with negative experiences of coercion express and conceptualise these experiences? 2) Is it possible to establish a scale to measure "experienced coercion" that has good psychometric properties, and can be applied in a variety of care settings? 3) What is the level of experienced coercion in Norwegian adolescent inpatient care, and which variables predict experienced coercion in this population? 4) Can the relationship between use of coercion and experienced coercion found in our data and in the knowledge base be combined into a simple explanatory model?

In Paper 1, we investigate the experience of coercion through a qualitative analysis of statements from 35 persons with personal experience of being subjected to coercion in mental health care. Data was notes from 15 dialogue seminars on Coercion and Voluntariness, held in Oslo, Norway, from 2006 to 2009. The notes included strong, negative descriptions of coercion in mental health care, such as *violation*, *communism*, and a *concentration camp*. We identified two pathways towards those expressions: First, patients described encountering a medical approach that did not fit the crisis they experienced, and that they were pressured or coerced to take medication that they did not think helped, or that had strong negative side effects. When they brought this up with the professionals, they experienced that their concerns were ignored or dismissed as a sign of their disorder and lack of insight, and the involuntary medication or treatment pressure continued. As a result, the treatment was experienced like abuse and violation. Second, the accumulated effects of repeated instances of minor, unwanted, yet inescapable incidents of pressure were found to undermine self-image over time. This was also described as a serious violation.

In Paper 2, we develop the Experienced Coercion Scale (ECS) using classical test theory. We used descriptions and categories from Paper 1 and the relevant literature to develop statements within nine possible domains of experienced coercion. Eighty-four statements were tested in a cross-sectional study with 212 patients in five different care settings. We selected 20 candidate items based on an evaluation of factor analysis results, number of missing answers, overlapping content, and items that discriminated between patients in typically coercive and voluntary care arenas. Then these 20 statements were tested in 219 patients in four different care settings with additional information from staff about treatment, compulsion, and diagnosis. We used factor analysis to select 15 items in the final version of the ECS. The sum scores in the sample approached the normal

distribution, and the scale showed high internal consistency. In a linear regression model, involuntary admission and continued involuntary antipsychotic medication significantly predicted high experienced coercion, while demographic and clinical variables did not.

In Paper 3, we examine experienced coercion in a cross-sectional study of 96 patients in 10 adolescent acute and combined acute and sub-acute wards. The patients responded to questionnaires with two scales for experienced coercion (the ECS and the Coercion Ladder), and rated the relationship with parents and staff. Staff reported information on compulsion, diagnosis, and psychosocial functioning. One third of the adolescent patients reported high experienced coercion. Patients diagnosed with eating disorder reported the highest experienced coercion, while patients diagnosed with psychosis reported the lowest. This might be explained by few adolescents with psychoses being under compulsion and that treatment of eating disorders being associated with more restrictive care arrangements. A mixed effects model that included compulsion, eating disorders, relation to parents and psychosocial functioning as predictors, showed that high levels of experienced coercion were significantly predicted by compulsion, a worse psychosocial function, and a worse relation to the parents.

In the discussion section of this thesis, I combine the findings and conceptualization of experienced coercion into a model of the relation between use of coercion and experienced coercion in mental health care. The model is based on the appraisal model for emotions. The starting point is freedom restrictions that are effected, ordered, or enabled by mental health care. These restrictions are appraised by the patient in a process that assesses the legitimacy of the freedom restriction according to the proportionality and the procedural justice in the situation. If the freedom restriction violates these implicit standards, the patient reports high experienced coercion, and often feels humiliated. If the restrictions are appraised as proportionate and procedurally just, the patient reports low experienced coercion. This model may go some way to explain why a substantial number of patients under compulsion report low experienced coercion.

The thesis demonstrates that coercion is experienced as strongly negative by some patients. According to findings in Paper 1 and 2, continued involuntary treatment with medications is a pivotal element in negative evaluations of experienced coercion in adults. An unexpected finding was that in the main, adolescents with psychosis were in voluntary inpatient care, and reported low experienced coercion. More research is needed before implications of these findings can be properly understood.

## Norsk sammendrag [Summary in Norwegian]

Tvang i psykisk helsevern kan deles inn i lovhjemlet tvang, uformell tvang, og tvang slik det oppleves hos pasienten. Denne avhandlingen har fokus på den tredje kategorien: Tvang slik pasienten opplever det.

I avhandlingen reiser jeg disse forskningsspørsmålene: 1) Hvordan uttrykker pasienter med negative erfaringer med tvang disse erfaringene? 2) Er det mulig å utvikle et mål på opplevd tvang som har gode måleegenskaper hos voksne og som kan brukes på tvers av ulike behandlingssituasjoner?

3) Hvordan er nivået av opplevd tvang hos pasienter i ungdomspsykiatriske døgnposter, og hvilke faktorer samvarierer med opplevd tvang i denne gruppen? 4) Er det mulig å lage en modell for forholdet mellom bruk av tvang og opplevd tvang basert på tenkningen og resultatene fra disse undersøkelsene samt eksisterende forskningsfunn?

Artikkel 1 undersøker opplevelsen av tvang ved innholdsanalyse av utsagn fra 35 personer som selv hadde vært under tvang i psykisk helsevern i referatene fra 15 dagsseminarer om tvang og frivillighet som ble arrangert i Oslo fra 2006 til 2009. Referatene uttrykte sterkt negative oppfatninger av tvungent psykisk helsevern, som *krenkelse*, *kommunisme* og *konsentrasjonsleir*. Vi fant to sett av beskrivelser som ledet fram til slike sterke ord: 1) Møtet med en medisinsk forståelse som de ikke syntes passet for krisen de var i, der de ble presset eller tvunget til medisiner som de syntes ikke hjalp for dem eller hadde mange negative bivirkninger. Når de tok opp dette med behandlerne ble det ignorert eller avvist som sykdomstegn eller manglende innsikt, mens press og tvang for å ta antipsykotisk medisinering fortsatte, og de følte behandlingen som misbruk og krenkelse. 2) Den samlede virkningen av gjentatte, mindre, uønskede hendelser som de ikke kunne unnslippe kunne bryte ned selvbildet og ble også beskrevet som alvorlig.

I artikkel 2 utvikler vi Experienced Coercion Scale (ECS) innen rammen av klassisk test-teori. Vi brukte beskrivelser og kategorier fra artikkel 1 og annen relevant forskning til å utvikle utsagn innenfor ni mulige opplevelsesmåter for opplevd tvang. Først prøvde vi ut 84 utsagn i en tverrsnittstudie med 212 pasienter i fem ulike behandlingssituasjoner. Vi valgte ut de 20 beste utsagnene basert på faktoranalyse, antall manglende svar, overlappende utsagn og sammenheng med typisk tvungen og typisk frivillig behandlingsarena. Disse 20 utsagnene ble deretter prøvd ut på 219 pasienter i fire behandlingssituasjoner og sammenholdt med opplysninger fra ansatte om behandlingen, bruk av press og tvang og om diagnose. Vi valgte deretter ut de 15 beste utsagnene til ECS basert på faktoranalyse. Sumskårene var tilnærmet normalfordelt i utvalget, og skalaen hadde høy indre konsistens. En lineær regresjonsanalyse viste at å være under tvang (tvangsinnleggelse/tvang uten

døgnopphold og vedtak om tvangsbehandling) predikerte høyere opplevd tvang, mens demografiske og kliniske variabler ikke spilte noen selvstendig rolle.

I artikkel 3 undersøker vi opplevd tvang i en tverrsnittstudie av 96 pasienter i 10 ungdomspsykiatriske akuttposter og kombinerte akutt og intermediærposter. Pasientene fylte ut spørreskjema med to skalaer for opplevd tvang (ECS og Coercion Ladder) og opplysninger om forholdet til foreldre og de ansatte. Ansatte ga opplysninger om bruk av tvang, diagnose og psykososialt funksjonsnivå. En tredel av pasientene svarte at de hadde høy opplevd tvang. Blant gruppene i utvalget var det pasienter med spiseforstyrrelsesdiagnose som rapporterte høyest opplevd tvang, mens pasienter med psykoselidelser var gruppen med lavest opplevd tvang og få av dem var tvangsinnlagt.

Spiseforstyrrelser henger sammen med mer restriktive behandlingsopplegg, og i en mixed effects modell der tvang, spiseforstyrrelse, relasjon til foreldrene og psykososial fungering inngikk, fant vi at å være under tvang, ha dårligere psykososial fungering og dårligere relasjon til foreldrene samvarierte signifikant med høyere opplevd tvang.

I avhandlingens diskusjon sammenfatter jeg funnene og forståelsen av opplevd tvang til en modell for forholdet mellom bruk og opplevelse av tvang i psykiske helsetjenester. Frihetsinnskrenkelser som utføres av eller muliggjøres av psykisk helsevern og psykisk helsevernloven er startpunktet. Deretter følger en vurderingsprosess, der pasienten vurderer om inngrepet er legitimt i form av forholdsmessighet i situasjonen og om inngrepet er besluttet og gjennomført på en rettferdig og korrekt måte. Hvis inngrepet bryter med disse implisitte standardene, rapporterer pasienten høy opplevd tvang og føler seg ofte samtidig ydmyket. Hvis inngrepet vurderes som forholdsmessig og korrekt besluttet, så rapporter pasientene lav opplevd tvang. Dette kan forklare at en betydelig andel pasienter som er under tvang, likevel rapporterer lav opplevd tvang.

Avhandlingen viser at tvang oppleves sterkt negativt av enkelte pasienter. Artikkel 1 og 2 tyder på at tvangsbehandling med medikamenter er det som oppleves mest inngripende. Det var uventet at ungdommer med psykose stort sett var frivillig innlagt og rapporterte lav opplevd tvang. Det er behov for mer forskning før man kan si noe om bakgrunn og implikasjoner for dette funnet.

## **List of Papers**

#### Paper 1

Nyttingnes, O., Ruud, T., & Rugkåsa, J. (2016). 'It's unbelievably humiliating' – Patients' expressions of negative effects of coercion in mental health care. *International Journal of Law and Psychiatry, 49*, 147-153.

#### Paper 2

Nyttingnes, O., Holmén, A., Rugkåsa, J., & Ruud, T. (2016). The Development, Validation, and Feasibility of the Experienced Coercion Scale (ECS). *Psychological Assessment,* Advance online publication.

#### Paper 3

Nyttingnes, O., Ruud, T., Norvoll, R., Rugkåsa, J., & Hanssen-Bauer, K. (in review). A cross-sectional study of experienced coercion in adolescent mental health inpatients. Submitted to BMC Health Services Research.

#### 1 Introduction

The theme of this thesis is patients' experience of coercion in mental health care. It denotes the experience, consideration, or feeling of being the subject of coercion. The study of experienced coercion can improve the knowledge of what goes on between patient and staff where coercion is considered a possibility by at least one of the parties. It may shed light on the strong disagreements between some users and professionals regarding the practice, ethics, and effects of coercion in mental health care. Detailed knowledge of experience of coercion can inspire changes that may reduce experienced coercion.

The content of this thesis are more modest: To report a study of how adult mental health patients describe and experience coercion, construct and validate a scale of experienced coercion, and report experienced coercion in the adult care setting. This scale is then used to measure experienced coercion in the adolescent mental health care setting.

The papers included in this thesis investigate experienced coercion from varying perspectives and in different groups. A more detailed overview of sub-studies, data sources, and methods is presented later, in Table 1 in Chapter 3.1. Finally, in the discussion, I will combine this information into a more comprehensive and compact understanding of the relationship between the use of coercion and experienced coercion.

In this chapter I discuss the coercion concept, and present the results from studies of experienced coercion, as well as the existing measurement scales for experienced coercion.

#### 1.1 What is Coercion?

Coercion is a broad concept, encompassing several more specific meanings. To give an initial overview, I suggest a simple taxonomy of coercion in mental health care, before I look briefly at the roots of coercion in mental health care, and then how coercion has been covered in philosophy.

Against this background, I discuss some imprecisions and problems that appear when trying to define and operationalize coercion and experienced coercion.

#### 1.1.1 A Taxonomy of Coercion in Mental Health Care

Coercion is a general concept, which has been applied with several meanings, and used to describe events in several arenas. An example of a dictionary definition of "coerce" and "coercion" is to "use force to make somebody obedient" and "government by force" (Hornby, Cowie, & Gimson, 1974). The essence of such definitions is that an agent uses some form of power to make the target, sometimes called the coercee, to act in another way than he or she would otherwise do. In mental health care,

"coercion" is used as a common term for different forms of coercion and different aspects of coercion.

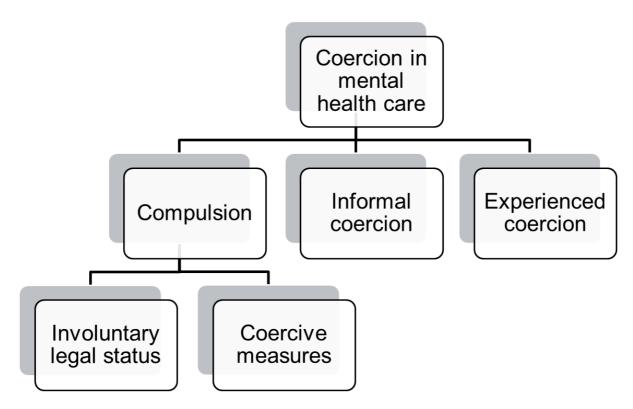


Figure 1. A Taxonomy of Coercion towards Patients in Mental Health Care

I present and clarify the terminology used in this thesis by suggesting a taxonomy of coercion towards patients in mental health care (see Figure 1). Parallel taxonomies of coercion in other spheres of society, such as the penal code, between countries, or in the family, could be placed side by side with this figure.

*Coercion in mental health care* is the overarching concept, and can be subdivided into compulsion, informal coercion, and experienced coercion.

*Compulsion* denotes coercion according to mental health legislation. This legislation usually specifies forms of legal care status and the forms of coercive measures allowed by the law.

Involuntary legal status means that a person is put under involuntary care, or continues to be held under involuntary care. The person is obliged to receive mental health care, and is not allowed to quit or avoid care. Outpatients as well as inpatients can be under involuntary legal status. Involuntary inpatient care is often called involuntary admission, and involuntary outpatient care is often called community treatment order (CTO). In Norway, these forms of compulsion apply to patients from 16 years and older, but CTOs are rarely if ever used for patients under 18. For patients younger than 16,

admission is based on parent consent. According to the Norwegian Mental Health Care Act §2-1, when a patient above 12 years is admitted based on parent consent, but does not agree, the control commission shall be notified. This situation, where the younger adolescent patient is recognized as opposed to the admission, is closer to involuntary legal status than to no coercion or informal coercion.

Coercive measures approved by the law are the other major forms of compulsion. These are coercive treatment, such as medication or nutrition administered against the patient's will, or other coercive measures, such as seclusion, restraints, or isolation. The particular measures allowed vary somewhat between jurisdictions (Bowers, Alexander, Simpson, Ryan, & Carr-Walker, 2004). In Norway, continuing involuntary treatment with medication or nutrition requires an additional medication order, in other jurisdictions it may be administered to protesting patients under involuntary care based on the medical doctor's discretion. In some cases these measures are implemented through verbal commands, in other cases physical force is used. In Norway, isolation and mechanical restraints are not allowed in respect of patients younger than 16 years (§4-8).

*Informal coercion* is treatment pressures or other coercive aspects of mental health care not directly defined or codified as coercion in the mental health legislation. These pressures should have a form or degree which merit the use of the coercion concept, which I shall discuss in sections 1.1.3, 1.1.6 and 1.2.5.

*Experienced coercion* is the third aspect of coercion in mental health care. This denotes coercion as viewed from the recipient's point of view, which is a major theme in this thesis.

The taxonomy covers several meanings and uses of the coercion concept, and subcategories are not mutually exclusive. Compulsion may be accompanied by informal coercive elements, and may or may not be accompanied by experienced coercion in the patient.

#### 1.1.2 A Brief Sketch of Some Roots of Coercion in Norwegian Mental Health Care

Norwegian written sources documenting coercion in the case of behavior that today would be called severe mental disorders date back to a late Viking law of the 10<sup>th</sup> century. This law stated that persons with what we today would call dangerous manic behavior were to be restrained by their relatives (Høyer & Dalgard, 2002). When the Enlightenment era arrived, ideas of treatment and cure rose in importance. Medical experts gradually replaced the clergy and law enforcement as experts and governors of severe mental disorders, and institutional care increased, but was still rare (Blomberg, 2002). With the Norwegian Mental Health Act of 1848, it was stipulated that coercive care and treatment should take place in asylums, and be expanded to most mental disorders above a

given level of severity (Fause, 2007, chapter 3; Kringlen, 2007, chapter 2). From the 1850s, a growing number of patients came under mental health care, accompanied by formal coercion in asylums. In the 20<sup>th</sup> century, involuntary mental health care expanded to hospital clinics and nursery homes as well. Private care, with some degree of pressure and coercion, existed in tandem with institutionalized care throughout this period (Fause, 2007; Norges offentlige utredninger, 1995). From 1975 onwards, care for severe mental disorders in adults was gradually deinstitutionalized (Haave, 2008), with a reduction in the average length of inpatient stays (Norges offentlige utredninger, 2011, chapter 8). In the new Mental Health Act of 1961 a form of CTO called "tvungent ettervern" [Eng: "involuntary aftercare"] was implemented without much debate (Sjöström, Zetterberg, & Markström, 2011), and similar legal schemes were later approved in most Western countries (Rugkåsa, 2016). CTO is thought to be a less restrictive alternative to involuntary inpatient care (Szmukler & Appelbaum, 2008). On the other hand, CTO may accommodate a larger number of patients under coercion in mental health care (Sjöström et al., 2011), as CTOs are not as severely limited by the capacity of staff, beds, and buildings as involuntary inpatient admissions are.

#### 1.1.3 Forms of Coercion in the Current Norwegian Mental Health Care Setting

In Norway, health care is usually based on informed consent. There are explicit exceptions for specific classes of situations in the health legislation, such as for somatic health care for persons without competency to consent, persons with drug addiction who are also pregnant, or persons with severe communicable diseases. One of these classes of situations is when a person is considered to have a severe mental disorder. Norway passed its first Mental Health Act in 1848, and the current iteration is the Norwegian Mental Health Care Act of 1999 (Mental Health Care Act), which was revised in September 2017 (Helse og omsorgsdepartementet, 2015-2016).

The act permits several classes of coercive interventions:

- 1. Involuntary medical examination to ascertain whether the legal conditions for involuntary mental health care are satisfied;
- 2. The establishment of involuntary observation or involuntary care for a person, that can take place in institutions or in the community;
- 3. Involuntary treatment, most often comprising antipsychotic medication and nutrition;
- 4. Coercive measures during care, such as holding, belts, fast-acting sedative medication, and isolation, when an inpatient constitutes an immediate and significant danger to health or property;
- 5. Segregation / open-door seclusion;

- 6. Other decisions of involuntary and controlling measures, such as searches and forfeitures for dangerous items, urine samples for drug screening, restrictions in communication outside the institution, including forfeiture of cell-phone, and individual restrictions in eating, drinking, and smoking; and
- 7. Enforcement of local house rules for the institution.

Involuntary treatment is permitted for patients under involuntary care only, and requires a separate medication order. Fast-acting sedative medication is not considered a *treatment* for severe mental disorders under the Norwegian Mental Health Care Act, but is considered a coercive measure to prevent danger to person or property. The same applies to physical holding, belts, fast-acting sedative medication, isolation, and open-door seclusion, which can be used if an inpatient in the mental health institution constitutes an immediate and significant danger to health or property. These measures are allowed towards inpatients in voluntary care, and are sometimes used towards voluntary patients.

There are public annual statistics of selected forms of formal coercion in current Norwegian mental health care. In recent years mental health care has been characterized by a stable population rate of involuntary admissions, with substantial variation between health enterprises (see Figure 2).

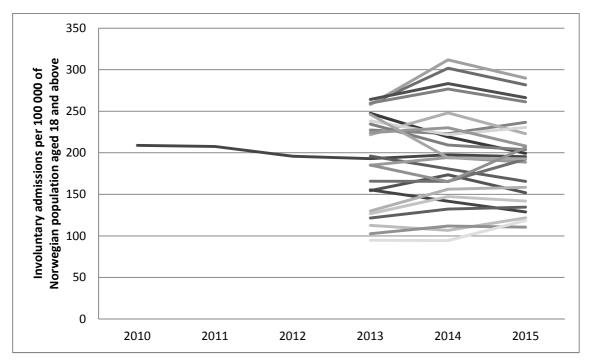


Figure 2. Rates of Involuntary Admissions per Year for Norway (2010-2015) and for Each Norwegian Health Enterprise (2013-2015). Source: Helsedirektoratet (2017).

While the data quality of rates of CTOs are questioned, one of the most recent estimates is that 60

patients per 100 000 of the population above 18 was under a CTO during some part or all of 2013 (Helsedirektoratet, 2014). Annual figures of the rates of involuntary care formality for 16- and 17-year-olds, and of the rates of patients under 16 that are admitted under parental consent against the patient's protest are not available. In 2010 it was estimated that 20% of admissions among 16- to 17-year-olds in 2007 and 2008 were involuntary (Furre & Heyerdahl, 2010). In 2009 and 2010, 6.5% of inpatients in acute adolescent psychiatric units were subjected to one or more coercive measures during their stay (Furre, Sandvik, Friis, Knutzen, & Hanssen-Bauer, 2016).

Some studies have investigated or reported on the importance of police assistance in the admission process (Hoge et al., 1997; Lidz et al., 1997; Seed, Fox, & Berry, 2016; Watson, Angell, Vidalon, & Davis, 2010), and police involvement during CTOs (Rugkåsa, Canvin, Sinclair, Sulman, & Burns, 2014; Swartz, Wagner, Swanson, Hiday, & Burns, 2002), including the Norwegian CTO practice (Riley, Høyer, & Lorem, 2014). Police involvement in mental health care can therefore be seen as coercion related to mental health care.

Power is amorphous and present in most relations, so I expect to find forms of coercion in mental health care that are not explicitly mentioned in the law. Some studies have identified different forms of influence used in mental health care, and argue that some of these are coercive. Szmukler and Appelbaum (2008) suggest a five-level hierarchy of treatment pressures: Persuasion, interpersonal leverage, inducements, threats, and compulsion, where only threats and compulsion are considered coercive. The MacArthur group divided nine different treatment pressures into three groups: Positive symbolic pressure (request for preference, persuasion, inducement), negative symbolic pressure (giving orders, threats, show of force, deception), and use of force (physical force, legal force) (Lidz et al., 1998). Some studies focus on the leverage concept, where economic benefits, reduced punishment for criminal offences, access to sheltered or inexpensive housing, or help to maintain contact with child / custody are made dependent on the patient's consent to mental health care or medication (Burns et al., 2011; Jaeger & Rossler, 2010; Monahan et al., 2005). Canvin, Rugkåsa, Sinclair, and Burns (2013) specify leverage as a pressure where consequences are contingent upon a specified response, is used as a lever, and is communicated directly to the patient by someone with relevant influence over the consequences. It can be debated whether or when such treatment pressures are coercive, and whether a particular proposal is an offer, or a threat. Unwelcome predictions can be framed as coercive threats, or they can be relevant and accurate predictions (Szmukler & Appelbaum, 2008). Repetition of the same question or request can be experienced as a form of pressure (Canvin et al., 2013). In an observation study of encounters in a psychiatric emergency room, the researchers saw few episodes with direct threats, pressures, or use of power. The authors nevertheless found that what seemed like simple expressions of opinion or advice could

reasonably be interpreted as threats of commitment in the context of the emergency room, and the power to use force and decide involuntary care (Lidz, Mulvey, Arnold, Bennett, & Kirsch, 1993). The architecture, locked doors, and formal coercive powers may create coercive context, where freedom can be restricted through subtle actions and requests (Sjöström, 2006). Thus, when staff or carers are giving predictions or advice, or stating opinions, the context and form is important: When delivered in a context where coercion is often decided, or in a tense situation or conflict, such action can easily be seen as a threat, and thus coercive. When discussed calmly as one of several possible alternatives or consequences, communicated with care for the person, statements with predictions and advice can be just that — valuable expert advice and predictions.

Holding back information or refraining from correcting patient misconceptions about rights or treatment can be called deception (Szmukler & Appelbaum, 2008), and giving misleading information such as exaggeration of treatment effects can be called manipulation (Nelson et al., 2011). Deception and manipulation may change a person's actions in a way similar to coercion, although it can be debated whether this should be seen as coercion or a morally dubious form of influence different from coercion. If a patient discovers deception or manipulation, it may well be evaluated as coercive, if this act effectively removed a feasible alternative from the patient's range of available actions in the situation.

#### 1.1.4 What is Coercion according to Western Philosophers?

Early philosophical accounts of coercion focused on the power and responsibility of the very powerful, such as a king or a noble, over and towards the common people. Thinkers with several opposing views, such as Aquinas (1225-1274), Hobbes (1588-1679), Locke (1623-1704), and Kant (1724-1804) discussed the rule of law in terms of the use of power and threats of punishment, and all found such arrangements necessary or preferable to the theft and violence that would otherwise occur (Anderson, 2011). This seems to reflect important conditions in the Middle Ages and early Enlightenment era, where extended lawlessness was a realistic prospect, which is also mirrored in the current attention on "failed states", and the grave security and welfare consequences in areas with weak or absent government. Kant, for example, discussed the responsibilities of the powerful. He suggested several requirements for the fair use of power, such as protecting the weak from violence, and warned against governing too strongly against the will of the governed (Anderson, 2011), but accepted coercion for the good of the society (Newton-Howes, 2010). Locke and Mill (1806-1873) paid more attention to the limits of legitimate governmental coercion, and Mill stressed the value of liberty, concluding that coercion should only be used to secure others' liberty, and that coercion should not be used against an individual to improve his or her own good. Mill also recognized that the rule of law coerced through stigmatizing the law-breaker, and that civil

institutions, such as marriage and families, facilitated coercion of women and children (Anderson, 2011). This clear focus on the potential misuse of power may reflect the stronger and more efficient rule of law in England at the time, with a corresponding potential of misuse, and lowered risk of collapse into anarchy.

The sociologist and economist Max Weber defined power as "the probability that one actor within a social relationship will be in a position to carry out his own will despite resistance, regardless of the basis on which this probability rests" (Weber, 1978, p. 53). In spite of Weber's main interest in hierarchy and power in society and bureaucratic systems, his definition is applicable to power (and coercion) between two persons. More recent philosophers have tried to delineate coercion at this dyadic level, starting with Nozick's analysis of coercion as a person putting pressure on another person by means of a threat, and how and why that person is or feels pressured (Nozick, 1969).

Wertheimer (1993) developed this approach further with special attention to mental health care, and has been extensively used in later accounts of coercion in mental health care. One important contribution clarifies the difference between threats and offers. They can both be seen as conditional propositions, where one person lines up two (or more) alternatives and the other person must choose between them. Such propositions qualify as offers where at least one of the alternatives leaves the second person no worse off than if the proposition had never been made (Nozick, 1969; Wertheimer, 1993). A job offer is an example, where declining the job offer leaves the person in the same baseline situation as before the offer. In the case of a typical threat, such as the gunman situation, the statement demands that you give up either your money or your life, where both alternatives will leave you clearly worse off than before the proposition. A challenge, or source of ambiguity, arises when deciding the characteristics of the baseline situation. Wertheimer argues that this is not simply an empirical question; it is also a moral issue, where what ought to be the baseline situation in a society can count as the baseline. A lone bystander to the emergency of person A is morally obliged to help. If the bystander demands a large sum of money before assisting, then this is coercion, because person A is now worse off than the baseline situation – which is to be helped. The bystander would be morally wrong in making such propositions (Wertheimer, 1993). These lines of reasoning are of some help in deciding if alleged offers, advice, persuasion attempts, or warnings constitute coercive threats.

#### 1.1.5 Some Challenges in Defining Coercion

Weber's definition of power and how it can be used correspond to the dictionary definition cited in section 1.1.1. It emphasizes that an agent can use some form of power to make the target,

sometimes called the coercee, to act in another way than he or she would otherwise do. This can be done privately, or on behalf of different kinds of institutions, such as government agencies.

In spite of these seemingly simple dictionary definitions, coercion is difficult to delimit; it is valueladen and contested, and the concept is sometimes used in different areas with more analog or familial resemblance than directly fits the definitions above, such as using the term "coercion" when exploitation would be the proper term (Rhodes, 2000). The following are some sources of conceptual imprecision:

- The term "coercion" can describe both the act and the result of the act;
- Coercion can be described from the perspective of the actor, the target, or an observer;
- Force is related to power, and power comes in many forms; and
- Using force "to make somebody" do something requires an intentional agent:
  - o Intentions are difficult to observe and may be contested; and
  - o What counts as the requirement for an agent may be contested.

The topic of this thesis is experienced coercion, and although this is not stressed in the dictionary definition above, "coercion" can describe the result of coercion in terms of a feeling or evaluation by the coercee. A concept that can be used to describe both an act, and the intersubjective or subjective result of an act, creates ambiguity, because the act may seem different from the perspectives of the coercer, the coercee, and an independent observer.

Next, several measures can be utilized to force another party, making the concept difficult to delimit. Weber insisted that power is amorphous (Weber, 1978, p. 53), which makes it a powerful analytical concept, but it increases the risk of miscommunication due to different views on forms of power.

The dictionary definition requires an intentional agent for an action to qualify as coercion. This distinguishes coercion from pressuring natural incidents and consequences, such as accidents, weather, hunger, or disabilities, that are usually considered non-coercive (Nelson et al., 2011). Intentions, including the intention to coerce, may be ambiguous, unclear, or concealed, and even clear intentions to coerce can be difficult to observe or measure. Careless acts may have similar consequences for the coercee as intended coercive acts, and may cause disagreements between the alleged coercer and coercee about whether coercion took place. Some acts may exert unpredicted influences on future situations that may exhibit similarities to coercion. What kind of intention should be satisfied before considering a societal or other kind of system-level arrangement as coercive may be debated, and the distribution and delegation of power in a modern welfare state add strongly to the complexity of coercion. In the case of mental health care, compulsion is usually

explicitly intended by the legislator and parliament, but other aspects of the law are less clear in this regard. Maybe, as a solution to these sources of imprecision, both philosophers (Rhodes, 2000) and mental health care researchers (Szmukler & Appelbaum, 2008) have found value in a subjectivist perspective on behalf of the coercee, where feeling coerced gains prominence, and unintended coercion from persons and systems is possible. Mental health care for severe mental disorders is a situation with large power differentials. Here, patients may reason, perhaps based on previous experience, that their reactions to a suggestion, question, or piece of information from the clinician may lead directly or indirectly to some negative consequence in the future, even though the clinician may have no intention to coerce.

Coercion can be regarded as a special quality, form, or intensity of use of power. Power comes in different forms and degrees, and is even considered an ubiquitous aspect of most or all relations (Haugaard & Malesevic, 2008). Some forms of power are clearly manifest, such as the use of physical force and clear threats of physical force. It is less clear whether subtler forms of power, such as social influence, symbolic power, or soft power in close relationships can coerce, and if they can, under what conditions. Again, a subjectivist recipient perspective may be important. Expert opinion and special skills can also be considered forms of power, but they are often considered uncoercive. The power to rationally persuade others – that is, a person changes behavior or beliefs because of truthful reasons given by one with better knowledge – is usually not considered coercive (Nelson et al., 2011).

Coercion is often considered the opposite of freedom, but upon closer analysis, this relationship is more complex than a straight dichotomy. There are many restrictions and reductions of freedom that humans regularly and willingly submit to; commitments such as friendship and marriage, and contracts of work, education, or military enrolment. Many of us enjoy some commitments that restrict our freedom, and they are usually not considered coercive. Coercion is usually reserved for unwanted restrictions of freedom. Instead of a dichotomous line with different freedom restrictions of different degrees, and a threshold for the coercive freedom restrictions, Table 1 shows a two-bytwo table with pleasant freedom and coercion as two of the quadrants, illustrating that lack of freedom and coercion are not always simple opposites.

Table 1. A Four-field Table of Wanted and Unwanted Freedom and Freedom Restrictions

	Wanted	Unwanted
Freedom	Classical freedom and autonomy. A situation with some relevant alternatives that are both desirable and achievable. Example: Being able to choose between two modes of treatment or abstaining from treatment.	Unpleasant freedom and choice. Required choices a person do not want. Examples: Being asked to consent to or abstain from a test for severe disorder running in one's family; disintegration of norms that creates freedom where one would prefer safety and belonging.
Restrictions	Desired freedom restrictions.  Examples: A work agreement; marriage; desired protection from acting out suicidal impulses.	Classical coercion. Examples: Lawfulness under threat of punishment; involuntary admission under protest.

Complicating the issue further, we are born as strongly dependent beings, both physically and psychologically, which usually decreases through childhood and adolescence. This dependency is usually mirrored in a strong positive attachment to the primary caregivers (parents and other caregivers), an attachment bond that changes as the child matures. A frequent theme of negotiation is the increasing ability and drive in the adolescent for independence from parents and the increasing influence from the peer network (Grotevant & Cooper, 1985). The forms of power that are acceptable in different social roles vary between cultures and through history. An example is the controversy and different regulations in respect of the right of, or the prohibition on, parents to beat or spank their children. The common experience of dependency during childhood clarifies that there are instances where it is acceptable to use some form of power in order to influence the behavior of others, and instances where a person is less able to act autonomously with good results. Positive attachment is not always dependent on a caring, empathic, and benevolent primary caregiver. Positive attachments may be formed even in abusive parent-offspring relations (Finzi, Ram, Har-Even, Shnit, & Weizman, 2001), and may continue in spite of enduring intimate partner violence (Zink, Jacobson Jr, Pabst, Regan, & Fisher, 2006). Here, coercion and exploitation may take place that is not acknowledged as such by the coercee. The subjectivist perspective may therefore underestimate the use of coercion in some circumstances.

