# Factors affecting shared decision-making in mental health care

A cross-sectional explorative study in specialist mental health care and addiction services

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# Table of contents

Α	cknowledge	ments	i
Τl	hesis summa	ary	ii
N	orsk samme	ndrag [Summary in Norwegian]	.iv
Li	st of papers		v
Α	bbreviations	5	.vi
1.	. Introduc	tion	. 1
	1.1. Me	ntal health care	. 1
	1.1.1.	Historical development	. 1
1.1.2.		Mental disorders	. 2
	1.1.3.	Structural organization of mental health care	. 4
	1.1.4.	Treatment options	. 5
	1.1.5.	Medication treatment	. 5
	Antide	epressants	. 6
	Antips	ychotics	. 6
	Mood	stabilizers	. 7
	Centra	al stimulants	. 7
	Anxiol	ytic agents	. 7
	1.1.6.	Adaptation of treatment to the patients' life	. 7
	1.2. Dev	relopment of user involvement	. 8
	1.3. Sha	red decision-making	. 9
	1.3.1.	Legislative aspects of shared decision-making	10
	1.3.2.	Relevance of shared decision-making	10
	1.3.3.	Shared decision-making in mental health care	10
	1.3.4.	Benefits of shared decision-making	11
	1.3.5.	Barriers and facilitators in shared decision-making	12
	Patien	t perspectives	13
	Clinici	an perspectives	13
	Organ	izational perspectives	14
	1.3.6. S	hared decision-making in treatment with medication	14
	1.3.7. N	Nonitoring shared decision-making	15
	1.4. Kno	wledge gaps	15
2.	. Aims	5	
2	Mathada		10

3.1.		Stuc	ly setting	18
	3.2.	Stuc	ly design	18
	3.3.	Prod	cedures	18
	3.3.	1.	Recruitments	18
	3.3.	2.	Participants	19
	3.3.	2.1.	The patient sample	19
	3.3.	2.2.	The clinician sample	19
	3.4.	Insti	rument applied for the patient sample and the clinician sample	20
	3.4.	1.	The Collaborate	20
	3.5.	Insti	ruments applied for the patient sample	21
	3.5.	1.	The Beliefs about Medicines Questionnaire	21
	3.5.2.		The MedSupport	21
	3.6.	Insti	rument applied for the clinician sample	22
	3.6.	1.	The Patient-Practitioner Orientation Scale	22
	3.7.	Ethi	cs and study approvals	22
	3.8.	B. Data handling and statistical analyses		23
	Statistical analyses for paper I		nalyses for paper I	23
	Statistical analyses for paper II		nalyses for paper II	24
	Statistical analyses for paper III		nalyses for paper III	25
	3.8.	1.	Validation of the MedSupport inventory	26
4	Sum	ımary	of results	28
	4.1.	The	sample	28
	4.1.	1.	The patient sample	28
	4.1.	2.	The clinician sample	30
	4.2.	Pape	er I	31
	4.3.	Pape	er II	31
	4.4.	Pape	er III	32
5	Disc	ussio	n of main findings	34
	5.1	The	patient-clinician relationship	34
	5.2	The	therapeutic atmosphere	36
	5.3	Shar	red decision-making for patients receiving involuntary treatment	36
	5.4	The	MedSupport inventory	37
	5.5	Fact	ors relevant for support	38
	5.6	Gen	der and age	39

5.6	5.1	Experiences of shared decision-making	39
5.6	5.2	Support with medication	39
6.	Met	ethodological considerations	40
6.1		Design	40
6.2	2.	Sample and selection bias	40
6.3	3.	Information bias	42
6.4	١.	Confounding factors	43
6.5	j.	Procedures	43
(	6.5.1	5.1. The MedSupport inventory	43
(	6.5.2	5.2. Patients with multiple diagnoses	43
6.6	ò.	Validity	44
6.7	<b>'</b> .	Strengths	44
6.8	3.	Reading and interpretation of the reports	45
6.9	).	Description of shared decision-making	45
7.	Impl	plications	47
7.1.	Cl	Clinical implications	47
7.2.	In	Implications for future research	47
8.	Cond	nclusion	48
Refer	enc	nces	49

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# Thesis summary

Multiple treatment approaches are presently in use in modern mental health care. Medication is one of the most frequent used treatment options, alone or in combination with other treatments. In the last decades, increased expectations of patient involvement in decisions about treatment in all parts of the health care service have been stated.

Shared decision-making (SDM) is a conceptualization of patient involvement, described as a meeting of two equal parts with different expertise to make a decision: the professional as expert on the discipline, and the patient as expert on his or her own life. Present descriptions of patient preconditions for SDM are mainly restricted to education of the patients. However, the concept needs a broader approach, where the contributions from health professionals and service structures, as well as further sides of patient contribution should be included. We wanted to increase the understanding of how the patients experienced SDM, and how clinicians and organisation of the health care service affect the experience.

We performed an observational cross-sectional study at Division of mental health at Sørlandet hospital in Norway during the third week of January 2017. In the study, 992 patients and 315 clinicians were included. We explored the patients' experiences of SDM; the concurrence of experienced SDM between patients and their clinicians; how the attitudes of the clinician influenced the patient experiences of SDM, and to which degree patients experienced support with medication issues, as preparation for SDM.

The participants reported adequate experiences of SDM. Male patients, patients with diagnoses involving psychotic symptoms, patients with longer treatment durations, and involuntary treated patients experienced less SDM. Patients with longer treatment durations and involuntarily treated patients also had a higher probability of reporting less SDM than their clinician. Patients, whose clinicians expressed a more patient-centred attitude, experienced more SDM. Regarding support with medication, older patients, and patients with beliefs of stronger needs for psychotropic medication experienced more support. Patients with beliefs of higher concern towards use of psychotropic medication experienced less support.

SDM is a complex concept and should pervade the service, and implementing SDM in all parts of the service presupposes multiple approaches. The organization of the health care service, as well as the clinicians and the patients, are important for implementation. In this study, we have pointed out some parts of the service particularly suitable for improving SDM. Further explorations of how SDM

is proportionate to patients, clinicians and the service are needed in order to make appropriate steps	
towards achievement of SDM throughout the service.	

# Norsk sammendrag [Summary in Norwegian]

Flere behandlingsmetoder brukes i dag i moderne psykisk helsevern. Medisiner er en av de hyppigst brukte behandlingsstrategiene, alene eller i kombinasjon med annen behandling. Det er i løpet av de siste tiårene økte forventninger om pasientmedvirkning i alle deler av helsetjenesten hvor det fattes beslutninger om behandling.

Shared decision-making (SDM) er en anerkjent konseptualisering av brukermedvirkning. SDM beskrives som et møte mellom to likeverdige eksperter som fatter beslutninger om videre behandling: helsepersonell som ekspert i faget og pasienten som ekspert på eget liv. På norsk brukes gjerne begrepet samvalg, selv om det i noen sammenhenger kan oppleves upresist. Til nå har utvikling av SDM hovedsakelig fokusert på opplæring av pasienter. For videre utvikling av SDM trengs en bredere tilnærming der andre pasientaspekt enn opplæring er inkludert. I tillegg bør både helsepersonells og tjenestestrukturens roller ha fokus. Derfor ønsket vi å undersøke hvordan pasientene opplever SDM, og hvilke tjenesterelaterte faktorer som påvirker opplevelsen.

Vi utførte en tverrsnittsundersøkelse ved Klinikk for psykisk helse ved Sørlandet sykehus i den tredje uken av januar 2017. Målet var å kartlegge pasientenes opplevelser av SDM, om det var samsvar mellom pasienters og behandleres opplevelse av SDM, om behandleres holdninger påvirker pasienters opplevelse av SDM, og i hvilken grad pasienter opplevde støtte fra tjenesten i å håndtere medisinene sine. Vi inkluderte 992 pasienter og 315 behandlere i studien.

Pasientene rapporterte generelt høy opplevelse av SDM. Mannlige pasienter, pasienter med diagnoser som involverer psykosesymptomer, pasienter med lengre behandlingsvarighet og pasienter underlagt tvungent psykisk helsevern opplevde mindre SDM. Pasienter med lengre behandlingsvarighet og pasienter underlagt tvungent psykisk helsevern hadde også en større sannsynlighet for å rapportere mindre SDM enn sine behandlere. Pasienter, hvis behandler rapporterte en mer pasientfokusert holdning, opplevde mer SDM. Økende alder og sterkere opplevd behov for medisiner var faktorer som økte sannsynligheten for å ha opplevd god støtte i fra tjenesten i å håndtere medisiner, mens større bekymring rundt egen medisinbruk var forbundet med opplevelsen av mindre støtte.

SDM er komplekst å gjennomføre, og implementering forutsetter tiltak i alle deler av tjenesten. Både helsevesenet på organisasjonsnivå, behandlerne og pasientene er viktige for implementering. I denne studien har vi identifisert spesifikke deler av tjenesten der pasientene opplever SDM som lav. Mer kunnskap om hvordan pasient, behandler og tjeneste sammen påvirker SDM er nødvendig for å nå målet om implementering i hele helsetjenesten.

# List of papers

Paper I

Drivenes K, Haaland VØ, Mesel T, Tanum L. Practitioners' positive attitudes promote shared decision-making in mental health care. *Journal of Evaluation in Clinical Practice*. 2019; 1-9.

Paper II

Drivenes K, Haaland VØ, Hauge YL, Vederhus JK, Irgens A, Regevik H, Falk RS, Tanum L. Discrepancy in ratings of shared decision-making between patients and health professionals: A cross-sectional study in mental health care and interdisciplinary specialized addiction services. *Accepted for publication in Frontiers Psychology*.

Paper III

Drivenes K, Vederhus JK, Haaland VØ, Ruud T, Hauge YL, Regevik H, Falk RS, Tanum L. Enabling patients to cope with psychotropic medication in mental health care: Evaluation and reports of the new inventory MedSupport. *Medicine*. 2020;99(1):e18635.

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Other thematically related co-authored papers:

Drivenes K, Bergan S, Saether O. Drug therapy in patients subject to outpatient compulsory mental health care. *European Journal for Person Centered Healthcare 2016 Vol 4 Issue 1 pp1-6.* 

Ruud, T., Drivenes, K., Drake, R.E. et al. The Antipsychotic Medication Management Fidelity Scale: Psychometric properties. *Administration and Policy in Mental Health and Mental Health Services*Research (2020). https://doi.org/10.1007/s10488-020-01018-1

### **Abbreviations**

# **ABBREVIATION FULL FORM BMQ** The Beliefs about Medicines Questionnaire **DALY** Disability-Adjusted Life Year DSM-5 Diagnostic and Statistical Manual of Mental Disorders 5th Revision GP General practitioner ICC Intra-class correlation coefficient **ICD-10** World Health Organization International Classification of Diseases 10th Revision MAO-I Monoamine oxidase inhibitors NICE The National Institute for Health and Care Excellence, the United Kingdom OR Odds ratio **PPOS** Patient-Practitioner Orientation Scale PRO Patient reported outcome SD Standard deviation SDM Shared decision-making SPSS Statistical Package for the Social Sciences SSRI Serotonin reuptake inhibitors **STATA** Software for statistics and data science **TCA** Tricyclic antidepressants UK The United Kingdom WHO World Health Organization

### 1. Introduction

### 1.1. Mental health care

### 1.1.1. Historical development

The World Health Organization (WHO) has defined mental health as 'a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community' (1). Mental disorders include a number of different illnesses presenting different symptoms and functional impairments (2). The symptoms and extents of disability and severity vary widely within individual mental disorders (3). Despite the variations, mental disorders are generally characterized by some combination of abnormal thoughts, emotions, behaviour, and difficulties in relationships with others (4).

The first descriptions of mental disorders are from ancient Egypt, where it was thought that some people could be possessed by demons and lose control of themselves and their actions. However, the ancient Greeks did not distinguish between body and mind, and mental illnesses were described as symptoms of the heart and uterus (5). From the 5th century, Hippocrates's humoral-pathological theory was applied (6, 7). Among the interpretations of mental illness, one was that melancholy originated from too much 'black bile' in the body. This view of health and illness, originating from ancient Greece, was the prevailing understanding in Christian as well as Muslim communities for almost 1,000 years. In contrast, the Roman Empire had a more metaphysical approach to mental illnesses, in which, for example, psychoses were considered to be an expression of possession by spirits (8). This approach bore similarities to that of ancient Egypt. The Egyptian and the Roman understandings of mental health persisted until around the 13th century, when a greater emphasis on anatomy and physiology in the understanding of illness in general challenged the theories of ancient medicine.

Institutions for mentally ill people were established gradually from the first millennium, and were mainly founded by Orders of the Catholic Church. In the 17th century, philosophers like René Descartes advocated a philosophy that regarded the human as a machine, and madness as a manifestation of a bodily defect (9). The philosopher and physician John Locke saw various forms of insanity as cognitive failures. From his point of view, mental illness was primarily a lack of rationality. Locke is now considered an important ancestor to psychology (10).

During the 19th century, there was a close association between mental illness and poverty. In this period, institutions for the mentally ill developed further and were called asylums. The name

indicated the intention of the institutions: to provide shelter and protection for the patients. Additionally, an intention to provide treatment grew, although the treatment possibilities were limited (11). Simultaneously, psychiatry grew as a discipline, and begun to be taught at universities. Throughout the 20th century, various forms of psychotherapy came to exert a great influence on psychiatry. With this, a greater concern with explaining mental illnesses grew. Additionally, an interest in preventing diseases became prevalent, and 'mental hygiene' became an important direction for public psychiatric work. In the second half of the 20th century, public psychiatry turned from mental hospitals to mental health care, reflected in its conceptual use and through legislation. In Norway, the Mental Health Protection Act (12) applied in 1961, and replaced the 'insanity law' (Sinnsykeloven) from 1848 (13), which was the first law in Norway to establish care for mentally ill people as a responsibility of society.

Until the late 19th century, the focus regarding mental illnesses was to protect society from insanity. The needs of society outweighed the needs of the individuals involved. The patients' needs were not considered to be relevant, or they were ignored. Their needs were defined from others, to serve society as a whole. Over the last century, this has changed dramatically. There has been a rapid development of modern mental health care services, and several laws on patient rights and user participation have been adopted (14-16). Additionally, the concept of patient involvement is currently permeating an increasing variety of medical health disciplines (17-20).

In the development of modern mental health care, descriptions about how the patients experience their situation have been lacking. In earlier times, there was no culture for involving the patients' wishes in choices regarding treatment. After World War II, a growing recognition emerged in the population. Organizations that fought for peoples' rights got great endorsements, especially in the United States of America. Individual rights were the main issue, including self-determination over their health and treatment. In Norway, user organizations have kept a focus on this issue, resulting in various laws and recommendations (14, 21-23). However, even today there are shortcomings when it comes to trusting patients to know what is best for them (24-26).

### 1.1.2. Mental disorders

A systematic review found that 30% of respondents worldwide had experienced a mental disorder at some time during their lifetime (27). Unipolar depressions are responsible for most disability in the developed world, measured as Disability-Adjusted Life Years (DALY) (28, 29). DALY is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death. One DALY can be thought of as one lost year of "healthy" life (29). Affective and anxiety disorders are the most common mental disorders in Europe, with an estimated lifetime incidence of

one out of four persons and affecting one third of all patients seeking primary health care (30-32). In Norwegian specialist mental health care and addiction services, affective disorders, anxiety disorders, and substance-related disorders are the most prevalent diagnoses, covering about 70% of patients (33).

The main diagnostic system currently available in Europe for the classification of mental disorders is the WHO International Classification of Diseases, which is on its 10th revision (ICD-10) (34). In the United States, a diagnostic classification developed by the American Psychiatric Association is mainly used. This classification system is called the Diagnostic and Statistical Manual of Mental Disorders, presently on its 5th revision (DSM-5) (35). While the ICD-10 covers both psychiatric and somatic health disorders, the DSM-5 is restricted to mental disorders only. The referrals to diagnoses in this thesis are in accordance with the ICD-10 system.

The F10 *substance-related disorders* are considered as part of the spectrum of mental disorders. The substance-related disorders include addictions to alcohol, opioids, and other illicit or prescribed addictive substances (34). Frequent symptoms are a strong desire or compulsion to use the substance, difficulties with controlling the extent of use, continued use despite negative consequences, and craving symptoms when not using the substance.

The F20 *psychotic disorders* occur less frequently than do affective disorders or anxiety disorders. Nevertheless, psychotic disorders are resource-demanding, due to the long-term treatment perspective, the severe suffering, and the functional losses. Patients suffering from psychotic disorders are often in need of longer-term treatment and care with higher intensities (19, 36) due to greater functional losses and severe symptom pressure. Schizophrenia is the most frequent specific diagnosis among the psychotic disorders. The most common psychotic symptoms are hallucinations (most frequent: hearing, vision; less frequent: odour, taste, touch), delusions, and ideas of persecution.

The *affective disorders* are classified as the F30 group (34). *Affective disorders* include unipolar depressions and bipolar spectrum disorders – both acute and recurrent states – as well as other affective disorders of unipolar or bipolar forms. Frequently occurring symptoms of unipolar depressions are lowered mood, reduced energy and activity, poor self-esteem and confidence, and an impaired ability to rejoice. Bipolar disorders cause periods of varying degrees of excitement (mania), expressed as faster thoughts and speech, a strong self-image, and high motor activity, as well as periods of depression with the same symptomatology as unipolar depressions, often with variable periods without symptoms in between. The manic periods may have the symptoms of psychosis.

The diagnostic group F40 – *anxiety disorders* – includes anxiety disorders and phobias, in addition to obsessions, compulsive acts, and post-traumatic stress disorders (34). Anxiety may be characterized by persistent worries, restlessness, and irritability, or occur as sudden attacks related or not to specific objects or situations. A number of physical symptoms, like breathing difficulties, nausea, numbness, muscle tension, and/or muscle pain may be present in anxiety.

The F60 *personality disorders* include different personality disorders and disorders related to gender and sexuality (34). The symptomatology in the personality disorders includes emotional fluctuations and difficulties in emotion regulation, poor and/or fluctuating self-esteem, and impaired interpersonal function.

From the F90 *behavioural disorders* the attention disorders mainly affecting children and youths are most relevant in this context (34). About one third of the patients diagnosed with F90 during childhood or adolescence carry their symptoms into adulthood (37). A number of adults are diagnosed for the first time as grown-ups. The most prominent symptoms in attention disorders are inattention, hyperactivity, and impulsivity.

## 1.1.3. Structural organization of mental health care

In Norway, the first line community mental health care includes general practitioners (GPs) and community psychiatric teams staffed by psychiatric nurses and, usually, psychologists. General practitioners serve as a hub for all treatment and coordinate the needs of every individual patient (16). Persons in need of more specialized treatment are referred to the specialist level of care, which includes hospitals and private specialists (36, 38). Health care services in Norway are mainly a governmental responsibility, and they are financed by public funds.

Currently, the treatment of mental illnesses at specialist level includes a variety of approaches (23). On the structural level, specialist mental health services offer out-patient treatment to most patients, whereas in-patient treatment and day care treatment are higher levels of care offered to patients with more severe symptoms and/or higher functional losses. Ambulatory care treatment is offered at patients' residents, and is a growing part of mental health services due to guidelines and efforts to meet patients' needs (39). In recent years, there has been a movement away from long-term institutionalization where self-determination is not a focus towards decentralized services centred on patient preferences. The emergence of ambulatory care is a consequence of this movement, focused on patents staying at home, maintaining daily living functions, and receiving treatment in a familiar environment (17).

### 1.1.4. Treatment options

There are different treatment approaches for different mental disorders, and knowledge-based practices are made accessible for clinicians through various guidelines. However, compliance with the guidelines is not straightforward. The choice of effective treatment depends on illness severity and individual factors, as well as on the diagnosis. Additionally, the implementation of clinical guidelines is difficult, often due to insufficiencies in details and measures (40). Patients with high symptom severities and massive losses of function are usually offered in-patient treatment with higher-level care courses and close monitoring. Patients with lower symptom severities are treated at out-patient clinics. Day care treatment and ambulatory treatment are offered mainly to patients with severe mental disorders in more stable phases, as a continuation of in-patient treatment or as an early relapse intervention. The treatment contents are not directly related to the structural organization of the service, although some premises are set. Patients with mild mental disorders are usually not treated at a specialist mental health clinic, but rather are offered treatment at a first-line community level (38).

For patients suffering from a severe mental disorder (i.e. a psychosis or equivalent), where treatment was regarded necessary and/or the patient was considered a danger to him/herself or to others, there is the legal possibility of involuntary admission to psychiatric hospital, or involuntary treatment outside hospital (12). This alternative is managed by the specialist mental health care services, but is externally regulated and monitored by a committee appointed by the Norwegian Board of Health Supervision (41, 42).

### 1.1.5. Medication treatment

Medication is one of the treatment options recommended in guidelines for mental disorders (19, 43-45). The efficacy of medication is related to correct use, and monitoring is essential to reach an optimal treatment outcome. Treatment with medication should follow the protocol for correct use, as the predefined use has shown efficacy in clinical studies that are precursors to bringing the medications to market. To monitor the implementation of recommendations given in clinical guidelines, monitoring instruments are necessary. An example is a recently developed fidelity scale for antipsychotic medication (46).