#### 1.1.6 Complexity of Coercee Behavior

The theme of this thesis is experienced coercion, which is coercion as seen from the coerced person's point of view. According to the dictionary definition, coercion changes the behavior of the target of coercion – the *coercee*.

Whether behavior changes *because* of the coercer's use of force may be difficult to decide. Finding the cause of individual behavior is a field of scientific study on its own. In many cases, it will be clear to the coercer, the coercee, and an observer, that the behavior of the coercee changes because of the coercer's use of power, while they may disagree in other cases. In some cases the observer may claim coercion, while the target may have internalized the influence and behavior pattern, and disagrees. In other cases, the coercee may think or feel he or she is being coerced, but the influencing force may be subtle, invisible, or may have been unintended.

To know if the behavior changed, one needs to know the behavior that would have taken place in the absence of coercion. Predicting behavior is not easy or straightforward. Decisions and behavior range from the trivial to the existential, and take place within frameworks ascribed by natural and physical restrictions, culture, laws, and relations, to name some. The framework at one level can influence the range of choices on other level, and the salient framework in the situation may influence whether one thinks of coercion or not. One can be involuntarily admitted to a ward, but make some choices within this arena. Background pressures, such as strain, pain, and trauma can restrict the range of alternatives and the ability to give informed consent, while immediate decisions are necessary to avoid fatal consequences. We may also have higher-order wishes and plans – wishing that our plans or behavior patterns were different (Burns, 2007). This means that deciding how someone would act in the absence of external powers is not at all straightforward, if not impossible. Thus, absence of consent or explicit voluntariness does not in itself create coercion. We all live under physical restrictions, and are equipped with emotions and motivations that facilitate some sort of balance between adapting to the norms and requirements of our social circumstances, and being an individual with choices and some freedom.

Different people may evaluate the influence and power from others within different frameworks, and their evaluation of coercion in an otherwise similar situation may vary accordingly. The level of freedom that may be regarded as the baseline may vary between individuals and groups, based on factors such as culture, cohort, or life situation. For example, the baseline situation for adolescents is less autonomous than for the typical adult in Norway. For example, the adult has the right to change jobs, stay up late, spend their money, have sexual relations, and consume alcohol, while the adolescent often lacks at least some of these freedoms.

As can be expected from the pivotal importance of autonomy and control of one's future, being forced to do something against one's strong will or protest is not trivial. As will be shown in section 1.2.1, being subjected to coercion is a deeply personal and emotional experience, laden with

meaning and even symbolic properties. This makes *experienced coercion* the preferred term, compared to *perceived coercion*, which is often used in the literature.

#### 1.1.7 The Working Definition for Use and Experience of Coercion in this Thesis

The overview of coercion in section 1.1.1 needs a few modifications following the discussion above. In addition to compulsion, threats of using compulsion and police assistance under the admission process, or bringing a patient under outpatient commitment to treatment should also be included in the definition of "compulsion". Milder forms of treatment pressure, such as persuasion, inducements, and leverage that does not detract from the baseline situation, do not qualify as coercion based on the discussion so far, but may be regarded as coercive from the subjectivist perspective. The baseline situation may vary between individuals, so one can expect that the threshold for feeling coerced will have variations. In line with Nelson et al. (2011), I shall not include deceit and manipulation in the working definition of "the use of coercion", but this does not imply the endorsement of such actions. These two forms of influence are "successful" only when the patient does not discover them. If they are exposed, they will no longer be an effective source of influence, and may have severe adverse consequences, such as lack of trust or formal complaints.

Experienced coercion is the consideration and feeling in a patient that he or she is being coerced. This corresponds to the recipient perspective acknowledged by Rhodes (2000), and Szmukler and Appelbaum (2008). There will often, but not always, be a correspondence between the use of coercion and experienced coercion.

# 1.2 Major Themes in Studies of Experienced Coercion in Mental Health Care

There are a number of qualitative and quantitative studies on experienced coercion, with important findings on the relationship between the use and the experience of coercion. I shall first discuss the main findings of how patients describe their experience of coercion, and then turn to the quantitative studies with the MacArthur Perceived Coercion Scale (MPCS) and the Coercion Ladder (CL). Then I look at studies on special aspects of coercion, such as CTOs, and informal coercion studied by any method. I also look at findings on the experience of humiliation and procedural justice related to coercion in mental health care, and then at research on the effects of experienced coercion.

#### 1.2.1 Adult Patients' Descriptions of Coercion – Qualitative Studies

Three different reviews of qualitative studies of inpatients found that negative emotional consequences were a central aspect of the experience of coercion in mental health care. There were

important overlaps in the results of the reviewed qualitative studies. Among the reported themes were feeling disrespected, violated, isolated, and dehumanized (Newton-Howes & Mullen, 2011); feeling rejected, aggrieved, and punished (Katsakou & Priebe, 2007); and feeling disempowered and terrified (Seed et al., 2016). Positive consequences and evaluations were also reported by some patients in some studies: Retrospective acceptance of the interventions, feelings of protection or safety, and restoration of normality (Katsakou & Priebe, 2007; Newton-Howes & Mullen, 2011; Seed et al., 2016). It was not clear in the literature whether it is common that the same patient reports both positive and negative consequences of coercion (Katsakou & Priebe, 2007). While the studies indicated that all or most inpatients initially thought the admission was unnecessary, some felt that person-centered care from staff instilled respect, and made them feel protected and safe; this was often in connection with patient influence on decisions regarding medication. Other patients showed different patterns, where they "fought back" against staff, using complaints or aggressive behavior (Seed et al., 2016).

According to two reviews of studies of patients' experiences with restraints, patients reported strongly negative experiences and consequences from restraints, including fear, humiliation, resignation, re-traumatization, and punishment (Strout, 2010; Stubbs et al., 2009). Strongly negative depictions of the restraint experience were reported by some patients, such as "like I was a slave", "like a bug", and "ready to be raped" (Strout, 2010). In some studies, particularly outside psychiatry (patients in surgery or people with learning disabilities), patients also reported feeling safe and protected against physical injury (ibid). Seclusion was viewed similarly, with mainly negative evaluations, and a few patients feeling safe or protected (Van Der Merwe, Muir-Cochrane, Jones, Tziggili, & Bowers, 2013), although a Finnish study found that a majority of secluded patients in forensic and general inpatient care viewed seclusion as beneficial, but also as punishment (Keski-Valkama, Koivisto, Eronen, & Kaltiala-Heino, 2010). A recent, broader review on coercive measures confirmed the negative impact from restraints and other coercive measures on the patients' experiences. The authors stressed that being subjected to staff's control was regarded as an important antecedent for aggression that led to coercive measures, and that respectful communication was important before, during, and after the episode. Patients reported that lack of respectful communication damaged the relationship to staff (Tingleff, Bradley, Gildberg, Munksgaard, & Hounsgaard, 2017). A Norwegian study with mental health inpatients described several of the negative experiences referred to above, and no patient saw the restraints as a positive or therapeutic event. This did not hinder some of them to acknowledge that staff had reasons to resort to restraints, but many also thought that the situation could have been handled with less restrictive measures (Wynn, 2004).

These studies show that some patients experience compulsion as strongly aversive. Some questions remain unanswered, such as why these strong sentiments develop in spite of the good intentions that accompany involuntary mental health care and lie behind the mental health legislation.

#### 1.2.2 Overview of Quantitative Studies with Adult Inpatients

Several quantitative studies have used scales to measure the level of experienced coercion. I cover the findings here and shall discuss the experienced coercion scales later, in section 1.3.

A meta-regression analysis summed up the results across studies using the original papers' cut-offs. The studies in the analysis, with a combined sample of 3,489 patients, reported that 22% to 87% of patients reported high experienced coercion on the MPCS or the CL. The proportion of high experienced coercion among patients subjected to involuntary legal status was 74%, while the corresponding proportion for informal patients was 25%. Nevertheless, a substantial number of patients in involuntary care report low experienced coercion (Newton-Howes & Stanley, 2012). A European study from 11 countries reports substantial variations between countries in terms of experienced coercion and its predictors, which illustrates that one cannot assume that findings on coercion in one country apply in another country. Formal coercion has revealed limits as a predictor of experienced coercion in several countries, including Norway. A study from two Norwegian hospitals revealed that 32% of patients in voluntary inpatient care reported high experienced coercion, while 41% of involuntary inpatients reported low experienced coercion (Iversen, Høyer, Sexton, & Grønli, 2002).

High experienced coercion was less frequent in samples from the USA compared to other Western countries. Studies using the MPCS tended to report a higher percentage of high experienced coercion compared to studies using the CL. Generally, quantitative studies on experienced coercion were heterogeneous in design, variables, and results (Newton-Howes & Stanley, 2012). Another review showed that significant demographic and clinical predictors of experienced coercion in one study were often insignificant in other studies, without a consistent pattern. The studies were diverse and observational, so the level of the independent variables were observed in a natural setting, and not randomized, changed, or manipulated by the researchers (Newton-Howes & Mullen, 2011). This, in turn, means that the effect of the measured independent variables may well be moderated, mediated, or confounded by uncontrolled variables. For example, a covariance between a diagnosis and experienced coercion could be mediated by compulsion, or traumatization might be a common cause of diagnosis and sensitivity to coercion, and thus confound the relationship between compulsion and experienced coercion.

The MacArthur group studied coercion in admission episodes from three perspectives (patient, professional, relative/friend). In a complex procedure to construct a "most plausible account" of the incident, patient ratings of experienced coercion could most often be explained by compulsion, and the patient seemed to have a better overview of the coerciveness during the admission process than informants with either of the two other perspectives (Lidz et al., 1997; Lidz et al., 2000). A Swedish study found that patients' reports of coercion corresponded with the head nurse's account in 70% of cases, and that a main source of disagreement was whether staff had induced or threatened the patient to take medication (Eriksson & Westrin, 1995).

#### 1.2.3 Experienced Coercion in Adolescent Patients

There are few published studies on coercion and experienced coercion in adolescent patients, even though coercion is often present in adolescent mental health care. A Norwegian study reported that 20% of admissions among 16- to 17-year-olds were involuntary (Furre & Heyerdahl, 2010), while a German study reported that this percentage was 36.5% (Jendreyschak et al., 2014). A Finnish register study reported that 22% of admissions among adolescents between 12 and 17 in 2000 were involuntary, and that substance abuse and schizophrenia group disorders were more frequently among involuntary patients (Kaltiala-Heino, 2004). A Finnish chart review study found that severe symptoms, such as suicidal ideation, psychotic symptoms and violent behavior was more common among involuntary admitted than voluntary adolescents. In this study, patients with diagnoses in the schizophrenia group (F20-29) and the group containing eating disorders (F50-59) were more often involuntary than voluntary admitted, while adverse family events were unrelated to use of involuntary care (Kaltiala-Heino, 2010). Internationally, adolescent inpatients may be subjected to forced medication or nutrition for treatment purposes, as well as coercive measures, such as holding, mechanical restraints, seclusion, and medication, in order to prevent harm to people or property. A few studies have found that coercive measures are used more frequently in respect of younger adolescents (Gullick, McDermott, Stone, & Gibbon, 2005; Sourander, Ellilä, Välimäki, & Piha, 2002). The reported rate of inpatients subjected to one or more of these coercive measures ranged from 30% for inpatients in New York (Pogge, Pappalardo, Buccolo, & Harvey, 2013) and Finland (Siponen, Välimäki, & Kaltiala-Heino, 2012), to 6.5% in Norway (Furre et al., 2016).

A review of adolescent experiences with mental health care found few inpatient studies, and the main topic was patient satisfaction (Biering, 2010). One recent American interview study with recently discharged mental health adolescent inpatients found that approximately 70% of patients were dissatisfied with some aspects of the care: Confinement to their room and rigidity regarding personal items and other house rules were frequently mentioned. Others found some treatment measures unhelpful and the staff unhelpful or passive. Finally, some patients were frightened or

discomforted by extensive inquiries, seeing other patients self-harming or restrained, and long-term hospitalization or stigma (Moses, 2011). There are also studies on the treatment experiences of adolescent and young adult inpatients with anorexia. These patients are aware of non-coercive strategies for influence, such as persuasion and use of patient privileges. Some patients attempt to resist or circumvent treatment, i.e., some play by the rules to get out, and some attenuate staff authority by questioning their competence (Boughtwood & Halse, 2010). The young patients with anorexia spoke about formal coercion and informal pressure, with some saying that coercion and restrictions could at times be justified and helpful (Tan, Stewart, Fitzpatrick, & Hope, 2010). One study used the Admission Experience Interview and Admission Experience Scale for adolescent and adult inpatients with eating disorders, and found that adolescents reported higher experienced coercion than adults did, and patients with anorexia reported higher experienced coercion compared to patients with bulimia (Guarda et al., 2007).

There are only a few studies on experienced coercion in adolescent mental health care. I am not aware of studies that have used existing scales of experienced coercion in general adolescent inpatient or outpatient populations.

#### 1.2.4 Adult Patients' Experience of Community Treatment Orders (CTOs)

In modern Norway, the outpatient community treatment order was codified in the Mental Health Act of 1961, allegedly one of the first countries in Europe to do so (Riley, Straume, & Høyer, 2017). The care and containment of manic persons in the community took place as far back as the Viking era, as described in section 1.1.2. Publicly financed, involuntary private care for mental disorders was allowed under the Mental Health Act of 1848, often on farms in rural areas (Fause, 2007), and this scheme of private care continued throughout the 20<sup>th</sup> century (Norges offentlige utredninger, 1995).

Experienced coercion under CTOs were reviewed recently (Corring, O'Reilly, & Sommerdyck, 2017; Pridham et al., 2015). Patients report feeling controlled and coerced by the order, and that the CTO mainly revolves around medication, which some patients believe they need and others do not. Lack of information about the legal details of the order and decision is a theme frequently raised in qualitative studies. On the positive side, CTOs are often considered a better alternative than being in hospital, and some perceive the order as a safety net, with assured access to services. Positive and helpful relationships with clinicians can be present under a CTO (Corring et al., 2017). The results from quantitative studies seem inconclusive. Levels of experienced coercion vary substantially between studies; several studies report rather low levels or low proportions of high experienced coercion under a CTO (Pridham et al., 2015).

While Pridham et al. (2015) conclude that coercion in the form of a CTO tends to covary with higher experienced coercion, pooling the results from two American randomized controlled trials on CTOs and the results from the Oxford Community Treatment Order Evaluation Trial (OCTET) trial indicates that being randomized to CTO did not result in increased experienced coercion (Burns, Rugkåsa, Yeeles, & Catty, 2016, p. 61; Rugkåsa, 2016). The CTO schemes and enforcement vary greatly between jurisdictions, and may explain some of the variations (Pridham et al., 2015). The Norwegian CTO scheme is enforceable by the police, and according to recent qualitative studies, patients may have a rather correct view of the scheme (Riley et al., 2014), or feel unsure about the necessary conditions to get off the order, feel dependency on the care providers and coerced in their situation, but also more safe due to increased access to health services (Stensrud, Høyer, Granerud, & Landheim, 2015).

Assertive Community Treatment (ACT) teams were implemented in Norway in 2009, and patients in these teams who were also under a CTO, reported higher patient satisfaction than patients not under a CTO (Lofthus et al., 2016). The authors suggest that patients compare the combined ACT and CTO to a situation with many negative treatment experiences prior to enrollment in the ACT.

#### 1.2.5 Extra-legal Treatment Pressures and Coercion

According to the taxonomy in Figure 1, some treatment pressures are not directly codified as coercion in the Norwegian Mental Health Act of 1999. Hotzy and Jaeger (2016) review research on informal coercion and define it as "a large range of treatment pressures and interventions that can be applied by the professional with the intention to foster treatment adherence or avoid formal coercion". They find that between 29% and 59% of patients have experienced juridical reactions, economic benefits, housing, or custody as leverage for some form of mental health care. Leverage was more frequent in the US than in England or Switzerland, and housing was the most frequently used leverage tool. Between 34% and 81% of patients considered leverage as helpful, and there was a tendency for patients with personal experience of leverage to rate it as more efficient, while some qualitative studies conclude that patients view informal coercion as ineffective and inferior to true voluntary care (Hotzy & Jaeger, 2016). In a Norwegian interview study, patients talked about a grey zone of hidden or subtle coercion, a lack of real voluntariness that they called "voluntary coercion", and coercive shaping within the hierarchical system that influenced formal voluntary care as well (Norvoll & Pedersen, 2016a). A Swedish study suggested that patient freedom and autonomy could be restricted in opaque ways that were not readily understood or communicated by the patients, such as when staff stalled a discharge attempt from an informal patient (Sjöström, 2006).

When adolescents receive care, the age, status, and knowledge differences between adolescents and staff may be more profound than in the case of adult care. Informal coercion in the form of pressure, more or less explicit threats, and house rules can influence adolescents' coercion even more than for adults. Adolescents are usually materially, financially, and emotionally dependent on parents or guardians (Group for the Advancement of Psychiatry, 1994), so that control and pressure may relate to care, trust, and family loyalty. Adolescents' dependence also means that they usually do not decide sleeping arrangements, use of money, alcohol and drug use, and school attendance with similar autonomy as is common for adults. There is also a risk that some adolescent patients lack or lose trust in parents and staff during hospitalization, and consequently feel isolated in the ward.

The definition of informal coercion above, and the typologies of different treatment pressures covered in section 1.1.3 (Lidz et al., 1998; Szmukler & Appelbaum, 2008), look for different strategies staff use to influence patients' behavior. This is a staff perspective on informal coercion. It is still possible that patients can find other staff behavior coercive as well. Qualitative studies have found that feeling punished and humiliated is connected to feeling coerced. Expressive behavior from staff, especially if it expresses anger or frustration, may therefore be experienced as coercive. In addition, if feeling disrespected or dehumanized is a part of experienced coercion, then routine behavior, procedures, and nomenclature that are not tailored to the particular patient may raise feelings of experienced coercion. Overall, studies on informal coercion show that leverage and the hierarchy of treatment pressures are important contributions to coercion research. There seems to be room for improvement of the understanding of the link between patient reports, and theories and forms of informal coercion and treatment pressures in future research.

#### 1.2.6 Humiliation and Experienced Coercion

Some of the more recent studies on experienced coercion have found connections between experienced coercion and (experienced) humiliation (Bergk, Flammer, & Steinert, 2010; Svindseth, 2010), corresponding to findings from the qualitative studies reviewed in section 1.2.1. The internal experience of humiliation can be defined as "the deep dysphoric feeling associated with being, or perceiving oneself as being unjustly degraded, ridiculed or put down – in particular, one's identity has been demeaned or devalued" (Hartling & Luchetta, 1999). A Norwegian study found that involuntarily admitted patients in acute wards felt significantly more humiliated than patients admitted voluntarily. Semi-structured interviews with some of these patients even indicated that "the patients did not clearly separate the meaning of the words coercion and humiliation" and "did not see any practical difference between the feelings of *humiliation* from the practical intervention of *coercion* that triggered their emotional reaction" (Svindseth, Dahl, & Hatling, 2007, p. 52). A strong connection between experienced coercion and humiliation may explain the relative lack of patients

reporting intermediate levels of experienced coercion on the MPCS and the CL: Feeling humiliated or not is likely to be connected to integrity, which is usually considered to be present or absent, and difficult to grade (Høyer et al., 2002).

#### 1.2.7 Procedural Justice and Experienced Coercion

Procedural justice has been important in the research on coercion in mental health, and can be described as participation and voice, dignity and respect, and trust (Watson et al., 2010). The concept was developed in research on conflict resolution. It was partly inspired by organizational psychological findings on the merits of autocratic, democratic, and laissez faire group climate, which again can be rephrased as norms and procedures for decisions in a group. Humans are commonly interested not only in a favorable result of a decision. It is also important that authorities have our needs in mind and make fair decisions (benevolence), that the decision procedure implies that we are considered a fully-fledged member of the group (status recognition/respect), and that decisions are made on transparent and accurate assessment of relevant facts (neutrality) (Lind & Tyler, 1988; Lind, Tyler, & Huo, 1997). In an interview study on involuntary admissions, the MacArthur group found that patients wanted to be included in the decisions, that the persons involved in the admission process should be motivated by concern for the patient, and that they should behave honestly and openly (Bennett et al., 1993). Similarly, a Swedish interview study found that patients emphasized disrespect and not being listened to when talking about their involuntary stay in a ward (Olofsson & Jacobsson, 2001). The elements of procedural justice are morally charged themes, and resonates well with the earlier philosophical analyses by Nozick and Wertheimer, suggesting that coercion fundamentally is a moral issue (Nozick, 1969; Wertheimer, 1993).

The MacArthur group included a "voice" or "procedural justice" subscale in the Admission Experience Interview, with items covering the perceived presence of fairness, respect, and deceit in the admission process, and whether others gave them a chance to state their opinion, took it seriously, and acted out of concern for them (the patient). In a regression analysis of patient-reported pressures and processes during admission, procedural justice was the strongest predictor of experienced coercion (Lidz et al., 1995). The strong relationship between patient-reported procedural justice and experienced coercion has been confirmed in later studies on the admission process in different countries (Iversen et al., 2002; McKenna, Simpson, Coverdale, & Laidlaw, 2001). When procedural justice is measured by asking the patient items such as "How much respect did s/he [the person in charge of the admission process] treat you with?", and experienced coercion is measured by items such as "I had a lot of control over whether I went into the hospital", the strong association is interesting. As stated above, later studies suggest that feeling humiliated during the admission process is an inherent part of reporting experienced coercion (Svindseth et al., 2007). In

that case, it is expected that humiliating events, such as disrespectful treatment, will predict high experienced coercion. The patient's interpretation of staff action as fulfilling or violating standards of procedural justice may simply be a part of feeling humiliated, and, consequently, coerced or not. It would therefore be interesting to see research using observer-rated procedural justice and study its relation to patient-rated procedural justice or experienced coercion.

#### 1.2.8 Effects of Experienced Coercion

There are few prospective studies on experienced coercion. A review of these studies shows that experienced coercion has a weak or absent effect on the studied variables (Newton-Howes & Mullen, 2011). The results so far indicate that the level of experienced coercion during inpatient care do not predict changes in psychosocial functioning in the near future (Wallsten, Kjellin, & Lindstrom, 2006), one-year risk of readmission (Priebe et al., 2009), or engagement with outpatient services in the next year (Bindman et al., 2005). Two studies with outpatients in the USA have found significant negative effects from high experienced coercion: Higher experienced coercion was associated with worse quality of life and psychosocial functioning (Link, Castille, & Stuber, 2008). High experienced coercion was also associated with a less positive outcome of CTO in the North Carolina CTO study (Swanson, Swartz, Elbogen, Wagner, & Burns, 2003). A Finnish study used an unvalidated interview measure of experienced coercion after two weeks of inpatient stay. In the follow-up six months later, high experienced coercion predicted several negative outcomes: Patients with high experienced coercion six months earlier less frequently saw the admission as necessary (40% vs 89%), would not accept a new admission (46% vs 3%), were less likely to use medication (71% vs 89%), and were less likely to visit the mental health center (50% vs 77%). These predictions were far stronger than those that could be made from compulsion data (Kaltiala-Heino, Laippala, & Salokangas, 1997). I am not aware of any replication of these findings, so they should be treated with some caution.

#### 1.3 Measurement of Experienced Coercion

Experienced coercion can be considered a measureable variable. Scales of experienced coercion are important in the study of the relationship between compulsion and experienced coercion, and a few measurement scales for experienced coercion have been utilized in research on coercion in mental health care. The results of a systematic search for scales of experienced coercion are reported in section 4.1. Three scales of experienced coercion have been used frequently or recently: The MacArthur Perceived Coercion Scale (MPCS), the Coercion Ladder (CL), and the Coercion Experience Scale (CES). They are discussed in the following paragraphs.

#### 1.3.1 The MacArthur Perceived Coercion Scale (MPCS)

The Admission Experience Scale and its subscale, the MPCS (Gardner et al., 1993), constituted a groundbreaking development in the early 1990s. The MacArthur Research Network on Mental Health and the Law saw many obstacles in the development of a measurement scale of patients' perceived coercion, such as ethical constraints on experimenting with compulsion, the difficulty of operationalizing coercion, or observing it as it happens. The researchers noticed that in interviews, patients could speak coherently and consistently of their admission experiences. Accordingly, it could be possible to construct a structured interview and scale in respect of the admission experience, including perceived coercion (ibid). They noticed that the words "pressure" and "coercion" were rarely used by the patients, and that such phenomena were rather implied by the context, tone of voice, and body language (Hoge et al., 1993). The researchers concluded that when patients told them that their own control, choice, and freedom were absent, then coercion was present. The MPCS contains items of perceived autonomy, in the form "I had more influence than anyone else on whether I came into hospital", with a true/false answer format (Gardner et al., 1993), and is essentially an operationalization of perceived coercion as self-reported absence of autonomy. This approach seemed to work well, and the MacArthur group reported acceptable psychometrics (ibid).

Nevertheless, there are problems with this approach and scale. The interview study behind the scale showed a complex relationship between patient autonomy and perceived coercion (Bennett et al., 1993). As Nozick and Wertheimer had predicted, patients seemed to evaluate coercion and pressure based on a moral evaluation of the totality of the situation, including their knowledge of the staff's, or the carer's, motivation and behavioral style (Hoge et al., 1993). I do not find this reflected in the items of perceived autonomy. Perceived autonomy and experienced coercion will often be inversely related, but there may also be important exceptions. One may find low experienced coercion in situations where one is deprived of autonomy, but one approves of the overall morality of the actions taken, or when one's autonomy is already compromised by pain, intoxication, or mental distress. To measure experienced coercion negatively, i.e., by asking for qualities presumed *not* to be present when one experiences coercion, seems counterintuitive and conceptually unsatisfactory.

The distribution of scores in the initial and several later studies in different countries also showed an unexpected bimodal distribution, with a majority of patients scoring at one of the extremes (Fu, Chow, & Lam, 2008; Gardner et al., 1993; Høyer et al., 2002; Iversen et al., 2002; Kjellin et al., 2004; Längle et al., 2003). This could be due to something in this scaling approach, such as the statements' threshold or "difficulty", the answer format, or the autonomy approach. Or the bimodal distribution could be due to something connected to the coercion concept itself that discourages reports of intermediate experienced coercion.

Another limitation of the MPCS is that it was developed for the admission process. To my knowledge, it has not been validated for other inpatient care situations. The admission process was a relevant starting point for measuring experienced coercion, but it limits the proper use of the scale. On the other hand, the scale has been adapted to outpatient treatment and CTO. The Perceptions of Mental Health Services Questionnaire (Tschopp, Berven, & Chan, 2011) and the MacArthur Modified Admission Experience Survey (Swartz et al., 2002) are two such adaptations. To rewrite items regarding the admission process to cover pressures and coercion in respect of outpatient treatment was not easy, and I find the results wordy, such as the item "I had more influence than anyone else on whether I went to the mental health center". The original MPCS covers autonomy in a situation where involuntary admission is a likely outcome. It is not obvious that this is similar or parallel to the pressure and coercion common in CTOs, that is, to be compelled to attend outpatient treatment at the mental health center or to be ordered to repeated depot injections over months or years.

#### 1.3.2 The Visual Analogue Coercion Ladder (CL) scale

The Nordic Coercion Study (Høyer et al., 2002) took a different approach and developed the Coercion Ladder (CL) based on Cantril's one-item self-anchoring approach (Cantril, 1965).

The CL is a one-item visual analogue scale that asks the patient to rate their experience of care from 1 (minimum use of coercion) to 10 (maximum use of coercion); see Figure 3. The CL is introduced by a preamble of about 150 words, which mentions coercion, threats, pressure, and inducements, and asks the participant to rate which "step on the ladder ... that best corresponds with the amount of pressure from others". Patients anchor the numbers 1 and 10 in their own intuitive definition of the terms coercion (printed on the ladder) or pressure (as instructed in the preamble), and their image or opinion of what constitutes minimum and maximum use of coercion. This approach depends on the patients being able to relate their current care experience to the words pressure and coercion – something the MacArthur group found difficult.

10	Maximum use of coercion
9	
8	
7	
6	
5	
4	
3	
2	
1	Minimum use of coercion
	(I came totally on my own will and initiative)

Figure 3. The Coercion Ladder, reproduced from Høyer et al., 2002.

The self-anchoring approach has pros and cons. When a concept is established in the language, but difficult to define in the scientific discourse, self-anchoring will reflect the meaning attached to it by the studied sample. The CL is therefore useable across care settings, and has been used to measure individual changes in experienced coercion over time (Bennewith et al., 2010; Fiorillo et al., 2011; Katsakou et al., 2010). Self-anchoring can therefore be an advantage when approaching experienced coercion in new populations or arenas, where those involved may use the coercion concept in different ways than an original validation sample. The downside is that the anchoring process is left to the patient and therefore may vary between patients, and is not readily available to the researcher. It is therefore unsurprising that single-item scales such as the CL are shown to have lower reliability than multiple-item scales (Larsen, Diener, & Emmons, 1985). Notwithstanding, the CL seems to work reasonably well (Høyer et al., 2002), and shows acceptable correlations with the Admission Experience Scale at .58 (Iversen et al., 2002), and with the MPCS at .82 (Fiorillo et al., 2011). The latter figure indicates that they measure overlapping or similar constructs. The CL have produced bimodally distributed scores, just like the MPCS, with a majority of patients scoring at one of the extremes (Høyer et al., 2002). This indicates that some aspects of the experience of coercion tend to be rated as present or absent, on or off. One interpretation is that coercion may resemble the moral-philosophical concept of integrity, which is either intact or violated, and does not invite grading (ibid).

#### 1.3.3 The Coercion Experience Scale

The Coercion Experience Scale was constructed more recently, to measure whether seclusion or restraint is the less coercive alternative (Bergk, Einsiedler, Flammer, & Steinert, 2011; Bergk et al., 2010). The items seem tied to inpatient coercive measures, such as this one: "During the measure, to what extent did you feel limited in the freedom of movement" (Gómez-Durán et al., 2016). This scale has five sections with different topics. The first three are a "memory precision ladder"; a "stressfulness ladder" and items on adverse effects and restrictions. The fourth consists of items rating how unpleasant the restrictions were, and the fifth has 22 items asking the patient to rate the stressfulness of different aspects of coercive measures.

This scale is not designed for rating experienced coercion outside of other aspects of care than these two coercive measures. An interesting finding from the development of this scale is that "humiliation" emerged as the strongest factor in the analysis of patient responses (Bergk et al., 2010).

#### 1.3.4 Room for Improvement in Scales Measuring Experienced Coercion

These three scales on perceived and experienced coercion illustrate that it is possible to approach perceived or experienced coercion in more than one way: The MPCS essentially asks patients to rate whether they exercised or could exercise autonomy in the admission situation. The CL asks patients to rate the amount of pressure and coercion they experienced in the situation. The Coercion Experience Scale, on the other hand, separates the acts as such, and measures how stressful the acts were. This leaves room and may suggest directions for improvement.

First, discussion of coercion with patients seems feasible. The reported problems of using terms and feelings denoting coercion and pressure in talking about and reporting patient experience do not follow from the evidence reviewed in this chapter. The current patient movement is vocal, and coercion in mental health care has repeatedly been a theme in public discourse. In addition, the coercion concept worked acceptably in the CL. Several qualitative studies reveal concepts and phrases that patients find meaningful as descriptions of coercion, and studies that document patients' own words and descriptions of coercion can give information about how patients in the target population talk about coercion and its consequences. Such descriptions are valuable in their own right, but can also be utilized for the improvement of existing scales of experienced coercion.

Second, in order to find the least restrictive forms of care or intervention, one needs to compare levels of coercion across these forms of care. It is useful to be able to estimate the level of coercion for formal *and* informal patients, and to measure experienced coercion through the pathways of care. CTOs are often considered less restrictive than involuntary admissions, but such claims should

be followed by empirical investigation. Ideally, a scale of experienced coercion should be applicable across different care settings and care measures.

Third, the MPCS and the CL have repeatedly shown bimodal distribution in patient samples. A possible explanation is that the concept of experienced coercion is truly bimodal, that is, tends to be experienced as an on or off phenomenon. This contrasts with the observation that "perceived coercion clearly varies from patient to patient, and philosophically this experience has many shades of grey" (Newton-Howes & Stanley, 2012, p. 336). If the theoretical variable "experienced coercion" is truly continuous, then it is a shortcoming if such nuances are not reflected in the existing measurement scales. If experienced coercion is truly continuous, it should be possible to construct a scale that reflects this in a distribution that is evenly or normally distributed. In order to be able to discriminate between medium and strong experienced coercion, it seems necessary to find descriptions of the most intensely negative experiences of coercion. When asked about such sentiments, patients with intermediate experienced coercion may be able to respond with an answer conveying intermediate experienced coercion.

Finally, research findings accumulating since the publication of the MPCS support the notion that when patients report their experienced or perceived coercion in mental health care, they report an emotionally charged phenomenon. Their perspective is not simply a mirror of the coercive measures and provisions carried out; it is a more complex evaluation of several aspects of the context, situation, and how the measures are implemented. For instance, their reports of coercion seem to be potently influenced by their feeling of being humiliated. Accordingly, experienced or perceived coercion can, and maybe even should, be re-conceptualized as an emotional result of experiencing formal or informal coercion. In this case, it can be fruitful to borrow from models and concepts used in the scientific study of emotions.

# 2 Aim of the Thesis

The theme of this thesis is the experience of coercion in mental health care. As shown in the previous chapter, there are several gaps in the knowledge base regarding coercion, and in some areas the accumulated knowledge points towards areas where the knowledge and research tools can be improved.