Psychopharmacological medications differ in their pharmacokinetics, or how the body handles them (47). There are individual variations in the dosage needed for optimal effect and in the frequency of adverse effects. Due to genetic variations, general health conditions, and intake of food or other medicines, metabolic and excretion rates may differ greatly between individuals for some active substances. Additionally, there is great variety in the pharmacodynamics of the substances. The

tolerability and sensitivity to the medication effects differ between individuals. The effect of the substances is potentially amplified by the simultaneous use of other medications that act similarly or weakened by medications that act conversely (48). Thus, tailoring treatment with medication increases the chances of achieving both optimal effects and minimal adverse effects (49).

Individual variations in the effects of medication will only be discussed in this thesis to a limited extent.

### **Antidepressants**

Antidepressants are the most frequently used group of psychopharmacological agents, and are mainly used for affective disorders and anxiety disorders. The first generation of antidepressant agents was developed in the 1950s, and included tricyclic antidepressants (TCAs) and monoamine oxidase inhibitors (MAO-Is). Tricyclic antidepressants are effective for depression and anxiety and are still in use, but their use should be restricted due to their toxicity, especially in elderly patients (50).

Among second-generation antidepressants, selective serotonin reuptake inhibitors (SSRIs) have been the most frequently used antidepressants for the past few decades (51). Their effect is caused by increasing the serotonergic signals of neurons in the brain. Additionally, reuptake inhibitors affecting other monoamine systems have gained applicability, and combined noradrenergic and serotoninergic reuptake inhibition is frequently used (51).

### **Antipsychotics**

Specific antipsychotic treatment with medication started in the 1950s, when dopamine activity in the brain's neural pathways was identified to be relevant for psychotic symptoms. Dopamine antagonists prevent signal transmission and thereby inhibit the dopamine response (52). The substance haloperidol was developed in the late 1950s, and up until today was used for the benchmarking of antipsychotic effects in clinical studies (52-56) when new treatment approaches were explored.

While the dopamine antagonists are regularly referred to as first-generation antipsychotics, medications with other mechanisms of action are called second-generation antipsychotics (57). Based on different theories on the causes of psychosis, new approaches for symptom reduction are introduced (58-60). Currently, the second-generation substances have largely replaced the first-generation antipsychotics, and they are preferred over first-generation medications (36). Second-generation antipsychotics do not show superior effects over first-generation antipsychotics (61, 62), but they inhibit the dopamine receptors to a lesser extent, and they carry out their effects by antagonizing a range of monoamine receptors in addition to dopamine (63, 64).

Antipsychotics are also used in bipolar spectrum disorders, dementia, and in some somatic disorders (65-69).

### Mood stabilizers

A number of mood stabilizers originally intended as epilepsy treatment are currently widely used in the treatment of bipolar disorders, either as monotherapies or in addition to other medications (18, 70, 71). Lithium is an inorganic salt and is among the mood stabilizers most frequently used in bipolar disorders. Mood stabilizers mainly increase the threshold for signal triggering in the brain by blocking ion channels, thereby modifying the release of monoamines for further signalling.

### Central stimulants

Central stimulants are used for hyperkinetic disorders together with psychosocial initiatives (72). Their effects include reducing impulsivity, disorganization, and motoric and mental turbulence (73) and enabling users to better cope with everyday challenges (74). The most frequently used central stimulants are methylphenidate and amphetamine derivates (75).

### Anxiolytic agents

Anxiolytic agents have shown effects for anxiety disorders. For other diagnoses, they are mainly applied as supportive medication or symptom reducers. These symptoms may be part of their disorder, adverse effects from treatment, or additive symptoms in specific phases of the disorders. The most commonly used anxiolytic agents are the benzodiazepines, which are effective short-term treatment. Their usefulness as long-term treatment is limited due to their dependency potential (76).

### 1.1.6. Adaptation of treatment to the patients' life

The quality of health care services is interpreted differently from different perspectives. From the professional point of view, a service may be considered of high quality, adhering to guidelines and meeting the governmental requirements. However, a patient may not percept the quality of a service as adequate due to personal experiences and alternative needs and goals for the treatment. This complexity is a major challenge in the development of modern health care, particularly in services for people with chronic mental diseases (77, 78).

In many situations in mental health care, medication is regarded as a relevant main treatment option (18, 19, 79). Integration of medication-related treatment into patients' lives is essential for adherence, and thus to achieve good treatment outcomes (80, 81). Barber et al. have shown that almost one third of patients with chronic diseases are non-adherent 10 days after starting medication, about half intentionally and half non-intentionally (82). A focus on adherence-enhancing measures has been shown to have positive effects (83, 84). Therefore, it is essential for mental

health care services to support patients in order for them to harness the potential of medication.

Relevant approaches may include empowering patients to take responsibility for their own treatment and adapting treatment to fit with patients' personal lives.

### 1.2. Development of user involvement

In earlier times, people with mental disorders were shielded by society. Today, we may consider the shielding as compulsion, as the patients' needs and preferences were pushed aside in favour of the society's need for security. The expectations of society were driven by the idea that illness was a collective risk (85), and what was best for the group was best for each individual as well. The paternalistic attitudes of health care professionals – and the subsequent obedience from the patients – created a distance between patients and carers, and contributed to blind compliance and less questioning from the patients regarding treatment and treatment plans (86).

The trend towards patient-centredness in health care is a construct developed from gradual changes in the holistic understanding of what it is to be a human being (87). More overriding societal changes regarding social and ethical principles took place during the middle of the 20th century, and the term 'informed consent' came to apply (88). Informed consent is a process in which a health care provider educates a patient about the risks, benefits, and alternatives of a given treatment. The patient must be competent to make a voluntary decision about whether to undergo the said treatment (89). The requirement for informed consent highlighted the patient's view and was an important step in changing health care from a paternalistic institution to a service where patients' preferences are included in treatment decisions. From the middle of the 20th century and up until today, the focus of modern health care services has progressively moved from curing illness towards a broader care perspective, where patient perspectives, quality of life, and empowerment of individuals are taken into account (90). This has also contributed to a shift from focusing solely on scientific explanations to relieve patients' suffering, towards a state where clinicians understand the patient as a unique human being and offer treatment with this additional recognition in mind (87). There are multiple motivations for patient participation in treatment decisions: that legislation emphasizes the right to autonomy, that professionals consider a patient's competence a prerequisite for decision-making, and that patients carry responsibility for treatment if they are involved in the treatment decisions (91).

The Council of Europe has stated that a patient should be regarded as 'an agent of change instead of a passive object of care', and that the clinician role is to 'defend the dignity of the individual and catalyse the commitment of the patient as the subject of his/her speech' (92). This statement has entailed a shift for the health services from treatment-oriented to patient-oriented (93), recognizing

that patients hold a specific competence essential for treatment success. This new perspective needed a structured approach from health care services to translate the intentions into clinical work. Decision-making processes are founded on the recognition that participants' contributions evolve in a socially distributed process, where a more extensive knowledge than the individual knowledge carried by each participant evolves (94). One concept developed to deal with this is shared decision-making (SDM).

### 1.3. Shared decision-making

Shared decision-making has evolved from the dawning of the recognition to place the patient – rather than the disease or the health care service itself – at the centre of health care (95). It emphasizes the principles of patient-centred care, and is unlikely to be developed and exhibited unless the clinicians agree with the guiding ethical principles (96). Health care services have gradually turned their focuses towards individual needs and expectations. This transformation has been facilitated through expectations from authorities, patient organizations, and health care services themselves.

Shared decision-making is a conceptualization of the mutual process whereby the patient and the clinician acknowledge each other's expertise and collaboratively identify the best treatment decisions (97). The interdependence has been underscored by Drake and Deegan, who set up SDM as an ethical imperative, addressing the moral obligation included in all professional practice (98). Nevertheless, recent literature suggests there may be provisos from clinicians in SDM practice (24, 99). Ethics are strongly associated with SDM, and there is hope for better treatment outcomes as patients become more familiar with their own illnesses and suffering, get a better understanding of treatment options, and achieve the opportunity to influence their treatment course as desired (100-104).

A variety of definitions of SDM have been suggested since the concept was introduced in the 1990s (105). An early description of SDM states that it involves at least two parties: a patient and a clinician (106). Most commonly used is the definition by Glen Elwyn: SDM is 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preferences' (107). The core components of SDM are not unambiguously described, but the most frequently used components are patient values and options (108). A crucial prerequisite for enabling SDM is that the perspectives of patients and clinicians are equally valued despite being different in many aspects (108).

Shared decision-making practice requires that the patient and the clinician both actively participate in making decisions about treatment. The patient must be provided with sufficient knowledge about the pros and cons of different treatment possibilities to be able to make informed choices in line with his or her own perspectives and views on life, and real choices must exist (108, 109).

### 1.3.1. Legislative aspects of shared decision-making

To participate in decisions about treatment is currently stated as a right for patients, and is enshrined in the Norwegian Patient and User Rights Act (14). This statutory right is derived from respect for the individual patient's right to self-determination, and in the context of this principle, health care should be provided with the patients' consent. The National Institute of Health and Care Excellence (NICE) in the United Kingdom (UK) has stated that SDM is a key point with regard to medicine optimization (91). Additionally, the first principle in the Royal Pharmaceutical Society's good practice guidelines on medicine optimization published in 2013, is 'aim to understand the patient's experience' (110). In the Netherlands, patient participation in medical decision-making is a widespread research topic theme (111). A Norwegian public inquiry from 2018 entitled 'First things first' has called SDM a requirement for patients to perceive treatment initiatives as useful (112). Today, the principal is rooted in the specialist care level in the Norwegian health services system, including in the National Health and Hospital Plan (23, 113).

### 1.3.2. Relevance of shared decision-making

Expectations regarding a focus on patients beyond their illnesses are increasing. Health leaders and governmental authorities have continuously expressed stronger expectations for the inclusion of SDM in all decisions about treatment in health care (22, 114). Shared decision-making is considered fundamental to safe and effective health care when licit options are available to the patients (115). Decision-making processes aim to provide space for the mutual exchange of information and interpretations of the situation, which should converge into a shared decision based on the knowledge of different experts (94). Such processes are suggested to lead to better treatment choices that support patients' individual needs (116). Individual needs comprise the perspectives of the patient, including family traditions and cultural affiliations (117). It is a prerequisite for fulfilling the SDM process that the healthcare service facilitate and encourage the patient in bringing individual perspectives into the process.

### 1.3.3. Shared decision-making in mental health care

Morant et al. have suggested that the understanding of SDM as a process restricted to one clinical encounter, in which the patient and the clinician make a decision, is too narrow and limited for mental health care (118). This perspective lies in the nature of mental illnesses and the demand for

complex management. This model for understanding is emphasized by a review concerning SDM for patients with psychotic disorders and related disorders (119). Shared decision-making in mental health care includes longer term relationships, and applies in a context where other key players, like people in the patients' supportive network, are included (120). Additionally, functional and cultural features of the health care system are relevant, as well as the recognition that mental illnesses evolve through periods of recovery and relapse (97, 118, 119). This multiple involvement and long-term perspective emphasize the complexity of the SDM processes in mental health care. Clayman et al. have stated that SDM is an ongoing process for patients and their relatives (90). These elements call for considering SDM in mental health care as a continuous, multi-person process (121, 122).

Ozdemic and Finkelstein have suggested that the long-time nature of chronic conditions provides knowledge of how the illness and its suffering is understood by the patient. According to this, we should be aware of changes in the patients' self as they are recovering, and through possible relapses (123). Previous work has revealed that patients' preferences for involvement in SDM processes are likely to develop over time as they gain experience. Additionally, their preferences may change at different stages of their illness (124). This might reveal a gap between the scientific explanation of the condition and the patients' understanding of their suffering and the restrictions in their lives. The health care service should attempt to narrow this gap through increasing application of SDM. This obligation is supported by Scholl and Barr, who have emphasized the need for translating knowledge from implementation science into mental health care in order to implement SDM (125).

Narrowing the gap between the patient understanding and the professional understanding is further challenged by involuntary treatment. Although involuntary treatment may include lapse of participation in treatment decisions, efforts from health care service to include the patients in such decisions may improve the patient experience (126). It is a comprehensive task for the health care service to handle the potential contrast between involuntary treatment and SDM well.

### 1.3.4. Benefits of shared decision-making

Shared decision-making has been demonstrated to improve decision quality across clinical specialties (25). As with other chronic diseases, patients within mental health care wish to participate in decision-making, and are particularly interested in taking a more active role in relation to psychopharmacologic medication (100). Within mental health care and addiction services, studies have suggested that shared decision-making provides better patient satisfaction and higher experiences of autonomy (127), which may also have positive impacts on compliance (128). Shared decision-making is suggested to prevent cases of non-adherence to treatment based on disagreement (129), and it is valued by patients (130).

The goal for SDM is to optimize treatment regimens in line with patients' wishes and needs (131). A systematic review suggested that higher perceptions of SDM by the patient increases beneficial affective-cognitive outcomes, but findings related to improvements in health outcomes were lacking (132). As SDM is based on the acknowledgement of the patients' expertise, the term contains an underlying factor of a relationship and mutual recognition between patient and clinician, which is suggested, for example, to improve medication adherence (83). A systematic review found one study that suggested that patient education regarding disease characteristics and treatment possibilities increased patient satisfaction (133).

Although SDM is considered to be the gold standard when it comes to decision-making in the health care services and recommended by authorities in Western countries (115), its benefits are difficult to demonstrate and its prevalence is inadequate (114, 134). Previous studies with aims to evaluate the implementation of SDM in mental health care have mainly focused on elements describing the benefits of SDM education for patients (22, 135, 136). More positive experiences with SDM in this regard have been associated with higher patient age and the female gender (137), but patients are also reported to be unaware that decisions have been made, and do not feel that they could or should have participated in them (138).

### 1.3.5. Barriers and facilitators in shared decision-making

Earlier studies have suggested that the clinicians' attitudes towards patient-centredness, but not the patients' attitudes, are important for generating higher patient satisfaction, better treatment adherence, and improved health outcome (139, 140). The converse has also been postulated: that patients whose doctors were less patient-centred were less satisfied (141). It has been suggested that the application of different clinician behavioural styles fit patients with equal orientations at best (139). Hence, not all clinicians necessarily need to show patient-centred attitudes, or develop these attitudes further in order to increase patient satisfaction. However, a large discrepancy between clinician behavioural styles and patient orientations might indicate that the patient and clinician do not share or communicate common goals or that they do not have a similar appreciation of the usefulness of the treatment.

A systematic review concerning patient-reported barriers and facilitators for SDM revealed two analytical themes: how the health care system is organized, and what happens during the decision-making interaction (142). The review argued that barriers to SDM at the clinician- and organizational-levels and patient-reported barriers should be addressed simultaneously to implement SDM throughout health care services.

An earlier study has shown that a good relationship between the patient and the clinician is one of the most important factors in patient satisfaction (143). An evaluation of a SDM implementation programs claimed that implementation requires clinicians as well as patients to undergo attitudinal shifts (144). Experts have argued that a broader assessment of SDM would provide a more substantive evidence base with which to guide implementation (145).

### Patient perspectives

Traditionally, compliance to treatment has been defined as how closely patients follow the treatment instructions given by clinicians. A range of methods, both electronic and manual, have been developed to assess compliance to medications (146-148). All methods aim to detect whether the patient takes the medicines as prescribed by their doctor. Studies have shown that adherence improvements are difficult to obtain, even with cost-intensive initiatives (149-151).

Today, the paternalistic attitude where patients are regarded as passive recipients of treatment has been replaced by the understanding that patients should have active roles in decisions regarding their treatment (152). Better treatment outcomes are suggested for patients included in the decision-making process (153). Education and awareness are two synergistic factors influencing patients' abilities to take hold of their own lives and health (154), and are premises for establishing SDM.

It is a prerequisite that patients become aware of their own perspectives and needs, but it is equally important that patients understand what their choices entail. In other words, what will be the consequences of the choices made? To handle this matter properly, training and information from the heath care service are required. A systematic review has suggested using evidence-based tools to engage patients in SDM (155). Importantly, SDM cannot be performed at a group level. The decision process will be different for different patients, precisely because they have individual needs and preferences.

### Clinician perspectives

It is well-known that attitudes among those involved are important in the implementation of new knowledge from science into practise. There is need for a new understanding of the role of attitudes among clinicians to decrease the gap between patients' perceptions and professionals' attitudes (120). For example, efforts from clinicians to provide patients with the best evidence about available treatment are futile if the patient refuses to take medication, even with the knowledge that medication will enable them to live a 'normal' life (156). To face this challenge, changes in the attitudes of clinicians are suggested to be necessary in order to fully integrate the concept of SDM in all areas where treatment is offered (157). A study from 2006 on a general patient population and

their GPs suggested that the GPs' positive attitudes towards SDM had a positive effect on patient satisfaction (158). Even patients not wanting to actively participate in SDM were more satisfied with treatment if their GPs showed a positive attitude towards SDM. The authors' suggested explanation for this was that the GPs who were positive to SDM were more responsive to their patients' needs.

### Organizational perspectives

The content of mental health services is ultimately the clinicians, including their attitudes, skills, and working methods, and the clinicians' attitudes are necessary to improve and maintain treatment quality (95, 159). The development of an autonomous patient capable of practicing SDM requires the health care service to be the driving force. Patients developing knowledge is suggested to facilitate effective treatment and positive treatment outcomes (109, 160). The focus on factors relevant to positive treatment outcomes has recently shifted from looking at solely the efficacy of the treatment itself to including the structural and organizational factors of the service (161, 162).

### 1.3.6. Shared decision-making in treatment with medication

There is growing interest in the benefits of SDM in the decision-making processes regarding treatment with medication. A study from the UK explored the use of a tool designed to enhance collaborative antipsychotic prescription (163). The study identified a dissonance in clinicians' and patients' perceptions of each other that challenged the mutual recognition of each other's expertise, which is a prerequisite for SDM. A recent study concerning the discontinuation of antidepressants revealed that more guidance from professionals lowered discontinuation rates (164). Community pharmacies have initiated medication counselling among patients with long-term conditions, including mental health conditions, as a measure to facilitate and monitor SDM. Their suggestion is that additional initiatives from community pharmacies are advantageous in supporting SDM, and that patients request such initiatives (165, 166).

A recent qualitative study revealed information about medication important for medication adherence (167). Descriptions of patients' lack of knowledge regarding medication exist, although the associations between knowledge and medication adherence remain unclear (168). A qualitative review concerning influences on SDM experiences pointed out the necessity of tailoring the education of patients regarding medication (169). Patients' knowledge about medication use varies, and professionals' skills in providing knowledge in a reasonable way for individual patients are emphasized. In line with this, the development of competence among patients regarding their medication is a step to make patients capable of participating in SDM by clarifying and expressing their opinions in decision-making situations (170).

### 1.3.7. Monitoring shared decision-making

A number of instruments for assessing SDM have been developed and validated. The available instruments are interviews, paper-based self-report forms, interactive voice response calls, or operations on tablet computers (108, 171, 172). Assessments of SDM can be done during visits at a health care service or retrospectively (173). Despite the development of diverse instruments to measure SDM, a systematic literature review called for patient-relevant disease-related endpoints of sufficient quality to assess SDM, as insufficiencies in the present literature were revealed (134). Additionally, the available monitoring options have been criticized as being too technical, and leaving important aspects like empathy, respect, and interpersonal skills out (174).

A systematic review concluded that there is a scarcity of generic measures of medication experiences among adult patients living with chronic diseases (175). The newly validated Living with Medicines Questionnaire concerns patients' experiences on medicine use, but does not include the topic of support for medication use (176, 177). A cross-sectional study on patients diagnosed with schizophrenia revealed that patients lacked knowledge about their medication, but increased knowledge did not directly increase medication adherence (168). This underpins the need to expand medicine management designs beyond adherence, which is also stated in a literature synthesis (166). Patient-related factors are suggested to be relevant in the knowledge of medication and experiences of support (168, 178), and feasible instruments are necessary to monitor support and develop support initiatives.

### 1.4. Knowledge gaps

To further improve the patient involvement in decision-making processes, extended knowledge about how the health care service includes patient perspectives is needed. Previous studies with the aim to evaluate the implementation of SDM in mental health care have focused on elements describing the patient benefits from SDM education (22, 135, 136), but this framework has been criticized for being too narrow. Shared decision-making processes in mental health care are considered continuous or recurrently occurring because patients' illnesses develop over time. This calls for considering SDM in mental health care as a multi-person process and part of a wider context, not to be completed within a limited period or with a single decision (121, 122). However, points of action to meet this complexity are not well described.

Even though is the consensus that SDM is the 'right' thing to do, efforts to achieve SDM have usually fallen short when it comes to incorporating the broader range of factors relevant for successful accomplishment (145). This emphasizes the complexity of SDM and the need for addressing patient-, clinician-, and structure-relevant factors in order to make SDM the norm in mental health care

services (142). Moreover, even if there is agreement on implementing SDM, we do not have a common education or a consensus on what 'sufficient' SDM includes, or a common set of attitudes or skills to apply when exploring these processes (179).