# 2.1 Personal Experiences of Being Subjected to Coercion

What are the most salient aspects of being subjected to coercion, and why is it sometimes experienced as strongly aversive? We were especially interested in descriptions that elaborated on coercion when it is experienced at its most negative, and posed the following research question:

1. How do patients with negative experiences of coercion express and conceptualise these experiences?

This research question is addressed in Paper 1.

# 2.2 A New Measurement Scale for Experienced Coercion

After examining existing scales and the literature, as shown in Chapter 1, we saw important shortcomings in the existing scales measuring experienced coercion. We posed the following research question:

2. Is it possible to establish a scale to measure "experienced coercion" that is based on patients' varied experiences, has good psychometric properties, and can be applied in a variety of care settings?

This research question is addressed in Paper 2 and the resulting Experienced Coercion Scale (ECS).

# 2.3 Experienced Coercion in Adolescent Inpatients

There is a severe shortage of quantitative studies on experienced coercion by adolescent inpatients in mental health care. We found no attempt to establish the level of experienced coercion, or to determine whether the important predictors from adult care predicted experienced coercion in adolescents, and posed the following research question:

**3.** What is the level of experienced coercion in Norwegian adolescent inpatient care, and what variables predict experienced coercion in this population?

This research question is addressed in Paper 3.

# 2.4 A Model of the Relationship between the Use and the Experience of Coercion

A model or theory of the relationship between the use and the experience of coercion in mental health care could be a useful tool to simplify and structure an understanding of this relationship. It should be possible to suggest such a model by combining 1) an understanding of personal experiences of coercion; 2) the conceptualization work that should underlie a scaling attempt; 3) results obtained with the new scale; and 4) the existing literature on experienced coercion. I therefore pose an additional research question:

4. Can the relationship between the use and the experience of coercion in mental health care, found in our data and in the knowledge base, be combined into a simple explanatory model?

This research question will structure the combination of findings between the papers in the discussion, and is addressed solely in the discussion section of this thesis (Chapter 5).

# 3 Methods

In this chapter I present the project design, and discuss the methods used. I first give an overview of the study and its different parts. Then I discuss important parts of my preunderstanding of coercion, and the prospect of remaining open to new experiences. I finish this chapter with a discussion of some aspects of the quantitative analyses to supplement the descriptions in Papers 2 and 3.

# 3.1 Design and Data

In this study, we have used four different datasets, as well as a literature search. We analyzed the data with methods from the quantitative and qualitative domains, and the study can be described as a mixed-method study, using different kinds of data in a sequential approach, as shown in Table 2.

We wanted the scale for experienced coercion to be valid, practical, and acceptable for staff and patients. Therefore, we wanted to get advice from persons outside of the project. We drew up shortlists of users, researchers, and clinical experts, and recruited a reference group consisting of two members from each of these categories. The group met three times during scale development, and discussed design, conceptualization of coercion, the initial item pool, and the results from Stage 2.

#### 3.1.1 Seminar Notes on "Coercion and Voluntariness"

In Paper 1 and in Stage 1 of Paper 2, we used a dataset consisting of notes from a series of dialogue seminars on "Coercion and Voluntariness", which took place at regular intervals over four years. The seminars were open for anyone to attend, and participants were self-recruited following announcements on the Norwegian Council for Mental Health's web pages. The aim of the seminars was to discuss coercion and voluntariness, and possibly increase the understanding of how coercion could be avoided in favor of voluntary help. The notes are on-site transcriptions of participants' contributions to the seminars, transcribed as verbatim as possible by me. As such, they are similar to field notes (Clifford, 1990). The notes used in Paper 1 are transcribed contributions from 35 persons with user experience of coercion in mental health care. The seminar notes were analyzed in a stepwise thematic analysis (Braun & Clarke, 2006), and supplied with some elements from grounded theory (Boeije, 2002) and analytical induction (Glaser & Strauss, 1965). The main results from this analysis are reported in Paper 1. We also used the categories from the personal accounts in this dataset to help formulate possible domains of experienced coercion in Paper 2, Stage 1. Particular words and phrasings used by the participants also informed the coining of items and item wordings in this stage.

Table 2. Overview of Dataset and Papers Used in the Study

Paper		Data	Analyses	Result
Paper 1		Notes from 15 seminars on "Voluntariness and coercion"	A stepwise thematic analysis, with elements of constant comparison and analytical induction	Description of patients' negative accounts of experienced coercion
Paper 2	Stage 1	Literature on scales measuring experienced coercion	Review of existing scales measuring experienced coercion	Possible domains of experienced coercion
	Stage 2	Questionnaires from patients in diverse care settings	Principal components, analyses of scores, and distribution in known groups	20 candidate items for a scale measuring experienced coercion
	Stage 3	Questionnaires from patients in diverse care settings and related staff	Confirmatory factor analyses, Alpha, Kurtosis, skewness, correlation analyses	The Experienced Coercion Scale (15 items) with some psychometric properties
			T-tests, correlations, ANOVA, and regression analyses	Predictors of experienced coercion in the sample
Paper 3		Questionnaires from adolescent inpatients and their contact staff/responsible clinicians	T-tests, correlations, ANOVA, and mixed-model analyses	Comparison of experienced coercion in adolescents and adults, estimation of predictors of experienced coercion in the adolescent sample

# 3.1.2 A Systematic Literature Search of Scales Measuring Experienced Coercion

We conducted this search and review in order to find all attempts at scaling of perceived or experienced coercion. We sought for existing scales measuring experienced coercion in Medline, PsycINFO, and CINAHL: Details of the search strategy are given in Appendix IV. All items from these scales were considered as possible candidate items for our scaling attempt.

#### 3.1.3 Cross-sectional Questionnaire Data on Experienced Coercion in Adult Patients

For Stage 2 in Paper 2 we collected questionnaire data with patients' responses to several items on each named domain of experienced coercion, their responses on the CL, and some demographic information. Participants (n=212) were recruited from four care settings in specialized mental health care (combined forensic and high-security wards, acute wards, inpatient care in local mental health centers, and outpatient treatment teams for severe mental illness), and residents in supported municipal housing for people with mental disorders. Participants were recruited from the catchment

area of one mental health trust in each of Norway's four regional health trusts. We also recruited patients from outpatient treatment teams from a fifth hospital.

For Stage 3 in Paper 2 we collected questionnaire data with patients' responses to candidate items for the new scale. Staff filled in forms with information from the hospital records regarding patient and clinical variables, such as diagnosis, compulsion, and informal pressure. The patient items were restricted to candidate scale items and a few demographic variables. Recruitment was restricted to consenting patients in four care situations: Acute wards, inpatient care in local mental health centers, outpatient treatment teams for severe mental illness, and residents in supported municipal housing for people with mental disorders. This time participants were offered lottery tickets worth 50 NKR for participation. For patients in supported municipal housing we lacked access to hospital reports. We therefore asked these participants to report their own diagnoses, restrictions of freedom, and formal involuntary care or medication on a second page of the questionnaire.

# 3.1.4 Cross-sectional Questionnaire Data on Experienced Coercion in Adolescent Inpatients

This dataset combined self-reported experienced coercion and staff reports of clinical variables, compulsion, and informal pressure. Adolescent inpatients were recruited from acute and combined acute and sub-acute adolescent wards. Norway has 16 such wards, and 10 of them participated in recruitment. Data for each patient was collected on a self-report form from the patient with an item set that included the experienced coercion scale. In addition, the patients rated their alliance with the staff and their parents/guardians. Information regarding clinical variables and compulsion was reported by the patients' contact staff or responsible clinicians.

#### 3.2 Epistemological Position in the Thesis

Coercion in mental health care is simultaneously dependent on physical, social, and juridical conditions. Coercion research is therefore often of a multidisciplinary nature, combining elements from law, medicine, nursing, psychology, and sociology, all of which can be considered life sciences. Both objective and subjective conditions are important in order to understand coercion. The intervention is complex, and it is often difficult to conduct randomized controlled trials, for example because randomization will often be considered unethical (TvangsForsk, 2014). This calls for a flexible approach towards methodology and epistemology, combined with both acknowledgement and critical evaluation of existing methodology and studies. The need for flexibility and critical evaluation of existing research has led me to adopt a pragmatist and post-constructivist position. There are room for both of these positions within a social realism paradigm (Rogers & Pilgrim, 2010)

In psychology, pragmatism is often linked to William James' work in the early 20<sup>th</sup> century. Pragmatism is a common paradigm in mixed methods research with focus on actions, experiences and likely consequences (Morgan, 2014). According to pragmatism, it is advantageous to use multiple paradigms when addressing a research problem (Creswell & Clark, 2007, Chapter 2) but some methods are better suited than others to reduce uncertainty in certain situations (R. B. Johnson & Onwuegbuzie, 2004). In this study, pragmatism is reflected in an interest in the experience of persons, their history, and an expectation that seemingly similar actions may have different consequences. I used a pragmatic approach when I decided to use multiple research paradigms, and to mix analytic methods from the qualitative and quantitative domains in a sequential approach. I have tried to find feasible and appropriate methods to approach the aim and address the research questions, in order to reduce uncertainty. In line with pragmatism and social realism, both objectivism and subjectivism can be meaningful at the same time.

Post-constructivism pays attention to the laborious work of constructing and establishing more reliable research tools, and building small blocks of increasingly trustworthy and useful tools and knowledge (Knol, 2011). From this position it followed that I should use the existing methodology, tools, and findings to see how we could improve upon the existing scales measuring experienced coercion, but also be critical of weaknesses within the knowledge base. I have therefore borrowed from relevant research fields, such as when I use the appraisal model, developed within psychological research on perception and emotion (Lazarus, 1991). I used this model to help delineate and delimit the latent variable "experienced coercion". The appraisal model can be seen as bridging the physical and social realities, because "appraisal" is an attempt to describe the processes whereby a physical aspect of the world is given subjective and emotional meaning and consequences.

Coercion in mental health care is made possible by interplays between specially designed physical realities, such as architecture, locks, belt-beds, and mind-altering medication, and social reality, such as laws, norms, authority, care professions, and stigma. These aspects of reality also interplay with the subjective reality, such as feeling humiliated, violated, or protected. Coercion has a local history in each country or region, and has been carefully designed, institutionalized, and revised over centuries, up to the practices of today. Post-constructivism directs attention towards the pragmatic techniques that are developed and used in scientific study of the physical and social constructions that make empirical inquiry possible (Knol, 2011), renewing and improving empiricism through critical inquiry (Latour, 2004). A post-constructivist perspective therefore study the relationship between the physical and social realities.

Our development of the Experienced Coercion Scale fits well into the post-constructivist perspective, where we want to understand the merits and weaknesses of similar scales, and try to design a more sensitive, yet feasible measurement tool. We attempt to measure experienced coercion using psychometric techniques that ascribe a numerical value to a selected part of human experience. The psychometric approach and the classical test theory have been shown to work reasonably well in creating measurement tools for the subjective domain (DeVellis, 2003; Judd, Smith, & Kidder, 1991, chapter 3 and 7). With the numerical format, it is possible to apply several domain-independent mathematical and statistical procedures to investigate the relations between variables, with the corresponding advantages and pitfalls. In classical test theory it is recommended to pay strong attention to the theoretical concept, and be pragmatic and creative in exploring its breadth (DeVellis, 2003). I have used qualitative and quantitative data in a sequential approach, where the unstructured life-world data from the dialogue seminars informed the content and some parts of the design of the scale development.

What are the warranted beliefs about the research findings on coercion, how far are they likely to reach? Many aspects of coercion in mental health care are linked to language, norms, relations, self-reflection, and social conditions, and will to a great extent be anchored in time and context. Some findings, such as a certain level of experienced coercion in Norwegian adolescent wards, will have a narrow and local scope. Other findings, such as that a substantial minority of involuntary inpatients tend to report *low* experienced coercion, have been shown in several studies across countries over the past 25 years (Newton-Howes & Stanley, 2012). So while our findings will be historically and culturally bound to current Norway, a pragmatic warranted belief is that some will be relevant to other contexts. In the post-constructivist perspective, this thesis is one small piece of work in the vastly larger fabric of different and interplaying attempts to understand the world. I also expect discussions, criticism, and disagreement regarding methods and findings, and in particular in how far conclusions from this project can reasonably be presumed to reach.

#### 3.2.1 Mixing Information Sources and Methods

We used the first dataset with content-rich descriptions of personal feelings and thoughts of coercion to describe important aspects of experienced coercion in Paper 1. These descriptions of feelings and thoughts on coercion were further used as important information when evaluating existing measurement scales of experienced coercion, and pragmatically utilized as building blocks when we developed possible domains of experienced coercion in Paper 2, Stage 1. We also utilized these qualitative descriptions when we wrote, rewrote, and developed items for each domain of experienced coercion. The personal descriptions from patients influenced item development, so the content of items followed and *depended* on these descriptions. These descriptions remained as

background information in the interpretation of the results of the questionnaire study in Stages 2 and 3 of Paper 2. In Paper 3, we used the Experienced Coercion Scale to measure experienced coercion in another population of patients, namely adolescents. Here, the influence of patients' experiences was more indirect, mediated by the scale and understanding resulting from Paper 2. The questionnaire data did not do much to modify our understanding of the seminar notes, so the type of mixture of methods was mainly sequential and unidirectional. This notwithstanding, the results in Papers 2 and 3 may also support, strengthen, qualify, or delimit some of the results in Paper 1.

I also gradually realized that data used in our different papers (see column 2 in Table 2), could be used to sketch a model of the relationship between the use of coercion and experienced coercion in mental health care. Here, the influence between different sources of knowledge is more complex and multidirectional. All sources of data contributed to the development of the model of the relationship between the use and the experience of coercion. The jigsaw puzzle is sometimes used as an illustration of mixing methods, but when I assembled the model I did not use a finite set of pieces with a predesigned pattern and a correct placement. I think Lego construction has some features that are more illustrative of this part of the thesis: Several different bricks and pieces are necessary to sketch a model of the relationship between the use of coercion and experienced coercion, but our model would have been rather similar, even if some bricks had been omitted or exchanged with other bricks. For example, if the concept of procedural justice had not been illuminated in the MacArthur studies, qualitative studies nevertheless point towards an appraisal of coercive care in light of individual patients' context and the way coercive measures are applied, explained and adapted to the individual (Katsakou & Priebe, 2007; Strout, 2010). However, if broader parts of the current research were lacking, such as any scaling of experienced coercion, or any semi-structured interview study, I think I might have been unable to connect the rest of the bricks in a similar way.

### 3.3 The Qualitative Approach

Several methods exist, more or less tailored to gather data from different aspects of the world, spanning from technical measurements, to observations and dialogue. Our topic was experienced coercion, and when people's experiences are the topic, some form of observation or personal inquiry is a pragmatic solution. The experience of coercion in mental health care is not very common, so persons with this experience cannot be reached through a random draw from the general population, but must usually be recruited through a suitable channel or arena. We were interested in what coercion means, how it feels, and how patients handle it, so we wanted to start with an approach that could elicit and analyze communication that was not strongly structured (Willig, 2013). Being under involuntary care is a complex situation, with possible mixtures and ambivalence

between care and control, stigma and relief, and need deprivation and need fulfillment (Gault, 2009). The experience of coercion is emotionally charged (Johansson & Lundman, 2002), and often stigmatized (Link et al., 2008). Time may add additional complexity, for example immediate reactions may or may not differ from later attributions and considerations (Priebe et al., 2009). We therefore initially preferred a long and flexible answer format, and a data format that reflects some parts of these complexities. Also, we could not expect people to readily share these experiences in any setting. Often a confidential interview setting is preferred in this situation, but we had access to the seminar notes data that came from a public setting that was nevertheless experienced as supportive and safe.

#### 3.3.1 Preunderstanding Coercion in Mental Health Care

Within the discourse of qualitative and interpretative methods, the influence of the researchers' preunderstanding of the selection of topics, research questions, methods, analysis, interpretation of evidence, and conclusions is often discussed (Kvale, 1997). I therefore outline parts of my professional training and preunderstanding regarding coercion, so the reader can consider this when evaluating my work. In predominantly quantitative studies such discussions are often absent, but even here, preunderstanding can influence the research process, for example through choice of research questions, selection and operationalization of variables, and choice of statistical techniques (Onwuegbuzie, Johnson, & Collins, 2009).

I first encountered coercive practices as an apprentice in a mental hospital, during my training as a clinical psychologist in the mid-1990s. Coercion was not brought up as an explicit topic during the supervision. I recall my overall impression of the patients – passive, reserved, and peculiar, rather than "mad" or insane. Staff were trained in doing things that seemed unusual to me, such as running towards incidents if someone sounded the alarm, or considering their placement in the room for safety reasons. I did not see any dramatic incidents myself, but reasoned that the alertness could be necessary in rare episodes. I did not think about it at the time, but the importance of damage control in rare episodes, and the indirect consequences of many such measures on staff and patient attitudes and relationships may be a true dilemma without obvious solutions.

In my work for the Norwegian Council for Mental Health during the 2000s, I participated in various activities related to severe mental disorders and coercion. These included the seminar series on Coercion and Voluntariness (Paper 1), the Health Directorate's workgroup for the consideration of the treatment criterion in the Norwegian Mental Health Care Act of 1999 (Helsedirektoratet, 2009), and a study trip to Iceland's belt-free mental health care (Nyttingnes, 2011). I then worked as a cosecretary for the governmental law committee, preparing a white paper for a revised mental health

act (Norges offentlige utredninger, 2011), before starting as a project worker on the topic of experienced coercion at Akershus University Hospital, which later expanded into this project and thesis. In these and other activities I met many users, carers, and professionals, and was repeatedly fascinated by the diverse and contradictory considerations of coercion that existed between and within all these groups – ranging from the positive to the strongly negative evaluations of current practice in Norway. Sometimes these views seemed influenced by personal experiences, be it the shock from a totally unexpected involuntary admission, that a loved one committed suicide after discharge, or needing to take control over a dehydrated patient isolated in her apartment in order to save a human life.

I came to this project with the view that coercion is a complex phenomenon, with severe gaps in research and understanding, and signs of substantial disagreement between stakeholders regarding optimal practice. For patients, coercion is not just involuntary care, treatment, medication, side effects, improvement, or lack thereof. Coercion is often intertwined with a personal crisis, identity, powerlessness, and with restrictions in freedom, rights, legal standing, as well as stigma, and self-stigma. It seems necessary to understand how and why patients or users experience coercion as they do, in order to gain significant improvements in the understanding and practice of care and involuntary care in mental health.

I hope that the strong and conflicting opinions I have met, have helped me maintain openness for diverse opinions, new data, and new perspectives.

# 3.4 Reflexivity and Openness

In this section, I want to explore whether it is possible for the researcher to be open to change of opinion and positions, in light of communication with other persons about their life worlds. I shall discuss how my presence as a project worker and researcher may have influenced data. I also discuss examples from the work behind this thesis, partly in the light of empirical findings from research on behavioral schemata and attitudes.

#### 3.4.1 Seminars on Coercion and Voluntariness – Planning and Influence

In the seminars on Coercion and Voluntariness, I had a role as co-arranger and secretary. The seminars followed as a sequel to an engaging national conference, "Tvang og frivillighet i psykisk helsevern" [Coercion and Voluntariness in Mental Health Care] in 2004, with the Norwegian National Organization for Carers in Psychiatry as the main organizer. When evaluating the conference, the arrangement committee – with co-arrangers including professionals, researchers, and users' NGOs – wanted to continue the dialogue from the conference. I joined the committee on behalf of the Norwegian Council for Mental Health, as I was working with a quality improvement project financed

by the Norwegian Directorate of Health, focused on shared decision-making, user knowledge, and decentralized care. The aim of the seminars was to continue and improve the discussions on coercion between stakeholders beyond the conference, hear experiences of coercion in mental health care, and, if possible, learn more about whether voluntary care could be a substitute for coercion in mental health care. The researcher and psychiatrist Tom Andersen (1936-2007) was pivotal in the committee, and in suggesting the topic and format of the seminars. He also suggested placing all seats in a circle to convey the equal value of all persons present, and moderated the seminars up to his death in 2007. The atmosphere, openness, and reflective qualities in these seminars owed much to Andersen's skills in facilitating dialogue. In order to acknowledge each participant after they said something, he summarized shortly the theme he thought this participant was most concerned with, and asked for elaboration, regardless of how well it seemed to correspond with the aim of the seminars. His skills and sensitivity in this endeavor were impressive, if not unique. As a result, Andersen carefully exemplified and enabled a listening attitude that opened participants to a wide range of experiences, including critique of mental health services, from persons who could be angry, disillusioned, or lack trust. Andersen would not interrupt any participant, and did not comment on the relevance of contributions, but warned against and discouraging opinions regarding others' opinions. I think this last norm avoided escalating discussions regarding implication and imprecision of statements, and I think this relative absence of direct criticism of statements increased the feeling of a safe seminar environment.

Seventeen seminars were held between 2006 and 2009. Following Andersen's death in 2007, the documentary filmmaker Håkon Sandøy moderated the remaining seminars, continuing the openness.

The members of the arrangement committee were clearly influencing the seminars. Non-influence seems an impossible ideal when co-arranging seminars and taking notes. These two roles can be performed with differing degrees of influence, however. The seminars followed an ideal of dialogue and openness, and for my part they can be described as following a script; a schema of action sequences that guides behavior in a class of situations. Important parts of my dialogue seminar script were to invite all stakeholders, regardless of the sentiment held towards them, give all of them due talking time, and attempt to give also the least privileged positions due coverage. During breaks and meals, one shall be curious of any participant, and as an organizer, initiate conversations with those alone or unknown to oneself. One should listen to negative evaluations of aspects of the seminars, but reserve most of one's own negative evaluations to arrangement committee meetings. Two general guiding values and ideals in this script are openness and curiosity.

The arrangement committee wanted to continue the dialogue from the original conference, and create an arena where the patient and carer voices were strong, and where professionals could learn and engage in dialogue. From the first seminar it became clear that several participants with a patient background held strong negative opinions of coercion. A few professionals followed several seminars, but the arrangement committee did not succeed in catching a broad range of professionals' interest in the discussions. This was discussed in the committee, and we decided to continue the seminars as the first ones had unfolded, while continuing to tell other professionals of the seminars. We accepted that the user voice remained a main stakeholder in the following seminars, and did not change the format or topic in order to be more attractive to professionals. I think the content of the patient contributions changed the aim and content of the seminars towards expressing and discussing different user perspectives on coercion. Such flexibility can follow from Andersen's moderator script and principles: Reflect what seems most important to the participant, not what the organizer or moderator had aimed for.

My role as secretary for the seminars is partly described in Paper 1. In the second seminar, content transcripts were called for by some participants. As a co-organizer with fairly fast typing skills, I volunteered to type notes. The feasible solution for writing extensive content minutes was to write down the discussions as verbatim as possible, but anonymized, on a laptop computer on site. I could then proofread during the following days, and send it by email to all participants. This arrangement satisfied the participants. The notes were not word-for-word transcriptions. During the discussions I think I was able to write approximately half of the words, preserving most of the meaning, but omitting — and losing for future analysis — the many hesitations, repetitions, breaks, and non-verbal information that can accompany transcriptions from tape or video. The minutes are therefore condensed, and citations are less oral in style than could be expected from word-for-word transcription.

Although the ideal was a fair representation of what was said, there was a risk of transcription bias. Following Tom Andersen's ideal of allowing the full breadth of experiences and opinions; I carefully tried to make sure that minutes also reflected views that contradicted my own, whether these were religious, political, or views on psychiatry or professions. I also drew upon skills and scripts from my experience with observation from a behavioral perspective in my training as psychologist, and during practice as a school psychologist. Such observations gave me experience in writing down what happens, and avoiding or postponing the many possible interpretations or evaluations. Later I could look for connections and meaning in the notes, and discuss the events and their meaning with teachers, parents, and pupils. In the seminars I found it feasible to focus on writing down what was said, regardless of whether it resonated with my pre-existing opinion. I remember feeling motivated

to give a fair representation of statements I disagreed with, because I could easily anticipate criticism from participants if I failed this ideal. We offered the participants the possibility to correct and comment on the minutes during the subsequent meeting, but only few and minor corrections were suggested for the 15 seminar notes. Participants seemed to accept that limited writing speed led to some omissions, and considered the content to be a reasonable representation of the discussions. Some participants commented that reading the previous meeting's minutes the day before the next meeting brought back the atmosphere of the previous meeting, improving the continuity of discussions.

To sum up, the organization committee influenced the seminars, but I think the main influence was in the direction of openness and curiosity.

#### 3.4.2 Would My Preunderstanding Preclude Openness to Seminar Content?

Nyström and Dahlberg (2001) ask if the relationship between preunderstanding and openness is "a relationship without hope". Some of their reasons behind this pessimistic question are that we do not completely understand our own thoughts, and that different social groups understand the world differently. Furthermore, our feelings are influenced by early childhood relations and defenses, and we are embedded in our own history and cannot describe all its relevant parts. According to a pragmatic and post-constructivist approach, warranted beliefs about preunderstanding and openness might be examined by looking at relevant empirical studies. In my case, openness can be seen as the possibility that a message from a seminar participant might influence and thus change the researcher. During the past 100 years, a substantial body of empirical research on how persons change following communication has appeared under the heading of *attitude change* (B. T. Johnson, Maio, & Smith-McLallen, 2005).

Communication that leads to attitude change seems to work via one of two pathways: Using the central route or high-elaboration condition, the recipient pays attention to the content, logic, and validity of the statement, while using the peripheral route, attractiveness, celebrity, or slogans without reasoning are relatively more important (ibid). Note-taking, thinking, logging, categorizing, discussing, and drafting notes, papers, and this thesis clearly place the analysis in the high-elaboration condition.

If recipients' pre-existing attitudes are ambivalent, they tend to consider the arguments more carefully, compared to recipients who have a strong pre-existing attitude (ibid). My pre-existing attitude towards coercion was shaped by the lack of strong evidence and contradicting personal experiences, and I was motivated to learn more from the seminars.

The participants had a relevant background, were not paid and had no other obvious incentive to mislead the audience, which corresponds to source characteristics that yield high-persuasive power (ibid). Even if the recipient discounts the message because of some source characteristics, a *sleeper effect*, where a reasonable message is remembered, and the cue to the low-source credibility is forgotten (ibid), could have been facilitated by conducting the analysis work a few years after the seminars. While I remember the context of several statements, the importance of these seemed to fade during analysis, compared to the content of the notes.

If recipients expect to be interacting with the source in the future, and are not strongly involved with the attitude in question, they usually retain openness for attitude change, even if they anticipate an attitude-changing message (ibid). The seminars were long and repeated, and it felt natural to try to tune into the topic and be open for what could be said. While the quality of arguments was important, much of my impressions from the seminars revolved around the feelings and consequences that the participants told about, and the quality of argument seemed sufficiently strong regarding this subjective experience of the participants.

In the seminars, participant discussion included negative emotions, shame, and stigma, which is frequently attached to people with severe mental disorders (Thornicroft, Rose, Kassam, & Sartorius, 2007), and coercion in mental health care (Link et al., 2008). Research on attitude change has shown that sources who are stigmatized seem to raise message-relevant thinking if the recipient has low prejudice (B. T. Johnson et al., 2005). To the degree that I entered the seminars with prejudice and stigma towards psychosis and persons under coercion, I nevertheless followed the schemata of arranging a seminar, and behaving politely towards all stakeholders. To act incongruent with one's attitudes is a strong source of attitude change, usually explained by cognitive dissonance or self-perception that drives the attitude towards the implications of one's behavior (ibid), and this may well have happened with me during the seminars.

The discussion above indicates that several aspects of the seminar note analyses facilitated attitude change, and that empirical studies indicate a hope for openness, in spite of our cognitive and emotional biases. This does not mean that *all* relevant analytical options were considered, or that the best ones were chosen. Also, the attitude-incongruent behavior, and the very high elaboration of the message may even constitute a risk of over-identification. From the pragmatic and post-constructivist position, I think this will be dealt with by the critique of the findings and conclusions in this thesis.

# 3.5 Measuring Experienced Coercion

We wanted to develop a scale of experienced coercion in mental health care that could be used across care settings, and be relevant for various coercive measures. The scale should be easy to use, and relevant for research and quality improvement work. We therefore wanted to use the questionnaire form, ready for paper-and-pencil response, and easily adaptable to an online response format. The validity of questionnaire data rests on several necessary requirements, which seem to be discussed less extensively than the parallel requirements behind qualitative data. Here I try to make explicit some of the assumptions and decisions we made that may point toward weaknesses and limitations in this work.

# 3.5.1 Some Necessary Conditions for the Questionnaire Method

Research methods that ask a standardized question to several people, such as in a questionnaire, rest upon many assumptions. These include that the responders have sufficient reading ability to understand the instructions, language, and phrases as expected; are motivated to comply with the instructions; and have the motoric ability to mark or write their responses. In many target populations, these assumptions are easily satisfied, and maybe therefore seldom discussed. Some patients in our target populations will have severe symptoms, or be affected by tranquillizing medication, so their concentration span or motivation to comply may more often be compromised than in the general public. In Paper 2, we saw a very different participation rate in Stage 2 (37.1%) and Stage 3 (69.8 %). While the lottery tickets offered to the participants in Stage 3 may have been effective in this regard, the questionnaire in Stage 3 consisted of one page only, which may have been more acceptable to the prospective participants than the longer questionnaire in Stage 2.

#### 3.5.2 The Conceptualization of Experienced Coercion and the Appraisal Model

After reading the research on perceived and experienced coercion, as described in section 1.2., I found that patients' reports of this variable had characteristics that resembled the psychological descriptions of emotions. The seminar notes and Paper 1 also showed that being under compulsion could raise strong negative emotions. I gradually realized that experienced coercion could be thought of as an emotional product of a special kind of event, and this might facilitate items that could be used across care settings, and be relevant for different forms of coercion. In addition, research on emotion has shown that there is usually not a one-to-one relation between stimulus and emotional response, inspiring some form of three-step appraisal model in the study of the link between perception and emotion (Lazarus, 1991). The following applies to our topic: 1) A restriction of freedom is registered through the senses of a person; 2) the sensation is appraised, interpreted, or evaluated; and 3) the person reports either little or much experienced coercion if asked in an interview or questionnaire. Different appraisals may explain why patients under similar forms of

compulsion report different levels of experienced coercion. Some elements from the appraisal model have been utilized in the literature on experienced coercion (Newton-Howes, 2010; Szmukler & Appelbaum, 2008), but I have not seen the model presented or discussed explicitly.

The appraisal model is not the only conceivable model for studying experienced coercion. A competing idea is that coercive measures have intrinsic properties that are directly connected to experienced coercion, without being appraised. If that is the case, one could measure experienced coercion by asking whether the patient has been exposed to particular forms of compulsion, and weigh and add these to a measure of experienced coercion. Another possibility is that forms of compulsion in care are so unique that the emotionally charged experience of coercion cannot be added across measures, or captured meaningfully by scales such as the CL, the MPCS, or the ECS.

The appraisal model may be overly flexible, in that the appraisal process can be used as a placeholder for almost any internal factor that moderates the relationship between an event and the resulting emotion and evaluation. Another problem with this approach could be that emphasizing the emotional end result of the appraisal process in the scale, will remove attention from the influence of different coercive measures. An alternative approach could have been to ask whether the patient had experienced certain coercive measures, such as involuntary medication or locked doors on the ward. We could then have developed specific items evaluating these measures, which could facilitate analyses of these relations using only data from the scale. During our work with the item pool (Paper 2, Stage 1), we evaluated these possibilities, and decided to choose the appraisal model approach. A coercive measure-oriented approach would be complex, and a simple response format was preferred for patients in severe distress. A coercive measure approach will be anchored to these measures, and in principle ought to be revised as soon as new coercive measures come into practice. There are also variations in the particular measures allowed in different jurisdictions (Bowers et al., 2004), and their application will vary, so the result of such a scale would be more difficult to compare across jurisdictions. The complexity of this approach can be illustrated by the CES, which is designed to compare two coercive measures and has 33 items (Gómez-Durán et al., 2016).

The emotional and evaluative end result is more abstract and general than the particular consequence of a certain care measure. The emotional end result therefore lends itself to comparison, regardless of the particular form of coercion that has been used, which is a good fit for the aim of applicability across care situations. Also, the patient has privileged access to these end results, while the compulsion used should be readily available to staff. Some forms of compulsion, such as the legal status, are not always known by the patient (Prebble, Thom, & Hudson, 2015). These arguments added up, and resulted in our decision to use the framework of the appraisal model

for the scale development. A model such as this makes a part of the world easier to understand, by placing different classes of variables in a structure, and emphasizing the most important ones, and is more or less useful for different purposes, and not true or false as such. Although the model appears sequential, there has been controversy in emotion research regarding whether the appraisal is a cause or a part of the resulting emotion (Moors, 2013), or whether the appraisal precedes the emotion (Ellsworth, 2013). For practical purposes, emotional reactions and evaluations happen so fast that use of coercion, appraisal, and experienced coercion will appear to happen simultaneously. In addition, emotions are frequently reappraised (Moors, 2013), so reports of experienced coercion may change over time. I expect that interviewing or asking patients to complete a questionnaire regarding experienced coercion will make the appraisal salient, and trigger a reappraisal. This reappraisal may help the patient to rate their current overall experience and evaluation.

In qualitative studies, patients can relate different forms and aspects under the heading of coercion (Johansson & Lundman, 2002; Norvoll & Pedersen, 2016b). In addition, the results from the MPCS and the CL (Newton-Howes & Stanley, 2012), and patients who compare and evaluate different coercive measures in quantitative studies (Whittington, Bowers, Nolan, Simpson, & Neil, 2009), indicate that scaling should be possible, and that the appraisal framework can be applicable and meaningful across different forms of compulsion.