We lack consistent knowledge regarding the relationship between patient knowledge of diseases and treatment, in particular with medications, and patient satisfaction. Shared decision-making is stated to have the potential to better tailor psychiatric medication (118), but how SDM can be exploited for this purpose is presently not sufficiently explored. There are only a few scales to measure how patients receive support to handle their medication, even though medication is one of the most frequently used treatment options in health care services today. Thus, a global instrument to assess support, regardless of diagnosis or medication, would be useful.

# 2. Aims

The overall objectives for this thesis were to 1) generate knowledge on SDM in mental health care and addiction services, to 2) describe factors important for SDM, 3) to evaluate a new instrument to assess health care services' support for patients regarding medication issues, and to 4) investigate factors important to patients' perceptions of such support.

This led to the following specific aims:

- 1. to describe the person-centred and disease-centred attitudes of clinicians (paper I),
- 2. to describe patients' and their clinicians' experiences of SDM (paper II),
- 3. to describe the congruence in SDM experiences between patients and their clinicians (paper II),
- 4. to identify factors associated with situations in which patients' SDM experiences were more negative than their clinicians' experiences (paper II),
- 5. to investigate the influence of clinicians' attitudes on patients' perceptions of SDM (paper I),
- 6. to evaluate the internal consistency of the MedSupport inventory (paper III),
- 7. to describe patients' perceptions of support with medication (paper III), and
- 8. to investigate factors influencing patients' perceptions of support with medication (paper III).

# 3. Methods

### 3.1. Study setting

This thesis is based on a study at the Division of Mental Health Care and Addiction Services at Sørlandet hospital trust in the southern part of Norway. The hospital provides specialist level care for both rural and urban communities, covering a population of 307,000 (180). The Division of Mental Health has 12 different locations that provide the following levels of care: ambulatory care, day care, in-patient care, and out-patient care. The Division offers treatment for patients with mental and/or substance use disorders. All patients have referrals from their GPs. The Division serves those with medium to severe illnesses including considerable functional losses. The Division provides general mental health treatment, forensic psychiatry, child and adolescent psychiatry, geriatric psychiatry, and treatment for substance use disorders for the region. It holds 280 beds, and manages 4,150 admissions and 184,000 consultations per year (181).

### 3.2. Study design

We performed a cross-sectional study with data collection during the third week of January 2017. We included patients and clinicians from all locations and levels of care at the Division of Mental Health.

All data collected was based on self-report questionnaires answered by patients and clinicians.

### 3.3. Procedures

### 3.3.1. Recruitments

For the recruitment preparation, we gave written information by e-mail to relevant staff at the Division prior to the study conduction. Moreover, we announced the study through leaflets in waiting rooms and in other areas of the hospital available to patients. We also arranged information meetings at the different locations for the staff to further inform and motivate them for recruitment.

We included patients 16 years of age or older with at least one earlier appointment at the service. Patients with more than one appointment at the division within the study week were only included at their first visit. Patients were not included if, for any reason, their clinician contraindicated participation, or if the patients were unable to complete a paper-based questionnaire. Only patients who could read the Norwegian language were included.

We included clinicians with independent treatment responsibilities who were on duty during the study week.

### 3.3.2. Participants

### 3.3.2.1. The patient sample

Following inclusion, the clinicians or members of the staff handed out the questionnaires to the patients. The patients were provided with a place to sit down, and answered the questions directly after their clinical visits. Then, the members of the staff collected the completed patient questionnaires. The patient questionnaires included questions about age, gender, intake of medicines on the day before, medicines used occasionally, the CollaboRATE, the specific section of the Beliefs about Medicine Questionnaire (BMQ-specific), and the MedSupport. After patient completion, the clinicians with treatment responsibility for the individual patients filled out a corresponding clinician questionnaire regarding the individual patient for the patient sample requesting information about main diagnosis, level of care, treatment duration, any involuntary treatment, and a clinician rating of patient involvement in the last decision-making situation using the CollaboRATE (figure 1).

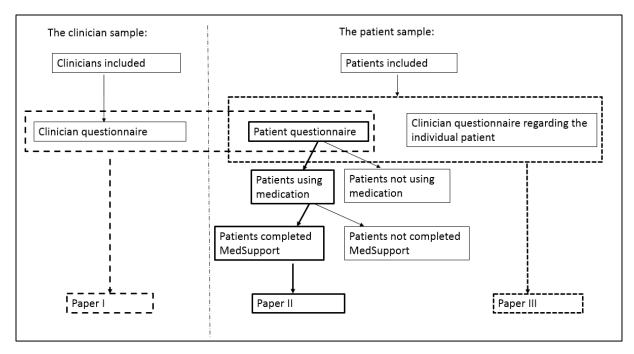
For paper II, the patient sample was the subject of the investigation. The n=992 patients received treatment from n=267 clinicians. We explored experiences of SDM in patients and clinicians by comparing the CollaboRATE scores from the patients to the CollaboRATE scores from their corresponding clinicians. We also investigated the congruence of the CollaboRATE scores and factors of importance for congruence.

The patient sample formed the basis for paper III. Data from the patients who used medication for their mental health concerns and completed the new inventory MedSupport was used to evaluate the MedSupport and to explore patients' experiences of support regarding medication issues.

### 3.3.2.2. The clinician sample

The questionnaires for the clinician sample included questions regarding age, gender, profession, examination year, working site (level of care), and the Patient-Practitioner Orientation scale (PPOS). The clinicians completed the questionnaires at their working sites within the study week and the staff collected them.

We based paper I on the clinician sample, which was linked to the patient sample in a mixed method model. From the linking, we got patient-clinician pairs available for exploration. There was n=206 clinicians in the clinician sample who had treatment responsibility for one or more patients in the patient sample – a total of n=772 patients. We explored the clinicians' answers to the PPOS, and associations between the clinicians' answers to the PPOS and the patients' responses to Collaborate.



**Figure 1.** Overview of the patients and clinicians included in the study.

### 3.4. Instrument applied for the patient sample and the clinician sample

### 3.4.1. The CollaboRATE

We based the experiences of SDM presented in this thesis on the CollaboRATE instrument. The CollaboRATE instrument is a well-validated pen-and-paper self-reporting assessment tool that has been shown useful in different patient populations and at different levels of care (137). The CollaboRATE was developed to accommodate both patients' and clinicians' experiences, and was thus collected from both (96). It comprises three questions related to the following themes: education about the health situation, whether professionals pay attention to what matters most to the patient, and the inclusion of patients' preferences in treatment decisions. Response options are ordinal on a scale 0-9, where 0 represents 'no effort was made' and 9 'every effort was made' (182). The responses from the three questions were summed, giving a score of 0-27. According to the CollaboRATE manual, we multiplied the ordinal score by 3.704 to get a recalculated response percentage score between 0 and 100. We were aware of a reported ceiling effect with patient-reported SDM (137, 182, 183). The patients reported their experienced SDM, referring to their latest decisional situation regarding treatment, and the clinicians reported their SDM experiences on the same decisional situation. Hence, it was possible to explore concurrence regarding SDM experiences.

### 3.5. Instruments applied for the patient sample

### 3.5.1. The Beliefs about Medicines Questionnaire

The Beliefs about Medicines Questionnaire (BMQ), developed by Horne et al., is an instrument for assessing patients' beliefs about their medication (184). It is available in several versions for patients and clinicians, and has been translated into Norwegian and validated for use in psychiatric practice (184-188). We applied one part of the BMQ instrument: the BMQ-specific, which concerns patients' present use of medication. The 10-item BMQ questionnaire comprises two five-item factors regarding beliefs about medication prescribed. The two factors are beliefs about the necessity of prescribed medication (need-score), and beliefs about the danger of dependence and long-term toxicity and the disruptive effects of medication (concern-score) (184). The items are presented as statements and are scored by the patients on a five-point Likert scale, which ranges from one (strongly disagree) to five (strongly agree), with three as a neutral mid-point. Calculations of need-scores and concern-scores were done by summarizing the scores on the five corresponding items related to each factor. Higher scores referred to stronger beliefs.

### 3.5.2. The MedSupport

The MedSupport inventory is a newly developed six-item instrument to assess whether patients have received support in dealing with medications. A task force consisting of clinicians and researchers in Norway constructed it for an ongoing Norwegian multi-centre cluster randomized study on the implementation of guidelines and evidence-based treatment of psychoses. However, it has not yet been validated (43).

The MedSupport inventory was equipped with answer options on a five-point Likert scale. Patients expressed how they agreed with each statement on a scale from one (strongly disagree) and five (strongly agree), with three as a neutral mid-point. A higher mean score indicated that the patients perceived better support for the measured core aspects of using medicines. An important issue for the task force when constructing the questionnaire was that every item should contain a reasonable alternative for all patients. This premise was fulfilled by providing a 'not applicable' alternative. This is shown as a separate response alternative in Figure 2. We calculated a mean score for the cases where at least four out of the six questions were answered, as these cases were included in the validation procedures.

The first five questions in the MedSupport questionnaire are statements covering core aspects regarding patients' perceived support with medication, including the experienced need for medication, how to optimize psychotropic medication, ways to remember to take medication, how to reduce adverse effects, and how to recognize the improvement of symptoms due to medication. The last question discloses the perceived cooperation between the mental health care service and

the GP. For publication purposes, the MedSupport was translated into English, and then back-translated by a professional translation company (189).

### 3.6. Instrument applied for the clinician sample

### 3.6.1. The Patient-Practitioner Orientation Scale

The Patient Practitioner Orientation Scale (PPOS) explores attitudes towards SDM among clinicians (139, 190). The instrument is a self-report assessment tool that has been validated and translated into Norwegian and has been used in previous studies (158, 190). The paper-and-pencil instrument was originally developed to measure patients' attitudes towards their roles in medical care and is well-validated for this purpose. Later, the instrument was refined to measure clinicians' attitudes. Validation studies have suggested that the PPOS is an indicator of doctor-patient fit, and a suitable measure to explore the extent to which provider orientation influences patient communication (140, 141). The PPOS consists of 18 statements through which the clinicians rated the degree of agreement on sharing information and power during the visits. The ratings are on a six-point Likert scale, with one corresponding to 'strongly agree' and six corresponding to 'strongly disagree'. Nine of the statements refer to the sharing dimension, explained as an expression for a patient-centred behavioural style. The remaining statements refer to the caring dimension, described as a diseasecentred behavioural style. According to the manual, the sharing and caring dimensions represent independent features, and are not appropriate for comparison (190). A third behavioural style – the doctor-centred style – is expressed by low scores on both dimensions, but this is not further explored in this thesis.

### 3.7. Ethics and study approvals

The study was conducted according to the Helsinki Declaration with written consent for participation and the insurance of no harm to the patients (191). Patients gave written consent for participation after being given oral and written information on the study. The consent included questioning the patient and their corresponding clinician about patient matters. For the clinician sample, the clinicians gave a separate written consent after being given oral and written information. The consent included a paragraph dealing with the possibility of withdrawing from the study at any time without further questioning and a contact person for this matter.

Patients in mental health care can be a vulnerable group of patients. Despite this not being an intervention study, it might be unfavourable for some patients and eventually lead to emotional reactions or regress in the treatment processes. Therefore, the clinicians made individual decisions as to whether each patient was fit for inclusion in the study after individual reviews.

In general, the purpose of study participation is to facilitate the development of better health care services beneficial to future patients. The benefits are seldom significant to each single participant. However, in the present study it was a possibility that the questionnaires acted as incentives for the patient and the clinician to focus on SDM in the treatment courses. Additionally, included patients potentially gained something from participation in that they might be in need of future treatment from mental health care services, and thereby profit from developments of the service due to the findings in the present study.

The study obtained permission from the copyright holders of the CollaboRATE and the BMQ instruments.

The Division of Mental health, Sørlandet hospital, Norway, and South Eastern Norway Hospital Pharmacy Enterprise, Norway funded the study. The study was approved by The Norwegian Regional Committees for Medical and Health Research Ethics 21.11.2016 (no 2016/1781) and the Research Department at Sørlandet Hospital (including the Data Protection Officer) 18.01.2017 (no 17/00104).

### 3.8. Data handling and statistical analyses

We used EpiData 3.1 to manually record all responses in the study. An independent researcher controlled a randomly selected sample of the responses to ensure the quality of the registrations, and less than 2% errors were found. Thereafter, all collected data was exported to IBM SPSS Statistics 23 prior to statistical analyses (192). We used Microsoft Excel 2013 to visualize data results. We used the Statistical software package (STATA), release 15 (193) to perform and present the mixed effect models in papers I and II.

For the descriptive statistics, we performed Pearson's Chi square tests to compare patient groups on categorical variables such as gender, diagnosis, and level of care. We used independent t-test to compare patient groups for continuous variables. One of the prerequisites for a t-test is normal distribution, which was verified by looking at the histogram of the data. We checked the assumption of similar variance using Levene's test. If this assumption was not met, we used a modified t-test where equal variances were not assumed. For the regression analyses, we presented the results as beta coefficients and odds ratios (ORs) with 95% confidence intervals. We considered an association with a p-value < 0.05 as statistically significant.

### Statistical analyses for paper I

We performed descriptive analyses to explore the Patient-Practitioner Orientation Scale (PPOS) reports from the clinicians. We kept the clinicians' age continuous in the analyses, as we assumed a linear effect. We divided the professions into five groups for the descriptive presentation: medical

doctors, psychiatrists, psychologists, psychologists with a postgraduate clinical specialization, and college-educated clinicians including nurses, social workers, and pedagogues. Clinicians holding other professions were not included in the analyses. We set the college-educated clinicians as a reference group, due to the majority of clinicians being in this group. The clinicians' working sites, where the patients received their treatment, were called levels of care according to patient treatment and categorized into four groups: out-patient care, ambulatory care, day care, and in-patient care. The group of clinicians working in out-patient care was set as a reference group during analyses, as this level of care was provided to the majority of patients, and out-patient treatment is regarded as the cornerstone of the services offered by specialist mental health care among the clinicians.

To investigate possible associations between the clinicians' reports on PPOS and the patients' reports on CollaboRATE, we set up a mixed effect logistic regression model. The patients' CollaboRATE scores were dichotomized, and scores of more than 80 were defined as 'high' SDM scores and used as the outcome variable. The dependency structure of the data – that the different sets of patients and clinicians were connected to each other – was taken into account by adding random effects into the model. Fixed effects were the factors of interest. We kept the two dimensions (sharing and caring) of the PPOS scores as continuous variables that were independent of each other during analyses. Medical doctors and psychiatrists were merged into one group. The psychologists with or without clinical specialization were merged into a second group. The college-educated clinicians were kept as a third group. We did this due to the similarity in educational topics and clinical tasks and limited numbers in some of the groups used for descriptive analyses. The medical doctor group was set as reference group in the regression analyses because of their main role in treatment-related decisions. Results were presented as odds ratios with 95% confidence intervals.

### Statistical analyses for paper II

To describe the CollaboRATE scores among the cases, we presented frequencies, proportions, and means and standard deviations. Age was considered a continuous variable, while gender, use of psychotropic medication (yes/no), and involuntary treatment (yes/no) were dichotomized. The patients' diagnoses were categorized into diagnostic groups according to the ICD-10 (34), although we rearranged the diagnoses where psychotic symptoms regularly occur. The diagnostic groups used for analyses were: F10 substance-related disorders; F20 plus the F30 subgroups F30.1, F30.2, F30.8, F30.9, F31.1, F31.2, F31.5, F32.3, and F33.3 psychotic disorders; the remaining F30 subgroups affective disorders; F40 anxiety disorders; F60 personality disorders; and F90 behavioural disorders. We merged patients with other main diagnoses into the group 'other'. We dichotomized treatment duration with a cut-off of 2.2 years, which corresponded to the median treatment duration. We

could not retain treatment duration as a continuous variable as there was no linear relationship to the dependent variable. The levels of care were categorized into four groups (in-patient care, day care, ambulatory care, and out-patient care).

We calculated SDM dyadic deviation values for the patient-clinician pairs, which we thereafter dichotomized. The basis for the calculation was the patient's CollaboRATE score minus the clinician's corresponding score. According to a consensus between members of the local expert group that initiated the study and clinicians experienced in the field, a clinically relevant negative difference between patient and clinician experiences was defined by a cut off value set to −22 on the Collaborate (range 0-100). When the negative discrepancy was -22 or lower, the patients reported at least six points less than their clinicians did on the CollaboRATE ordinal scale (range 0-27), corresponding to mean two points less per question. Shared decision-making dyadic deviation values of ≤-22 were classified as being in disagreement, whereas patient-clinician pairs with SDM dyadic deviation values of >-22 were classified as being in agreement. To take into account the nonindependence in the data, we performed mixed effect logistic regression analyses to identity variables that influenced the SDM dyadic deviation value. Then, patients belonging to the same therapist were grouped together, and dependencies within therapist were estimated by including a random effect to the model. First, univariable analyses of the following variables were performed: age, gender, diagnosis, level of care, involuntary treatment, drug treatment, and treatment duration. The purposeful selection approach was used for the selection of variables (194). Variables with a p value of <0.2 were included in the multiple analyses. Then, the variables with the largest p values were deleted one-by-one until all variables were significant at the 5% level. The results were presented as odds ratios with 95% confidence intervals.

Additionally, we performed a sensitivity analysis to study the sensitivity of the chosen cut point of -22 for the reported SDM. The logistic regression analysis was repeated for cut point values of -18 and -26 respectively.

Given the expected correlations between patients' and clinicians' SDM responses, we used an intraclass correlation coefficient (ICC) analysis (194) to identify the correlations. We used Spearman's rho to measure the strength of association between the patients' SDM responses and the SDM dyadic deviation value.

#### Statistical analyses for paper III

The reliability of the MedSupport inventory was tested with Cronbach's alpha coefficient to establish internal consistency. We identified the latent factor structure by exploratory factor analysis with the

maximum likelihood technique to test the dimensionality of the MedSupport. Factors were identified by promax oblique rotation. We used the Kaiser eigenvalue-greater-than-one rule to determine the number of factors. We applied Pearson's correlation to evaluate the concurrent validity of MedSupport by identifying correlations to the scores on BMQ needs and BMQ concerns and to explore correlations between the items in the scale. Thereafter, we explored discriminant validity by comparing the means of MedSupport scores between patients subject to involuntary treatment and voluntarily treated patients.

We performed descriptive analyses to describe the patient population and to examine patients' perceptions of the support given. Results were expressed as frequencies, proportions, means, and standard deviations. Age at inclusion showed a linear relationship with MedSupport, and was presented per 10 years in the regression analyses. We considered gender (male/female) and involuntary treatment (yes/no) as dichotomic variables. The median treatment duration was used as a cut-off value to dichotomize the variable to distinguish longer- from shorter- term treatment. We categorized treatment into four different levels of care: ambulatory care, day care, in-patient care, and out-patient care. The out-patient care group was set as a reference category in the analyses, as the majority of the included patients were in this group. The diagnoses were classified as F10 substance-related disorders, F20 psychotic disorders, F30 affective disorders, F40 anxiety disorders, F60 personality disorders, and F90 behavioural disorders. We kept the two factors BMQ needs and BMQ concerns continuous.

We set up univariable and multivariable linear regression models to explore associations with MedSupport scores. The following variables were considered relevant for the extent of support regarding medication: age, gender, diagnosis, any compulsion, treatment durations, and levels of care. The diagnosis group affective disorders F30 was set as the reference diagnostic group in the regression analyses, as it was the most frequent diagnosis group among the included patients. The two BMQ-specific factors – the BMQ needs and the BMQ concerns – were analysed separately in the regression models as two independent continuous variables. Results were presented as beta coefficients with 95% confidence intervals.

#### 3.8.1. Validation of the MedSupport inventory

The MedSupport is a newly developed, non-validated instrument. We performed statistical analyses to evaluate its properties. We analysed the reliability by measuring the Cronbach's alpha coefficient. This is a measure of internal consistency indicating how well the questions in the scale are interrelated and explain the same overall concept. A Cronbach's alpha coefficient over 0.7 is considered acceptable, but values above 0.8 are preferred (194, 195). However, very high values

(near 1.0), are not optimal, as they would suggest that the questions are overlapping and concerning the same subject. We also performed an exploratory factor analysis to uncover the relationship between questions in the scale (concept validity). A scale may consist of several factors that represent an overall concept. The Kaiser-Guttman rule was used to investigate the number of factors the questions in the MedSupport scale represented. Factors with a Kaiser's intrinsic value over one met the requirements. Factor values indicated which questions belonged to which underlying factors. Factor values > 0.4 for each factor indicate that the questions represented the same factor (196).

# 4. Summary of results

### 4.1. The sample

#### 4.1.1. The patient sample

The included n=992 patients had a mean age of 36 years. A total of 42% were males, and anxiety disorders, affective disorders, and substance use disorders were the most frequent diagnoses. Outpatient care was received by 77% of the patients, whereas 10% were in-patients. Medication for mental health concerns was part of the treatment for 567 (57%) of the patients (Table 1).

We included 38% of the patients receiving treatment during the study week, which is comparable to an earlier study concerning the same patient population (197). The n=1,601 patients not included in the study served as the reference population. We had access to information at an overarching level for all patients from the electronic patient reports. The included patients were slightly younger than the reference population, and fewer were males. There was no difference in levels of care between the included patients and the reference population, although incomplete data from the reporting system prevented us from discriminating between ambulatory care, day care, and out-patient care in the reference population. Information about diagnoses was particularly deficient in the electronic reporting system. Therefore, we got a disproportionately large proportion of patients without a specific diagnosis in the reference population. The proportion of patients with the diagnosis of behavioural disorders was similar in the included patients and the reference population, but differed for the rest of the diagnoses (Table 1).

**Table 1.** Characteristics of the included patients (n=992) compared to the reference population (n=1,601). The reference population contains the patients who received treatment during the study week, but who were not, for any reason, included in the study.

Description	Included patients	Reference population	P-value
Total number	992	1601	
Demographic variables			
Age [years], mean (range)	36 (16-82)	37 (16-92)	0.048
Male, n (%)	417 (42.0)	750 (46.8)	0.017
Use of medication for mental health concern, n (%) Main diagnosis*, n (%)	567 (57)		
Substance use disorders (F10)	187 (18.9)	267 (16.7)	0.157
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Psychotic disorders (F20, F30.1, F30.2,	82 (8.3)	182 (11.4)	0.011
F30.8, F30.9, F31.1, F31.2, F31.5, F32.3,			
F33.3)			
Affective disorders (The remaining F30)	192 (19.4)	212 (13.2)	<0.001
Anxiety disorders (F40)	285 (28.7)	351 (21.9)	<0.001
Personality disorders (F60)	75 (7.6)	70 (4.4)	0.001
Behavioural disorders (F90)	48 (4.8)	67 (4.2)	0.432
Other diagnoses	83 (8.4)		
Missing information	40 (4.0)	452 (28.2)**	
Level of care, n (%)			
In-patient care	106 (10.7)	282 (17.6)	0.769
Day care	38 (3.8)		
Ambulatory care	73 (7.4)	1319 (82.4)**	
Out-patient care	761 (76.7)		
Missing information	9 (0.9)		

<sup>\*</sup> ICD-10 diagnosis in parenthesis

<sup>\*\*</sup> The reference population could not distinguish between other diagnosis and missing information regarding diagnosis, and only between in-patient care and the remaining levels of care regarding levels of care.

## 4.1.2. The clinician sample

The 312 clinicians had a mean age of 46 years. Two thirds were female, half of the clinicians held a university degree in medicine or psychology, 40% held a college degree, and 70% had their working sites in out-patient care. All the included clinicians reported their profession, 305 answered the question regarding age, 303 reported their genders, and 213 clinicians specified their working sites (Table 2).

We did not explore the characteristics of clinicians not included in the study.

**Table 2.** Characteristics of the clinician sample regarding gender, profession, and working site. N is the number of clinicians who responded to the different variables.

CLINICIANS	MEAN	SD	n	%
AGE (YEARS), N=305	46.1	11.6		
GENDER, N=303				
MALE			101	33.3
FEMALE			202	67.7
EDUCATION, N=312				
MD			44	14.2
MD PSYCHIATRIST			16	5.2
PSYCHOLOGIST			85	27.4
PSYCHOLOGIST SPECIALIST			12	3.9
COLLEGE EDUCATION			127	40.3
OTHER <sup>1</sup>			28	9.0
LEVEL OF CARE, N=213				
OUT-PATIENT CARE			151	70.7
AMBULATORY CARE			25	11.6
DAY CARE			14	6.5
IN-PATIENT CARE			23	10.7

<sup>&</sup>lt;sup>1</sup>Other professions were not further described, and not included in the analyses

#### 4.2. Paper I

In paper I we investigated the clinicians' attitudes towards SDM. For this purpose, we applied the PPOS instrument. Higher PPOS sharing scores referred to an attitude of more patient-centredness, whereas higher PPOS caring scores referred to more disease-centred attitudes. Additionally, we linked the clinicians' attitudes to their patients' experiences of SDM, for which we used the Collaborate instrument.

Female clinicians reported higher patient-centredness (mean PPOS sharing 4.79 vs. 4.67 (range 1-6) p=0.04) and disease-centredness (mean PPOS caring 4.77 vs. 4.65 (range 1-6), p=0.02) than males. Compared to the college-educated health professionals, medical doctors without postgraduate specialist education reported lower patient-centredness (mean PPOS sharing 4.46 vs. 4.83, p<0.001) as well as a lower disease-centredness (mean PPOS caring 4.61 vs. 4.75, p=0.005). There were no differences among the other professions or between males and females. We found a lower patient-centredness among the clinicians working in in-patient care compared to clinicians working in out-patient care (mean PPOS sharing 4.44 vs. 4.81, p=0.002). We found no differences among the other levels of care regarding clinicians' patient-centredness. There were no differences in clinicians' disease-centredness between levels of care.

The mixed effect model suggested that patients were more likely to report high SDM scores if their clinicians reported a more patient-centred attitude (OR 1.97, p=0.03). Patients whose clinicians worked in ambulatory care were less likely to report a high SDM score compared to those whose clinicians worked in out-patient care. There were no differences in the probability of patients to report high SDM scores among clinicians at the rest of the working sites. The probability of patients to report high SDM scores was not associated with their clinician's age, gender, or profession, or by the clinician's reports on disease-centredness.

#### 4.3. Paper II

Paper II reported the experiences of SDM by patients and their clinicians reflecting on the same, most recent decisional situation related to making treatment choices. The CollaboRATE instrument was used for the SDM assessments. The mean SDM score was 80.7 (SD 20.8) among the participants. Male patients reported lower SDMs than female patients (means of 77.7 and 83.3 respectively, p<0.001). The patients using medication for their mental health concerns had a lower SDM mean score than the patients not using medication (means of 79.8 and 82.6 respectively, p=0.03). The patients with psychotic disorders reported lower SDM scores (mean 66.8), than the patients with other diagnoses (mean 82.3, p<0.001). The involuntarily treated patients experienced lower SDM than the voluntary treated patients (mean 50.6 vs. 82.0, p<0.001). In addition, patients with

treatment durations of more than the median of 2.2 years reported lower SDM than patients with shorter treatment durations (78.0 vs. 83.9, p<0.001). Out-patients experienced higher SDM than the other levels of care (83.8 vs.71.9, p<0.001).

The top SDM score was reported by 27.4% of the patients, and more frequent by females than males (32.3 % and 20.6% respectively, p<0.001). Only 11.0% of the patients with psychotic disorders reported a top SDM score, in contrast to 28.6 % in the other diagnosis groups (p<0.001).

Patients subject to involuntary treatment had more than a three times higher risk (OR 3.2, 95%CI 1.2-8.5) of expressing negative SDM dyadic deviation values compared to patients experiencing only voluntary treatment. Patients who received in-patient care or day care were also more than three times more likely to have negative SDM dyadic deviation values compared to those receiving outpatient care (OR 3.2 (95% CI 1.7-6.0) and OR 3.2 (95% CI 1.3-8.0), respectively. Additionally, patients who had been in treatment for more than 2.2 years had a 1.9-fold higher probability (95% CI 1.3-2.8) of having negative SDM dyadic deviation values compared to patients treated less than 2.2 years. Patients' age, gender, diagnosis, and use of medication for their mental health concerns were not associated with negative SDM dyadic deviation values.

#### 4.4. Paper III

Paper III explored the MedSupport inventory, showing adequate internal consistency with a Cronbach's alpha of 0.87 (95% CI: 0.86-0.89) and convergent validity towards the available variables. We found a positive correlation between the MedSupport and BMQ needs (.28, p<.001) and a negative correlation between the MedSupport and BMQ concerns (-.34, p<.001). These findings mean that patients with greater beliefs about the necessity of their medicines to maintain or achieve good health report more support with medication issues from their health care services. The patients who have greater beliefs that their medication may harm them report worse support.

Among the patients, the MedSupport mean score was 3.8 (SD 0.9) on the statements (range 1-5). Question 1 (I have received good support in considering whether I need my medication) had the highest mean score (4.1, SD 1.0); 78% of patients agreed (agree or strongly agree) with the statement. Question 4 (I have received good support in reducing the side effects of my medication) had the lowest mean score (3.4, SD 1.2). Only 43% of patients agreed (agree or strongly agree) with this statement. The correlations between the items ranged from .32 to .73, with the highest correlation between questions 1 and 2 (I have received good support in finding the correct medication) and the weakest between questions 1 and 3 (I have received good support in ways to remember to take my medicine).

Of the n=567 patients who used medication for their mental health concerns, n=514 completed the MedSupport inventory and were included in the analyses. The wordings of the questions and the distribution of the answers are shown in Figure 2.

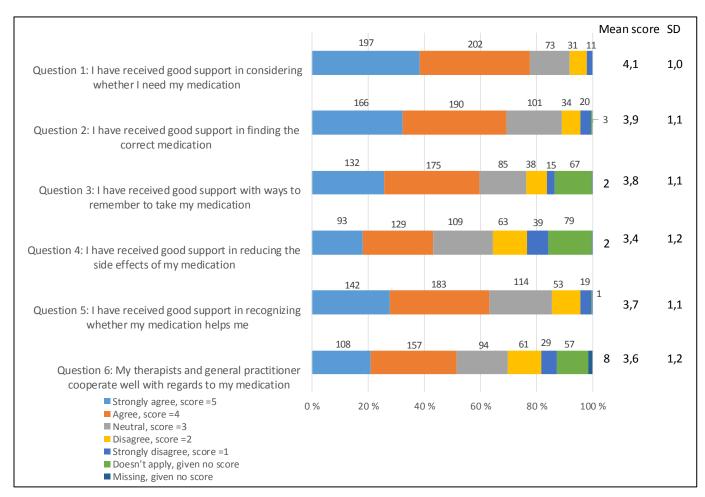


Figure 2. The MedSupport inventory items and the distribution of responses; n=514.

Reports of a greater belief in the need for medication were associated with higher MedSupport scores (beta .05, 95% CI .03 to .06, p<.001). In contrast, greater concerns about medication use were associated with lower MedSupport scores (beta -.06, 95% CI -.07 to -.04, p<.001). Higher patient MedSupport scores express an experience of more support with medication issues from the health care service. Patients at higher ages reported higher MedSupport scores; an increase of 10 years yielded an average of .06 higher score on MedSupport (p=.03). Patients diagnosed with behavioural disorders reported higher MedSupport scores than patients with affective disorders, which we set as the reference population in the analyses (beta .34, 95% CI .04 to .64, p=.03). We found no associations between the other diagnostic groups and the MedSupport scores. There were no differences in MedSupport scores between males and females, treatment durations above or below the median, or between patients subjected to different levels of care.

# 5. Discussion of main findings

Our findings on patient SDM experiences were comparable to those previously reported by Forcino et al. in primary care, where the mean SDM varied from 68 to 86 out of 100 and men reported more negative SDM experiences than women (137). Difficulties in establishing effective treatment might lead to a poor SDM experience for the patient. These difficulties may, for example, be caused side effects from medications, persistent delusional symptoms, or unrealistic treatment goals. Based on similar findings from previous studies (170, 198), it was not surprising that patients that received involuntarily treatment, prolonged treatment, or required higher levels of care reported the lowest SDM scores. Nevertheless, it has previously been suggested that the application of SDM is feasible and beneficial for these groups of patients as well (128, 132). Therefore, we explored the characteristics of SDM further by looking into the concurrence of SDM experiences between the patients and their clinicians.

### 5.1 The patient-clinician relationship

Shared decision-making is described as a conceptualization of the mutual process in which the patient and the clinician acknowledge each other's expertise and collaboratively identify the best treatment decisions (97). From our findings, we suggest the contributions from the clinicians to be as important as the contributions from the patients to fulfil the conditions for SDM. A recent study pointed out clinicians' attitudes regarding SDM as important for SDM implementation, but the main focus of the study was education, and other measures to influence attitudes were not explored (199).

In our study, we found lower scores on patient-centred attitudes in medical doctors without postgraduate specialist education, but not in psychiatrists. Whereas medical education mainly concerns biomedical factors, the post-graduate specialist education concerns comprehensive clinical experience, including on psychosocial factors, which we suggest are important for patient-centredness. Those with post-graduate specialist education were also older and more experienced in general. The positive association between clinicians' patient-centred attitudes and SDM found in the present study underscored this. The findings affirm the relevance of the clinicians' attitudes towards SDM for the accomplishment of SDM processes in mental health care. Earlier studies support this, as they have suggested that the clinicians' attitudes, but not patients' attitudes, towards patient-centredness are key factors in generating higher patient satisfaction, better adherence to treatment, and improved health outcome (139, 140).

A study by Street et al. examined attitudes of patient-centredness in clinicians and communication control patterns, and pointed out the importance of communication in quality health care (200).

They suggested that attitudes enhancing active patient participation and clinician partnership building mutually reinforce each other. Additionally, it has been suggested that different clinician behavioural styles fit patients with equal orientations best (139). Some patients prefer disease-centred clinicians, and should be equipped with treatment plans according to this. The clinicians should be in possession of flexibility in order to adjust their behavioural styles based on the patients' orientations.

A recent study explored the therapeutic bond in mental health care services and suggested that when both the patient and clinician perceived similar changes in the therapeutic bond, they worked more effectively towards symptom improvements (201). Additionally, a study from Rosenberg et al. suggested that the patient-clinician relationship was a key factor in facilitating SDM (202). On the basis of this understanding of patient-clinician relationships, we chose to focus on the patients experiencing more negative SDM than their clinicians, as the patient experience is suggested to be more critical in achieving good treatment outcomes (139). Earlier studies have shown the importance of the patient-clinician bond for SDM, and have shed light on clinician attitudinal- and relationship-based factors important for implementing SDM in mental health care (170). The results from our study also suggest that patients receiving prolonged, higher-level care or involuntary treatment have a higher probability of reporting lower SDM than their clinicians. An experience of lower SDM by the patient than by the clinician might be due to a basic discrepancy in the understanding of the current situation between the patient and the clinician. For example, the clinician might feel that sufficient effort has been devoted to treatment and that all available treatment options have been explored, while the patient feel the opposite.

Some levels of care might facilitate SDM to a lesser extent due to a strict framework or a lack of alternative treatments to choose from. Thus, disagreements between patients and clinicians might be more likely to occur. Indeed, treatment for in-patients probably includes many predetermined factors that may hinder the potential for the individual patient's needs and preferences to be met. The same caveat applies to the remaining levels of care. Structural frameworks, like house rules in inpatient clinics and schedules in other clinics, may restrict the range of possible adjustments. Another explanation might be that some patients in our study lacked sufficient competence to participate in SDM due to a serious debilitating mental illness or an impaired ability to modulate emotions or understand their mental health prognosis, which has previously been shown to be relevant (203).

Patients receiving short-term or out-patient treatment reported a higher SDM score, were less likely to report negative SDM dyadic deviation values, and more frequently reported top SDM scores compared to patients receiving prolonged treatment or other levels of care. This indicates that

patients with less severe disorders, and perhaps, less distress and higher functioning, had better SDM experiences. This suggests that SDM is more troublesome to implement for patients in need of more comprehensive care. Although not included in the model in our study, the severity of the disorder is a variable likely to be correlated with SDM.

The development of the autonomic patient capable of practicing SDM requires the health care service to be the driving force. Based on patients' preconditions, the health care service should guide patients in the best possible way into an active and autonomous mode in order to incorporate patient-centredness in health care services. Possible entanglements might appear when the health care service first allows the patient active participation in SDM processes, and thereafter complies with the patients' requirements independent of the frames of the health care service.

## 5.2 The therapeutic atmosphere

The International College of Person-Centered Medicine has aimed to reframe our understanding of the concept of health by recognizing health and health care as dynamic and complex systems that are changing over time (204). A previous study suggested that the therapeutic atmosphere changes over time during long-term treatment, and patients new to treatment have a more positive experience of SDM than patients who have been undergoing treatment for a long time due to a fundamental shift in their understanding of therapeutic benefits (205). This is in line with findings in our study, and contrary to the general assumption among clinicians that treatment alliances arise by themselves over time. Moreover, the treatment atmosphere reflected in a negative SDM dyadic deviation value might hinder the success of the treatment.

Recognition of the human experience and insight in the life-world of the other are considered among the soft skills that tap deep into our empathy. These soft skills are products of our life as a whole, but also of clinical experience and learned clinical skills (117). Set against this, the attitudes and the clinical experience of clinicians are essential attributes in facilitating the SDM process. They are elements of the clinicians' skills, and thus a prerequisite of finding the best treatment that integrates patient experiences and perspectives.

5.3 Shared decision-making for patients receiving involuntary treatment Although patients that received involuntary treatment had a higher probability of reporting more negative SDM scores than their clinicians, we would emphasize the service's responsibility to actively include these patients in decisions when possible. Patients treated involuntarily might evaluate their health situations differently from how the health care service evaluates them, and thus, they might not agree to the treatment arranged. However, the negative SDM scores may not be explained by the involuntary situation alone.

A recent study revealed that involuntarily treated patients identified involvement in clinical decisions as a key factor in improving their experience of care (126), and a study concerning patients subject to involuntary out-patient treatment found that treatment with medication was adjusted in accordance with the request of the patient over guideline recommendations (206). We suggest that involuntarily treated patients should be involved in decisions regarding treatment options. Continuous efforts to facilitate SDM for patients experiencing involuntary treatment should be encouraged.

In our study, involuntary treatment did not affect the perceived support with medication. We do not know the reason behind this unexpected finding, but it could perhaps be coincidental due to the rather small patient subgroup (n=23; 4.5%). As we did not perform assessments of adherence to treatment or treatment satisfaction in this study, it remains unknown if support with medication issues is related to this. However, patient-centred health care requires and facilitates the autonomous patient, and SDM is one element in this accomplishment (204).

## 5.4 The MedSupport inventory

Our study found adequate internal consistency of the MedSupport inventory. It showed one factor explaining a high proportion of variance, a weak positive correlation between MedSupport scores and BMQ needs, and a moderate negative correlation between MedSupport scores and BMQ concerns. The internal correlations between the six questions were moderate to high. We interpret the correlations found in line with earlier findings where patients who perceive adequate support and education regarding medication to a greater degree will be more likely to agree on using the medication (143).

The patients in our study perceived reasonable support for medication issues, with mean scores on all items above the neutral mid-point on the scale. The lowest score was for the question concerning support in reducing the adverse effects of medication. Adverse effects are an important reason behind patients discontinuing medication treatment in general (83), and psychotropic medications might be encumbered with troublesome adverse effects. The lower scores on this question emphasize the need to reduce the adverse effect burden as much as possible for the patients. On the other hand, the question showed the highest proportion of scores 'does not apply' as well. We suggest that these scores express that many patients experience a straightforward experience without problematic adverse effects. If adverse effects have never been a problem for them, the patients may view the question as irrelevant. We interpret this as a description of a situation where the majority of patients do not experience adverse effects. Nevertheless, for the patients who do, the health care service may not have taken sufficient initiatives. This group of patients should be a target for closer attention.

Further, the higher proportion of patients reporting 'does not apply' to the questions concerning support with remembering to take the medicines and cooperation between the clinician and the GP can also be explained by the patients' lack of experience in any problem regarding these subjects. Not all patients struggle with remembering their medicines, and a number of patients do not visit their GPs on a regular basis. The patients in need of additional support may be identified through the MedSupport inventory. Hence, the instrument might be feasible to target patients in particular need of relevant initiatives.

Patients diagnosed with F90-98 behavioural disorders reported more support regarding medication issues than the reference population (patients with F30-39 affective disorders). We propose there might be differences in the way that medication treatment is organized. The medications frequently used for behavioural disorders are stimulants. Stimulants are categorized as narcotics in the Norwegian prescription system (207), and the authorities claim thorough reviews and tight control with the medications. Therefore, tighter monitoring occurs. These regulatory measures might have a positive effect on the patients' perceptions of support.

#### 5.5 Factors relevant for support

In our study, a greater belief in medication as a necessity among patients was associated with the perception of better support with medication issues. Greater concerns related to the use of medication were associated with less support. This suggests a correlation between beliefs regarding medication and support from the health care service in our sample. Our finding that support with medication is associated with beliefs regarding the necessity of and concerns about medication is supported in a previous study by Horne and Weinman, who found that believing in medication as a necessary part of treatment promoted adherence, and conversely; concerns about medications hindered adherence (186). Additionally, this is consistent with previous studies that found patient understanding and acceptance of the treatment (e.g., how to use the medicines) important for medication adherence (130, 208, 209), and thus, for positive treatment outcome (79, 80, 185).

Good clinical practice implies that longer treatment durations contain more psychoeducation, including the patients' use of medication. However, we could not demonstrate better support with medication issues among patients with longer treatment durations. Longer treatment durations should facilitate therapeutic alliances and knowledge of the patients' needs. On the other hand, the patients suffering from more severe disorders are more often in need of longer treatment, and cooperation may be impeded the disorder severity.

#### 5.6 Gender and age

#### 5.6.1 Experiences of shared decision-making

Female patients reported higher experiences of SDM. This finding is in line with the findings of Forcino et al. (137). However, as female patients did not report more support regarding medicine issues, we suggest that the differences between males and females are internal features at the patient level rather than differences in health care services. Female clinicians expressed more patient-centred and disease-centred attitudes than male clinicians. However, the patients who had a female clinician did not report higher experiences of SDM. This may indicate a discrepancy between the clinicians' attitudes, which are regarded as an internal feature, and what happens in clinical practice. Alternatively, other aspects of the treatment situation overshadow the effect of clinicians' attitudes.