#### 3.5.3 Non-coercive Freedom Restrictions are Common

I gave examples of neutral or positive freedom restrictions in Table 1, while the literature covered in section 1.2 depicts experienced coercion as mainly negatively valenced. In the work with the seminar notes, I found it illuminating when a participant distinguished lack of freedom in other arenas, such as being "wage slaves", from abuse under coercive mental health care that was the topic of the seminars. My interpretation of this was that experienced coercion is not simply any form of forced choice, or any freedom restriction compared to full freedom, but rather a special and negative class of freedom restrictions. This resonated well with findings that experienced coercion and humiliation are strongly connected (Bergk et al., 2010), and even a tendency for patients to equate the one with the other (Svindseth, 2010). The quantitative studies of experienced coercion show that a substantial percentage of involuntary patients – who are objectively restricted in freedom compared to a baseline situation – report no or low experienced coercion. Freedom restriction is not sufficient to create perceived coercion, indicating that perceived coercion is not a "cold" or direct evaluation of the level of factual autonomy or restrictions in freedom. These findings also resonate with the observation that we usually do not use "coercion" to describe restrictions of freedom that we accept, such as driving on the correct side of the road, being obliged to pay at the bus, or showing up at work in time in order to get paid. For traffic rules and bus payments there exists a threat of punishment, or significant loss, if one does not comply with the norms, which could amount to a coercive threat. Nevertheless, the common use of the concept "coercion" seems to be reserved for lack of freedom that is illegitimately or immorally inflicted on individuals, or when a reasonable requirement is enforced against protest, such as when law enforcement actually uses force. This seems reflected in the philosophical studies of coercion emphasizing the moral quality of coercion (Nozick, 1969; Rhodes, 2000; Wertheimer, 1993). It therefore seems reasonable to regard experienced coercion as an evaluative result with a negative valence, that has similarities to complex emotions, and that an appraisal model is a reasonable starting point when sorting items and variables relevant to experienced coercion.

In the construction and validation of the scale, we had planned two quantitative data collections. It was therefore possible to test items in respect of many possible ways of experiencing coercion, both more emotional ones and items with words of negative valence, but also items from other domains, such as rating the current grade of restricted freedom. This was tried out in Stage 2 of Paper 2.

#### 3.5.4 The Scale and Measurement Model

In psychology and related sciences, several variables such as attitudes or internal mental states are not directly observable. Measurement of such *latent variables* is difficult, and has been an important methodological issue in psychology, spurred partly by the development of measures and theories of human intelligence.

We developed and validated the ECS with a classical test theory (DeVellis, 2003), or social relations measurement model (Judd et al., 1991, chapter 3 and 7). Here the *observed score* consists of *true score* + *systematic error* + *random error*. The true score of a population is never observed or measured directly, but estimates of the relative size of the true score and random error score, such as reliability measures, can be calculated and used to evaluate the quality of the items and the test. A core foundation of classical test theory was invented in 1904, when Spearman developed a method for calculating the reliability index, and thus could correct a correlation coefficient for the effect of random measurement errors (Lubinski, 2004). If one tests one trait or attitude several times and aggregates the scores, the average of the sum of truly random errors in the test will approach zero. In addition, some errors that are systematic and similar for identical or very similar items, will vary more and be more un-systematic if the tasks, items, or measurement methods are more diverse. Therefore, a common strategy for improving reliability is to use multiple and diverse items when trying to measure the level of a latent variable (Judd et al., 1991, chapter 3). In classical test theory it is pivotal to develop different items that reflect different but related parts of the latent variable, and combine them into an aggregated measure: The sum score.

According to Fan (1998), weaknesses of classical test theory include a primary focus on the test-level properties, and that both the individual's score and the estimate of item difficulty and item discrimination are sample dependent. The theoretical assumptions are not strong or difficult, so the approach can be utilized in many circumstances. Nevertheless, the sample dependency makes it difficult to equate the difficulty of different versions of a test, which is important in some test situations, such as achievement tests. Later test theory developments, most importantly item response theory (IRT), address item characteristics. Here one can model item difficulty, item discrimination, and a guessing factor for each item that is in principle independent of examinee samples (ibid). This model is statistically more complex, and procedures are not readily available in the commonly used statistical software package SPSS. Based on problems of existing scales for measuring experienced coercion, I considered the development of sensitive and relevant items to be the most important challenge. Furthermore, our interest was primarily in the sum score of patients, and there is little need to have interchangeable versions of a scale measuring experienced coercion. Several important and valuable measurement scales in medicine and psychology are constructed within the classical framework, and we therefore decided that the simpler and more intuitive classical test theory would be a practical and feasible solution. Interestingly, when testing both approaches on the same data, estimates of item statistics from both classical test theory and item response theory were rather similar, and item response theory did not show the expected superiority and stability across different samples (Fan, 1998).

#### 3.5.5 The Choice of Item Format

When it comes to the answer format of items, there are different approaches, such as graphic rating scales exemplified by the CL, verbal grading, and bimodal formats such as *true/false* or *yes/no* options.

In the light of the bimodal distributions of both the MPCS and the CL, a *yes/no* answer format could be appropriate for experienced coercion. On the other hand, I had already chosen to conceptualize experienced coercion analogue to an emotional dependent variable, which may vary in both presence and intensity. An item with a bimodal answer format will have a threshold, and intensities lower than the threshold should be scored a *no*, and above should be scored a *yes. Yes/no* is thus a severely truncated response format, if the latent variable is continuous (Carifio & Perla, 2007). If experienced coercion and appropriate items are indeed dimensional, a *yes/no* format will give the person with intermediate levels of the variable few clues as to what threshold the researchers will interpret a yes-response to represent. In addition, the *yes/no* solution will lose some information on the intensity of the respondents' sentiments. In case of a measurement error or untypical threshold interpretation for a respondent, the response will necessarily be grouped with many responses that

reflect strongly different levels, because of the severe bimodal truncation. If the variable is truly dimensional or the situation is complex, a question with a bimodal answer format will be underspecified. In the example of an item on humiliation, a *yes/no* answer format gives no information to the respondent on whether feeling humiliated by two of five important ward professionals should result in a yes-response or a no-response. These concerns led us to opt for a graded answer format in Stage 2 of Paper 2.

An important contribution to graded answer formats was made in Rensis Likert's PhD thesis (Likert, 1932). Here he showed that it was possible to scale single items with grades of agreement, instead of the bimodal formats, card-sorting procedures, and pre-testing of item strength that was common at that time. The simplicity and efficiency of Likert's solution is illustrated by the current ubiquity of his agreement-rating approach, using a five-point grading, although the ideal number of rating alternatives has not been resolved definitively (Jacoby & Matell, 1971; Pearse, 2011). A five-point Likert item on humiliation is shown in Figure 4. It essentially combines five questions regarding the intensity of a sentiment into one line: Rather than asking "Do you strongly disagree that you feel humiliated? yes/no. Do you disagree that you feel humiliated? yes/no" etc., a common preamble and stating of agreement alternatives enable a simple and easy one-line statement regarding humiliation. The preamble and grading alternatives are then reused for the following items.

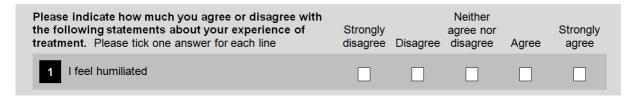


Figure 4. Example of an Item in a Likert Graded Answer Format

The Likert answer format is very easy to read and understand, and the answer format is familiar to most people. It is implicit in this response format that the response will be interpreted as a point on a continuum. Compared to five separate questions, it also visually invites the respondent to think of their most and least intense experiences in respect of the statement topic – such as their most intense feeling of humiliation, and situations with absence of humiliation – and then consider whether one of those, or an alternative in between, best corresponds to their current situation and feeling. When using an uneven number of alternatives, there will be a middle response that will signal a neutral evaluation. If the situation is complex, or the respondent is ambivalent regarding his or her agreement with the item content, the midpoint should correspond well to such sentiments. In a three-point scale there are no other grades, while seven or more points will place demands on

participants for grading the response. We decided to use a five-point agreement-rated Likert item format, because this seemed like a sweet spot for patients with concentration challenges, placed in a complex environment, or with potentially ambivalent attitudes towards care.

#### 3.5.6 Statistical Properties of Data on Likert Items and Likert Scales

There are disagreements regarding the measurement level that can be achieved by Likert items and Likert scales, and the proper statistical tests to use. Likert items are often coded in ascending numerically order, such as from 1 to 5, and it has been common to analyze data from Likert items with factor analyses and parametric statistical tests. This practice has been criticized, as the single Likert item gives ordinal information, while the precise interval between the different agreement alternatives is usually not estimated or precisely known. Results from parametric tests can therefore be biased (Jamieson, 2004). On the other hand, the measurement level achieved is not necessarily constricted by each single item: When several items representing a continuous variable are organized by content, logic, and empirical data into a reasonably well-constructed scale, the full scale can acquire emergent qualities (Carifio & Perla, 2008). Simulation studies have shown that the statistical F-test is robust with regard to moderately skewed distributions and violations of the interval data assumption. Also, several different answer formats to similar attitude statements produced isomorphic data with linear and interval quality. Replacing severely truncated answer formats, such as true/false, with a Likert-like answer format tends to improve the linear and interval properties of the resulting composite scale, and Likert-like formats are often a reasonable measure to repair the imperfect coining of items (Carifio & Perla, 2007, 2008). The level of measurement in social science cannot be assured by a scaling method, but should be decided by examining data (Judd et al., 1991, chapter 7).

In this thesis, I have taken the common, latter approach, that a sum score of Likert-scaled items may approach interval qualities, and if so, can be analysed with parametric statistics.

#### 3.5.7 Finding and Sorting Scale Items

In the work reported in Paper 2, we developed an item pool using many sources. Aspects that are not covered among the candidate items can never make it into the scale. Therefore, the development of items and the content of items is a critical task in scale development (Carifio & Perla, 2008). In classical test theory, the ideal is that the item pool should be a probability sample of all possible items tapping the theoretical concept (DeVellis, 2003) – in our case experienced coercion. However, it was not (and usually is not) possible to construct a population of all possible items, so we attempted to mitigate this weakness by looking for possible "branches" of experienced coercion in the following ways:

- A systematic literature search to find scales of perceived coercion, so no item used by others would escape our initial pool;
- A narrative review of qualitative and quantitative literature, looking out for how experienced coercion is described and given meaning;
- A search for items from scales that covered three of the possible domains of experienced coercion (humiliation, negative impact from previous treatment, trust or distrust in authority decisions);
- Descriptions of how coercion is experienced in the notes from the seminars on Coercion and Voluntariness; and
- Discussions on the domains and item pool in the project reference group.

We sorted the existing items into domains, and coined new items when the domains had few items or seemed incomplete. We could now use the appraisal model as a practical tool for evaluation of some aspects of the items. The appraisal model distinguishes between the stimulus (use of coercion), the appraisal process, and the response (experienced coercion). We had decided to construct a scale that could measure the resulting experience. I now saw that several possible items asked for patient reports of compulsion, and of the use of particular coercive care practices or measures. Even though the MPCS refers to autonomy, the scale is so closely tied to the admission process that all items are about coming "into the hospital". As illustrated in Paper 2, in order to find a wording that could cover the parallel feeling of lacking autonomy because of any coercive provision or measure, these items were rewritten. For example, the MPCS item, "I felt free to do what I wanted about coming to the hospital" was rewritten to "The treatment makes me feel restricted" and "If I wish to, I can end the current treatment." The Admission Experience Scale's subscale of negative pressures, with items such as "Someone physically tried to make me come into the hospital (true/false)", could now be seen as patient-reported compulsion. The voice / procedural justice subscale had items such as the following: "I had enough of a chance to say whether I wanted to come into the hospital." This subscale, which is not a part of the perceived coercion scale, covers qualities in the process of deciding to commit the patient – or not to commit. I see it as a patient-reported aspect of attending to justice standards in the admission procedure, or, in short: Patient-reported procedural justice. We could now look for items that were patient-reported compulsion and patient-reported procedural justice - not to include such items, but to let them inform new items covering a sentiment or feeling that would often follow from the event covered by the item. For example, a low or high score on the procedural justice subscale item "How fairly did s/he treat you" could give rise to a feeling relevant to the domain of discrimination or fair treatment. This reasoning gave rise to candidate items such as "I feel

treated similarly to everybody else" and "I feel punished", where the latter survived the item selection process in Stages 2 and 3 of Paper 2.

#### 3.5.8 Selecting Items for the Scale and Reporting Measurement Properties

Administration of questionnaires and selection of items are covered in Paper 2, Stage 2. I saw no available gold standard for experienced coercion to evaluate item performance. Using pragmatism, this should be solved by practical remediation measures, and using post-constructivism, we should look for suitable existing indicators of the latent variable, in order to develop the measurement method one step further. We tried to rectify the absent gold standard by combining several approaches: We used principal component analyses, expected differences in experienced coercion in typical voluntary and coercive care settings, the similarity to the scoring pattern on the CL, and item distribution, as described in Paper 2. Most importantly, we knew from the research referred to in section 1.2 that compulsion predicts experienced coercion. Some care settings rarely use compulsion, and other care settings use it more often. The district psychiatric inpatient wards in our study typically admit patients for planned inpatient stays, under voluntary care, where the patients not infrequently want a longer stay than they are offered (Lauveng, Tveiten, Ekeland, & Ruud, 2015). Supported housing for persons with severe mental disorders are also typically voluntary, and for many older residents it has replaced long-term asylum-ward stays. On the other hand, acute wards frequently commit patients, usually have equipment and staff trained for using coercive measures, and often initiate involuntary medication. Combined high-security and forensic wards are similarly equipped, and patients are often committed or sentenced to stay in these wards. Finally, teams that are responsible for CTOs can also be expected to have a substantial share of patients that are coerced, and feel treatment pressure and coercion. Not all of the patients in these teams and wards are under coercion or feel coerced. According to the literature reviewed in section 1.2.2, we can expect several cases of low experienced coercion in typically coercive care settings, and some cases of high experienced coercion in typically voluntary care settings. I nevertheless reasoned that items that were endorsed to a similar degree by patients in coercive and non-coercive care settings would likely have small discriminating value, and would be a weak or unsuited indicator of the latent variable experienced coercion. Items that could differentiate between voluntary and coercive care settings could be better candidates for the scale. Viewed another way, typically voluntary care settings could be seen as some form of control setting, that we could use to discover if items we thought would reflect experienced coercion were as highly endorsed in this "control group", and possibly reflecting other latent variables. I found no mentioning of attempts to use similar known groups or control groups in the development of the MPCS, the CL, or the CES.

For our reports of the psychometric properties of the ECS, we decided to use common techniques within classical test theory, such as looking at the distribution skewness, kurtosis, and histogram, calculating alpha value, inspecting the factor structure, and comparing average scores in different subgroups.

#### 3.5.9 Studying Experienced Coercion in Adolescents

The methods used in Paper 3 have many similarities to the methods used in Stage 3, Paper 2, and several of the same considerations regarding scales, items, and statistical methods apply. A main issue is how to approach the measurement of experienced coercion in adolescent mental health patients when existing scales are not validated in this population. The existing studies on experienced coercion in adolescents referred to in section 1.2.3 did not point towards strong differences in the experience of coercion in adolescent mental health patients, compared to adult patients.

Nevertheless, I can think of at least three problems with adult scales on experienced coercion applied to adolescent populations: 1) Adolescents may use the coercion concept differently compared to adults; 2) important aspects of experienced coercion in adolescents may be omitted in adult scales; 3) some items may use words that are difficult to understand for adolescents.

The CL uses a self-anchored rating scale, which should limit the problems stemming from all of these problems. For adolescents, the admission situation, with involvement from parents, is different compared to the situation for adults, and the common baseline level or situation regarding autonomy is different in adults and adolescents. Therefore the MPCS would be especially vulnerable to all three problems. The ECS, with the easier wording and focus on the emotional result of compulsion is less, but still somewhat, susceptible to these problems. We therefore combined the self-anchored CL with the ECS. With this design, we could compare the scores on the ECS and the self-anchoring CL, and look for signs that Norwegian adolescent inpatients understand and use the coercion concept radically differently from adults.

#### 3.6 Ethical Considerations

Coercion in mental health care is an important and sensitive theme, and the need to expand the knowledge base is strong. A group of Finnish authors argued that the most important ethical issues in research on experienced coercion is whether patients understand the meaning of the study, whether consent is really voluntary, and whether the responses of participants are valid or adapted to please the researcher (Soininen, Putkonen, Joffe, Korkeila, & Välimäki, 2014). In this project, the data used in Paper 1 is of a type not often used in medical research, and warrants a more detailed discussion than the cross-sectional questionnaire data used in Papers 2 and 3.

#### 3.6.1 Ethical Considerations regarding the Use of the Seminar Notes

In Paper 1, our data were anonymized seminar notes that had already been distributed to all participants and the arrangement committee in electronic format. As stated in section 3.4.1, participation in the seminars was voluntary, and one of the pivotal aims was to increase understanding and dialogue regarding coercion in mental health care, and to exchange views and improve discussions between stakeholders. The seminar notes were called for by the participants during the second meeting, and the nature of the notes, note-taking and distribution was repeated at the beginning of each subsequent seminar. Several participants regretted that content from the seminars was not disseminated to a greater audience, complained about lack of understanding of their situation from the greater society, and welcomed the occasional journalist and researcher that attended.

Persons with experiences of coercion can be considered vulnerable persons. Qualitative researchers have argued that a thoughtful consideration of the situation, rather than considering a pre-existing trait or status of the person, can be a preferred or at least additional guard against harm under some circumstances (Hem, Heggen, & Ruyter, 2007; Oeye, Bjelland, & Skorpen, 2007; Øye, Sørensen, & Glasdam, 2016). In the seminars, several of the mentioned common problems in research on coercion were absent: There was no pressure to participate from staff responsible for treatment, and it was socially acceptable to decline to discuss, not to attend, or to leave. Obtaining written consent from participants for the note-taking was not considered at the time, because the nature of the situation was clear, contributions were voluntary, and implied consent was evident. When I later got the opportunity to analyze and disseminate these notes under the current PhD project, it was thus a welcome follow-up of the aims and wishes conveyed in the seminars.

Recruitment of patients with first-hand experiences of coercion is difficult (Corring et al., 2017; Soininen et al., 2014), and dissatisfaction and unfortunate treatment outcome may well be predictors of reluctance to participate, or of gatekeeper censoring (Øye et al., 2016). Seminar attendees were strongly dissatisfied with coercion, and this project could potentially funnel some of their sentiments into the research literature. We considered the possibility of trying to ask all seminar participants for explicit consent before writing Paper 1, but in addition to a partly outdated email list, the anonymized notes would require a re-identification of data from the consent-withdrawing participant, which we deemed very difficult to carry through.

We consulted the Regional Ethical Committee, which advised that the study fell outside the remit of the Norwegian Health Research Act, and did not require their approval. We also consulted the Privacy Ombudsman at Akershus University Hospital, who did not consider the anonymized notes confidential patient information. Further, we discussed our planned use of seminar notes with experienced researchers and some of the seminar participants, and none of these opposed dissemination. We concluded that dissemination in Paper 1 was a natural extension of the seminar aims, the risk of compromising confidential information was low, and that important knowledge and voices were likely to be lost if the data were not further analyzed and disseminated. We followed the regulations of the Privacy Ombudsman at Akershus University Hospital, and the standards for confidentiality in scholarly publications. In a few citations we omitted details to ensure anonymity.

#### 3.6.2 Ethical Considerations regarding Questionnaire Data on Experienced Coercion

The data in Papers 2 and 3 are more typical for medical research, and fell under the remit of the Norwegian Health Research Act. We decided that we could collect answers using a large item pool without collateral staff information for each patient, but that staff information was important for evaluating the validity of the scale, and to study the relationship between the use and the experience of coercion. Consequently, we dropped staff information in Stage 2, Paper 2, but included it in Stage 3.

All patients were asked for written consent to participate in Stages 2 and 3 in Paper 2. In the instructions to the approaching clinicians, we emphasized that a "no" should be respected, and that if the patients were unsure, they should be given time to think it over, and only be asked one more time to participate. The approaching clinicians did not receive any benefit for recruitment, and the high rate of approached patients who declined to participate in Stage 2 indicates that the approaching clinicians did not put undue and effective pressure on these patients.

The purpose and design of the study were explained to the patients in written and oral form, and they were instructed to fill out the form in private, and enclose the envelope themselves to ensure confidentiality. The instructions mentioned the risk of reactivation of negative memories and feelings of mental health care, and gave a phone number to the project should patients wish to talk to someone after the interview.

The South and East Regional Committee for Medical and Health Research Ethics, Norway approved the project (No 2011/2574/REK sør-øst).

For Paper 3, we added some additional considerations. We did not need or collect names, social security number, or patient record number. Collecting written consent increases transparency and safeguards that consent is given, but it also introduces a small risk for compromising the participant's name, which may increase the fear of confidentiality breaks. In an amendment to the research ethics committee, we suggested basing the data collection on the Norwegian Health Research Act §20,

regarding use of anonymous health information. The committee agreed that our procedure with written information and oral consent to utilize anonymous information was acceptable in this study. The written information contained similar information as for Paper 2, although the language was edited to be easier to read and comprehend.

According to the Norwegian Patient Right Act §4-4, children between 12 and 16 years are entitled to have their say in all questions regarding their own health, and according to the Norwegian Health Research Act §17, children between 12 and 16 sometimes have acceptable reasons for discretion visà-vis their parents. It is well known that sometimes patients under 16 years are admitted to mental health inpatient stays based on parent consent, but accompanied by considerable protest from the adolescent. It was therefore a risk that a patient between 13 and 15 years would want to participate, but that the parent would not consent to this, because of reasons unrelated to the adolescent's risks and wishes. We therefore asked the committee to approve a procedure where parents of patients at this age could not stop their adolescent child from participating, but this was dismissed. We then followed our subsidiary procedure, where participation was dependent on both the patients' and the parents' consent before collecting data from patients below 16 years.

# 4 Results

In this chapter, I briefly summarize the results of the systematic literature search, and then of the three papers included in this thesis.

# 4.1 A Search for All Scales of Experienced Coercion

The systematic search for scales of perceived coercion yielded 882 papers (745 from Medline or PsycINFO, and an additional 137 papers indexed only in CINAHL). The titles of 606 papers did not cover experienced coercion or its measurement, and were omitted. Abstracts for the remaining 276 papers were read by the candidate, and 243 of them revealed no indication of measurement of experienced coercion and were omitted. The remaining 33 papers were read in their entirety. The scales covered in these papers are described in the following paragraphs.

The MacArthur Admission Experience Interview and Admission Experience scale, including the subscale MPCS (Gardner et al., 1993): These scales have been influential and frequently used, but the items are restricted to the admission setting, and it is questionable whether they can be readily applied after this care phase or to outpatient care settings (see section 1.3.1).

The MacArthur Admission Experience Scale has been subjected to two adaptations for outpatient care. One is a combination of adapted items from the Admission Experience Scale and the Therapeutic Limit-Setting Scale (Neale & Rosenheck, 2000), called the Perceptions of Mental Health Services Questionnaire (Tschopp et al., 2011). The other is the MacArthur Admission Experience Survey (Modified) (Swartz et al., 2002). Another adaptation and extension was made for experienced coercion in situations where a person with mental disorders is dealt with by the police. This scale is called the Police Contact Experience Survey (Watson et al., 2010).

In the Nordic Coercion Study, a single-item scale was developed based on Cantril's ladder approach, and called the Coercion Ladder (Høyer et al., 2002). This scale is discussed in section 1.3.2.

One scale has been developed to measure experienced coercion following seclusion and restraints. This scale is called the Coercion Experience Scale (Bergk et al., 2010), and was discussed in section 1.3.3.

Some papers presented scales that measure attitudes towards coercive measures, such as the Attitude to Containment Measures Questionnaire (Whittington et al., 2009), and the View of Seclusion Questionnaire (Hammill, McEvoy, Koral, & Schneider, 1989), but this is less closely related to experienced coercion.

One scale covered whether the patients had experienced acts of leverage (Jaeger & Rossler, 2010), which can be called patient-reported leverage in the terminology used in this thesis.

Another scale covered pressure in different domains to enter treatment for substance abuse, such as having great financial problems (Klag, Creed, & O'Callaghan, 2006).

The scale Perceived Control over Everyday Life covered freedom in respect of food, spending money, and selecting programs on TV (Steadman & Redlich, 2006).

Other scales from the papers in the search were either general patient satisfaction scales or care quality scales, with or without items covering coercion and restrictions in freedom.

#### 4.2 Paper 1

Some mental health patients criticize coercive mental health care and treatment using very strong language. This may be connected to poor therapeutic relationships and unfavorable treatment outcomes, so a better understanding of this criticism is warranted, both in order to improve services, and to evaluate and attend to patient rights.

Data consisted of detailed notes from 15 all-day dialogue seminars on coercion and voluntariness in Oslo, Norway from 2006-2009. Severely dissatisfied patients and ex-patients were a central voice throughout the seminars. To gain a better understanding of their negative experiences of coercion, we conducted a stepwise qualitative thematic analysis of the seminar notes (Braun & Clarke, 2006), with a mix of inductive and deductive coding, followed by focused coding (Ghezeljeh & Emami, 2009), and analytic induction (Glaser & Strauss, 1965).

Coercive care was described in strong terms, such as "humiliation" and "Nazism". To explain this, we suggested a model with two pathways (see figure 5). The beginning of both pathways is that participants understood their symptoms as mental crises following trauma or spiritual problems. In the first chain of events and evaluations, they perceived involuntary medication to harm rather than help. Some found that their complaints were dismissed as lack of insight. In the second pathway, minor incidents were experienced as coercive, such as being "defined" by the medical model, receiving repeated negative remarks, and feeling they had to succumb in order to get care. The accumulated effect could be experienced as eroding self-confidence and trust in their own feelings and thoughts.

The participants signaled awareness that aspects of their opinions were at odds with other stakeholders, and they had a hard time being understood in the public discourse of coercion in mental health care.

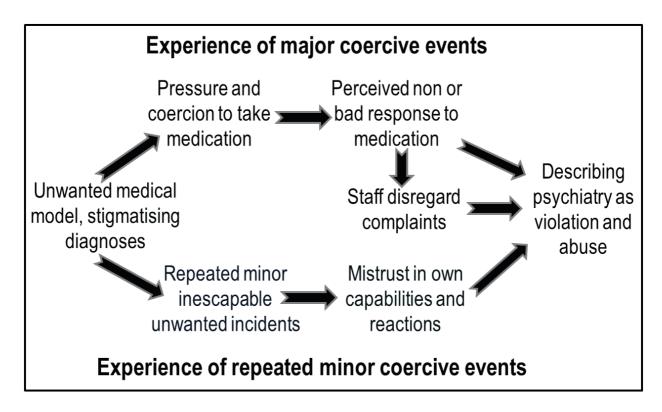


Figure 5. Two Pathways Towards a Strongly Negative View of Coercion in Mental Health Care.

According to the data from the seminars, involuntary medication and dismissal of patient perspective, combined with the accumulated effects of minor negative incidents, seem to explain the feelings of humiliation, oppression, and the use of metaphors such as imprisonment by totalitarian systems. Our model can help explain such patient reactions that exist in clinical practice and the literature, and may assist staff in retaining understanding and alliance when they meet such strong sentiments in their practice.

#### 4.3 Paper 2

In this paper, we report the development and validation of a short self-report form for experienced coercion for use across care settings, care phases, and care measures in three stages. In Stage 1, we developed an item pool, based on the literature, patient accounts, interviews, and expert feedback. Stages 2 and 3 consisted of two cross-sectional studies, with patients from acute and non-acute inpatient wards, outpatient care, and supported housing.

In Stage 2, patients (*N* = 212) responded to the Coercion Ladder and the pool of experienced coercion items from Stage 1. We selected 20 items for Stage 3, based on item performance in typically coercive vs. voluntary care settings, each items' relation to the CL score, and the component structure from the principal component analysis. In Stage 3, we collected and examined item

responses from patients and clinical staff, and reported compulsion, diagnoses, and psychosocial functioning for each participating patient (*N* = 219). We selected 15 items based on factor loadings to form the final Experienced Coercion Scale (ECS). The internal consistency was high, and score distribution approached the normal distribution. ECS sum scores correlated strongly with CL scores. In a regression analysis, demographic variables, diagnosis, duration of treatment, and care setting did not predict ECS scores, while legal status and continuing involuntary medication significantly predicted scores. In this initial study, the ECS scores showed promising psychometric properties, suggesting the scale could be used across care settings, and is suitable for research and service evaluation.

This study shows that it is possible to measure how coerced mental health patients feel with a new 15-item questionnaire, which can be used both in inpatient and outpatient treatment. The ECS will make it easier to compare the coerciveness of different forms of mental health care, or to find out how experienced coercion changes in the patient as care proceeds.

# 4.4 Paper 3

Coercion is not applied exclusively in adult care settings. Involuntary care and coercive measures and treatment are used also in mental health care for adolescents. The purpose of this study was to examine the level of adolescents' experienced coercion in inpatient mental health care, and to examine predictors of experienced coercion in this setting.

A cross-sectional sample of 96 adolescent inpatients from 10 Norwegian acute and combined (acute and sub-acute) psychiatric wards reported their experienced coercion on the CL and the ECS in questionnaires. Staff reported compulsion, diagnoses, and psychosocial functioning. We used two tailed t-tests and mixed effect models to analyze the impact from demographics, alliance with parents, compulsion, diagnostic condition, and global psychosocial functioning.

High experienced coercion was reported by a third of all patients. In a mixed effects model, compulsion (including admission based on parental consent where the adolescent disagrees (see section 1.1.1); a worse relationship between patient and parent; and lower psychosocial functioning significantly predicted higher experienced coercion. Twenty-eight percent of the total sample of patients reported a lack of confidence and trust both in parents and staff.

Roughly one third of patients in the sample reported high experienced coercion. Involuntary care was the strongest predictor. The average scores of experienced coercion in subgroups were comparable with adult scores in similar care situations, with some exceptions: In the adolescent sample, 14.6% of patients had eating disorders, and they were the subgroup that reported the

highest experienced coercion in the sample. In the adult sample in Stage 3, Paper 2, only 3.1% had this diagnosis. Adolescents with psychosis reported low experienced coercion, and almost all of them were under voluntary care.

There are few published studies available on coercion in adolescent mental health care, and very few related to experienced coercion. Even in the well-staffed Norwegian adolescent wards, with low use of formal coercion compared to reports from some other countries, one third of the inpatients report high experienced coercion. The main driver of high experienced coercion is compulsion, pointing towards the importance of careful evaluation of both formal coercion and informal pressures during adolescent care.

# 5 Discussion

In this chapter I first sum up the main limitations and strength of the findings from the three papers. Then I discuss the findings across the papers, and relate them to relevant findings from the literature, in an attempt to answer the fourth research question. This means that the discussion across the papers is done by suggesting a model of the relationship between the use and the experience of coercion in mental health care.

# 5.1 Limitations and Strengths

Several of the reasons for conceptual and methodological choices in the chapters above are implicit arguments for strengths and limitations in this work. Here I discuss some of the limitations and strengths of the findings in this thesis.

#### 5.1.1 Limitations and Strengths in Paper 1

In Paper 1, the participant recruitment process is an important limitation that is simultaneously connected to the paper's strength. The seminars on Coercion and Voluntariness seem to be a unique case of open discussions on coercion, with accompanying notes from the content of the discussions. Patient and ex-patient group discussions on coercion have been reported (Appelbaum & Le Melle, 2008; Brophy & Ring, 2004), but are rare. Paper 1 gives insight into the premises and logic of two possible pathways to strong negative evaluations of coercive care and treatment.

The participants self-selected to participate in one or more seminars, and they said that their sentiments were not of the most common kind. Each participant did not contribute equally to the discussion, so a strong influence from a few outspoken participants is possible. Furthermore, some of the narratives that were told in the seminars may have been told and re-told previously by the participants, representing rehearsed stories that have been scripted and adapted over time to be a "good" story of some sort. I think this means that the particular stories of what different actors, such as carers and professionals, had done are subjective, with a risk of being skewed, compared to an intersubjective account of the events. For such reasons, our analysis in Paper 1 did not focus strongly on the particularities of particular events.

After coding and examining the connection between themes in the notes, our analysis started with the strong negative descriptions, and followed their experienced antecedents in the eyes of the participants. The conclusion, that participants consider themselves as non-responders, partial responders, or bad responders to antipsychotic medication, is based on their personal evaluation, and is not connected to a thorough discussion or operationalization of non-response. We nevertheless showed in Paper 1 that current evidence points towards substantial incidence of side

effects and lack of response to antipsychotic medication. In this light, Paper 1 raises the hypothesis that non-response and/or aversive side effects fuel complaints and negative evaluations, and if this is not detected by staff, or even is dismissed as signs of lacking insight, it may lead to severely negative sentiments towards involuntary mental health care. I think a major contribution of this paper is that it combines several known elements from the literature into a coherent process: The strong negative sentiments, criticism of the medical model, a focus on rights rather than care, and the staff's power to interpret some criticism of care and treatment effect as lack of insight. When combined into a process in Figure 5, the description of psychiatry as Nazism, that seems unreasonable to many people, is more understandable. The different parts of these processes, presented in the figure can then be studied with other designs. For example, it should be possible to operationalize non-response to antipsychotic medication, and study the relation between non-response, protest, and the staff's evaluation of patient insight. In this way, Paper 1 illustrates the hypothesis-generating strength of qualitative analyses.

## 5.1.2 Limitations and Strengths in Paper 2

In Paper 2, we made several choices and selected priorities that led the scale development in particular directions, which can be viewed as limitations. One such limitation is that we used wordings and phrases from the seminar notes to inform coining and rewriting of items. Therefore, sentiments that were absent from the seminars lacked this channel into the item-making process. Nevertheless, the use of several sources, including the systematic search for existing scales, should acknowledge other sentiments and give a broad item pool for Stage 2. In addition, the discussion of the item pool in the project reference group did modify the item pool, and could potentially correct omissions in the pool. The main reason to use the seminar notes for this purpose was the problems that the MacArthur group reported from talking with coerced patients about these experiences. After piloting items and testing 84 items in five care settings in Stage 2, there should be sufficient variation for most strong ways of experiencing coercion in the data, to aid selection of suited items.