### 5.6.2 Support with medication

In our study, patients with higher ages reported more support regarding medication issues. However, our findings indicate that patient age was not relevant with regard to the experience of SDM. Additionally, we did not find clinician age relevant for clinician attitudes. Due to the development of views on mental illness, we suggest that older patients might have lower expectations of support from services, and lesser desire for SDM. Additionally, older patients may more often receive support from other parts of the health care system, and they may have become familiarized with their illness and treatment over time.

## 6. Methodological considerations

### 6.1. Design

This study had a cross-sectional design, which limits the ability to draw causal inferences. Thus, the chosen design was not suitable for predicting initiative effectiveness or causality of the variables explored.

We based the study on reports from patients and clinicians. This leaves the responsibility of the reliability of the answers to the participants. However, without turning to the patients, we would not have been able to explore the patients' experiences.

Patient Reported Outcomes (PROs) may be influenced by the patients' physical and mental statuses, by previous experiences, and by other factors relevant for the patients at the response time (210). An individual's responses are subjective and not reproducible for other persons or at other times. Due to this, the results may be considered temporary. Patients' experiences and considerations change over time (123), and the attitudes and experiences of clinicians mature from experience (99). However, we aimed to explore patients' experiences and attitudes, and objective assessments would not have been suitable.

## 6.2. Sample and selection bias

Selection bias refers to any factor other than the study that leads to a situation where the study sample differs from the population that it is supposed to represent (211). The selection bias should be minimized to make the sample as representative as possible (212).

For the statistical analyses, we set the significance level to identify associations between the variables at 5%. Type 1 error involves reporting an association that is not real. A type 1 error occurs when an association is false. With multiple trials, 5% of the trials would show an association that is not real. However, as we performed the study only once, there is a small but unknown probability that the demonstrated associations are not real. Type 2 errors occur when statistical tests fail to demonstrate a true association or a true difference between groups. We performed an observational study, and did not perform sample size calculations prior to the study. Type 2 errors are more likely to be found in small sample sizes, so participation in the study should be high enough to minimize the risk (194).

We recruited as many patients as possible over one week. We considered the eligible patients as random, as we did not have any impact on which patients were admitted or were scheduled for appointments at this week. The clinicians included patients themselves. Therefore, there might have

been a selection bias in the recruitment process. The advantage of this recruitment process might be that the clinician was able to do an assessment of whether it was justifiable to include each patient. The disadvantage might be that the patients did not feel completely free to answer all questions honestly, and perhaps had a desire to please the clinician. The clinicians may also have refrained from asking potentially complicated patients to participate, which might have reduced inclusion of patients with more severe illnesses.

The study week came with an extra workload for the clinical staff, as it demanded extra time and resources to organize patient inclusion, the practicalities around patient completion of the patient questionnaires, and collection of the questionnaires. We believe there were capacity challenges in recruiting patients. Additionally, the clinicians had to complete one clinician questionnaire regarding the individual patient for every included patient. This might have led to some clinicians avoiding including all eligible patients in order to avoid the extra work of completing more clinician questionnaires.

Due to the inclusion criteria, patients were not included if, for any reason, their clinician contraindicated participation, or if the patients were unable to complete a paper-based questionnaire. Additionally, only patients who could read the Norwegian language were included. Almost all the patients receiving treatment in our division do speak the Norwegian language, and the use of interpretation services is rare. However, we might have missed information by setting this criterion.

Not all patients were asked to participate after individual assessment by the patients' clinicians. The purpose was to minimize any negative impact on the individual patients. Nevertheless, this could also have led to the omission of patients who themselves may have had the desire to participate but were not deemed eligible by the clinicians.

As the study concerned contributions from health care services regarding the accomplishment of SDM in terms of patient-centred care and support with medication, we did not include patients who were having their first visit at the out-patient care centre or those who had been inpatients for less than 24 hours. For these patients, we assumed that few or no decisions were made.

We do not know to which extent the one-week inclusion period affected the selection bias. With a longer inclusion period, the clinicians would have the opportunity to consider more precisely which patients to include, and this would possibly have given higher selection bias.

Perhaps patients would have completed the patient questionnaires more correctly if they had received the questionnaires at home, reducing the information bias. Nevertheless, we believe this would have led to significantly fewer answers.

#### 6.3. Information bias

Information bias refers to the uncertainties regarding the real contents of the patient responses.

As we did not use any objective measures, we must rely on the patients' subjective responses. In the use of PROs, a fundamental factor is the inability to verify the patients' reports. Information bias is, for example, if the patients understand the questions in a different way than intended, or if their reports concern another situation than the current situation. Information bias may also occur if variables are misclassified.

The patients completed the questionnaires directly after their clinical visits, as they still were on the hospital premises. This way, the patients had the clinical visit fresh in their minds. We assume that data collection in the hospital area increased the response rate. If the patients had brought the questionnaires home, we assumed that there would have been a higher risk that they would not complete and return them. However, responses given at the treatment site, with clinicians present in the hallways and completed patient questionnaires delivered to hospital staff at the treatment sites, may have affected the responses. A number of patients may perhaps have avoided sharing their true opinions. However, the questionnaires contained only questions about their opinions, experiences, and beliefs. There were no questions where one answer was considered 'correct' and another 'wrong'. We assume that there was little impact on the information bias from the time for response.

It could be a challenge if a patient received treatment from several locations during the study week. More visits at the same location may have occurred, but the patients were automatically included only the first time. If a patient received treatment from multiple clinics, this patient may have been included more than once. However, we assumed this was a rare possibility and that only very few patients would have been possibly included more than one time.

Although we unequivocally asked about the most recent time a decision was made, we are not sure that the patients responded solely regarding this situation. Some patients might have answered more generally than just on the specific situation. However, we do not assume this is a pervasive problem as the participants answered their questionnaires shortly after their appointment. To ensure that choices were made prior to inclusion, we did not include patients who arrived for their first visit or who had been hospitalized for less than 24 hours.

The clinicians were included during the same week as the patients. This may have created confusion among the clinicians regarding the different parts of the study, as they had to fill out the clinician parts of the patient sample at the same time as the questionnaire for the clinician sample. However, we think that the division was well prepared and motivated for the additional effort during this one week. A later time for clinician reports would have lowered the motivation to respond, as the clinicians would have had the attitude that the study was finished.

## 6.4. Confounding factors

Confounding factors are factors affecting the data in an unknown way.

The study asked for opinions about the last time that decisions on treatment that included choices were made. A confounder for the reports referred to in this thesis might be that patients with higher levels of care interact with more professionals during treatment. Their reports potentially reflect decision processes involving other professionals and treatment decisions other than those made by their reporting clinicians. In addition, in-patients and patients in day care might experience uncertainty about which decisional processes to report on, as more decisions are made over a short time period than during out-patient treatment. On the other hand, hospitalization often implies a specified set of rules, limiting the situations in which real choices exist.

#### 6.5. Procedures

#### 6.5.1. The MedSupport inventory

Despite a lack of previous validation, we used the newly developed MedSupport inventory in this study. With a completion of more than 90%, the MedSupport was found to be easy to apply.

Additionally, it contains global items not restricted to a defined disease or treatment.

Our study design did not give us the possibility of performing a complete validation including a test-retest design of the exploration. This would have strengthened the validity process and contributed to a better understanding of the instrument. Thus, validation of the MedSupport should be repeated in other studies to confirm our findings. However, Hawkins et al. have suggested that evaluations of patient-report instruments are not limited to the statistical features of the instrument; they include empirical evidence that supports its intended use (213). Due to this, patient reports gain empirical evidence as a supplement to validity explorations. Therefore, our patient reports on the MedSupport underpin the application suggested by reliability and validity testing.

## 6.5.2. Patients with multiple diagnoses

We requested the patients' main diagnosis on the clinician questionnaire regarding the individual patient. Prior to the study, we agreed on not to include bi-diagnoses, as we regarded them too complicated to analyse. However, we know that some bi-diagnoses may interfere with the patients'

abilities to participate in SDM (214), so the lack of complete diagnosis information was a limitation for the study. Some of the patients had diagnoses outside the categories set for this study. These patients were placed in a group called 'other diagnosis', and were excluded from regression analyses. In this way, we excluded patients from the analyses without controlling for the possible alterations this would cause. Additionally, illness severity may vary widely within a diagnosis group. Therefore, we should have included information about illness severity in the clinician questionnaire regarding the individual patients. We assume that this information would have shown relevant associations with SDM.

#### 6.6. Validity

External validity concerns the question of whether the results observed in the sample appear to be generally true, and valid in comparable populations (211). For the patient study, we compared the included patients (n=992) with the population (n=2,593), that is, the total number of patients receiving treatment at the division during the study week, in terms of available variables. This gave an inclusion rate of 38%. The included patients were not representative of the population for all parameters, as shown in Table 1. However, the deviations are small for most of the variables, so we regard the finding in our sample as generalizable to the population. Thus, we regarded the external validity to be fair. The division where the study was performed represents a normal mental health care division in a Norwegian hospital (180), although comparisons are scarce regarding the patient population.

A previous study has shown that patients with lower education levels, lower socioeconomic status, and cognitive impairments are left out of or are more difficult to recruit for patient examinations in mental health care (197). Such factors may cause selection bias, and affect external validity. Due to our experiences, most patients want to express their experiences of their treatment. However, we were not allowed to collect any data from the patients not included. Only retrospective information in electronic reports produced for activity report purposes were available.

Internal validity concerns how well the study is performed. The confounding factors discussed weaken the internal validity. However, unknown confounders are the biggest threats to internal validity. These threats may exist in a large degree, especially due to the use of PROs.

#### 6.7. Strengths

We recruited almost n=1,000 patients receiving treatment at a specialist level mental health care service, and more than n=300 clinicians. The included patients had different diagnoses. All ages within the inclusion criterion were represented, the patients received treatment at different levels of care, and different clinicians were offering the treatment. The clinicians were males and females,

held different professions, were diverse regarding age, and worked in all parts of the division. Few similarly sized studies have been performed in mental health care in Norway (187, 197, 215).

#### 6.8. Reading and interpretation of the reports

We explored the attitudes among professionals using only one instrument. All the concepts we have engaged with in this study are complex and multifaceted, and may not be sufficiently explored using one instrument. The soft skills necessary for SDM are challenging to teach, describe, and measure. Attitudes are complex internal characteristics, which are continuously matured through experiences. Therefore, one single instrument may be too superficial for identifying attitudes. We preferably would have explored attitudes from multiple angles using instruments covering more aspects than just patient-centredness and disease-centredness. Additionally, patient-clinician relationships mutually influence each other. If we had investigated patient characteristics further, we may have identified additional factors relevant for experiences of SDM.

Patients who clearly reported more positive SDM experiences than their clinicians were an interesting subgroup, but were not the focus of this study, and are not further examined here. They were included in the group of patients reporting similar SDM experiences as their clinicians.

When preparing the data for analyses, we categorized the patients into groups that we considered appropriate. Despite that, the chosen categories might have hidden some true associations and/or revealed some false associations. We were only able to correct for known uncertainties. Some of the groups contained few patients, which may have hindered the demonstration of statistically significant differences.

We used pen-and-paper questionnaires to collect data. This made data collection flexible, as it did not require any login information or electronic equipment, but also made it more demanding to ensure coding of the correct patient identity. In addition, it was laborious to record and quality-check all the data before analyses, and manual mistakes may have occurred.

#### 6.9. Description of shared decision-making

Presently, we do not have a consensus on what 'sufficient' SDM involves. A common set of attitudes or skills to apply when exploring these processes is also not present (179). Therefore, even if there is agreement on the benefits of SDM, there are no benchmarks or stated goals of what we are aiming for with our efforts to implement SDM. We do not have a standard that indicates when SDM has been achieved, nor one that indicates which premises to fulfil. This makes it complex to develop services further in order to implement SDM. Additionally, SDM is complex and not restricted to one actor or situation in treatment. Therefore, our efforts to describe factors relevant for SDM in mental

health care are fragmented and insufficient to cover the SDM phenomenon. In light of opacities about how the achievement of SDM is defined, implementation methodology emphasizes the need for assessments to monitor the processes (216).

# 7. Implications

## 7.1. Clinical implications

Shared decision-making in mental health care requires involvement at the patient, clinician, and organizational levels. To increase SDM, clinicians' patient-centred attitudes should be improved, and specific measures should be taken in parts of the service where involuntarily treatment, longer lasting treatment, and higher levels of care are given. We suggest that the MedSupport may be a suitable instrument to monitor patients' perceptions of support regarding medication, which in turn may adjust patients' experienced needs for medication and reduce their concerns related to their medication.

### 7.2. Implications for future research

This study has described some parts of the complexity of SDM in mental health care. Shared decision-making is the gold standard for patient involvement in treatment decisions. It is requested by authorities and enshrined in guidelines. However 'sufficient' SDM needs further exploration to be adequately defined. Currently, the focus for implementing SDM has been on patient education. Our results indicate that this stance is too narrow, pointing out the necessity of professionals' attitudes and organizational features of the health care system to be included as well. There is a need for future research to explore the significance professionals' attitudes and health care system organization for SDM, and to broaden measures in which those factors are included. Explorations of the MedSupport inventory should be repeated to confirm our findings, as this instrument was not previously validated.

## 8. Conclusion

Patients whose clinicians reported more patient-centred attitudes experienced more SDM. Patients receiving prolonged treatment durations, higher levels of care, and involuntary treatment experienced less SDM. Patients from these treatment situations more often have severe mental disorders, and are among the patients for whom efforts should be tailored to increase SDM.

It is of importance to ensure that patients have sufficient support, knowledge, and power to participate actively in treatment choices. For assessment of support with medication issues, the MedSupport inventory is a suitable instrument.

SDM is complex, but presently not sufficiently defined or benchmarked. Shared decision-making requires profound changes in the structure of health care services as well as effort, knowledge, and skill from patients and clinicians. In mental health care, SDM is a multifaceted long-lasting concept not restricted to one single consultation or decision-making situation.

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## **SPECIAL ISSUE**



# Practitioners' positive attitudes promote shared decisionmaking in mental health care

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## Abstract

Rationale and aims: There is a growing expectation of implementing shared decision making (SDM) in today's health care service, including mental health care. Traditional understanding of SDM may be too narrow to capture the complexity of treatments of mental health problems. Although the patients' contribution to SDM is well described, the contribution from the health care practitioners is less explored. Therefore, our aim was to explore the attitudes of practitioners in mental health care and the associations between practitioners' attitudes and SDM.

Method: We performed a cross-sectional study where practitioners reported their sharing and caring attitudes on the Patient-Practitioner Orientation Scale (PPOS) and age, gender, profession, and clinical working site. The patients reported SDM using the CollaboRate tool. We used a mixed effect model linking the data from each practitioner to one or more patients. We presented the findings and used them as background for a more philosophic reflection.

Results: We included 312 practitioners with mean age 46.1 years. Of the practitioners, 60 held a medical doctors degree, 97 were psychologists, and 127 held a college degree in nursing, social science, or pedagogy. Female practitioners reported higher sharing (4.79 vs 4.67 [range 1-6], P = .04) and caring scores (4.77 vs 4.65 [range 1-6], P = .02) than males. The regression model contained 206 practitioners and 772 patients. We found a higher probability for the patient to report high SDM score if the practitioner reported higher sharing scores, and lower probability if the practitioner worked in ambulatory care.

Conclusions: SDM in mental health care is complex and demands multifaceted preparations from practitioners as well as patients. The practitioners' attitudes are not sufficiently explored using one instrument. The positive association between practitioners' patient-centred attitudes and SDM found in this study implies a relevance of the practitioners' attitudes for accomplishment of SDM processes in mental health care.

The work was carried out at Sørlandet Hospital, Division of mental health, PO box 416, 4604 Kristiansand, Norway,

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# KEYWORDS

mental health services, Patient-Practitioner Orientation Scale, personnel attitude, shared decision-making

## 1 | INTRODUCTION

In the last decades, the focus of modern health care service has moved from strictly illness cure towards a broader care perspective where patient perspectives, quality of life, and empowerment of the individuals are included. Expectations regarding patient focus beyond illness focus are increasing. Health leaders and governmental authorities have continuously expressed a stronger expectation of inclusion of shared decision making (SDM) in all decisions about treatment in health care.<sup>2,3</sup> The core components of SDM are not unambiguously described, but the most frequently used components are patient values and options.<sup>4</sup> SDM is a conceptualization of the mutual process where the patient and the practitioner acknowledge each other's expertise and collaboratively identify the best treatment decisions.<sup>5</sup> Such processes are expected to lead to better treatment choices supporting the patient's individual needs. 6 This has been underscored by Drake and co-workers who has set up SDM as an ethical imperative, addressing the moral obligation included in all professional practice<sup>7</sup>; although recent literature suggest there may be provisos from the practitioners to the SDM practice.<sup>8,9</sup>

The turn towards patient-centeredness in medicine is a construct developed from gradual changes in the holistic understanding of what it is to be a human being. 10 More overriding societal changes regarding social and ethical principles, like the shift towards selfrealization and individualism, lead the main focus in health care from information and adherence. This also contributes to a shift from the scientific explanations to relieve the patients' suffering into a state where the practitioners understand the patient as a unique human being and offers treatments along with this recognition. 10 SDM is suggested to prevent cases of non-adherence to treatment based on disagreement<sup>11</sup> and is valued by patients.<sup>12</sup> Consultations prepared for SDM aim to provide space for mutual exchange of information and interpretation of the situation to converge into a shared decision on the basis of the knowledge of the different experts. Therefore, it is a premise that the patient perspective is explored and taken sufficiently into account by the service. Patients must be empowered to participate without specific limitation in SDM, both when it comes to recognition of the situation and its possibilities, and regarding personal preferences. 1,13 The situation is unique for each patient and every patient is an expert on his or her own life, being in possession of core knowledge necessary to perform SDM. The personal aspects include the life-world of the patient, including family traditions and cultural affiliation.<sup>14</sup> It is a premise for fulfilling the SDM process that the service facilitates and encourages the patient to bring individual perspectives into the process. To assess the extent and the quality of SDM several tools have been developed. 15

# 1.1 | The complexity of SDM in mental health care

Morant and co-workers have suggested that the understanding of SDM as a process restricted to one clinical encounter is too narrow and limited for mental health care. 16 The main objection to this understanding lies in the nature of mental illness and its demand for complex management. As the traditional SDM is a microsocial process limited to the particular consultation involving the patient and the practitioner, SDM in mental health care includes a longer-term relationship, a context where other key players like relatives and people in the patients' supportive network are included, functional and cultural features of the health care system, and the recognition that the illness evolves through periods of recovery and relapse. 5,16,17 This multiple involvement and long-term perspective emphasize the complexity of the process. Taken together, all these elements call for considering SDM in mental health care as a continuous, multipersonal process, not completed within a limited time period or with a single decision. 18,19 Ozdemic and Finkelstein have suggested that the longtime nature of chronic conditions provides a knowledge ripeness of how the illness and its suffering is understood and that we should be aware of the changes in the patients' self when recovering and the complexity that develops regarding decisions made.<sup>20</sup> As many of the mental illnesses are long-term conditions, we suggest this is relevant for how practitioners in mental health care understand the patient views. This recognition eventually reveals the gap between the scientific explanation of the condition and the patient's understanding of the suffering and restriction of life.

# 

Besides availability of practical tools like questionnaires or internetbased programs, practitioners should advantageously be aware of the understanding of the more theoretical aspects forming the basis for good outcome of the SDM. Self-determination theory (SDT) postulates three psychological needs for human identity, the forming of the self, and well-being.<sup>21</sup> The first is the need for competence, which powers human exploration in order to master the environment. The second is the need for autonomy, understood as the experience of making your own choices and being the author of your own life. The third need is the need for relatedness, where people try to achieve a sense of belonging to others in their surroundings. We emphasize that fulfilment and continuous recognition of these existential needs are important requisites in an SDM process, and that the interventions that facilitate fulfilment of these needs can improve the quality of life and support patients breaking thought behavioural patterns.<sup>22</sup> By taking the self-determination

experiences of treatments.

Journal of Evaluation in Clinical Practice

influences the attitudes and contributes to beneficial patientpractitioner meetings, which elevate the unique knowledge each individual patient develops regarding his or her own challenges. 11,29 We hypothesized that practitioners' attitudes towards SDM are diverse, but play an important role for the treatment climate and the patients'

theory-perspective of successful decision-making processes into account, we should reframe how knowledge is valued in the patient-practitioner interaction.

### 1.3 The importance of practitioner attitudes

Yelovic argues that the patient's experience must be understood and utilized by the practitioners in a more consistent manner to fully exploit the potential present in the clinical encounter. 11 Expertise among health care professionals in this field expands from informal clinical experience working on a specific field, rather than from formal skills gained from education. Such informal experience is not reachable solely through any certification or formal education. Additionally, the recognition that the patient has a valuable expertise to offer must be present. Together, these skills facilitate fruitful interactions in SDM processes.