Patients under coercion are the key population for this scale. Therefore we prioritized the scale's ability to differentiate between very high, high and not so high experienced coercion. The results from Papers 2 and 3 indicate that we succeeded. It is possible that we have sacrificed similar nuances towards the low end of the continuum. The skewness of the ECS reported in Paper 2 indicates that there were slightly more very low scores in our total sample than in a normal distribution, but the skewness was not large. As a crude rule of thumb, if skewness divided by standard error of skewness deviates more than two from zero, this indicates a substantial deviation from the normal distribution (Nye & Drasgow, 2011). In the full sample from Stage 3 in Paper 2, this parameter is calculated as 0.55/0.16 = 1.96, and bordering towards a skewed distribution. If we calculate skewness of the

subsample from alleged coercive care settings, this parameter is 0.28/0.22 = 1.27. This indicates that the ECS does not cluster most patients with low experienced coercion close to a score of zero, but that it is somewhat better adjusted for mental health populations in alleged coercive care settings, corresponding well with the target population for this scale.

Other conceptual choices can also be criticized. In Paper 1, we noted the importance of feeling violated during coercion. Furthermore, humiliation was also strongly emphasized in the thesis of Marit Svindseth (2010). We therefore included items adapted from the Humiliation Inventory (Hartling & Luchetta, 1999) in Stage 2 in Paper 2. Following the principal component analysis of 84 items on experienced coercion in Stage 2, we found that adult patients rated items on lack of freedom sufficiently similar to items on violations and humiliations, so that items from these two domains were not reflected in separate components. This finding increased our confidence in the importance of violation and humiliation in Paper 1, and in Svindseth's (2010) findings.

The connection between humiliation and experienced coercion could give rise to different approaches than the one chosen in Paper 2. This connection may be used to argue that experienced humiliation is a more important aspect of involuntary care than the existing focus on experienced coercion. One could rather prioritize the measurement of experienced humiliation. Our solution may be criticized for blending these concepts and blurring the theme, or may be acknowledged for clarifying the connection, and bringing this connection into the scale. To me this is a conceptual issue, which cannot be settled using our data. Early project descriptions, preunderstanding, and the aim of developing a scale for measuring experienced coercion likely influenced this work, such that the possibility of discarding the concept of experienced coercion in favor of experienced humiliation would have required stronger tendencies in data. An example of tendencies in the data that might have led to a sole focus on humiliation could have been if seminar participants frequently dismissed the coercion concept in favor of humiliation, or that items describing lack of freedom were answered similarly by patients and items of humiliation very differently in coercive and non-coercive care settings in Paper 2.

## Accuracy of ECS Responses

Can I know that the responses to the questionnaires in Papers 2 and 3 are honest and accurate?

Some patients may doubt the anonymity, and respond with less experienced coercion than their true score, in fear of sanctions from staff. Other patients may be angry or dissatisfied with care for other reasons than experienced coercion, and tailor their responses to stage care and staff in a bad light.

To mitigate fear of retaliation from staff, we emphasized anonymity with closed envelopes and lack of patient identification on the forms, and that the purpose of the study was to develop a

measurement scale, and our need for sincere responses. The low number of missing data in the forms in Papers 2 and 3 indicate that patients did not find it difficult to respond. If they feared retaliation from staff, we could expect them to refrain from answering items that implied strong critique. My impression from the item selection in Stage 2, Paper 2 was the opposite: The strong and easily read items discriminated better between coercive and non-coercive care settings, indicating that a substantial percentage of patients did not hesitate to state their negative experiences. It cannot be ruled out that some patients over-reported their experienced coercion, but it I find it unlikely that this has been a major driver for the results. We had informed participants that the results would be anonymous, and results would be aggregations of several participants from several catchment areas, so dissatisfied patients would not be able to affect their care provider. I therefore expect that the strategic motive to exaggerate experienced coercion is weak or absent.

Major strengths of the scale are reported in Paper 2, such as a thorough development process, and two data collections designed for the scale development. We achieved several seemingly contradictory aims for the scale: The scale should be applicable across care settings and care phases, and sensitive, while still being tolerable, short, and easy to use. Our conceptual work prior to item development, and the vivid descriptions of experienced coercion in the seminar notes, may have contributed to the achievements of all of these aims. One finding from Stage 3, Paper 2 is still puzzling: The ECS was not sensitive for coercive measures used during the last three weeks before filling out the form. According to the reviews of coercive measures in section 1.2.1, I do not see obvious reasons for rendering the items used in Stage 3 insensitive for coercive measures. The possible explanations I can see for the apparent lack of sensitivity is a low number of 18 patients in this subgroup, with a possible lack of power to detect a small to moderate effect. However, the finding could also indicate that the ECS is not sensitive for coercive measures in current Norwegian mental health care. Some findings may support a hypothesis that, in certain circumstances, coercive measures may not strongly influence true experienced coercion. For example, if most coercive measures were used under high procedural justice, or if involuntary medication is considered more important, as implicated in Paper 1, then a non-significant finding may be a good description of the matter. Patients can understand the intended purpose of coercive measures (Olofsson & Jacobsson, 2001), and because these measures are often used in response to unsettling episodes on the ward, and are of short duration compared to the involuntary stay, they may not increase the experienced coerciveness significantly. Aggression and unrest on the ward may be connected to high symptom load and poorer functioning, and patients may take their own functioning into account, when judging whether the coercive measure was justified, and modifying the evaluation of experienced coercion accordingly. This explanation may also be reflected in a citation from Paper 1, where the seminar

participant Gabriel separated "the use of physical force, which sometimes is necessary, from forcing chemicals and poison into people". Indeed, this citation anticipated the far stronger role of medication orders for experienced coercion in Stage 3, Paper 2.

## 5.1.3 Limitations and Strengths in Paper 3

The method and design of Paper 3 bear similarities to Stage 3 in Paper 2, and share several limitations. Response honesty and accuracy can be questioned, as for Paper 2. One could suspect that adolescents could approach the study in a less mature way, perhaps with jokes or sabotage of the questionnaire. On the contrary, when I coded the adolescent forms, the apparent seriousness of the vast majority of the responding patients was impressive. Some adolescents wrote on the form and explained why they did not answer an item, and some added information on how they had interpreted a certain item. In the second histogram in Figure 2, Paper 3, I see a sign of a somewhat skewed distribution in the lower end of the ECS histogram. As in Stage 3, Paper 2, there are more very low average scores (0-0.4), compared to scores from 0.4 to 0.8.

The design was cross-sectional both in Papers 2 and 3, which precludes observations over time. The relation between dependent and independent variables is correlational, and does not imply causation. The data in these studies do not prove that the predictors in the regression and mixed-effects models are causing the scores on the dependent variables. For example, psychosocial functioning may influence the care arrangement and the accompanied experienced coercion. However, it is also possible that a care arrangement interplays with protest and high experienced coercion, and that such conflicts escalate and contribute to deterioration of psychosocial functioning.

We measured a limited set of variables, so our models may be incomplete, and unknown factors may confound, moderate, mediate, mask, or interact with the relation between the predictors and experienced coercion reported in Papers 2 and 3.

The number of participants in the analyses in Paper 3 was 96, which is low. This limited the number of variables in the mixed-effects model. It also limits the power to detect smaller differences between subgroups. The study can also be susceptible to accidental tendencies in the sample that do not represent corresponding tendencies in the population. Notwithstanding, we found highly significant relations between compulsion and experienced coercion, and for the level of experienced coercion in patients with a diagnosis of eating disorder vs psychosis.

Ten of Norway's sixteen adolescent mental health wards participated in Paper 3. This means that data were collected from adolescents in several different ward cultures. Thus, relations between variables that are important in one ward may be masked by data from other wards lacking this

relation. On the other hand, the significant findings reported describe conditions that we can expect to find in Norwegian adolescent mental health wards. For Paper 3, we decided to estimate a mixed-effects model that considers ward-level variance. The intra-class correlation for ward-level effects on experienced coercion was below 0.1, indicating that ward-level variation in experienced coercion was low.

Important strengths of Paper 3 are the high participation rate, and a low number of missing data and excluded questionnaires. This makes a strong case for the conclusion that quantitative studies of experienced coercion in adolescent mental health patients are feasible. With some caution, the main results can be expected to reflect current Norwegian mental health adolescent inpatient care. On the other hand, the resources, situation, patient characteristics, and culture in adolescent wards may be markedly different outside Norway.

# 5.2 The Relationship between the Use and the Experience of Coercion

What is known about the relationship between the use of coercion and experienced coercion in mental health care? Below I sum up some main findings from the three papers as elements in a model of this relationship. I combine the empirical findings from Papers 1, 2 and 3 with existing findings in the literature, as I try to describe and assemble central aspects of this relationship into a model of experienced coercion.

A model is a representation of a particular phenomenon in the world. Models often combine a few elements and predictor variables into a structured whole. It is a simplification of the world, often omitting some elements, consequently emphasizing others. A model is not true or false as such, but can be more or less fruitful, and it may have a better or worse fit with data, or be more or less able to capture important parts of how the world seems to work. A model can inspire new hypotheses and sometimes predict future empirical findings.

#### 5.2.1 The Definition of Coercion Revisited

In section 1.1 I discussed the coercion concept at length, and suggested a taxonomy and working definition. As I now set out to develop a model of the relationship between the use of coercion and experienced coercion, I shall first reconsider the coercion concept in light of the findings from the papers.

In Paper 1, we saw how patients found that minor incidents could appear as powerful and coercive. This means that within mental health care, a broader range of incidents than compulsion may potentially spark an experience of coercion. I therefore suggest using *freedom restrictions* as the starting point in the model. Our topic and discussions centered on coercion *in mental health care*, so

expansion of this model beyond mental health care would require additional work and data. Actions related to involuntary mental health care, such as police transportation to the emergency ward (Watson et al., 2010), or being pressured to seek or accept treatment by family (Canvin et al., 2013), landlords, or the court (Monahan et al., 2001), are covered in the literature on coercion in mental health care as related to coercion. Seminar participants told of biased information regarding medication, and a lack of opportunity to discuss medication and have their complaints taken seriously. Manipulation and deceit are reported by staff (Rugkåsa et al., 2014) and patients (Canvin et al., 2013) in other studies, and these actions also restrict freedom. By using freedom restrictions in the model, deceit and manipulation from staff are special forms of freedom restrictions that are included as possible precursors of experienced coercion. Human communication, perception, and attribution are complex processes, where subtle nuances, including context, tone of voice, and body posture matter, and a clear boundary between influence and coercive influence is beyond the scope of this work. By including freedom restrictions enabled by mental health care and mental health legislation, threats from families, landlords regarding involuntary admissions, and police assistance to mental health care providers are also included. I therefore suggest that the starting point in a model of experienced coercion is freedom restrictions that are effected, ordered, or enabled by mental health care.

Can a patient in mental health care report experienced coercion without having been subjected to freedom restrictions effected, ordered, or enabled by mental health care? In other words, can we expect a substantial problem of something that could be called unfounded experienced coercion? This issue points to a weakness in designs that ask patients to report experienced coercion based on their own experiences and evaluations: People's self-report may reflect evaluations that will fail to reach intersubjective agreement. We have focused on patients' self-report to get a better understanding of their subjective experiences, and defined experienced coercion as subjective experience. If a person experiences coercion on seemingly unsubstantiated grounds, it will be interesting to discuss how he or she came to that experience. In the seminars, the experience of patients who told of "minor coercion" was not challenged or refuted, but these patients were listened to and sometimes asked for elaboration. In Paper 1, participants indicated that staff's defining power, their vulnerability in the situation, and their difficulty in achieving the support they desired contributed to an experience of self-depreciation. This experience was then connected to the effects and experiences of coercion. Indeed, the power differentials and the lack of voice reported in Paper 1 is an argument supporting the importance of the patient perspective in matters of coercion in mental health care.

Lack of intersubjective agreement regarding coercion can be studied empirically: Is it common for patients to report experienced coercion under care arrangements and care measures, where observers, staff, or carers will disagree strongly with the notion that the patient had experienced *freedom restrictions that were effected, ordered, or enabled by mental health care?* In Papers 2 and 3, we report that at a group level, patient reports seem to reflect the level of staff-reported use of restrictive treatment. On the other hand, we interpret apparent contradictions with reference to the patient perspective. One example from Paper 3 is the second mixed-effects model, where adolescent patients under coercion reported lower experienced coercion if parents pressured more for treatment. Here, we suggested an appraisal mechanism to account for interaction effect: Without compulsion, parent pressure predicts higher experienced coercion than would be expected. When the adolescent is under compulsion, parent pressure for treatment may increase the legitimacy of the admission, and perhaps let staff borrow from the parents' authority.

One study mentioned in section 1.2.2 did a comprehensive triangulation of accounts of coercion during admission, where the researchers collected information from the patient, staff, and a family carer or friend. They combined all information on each admission in a "most plausible account", using a method developed for the study. They concluded that the patients seemed to have the best overview of the use of coercion. Patients were the agents with the strongest agreement with the "most plausible account" developed in this study, although a few "false positives" were also found (Lidz et al., 1997).

The studies of leverage and informal coercion have shown that leverage is frequently encountered by patients, but also accepted and deemed acceptable by a majority, and to a greater degree by those with personal experience of leverage (Hotzy & Jaeger, 2016). Actually, this might be expected as inducements and leverage leave one free to turn down the suggestion, and retain one's baseline situation, but might also depend on what is at stake, and the internal pressure to change or stay well (Canvin et al., 2013; Klag et al., 2006).

Summed up, *freedom restrictions* seem to be a suitable starting point in a model of experienced coercion. It captures a wide range of events that have been discussed in the literature, and reported by patients and staff.

#### 5.2.2 Freedom Restrictions are Appraised

Findings reported in all three papers indicate that freedom-restricting acts by mental health care workers are not automatically or directly followed by experienced coercion. Rather, freedom-restricting acts are appraised by the patients in their situation and context, and they may take a wide range of aspects into account.

In the fifteenth seminar on Coercion and Voluntariness, the participant Gerd related and contrasted mental health coercion to powers and coercion in general:

At work, we have a bit of being told what to do [by others]. We are wage slaves, aren't we? On many arenas, we have to be coerced to find our place. We can live with that, and it isn't necessarily that bad. But here [in the seminars], we have been talking about the abuse. (Paper 1, p. 149)

In other words, restrictions of freedom are a part of many arenas of life. Some of it is acceptable, and even necessary to keep the fabric of social life together. When Gerd says that the abuse has been the topic of the seminars, she draws a line between acceptable freedom restrictions and abuse. The participants were invited to talk about coercion, but in Gerd's view, they talked about the abuse. What she calls "coercion" is not necessarily abuse, but when coercion in mental health care is the topic, she observes that patient experience of abuse becomes the main theme. Other participants also stressed the need for nuances, such as when Gabriel needed "to separate between the use of physical force, which sometimes is necessary, from forcing chemicals and poison into people". This implies that some episodes with compulsion are not judged as coercive, and may be different following patient factors, circumstances, or context.

Data from Paper 2, Stage 3 and Paper 3 indicate that patients do some form of appraisal of coercive acts. Here, patients that are subjected to certain freedom restrictions, such as involuntary care or ongoing involuntary medication, nevertheless vary greatly in their reports of experienced coercion. More than a quarter of adolescents under compulsion reported low experienced coercion (Paper 3). For adults, more than half of patients under compulsion reported low experienced coercion. For patients under an additional medication order, the ECS scores are sensitive enough to indicate more experienced coercion in that only 30% in this group reported low experienced coercion (Paper 2). As implied by Gabriel: The appraisal of involuntary medication can be different for patients in seemingly similar situations, depending on the positive and negative effects of this treatment. Therefore, experienced coercion seems to reflect some aspects of the person and the situation other than the compulsion, indicating that the compulsion has been appraised.

Several other studies support the idea of some form of appraisal process before patients report experienced coercion. Compulsion is a strong predictor of experienced coercion, but its predictions are far from perfect. A meta-analysis found a combined raw prevalence rate for experienced coercion of 74% in involuntary inpatients (Newton-Howes & Stanley, 2012), implying that 26% of patients reported low experienced coercion. A Norwegian study reported that patients interviewed about coercion did not report an objective analysis of the episode, but their subjective emotions.

When patients report their experienced coercion, this is not a simple reflection of their lack of freedom (Svindseth et al., 2007), and this variable cannot be judged inter-subjectively or derived directly from the care formality, care order, or presence of a medication order.

A model of the relationship between the use of coercion and experienced coercion needs a separate "box" for the appraisal of the coercive event, and the content of this box will be elaborated below. What aspects of the situation and the person seem to influence or moderate the relationship between freedom restrictions and experience of coercion, and can fit as elements in the appraisal process? Several variables are interesting, and many of them can be grouped into three broad classes of variables that will be discussed below:

- Individual patient characteristics;
- · Characteristics of the care situation and context; and
- Relational variables.

### 5.2.3 The Role of Patient Characteristics in the Appraisal of Freedom Restrictions

Relevant patient characteristics can be broadly divided into clinical characteristics and several other individual characteristics, such as demography, individual biography, personality, values, and so forth.

Findings regarding patient variables and experienced coercion are ambiguous. Demographic variables such as sex and age have been non-significant in several studies (Iversen et al., 2002), including our findings in Paper 2. One exception was a large European multisite study that found significantly higher experienced coercion in women (Fiorillo et al., 2011). Ethnic minority populations may report more (Swartz et al., 2002) or less experienced coercion (Rain, Steadman, & Robbins, 2003), seemingly without a consistent pattern across studies (Newton-Howes & Mullen, 2011). Clinical patient variables, such as psychosocial functioning, symptoms, diagnosis, or former admissions have yielded mixed results, with absence of significant effects in several studies (Iversen et al., 2002; Katsakou et al., 2010; Poulsen, 1999), or small effects. Nevertheless, a better psychosocial functioning has been associated with lower experienced coercion in outpatients (Swartz et al., 2002) and inpatients (Kjellin et al., 2006), and among adolescents studied in Paper 3. Link et al. (2008) studied outpatients with and without CTOs, and found that a history of compulsion in the form of many previous involuntary admissions predicted higher experienced coercion, while being put under a CTO did not. Qualitative studies have shown that patients under CTOs compare their current situation to severe compulsion under previous involuntary admissions, and may find the CTO a better alternative (Riley et al., 2014). I am not aware of studies of the relationship between personal biography or personality and experienced coercion, other than the role of a history with coercive care.

What may be explanations for the small and conflicting findings? Surely the importance of different factors may vary between wards, districts, or countries, and therefore between studies. In addition, compulsion may be an important confounder of the relationship. In Paper 3, we discussed how patients with a diagnosis of eating disorders reported higher experienced coercion, but also that compulsion seemed to mediate this relationship. Patients with eating disorders were frequently under compulsion, and they reported more experienced coercion than other groups that were infrequently subjected to coercion. Current legal standards imply that compulsion should only be used when necessary, and in the least restrictive way (World Health Organization, 2009). This is also mirrored by acceptance of containment measures, but only to contain dangerous or severely disruptive behavior (Whittington et al., 2009). Some patient variables can contribute to such behavior, and thus to compulsion, which in turn predicts elevated experienced coercion. I expect that this is a common path of events leading to experienced coercion in mental health care.

The presumed connection between patient characteristics and compulsion means that the quality and comprehensiveness of measurements of compulsion and other treatment pressures can be important for the results. If we had not measured and controlled for compulsion in Paper 3, we may have ignored compulsion as a mediating variable, and wrongly concluded that eating disorders as such predicted experienced coercion. When a patient is under mental health care, the totality of informal pressure and different forms of compulsion will be influenced by patient characteristics. While it is feasible to measure and control for compulsion, it seems difficult to control for all restrictive aspects of the care situation, especially less noticeable events that may accumulate over time or influence the self-image, such as the minor coercive incidents elaborated in Paper 1. The influence of patient variables on the milder forms of treatment pressures is illustrated by the finding that lower psychosocial functioning was associated with more use of all kinds of leverage and coercion studied, such as economical, housing, reduced penalties, or treatment orders (Monahan et al., 2005). In another study, patients with lower psychosocial functioning, addiction problems, or a longer outpatient treatment order reported higher experienced coercion than other patients. However, after a stepwise variable exclusion process using logistic regression, where the final step was adding the number of warnings and reminders from case managers, these patient variables lost significance (Swartz et al., 2002).

Patient characteristics may nevertheless influence the way the patient evaluates freedom restrictions. For example, a high degree of suspiciousness may increase the likelihood of attributing bad intent to staff, and can possibly increase experienced coercion in an otherwise similar situation. When I thought more closely of the clinical variables, they could have complex effects on compulsion and experienced coercion. The diagnosis of schizophrenia can illustrate this: Some of the symptoms

may increase the likelihood for compulsion. Nevertheless, increased confusion and suspiciousness seen in some cases of this diagnosis may lead to higher experienced coercion, even in a care situation with a similar care arrangement. On the other hand, negative symptoms and feelings of guilt could influence evaluation through the moral standards applied by most patients, and may subtract from the experienced coercion. Also, the personal history, including previous experienced coercion, may be relevant. Patients with a long history of involuntary care may be used to involuntary care, and rate the experienced coercion of the current care situation lower, or may be sensitized, and rate it higher.

## 5.2.4 The Importance of Procedural Justice

I briefly presented research on procedural justice in section 1.2.7. Several of the early studies on experienced coercion focused on the admission process, where the decision of a voluntary or involuntary admission is pivotal. As noted, patients emphasized that persons involved in the admission process should be motivated by concern for the patient, and that they should behave honestly and openly (Bennett et al., 1993). Better procedural justice was a strong predictor of low experienced coercion (Lidz et al., 1995). This might be expected, given the findings of the importance of procedural justice from research on conflict resolution in the general population (Lind & Tyler, 1988), and from the view of coercion as concerning moral behavior (Nozick, 1969; Wertheimer, 1993). Even though procedural justice predicts experienced coercion, both variables are usually patient-reported and measured at the same time. During Stage 2, Paper 2, we saw that items on humiliation are closely connected to the patients' experience of coercion as measured by the CL. If patients include humiliation in their experienced coercion, there may be a conceptual overlap between experienced coercion and procedural justice. Feeling humiliated, is feeling "unjustly degraded, ridiculed or put down" (Hartling & Luchetta, 1999, p. 264), which would indicate that status recognition and respect that follows from high procedural justice did not take place or was not recognized by the patient. Patients who feel respected and that their opinions were seriously considered will not be expected to feel as humiliated, violated, powerless, and punished as other patients do, and there is therefore a relationship between procedural justice and the ECS, mediated by humiliation. The aforementioned study from Norwegian acute wards found that perceived humiliation was predicted both by use of force and police assistance, but also by patient-reported items on procedural justice, and whether the admission was seen as necessary. In the semistructured interviews, patients indicated that if care personnel listened and responded to them with rationality and explanations, they would experience less humiliation (Svindseth et al., 2007). When a German research team tried to build a scale of the experience in an episode of coercive measures, and factor-analyzed the candidate items, the main factor was humiliation (Bergk et al., 2010). Several qualitative studies have found humiliation and violations of integrity to be important aspects in

reported experienced coercion (Haglund, Von Knorring, & Von Essen, 2003; Meehan, Vermeer, & Windsor, 2000; Olofsson & Jacobsson, 2001; Riley et al., 2014), in line with our own findings in Paper 1. Further support for accepting humiliation as a part of experienced coercion is the finding that "patients did not clearly separate the meaning of the words coercion and humiliation" (Svindseth et al., 2007). In Paper 1, we found that patients emphasized humiliation, and in Paper 2, we found that several items of humiliation and related terms survived the different item-exclusion criteria that we applied.

These findings notwithstanding, the possible overlap in the concepts of procedural justice, humiliation, and experienced coercion should be considered more carefully. One methodological improvement could be to supplement or replace the current procedural justice subscale of the Admission Experience Scale with reports of acts conveying procedural justice reported by neutral observers or staff. It could then be possible to study to what degree different acts that should convey procedural justice will influence experienced coercion in patients. This reasoning also emphasizes procedural justice as staff actions. Such actions could be trained and measured, and may be easier to operationalize, compared to more abstract features, such as respect or a good ward culture.

## 5.2.5 Are Ward Variables Important?

Variables such as ward atmosphere may influence experienced coercion, but few studies measure both of these variables. An English study compared residential alternatives to acute wards, and found higher support and autonomy, and lower perceived coercion in the residential alternatives (Osborn et al., 2010). In this study, the residential alternatives had fewer patients under involuntary care, so the results may be confounded by compulsion. There seems to be a lack of studies comparing experienced coercion under similar levels of control and coercion, but under different ward atmospheres. Such studies might be difficult to conduct, as the levels of control and coercion are legally obliged to be dependent on the relevant patient characteristics. Some ward variables, such as order, organization, and staff control measured by the Ward Atmosphere Scale, are likely to covary with informal pressures and coercion. Patient-reported ward atmosphere, the extent of compulsion and informal pressures, and procedural justice may even be overlapping concepts, making the interpretation of results difficult, because there is a risk of circular conclusions.

Qualitative studies suggest that patients' appraisals of potentially coercive actions and measures are complex (Katsakou & Priebe, 2007). In Paper 1, data indicate that the participants evaluate compulsion against some form of proportionality standard, such as when Ragnar talks of "far too much force", Kirsten of a "totally incomprehensible admission", and Gabriel said that use of physical force "is sometimes necessary". A recent Norwegian study found proportionality to be a main theme

when patients discussed when compulsion could be justified (Norvoll & Pedersen, 2016b). Proportionality is a central aspect of the concept of fairness, and is a core concept in several juridical areas and in other domains of life. If proportionality is important in the appraisal of freedom restrictions, this will complicate the relationship between patient variables, compulsion, and experienced coercion, which was discussed in Paper 3: A crisis with severe deterioration of functioning is expected to lead to a more restrictive care regime. While these restrictions may contribute to higher experienced coercion, the severity of the crises may contribute to lower experienced coercion, because the intervention might be appraised as more proportionate than it would have been in a less severe crisis.

## 5.2.6 The Role of Supporting and Therapeutic Relationships

When discussing the coercion concept in section 1.1.5, I stressed that most of us, often happily and willingly, engage in relations that restrict our freedom, with work contracts and marriage as common examples. Partners in a trustful and supporting relationship often accept doing things that the other person wants. In mental health care, building a supporting and trustful relationship is considered essential (Gilburt, Rose, & Slade, 2008; Priebe, Richardson, Cooney, Adedeji, & McCabe, 2011; Topor, 2004, chapter 6). Some interview studies indicate that being respected, protected, and cared for may alleviate and sometimes remove the negative effects of coercion (Johansson & Lundman, 2002; Seed et al., 2016). Nevertheless, the concepts of a good relationship, procedural justice, and experienced coercion may overlap, at least under some definitions and operationalizations. For example, experiencing that one's feelings are respected may be an important part of both procedural justice and a good relationship, and several items in the ECS, such as feeling humiliated or treated as an object, might be incompatible with most descriptions of good relationships. It follows that when staff manage to establish or maintain a good and caring relationship when a patient is under coercion, the patient will tend to report low experienced coercion in the ECS. When we included items of humiliation in our operationalization of experienced coercion, it followed that an important and good relationship between staff and patient might attenuate the effect of compulsion on experienced coercion. Using the ECS may thus preclude the study of the effect of therapeutic relations on experienced coercion, because the ECS is tied to humiliation, which seems incompatible with a therapeutic relationship. On the other hand, informed by the discussions in this thesis, the ECS explicates the importance of humiliation in experienced coercion.

# 5.3 Experience of Rights Violations and of Coercion

In Paper 1, we briefly discuss the connection between affirmation from others, violation of rights, humiliation, and experienced coercion. In addition, violation of human rights and a wish for better protection of them are implicit themes, both in the use of "communism and Nazism" to describe

coercion in mental health care, and in discussing the inability to escape unwanted medication. Human rights and coercion are frequently mentioned in studies on the rise of the user movement (N. Crossley, 2004; Everett, 1994; Trangy, 2008). The lack of voice and the perceived lack of definitional or symbolic power discussed in Paper 1 can be expected to evoke attempts to redefine the central issues of coercion in mental health care. This fits well with the creation of an oppositional habitus found in the rise of the British user movement (M. L. Crossley & Crossley, 2001). When patients raise the issue of human rights, this enables a discussion that is somewhat or fully detached from concepts such as mental disorder, diagnosis, prognosis, and treatment, which would be core areas of staff expertise. In a study with repeated interviews, patients did not usually revise their ratings of experienced coercion, and the researchers suggested that "patients' aversion to commitment is a moral response to the loss of dignity and respect implicit in the deprival of autonomy" (Gardner et al., 1999, p. 1390). If this is a core experience of coercion, discussion of one's rights in this situation seems more obvious than discussing core medical topics such as prognosis or differential diagnosis. In the appraisal of a freedom-restricting act, violation of human rights may certainly be a parameter that the patient evaluates. This may even be reflected in some of the items that survived the itemselection process. The item "I feel violated" is likely to tap into a feeling of human rights violation.

Nevertheless, given the current state of evidence, I suggest that in a model of the relationship between freedom restrictions and experienced coercion in mental health care, rights violations will be relevant both to patients' evaluation of procedural justice and proportionality.

# 5.4 The appraisal model of experienced coercion

Experienced coercion, an individual negative emotionally charged state, is the end-point in the model. During this project and this thesis, I have developed an understanding, working definition and operationalization (the ECS in paper 2) of experienced coercion in mental health care.

# Use and experience of coercion in mental health care

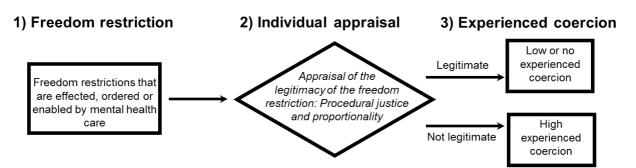


Figure 6. The Appraisal Model of the Use and the Experience of Coercion in Mental Health Care

In the appraisal model of experienced coercion, the first focused element is *freedom restrictions that* are effected, ordered, or enabled by mental health care. The next element is the appraisal process. According to the appraisal models for emotions, this process will often be automatic and implicit. The qualitative studies show that many patients are able to speak of the appraisal later, and that they have evaluated the freedom restrictions according to some sort of standard, such as a proportionality-standard.

Current research indicates that a number of variables are taken into account in this process, including the relationship (Seed et al., 2016), humiliation (Svindseth et al., 2007; Paper 1; Paper 2), decision-makers' intent (Bennett et al., 1993), the degree of freedom restrictions as seen ion Paper 2, and lack of coping in the patient (Norvoll & Pedersen, 2016b). To make the model simple, I suggest grouping these variables under the subheadings of *proportionality* and *procedural justice*.

Proportionality is related to the freedom restriction and the need for action in the situation: What is done in what kind of situation? Being committed in a profound crisis, or being sedated to stop a patient from fighting in the ward, may be considered acceptable proportionality by many patients. Being committed after a patient has asked for admission a week previously, or put in belts after non-violent protest against a staff member, might be seen as disproportionate.

Procedural justice is related to the steps taken in the pathway towards the decision to use coercion, and what qualities these steps have. Decision-makers' intent, and having one's say, and possibly lack of humiliation, can be grouped as elements of procedural justice.

Proportionality and procedural justice have a parallel in the analytical separation between substantive law and procedural law (Procedural law, 2017). If most of the different aspects involved in the appraisal process can be subsumed under proportionality and procedural justice, then a possible common denominator for these two headlines is the experienced *legitimacy* of the freedom restrictions. Patient-evaluated *legitimacy* summarizes several of the findings of the relationship between freedom restrictions and experienced coercion reviewed and studied in this thesis. If the patient's implicit standards of proportionality and procedural justice are satisfied, the freedom restriction is legitimate, and experienced coercion is reduced or absent, as depicted in **Figure 6**. When the freedom restriction fails to meet these implicit standards, then experienced coercion is present or increased. The interaction between proportionality and procedural justice needs further research. Will they add or subtract from each other, or perhaps the experienced violation of both aspects is necessary for high experienced coercion? Also, what factors may lay behind individual differences in the appraisal process?

In many ways, the appraisal model is straightforward. It follows roughly from recognizing the analogy between an emotion-eliciting stimulus and the corresponding emotion on the one hand, and the use of coercion and experienced coercion on the other. After framing experienced coercion in an appraisal model, the different factors that moderate the intensity of experienced coercion needed to be integrated and summarized. The model thereby simplifies some aspects of the complexity involved, directs our attention towards some aspects, and pays less attention to others. The parallel between the main aspects of the appraisal process and the general legal concepts of substantive and procedural law suggests that the appraisal model of freedom restrictions may apply beyond mental health care, with smaller or greater modifications.

### 5.4.1 Individual Differences in the Appraisal Model of Experienced Coercion

The appraisal model for experienced coercion has room for individual and group differences in the settings and workings of the appraisal. If the patient applies implicit standards in the appraisal, these standards may be influenced by the personal biography, personality, vulnerability, values, and cultural, religious, and other variables. For example, in a more paternalistic culture, a certain directive from a male doctor may be acceptable to most patients, while they may be appraised as a coercive directive in a strongly egalitarian culture.

The study of differences in experienced coercion should take factual differences in care into account. A striking difference between experienced coercion among adult patients in Paper 2 and adolescent patients in Paper 3 was the low experienced coercion in adolescents with psychosis. I can see several interesting hypotheses for this difference, such as a cohort effect, different care practice, etc., many of which could not be evaluated in our design. However, the most straightforward hypothesis, from looking at the model, is that different levels of experienced coercion are a result of different levels of freedom restriction. This hypothesis has some support in our data: In the adolescent sample in Paper 3 almost all patients with psychosis were treated voluntarily. This was clearly not the case in the sample of adult patients.