The importance of patients' preparations for SDM processes have been emphasized, while the practitioners' entrance to the same process is less investigated. Practitioners' attitudes can be understood and conceptualized in different ways. Some efforts have been done to explore the health care providers' perspectives of the service, but these do not specifically concern the attitudes of the practitioners.<sup>23</sup> Earlier studies regarding the attitudes of practitioners in mental health mainly concern the attitudes towards mental disorders and people suffering from these.<sup>24-27</sup> A broader insight into more fundamental attitudes regarding illness itself and treatment approaches would extend our understanding of the conditions influencing the outcome of clinical encounters. This should include considerations about sharing information and power in clinical decisional processes. However, the literature in the field are rather scarce.

The attitudes towards the content of clinical encounters held by the practitioners, expressed by behavioural styles, influence the clinical encounter and the patient-practitioner relationship.<sup>14</sup> The behavioural styles are outlined as a patient-centred style and a disease-centred style, respectively. The patient-centred style is referred to as a sharing dimension, where information is abundantly shared between the patient and the practitioner, and where the practitioner focuses on the patient's life more than strictly on the illness. The disease-centred style is referred to as a caring dimension, where the practitioner shares less information with the patient and keeps a dominant focus on the illness when decisions are made. The practitioner's attitude influences the decisions made for the patient treatment and follow-up, and safeguarding the patient needs and facilitating the SDM processes have different conditions. Thus, the practitioners' attitudes should be the centre-of-attention and integrated in educations throughout their professional lives. We presume that the behaviour styles among the practitioners are linked to their personality, their education, and their professional experience.<sup>28</sup> Findings in previous studies indicate that the comprehensive clinical experience included in post-graduate education contributes to practitioners' developing sensitivity to the needs of the patient and what they express as important to themselves. This sensitivity in turn

## 1.4 | Aim

This study aimed to explore (a) sharing and caring attitudes of practitioners in mental health care and (b) the influence of practitioners attitudes on patients' perceptions of SDM.

We will present and use empirical data as a starting point for a philosophical analysis of the associations between the practitioner attitudes and the concept of SDM.

# 2 | MATERIAL AND METHODS

## 2.1 | Context

This was a cross-sectional study including patients and practitioners at the Division of Mental Health and Addiction Service at Sørlandet Hospital Trust during the third week of January 2017.

Sørlandet Hospital Trust is a publicly run hospital which serves a population of 300 000 people in the southern part of Norway.<sup>30</sup> The Division of Mental Health and Addiction Service provides acute and long-term treatment as well as forensic psychiatry, child and adolescent psychiatry, geriatric psychiatry, and specialized treatment of substance-related disorders. In 2017, the division held 280 beds, had 4150 admissions, and 184 000 consultations.

Professionals with independent treatment responsibility were included in the study by the study personnel after written and oral information from the head of the division and from the study team. They completed a questionnaire covering background demographic information, education, and clinical experience, and topics regarding practitioner attitudes and beliefs.

The inclusion of patients were done by their practitioner as they arrived for their appointment. Patients received information about the study from posters in the clinics and from the hospital staff at their arrival. Participating patients must be aged 16 years or older, with at least one earlier contact regarding the current issue. Patients were only included at their first visit if they had more than one contact with the service during the week of the study. Inpatients were included after 24 hours of hospital admission. Ambulatory-treated patients were given domestic treatment and follow-up, on account of lacking the ability to attend an outpatient clinic or benefit from its treatment offers. Patients receiving ambulatory treatment are less attentive to regular treatments, and thus more likely to be subject to compulsory treatment.

Patients were not included if, for any reason, participation was considered contraindicated or if the patient was considered unsuitable for a paper-based questionnaire. The patients completed a questionnaire containing demographic information and experiences and attitudes regarding mental health care service. Clinical information and information about their treatment were obtained from the patient records.

All patients and practitioners provided a written informed consent.

## 2.2 | Instruments

# 2.2.1 | The Patient-Practitioner Orientation Scale

The Patient-Practitioner Orientation Scale (PPOS) explores attitudes towards SDM among practitioners. 31,32 The instrument is a self-report assessment tool and has been validated and translated into Norwegian, and has been used in previous studies. 32,33 As attitudes are internal orientations, we found it appropriate to use a self-report assessment tool for this study. The paper and pencil instrument was originally developed to measure patients' attitudes towards their role in medical care and is well validated. Later, it was refined to also measure practitioners' attitudes and is shown to be a relevant assessment tool with regard to patient satisfaction. 34,35 The PPOS consists of 18 statements where the practitioners rate the degree of agreement on sharing information and power during the visits rated on a 6-point Likert scale, where 1 = "strongly agree," 2 = "moderately agree," 3 = "slightly agree," 4 = "slightly disagree," 5 = "moderately disagree," and 6 = "strongly disagree." Nine of the items refer to the sharing dimension, which is explained as an expression for patient-centred behavioural style. The remaining items refer to the caring dimension, which is described as the disease-centred behavioural style. The sharing and caring dimensions represent independent features and are not appropriate for comparisons. A third style, the doctor-centred style, is explained with low scores on both dimensions according to the manual, but is not further explored in this study. Reliability analyses showed a Cronbach's  $\alpha$  of.64 on the sharing dimension and a Cronbach's  $\alpha$  of .42 on the caring dimension. All values in the corrected item-total correlation analysis were low positive, and no item weighted particularly negative.

## 2.2.2 ☐ The CollaboRate

The CollaboRate measurement tool evaluates the patient experiences of SDM. In order to assess patient experiences, we found it appropriate to apply a patient-related outcome measure (PROM).<sup>36</sup> The CollaboRate is translated into Norwegian,<sup>37</sup> and is well validated. It has been shown to be useful in different patient populations and levels of care, and is equipped with a comprehensive description of interpretation.<sup>4,38</sup> According to this, we appraised it to be a suitable instrument for our purpose. The CollaboRate comprises three single questions dealing with tutoring and feedback to the patient about the health situation and attention payed by the practitioners to what matters most to the patient. Response options are ordinal on a scale 0 to 9, where 0 represents "no effort was made" and 9 "every effort was made." After adding the responses from the three questions, an ordinal score of 0 to 27 emerges. This score is multiplied by

3.704 to give a recalculated response percentage score between 0 and 100. A ceiling effect is described for the instrument as a considerably share of the patients reported on the upper part of the scale in earlier studies.  $^{38\text{-}40}$  As our purpose was to investigate associations between practitioner attitudes and patient experiences, we considered the CollaboRate suitable for this study, in spite of these reports. Reliability analyses yielded a Cronbach's  $\alpha$  of 91 on the patient version and 89 on the therapist version. All values in the corrected item-total correlation analysis were high positive, so the questions partly overlapped.

## 2.3 Data analyses

We performed descriptive analyses to explore the PPOS reports from the practitioners. Comparisons of means were performed by independent t tests.

To investigate associations between the practitioners' reports on PPOS and the patients' reports on CollaboRate, we performed a logistic mixed effect model. Then, the individual patient scores on CollaboRate were correlated to the scores on PPOS of their practitioner.

The outcome of the model was "high SDM score," defined as a score of 80 or more on the CollaboRate scale, which corresponds to a sum score of more than 21 out of maximum 27; eg, represents a score of a minimum of 8 at one question and 7 at the two others.

Several independent factors were included in the model. The practitioners' age was kept as a continuous variable in the analyses, as we assumed a linear effect. The practitioners professions were divided into five groups for descriptive presentation: medical doctors, psychiatrists, psychologists, psychologists holding a post graduate clinical specialization, and college-educated practitioners, which were nurses, social workers, or pedagogues. Practitioners holding other professions were not included in the analyses. The college-educated practitioners were used as reference group during comparisons of means because of the majority of practitioners in this group. For the regression analyses, the medical doctors and psychiatrists were merged into one group and the psychologists, with or without clinical specialization, were merged into a second group; whereas the college-educated practitioners were kept as a third group. This was done because of their similarity in educational topics and clinical tasks, and limited numbers in some of the groups used for descriptive analyses. The medical doctor group was set as reference group in the regression analyses because of their main role in treatment-related decisions. The working sites, wherein the patients received their treatment, were divided into four: outpatient care, ambulatory care, day care, and inpatient care. The outpatient group was set as the reference group during analyses as this treatment was provided to the majority of patients and is regarded among the practitioners as the cornerstone of the services offered by specialist mental health care. The two dimensions of the PPOS scores, sharing and caring, were handled as independent, continuous scores during analyses.

Results were presented as odds ratios (OR) with 95% confidence intervals (CI). An association with a P value < .05 was considered

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statistically significant. Data analyses were performed using IBM SPSS<sup>41</sup> version 23 and Stata 15.

## 2.4 | Ethical approval

The study was approved by the Norwegian Regional Committees for Medical and Health Research Ethics 21.11.2016 (no 2016/1781) and the Research Department at Sørlandet Hospital 18.01.2017 (no: 17/00104).

## 3 | RESULTS

Among the 312 practitioners included in the study, mean age was 46.1 years (SD 11.6) and two thirds were women. There were 60 medical doctors, 97 psychologists, 127 with a college degree in nursing, social science or pedagogy, and 28 holding other professional degrees. There were most practitioners (n = 151) working in the outpatient care, whereas 25 practitioners had ambulatory work, 23 worked at inpatient care, and 14 worked at day care. Characteristics of the study population are shown in Table 1. Not all practitioners answered all the questions on the questionnaire. Working site in the clinic was specified by 213 practitioners. Therefore, information about working site was missing for 99 practitioners. Age and gender was specified by 303 and 305 practitioners, respectively.

**TABLE 1** Baseline characteristics of the study population and distribution regarding gender, profession, and clinical treatment site

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Practitioners	Mean	SD	N	%
Age (years), $n = 305$	46.1	11.6		
Gender, <i>n</i> = 303				
Male			101	33.3
Female			202	67.7
Education, $n = 312$				
MD			44	14.2
MD psychiatrist			16	5.2
Psychologist			85	27.4
Psychologist specialist			12	3.9
College education			127	40.3
Other <sup>a</sup>			28	9.0
Working site, $n = 213$				
Outpatient care			151	70.7
Ambulatory care			25	11.6
Day care			14	6.5
Inpatient care			23	10.7

*Note.* N is the number of practitioners responding to the different variables.

Abbreviation: SD, standard deviation.

<sup>a</sup>Other professions were not further described, and not included in the analyses.

The practitioners reported a slightly higher mean score on the sharing dimension than on the caring dimension using the PPOS instrument. For the sharing dimension, mean score was 4.75 (range 1-6; 95% CI, 4.69-4.81). The mean score for the caring dimension was 4.72 (range 1-6; 95% CI, 4.67-4.77). Distribution and comparisons of the PPOS scores among the practitioners are shown in Table 2.

The female practitioners showed significant higher scores on both sharing and caring dimensions, compared with the male practitioners (4.79 vs 4.67, P = .041 and 4.77 vs 4.65, P = .023, respectively).

Compared with the college educated practitioners, medical doctors without postgraduate specialist education reported a lower score on the sharing dimension, which refers to a less patient-centred attitude (mean 4.46 vs 4.83, P < .001). There were no significant differences between the other professions. We also found a significant lower sharing score for the practitioners working in inpatient care compared with practitioners in outpatient care (4.44 vs 4.81, P = .002). The medical doctors without postgraduate education reported a lower caring score than the college educated practitioners (4.61 vs 4.75, P = .005). We found no differences between the other professions or on working sites on the scores on the caring dimension.

From our linked data, we identified 206 paired datasets with one practitioner and one or more patient. A total of 772 patients were linked to a practitioner, with a mean of 3.7 patients per practitioner (range 1-22). Results from the logistic mixed effects regression analysis with patient CollaboRate score more than 80 as dependent variable are shown in Table 3.

Our findings show that patients are more likely to report high SDM scores if their practitioner reports higher scores on the sharing dimension (OR 1.97, P = .03); ie, reports a more patient-centred attitude. The probability for patients to report high SDM scores was not associated with practitioner's age, gender, or profession, or by the practitioners' reports on the caring dimension of PPOS, which relates to disease-centeredness. Patients whose therapists work in ambulatory care were less probable of reporting a high SDM score compared with those whose therapists work in outpatient care. There were no differences in the probability of reporting high SDM scores among the rest of the working sites.

# 4 | DISCUSSION

This study points out that practitioners specific attitudes are relevant for the patient's experience of SDM. We found a positive association between practitioners' patient-centred attitudes and patient experiences of SDM in mental health care, which implies the relevance of taking the practitioner attitudes into account for accomplishment of SDM processes in mental health care.

An SDM process is a meeting between competent individuals that hold different expertise. Thus, each contribution is important for success. Recognition of the human experience and the life-world of the other is considered among the soft skills, which taps deep into our empathy and is a product of our life as a whole, but is also the quality of clinical experience and learned clinical skills. Set against this, both

**TABLE 2** Distribution of the sharing and caring scores of PPOS among the different gender, professions and working site of the practitioners

		Mean Sharing				Mean Caring			
Practitioners	N	Score	SD	95% CI	P value	Score	SD	95% CI	P value
Respondents	312	4.75	0.52	4.69-4.81		4.72	0.43	4.67-4.77	
Gender n = 303									
Male	101	4.67	0.57	4.55-4.77	.04 <sup>a</sup>	4.65	0.49	4.55-4.75	.02 <sup>a</sup>
Female	202	4.79	0.48	4.72-4.86	Ref	4.77	0.40	4.71-4.83	Ref
Profession $n = 284$									
Medical doctor	44	4.46	0.54	4.29-4.62	<.001 <sup>b</sup>	4.61	0.40	4.48-4.73	.05 <sup>b</sup>
Medical doctor specialist psychiatry	16	4.84	0.29	4.69-5.00	.86 <sup>b</sup>	4.67	0.57	4.36-4.97	.48 <sup>b</sup>
Psychologist	85	4.83	0.46	4.73-4.93	1.00 <sup>b</sup>	4.80	0.44	4.70-4.89	.40 <sup>b</sup>
Psychologist specialist psychology	12	4.81	0.40	4.55-5.06	.89 <sup>b</sup>	4.88	0.51	4.55-5.21	.41 <sup>b</sup>
College education	127	4.83	0.47	4.74-4.91	Ref	4.75	0.41	4.68-4.82	Ref
Working site n = 213									
Out-patient care	151	4.81	0.50	4.73-4.89	Ref	4.74	0.47	4.66-4.81	Ref
Ambulatory care	25	4.64	0.40	4.47-4.81	.12 <sup>c</sup>	4.72	0.32	4.58-4.86	.82 <sup>c</sup>
Day care	14	4.86	0.29	4.68-5.04	.73°	4.87	0.47	4.51-5.23	.35 <sup>c</sup>
Inpatient care	23	4.44	0.70	4.14-4.75	.002 <sup>c</sup>	4.68	0.35	4.53-4.83	.55 <sup>c</sup>

Note. N for gender and treatment site is the number of practitioners responding to the different variables. N for education is after omission of the practitioners who reported other professions.

Abbreviations: CI, confidence interval; PPOS, Patient-Practitioner Orientation Scale; SD, standard deviation.

the attitudes and the clinical experience of the practitioners are essential attributes for the SDM process. They are elements of the practitioners skills, and thus a premise to find the best way forward regarding treatment plans where the patient experiences and perspectives are integrated. This can explain our finding of lower reports on the sharing scores by medical doctors without postgraduate specialist education, but not by psychiatrists. As the medical education concerns mainly biomedical factors, the postgraduate specialist education to a greater degree concerns clinical experience of importance for patient centeredness.

Van Baalen and co-workers have discussed decision-making processes in professional multidisciplinary teams. PMultidisciplinary teams provide space where information and interpretations can converge into a shared team decision, a decision derived from the socially distributed process. So, rather than exclusively focusing on the individual clinician's reasoning and knowledge, clinical decision making is claimed as a social knowing. SDM processes have many similarities to clinical decisions made in multidisciplinary teams, although fundamentally different approaches. Contrasting to this multidisciplinary teams' decision-making processes, the principal contributor—the patient—is present in SDM processes. The fundamental quality in SDM lies in the outcome where the participations' contributions evolve to a socially distributed process, where the knowledge evolves to a more extensive knowledge than the individual knowledge carried by each participating individual.

The International College on Person-Centred Medicine (ICPCM) has produced declarations on different topics concerning personcentred medicine. Through this work, they have aimed to reframe our understanding of the concept of health by recognizing health and health care as dynamic and complex systems.<sup>42</sup> In addition to the aspects of attitudes that PPOS are dealing with, there are several other ways to consider and to assess the balance of power in clinical encounters and what kind of influence the practitioners' attitudes play. Street and co-workers have combined PPOS scores and communication control patterns and pointed out the importance of communication in quality health care. 43 They suggested that attitudes enhancing active patient participation and practitioner partnership building are claimed to mutual increase each other. From this, we interpret partnership building and active patient participation as important, but not exhaustive, facilitators for SDM because the complex and dynamic process involves individual factors that change over time.

Earlier studies have suggested that the practitioners' attitudes, but not the patients' attitudes, towards patient-centeredness are a key factor for generating higher patient satisfaction, better adherence, and improved health outcome. The opposite has also been postulated that patients whose doctors were not as patient-centred were less satisfied. Therefore, we assert that practitioners' attitudes are relevant features, which beneficially should be incorporated into the understanding of SDM processes. It has been suggested that the

<sup>&</sup>lt;sup>a</sup>Significance of differences in score between males and females.

<sup>&</sup>lt;sup>b</sup>Significance of differences in scores between the labelled profession and the college educated practitioners.

<sup>&</sup>lt;sup>c</sup>Significance of difference in scores between the labelled treatment sites and outpatient care.

**TABLE 3** Logistic mixed effects regression analysis with patient CollaboRate score more than 80 (ie, high SDM-score) as dependent variable, n = 772 patient-practitioner pairs contain all variables in the model

	Univariable N Logistic Regr		Multivariable Mixed Effect Logistic Regression			
Independent Variables	OR	95% confidence interval	P value	OR	95% confidence interval	P value
Age, years	1.02	1.00-1.04	.02	1.02	1.00-1.04	.08
Gender						
Male	1.00	0.66-1.52	.99	0.98	0.65-1.48	.91
Female	Ref			Ref		
Profession						
College education	1.03	0.60-1.78	.90	0.94	0.52-1.72	.84
Psychologist/specialist clinical psychology	0.95	0.54-1.68	.88	1.00	0.53-1.88	1.00
MD/psychiatrist	Ref			Ref		
Working site						
Ambulatory treatment	0.42	0.24-0.75	.01	0.44	0.25-0.79	.01
Inpatient treatment	0.59	0.31-1.13	.11	0.68	0.34-1.39	.29
Daycare treatment	0.73	0.37-1.40	.34	0.85	0.43-1.69	.64
Outpatient treatment	Ref			Ref		
PPOS score						
Sharing <sup>a</sup>	2.22	1.23-4.02	.01	1.97	1.09-3.56	.03
Caring <sup>a</sup>	0.67	0.35-1.29	.23	0.82	0.43-1.57	.54

Abbreviations: OR, odds ratio; PPOS, Patient-Practitioner Orientation Scale.

application of the different practitioner behavioural styles fit patients with the equal orientations at best. <sup>31</sup> Therefore, not necessarily all practitioners need to show sharing attitudes or develop their sharing attitude further to increase patient satisfaction. Some patients prefer disease-centred practitioners and should be equipped with treatment plans according to this. Nevertheless, the attitudes of the practitioners are relevant to pay attention to when patients are allocated in the clinics so that the best possible fit can be arranged and good conditions for successful treatments are facilitated.

The premise for implementing SDM is an active patient who is capable of making up an opinion of what matters most and is able to express it. SDM is one structured element in the ongoing turn from paternalistic health care, where the patient is a passive recipient of the health service's expertise, towards patient centeredness. A patient-centred health care requires and facilitates the autonomous patient, where SDM is one element in the accomplishment.<sup>42</sup> In mental health care, this can be a challenge because of the patients' condition. We believe, however, that also patients in mental health care are able to express their opinions and wishes for treatment despite significant burden of disease. We even think that being included in decisions about treatment is positive for mentally ill patients, and can facilitate the recovery process. We suggest that patient-centeredness should be regarded as an attitude permeating the entire service rather than isolated actions performed by individual practitioners.

The development of the autonomous patient capable of practicing SDM requires the health care service to be the driving force. The service is expected to guide the patient into an active and autonomous mode in order to develop patient-centeredness in health care service. Possible entanglements might appear when the autonomous patient, firstly, is activated by the health care service, and, secondly, is treated by the same clinics now supposed to practice patient-centeredness. It is a paradox, and could be demanding, for the service to both enable the patient for active participation in SDM processes and, thereafter, to comply the patients' requirements developed from facilitation of the autonomy process.

## 4.1 | Data considerations

As we linked the data from each practitioner to data from one or more patients, a mean regression with CollaboRATE score as a continuous variable was not possible. Additionally, the residuals of the patients CollaboRate scores were not normally distributed. Thus, the preconditions for linear regression models were not met. A dichotomizing into CollaboRate maximum score (a score of 100) or not did not yield any meaningful product, and a model with the maximum scores alone in one group was not regarded correct, mainly because of our experience of the diversity of the patient approaches to such scoring scales. As patients differ in personality and understanding of the questions, not

<sup>&</sup>lt;sup>a</sup>Sharing and caring scores on the PPOS, range 1 to 6.

only top scores should be regarded as "good." Some patients would never use the extremes on a scale, regardless of how strongly they agree or disagree to a statement. Because of this, with a scale ranged 0 to 100, the study group specified a cut-off of 80 as the dependent variable for the dichotomy CollaboRate score.

In this study, we collected information about the practitioners' attitudes towards their behavioural styles and explored associations towards patients' experience of SDM. We did not assess the patient attitudes towards their behavioural styles. As we regard attitudes as an internal feature and the experiences of SDM as an expression of an external event, they represent fundamentally different aspects. An additional exploration of patient attitudes towards behavioural styles using PPOS would add important contributions to understand the complexity of SDM processes. We searched in PubMed and Embase using the terms "PPOS," "CollaboRate," and the MeSH-terms "personnel attitudes" and "shared decision making," but could not find earlier studies exploring these associations.

# 4.2 | Strengths and limitations

In order to analyse and understand the underlying complexity in the SDM processes in mental health care, the assessment methods we used in this study have obvious shortcomings. As a measure of practitioners' attitude, we explored only one facet; the behavioural styles measured by PPOS. This is not sufficient to characterize the polygonal influence practitioners make on the patient perceptions. Thus, in order to suggest professional competencies necessary to implement SDM throughout the mental health care service, the sharing and caring attitudes measured by the PPOS is only one of many essential qualities to appraise. The person-centred health care, wherein SDM is a culmination of patient-practitioner relationship and communication, contain complex structures and high-dimensional interactions among multiple factors.<sup>42</sup> The competencies sufficient for this multiple task are comprehensive and not suitable to be assessed through one single instrument. Future initiatives for development of relevant instruments to identify and structure professional skills necessary for SDM are desirable.

The patients attending the service are diverse with regard to diagnosis, illness duration, symptom burden, and functioning. We did not analyse diagnostic information of function level in this paper. From service knowledge, we assume that inpatient care and ambulatory care are offered to patients with more severe disease symptoms or in more acute illness phases than outpatient care. As we know, patient-practitioner relationships are complex and mutually influenced. It would be of interest to investigate patient characteristics further. However, professional attitudes are suggested internal and exist overarching and prior to individual patient visits.

## 4.3 | Further implications

Until now, focus on SDM preparations and the barriers and facilitators have been on the patients' characteristics. We suggest that the focus

should be turned more towards the health care service and the role of the practitioners. Practitioners' attitudes affect patients' perceptions of SDM. Evolvement of attitudes are complex and develop to a great extent through clinical experience. The soft skills necessary to fulfil SDM are challenging to teach, describe, and measure. In spite of the difficulties, it is important that the service continues to implement SDM and assess the effort to realize the patient's health service.

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## **CONFLICT OF INTEREST**

The authors declare no conflict of interest.

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# Discrepancy in ratings of shared decision making between patients and health professionals: A cross sectional study in mental health care and interdisciplinary specialized addiction services

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List of abbreviations

SDM: shared decision-making

ICD-10: International Classification of Diseases, Tenth Revision

SPSS: Statistical Package for the Social Sciences developed by IBM Corporation, 23<sup>rd</sup> edition.

OR: Odds ratio

CI: Confidence interval

ICC: Intra-class correlation coefficient

**Declarations** 

Ethics approval and consent to participate

The study was approved by the Norwegian Regional Committees for medical and Health Research

ethics (no 2016/1781), and by the Research Department at Sørlandet Hospital (no 17/00104). All

patients gave written consent for participation after being given oral and written information.

Consent for publication

Not applicable

Availability of data and material

The datasets used and analyzed in the current study will be available from the corresponding author

on reasonable request.

2

# **Competing interests**

The authors declare that they have no competing interests.

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# Authors' contribution

VØH, ACI, JKV, YLH, HR, and KD designed the study. YLH registered all the questionnaires. YLH, RSF, JKV, and KD did the statistical analyses. VØH, YLH, JKV, RSF, ACI, and KD interpreted data. VØH, JKV, ACI, YLH, LT, and KD wrote the draft of the manuscript. All authors read and approved the final manuscript.

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# **Abstract**

Background: A defined goal in mental health care is to increase the opportunities for patients to more actively participate in their treatment. This goal includes integrating aspects of user empowerment and shared decision-making (SDM) into treatment courses. To achieve this goal, more knowledge is needed about how patients and therapists perceive this integration.

Objective: To explore patient experiences of SDM, to describe differences between patient and therapist experiences, and to identify patient factors that might reduce SDM experiences for patients compared to the experiences of their therapists.

Methods: This cross-sectional study included 992 patients that had appointments with 267 therapists at Sørlandet Hospital, Division of Mental Health during a one-week period. Both patients and therapists completed the CollaboRATE questionnaire, which was used to rate SDM experiences. Patients reported demographic and treatment-related information. Therapists provided clinical information.

Results: The analysis included 953 patient-therapist responder pairs that completed the CollaboRATE questionnaire. The mean SDM score was 80.7 (SD 20.8) among patients, and 86.6 (SD 12.1) among therapists. Females and patients that did not use medication for mental health disorders reported higher SDM scores than males and patients that used psychiatric medications (83.3 vs. 77.7; p<0.001 and 82.6 vs. 79.8; p= 0.03, respectively). Patients with diagnoses involving psychotic symptoms reported lower SDM scores than all the other patients (66.8 vs. 82.3; p<0.001). The probability that a patient would report lower SDM scores than their therapist was highest among patients that received involuntary treatment (OR 3.2, p=0.02), patients with treatment durations longer than 2.2 years (OR 1.9, p=0.001), and patients that required day care or in-patient care (OR 3.2, p=0.01 and OR 3.2, p<0.001, respectively).

Conclusions: We showed that both therapists and patients reported good SDM experiences in decisional situations, which indicated that SDM was implemented well. However, the SDM scores reported by in-patients and patients with prolonged or involuntary treatments were significantly lower than scores reported by their therapists. Our findings suggested that it remains a struggle in mental health care to establish a common understanding between patients and therapists in decisional processes regarding treatments for some patient groups.

# Keywords

Shared decision-making, SDM, mental health care, CollaboRATE, psychosis, user involvement

# **Background**

In the past few decades, awareness has been raised among mental health professionals, politicians, patient organizations, and health administrators regarding the advantages of patients playing a more active role in their own treatments. This approach entails a shift for health services from focusing on treatments to focusing on patients (1). Shared decision-making (SDM) is becoming part of modern health care worldwide (2), and it should preferably be integrated into all treatment programs, including mental health care and interdisciplinary specialized addiction services (3, 4).

A variety of definitions for SDM have been suggested since the concept was introduced in the 1990's (5). The most common definition was given by Glen Elwyn: "An approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported in considering options to achieve informed preferences" (6). A crucial prerequisite for SDM is that the perspectives of patients and therapists are equally valued, despite fundamental differences (7). The therapists hold a professional expertise based on education and clinical practice, whereas the patients hold an expertise from the experience of managing a life with illness.

Traditionally, SDM was understood as a micro-social process, limited to a single consultation involving the patient and therapist. Morant and co-workers suggested that this understanding of SDM was too narrow and limited for mental health care (8). Their main objection rested on the nature of mental illness and its demand for complex management. Mental health care most often includes long-term treatment that includes key players, like relatives and people in the patient's supportive network. Additionally, it is important to recognize that mental illnesses evolve through periods of recovery and relapse (8-10). All these elements call for considering SDM in mental health care a continuous process that involves multiple people, which cannot be restricted to a single decision or a particular consultation (11, 12).

To develop the mental health care service further, more knowledge is needed about the ability of our health service to include patient perspectives in treatment situations. Previous studies that aimed to evaluate SDM implementations in mental health care services were often restricted to specific clinical settings or diagnostic groups (13-16), or alternatively, they mainly focused on describing the patient benefits provided with SDM education (2, 17, 18). In those studies, more positive SDM experiences were associated with older patient ages and female gender (13). However, we lack knowledge about how a general population in a specialist mental health care setting experiences SDM (19).

A number of tools for assessing SDM have been developed and validated. These tools include interviews, paper-based self-report forms, interactive voice-response calls, or questionnaires conducted on a tablet or computer (7, 20, 21). SDM assessments can be conducted on site or retrospectively (22). However, in many publications, it is not clear which assessment tools were used to measure SDM experiences (23).

SDM implementation requires contributions from individuals with different perspectives; consequently, disagreements can occur. Previous explorations of the nature of patient-therapist relationships have indicated an existence of non-independency, as the clinical encounters contain multiple persons embedded within a social context (24). Such a context includes interpersonal relationships, suggesting the individual experiences of the participants mutually reinforcing and non-independent of each other (25). We suggest that a higher level of agreement on how to perform decisional processes represents a better foundation for good treatment decisions, which facilitate patient compliance. Although the level of agreement is rarely studied, psychotherapy studies have suggested that greater agreement on the quality of the patient-therapist alliance and stronger patient-therapist bonds could lead to better treatment outcomes (26, 27). A discrepancy can occur between the patient and therapist experiences in SDM, when either the therapist or the patient experiences a better SDM process. A study that explored the fit between patient and therapist

orientations suggested that a better fit could improve patient satisfaction, but that the patient's orientation was more important to patient satisfaction than the therapist's orientation (28). A large discrepancy might indicate that the patient and therapist do not share or communicate common goals or that they do not have a similar appreciation of the usefulness of the treatment. From the patient's perspective, it is irrelevant whether the therapist's experience is worse than the patient's experience in SDM, but when the patient's experience is worse than the therapist's experience, it might hinder an optimal decision process. Additionally, we hold the health care service responsible for facilitating patient involvement in decisions regarding their health and treatment. Therefore, in this study, we chose to focus on the fraction of patients that experienced more negative SDM processes than their therapists, because this situation was suggested to be more important for good treatment courses and outcomes (28). In this study, we termed this situation 'a negative discrepancy'.

# Materials and methods

# Aims

The aims of this study were to (*i*) explore patient experiences with SDM in a mental health care and addiction service setting, (*ii*) describe the congruence in SDM experiences between patients and their therapists; and (*iii*) identify factors associated with more negative SDM experiences for the patient than for their therapist (a negative discrepancy).

# **Population**

Sørlandet Hospital Trust serves a population of about 300 000 individuals (29) in the southern part of Norway. It provides medical health services to a number of rural and urban communities. The Division of Mental Health and Addiction Services has 280 beds, and it provides acute and long-term treatments in forensic psychiatry, child and adolescent psychiatry, geriatric psychiatry, and treatment

of substance-related disorders. The division has 1375 full-time-equivalent employees, and it manages 4150 admissions and 184 000 consultations per year.

# Data collection

We recruited patients that visited the division during the third week of January 2017. We recruited patients that received psychiatric health care at the hospital during the third week of January 2017. Patients over 16 years were included. Day care patients and out-patients were included from visit 2 when this was scheduled for this particular week. Patients receiving ambulatory care (treatment offered at the patients' residents) were included during the visit from health care professionals. Inpatients were included at a scheduled talk after 24 h of hospitalization. Patients receiving involuntary treatment were also included. Patients were only included at the first visit, when they had more than one visit or contact with the service during the week. Patients that received treatment from different parts of the division within the study week were only included once. Patients without legal capacity to make informed consent were not asked to participate. Patients were excluded, when for any reason, participation was contraindicated by their therapist, they could not complete a paper-based questionnaire, or they could not read the Norwegian language. All patients provided written informed consent after receiving oral and written information about the study from their therapist, from posters in the clinic, and/or from study personnel.

The assessment consisted of two parts: one part was completed by the patient, and the other part was completed by their therapist. All patients completed their part of the inventory during a visit at the clinic. The patients completed the CollaboRATE measurement tool and a form with questions about demographic characteristics and medication use. On the same day, the patient's therapist also completed the CollaboRATE and a form with questions about the patient's diagnoses and clinical characteristics.

# Research instrument

We based all SDM outcomes on the CollaboRATE measurement tool. The CollaboRATE is a well validated, self-reporting, paper assessment tool that was shown to be useful in different patient populations and at different levels of care (13). The CollaboRATE was developed to accommodate both patient and therapist experiences (30). It comprised three single questions related to education about the health situation, and whether professionals paid attention to what matters most to the patient. Questions were rated on a scale of 0-9, where zero represented "no effort was made" and nine represented "every effort was made" (31). The responses from the three questions were summed, and the range of total scores was 0-27. According to the CollaboRATE manual, this sum score was multiplied by 3.704 to convert it to a response percentage score that ranged from 0 to 100%. We were aware of ceiling effects with patient-reported SDM (13, 31, 32), therefore, we also reported the proportion of top scores (score=100).

# SDM dyadic deviation value

The different experiences with SDM were explored by calculating a SDM dyadic deviation value. This calculation was the patient's recalculated CollaboRATE percentage score minus the therapist's corresponding score. The result was positive, when the patient reported a higher SDM score than the therapist, and it was negative, when the patient reported a lower SDM score than the therapist. A larger absolute SDM dyadic deviation value indicated a larger difference between patient and therapist SDM experiences. A SDM dyadic deviation value of zero reflected situations where the patient and therapist reported the same CollaboRATE scores.

According to a consensus between the expert group that initiated the study and clinicians experienced in the field, a clinically relevant negative difference between patient and therapist experiences was defined by a cut off value set to -22 on the CollaboRATE (range 0-100). When the negative discrepancy was -22 or lower, the patients reported at least 6 points less than their therapist on the CollaboRATE ordinal scale (range 0-27), which represented about a 20% difference.

Patient-therapist pairs with a negative discrepancy of –22 or lower were designated group one.

Patient-therapist pairs with a SDM dyadic deviation value higher than –22 were considered to have corresponding experiences, and they were designated group two. Thus, group two contained pairs with SDM dyadic deviation values close to zero or in the positive range. We considered whether it would be appropriate to include patient-therapist pairs with SDM dyadic deviation values of -22 to 22 in the same group as those with SDM dyadic deviation values >22 in the model. To that end, we also analyzed patients with SDM dyadic deviation values >22 as a separate group. This alternative model produced the same results as those produced with the chosen model, for the available variables.

# Ethical approval

The study was approved by the Norwegian Regional Committee for Research Ethics (no 2016/1781) and the Hospital Research Board (no 17/00104). All patients provided written informed consent prior to participation.

# Data analysis

Patient diagnoses were categorized into diagnostic groups, according to the International Classification of Diseases, tenth revision (ICD-10) (33). The diagnostic groups were classified as follows (with shortened group names in parentheses): F10 (Substance related disorders); F20 plus the F30 subgroups F30.1, F30.2, F30.8, F30.9, F31.1, F31.2, F31.5, F32.3, and F33.3 (Psychotic disorders); all other F30 subgroups (Affective disorders); F40 (Anxiety disorders); F60 (Personality disorders); and F90 (Behavioral disorders). Patients with other main diagnoses were combined into a group called "Other" (Table 1).

Age was considered a continuous variable. Gender, use of psychotropic medication (yes/no), and involuntary treatment (yes/no) were dichotomized. Treatment duration was dichotomized, as greater or less than 2.2 years, which corresponded to the median treatment duration. We could not retain treatment duration as a continuous variable, because it was not linearly related to the

dependent variable. The levels of care were categorized into four groups: in-patients, day care, ambulatory care and out-patients.

Statistical analyses were performed with the Statistical Package for the Social Sciences (SPSS), developed by IBM Corporation, 23<sup>rd</sup> edition (34) and Stata Statistical Software (Stata) Release 15 (35). Patient characteristics were compared with the independent t-test and chi-square test. Variables that described the SDM experience for patients and therapists are expressed as the frequency, proportion, or the mean and standard deviation (SD).

To take into account the non-independence in the data, we performed mixed effect logistic regression analyses to identity variables that influenced the SDM dyadic deviation value. Then, patients belonging to the same therapist were grouped together, and dependencies within therapist were estimated by including a random effect to the model. We used the purposeful selection approach to select variables for these analyses (36). First, we performed univariate analyses with the following variables: age, gender, diagnosis, level of care, involuntary treatment, drug treatment, and treatment duration. Variables with a p-value <0.2 were included in the multivariate analyses. In the multivariate analyses, variables with the largest p-values were deleted one-by-one, until all variables were significant at the 5% level. Results are presented as the odds ratio (OR) with 95% confidence interval (CI). No effect of multi-collinearity was observed, because all variance inflation factors were <2.

We also performed a sensitivity analysis to study the sensitivity of the chosen cut-off value of -22 for the reported SDM. We repeated mixed effect logistic regression analyses with cut-off values of -18 and -26, which represented patient scores that were five and seven points less than the therapist scores, respectively.

An intra-class correlation coefficient (ICC) (36) was calculated to identify correlations between patient and therapist SDM scores. Spearman's rho correlation coefficient was calculated to evaluate the association between the patient's SDM score and the SDM dyadic deviation value.

# Results

# Patient characteristics

We included 992 patients with a mean age of 35.6 years, and 58% were female (n=575). Of these, 567 (57%) received medications for treatment. Anxiety disorders were the most common diagnosis (n=285 patients, 28.7%), followed by affective disorders (n=192 patients, 19.4%), substance-related disorders (n=187 patients, 18.9%), and psychotic disorders (n=82 patients, 8.3%). Involuntary treatment was established for 30 patients (3.0%). Most patients (n=761, 76.7%) received out-patient care, and 106 (10.7%) received in-patient care. The mean treatment duration for all patients was 5.2 years, and the median treatment duration was 2.2 years (Table 1).

The 267 therapists that completed the therapist parts treated a mean of 3.7 patients (range 1-22). Not all patients completed the CollaboRATE. The final SDM exploration included 953 patient-therapist responder pairs.

# **Experiences with SDM**

The patient CollaboRATE reports showed a mean SDM score of 80.7 (SD 20.8; Table 1). Male patients reported a significantly lower SDM score than females (mean 77.7 and 83.3, respectively; p<0.001). Patients that used medication for mental health concerns (n=567) reported significantly lower SDM scores than patients that did not use medication (mean SDM scores: 79.8 and 82.6, respectively; p= 0.03). The 82 patients with psychotic disorders reported significantly lower SDM scores than patients without psychotic disorders (mean SDM scores: 66.8 and 82.3, respectively; p<0.001). Patients treated involuntarily (n=30) reported significantly lower SDM scores than patients treated voluntarily (mean SDM scores: 50.6 and 82.0, respectively; p<0.001). Additionally, patients with treatment durations longer than the median of 2.2 years reported significantly lower SDM scores than patients with shorter treatment durations (mean SDM scores: 78.0 and 83.9, respectively; p<0.001). Out-

patients (n=761) reported significantly higher SDM scores than patients that received other levels of mental health care (mean SDM scores: 83.8 and 71.9, respectively; p<0.001).

The top SDM score was reported by 272 patients (27.4%), more frequently by females than by males (32.3% and 20.6%, respectively; p<0.001). Top SDM scores were also frequently reported by patients that received out-patient treatments (30.5%, p<0.001). In contrast, top SDM scores were reported less frequently by patients that received ambulatory and in-patient care (11.0%, p= 0.001, and 18.9%, p= 0.04, respectively). The proportion of top scores among patients that received day care was not significantly different from those reported by patients that received other treatment levels. Top SDM scores were reported by only nine out of 82 patients (11.0%) with psychotic disorders. In contrast, 261 out of 910 patients in the other diagnosis groups (28.6%) reported top SDM scores (p<0.001). No significant differences were found among the other diagnostic groups (data not shown).

The mean SDM score for therapists was 86.6 (SD 12.1), and a top score was reported by therapists for 188 patients (19.7%; data not shown).

(Table 1 to be placed here)

# Distribution of SDM dyadic deviation values

The mean SDM dyadic deviation value was -5.8 (SD 20.9, range: -82 to 96). The distribution of SDM dyadic deviation values are shown in Figure 1. Group one (SDM dyadic deviation values  $\leq -22$ ) contained 192 patient-therapist pairs (20%); group two (SDM dyadic deviation values > -22) contained 761 pairs (80%). Among the patient-therapist pairs in group two, 703 pairs (74%) had a SDM dyadic deviation value between -22 and 22; 58 pairs (6%) had a SDM dyadic deviation value >22.

(Figure 1 to be placed here)

# Factors associated with SDM dyadic deviation values

Patients that received in-patient care or day care were more than three-fold more likely of being in group one (having a negative discrepancy) compared to patients that received out-patient care (OR 3.2, 95% CI: 1.7-6.0 and OR 3.2, 95% CI: 1.3-8.0, respectively; Table 2). Patients that received involuntary treatment also had more than three-fold higher risk (OR 3.2, 95%CI: 1.2-8.5) of being in group one compared to patients that received voluntary treatment. Additionally, patients that had been in treatment for more than 2.2 years had a 1.9-fold higher risk (95% CI: 1.3-2.8) of being in group one compared to patients treated for less than 2.2 years. Patient age, gender, diagnosis, and use of medication for a mental health disorder did not reach statistical significance, and thus, not considered associated with a negative SDM dyadic deviation value.