In addition to a possible explanation of why several committed patients nevertheless report low experienced coercion, I can see at least two other interesting contributions of the model:

- Understanding the strong connection between humiliation and experienced coercion; and
- Bridging experienced coercion in mental health care with experiences of freedom restrictions in other spheres of life.

# 5.4.2 Acceptable Restrictions – a Link between Experienced Coercion and Humiliation

In the early phase of this work I was surprised by the strength of procedural justice as a predictor of experienced coercion: Are we really more accepting of commitment if we are invited to express our opinion? Thinking more carefully about the issue, there is a strong parallel to how freedom restrictions are considered in other life areas. Even though I do not enjoy doing tax declarations, paying the train ticket, or obeying a traffic regulation I find unnecessary, I would not call any of these regulations coercion, nor report high levels of experienced coercion of such events if I was given a questionnaire, even if there is a coercive threat of prison or monetary fines. However, if a stranger without a uniform came to my home and threatened with taking money if I did not tell him or her my income and assets, I would feel coerced. Why do I accept it from the government? I accept it for similar reasons that make a sizeable proportion of mental health care patients accept involuntary care: Procedural justice and proportionality. It is decided in the way that I have been socialized to accept: By government and parliament, elected by the people, and codified in laws, with legal and justified enforcements. It is also proportional – it applies equally for all, and is a reasonable measure to share the burden of financing common welfare services. In line with Gerd's reasoning: There are lots of freedom restrictions with an underlying coercive threat, and they are often acceptable. The model indicates that patients in mental health care evaluate freedom restrictions in mental health care according to similar or parallel standards that apply in other life areas – proportionality and procedural justice. Honneth's (1997) view of moral injury, discussed in Paper 1, links patients' unpredicted lack of affirmation from others during admission and treatment to lack of procedural justice, and simultaneously to humiliation. If I was forced or threatened to submit under freedom restrictions that did not pass my deep-felt standards of procedural justice and proportionality, I think I would feel "unjustly degraded ... or put down". If I was ascribed a stigmatized status during the process, I might easily feel ridiculed, and that my "identity had been demeaned or devalued" essentially feeling humiliated (Hartling & Luchetta, 1999). But if my implicit standards of procedural justice and proportionality were satisfied, the conditions for feeling humiliated would not be met, hence explaining why experienced coercion and humiliation are closely related.

# 5.4.3 The Bimodality of the MPCS and the CL revisited

This explanation may shed light on why scores on the Coercion Ladder and the MPCS are often bimodally distributed – with most persons scoring very low or very high experienced coercion, and fewer in the middle values (Gardner et al., 1993; Høyer et al., 2002). Høyer et al. (2002) suggested that perceived coercion resembles violations of integrity – which are usually absent or present. Violation of integrity is closely connected to humiliation. The feeling of humiliation is also a strong

motivating force, and influences the self-image and the whole person (Hartling & Luchetta, 1999). Therefore, the presence or absence of humiliating aspects in a coercive episode may direct the evaluation strongly towards the upper or lower part or the scale. Fortunately, these results from existing research could be taken into account when we developed the ECS. We therefore deliberately used items of humiliation, and the strong patient descriptions from Paper 1 and studies with similar results to coin items that we thought could have the potential to distinguish between different degrees of experienced coercion.

#### 5.4.4 Patient Characteristics Revisited

The model of the use and experience of coercion is also helpful in sorting out the role of patient characteristics in the use and experience of coercion. For example, it helped me to ask better questions regarding the potential role of psychosocial functioning, discussed in Paper 3. How will low psychosocial functioning influence the freedom restrictions? Looking at Figure 6, it seems likely that lower psychosocial functioning will influence the leftmost square – contributing to a more restrictive care arrangement, which in turn will contribute to higher experienced coercion. How will it influence the appraisal? All else being equal, proportionality will be better if the patient's functioning is severely compromised, and thus contribute to lower experienced coercion. However, it is also possible that it will influence the patient's ability to recognize and appreciate the level of procedural justice and proportionality that took place, and therefore increase experienced coercion. Following this reasoning, the model helps predict or explain that psychosocial functioning has a mixed relationship with experienced coercion, which corresponds to the empirical findings discussed in section 5.2.3. However, I note that the findings do not indicate that an apparently more acceptable proportionality incites patients with lower psychosocial functioning to report lower experienced coercion. One possibility is that it is common to meet lower psychosocial functioning with stronger care restrictions than the patient usually finds proportionate. The model illustrates the need to account for compulsion and other freedom restrictions before drawing conclusions regarding the role of predictors such as diagnosis, psychosocial functioning, and staff values.

## 5.4.5 A Few Implications for Reducing Experienced Coercion

Humiliation is a gravely negative experience, with profound negative consequences for the individual (Hartling & Luchetta, 1999). The close connection between experienced coercion and humiliation indicates that it is important to reduce experienced coercion in order to avoid humiliation of patients. The appraisal model of the relationship between the use and the experience of coercion illustrates two major strategies to reduce experienced coercion in patients: 1) Use freedom restrictions more sparingly, and 2) contribute to increase the legitimacy of the freedom restrictions used.

The first strategy is an aim in its own right, following the ideal and requirement of using the least restrictive care regimen possible. At several sites and in different countries, compulsion in the form of seclusion and restraints have been strongly reduced (LeBel et al., 2014; Putkonen et al., 2013). Evidence of programs for reduction in compulsion in the form of reduced frequency or duration of involuntary legal status is far less compelling, if not absent, even though there are reported substantial service variations in involuntary care between jurisdictions (Salize & Dressing, 2004), and rates can also vary strongly within jurisdictions for adults (Keown et al., 2016; Norges offentlige utredninger, 2011) and adolescents (Kaltiala-Heino, 2004).

The second strategy is to attempt to increase the legitimacy of the freedom restrictions. It should be feasible to train and motivate staff in acts and practices that promote procedural justice, and study the effect of such programs. It could also be possible to develop methods for discussing proportionality and procedural justice with patients, in order to improve staff awareness and knowledge of the consequences of the freedom restrictions they use.

The two main strategies will not be fully independent: If staff become more aware and more explicit regarding discussions of proportionality and procedural justice, then this may influence the decisions of compulsion through a better understanding of the downsides of experienced coercion. In addition, reduced experienced coercion may contribute to better alliance and more individualized care, possibly reducing the need for compulsion in the future.

# 6 Conclusion and Implications

The thesis shows that patient experience of coercion in mental health care is complex. When coercion is experienced negatively, some patients express this as a deeply personal and strongly negative experience. At its worst, it is likened to humiliation, war, torture, or totalitarian government systems. According to the descriptions from the participants in Paper 1, an experienced lack of a clear positive response to antipsychotic medication is an important reason for using these descriptions, and they will not be used by all patients experiencing coercion. When involuntary or strong pressure for antipsychotic medication is continued in spite of experienced non-response or negative effects, this adds to the negative sentiments towards mental health care.

We established the Experienced Coercion Scale (ECS), a questionnaire that is sensitive for compulsion, have high correlations with the CL, and has good psychometric properties, including a distribution in coercive care settings that approaches the normal distribution. The scale can be applied in a variety of care settings. Among adult patients, the subgroup with the highest experienced coercion was patients with a medication order. The first two papers thus point to involuntary medication as the most important theme in negative patient experiences of coercion in adults in Norway.

Adult acute ward patients and adolescent inpatients show important similarities in experienced coercion. The level of experienced coercion in adolescent inpatient care was similar to comparable results for adult inpatient care, on both the CL and the ECS. As for adults, compulsion is the strongest predictor of experienced coercion. This means that coercion in adolescent mental health care should receive similar attention as in research and policies for adult mental health care. Adolescent patients with eating disorders were the group most frequently subjected to compulsion, and they were the adolescent subgroup with the highest level of experienced coercion. We found that Norwegian adolescent wards treated psychosis with little formal coercion, and these patients reported low experienced coercion. The reason for this finding is not clear, and reasons may depend on differences in the wards' meeting and handling of adolescent psychotic patients, compared to the adult patients, differences in the symptoms or disorder situation, or that a first episode of psychosis lends itself more to a less restrictive care regimen or a strong focus on procedural justice from staff.

The findings of this study, combined with existing research on experienced coercion, enabled me to suggest a model of the relationship between compulsion and experienced coercion. I built the model on the appraisal model of emotions, and found that the appraisal model of experienced coercion was useful in sorting relevant variables in different classes, understanding the close connection between experienced coercion and humiliation, and suggesting proportionality and procedural justice as the

main themes or implicit standards that patients use when appraising the freedom restrictions they have experienced. This links experienced coercion in mental health patients to common themes in evaluating violations and freedom restrictions in other areas and groups.

This thesis has some implications for practice and research. According to the model, high experienced coercion can be seen as an indication that staff have not been successful in creating a care regimen that the patient experiences as proportional or with acceptable procedural justice. The potential negative consequences of coercion in mental health care can be severe, as seen in Paper 1. This study does not show whether the proportionality of care measures, or the procedural justice from staff can be improved, or that such improvements decrease experienced coercion. Intervention studies aimed at variables such as procedural justice are therefore important, but these studies should carefully reconsider the current conceptualization and measurement of procedural justice.

Paper 3 confirms that mental health care professionals have difficulties in establishing dialogue and alliance with adolescents with eating disorders. The thesis thus supports the call for directing resources towards further development of treatment and care for this group of patients.

The most surprising finding in this study is the low experienced coercion in adolescent patients with psychosis. An intriguing possibility is that Norwegian adolescent wards have developed a care practice that is capable of handling a majority of persons with psychosis with neither coercion nor experienced coercion. I would strongly like to see studies able to dismiss or confirm this finding. If confirmed, it would be interesting to study the possible explanations of how this is achieved. An interesting possibility is that care practices relevant for improvements in adult wards could be found and tried out.

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# **Appendix I**

# **Documentation of Approval**

- 1. Approval from South and East Regional Committee for Medical and Health Research Ethics, Norway
- Approval of amendment from South and East Regional Committee for Medical and Health Research Ethics, Norway
- 3. Approval of amendment from South and East Regional Committee for Medical and Health Research Ethics, Norway
- 4. Approval of project from the Privacy Ombudsman, Akershus University Hospital



 Region:
 Saksbehandler:
 Telefon:
 Vår dato:
 Vår referanse:

 REK sør-øst
 Øyvind Grønlie Olsen
 22845522
 30.01.2012
 2011/2574/REK sør-øst D

 Deres dato:
 Deres referanse:

 13.12.2011

Vår referanse må oppgis ved alle henvendelser

Aina Holmén Sykehusveien 25 1478 Lørenskog

#### 2011/2574 D Spørreverktøy for opplevd tvang i psykisk helsetjeneste

Vi viser til søknad av 13.12.2011 for det ovenfor nevnte forskningsprosjekt. Søknaden ble behandlet i komiteens møte 12.01.2012.

Prosjektleder: Aina Holmén

Forskningsansvarlig: Akershus universitetssykehus

### Prosjekttema

I dag finnes det ikke noe godt og enkelt måleverktøy for opplevd tvang som kan brukes i ulike behandlingssituasjoner og under gjennomføring av psykisk helsevern. Et slikt mål er viktig for å få vite mer om tvang i psykisk helsevern, og for å nå offentlige mål om reduksjon av tvang, herunder redusert opplevd tvang.

Helsedirektoratet har finansiert utvikling av et slikt verktøy i form av et spørreskjema om opplevd tvang. Utkast til et slikt skjema er utarbeidet ved Ahus med grunnlag i faglitteratur, eksisterende pasienttilfredshetsmålinger, samt kunnskap om erfaringer med tvungent psykisk helsevern i Norge.

Spørreskjemaet forsøker å operasjonalisere flere aspekter av opplevd tvang. Det skal prøves ut hos pasienter og brukere i ulike tjenestetyper i psykisk helsevern og kommunehelsetjeneste i to runder. Dette for å sikre kunnskap om hva spørreskjemaet måler.

### Vurdering

Hensikten med prosjektet er å utvikle og prøve ut et spørreskjema som omhandler pasienters egenopplevelse om bruk av tvang i psykisk helsevern.

Det skal inkluderes 600 inneliggende pasienter i psykisk helsevern, tvungne dagpasienter og pasienter med omfattende oppfølging. Svarene fra 400 pasienter blir brukt til å vurdere faktorstrukturen i de 100 spørsmålene i det første utkastet, svarene til de andre 200 blir brukt i en evaluering av det endelige skjemaet.

Det er for komiteen noe uklart hva forskergruppen har til hensikt å undersøke. Slik det er presentert oppfattes hensikten både å være å måle omfanget av opplevd tvang og hvordan pasienter responderer i form av svar i forbindelse med en utprøving av spørreskjema.

Til den første problemstillingen, *omfanget av opplevelsen av å bli utsatt for tvang*, kan ikke komiteen se at det er beskrevet hva en skal måle pasientenes egen oppfatning opp mot. Slik dette er beskrevet skal det ikke innhentes opplysninger om bruk av tvang enn det som fremkommer av selve spørreskjemaet. Komiteen deler søkers syn på viktigheten av å bli klar over eller bevisst den aktuelle pasientgruppens subjektive

Besøksadresse: Gullhaug torg 4 A, Nydalen, 0484 Oslo Telefon: 22845511

E-post:

Web:

post@helseforskning.etikkom.no

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff oppfatninger om bruken av tvang. Det stilles allikevel spørsmålstegn til behovet for å innhente opplysninger fra en så stor gruppe for å belyse dette.

Til den andre, hvordan pasienter responderer ved svar på spørreskjema om opplevd tvang, forstår komiteen det slik at samtlige pasienter som inkluderes allerede er underlagt administrativ tvang. Søker burde i større grad ha gjort noen refleksjoner rundt hvordan pasientenes situasjon kan påvirke deres vurdering av spørreskjemaet. Etter komiteens syn er det at pasienten blir bedt om å vurdere spørreskjemaet en utfordring i forhold til om utprøvingen er reell.

Selve prosedyren for å innhente samtykke beskrives slik av søker; "Pasienter som fyller inklusjonskriteriene informeres kort om undersøkelsen, og får utdelt informasjonsskriv. De gis tilbud om minst en dags betenkningstid. Samme pasient skal ikke spørres flere ganger, og de blir informert om adgang til å trekke samtykket."

Av informasjonsskrivet fremkommer det ikke at dette er en forespørsel om å delta i et forskningsprosjekt. Komiteen er av den oppfatning at informasjonsskrivet må inneholde informasjon om dette. I tillegg må det gis informasjon om bakgrunnen til at pasienten er kontaktet med spørsmål om deltakelse i forskningsprosjektet.

Spørreskjemaet er utviklet av Akershus universitetssykehus. Komiteen registrerer at skjemaet er ikke ferdig utviklet og at det forelagte utkastet inneholder språklige feil. Det forutsettes at skjemaet gjennomarbeides før det tas i bruk i prosjektet.

Søker beskriver opprettelsen av et "samleskjema". Dette skal blant annet inneholde opplysninger om faglig ansvarlig sin vurdering av den enkelte pasients samtykkekompetanse og informasjon om pasientenes reaksjon etter at de har fylt ut skjemaet. Prosjektdeltakerne blir ikke informert om at de selv skal vurderes i etterkant. Heller ikke at behandlende institusjon skal gi fra seg journalopplysninger om pasientene. Det kan synes som om det ikke er samsvar mellom det som fremkommer av søknaden med protokoll og hva som står i informasjonsskrivet. Av de innsendte dokumentene fremkommer det at flere enn de fagpersoner som følger opp den daglige behandlingen av den enkelte pasient skal ha tilgang på opplysningene i samleskjemaet. Personalet ved de ulike avdelingene har etter komiteens syn ikke behov for å vite hvem som deltar i spørreundersøkelsen. Pasientene som deltar kan være en del av forskernes egne pasientgrupper og det kan det ikke utelukkes at noen i forskergruppen vil få kjennskap til hva enkelte pasienter har svart.

Komiteen kan ikke se at det foreligger noen redegjørelse for etablering av samleskjemaet og behovet for at en utvidet krets personer skal ha tilgang til opplysningene. Komiteen er av den oppfatning at søker ikke har begrunnet nødvendigheten av eller belyst samleskjemaets funksjon på en slik måte at dette kan godkjennes og inngå som en del av prosjektet. Det forutsettes at den delen som omfatter samleskjemaet tas ut.

### **Oppsummering**

Komiteen mener at undersøkelsen som skal gjøres i dette prosjektet ikke er avhengig av innsamling av opplysninger som enten er direkte eller indirekte personidentifiserbare og kan gjøres på anonyme data. Det er ikke noe i prosjektopplegget som gjør det nødvendig å innhente identifiserbare helseopplysninger. Det forutsettes at forespørsel om utfylling av spørreskjema og bistand til uttrekk av anonyme opplysninger fra pasientjournalen kan gjøres uten at noen i forskergruppen får kjennskap til pasientenes identitet. På denne måten unngår en utfordringene som nevnt ovenfor i forbindelse med behandling av sensitive opplysninger. Komiteen mener også at dette i større grad sikrer at deltakelsen blir reelt frivillig. Komiteen antar også at et opplegg med en anonym spørreundersøkelse vil kunne føre til at en får tilgang på mer komplette data.

Helseforskningsloven § 20 oppstiller et krav om at forskningsdeltakere på forhånd skal samtykke til bruk av anonyme opplysninger. Søker beskriver i søknaden en prosedyre for å innhente samtykke. Etter komiteens syn tilfredsstiller denne de krav helseforskningsloven stiller til innhenting av samtykke forut for avlevering av anonyme opplysninger til forskning.

#### Vedtak

Med hjemmel i helseforskningsloven § 20, jf. samme lovs kapittel 4, godkjenner komiteen prosedyren for

innsamling av anonyme data.

Selve gjennomføringen av forskningsprosjektet er basert på anonyme opplysninger og kan gjennomføres uten krav om forhåndsgodkjenning.

Med vennlig hilsen,

Stein A. Evensen (sign.) dr. med. leder

Ingrid Middelthon Komitésekretær

Øyvind Grønlie Olsen Saksbehandler

Kopi til: <u>postmottak@ahus.no</u>

# Approval of amendment from South and East Regional Committee for Medical and Health Research Ethics, Norway



 Region:
 Saksbehandler:
 Telefon:
 Vår dato:
 Vår referanse:

 REK sør-øst
 Emil Lahlum
 22845523
 17.09.2012
 2011/2574/REK sør-øst D

Deres dato: Deres referanse:

21.08.2012

Vår referanse må oppgis ved alle henvendelser

Til Aina Holmén

### 2011/2574 Spørreverktøy for opplevd tvang i psykisk helsetjeneste - Holmen

Forskningsansvarlig: Akershus universitetssykehus

Prosjektleder: Aina Holmén

Vi viser til søknad om prosjektendring datert 21.08.2012 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK sør-øst på fullmakt, med hjemmel i helseforskningsloven § 11.

#### Endringene innebærer:

Det søkes om å benytte Flax-lodd i andre runde av datainnsamlingen. De som deltar vil da motta 2 Flax-Lodd, til en samlet verdi av 1000 kroner.

#### Vurdering

REK har vurdert endringssøknaden og har ingen forskningsetiske innvendinger mot endringen av prosjektet.

### Vedtak

REK godkjenner prosjektet slik det nå foreligger, jfr. helseforskningsloven § 11, annet ledd.

Tillatelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknad, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

REKs 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 sør-øst. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Vi ber om at alle henvendelser sendes inn via vår saksportal: <a href="http://helseforskning.etikkom.no">http://helseforskning.etikkom.no</a> eller på e-post til: <a href="mailto:post@helseforskning.etikkom.no">post@helseforskning.etikkom.no</a>.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Stein A. Evensen Professor dr. med. leder

> Emil Lahlum Førstekonsulent

# Approval of amendment from South and East Regional Committee for Medical and Health Research Ethics, Norway



Region: REK sør-øst Saksbehandler: Gjøril Bergva Telefon: 22845529

Vår dato: 25.04.2014 Vår referanse: 2011/2574/REK sør-øst

D

Deres dato: 19.03.2014

s dato: Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Torleif Ruud

Avdeling forskning og utvikling, Divisjon psykisk helsevern 1478 Lørenskog

### 2011/2574 Spørreverktøy for opplevd tvang i psykisk helsetjeneste - Holmen

Forskningsansvarlig: Akershus universitetssykehus

Prosjektleder: Torleif Ruud

Vi viser til søknad om prosjektendring datert 19.03.2014 for ovennevnte forskningsprosjekt. Søknaden er behandlet på komiteens møte 02.04.2014.

#### **Endringen omfatter:**

- Det søkes om utvidelse av prosjektet ved at ferdig utviklet spørreskjema for voksne nå skal utprøves i en versjon tilpasset ungdom. I den forbindelse skal det inkluderes ungdom i alderen 13 - 17 år som er til behandling i ungdomspsykiatriske tjenester.

### Rekrutteringsprosedyren er beskrevet slik:

1) Informasjon om formål og gjennomføring av prosjektet til enkeltpasienter eller gruppe av pasienter. Skriftlig informasjonsskriv (vedlagt) blir delt ut til de som godtar det.

2a) Pasientens kontaktperson forespør om deltagelse. Kontaktpersonen går gjennom vedlagte informasjonsskriv. Dersom pasienten nøler eller er negativ, tilbys det betenkningstid til neste dag. Dersom pasienten godtar betenkningstid, spørres det igjen om deltagelse neste dag. Det skal ikke spørres mer enn disse 2 gangene.

Søker ber om REKs vurdering av om framgangsmåten også kan benyttes overfor ungdom i alderen 13 - 15 år, det vil si uten samtykke fra foreldrene.

- I tillegg informeres det om ny kontaktperson ved forskningsansvarlig institusjon, Trond Ragnes, og ny prosjektmedarbeider, Aina Holmén.

#### **Vurdering**

Helseforskningsloven § 20 oppstiller et krav om at forskningsdeltakere på forhånd skal samtykke til bruk av anonyme opplysninger. Etter komiteens syn tilfredsstiller søkers prosedyre de krav helseforskningsloven stiller til innhenting av samtykke forut for avlevering av anonyme opplysninger til forskning, men det må innhentes samtykke fra foreldre eller andre med foreldreansvar dersom deltakerne er under 16 år, jamfør helseforskningsloven § 17.

Henvisningen til pasient- og brukerrettighetsloven § 4-4 i helseforskningsloven § 17 fjerde ledd første punktum, innebærer at selv om foreldrene e.l. har samtykkeretten, vil barnet etter hvert som det utvikles og modnes, få medbestemmelsesrett og såkalt «nektelseskompetanse». Dersom barnet er fylt 12 år, skal det få si sin mening i alle spørsmål som angår egen helse. Det skal legges økende vekt på hva barnet mener ut fra

alder og modenhet. I praksis har REK krevd at barn over 12 år informeres og spørres. Dette innebærer at barn mellom 12 og 16 år i realiteten kan nekte å delta i forskning, men kan ikke tolkes slik at de alene kan avgi samtykke til medisinsk og helsefaglig forskning.

### Vedtak

Med hjemmel i helseforskningsloven § 20, jf. samme lovs kapittel 4, godkjenner komiteen søknad om endring i prosedyre for innsamling av anonyme data. Det må innhentes samtykke fra foreldre eller andre med foreldreansvar for deltakerne som er under 16 år, jamfør helseforskningsloven § 17.

### Klageadgang

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

Med vennlig hilsen

Finn Wisløff Professor em. dr. med. Leder

> Gjøril Bergva Rådgiver

### Kopi til:

Akershus universitetssykehus HF ved øverste administrative ledelse: postmottak@ahus.no aina@ahus.no

Obligatorisk meldeskjema, versjon 1.0 12-041



### Meldeskjema for interngodkjenning av forsknings- og kvalitetsprosjekter

### Utfylt skjema med vedlegg sendes til: (R) Fellesmail Personvernombud

Meldeskjemaet skal utfylles for

- 1) Medisinsk og Helsefaglig forskning, og
- 2) Kvalitetsstudier og annen forskning enn medisinsk og helsefaglig forskning, eller
- Nyalitetsstudier og annen forskning en meddelste og all
   Intern kvalitetssikring
   som omfatter mennesker og humant biologisk materiale.
   Omfatter også pilotstudier og utprøvende behandling.

Råd og veiledning:

Personvernombud: <u>marianne.blair.berg@ahus.no</u> Biobankkoordinator: <u>Randi.Otterstad@ahus.no</u>

Datafangst: datafangst@ahus.no

Mer informasjon: internettsiden til Ahus (Gå til www.ahus.no > Forskning og utvikling > Rutiner for forskning).

1 INFORMASJON OM PROSJEKTANSVARLIG	OG PROSJEKTLEDER (SØKEREN)					
A. PROSJEKTANSVARLIG (div. direktør / klinikksjet	f)					
Navn og stilling:	Divisjon/klinikk (nivå 2):					
Trond Ragnes, divisjonsdirektør	Divisjon Psykisk helsevern					
B. PROSJEKTLEDER <sup>1</sup>						
Navn og stilling:	Klinikk/avdeling (nivå 3) hvor prosjektet gjennomføres:					
Aina Holmèn, forsker	Psykisk helsevern FOU-avdeling					
Telefonnummer:	E-postadresse:					
9866 4501	aina.holmen@ahus.no					
C. MULTISENTERSTUDIE						
Er prosjektet en multisenterstudie?	☐ Ja        Nei					
	en multisenterstudie, men det skal samles inn data fra tre s; Nordlandssykehuset, Møre og Romsdal HF, og Haukeland					
Skal noen av disse også ha kopi av elektronisk database/informa	sjon som etableres i prosjektet?					
D. ANNEN DATABEHANDLINGSANSVARLIG ENN	AKERSHUS UNIVERSITETSSYKEHUS HF <sup>2</sup>					
Er prosjektet organisert fra et legemiddelfirma eller annen ekstern virksomhet?						
Dersom ja, angi virksomhetens navn (Kopi av konsesjonen/godkj personvernombudet som meldepliktig prosjekt, dvs skjemaet fylle	enning skal sendes personvernombudet, og prosjektet skal meldes til s ut).					
Skal den eksterne også ha kodelisten/navnelisten over deltakere?						
2 PROSJEKTETS NAVN/TITTEL						
Spørreverktøy for opplevd tvang i psykisk helsetjeneste						
3 PROSJEKTPERIODE						

Utskriftstidspunkt: 30.05.12 14:10 Side av 8

# Obligatorisk meldeskjema, versjon 1.0 12-041



Studiestart (dd.mm.åååå): 01.03.2012	Studieslutt (dd.mm.âââå)³: 30.06.2013	Sletting/anonymisering av data legg til tid mht etterprøving (dd.mm.åååå): Beskriv hvordan data vil bli slettet/anonymisert:
		runde av datainnsamling: Innsamlede data vil være anonyme.  Informasjon fra svarskjemaene legges inn i datafil på forskningsserver, svarskjemaene oppbevares nedlåst til 2 måneder etter datainnsamlingen er ferdig, og makuleres deretter.
		2. runde av datainnsamling: Under innsamlingen oppbevares en nedlåst kodenøkkel ved tjenestestedene der datainnsamlingen foregår. Data er avidentifisert. Når datainnsamlingen avsluttes på det enkelte tjenestested og før de overleveres til prosjektet anonymiseres data gjennom makulering av kodelisten ved det enkelte innsamlingssted. Overføring av informasjon fra svarskjema til datafil og makulering av spørreskjema foregår etter samme prosedyerer som i 1. runde av datainnsamlingen.  Prosjektleder er selv ansvarlig for gjennomføring av sletting/anonymisering



4	FINANSIERING AV PROSJEKTET		
☐ Ne	ei 🛮 Ja Hvis ja – hvor (NFR, HSØ, interne midler etc): Prosjektet er	et fullfinansiert opp	odrag fra Helsedirektoratet
Prosje	ektnr/kostnadsted: 2707010		
5	BESKRIV FORMÅLET MED BEHANDLINGEN/PROSJEKTET (Idforskning) <sup>4</sup>	ovpålagt – varierer fo	or kvalitet og helsefaglig
Form	nålet er utviklin av et måleverktøy for å måle opplevd tvang i psykis	k helsevern til sene	re bruk i Norge.
6	AVKLARING FOR KONSESJON ELLER MELDING <sup>5</sup>		
a) Ko	Ja, det benyttes kobling mot forskriftsregulerte registre, som for eksempel fø interne konsesjonsbelagte registre. Hvis ja, angi hvilke registre:	dselsregister, kreftregist	er eller dødsårsaksregister, eller
b) Sto	ore datasett Angi totalt antall inkluderte: 600 fordelt på to runder av datainnsamlin	a	
	☐ Ja, studien inkluderer et stort omfang av personer og/eller data - dvs mer en		nger av svært inngripende karakter.
c) Vai	righet		3 1
	Angi antall år opplysningene vil bli lagret, inkludert oppbevaring for etterprøving datainnsamlingen er avsluttet ved det enkelte tjenestested. Data eventuell etterprøving i minst 5 år.		
7	RETTSLIG GRUNNLAG FOR BEHANDLING AV PERSONOPPL	YSNINGENE 7	
7.1	Samtykke		
	Skal det innhentes skriftlig samtykke fra den registrerte?	⊠ Ja	☐ Nei
	Skal det innhentes skriftlig samtykke fra andre enn den registrerte?	□ Ja	⊠ Nei
	Skal det søkes om unntak fra taushetsplikten?	☐ Ja	⊠ Nei
ELLE	:R		
7.2	Intern kvalitetssikring av pasientbehandling. <sup>8</sup>		
	☐ Ja, prosjektet oppfyller helsepersonelloven § 26. Opplysningene må være slett Må publiseres som kvalitetssikring, ikke som forskning. Det kreves ikke samtykke unntak for konsesjon, men krever melding. Det er ikke krav til samtykke, men pas skal respekteres.	(ref. punkt 5.1). Persono	opplysningsloven § 33 4. ledd gir
ELLE	R		
7.3	Annet som hjemler melding, angi årsak/hjemmel:		
7.4	Andre tillatelser		
	☑ Søknadsplik til de regionale komiteer for medisinsk og helsefaglig forskning første runde med datainnsamling. Etter samråd med personvernombudet meld for andre runde av datainnsamling. Begge runder er beskrevet i aktuelle poster	ler vi begge runder i dett	
	Søknadsplikt til Statend legemiddelverk		
	☐ Bioteknologiloven kommer til anvendelse (det uføres genetiske undersøkels	ser hvor deltageren gis t	ilbakemelding om resultatet) <sup>10</sup>

Utskriftstidspunkt: 30.05.12 14:10

☐ Øvrig (se pkt 11)



8 BRUK AV HUMANT BIOLOGISK MATERIALE						
BIOBANK						
Medfører prosjektet bruk av humant, biologisk materiale? ☐ Ja ☑ Nei						
Dersom ja:						
Benyttes en allerede eksisterende biobank?	☐ Ja	⊠ Nei				
Hvis ja, angi:  ☐ tematisk forskningsbiobank (basert på bredt samtykke)*  ☐ spesifikk forskningsbiobank (basert på samtykke til et spesifikt prosjekt)  ☐ generell biobank (legemiddelselskap som ansvarshavende)  ☐ diagnostisk biobank  ☐ behandlingsbiobank						
Navn på biobank:						
Biobankregisternr.:						
* Om prosjektet skal benytte seg av materiale fra en tematisk forskningsbiobank må det innhentes	godkjenni	ng fra prosjektleder av denne.				
Opprettes forskningsbiobanken som en ny spesifikk biobank?	☐ Ja	□ Nei				
Opprettes forskningsbiobanken som en ny tematisk biobank?	☐ Ja	□ Nei				
Ansvarshavende person for forskningsprosjektets biobank (Helseforskningsloven § 26):						
Forskningsbiobankens navn:						
Forskningsbiobankens innhold (vev, blod og lignende) og antall inkluderte:						
Gjøres genetiske undersøkelser som har diagnostiske, prediktive eller behandlingsmessige konsekvenser for deltakeren?	☐ Ja	☐ Nei				
Er genetiske opplysninger tenkt tilbakeført til deltakeren?	☐ Ja	☐ Nei				
Angi planlagt innsamlingsperiode og tidspunkt for opphør av biobanken:						
Hva skjer med biobankmaterialet:						
<ul> <li>☐ Materialet oppbevares etter prosjektslutt, til år:</li> <li>☐ Materialet destrueres fortløpende i prosjektet</li> <li>☐ Materialet destrueres ved prosjektavslutning</li> <li>☐ Materialet føres tilbake til eksisterende biobank</li> <li>☐ Materialet overføres til annen biobank. Hvilken:</li> <li>☐ Skal biobankmaterialet overføres til annen institusjon? Hvilken:</li> <li>☐ Skal biobankmaterialet overføres til annen institusjon utenfor EU/EØS? Hvilken:</li> <li>Annet:</li> </ul>						



9 DETALJER OM PROSJEKTETS INFORMASJONSBEHANDLING					
9.1 Type personopplysninger behandlingen skal omfatte:					
9.1.1 Ikke-sensitive personopplysninger	9.1.2 Sensitive personopplysninger (jf. personopplysningsloven § 2 nr. 8)				
Identifikasjonsopplysninger	Prosjektet omfatter opplysninger om				
☐ Navn, adresse, fødselsdato	Rasemessig eller etnisk bakgrunn, eller politisk, filosofisk eller religiøs oppfatning				
☐ Fødselsnummer (11 siffer)	☐ At en person har vært mistenkt, siktet eller dømt for en straffbar handling				
☐ Fingeravtrykk, irirs					
☐ Annet:	☐ Seksuelle forhold				
Opplysninger om tredjepersoner	☐ Fagforeningstilhørighet				
Navn, adresse, fødselsdato	Presiser nærmere: 1. runde av datainnsamling: Pasientens egenrapporterte				
☐ Fødselsnummer (11 siffer)	opplevelse av tvang, ufrihet og krenkelse i helsetjenesten.				
☐ Annet:	2. runde av datainnsamling. I tillegg behandlerrapporterterte opplysninger				
	om behandlingsparagraf i psykisk helsevern, diagnose, og tvangstiltak				
	siste par uker, behandlerrapportert sykdomsinnsikt.				
9.2 Utvalg i studien					
Behandlingen omfatter opplysninger om (besk	iv også eventuell kontrollgruppe):				
☐ Ansatt i egen virksomhet ☐ Elever/student	er/barnehagebarn 🗵 Pasienter 🔲 Tilfeldig utvalgte				
☐ Adgangskontrollerte ☐ Medlemmer	☐ Kunder/klienter/brukere ☐ Seleksjonsutvalgte				
☐ Friske frivillige Dersom det skal (	is godtgjørelse, beskriv nærmere: 100 kr til de som møter til retest.				
Inkluderer utvalget personer med begrenset sa	mtykkekompetanse, eks mindreårige, demente eller annet? 🛛 🖂 Ja 🔲 Nei				
Dersom ja, forklar: Deler av utvalget vil være	underlagt tvungent psykisk helsevern. Av disse vil noen mangle				
50007	om å delta i en spørreundersøkelse, mens andre forventes å ha				
samykkekompetanse i dette spørsmale	. Det skal gjøres en konkret vurdering av dette for hver enkelt pasient.				
9.3 Innsamling av opplysningene					
Hyordan nersonopplysningene samles inn /flo	o avkryesinger er mulig)				
Hvordan personopplysningene samles inn (flere avkryssinger er mulig)  ☑ Manuelt ☐ Elektronisk (bilde og tekst) ☐ Videoopptak ☐ Lydopptak ☐ Annet (beskriv hvordan):					
Marideit	Videoopptak ☐ Lydopptak ☐ Annet (beskriv hvordan):				
Tive inimentee percenteppiyetingene	ra den registrerte selv				
	nnet (beskriv hvor fra): 2. runde av datainnsamling skal ha et skjema som fylles ut				
	behandler/primærkontakt, uten identifikasjonsopplysninger, men med kode som				
kobler til det pasientutfylte skjemaet fra samme pasient.					
Hvis uttrekk av forskningsdata, hvem utfører uttrekk og anonymisering/avidentifisering av data i dette utrekket <sup>11</sup> :					
☐ Datafangstgruppen					
☐ Sykehuspartner					
☐ Andre – oppgi hvem (prosjektleder el andre registre, for eksempel NPR, SSB eller andre helseinstitusjoner):					



9.4 Utlevering av opplysningene				
Blir personopplysningene gjort tilgjengelige/utlevert til andre virksomheter?	☐ Ja	⊠ Nei		
Dersom ja, oppgi mottakeres navn og adresse, samt hvilken rolle mottakeren har i prosjektet: Dersom mottaker skal være databehandler må det inngås databehandleravtale. Er det inngått slik avtale? Dersom ja, legg ved avtale.	☐ Ja	☐ Nei		
Hva blir overført?				
$\square$ Informasjon med navn, personnummer eller annet som entydig angir det enkelte individ (kryptert overl	øring krev	es)		
☒ Anonymisert informasjon (ikke mulig å bakveiidentifisere)				
Avidentifisert informasjon (ikke mulig å bakveisidentifisere uten nøkkel). Forklar i såfall hvordan kryssr dette ikke er likt som i pkt 9.6:	eferanselis	ste beskyttes dersom		
Hvordan oversendes informasjonen til andre virksomheter ?				
☑ Personlig overlevering				
CD sendt med rekommandert post				
☐ Legges ut på sikret område for nedlasting av mottaker (kryptert)				
☐ Annet. Beskriv nærmere:				
9.5 Lagring og behandling av opplysninger				
Hvordan lagres opplysningene?				
☐ Elektronisk				
☑ Egen forskningsserver ved AHUS				
☐ Annen virksomhet – oppgi hvem:				
☐ Forskningsserver ved UiO (kun anonymiserte data)				
☐ Annet. Beskriv nærmere <sup>12</sup> :				
☑ På papir. Forklar hvordan dette sikres mot uvedkommende: Anonymiserte svarskjemaer opp puncing er ferdig. Etter kvalitetssikring av punchekvaliteten makuleres de anonyme anonyme svardata finnes kun på datafil på forskningsserver.				
☐ På video, tape eller annet opptak. Beskriv hvordan dette er sikret og om personen kan identifiseres:				
☐ Annet. Beskriv nærmere:				
9.6 Gjenfinning av opplysningene				
Hvordan gjenfinnes opplysningene? (Bruk av direkte identifisering som personnummer og navn skal forsøkes un	nngått)			
☐ Opplysningene lagres med navn, personnummer eller annet som entydig angir det enkelte individ				
Opplysningene lagres avidentifisert (ved bruk av krysslister, kodenøkkel, løpenummer eller lignende)				
Hvordan er krysslister/kodenøkler beskyttet/lagret? Forklar:				



10 DATO FOR UTFYLLING	
Prosjektet er forelagt for og godkjent av divisjonsdir/ klinikksjef	☐ Ja. Hvem: Trond Ragnes, divisjonsdirektør
Sted og dato Lørenskog, 30. mars 2012	Signatur (sendt fra personlig epostadresse godtas) :
11 BEHANDLING AV PERSONVERNOMBUD	
Skal det sendes søknad om konsesjon til Datatilsynet?	
☐ Ja, det må sendes søknad om konsesjon til Datatilsynet, Jfr P	OL §33)
x Nei, ikke nødvendig – oppgi begrunnelse: Pasientene samty informasjonen behandles som beskrevet her. Det er pro	
Sted og dato 30.05.2012	Navn personvernombud: Marianne Blair Berg
12 GODKJENNING FOR OPPRETTELSE AV REGIS	TER/PROSJEKT (fylles ut av direktør ved Forskningssenteret)
Anmodning om opprettelse av forskningsregister er:	
☑ Godkjent (skjema sendes personvernombudet)	
Avslått (skjema returneres avsender)	
Sted og dato	Navn forskningsdirektør:
30/ S - 2012	Lilde Linis
Vedlegg – kryss av hvis relevant for type str  ☐ Protokoll/prosjektbeskrivelse ☐ Vedtak fra Regional etisk komité (REK) ☐ Pasientinformasjon / Samtykkeerklæring ☐ Spørreskjema / Intervjuguide ☐ Legemiddelstudie – Legg også ved meldes	

Saken kan ikke behandles hvis relevante vedlegg mangler

## Obligatorisk meldeskjema, versjon 1.0 12-041



### Merknader

<sup>1</sup> Prosjektleder er ansvarlig for at studien formaliseres i henhold til gjeldende lovbestemmelser. Hvis prosjektleder ikke er ansatt ved Akershus universitetssykehus HF (Ahus) må det oppgis navn på den Ahus-ansatte som er ansvarlig for at studien formaliseres korrekt.

- Prosjektet er omfattet av personopplysningsforskriften §7-27. (Punkt a må være oppfylt, samt enten b eller c)
  - a) Prosjektet er tilrådd av personvernombud. For prosjekter med medisinsk eller helsefaglig forskning skal prosjektet i tillegg være godkjent av REK.
  - b) Ikke stort omfang, men lang varighet og identifiserbart, eller
  - c) store datasett og tilfredsstillende avidentifisert eller pseudonymisert.
- Prosjektet/behandlingen har hjemmel i lov og utføres i regi av organ i stat eller kommune (eks. kvalitetssikring etter helsepersonellovens § 26) – se personopplysningsloven § 33, fjerde ledd.
- 3. Prosjektet er regulert i forskrift som spesielt angir at det er unntatt fra konsesjonsplikt eller underlag meldeplikt (f.eks. de sentrale helseregisterforskriftene)

Frafallsanalyser (analyser av fordelinger over utdanning, inntekt og ytelser m.m. blant fremmøtte og ikke-fremmøtte for å beregne betydningen av frafallet) er også unntatt dersom de er basert på samtykke.

N.

<sup>&</sup>lt;sup>2</sup> For alle studier som startes i regi av Ahus og som bruker pasientdata som utgår fra Ahus vil normalt databehandlingsansvarlig være Forskingsdirektør ved Ahus. Hvis det foretas en utlevering av data til ekstern institusjon, skal navnet på denne virksomheten skrives her.

<sup>&</sup>lt;sup>3</sup> Når prosjektet er ferdigstilt. Dette inkluderer innsamling, analyse/vurdering, artikkelskriving/konklusjon.

<sup>&</sup>lt;sup>4</sup> Behovet for konsesjon/melding er knyttet opp til hvilket formål man har med behandlingen av personopplysningene. Pasientjournalsystemet er meldt i sin helhet, og har lovhjemlet formål. Når informasjon i journalsystemet skal benyttes til andre formål må konsesjon eller alternativt ny melding vurderes og man må angi formålet med den nye bruken/behandlingen av personopplysningene. Formulering av formålet er derfor viktig. Tilsvarende gjelder for annen innsamling og behandling av pasient-/personopplysninger. Formålet må samsvare med det som beskrives i samtykket fra hver enkelt person som deltar i studien.

<sup>&</sup>lt;sup>5</sup> Ett av de tre hovedpunktene under må være oppfylt for at studien skal være meldepliktig, og unntatt fra konsesjon:

<sup>&</sup>lt;sup>6</sup> Data skal lagres i en viss tid etter at prosjektet er ferdigstilt (analyse er gjennomført) for mulig etterprøving. I forskningsstudier skal data lagres 5 år (Norsk Lægemiddelforening) etter publisering, og for klinisk utprøving skal data lagres i minst 15 år etter innsendt sluttrapport til SLV. Enkelte større tidsskrifter krever 10 års oppbevaring for etterprøving. Data kan ikke oppbevares etter prosjektslutt for kvalitetssikring. Dersom forskningsprosjektet er finansiert av Norges forskningsråd, skal sluttrapport og prosjektdata arkiveres på betryggende måte i minimum 10 år etter avslutning av prosjektet (se punkt 5.3 i Norges forskningsråds generelle kontraktsvilkår).

<sup>&</sup>lt;sup>7</sup> Som hovedregel skal skriftlig informert samtykke innhentes.

<sup>&</sup>lt;sup>8</sup> Kvalitetssikring er intern kvalitetskontroll av diagnostiske og behandlingsmessige metoder som har som formål å forbedre diagnostiseringen og behandlingen av pasientene ved sykehuset.

<sup>9</sup> REK portal: http://helseforskning.etikkom.no

<sup>&</sup>lt;sup>10</sup> Når det skal gis tilbakemelding om genetiske resultater skal deltagerne informeres før, under og etter det utføres genetiske analyser. Det er ikke aktuelt å gi tilbakemelding til barn.

<sup>&</sup>lt;sup>11</sup> Ved prosjekt slutt er prosjektleder ansvarlig for at data blir anonymisert/slettet. Ta kontakt med datafangstgruppen (datafangst@ahus.no) hvis det er behov for bistand.

<sup>&</sup>lt;sup>12</sup> Krever gjennomføring og godkjenning av risikovurdering

# **Appendix II**

### Questionnaires used in Paper II

- 1. Patient Questionnaire, Stage 2, Paper 2
- 2. Patient Questionnaire, Stage 3, Paper 2
- 3. Staff Information Form, Specialist Services, Stage 3, Paper 2
- 4. Additional Information Form, Municipal Housing, Stage 3, Paper2

Spørreskjema om

## Opplevelse av tvang i helsetjenesten

Forsøk å svare på opplevelsen av *tvang* og *uønsket press* i hjelpe- eller helsetilbudet. Spørsmålene gjelder behandling eller hjelpetilbud du har nå eller har hatt i det siste, og ikke tidligere behandling eller hjelpetilbud. I spørreskjemaet brukes ordet behandler og behandling, og med det tenker vi for eksempel på leger, sykepleiere, psykologer og alle andre som jobber med å gi helsetjenester og omsorg, og de tiltakene og tilbudene som rettes mot deg.

A
Hvilket trinn på stigen passer best for opplevelsen du har av tvang eller fravær av tvang i
nåværende helsetilbud? Sett kryss på et av trinnene på stigen.

10 🖵	Høyeste nivå av opplevd tvang
9 🗖	
8 🗖	
7 🔲	
6 🗆	
5 🗖	
4 🔲	
3 🗖	
2 🖵	
1 🗖	Opplever ingen tvang

De aller fleste spørsmålene i resten av spørreskjemaet er lagt opp slik at du skal sette ett kryss på hver linje. Merk av for hvor enig eller uenig du er i innholdet i påstanden om din opplevelse av helsetjenesten.

B Ver						
Hvor enig eller uenig er du i utsagnene om		Svært		enig eller		Svært
din	opplevelse av behandlingen:	uenig	Uenig	uenig	Enig	enig
1	Jeg føler meg fornøyd					
2	Jeg føler meg trygg					
3	Jeg føler meg beskyttet					
4	Jeg føler meg takknemlig					
5	Jeg føler meg lettet					
6	Jeg føler meg ivaretatt					
7	Jeg føler meg ydmyket					
8	Jeg føler meg sint					
9	Jeg føler meg trist					
10	Jeg føler meg forvirret					
11	Jeg føler meg krenket					
12	Jeg føler meg redd					
13	Jeg føler meg prisgitt					
14	Jeg føler meg inkludert					
15	Jeg føler meg sett					
16	Jeg føler meg sterkere					
17	Jeg føler meg velkommen					
18	Jeg føler meg viktig					
19	Jeg føler meg anerkjent					
20	Jeg føler meg liten					
21	Jeg føler meg maktesløs					
22	Jeg føler meg handlingslammet					
23	Jeg føler meg ubetydelig					
24	Jeg føler meg som en ting					

С	Hvor enig eller uenig er du i utsagnene			Verken		
	om din opplevelse av behandlingen:	Svært		enig eller		Svært
		uenig	Uenig	uenig	Enig	enig
25	Jeg føler meg til bry					
26	Jeg har fått privatlivet invadert					
27	Jeg føler meg latterliggjort					
28	Jeg blir flau/brydd					
29	Jeg føler meg kritisert					
30	Jeg føler meg trakassert					
31	Jeg føler meg innestengt					
32	Jeg føler meg invadert					
33	Jeg blir omtalt på nedsettende måte					
34	Jeg føler meg mobbet					
35	Jeg blir dyttet					
36	Jeg blir fysisk hindret					
37	Jeg er blitt holdt hardt i					
38	Jeg er blitt holdt fast					

D				Verken		
Hvc	r enig eller uenig er du i utsagnene:	Svært		enig eller		Svært
		uenig	Uenig	uenig	Enig	enig
1	Jeg er ærlig overfor behandlere					
2	Jeg stoler på behandlerne					
3	Jeg viser fram hemmelighetene mine					
4	Jeg skjuler sannheten					
5	Jeg skjuler det når jeg er uenig					
6	Jeg sier det behandlerne ønsker å høre					
7	Jeg sier det pleiepersonalet ønsker å høre					
8	Jeg ydmyker meg					
9	Jeg underkaster meg behandlerne					

	E Hvor enig eller uenig er du i følgende utsagn om behandlingen:		Uenig	Verken enig eller uenig	Enig	Svært enig
1	Jeg føler meg behandlet som alle andre					
2	Jeg føler meg behandlet som andre i samme situasjon					
3	Jeg føler meg behandlet som et verdig menneske					
4	Jeg føler meg godt behandlet					
5	Jeg føler meg mindreverdig behandlet					
6	Jeg føler meg urettferdig behandlet					
7	Jeg føler meg behandlet som en kriminell					
8	Jeg føler meg straffet					
9	Jeg har tenkt på negative hendelser fra behandlingen, også når jeg ikke vil tenke på det					
10	Negative bilder fra behandlingen dukker spontant opp i tankene mine					

	or enig eller uenig er du i følgende utsagn om andlingen:	Svært uenig	Uenig	Verken enig eller uenig	Enig	Svært enig
1	De ansatte tilpasser seg mine ønsker					
2	Jeg forstår sammenhengen mellom mål for behandlingen og behandlingstiltakene					
3	Jeg er enig i at tiltakene bør gjennomføres					
4	Behandlingen blir endret hvis jeg ber om det					
5	Ansatte oppfører seg på samme måte uansett hva jeg gjør					
6	Jeg er usikker på hva som vil skje videre					
7	Jeg forstår ikke hvorfor jeg blir behandlet på denne måten					
8	Det føles som om en uønsket situasjon vil vare for alltid					
9	Jeg har ikke fått tilstrekkelig informasjon					
6				Manhan		
	or enig eller uenig er du i følgende utsagn om andlingen:	Svært uenig	Uenig	Verken enig eller uenig	Enig	Svært enig
1	I sum er behandlingen jeg får bra for meg					
2	Behandlerne vil mitt beste					
3	Jeg kan gå hvor jeg vil					
4	Min mening påvirker hjelpen					
5	Jeg har fått god informasjon om mulighetene til å klage					
6	Andre tvinger meg til å ta imot hjelp					
7	Behandlingsopplegget gjør meg ufri					
8	Situasjonen min blir verre av behandlingen					
9	Jeg er utsatt for tvangsbruk					
10	Jeg er truet til å ta imot behandling					
11	Viktige helsebeslutninger bør tas av behandleren, ikke pasienten					
12	Hvis jeg blir dårligere, vil jeg at behandlere skal ta mer kontroll					
13	Jeg bør være fri til å bestemme over hva					

	H Hvor enig eller uenig er du i følgende utsagn om behandlingen:		Uenig	Verken enig eller uenig	Enig	Svært enig
1	Jeg blir møtt som et menneske som	uenig				
_	fortjener omsorg			_		
2	Jeg blir møtt som et interessant menneske					
3	Jeg blir møtt som et helt menneske					
4	Jeg blir møtt med høflighet og respekt					
5	Jeg blir godt behandlet					
6	Jeg blir møtt som et likeverdig menneske					
7	Jeg blir møtt på en nedlatende måte					
8	Jeg blir møtt på en krenkende måte					
9	Jeg blir møtt som et barn					
10	Jeg behandles som en diagnose					
11	Jeg blir umyndiggjort					
12	Alt i alt har kontakten med behandlere gitt					
	meg bedre egenoppfatning/selvbilde	_	_			_
13	Alt i alt har kontakten med behandlere gitt					
	meg dårligere egenoppfatning/selvbilde					
Var	det andre forhold ved helsetilbudet som påvir	ket selvb	ildet ditt?			
1				Verken		
	or enig eller uenig er du i følgende utsagn om	Svært		enig eller		Svært
valg	valgalgernativer:		Uenig	uenig	Enig	enig
1	Det finnes ulike akseptable tilbud som jeg					
	kan velge mellom					
2	Jeg er fri til å velge mellom dette					
	alternativet og ingen / lite hjelp					
3	Jeg blir gitt valg mellom urimelige /					

4 Jeg er underlagt dagens hjelp, uansett hva

Hvis jeg ønsker eller hadde ønsket det, kan

uønskede alternativer

jeg avslutte behandlingen nå

jeg selv ønsker

J Mis	nøye, klage og protest	Svært	Honia	Verken enig eller	Enia	Svært
1	Jeg er misfornøyd med tvang i denne behandlingen	uenig	Uenig	uenig	Enig	enig
2	Jeg har skjult min misnøye					
3	Jeg har fortalt at jeg er misfornøyd					
4	Jeg har protestert på behandling eller tiltak					
5	Jeg har fysisk motsatt meg behandling eller tiltak					
6	Jeg har klaget til kontrollkommisjon eller fylkeslegen					
7	Jeg har tenkt å klage til kontrollkommisjon eller fylkeslegen					
8	Jeg har gitt opp å prøve å endre behandlingen					
9	Vi har kommet til forlik/enighet om behandlingen					
10	Jeg er tilbudt hjelp til å klage					
11 Jeg er blitt forhindret fra å klage						
	du forslag til andre ting vi burde spurt om, så					
K						
Til s	lutt ber vi deg fylle ut noen opplysninger om	deg selv:				
1 K	jønn: 🔲 Kvinne 🔲 Mann					
2 S	ivilstand:	amboer		Skilt		
3 A	lder: 🔲 Under 18 🔲 18-25	<b>26-45</b>		46-65 🗖 6	66 eller	mer
4 Hvilken utdanning er den høyeste du har fullført? ☐ Grunnskole 7-10 år ☐ Videregående skole ☐ Høgskole / universitetsutdannelse						
5 <b>H</b>	va gjør du til daglig?					
Yrk		attføring literingspe		Under tdanning <i>A</i>	Arbeidsl	edig

### Spørreskjema om opplevelse av tvang i helsetjenesten

Forsøk å svare på opplevelsen av **tvang og uønsket press** i hjelpe- eller helsetilbudet. Spørsmålene gjelder behandling eller hjelpetilbud du **har nå eller har hatt nylig**, og ikke tidligere behandling eller hjelpetilbud. I spørreskjemaet brukes ordet behandler og behandling, og med det tenker vi på alle ansatte som jobber med å gi omsorg eller helsetjenester, og på tiltak og tilbud som rettes mot deg.

	r enig eller uenig er du i utsagnene om din levelse av behandlingen:	Svært uenig	Uenig	Verken enig eller uenig	Enig	Svært enig	
1	Behandlingsopplegget gjør meg ufri						
2	Jeg er misfornøyd med tvang i denne behandlingen						
3	Jeg er enig i at behandlingstiltakene bør gjennomføres						
4	Jeg føler meg krenket						
5	Jeg føler meg maktesløs						
6	Jeg føler meg redd						
7	Jeg føler meg ydmyket						
8	Jeg føler meg handlingslammet						
9	Jeg blir møtt som et helt menneske						
10	Jeg føler meg behandlet som en ting						
11	Jeg føler meg ubetydelig						
12	Jeg har fått privatlivet invadert						
13	Jeg føler meg straffet						
14	Jeg stoler på behandlerne						
15	Negative bilder fra behandlingen dukker spontant opp i tankene mine						
16	Situasjonen min blir verre av behandlingen						
17	Jeg kan gå hvor jeg vil						
18	Jeg blir truet til å ta imot behandling						
19	Jeg behandles som en diagnose						
20	Det føles som om en uønsket situasjon vil vare for alltid						
Vor	nnligst fyll ut noen opplysninger om deg se	alv.					
Kjø			d: 🗖 Ensli	g 🖵 Gift/sar	mboer	☐ Skilt	
Ald	er: 🗖 Under 18 🗖 18-25 🗖 26-45 🗖	46-65	<b>□</b> 66 el	ler mer			
Den høyeste utdanningen du har fullført: ☐ Grunnskole 7-10 år ☐ Vid. skole ☐ Høgskole / universitetsutdannelse							
	Hva gjør du til daglig?  På attføring/  Under  Yrkesaktiv Sykemeldt Uføretrygdet rehabiliteringspenger utdanning Arbeidsledig						

### Opplevd tvang – Behandler / kontaktansvarligskjema

Skjemaet fylles ut av behandler, primærkontakt eller annen ansatt med god kjennskap til enkeltpasient som deltar i ovennevnte undersøkelse. Fylles ut samme dag som pasienten fyller ut sitt skjema (eventuelt med henblikk på situasjonen den dagen). Legg inn dato på pasientskjemaet også.

Opplysninger fra pasientadministrativt system - Diagnose, funksjonsnivå, paragraf, tvangstiltak:					
1) Datoen skjemaet fylles ut (dd mm åå):					
Dato for oppstart av nåværende behandling (poliklinikk) eller innlegg	gelse (dø	gnopph	old):		
(ICD-10-kode)					
2) Pasientens hoveddiagnose per i dag: F					
☐ Pasienten har rusdiagnose som tilleggsdiagnose					
2) Hya or naciontone GAE châro i daga	Cumnt	omor	CAE S-		
<b>3)</b> Hva er pasientens GAF-skåre i dag? (Hvis situasjonen er endret etter skåren, be evt. behandler vurdere dagens GAF)			=GAF-S =GAF-F :		
			. OAI I		
4) Hvilken bestemmelse i psykisk helsevernloven behandles pasient Eget samtykke:   § 2-1 om samtykke  § 2-2 samtykke til å være u			e om TPI	H i inntil	tre uker
■ § 3-2 om tvungen observasjon					
§ 3-3 om tvungent psykisk helsevern: $\square$ med døgnopphold $\square$ u	iten døg	noppho	ld		
☐ Psykisk helsevernlovens kapittel 5 Dom på overføring til tvungen	t psykis	k helsev	ern		
5) Er pasienten underlagt vedtak om tvangsbehandling etter § 4-4?					
Ja, pasienten er under vedtak om <b>tvangsbehandling med med</b>	dikamer	iter ette	r § 4-4a		
Ja, pasienten er under vedtak om ernæring uten eget samtyk					
Ja, pasienten er under vedtak om annen form for tvangsbeha	ndling e	etter § 4	-4		
Nei. <b>Hvis nei:</b> Vedtak om tvangsbehandling er opphevet i løp	et av de	siste 10	) dagene	: □Ja	□Nei
6) Har pasienten vært underlagt tvangsmidler i løpet av siste 3 uker?   Nei					
Ja, mekaniske tvangsmidler etter § 4-8 a	l. <i>l</i> !l	: <b>\</b>			
Ja, kortvarig anbringelse bak låst eller stengt dør etter § 4-8 l  Ja, bruk av korttidsvirkende legemidler etter § 4-8 c (medikar			midlar)		
Ja, bruk av kortvarig fastholding etter § 4-8 d	пептепе	tvarigsi	maler)		
Hvis ja; samlet antall episoder med tvangsmidler siste 3 uker:	2 🗖 3	-6	7-10	<b>□</b> 11 ell	er mer
7) Har pasienten vært under vedtakspliktig skjerming etter § 4-3 i lø					lei
Hvis ja; samlet antall dager pasienten faktisk var skjermet i siste tre u	uker: (	<b>⊒</b> 1-3 ∟	<b>1</b> 4-8 □	9-21	
8) Vurdering fra behandler, kontaktsykepleier eller tilsvarende: I					Svært
hvilken grad mener du at følgende er oppfylt for pasienten /	Ingen	Liten	Både	Stor	stor
passer for pasienten nå:	grad	grad	og	grad	grad
A) Pasienten mener at noe viktig er galt eller problematisk med     hans/hennes fungering					
B) Pasienten gjør egen innsats / egne tilpasninger for å bedre problemene					
C) Pasienten mener han/hun trenger hjelp					
D) Pasienten mener han/hun trenger hjelp fra psykisk helsetjeneste					
E) Pasienten klarer å resonnere rundt problemene					
F) Pasienten har en realistisk vurdering av årsakene til problemene					
G) Pasienten er enig i nåværende medikamentelle behandling					
H) Pasienten er enig i behandlingstiltakene vi mener er nødvendige					
I) Ansatte har lagt press på pasienten for å få gjennomført					
behandlingstiltakene  J) Pasienten har lett for å føle seg krenket					
K) Pasienten har lett for å føle seg motarbeidet					

### Opplevd tvang – Øvrige opplysninger

1) Datoen skjemaet fylles ut (dd mm): / 2013  Måned /år da du flyttet til nåværende bolig: Måned: År 20							
Måned /år da du flyttet til nåværende bolig: Måned: År 20							
2) Psykisk lidelse og diagnose							
☐ Jeg har ikke en psykisk lidelse nå							
☐ Jeg har en psykisk lidelse.							
Diagnosen som er satt er							
Har du en rusdiagnose eller et betydelig rusproblem i tillegg?   Nei  Ja							
3) Er du underlagt tvang uten døgnopphold fra psykisk helsevern (psykiatrien)	?						
□ Nei □ Ja Hvis ja: Blir du tvangsmedisinert? □ Nei □ Ja							
4) Er du underlagt noen av følgende former for restriksjoner eller kontroll fra kommunen / ansatte i boligen:	Ja	Nei	Vet ikke				
Restriksjoner på bevegelsesfrihet (f.eks restriksjoner på hvor du kan dra)							
Kontroll av døgnrytme (f.eks vekketider, måltider du <b>må</b> være med på, inne/leggetider etc)							
Restriksjoner på hvordan du får bruke pengene dine, (mer enn at husleie eller gjeld trekkes automatisk fra kontoen din)							
Kontroll av rusbruk (f.eks urinprøver, ransaking av rom etc)							
Er du underlagt andre restriksjoner eller kontrollformer i boligen? Beskriv hvilke	2:						
5) Har du vært tvangsinnlagt i psykisk helsevern?  □ Nei							
☐ Ja Hvis ja: Hvor mange uker har du vært tvangsinnlagt til sammen? (alle d	ppho	ıld til sa	mmen)				
☐ Inntil 1 uke ☐ 2-3 uker ☐ 4-12 uker ☐ mer enn 12 uker /	3 må	neder					

# **Appendix III**

### Questionnaires used in Paper III

- 1. Patient Questionnaire, Paper 3
- 2. Staff Information Form, Paper 3

Side '

# Spørreundersøkelse om opplevelse av tvang ved BUPA / ABUP

Svar først på disse spørsmålene om deg selv:

1	Kjønn:	Jente	Gutt						
2	Alder:	13-15 år	16-18 år ove	r 18 år					
3	(flere krys  Du selv  Foreldr  Annen	es er mulig)  ve / foresatte  familie	nne behandlingen ved B Skole / lærere Barneverntjeneste Politi		Fastle	/ ABUP			
	En veni	n / venninne	Legevakt	Svært uenig	Uenig	Verken enig eller uenig	Enig	Svært enig	
		kelig har behov for r e foreldre / foresatte	noe, hjelper det å gå til						
			re / foresatte, og viser har det innerst inne						
6	Jeg vil skå ikke hvord	ne mine foreldre / fo an jeg egentlig har o	oresatte, og viser dem det innerst inne						
7			noe, hjelper det å gå til ontakt i BUPA / ABUP						
	primærkon	ekker å ikke vise bet ntakten i BUPA / AB ar det innerst inne							
9	Sett krys	s ved det trinnet	y ved UK nå for tider på stigen som pass synes passer best fo	er best	handlinge	n du har nå	:		
10	Høyest	t mulig nivå av opple	evd tvang i behandlinger	า					
8 -	<u>'</u>								
7	]								
6	]								
5 [	]								
4 [	]								
2	<u>'</u>								
1	Lavest	mulig nivå av opple	evd tvang i behandlinge	n					
	_							S	nu arket

### Spørreundersøkelse om opplevelse av tvang ved BUPA / ABUP Side 2

Nedenfor står noen utsagn om opplevelse av behandling. Sett et kryss på hver linje som viser hvor enig eller uenig du er i hvert utsagn. Hvis forholdet varierer, skal svare gjelde *alt i alt* eller *til sammen*.

Når det står behandling eller behandler gjelder det tiltak fra BUPA / ABUP, og ansatte som jobber der.

	<b>på behandlingen du får nå for tiden.</b> Sett et kryss på nje for hvor enig eller uenig du er i utsagnet	Svært uenig	Uenig	enig eller uenig	Enig	Svært enig
1	Behandlingsopplegget gjør meg ufri					
2	Jeg får ikke lov til å gjøre det jeg ønsker					
3	Andre bestemmer over meg i behandlingen					
4	Behandlingen kontrollerer meg for mye					
5	Jeg blir behandlet mot min vilje					
6	Behandlingen gjør at jeg føler meg alene					
7	Jeg er misfornøyd med tvang i denne behandlingen					
8	Det nytter ikke å nekte behandlingen					
9	Jeg føler meg krenket i behandlingen					
10	Jeg føler meg maktesløs					
11	Jeg føler meg ydmyket					
12	Jeg er fysisk eller psykisk skadet av behandlingen					
13	Jeg er traumatisert av behandlingen					
14	Jeg har fått privatlivet invadert					
15	Jeg stoler på behandlerne					
16	Jeg er enig i at behandlingstiltakene bør gjennomføres					
17	Det føles trygt å få denne behandlingen					
18	Jeg blir truet til å ta imot behandling					
19	Jeg føler meg behandlet som en ting					
20	Jeg behandles som en diagnose					
21	Jeg føler meg handlingslammet					
22	Jeg føler meg ubetydelig					
23	Jeg føler meg straffet					
24	Situasjonen min blir verre av behandlingen					
25	Behandlingsopplegget er skremmende					
26	Det er plagsomt å bli passet på i behandlingen					
27	De ansatte prøver å bestemme alt					
28	Vil jeg klage, så har jeg ingen voksne å gå til					
29	Jeg har godtatt at andre bestemmer behandlingen					
30	Jeg føler meg maktesløs av behandlingen					
31	Jeg tør ikke å protestere på behandlingen					

# Ansatteskjema opplevd tvang ungdom

Skjemaet fylles i tilknytning til at pasienten har samtykket til å delta og fyller ut sitt skjema. Tenk på situasjonen på dagen pasienten fylte ut sitt skjema der ikke annet er oppgitt.

pplysninger om pasiente	n og innlegg	elsen						
Pasientens alder nå:	år		Hadde	fylt 16 år på	innleggelses	datoen:	ja 🗌 nei	
ICD-10-diagnose (sor	m kode)	Akse 1	Akse 2	Akse 3	Akse 4	Akse 5	Akse	<del>)</del> 6
Hoveddiagnose i de ul	ike aksene:							
Eventuell tilleggsdiagn	ose:							
3 Funksjonsnivå: CGA	S inn:		CG	AS nå (skår	ringsperiode s	siste tre døg	n):	
	jon har innleg a annen inst. bv, phv, fengse	fra fosterh	njem 🗌 fra i	rømt / gabondering	fra beredsl	kapshjem	annet	
5 Oppholdstid hittil i de	enne innlegge	lsen:	1-4	dager	5-21 dager	mer e	enn 3 uker	
Frammøte i skole elle som frammøte). For elle som frammøte). For elle lavt fravær (17 moderat fravær (5 tm svært høyt frav	enkelttimefravæ til 20 dagers sk r (11 til 16 dage til 10 dager sko	er teller 4 timer coleframmøte / ers skoleframm leframmøte / fr	som 1 dags fra fravær på 0-19 øte / fravær på avær på 50-79	avær, 8 time 9%) å 20-49%) 9%)	r som 2 dager ( likke a ufr		ksempel skoleplass)	)
Problemer med bruk ingen eller noe mildt forøket bru moderat alvorlige alvorlige proble	bruk, men inne uk av alkohol, s ge problemer m	enfor aldersnor toff eller løsem ed stoff, alkoho	mene iidler ol eller løsemid	dler, klart ute	Mang nfor aldersnorr	ller informas	sjon/Vet ikk	се
uk av tvang etter psykisl	k helsevernic	oven						
Pasientens nåværend § 2-1 om samtykke		ykisk helseverr ntykke til tph-re		-2 om tvunge	en obs	3-3 om tvun	gent vern	
Pasientens behandling Behandlingsparagraf	 gsparagraf ved	henvisning o	g oppstart av	nåværende	opphold:	Henvisning anmodet o	_	ja nei
Er innleggelsen pliktig ja nei		ntrollkommisjor t, ungdommen				mot ungdon	nmens vilje	<b>∍</b> ?
Er pasienten underlag	gt vedtak om tv (medikamenter		g etter § 4-4? 4b (ernæring)		er er mulig for se nnen form for tv			
Har pasienten vært ur nei ja, etter §	nderlagt tvangs 4-8a (mekanis		v siste tre uke 8b (isolasjon)			hold/belter v		g)
Har pasienten vært ur Skjerming med vedtak			et av siste 3 ul a, skjermet på		ei skjer ja, skjermet	met, men ute på 5 eller fle		
alitative vurderinger fra	primærkonta	akt eller pasi	entansvarlig	j behandle	r			
I hvilken grad mener du at som sitasjonsbeskrivelse				er Ingo gra				/ært grad
14 Pasienten mener selv	at han/hun tren	ger hjelp						
15 Pasienten har et godt t	forhold til minst	en av sine fore	esatte					
16 Pasienten har et godt t	forhold til perso	nalet hos dere						
Foreldre/foresatte har behandlingstiltak	lagt press på pa	asienten for å g	gjennomføre					_
18 Ansatte har lagt press	på pasienten fo	or å gjennomfø	re behandlings	stiltak				
19 Pasienten har lett for å	føle seg krenk	et						
20 Pasienten har lett for å	føle seg mota	rbeidet						

# **Appendix IV**

### Systematic literature search strategy

In cooperation with librarian Toril Marie Hestnes, a systematic literature search and review, was used to find all attempts at scaling perceived or experienced coercion. We conducted a systematic search of existing scales on experienced coercion in Medline, PsycINFO and CINAHL, We searched for papers published from 1991 to 2011 in English or Scandinavian languages with human subjects, with the following search terms:

"Commitment of Mentally III" or "Treatment Refusal" or "involuntar\*" and ("commit\*" or "Admit\*" or "admission\*" or "treatment" or "intervention" or "hospitalization" or "Coerc\*" or "restrain\*" or "constrain\*" or "seclu\*"

and "Mental Disorders"

and "Psychometrics" or "Psychiatric Status Rating Scales" or "Psychological Tests" or "Questionnaires" or "Reproducibility of Results" or "Outcome and Process Assessment (Health Care)" or "Outcome Assessment (Health Care)" or test adj (valid\* or reliabil\*)

- 1 exp "Commitment of Mentally III"/
- 2 exp Treatment Refusal/px [Psychology]
- 3 (involuntar\* adj2 (commit\* or admit\* or admission\* or treatment or intervention or hospitalization)).ti,ab.
- 4 (coerc\* or restrain\* or constrain\* or seclu\*).ti,ab.
- 5 exp Mental Disorders/
- 6 (3 or 4) and 5
- 7 1 or 2 or 6
- 8 exp Psychometrics/ or exp Psychiatric Status Rating Scales/ or exp Psychological Tests/ or exp Questionnaires/
- 9 exp "Reproducibility of Results"/
- 10 exp "Outcome and Process Assessment (Health Care)"/ or exp "Outcome Assessment (Health Care)"/
- 11 (test adj (valid\* or reliabil\*)).tw.
- 12 9 or 10 or 11

7 and 8 and 12

# Paper

Paper III

Paper III

# Title page:

# A cross-sectional study of experienced coercion in adolescent mental health inpatients

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## **Abstract**

**Background:** Involuntary care and coercive measures are frequently present in mental healthcare for adolescents. The purpose of this study was to examine to what extent adolescents perceive coercion during inpatient mental health care, and to examine predictors of perceived coercion.

**Methods:** A cross-sectional sample of 96 adolescent inpatients from 10 Norwegian acute and combined (acute and sub-acute) psychiatric wards reported their perceived coercion on Coercion Ladder and the Experienced Coercion Scale in questionnaires. Staff reported use of coercion, diagnoses, and psychosocial functioning. We used two tailed t-tests and mixed effect models to analyze the impact from demographics, alliance with parents, use of coercion, diagnostic condition, and global psychosocial functioning.

**Results:** High perceived coercion was reported by a third of all patients. In a mixed effects model, being under coercion (involuntary admission and / or coercive measures); a worse relationship between patient and parent; and lower psychosocial functioning, significantly predicted higher perceived coercion. Twenty-eight percent of the total sample of patients reported a lack of confidence and trust both in parents and staff.

Conclusions: Roughly one third of patients in the sample reported high perceived coercion.

Being under coercion was the strongest predictor. The average scores of experienced coercion in subgroups are comparable with adult scores in similar care situations. There was one exception: adolescents with psychosis reported low experienced coercion and almost all of them were under voluntary care.

#### **Keywords:**

Adolescent psychiatry, Involuntary admission, Cross-sectional studies, Perceived coercion.

## **Background**

Coercion in mental health care remains controversial. Research is increasingly focused on the use, effect, and patient's experience of coercive treatment forms, but little is published on adolescent patients. Coercion is present in adolescent mental health care: in Norway, 20% of admissions among 16- to 17-year-olds was involuntary [1], although it was 36.5% in a German sample [2]. Adolescent inpatients may also be subjected to forced medication or nutrition for treatment purposes, as well as other coercive measures, such as holding, mechanical restraints, seclusion, and medication, in order to prevent harm to people or property. Some studies found that coercive measures are used more frequently for younger adolescents [3, 4]. The reported rate of inpatients subjected to one or more of these coercive measures ranged from 30% for inpatients in New York [5] and Finland [6] to 6.5% in Norway [7]. There will also be age, status, and knowledge differences between adolescents and staff. Thus, informal coercion in the form of pressure, more or less explicit threats, and house rules can influence adolescents' perceived coercion. Furthermore, adolescents are usually materially, financially, and emotionally dependent on parents or guardians [8], so that control and pressure may relate to care, trust, and family loyalty. There is also a risk that some adolescent patients lack or lose trust in parents and staff during hospitalization, and consequently feel isolated in the ward. Given frequent use of coercion, the potential for informal coercion, and the vulnerable adolescent years, perceived coercion in adolescents should be an important research topic [9].

A review of adolescent experiences with mental health care found few inpatient studies, and the main topic was patient satisfaction [10]. One recent American interview study with inpatients found that rigidity and confinement were the most frequently disliked aspects of care [11]. A few interview studies have reported how adolescent and young adult inpatients with anorexia view treatment: patients are aware of staff strategies for influence, such as

persuasion and use of patient privileges. Some patients attempt to resist or circumvent treatment, i.e., some play by the rules to get out, and some attenuate staff authority by questioning their competence [12]. Patients spoke about formal coercion and informal pressure, with some saying that coercion and restrictions could at times be justified and helpful [13]. In one study, adolescents with eating disorders reported more perceived coercion than adults [14].

The literature on coercion in adults is far more extensive, with subfields such as outpatient coercion with community treatment orders, coercive measures, and perceived coercion. In 1993, the development of the Admission Experience Survey and its subscale the MacArthur Perceived Coercion Scale [15] stimulated a series of studies on perceived coercion. These studies found that legal status predicts perceived coercion, although approximately 35% of involuntary patients in acute wards reported low perceived coercion in several studies [16, 17]. Conversely, the number of voluntarily admitted patients who reported a high perceived coercion score, ranged from 10% in the original MacArthur studies [18] to 48% in a smaller English study [19]. Across studies, the odds ratio of legally-detained patients reporting high experienced coercion compared to informal patients was 8.6 [20]. Use of physical force or threats of social consequences for treatment also predicts higher perceived coercion in patients [21]. A higher level of perceived procedural justice – i.e., feeling that you had a say in the decision and considered the admission process to be fair – are associated with lower perceived coercion [22]. Also, a positive relation to the clinician is associated with lower perceived coercion [19]. Research on the impact of demographic and clinical characteristics displayed small and inconclusive effects [23]. Thus, we lack a clear and documented understanding of the interrelation between the main explanatory variables of perceived coercion, such as patient characteristics, care regimen, alliance, and procedural justice. Qualitative studies indicate that patients do not equate freedom restrictions to perceived

coercion, but restricts the coercion concept to negatively viewed restrictions, such as the humiliating ones [24]. In addition, they described coercion as a broader experience, sometimes with existential consequences, and affecting self-image [25, 26]. For patients, coercion seems to be more of a negative experience than merely a perception, making experienced coercion the preferred concept.

Our study aims to establish the level of experienced coercion and test candidate predictor variables in a sample of hospitalized adolescents. We hypothesized that younger age, use of coercion (involuntary care, coercive treatment or measures), eating disorders, and lower global psychosocial functioning would predict higher experienced coercion. However, eating disorders and lower psychosocial functioning likely increase experienced coercion through the increased use of coercion, so that we expected these variables to lose significance when controlled for use of coercion. Furthermore, we wanted to explore:

- Whether a good relation to the parent or guardian would predict higher or lower experienced coercion;
- Whether pressure for admission from parents would have different effects on experienced coercion for voluntary vs involuntary patients;
- What proportion of patients would report lack of trust or closeness towards both parents and staff.

For voluntary patients, we expected that pressure from parents (re: admission) would lead to higher experienced coercion compared to patients without such pressure. However, for involuntary patients, such pressure could be insufficient to add to experienced coercion, and might contribute to a sense of necessity and legitimate care, with less experienced coercion.

## **Methods**

#### The study context

In Norway, per 100,000 underage persons (aged 0–17), there are 26 mental health inpatient beds used yearly by 180 patients in 249 admissions [27]. The adolescent wards in this study accept patients from 13 to 17 years. This age group uses approximately 75% of the total underage inpatient capacity [28], indicating a yearly inpatient adolescent coverage of about 0.5% in 2014. Adolescent inpatients are a highly select group expected to have severe mental health problems, which services consider difficult to administer proper care in outpatient settings. Norwegian adolescent acute and sub-acute units are small but well-staffed, usually with 10 or fewer beds per ward, and with staffing (including administrative) of more than 4 employees per bed [27].

According to the Norwegian Mental Health Act, patients 16 and above can be involuntarily admitted and treated according to the same rules as adults. Patients less than 16 are admitted based on parental consent, and are thus formally seen as voluntary [29]. The ward shall notify the Control Commission (a tribunal board for complaints about involuntary mental health care) whenever an admitted patient under 16 disagrees with the parents' decision.

#### **Design**

We conducted a cross-sectional study of adolescent inpatients from 10 Norwegian acute and combined acute and sub-acute psychiatric wards. Data were collected from patients, staff, and clinical records.

#### **Recruitment of wards**

We sent an invitation to participate to all 16 Norwegian adolescent wards (acute and combined acute and intermediate inpatient) approved for involuntary care. Ten out of these wards participated in the study.

#### Patient inclusion and data collection

Data collection took place in 2015. Each participating ward chose a start-up day for recruitment. At this point, all admitted patients in the ward regardless of care formality, were considered for eligibility. Patients' inclusion criteria were being 13- to 17-years-old, competency to consent by understanding the consequences of participating, and the ability to comprehend a two-page questionnaire. Patients were approached by local clinicians, who gave them information about the study and requested consent to participate. For patients under the age of 16, parents were also asked for consent. The patient was asked to fill out a form with questions and statements, preferably in private, and to enclose it in an envelope themselves. Staff assisted with reading or explanations if needed. The patient's primary contact or responsible clinician also filled out a form about the patient and treatment based on the patient's record and past care. Recruitment procedures were repeated weekly for newly-admitted patients until the ward reached its goal, based on ward size, or gave up recruitment.

#### **Measurements**

We used paper forms filled out by patients and therapists to measure the variables selected for this study. Members of the adolescent group of the Norwegian Acute Psychiatric Network suggested clinically-relevant variables as well as their wording.

#### Experienced coercion

No measure of experienced coercion has been validated for adolescents, so we chose two measures developed for adults with complementary strengths, and we report and compare

both. *The Coercion Ladder* (CL) is a one-item, self-anchoring visual analogue scale based on the Cantril Ladder [30], measuring one's recent experience of being coerced. The score range is 1–10 and the respondents are instructed that the lowest and highest scores should correspond to the lowest and highest level of experienced coercion they can imagine. The participant's understanding of the word 'coercion' is the anchor. This may sacrifice reliability, as found in other iterations of Cantril's approach [31], but should be directly applicable to adolescent mental health care and adolescents' understanding of the word 'coercion.' *The Experienced Coercion Scale* (ECS) has 15 agreement-rated five-point Likert items, and the score range is 0–4. Items are applicable across care phases, care settings, and forms of coercion, focusing on patients' negative evaluations and feelings [32]. For both scales, we defined high experienced coercion as a score above the midpoints [> 5 on CL, > 2 on the ECS). Patients also noted if they *agreed with the admission* and if they thought their parents or other parties agreed with it too.

#### Use of coercion

Involuntary admission was coded 'yes' if the adolescent was 16 to 17 years old, and involuntary admitted according to clinical records. This variable was also coded 'yes' for younger patients who disagreed to being admitted, warranting a notification to the Control Commission. Data about *coercive measures*, such as involuntary medication, involuntary nutrition, restraints, and open door seclusion, which happened during the last three weeks of admission, was reported by staff. *Patients under coercion* were those who had experienced any involuntary admission or coercive measure described in this paragraph.

#### Clinical status

*Diagnosis* was measured as the main psychiatric disorder using Axis One (clinical psychiatric syndromes) in the multiaxial ICD-10 Classification of Child and Adolescent Psychiatric

Disorders from the World Health Organization [33]. This was found in the patient's record during data collection. *Global psychosocial functioning* was measured using the units' routine application of the Children's Global Assessment Scale (CGAS) [34] at admission, and by asking the clinician to rate the CGAS at the time of the patient's response. Staff rated the patient with Health of the Nation Outcome Scales – Children and Adolescents (HoNOSCA) for *use of alcohol or drugs* [35] in the last 6 months. HoNOSCA defines non-problematic use as no use or use within age norms. *Length of stay* and the *living situation from which the adolescent was admitted* were rated by staff with using the patient records.

#### Relation between patient and parent/guardian

The *quality of the patient's relation to parent* and *staff* was measured with a set of agreement-rated Likert-items. In this section, we rewrote and adapted the expectation of help from mother/father in the Conflict Behaviour Questionnaire [36]. The patient rated parent and staff on separate items. We were similarly informed of the theme of openness and trust from the Scale to Assess the Therapeutic Relationship [37], and coined an item of hiding inner feelings, which the patient rated for parents and staff. Also, staff rated the relation between patient and parent or guardian. We calculated a combined measure of *patients' relation towards the parent* as the average score on two patient-rated items and one staff-rated item, where higher scores indicated better relations. An item was added after the pilot interviews, acknowledging the nuance between hiding one's inner feelings from the parent due to lack of trust or in order to spare them from knowing convoluted feelings or situations. Staff rated the degree of *informal pressure from parents* on a self-made 5-point Likert item.

Gender was marked by the patients, and age was reported by the staff.

We piloted the patient questionnaire with a cognitive validation interview [38], with three patients at two sites, and inquired how items were understood, how the patient reasoned, and

how he/she thought other patients would reason when answering the form. Pilot interviews indicated that patient items, including experienced coercion scales, were understood.

## **Study sample**

Among 132 patients considered for participation, data from 96 (73%) were included in the analyses, as shown in Figure 1. We excluded three cases with more than 20% missing ECS items. For remaining participants, CL had no missing data and ECS items had a total of 15 missing answers (1.04%).

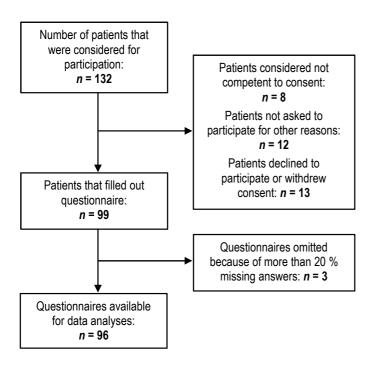


Fig 1. Flow chart of recruitment, exclusions, and refusals of patients.

## **Statistical analyses**

We analysed data with SPSS 23. CL scores showed a skewed distribution, so we utilized Spearman's rank order for correlation with this scale. Parametric tests were restricted to ECS scores, in which we studied the predictive value of use of coercion and diagnosis with two tailed t-tests and ANOVA, respectively. We used ECS sum scores as the dependent variable and estimated a linear mixed effect model. Here we entered age, relation to parent or

guardian, global psychosocial functioning, eating disorders, and use of coercion as fixed effects and estimated a random intercept for the effect of wards. Non-dichotomous predictors were centered at their grand mean. In a second model, we explored whether informal pressure for admission from the parents influenced experienced coercion differently for voluntary patients compared to patients under coercion, using an interaction variable.

Table 1. Patient characteristics

	13-15 years $n = 33$	16-17 years $n = 63$	Total $n = 96$
	n (%)	n (%)	n (%)
Gender	n (70)	n (70)	n (70)
Female	22 (66.7)	44 (69.8)	66 (68.8)
Male	11 (33.3)	19 (30.2)	30 (31.3)
Diagnosis (ICD-10 codes)	11 (33.3)	19 (30.2)	30 (31.3)
Psychosis (F20-31)	9 (27.3)	5 (7.9)	14 (14.6)
Pervasive developmental disorder (F84)	1 (3)	6 (9.5)	7 (7.3)
Eating disorders (F50)	5 (15.2)	9 (14.3)	14 (14.6)
Depressive disorder (F32-34)	9 (27.3)	20 (31.7)	29 (30.2)
Anxiety, dissociative disorders, PTSD (F40-44;	5 (15.2)	9 (14.3)	14 (14.6)
F92-94)	c (10 1 <b>2</b> )	7 (2)	11 (1113)
All other disorders <sup>a</sup> (incl. missing)	4 (12.1)	14 (22.2)	18 (18.8)
Living situation before admission	,	,	,
Living at home	26 (78.8)	50 (79.4)	76 (79.2)
Living in institution or foster care	6 (18.2)	9 (14.3)	15 (15.6)
Not specified (other or missing)	1 (3)	4 (6.3)	5 (5.2)
Length of stay at the time of data collection	( )	,	
Short (1-4 days)	8 (24.2)	23 (36.5)	31 (32.3)
Medium (5-21 days)	17 (51.5)	21 (33.3)	38 (39.6)
Long (22 days or longer)	8 (24.2)	15 (23.8)	23 (24)
Missing	,	4 (6.3)	4 (4.2)
Involuntary admission			
No	29 (87.9)	49 (77.8)	78 (81.3)
Yes	4 (12.1)	14 (22.2)	18 (18.8)
Episode of coercive measure <sup>b</sup> for last three weeks			
No	32 (97)	54 (85.7)	86 (89.6)
Yes	1 (3)	8 (12.7)	9 (9.4)
Missing	0 (0)	1 (1.6)	1 (1)
Children's Global Assessment Scale	mean (sd)	mean (sd)	mean (sd)
At admission <sup>c</sup>	38.5 (8.8)	35.7 (13.8)	36.7 (12.3)
At time of data collection <sup>d</sup>	44.6 (9.1)	40.7 (13.8)	42.1 (12.5)

<sup>&</sup>lt;sup>a</sup> Personality disorder (F60), Hyperkinetic disorder (F90), Unspecified mental disorder (F99), Auditory hallucinations (R44.0), Suicidal ideation (R45.8), Observation for suspected mental or behavioral disorder (Z032)

sd = standard deviation

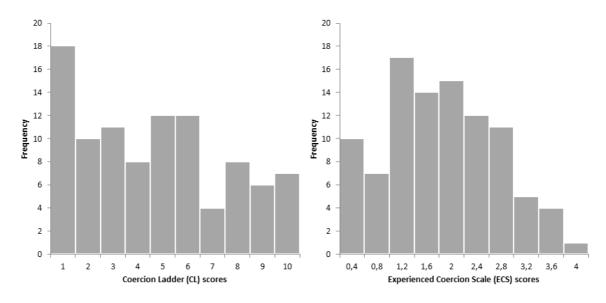
ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th Revision

#### **Results**

The sampling procedure resulted in adolescent inpatients with characteristics shown in Table 1. Staff reported that 81 (86.2%) patients had non-problematic use of alcohol and drugs.

#### **Experienced coercion among adolescent inpatients**

The patients' mean score on CL was 4.7 (SD = 2.9, median score = 5). The mean score for patients under coercion was 7.3 (SD = 2.6, median score = 8) while voluntary patients' mean score was 4.1 (SD = 2.6, median score = 4). The mean score on the ECS (scaled from 0 - 4) was 1.7 (SD = 0.9). The correlation between CL scores and the ECS sum scores was  $r_s$  = .68. The distribution of both scales is shown in Figure 2.



**Fig 2.** Histogram of Coercion Ladder scores and Experienced Coercion Scale (ECS) average sumscores in the sample. N = 96.

<sup>&</sup>lt;sup>b</sup> Coercive measures could include physical holding, mechanical restraints, medication, nutrition, isolation, or open door seclusion

<sup>&</sup>lt;sup>c</sup> Missing data for 3 patients

<sup>&</sup>lt;sup>d</sup>Missing data for 13 patients

The mean ECS difference between patients under coercion (2.4 points, n = 19) and the non-coerced patients (1.5 points, n = 77) was 0.9 points [0.5, 1.3], with t (94) = 4.16, p < .001, d = 1.01.

In the total sample, 33 of the patients (34.4%) reported high experienced coercion (ECS score > 2). For adolescents under coercion, the percentage was 73.7, while 24.7% of the voluntary patients reported high experienced coercion.

## **Predictors of Experienced Coercion**

Among the 96 patients, 46 (47.9%) agreed that they ought to be treated on the ward. Of these, 12 patients (26.1%) nevertheless reported high experienced coercion on the ECS. Fifty patients did not agree with treatment on the ward, and 28 of these (56.0%) reported low experienced coercion according to the ECS. A majority of 62 patients (64.6%) thought their parents endorsed the current stay. Only 16 patients (16.7%) disagreed with treatment on the ward <u>and</u> thought the parents did not endorse the current stay. Here, the adolescent considered Child Protection Services (5 patients (5.2%)) and Child and Adolescent Mental Health Care (10 patients (10.4%)) as proponents of their current treatment.

We found significantly different levels of ECS scores for patients in the diagnostic groups shown in Table 1, as implied by ANOVA with F(5,90) = 2.570, p = .032. A Tukey post hoc test revealed that the ECS score of 2.29 in patients with eating disorders was significantly higher compared to that of 1.20 in patients with psychosis (p = .016). Other differences were nonsignificant. Eight of 14 patients with eating disorders, but only 1 of 14 patients with psychosis were under coercion.

Table 2
Parameter estimates of predictors of patient scores on the ECS with a random intercept for wards in a mixed effects model.

Parameter	Estimate	95% CI
Fixed		
Intercept	1.466**	[1.163, 1.769]
Patient age <sup>a</sup>	-0.114	[-0.257, 0.028]
Patients' relation to parent or guardian <sup>a</sup>	-0.258*	[-0.425, -0.091]
Global psychosocial functioning (CGAS) <sup>a</sup>	-0.021*	[-0.039, -0.003]
Diagnosed with eating disorder (reference: no)	0.341	[-0.158, 0.840]
Patient under coercion (reference: no coercion)	0.805**	[0.353, 1.257]
Covariance		
Residual standard deviation	0.546	[0.393, 0.798]
Between wards standard deviation	0.062	[0.009, 0.450]

CI = confidence interval

In the first step of multilevel modeling, we estimated a model not including any predictors, but accounting for the variation in ECS scores between wards. The intraclass correlation (ICC) was 0.072. Akaikes information criterion was 225.443 for this model. Then we added the predictors shown in table 2 as fixed effect variables in the model. In this model, ICC for ward was 0.102, and the Akaike information criterion was 208.456. Parameter estimates with confidence intervals (CIs) are in Table 2.

<sup>\*</sup>  $p \le .05$ . \*\*  $p \le .001$ .

<sup>&</sup>lt;sup>a</sup> Non-dichotomous variables are grand mean centered.

To assess if informal pressure from the parents influenced experienced coercion differently in voluntary and coerced patients, we estimated a second mixed model with interaction between informal pressure from parents and being under coercion. In this model, ICC for ward was 0.088 and the Akaike information criterion was 231.895. The parameter estimates are given in Table 3.

Table 3
Parameter estimates for effect of parent or guardian pressure on patient scores on the ECS with a random intercept for wards in a mixed effects model.

Variable	Estimate	95% CI
Fixed		
Intercept	1.543**	[1.281, 1.805]
Patients' relation to parent or guardian <sup>a</sup>	-0.232*	[-0.392, -0.072]
Informal pressure from parent or guardian <sup>a</sup>	0.222*	[0.059, 0.385]
Patient under coercion (reference: no coercion)	0.902**	[0.489, 1.314]
Informal pressure from parent or guardian x	-0.358*	[-0.697, -0.019]
patient under coercion		
Covariance		
Residual standard deviation	0.573	[0.422, 0.777]
Between wards standard deviation	0.056	[0.009, 0.3570]

CI = confidence interval

The analyses show that voluntary patients rate higher experienced coercion when there is more informal pressure from parents or guardians. For patients under coercion, more informal pressure predicted *lower* experienced coercion.

<sup>\*</sup>  $p \le .05$ . \*\*  $p \le .001$ .

<sup>&</sup>lt;sup>a</sup> Non-dichotomous variables are grand mean centered.

## **Relation towards parents and staff**

Fifty-six (58.9%) patients agreed or strongly agreed they would not show their parents how they really felt, either due to lack of trust (14 patients) or to spare the parents (19 patients), or for both reasons (23 patients). Thirty-seven patients (38.5%) would not show staff how they felt. Twenty-six patients (27%) would not show how they felt to either parents or staff.

#### **Discussion**

To our knowledge, this is the first quantitative study of experienced coercion in adolescent mental health care. The study adds valuable knowledge regarding degree and predictors of experienced coercion.

The level of experienced coercion, as measured by the ECS and the CL, was in a similar range in reports from adult samples. On the ECS, adolescents under coercion scored 2.4 points, while patients under involuntary care in a Norwegian adult sample scored 2.2 points [32]. The scores for voluntary patients were 1.5 and 1.3 points in the adolescent and adult samples, respectively. The correlation between CL and the ECS was in the same range in this study as in the ECS validation study, with  $r_s = .68$  in both studies.

Experienced coercion varied with diagnosis. As expected, patients with eating disorders reported higher experienced coercion. Surprisingly, patients with psychosis reported low experienced coercion, and only one of these patients was involuntary admitted or subjected to coercive measures. Psychosis and psychotic symptoms have repeatedly been connected to more coercion and higher experienced coercion in adult samples [39, 40]. In Norway, 62% of all adult involuntary inpatient time was for patients with a main diagnosis of schizophrenia [41]. Nevertheless, Norwegian adolescent inpatient wards seemed able to care for most psychotic patients without formal involuntary care or experienced coercion for them. More

studies are needed to rule out bias in our results, and to investigate how non-coercive psychosis care is accomplished.

Although the strongest predictor of experienced coercion was being under coercion, approximately ¼ of patients under coercion reported low experienced coercion, and approximately ¼ of voluntary patients reported high experienced coercion. Other significant predictors in the model were negative relations with parents and lower global psychosocial functioning. While patients with eating disorders reported high experienced coercion, this may have been mediated by being under coercion, making eating disorders insignificant in the mixed effects model. The explanatory power of patient characteristics varies between existing studies of experienced coercion. Our results indicate that sometimes a more restrictive care regimen may mediate the effect of patient variables on experienced coercion. For some variables, there may be competing causal chains at work: better psychosocial functioning indicates that involuntary admission is less proportional, which may lead to less acceptance of the admission, as found in an English study [42]. However, better global psychosocial functioning may protect from some care restrictions, leading to lower experienced coercion. In the latter case a thorough multivariate control for all care restrictions should remove the significance of psychosocial functioning. A main effect cannot be ruled out either, in which lower psychosocial functioning may weaken a patient's ability to see the care situation from different perspectives, creating a sense of more experienced coercion in an otherwise comparable care situation. While studies may control for formal coercion, it is difficult to rule out that effect of patient variables are mediated by informal restrictions. In order to resolve these questions, a validated measure of informal coercion, preferably reported by sources other than the patient, would seem to be necessary.

Given adolescent dependency on parents, how does informal pressure from caregivers predict experienced coercion? Our post hoc mixed effects model shows that pressure from parents

predicted higher experienced coercion on the ward for voluntary patients. But for patients under coercion, informal pressure from parents was associated with lower experienced coercion, although the subsamples were small in this model. We speculate that this effect may be due to the parental legitimization of the involuntary care.

How did inpatients assess their alliance and trust in staff and parents? Almost half the patients agreed to treatment in the ward. Nevertheless, 27% of inpatients did neither report a good alliance with their parents nor the staff. The study sample is a highly select group based on problem severity. Lack of trust in adult relations may be a part of the situation for several adolescent inpatients. This may contribute to their problems, and make them particularly lonely and vulnerable. If, for some reason, understanding, empathy, or care quality breaks down, the staff, control system, and parents cannot rest assured that an adolescent will discuss it with a parent. As implied in the pilot interviews, some adolescents may hide their negative feelings and experiences from parents to spare them a burden. This may be the case if parents initiated or agreed with admission, and if the alliance or treatment results eventually soured.

#### Limitations

The study sample is small, partly reflecting the small adolescent wards. This sample size implies that findings on subgroups should be treated with caution. On the other hand, the rate of missing data was low from both patients and staff. Ten out of 16 Norwegian adolescent acute wards participated, and the participation rate on the wards was high. ICC for wards explained less than 10% of the variation in experienced coercion. Also, we received no reports of problems from the involved clinicians, such that the adolescents seem to have handled the questionnaire well.

Another limitation to this study is that the scales of experienced coercion have not previously been applied or validated in adolescent populations. We did not use the frequently-used

MacArthur Perceived Coercion Scale, as it was developed and validated for an *adult* admission process, with little regard for parent authority and involvement. We piloted the patient form, and included two measures of experienced coercion. The correlation between these two measures was  $r_s = .68$ , as for adults. This similarity between the self-anchoring CL and ECS with items of negative valence indicates that adolescents delimit the coercion concept to freedom restrictions that are experienced negatively. Scale revisions or separate development for adolescents is preferable, however. Some other variables were also measured with items adapted or developed for this study, which have not yet been validated.

Generalizability is limited by the sample size and the study context. The organisation of mental health services for children and adolescents shows great variation across countries [43]. In Norway, the proportion of underage persons in contact with the outpatient division of Child and Adolescent Mental Health Services was 5.1 in 2014 [27]. From 1998-2013, around 0.03% of underage persons were hospitalised each year [28], and inpatient adolescent coverage was about 0.5% in 2014.

The sample had a majority of girls (69%), close to the yearly national rates (65%) [27]. Severe diagnoses, such as psychosis, eating disorders, and pervasive developmental disorders made up 36.5% of this sample, while national all-year statistics for 2014 indicates that these disorders amounted to 21% [27]. Our sampling was cross-sectional, and patients with more severe problems often have longer stays and a greater likelihood for sampling than those with shorter stays. We think the reason for a low rate of externalizing behavioural disorders is that inpatient care for this group is often mandated by the Norwegian Child Protection Services.

# **Conclusions**

The level of experienced coercion in adolescent inpatient care found in this study was similar to comparable results for adult inpatient care. Use of coercion is the strongest predictor of

experienced coercion, so use coercion in adolescent mental health care should receive similar attention as in research and policies for adults. Norwegian adolescent wards treated psychosis with little formal coercion, and these patients also reported low experienced coercion.

## List of abbreviations

CGAS: Children's Global Assessment Scale

CL: Coercion Ladder

ECS: Experienced Coercion Scale

HoNOSCA: Health of the Nation Outcome Scales - Children and Adolescents

ICD-10: International Statistical Classification of Diseases and Related Health Problems, 10th

Revision

ICC: Intraclass correlation

#### **Declarations**

## Ethics approval and consent to participate

The study was approved by Regional Committee for Medical and Health Research Ethics, Norway, project No 2011/2574/REK sør-øst. Informed consent for participation in the study was obtained in verbal form, from all participants with additional consent from parents of patients from 13-15 years. No identifiable patient information was demanded by the study design and signing and collecting consent forms would increase transparency, but also the risk for confidentiality breaks. The Ethical committee deemed that a procedure where we asked patients for oral consent before they produced anonymous questionnaire information and allowed using anonymized patient record information was acceptable in this study. The same considerations applied for consent from parents of patients under 16 years.

#### **Consent for publication**

Not applicable

## Availability of data and materials

The dataset analyzed during the current study are available from the corresponding author on reasonable request.

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# **Competing interests**

The authors declare that they have no competing interests.

### **Authors' contributions**

TR, RN and ON planned and designed the study. ON organized data collection, conducted the statistical analyses and drafted the main manuscript. ON, JR, TR and KHB contributed to the interpretation of the data. All authors revised the work critically several times and approved the final manuscript.

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