(Table 2 to be placed here)

The correlation coefficient between patient SDM experiences and the SDM dyadic deviation values was 0.83, which indicated a strong positive relationship. The sensitivity analyses showed that cut-off values of -18 and -26 produced results similar to those produced with a cut-off of -22. The effects of covariates showed ORs similar to those obtained with the -22 cut-off value in the original model (data not shown).

# Discussion

Both patients and therapists reported average CollaboRATE scores greater than 80 out of 100. This suggested that the SDM experiences were good in decision situations and that SDM was generally well-implemented in the hospital. SDM experiences were less successful among patients in need of higher levels of care, patients that used medication for mental health concerns, patients that received involuntary treatments, and patients that required prolonged treatments. These groups of patients were most likely to report negative SDM dyadic deviation values.

Our findings on patient SDM experiences were comparable to those previously reported by Forcino and co-workers in primary care, where the mean SDM varied from 68 to 86 out of 100 (13). In both studies, patients with psychotic disorders or involuntary treatments reported more negative experiences with SDM than patients with other diagnoses. In our study, men reported more negative SDM experiences than women, also consistent with findings from Forcino and co-workers (13).

From the clinical perspective, patient groups that reported lower SDM scores more often had serious mental illnesses that demanded more comprehensive treatments, including long-term medications. Although not included in the present model, the severity of the disorder was likely to be correlated with the SDM score. Moreover, the implementation of SDM might be more difficult in these patient groups, due to multiple factors regarding treatments. These speculations are consistent with findings from a Swedish study performed by Rosenberg and co-workers, where patients with serious mental illnesses in municipal social psychiatry units reported variable SDM experiences (37).

Three quarters of our patient-therapist pairs reported similar SDM experiences. However, among one fourth of the pairs, patient SDM experiences were clearly different from those of the corresponding therapists. This discrepancy in experiences was suggested to be due to deficits among both patients and the therapists (38). A recent study that explored the therapeutic bond in mental health care services suggested that, when both the patient and therapist of a dyad perceived similar changes in the therapeutic bond, they worked more effectively toward symptom improvements (27). Additionally, the study from Rosenberg and co-workers suggested that the patient-therapist relationship was a key factor in facilitating SDM. However, the present study also included clinical and structural factors of the service; therefore, the discrepancy in SDM experiences might have been an expression of shortages on levels other than those explored in the study. The shortages may be patient-related, like opposition to the diagnosis or a wish to attend other treatment courses than offered. Shortages may also be related to the health care service, like therapist availability or practical organization of the treatments.

Based on findings from previous studies (39, 40), it was not surprising that patients that received involuntarily treatments, prolonged treatments, or required more intensive care reported the lowest SDM scores. Nevertheless, it has been suggested that the application of SDM was feasible and beneficial for these groups of patients (41, 42). Therefore, it was not quite clear why these patient experiences differed from the experiences of their therapists. We suggest that these findings might be contextually linked to the structure and/or framework of the service. Some treatment levels might not facilitate SDM implementation, due to a strict framework or lack of alternative treatments; thus, disagreements between patients and therapists might be more likely to occur in these circumstances. Indeed, treatments for in-patients include many predetermined factors that cannot be altered to meet an individual patient's needs and preferences. The same caveat applies to the remaining treatment levels. Structural frameworks, like house rules in in-patient clinics and attendence times in other clinics, can restrict the range of possible adjustments. Another explanation might be that some patients lacked sufficient competence to participate in SDM, due to a serious debilitating mental illness or an impaired ability to modulate emotions or understand their mental health prognosis (43). Although patients that received involuntary treatments had a higher probability of reporting more negative SDM scores than their therapists, we would like to emphasize that the service has the responsibility of actively including these patients in decisions, when possible. We suggest that it is particularly demanding to establish SDM among patients treated involuntarily, due to the fundamental difference in understanding. The patients treated involuntarily might have evaluated their health situation differently from how the health care service evaluated it, and thus, they might not agree to arranged treatments. However, the negative SDM scores cannot be explained by the involuntary situation alone. A recent study revealed that patients treated involuntarily identified involvement in clinical decisions as a key factor in improving their experience of care (44). We suggest these patients could be involved in some treatment options, and that therapists should be aware of and utilize those opportunities. Continuous efforts to facilitate SDM for patients treated involuntarily should be encouraged.

Difficulties in establishing an effective treatment might lead to a poor SDM experience for the patient. These difficulties might be caused by an ineffective treatment, side effects from medications, persistent delusional symptoms, or unrealistic treatment goals. Additionally, negative SDM dyadic deviation values might be due to a basic discrepancy in understanding the situation between the patient and the therapist. For example, the therapist might feel that sufficient effort has been devoted to treatment and that the available treatment options have been explored, while the patient conceives it differently. A previous study suggested that the therapeutic atmosphere might change over time during long-term treatments (45). Patients just starting treatment might have a more positive SDM experience than patients that have been undergoing treatment for a long time, due to a fundamental shift in their understanding of the therapeutic benefit of the treatment.

Moreover, the treatment atmosphere reflected in a negative SDM dyadic deviation value might affect the success of the treatment.

Patients that received short-term out-patient treatments reported higher SDM scores, they were less likely to report negative SDM dyadic deviation values, and they more frequently reported top SDM scores, compared to patients in other levels of care. These treatment profiles indicated that patients with less severe disorders, and perhaps, less distress had better SDM experiences. Hence, parts of the service treating other patient groups might adopt some treatment approaches that facilitate SDM. Despite the different premises for different treatments, there might be advantageous treatment elements that could be implemented in other service areas, where patients reported low SDM scores

In the statistical analyses, the SDM dyadic deviation values were dichotomized into two groups.

Patients that clearly reported a more positive SDM than their therapist was an interesting subgroup, but we found no differences in the variables between this group and the group of patients with SDM experiences similar to their therapists. Thus, these two subgroups of patients were considered one group in the statistical analyses. We speculated that, if the SDM dyadic deviation values in the

positive range were spaced into a separate group, then we might have detected other differences between the groups. However, we did not make such findings as we tested the model. In addition, if we had had access to data on more variables, we might have been able to reveal associations specific for patients with positive SDM dyadic deviation values.

#### Strengths and limitations

In Norway, both primary care and specialist care are mainly publicly operated. Therefore, we considered the patients in this study representative of patients that received mental health care at the specialist level in Norway. This was a major strength of the study. However, we could not determine whether all the characteristics of the included patients were representative of the national population with mental illnesses, because that information would be very difficult to acquire (46). Nevertheless, due to the relatively high number of participants in our study, we suggest that our findings were relevant to the understanding of the congruence between patient and therapist experiences in mental health care at the specialist level.

Another strength of this study was the high proportion of completed CollaboRATE questionnaires; thus, we retained nine tenths of the included cases in the analyses. The CollaboRATE questionnaire was a suitable tool for revealing the extent of SDM in specialist practice. Nevertheless, although SDM has been implemented for some time in many institutions, we lack a common definition for "sufficient SDM"; moreover, we lack a common set of attitudes or skills that should be applied when exploring these processes. Consequently, the definition of "sufficient SDM" should be explored further and discussed in future studies to establish a consensus on what comprises "sufficient SDM".

Patients in need of more complex care interact with more professionals during treatment. They meet one or more therapists for active treatment sessions, and other personnel for activity groups and other arrangements. Thus, the SDM reports from these patients could potentially reflect decision processes and decisions that involved professionals other than the main therapist. However, in the present study, only the main therapist provided the other half of the dyadic SDM value. Therefore,

the SDM reports from the patients, and thereby the dyadic SMD value, might not have reflected strictly the relationship between two reporting individuals. Due to our knowledge of the guidelines and management of our division, we knew that patients with serious mental illnesses were more likely to receive long-term treatment and more frequent follow-ups at the specialist care level. However, we did not request any assessment of illness severity or level function in addition to diagnostic information. Due to the variability in illness severity within each diagnostic group, it might have been advantageous to record the current illness severity, to get a wider foundation to understand patient situations. No information about comorbidity was available for analyses, which was a limitation preventing us to explore the patient situation in a more comprehensive way. Another limitation of this study was that the analyses of different independent variables led to several subgroups with very few patients. This limitation might have precluded the detection of significant differences between certain groups. Although we found a positive relationship between lower patient-reported SDM scores and a negative SDM dyadic deviation value, we did not find associations between the SDM dyadic deviation value and gender, medication use, or a psychotic disorder diagnosis among the patients in group one. This lack of associations may probably be due to low patient numbers in each subgroup in the statistical model. However, merging different subgroups was not considered correct from a clinical standpoint, due to the diversity between groups. Finally, factors other than those explored in the present study might, presumably, have influenced the SDM experiences.

#### **Implications**

The findings of this study indicated that the perceptions of SDM were generally high in the specialist mental health services in Norway, but differed between patients and their therapists. Moreover, these patient-therapist discrepancies varied in different groups of patients. Patients that received long-term, high level care or involuntary treatments reported more negative SDM dyadic deviation values than other patients. To address this problem, therapists should increase flexibility in the decision processes and facilitate a psychological compensation for strict frameworks, focusing on

treatment aspects where real choices exist. Patients that report more negative SDM dyadic deviation values consume a large proportion of mental health care resources. Therefore, initiatives to assimilate their perspectives into decision situations are likely to optimize the treatment courses.

#### Conclusion

Patients that required high levels of care, such as in-patient and day-care treatments, involuntary treatments, and prolonged treatments (more than 2 years), had a higher probability of reporting lower SDM scores than their therapists. Identification of these patient groups might facilitate the implementation of targeted service efforts to improve SDM and achieve better treatment outcomes.

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Table 1. Characteristics of the patients, CollaboRATE mean scores and proportion top scores for the different subgroups of patients, and statistical significance of differences between the subgroups, n=992

Patient characteristics	N (%)	Mean (SD)	CollaboRATE mean score (SD) <sup>a</sup>	p-value	CollaboRATE top score N (%)
Total	992		80.7 (20.8)		272 (27.4)
Age, years		35.6 (13.2)			
Gender					
Female	575 (58.0)		83.3 (20.1)	<0.001	186 (32.3)
Male	417 (42.0)		77.7 (21.0)		86 (20.6)
Medication for mental					
health concern	- c= (== a)		=0.0 (0.1.1)	2.22	1 1 1 (2 - 1)
Yes	567 (57.2)		79.8 (21.4)	0.03	144 (25.4)
No	425 (42.8)		82.6 (19.5)		128 (30.1)
Main diagnostic group					
F10 Substance related disorders	187 (18.9)		79.1 (24.1)		60 (32.1)
F20, F30.1, F30.2, F30.8,F30.9, F31.1, F31.2, F31.5, F32.3, F33.3 Psychotic disorders	82 (8.3)		66.8 (25.1)	<0.001 b	9 (11.0)
The remaining F30 Affective disorders	192 (19.4)		84.4 (18.7)		60 (31.3)
F40 Anxiety disorders	285 (28.7)		85.0 (17.4)		90 (31.6)
F60 Personality disorders	75 (7.6)		76.7 (21.1)		16 (21.3)
F90 Behavioral disorders	48 (4.8)		85.8 (15.7)		15 (31.3)
Other diagnosis or missing information	123 (12.4)		82.0 (16.8)		22 (17.9)
Involuntary treatment					
Yes	30 (3.0)		50.6 (29.6)	<0.001	2 (6.6)
No	962 (97.0)		82.0 (19.6)		270 (28.1)
Treatment duration					
Mean, years		5.2 (6.7)			
≤ median 2.2 years	496 (50.0)		83.9 (18.1)	<0.001	147 (29.6)
> median 2.2 years	496 (50.0)		78.0 (22.5)		125 (25.2)
Level of care					
In-patient care	106 (10.7)		70.3 (26.3)		20 (18.9)
Ambulatory care	73 (7.4)		73.1 (22.7)		8 (11.0)
Day care	38 (3.8)		72.4 (24.7)		8 (21.1)
Out-patient care	761 (76.7)		83.8 (18.3)	<0.001 <sup>c</sup>	232 (30.5)
Missing information	9 (0.9)				

a: n=956 patients completed the CollaboRATE

b: Compared to the patients with the remaining diagnoses (with mean CollaboRATE score 82.3)

c: Compared to the patients at the remaining levels of care (with mean CollaboRATE score 71.9)

Table 2. Variables associated with lower SDM dyadic deviation values. Results from mixed effect logistic regression analyses.

	Univariable analysis		Multivariable analysis <sup>a</sup>	
	OR (95% CI)	P-value	OR (95% CI)	P-value
Age (per 10 years)	1.0 (0.9-1.2)	0.57	-	
Gender			-	
Female	0.9 (0.6-1.2)	0.40		
Male	Ref			
Medication for mental				
health concern			-	
Yes	1.3 (0.9-1.9)	0.16		
No	Ref			
Psychotic disorders b			-	
Yes	4.0 (2.1-7.7)	< 0.001		
No	Ref			
Involuntary treatment				
Yes	6.6 (2.7-16.1)	< 0.001	3.2 (1.2-8.5)	0.02
No	Ref		Ref	
Treatment duration				
≥ 2.2 years	2.4 (1.6-3.5)	< 0.001	1.9 (1.3-2.8)	0.001
< 2.2 years	Ref		Ref	
Level of care				
In-patient	4.3 (2.3-7.8)	< 0.001	3.2 (1.7-6.0)	< 0.001
Ambulatory care	3.0 (1.5-6.1)	0.002	2.1 (1.0-4.3)	0.06
Day care	3.7 (1.5-9.2)	0.005	3.2 (1.3-8.0)	0.01
Out-patient	Ref		Ref	

OR=odds ratio, CI=confidence interval

a: n=943 observations with complete information about all variables in the multivariable model b: includes the ICD-10 diagnoses F20, F30.1, F30.2, F30.8, F30.9, F31.1, F31.2, F31.5, F32.3, and F33.3

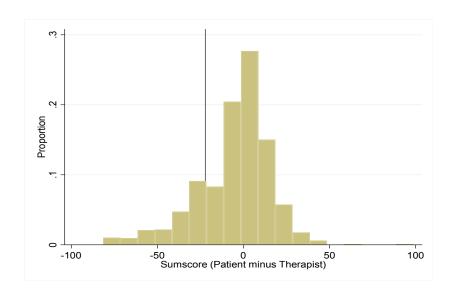


Figure 1. Distribution of SDM dyadic deviation values among the patient-therapist pairs in the study, n=953.





OPEN

# **Enabling patients to cope with psychotropic** medication in mental health care

### **Evaluation and reports of the new inventory MedSupport**

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#### **Abstract**

This cross sectional study examined patients' perceptions of professional support regarding use of psychotropic medication in a specialist mental health care setting. The aims were to evaluate reliability and validity of the MedSupport inventory, and investigate possible associations between MedSupport scores and patient characteristics.

A cross-sectional study was performed. The patients completed the MedSupport, a newly developed self-reported 6 item questionnaire on a Likert scale ranged 1 to 5 (1 = strongly disagree to 5=strongly agree), and the Beliefs about Medicines Questionnaire. Diagnosis and treatment information were obtained at the clinical visits and from patient records.

Among the 992 patients recruited, 567 patients (57%) used psychotropic medications, and 514 (91%) of these completed the MedSupport and were included in the study. The MedSupport showed an adequate internal consistency (Cronbach alpha.87; 95% CI.86–89) and a convergent validity toward the available variables. The MedSupport mean score was 3.8 (standard deviation.9, median 3.8). Increasing age and the experience of stronger needs for psychotropic medication were associated with perception of more support to cope with medication, whereas higher concern toward use of psychotropic medication was associated with perception of less support. Patients diagnosed with behavioral and emotional disorders, onset in childhood and adolescence perceived more support than patients with Mood disorders.

The MedSupport inventory was suitable for assessing the patients' perceived support from health care service regarding their medication. Awareness of differences in patients' perceptions might enable the service to provide special measures for patients who perceive insufficient medication support.

**Abbreviations:** BMQ = Beliefs about Medicines Questionnaire, ICD-10 = World Health Organization International Classification of Diseases, 10th Revision, PROM = Patient reported outcome measure, SD = Standard deviation, SPSS = Statistical Package for the Social Sciences.

Keywords: medication, Mental Health, PROMs, support

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The authors report no conflicts of interest

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#### 1. Introduction

Interdisciplinary specialized mental health and addiction services offer treatment for patients with different levels of symptom burdens and impairments in mental functions. During the past few decades, improvements of the health services for patients within this field have focused on increased patient involvements in decisions related to the treatment. [1–3] Clinical work and research within the mental health field have increasingly concerned patient reported outcome measures (PROMs). A PROM is an instrument for patients to report their function and symptoms related to their health and treatment, [4] and concerns the patient views on the outcome, which is an important, independent factor in treatment evaluations.

Modern health care services strive to improve treatment outcomes by engaging patients in treatment plans. Pharmacological interventions have their natural place in mental health services preferably in combination with other treatment modalities. The patients' existing attitudes to medication have been shown to be important for the treatment. It is also important to what extent the patients receive sufficient information about their medications, and their experience of support in connection with such treatment. [6,7] If the patients have negative attitudes to their

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medications and simultaneously receives inadequate support in medication issues, they will to a lesser extent be adherent to the treatment. Although medication is helpful to many patients, and has an indisputable place in the treatment of a number of psychiatric illnesses, they might also be contentious and encumbered with disadvantages like side effects, and administration difficulties. [8] More systematic measures to capture patients' experiences with medication treatments should be used to adjust and correct the individual medication and thereby improve the patients' compliance. Knowledge about the medication is suggested important, but is often insufficient for patients using antipsychotics. [9–11] A recent study has shown that low adherence to long-term medications is related to negative beliefs about medications and to inadequate information given to patients about their medications. [12] A Norwegian multicenter study was concerned about this as part of their outcome, but could not suggest any satisfactory tool that could measure the patients' perception of support in connection with the use of medication. As a consequence, the MedSupport inventory was developed to explore how patients perceived support from the mental health service regarding psychotropic medications. We find it important to explore the patients' perceptions in a structured way, in order to improve their handling of medication and to identify factors relevant for tailored measures.

As the existing Beliefs about medicines questionnaire (BMQ) discloses patients beliefs about medication as an internal attitude, [13] the MedSupport inventory enters the external issue; to which extent the patients perceive support from the service. This study aimed to evaluate the internal consistency of the MedSupport inventory and present data from the first study to use this instrument. Further, we aimed to investigate possible associations between patients' perceptions of medication support and demographic factors, clinical factors, and patient beliefs about medications. Our hypothesis was that the MedSupport score would be positively correlated with the BMQ-factor regarding needs of medication and negatively correlated with the BMQ-factor about concerns related to use of medications.

#### 2. Setting and methods

#### 2.1. Context

The health services in Norway are divided into a primary care level and a secondary, interdisciplinary specialist care level, which includes hospital care. Both primary and secondary care services are mainly publicly operated. Sørlandet Hospital provides specialist care for both rural and urban communities, covering a population of 302 000. [14] The Division of Mental Health has 12 different locations that provide ambulatory treatment, day care, in-patient treatment, and out-patient treatment. The division provides general mental health treatments, forensic psychiatry, child and adolescent psychiatry, geriatric psychiatry, and treatments for substance-related disorders for the region. The division holds 280 beds and manages 4150 admissions and 184,000 consultations per year.

#### 2.2. Study design and population

A cross-sectional study was carried out at the Division of mental health during the third week in January, 2017. Patients were included consecutively when they had regular treatment courses in the hospital, and were included from visit 2. Day care patients

and out-patients were included when they arrived for their regular appointment. Patients who receive ambulatory care were not capable of, or willing to, attend the hospital locations, or ambulatory care gave the best possible utilization of the treatment. They received treatment at home, and were included at their place of recidence during the visit from their therapist. Inpatients were included at a scheduled talk after 24hours of hospitalization. The patients were given information about the study from information posters in the clinics, from the receptionist, and from their therapist. We excluded patients under 16 years of age, patients attending their first consultation, patients that had been admitted for less than 24 hours, and patients that did not speak or read the Norwegian language. Patients were also excluded when inclusion would be harmful to the ongoing treatment or the patient-therapist relationship, or when the patient was considered unable to complete a written questionnaire. Patients were only included once if they were scheduled for more than 1 contact with the service during the study week. The patients were recruited from all parts of the service. They fulfilled the questionnaire during their regular visit, and the questionnaires were collected by the therapist or receptionist directly after the visit. Only patients using psychotropic medications as part of their treatment course and completing the MedSupport were included in this paper.

The patients reported age, gender, use of psychotropic medication, beliefs about medicines (using BMQ-specific which includes the factors needs and concerns regarding medication), and perceived support for medicines (the MedSupport inventory). Information on diagnoses, treatment durations, treatment modalities, and any compulsory treatments were obtained from patient records ().

The study was approved by the Norwegian Regional Committees for Medical and Health Research Ethics (no 2016/1781) and by the Hospital Board of Research (no: 17/00104). All patients provided written informed consent after receiving oral and written information prior to participation.

#### 2.3. Instruments

**2.3.1.** The MedSupport inventory. The MedSupport is a 6-item PROM instrument, constructed by a task force consisting of clinicians and researchers in Norway, to assess whether patients received support in dealing with medications. It was constructed for an ongoing Norwegian multi-center cluster randomized study on the implementation of guidelines and evidence-based

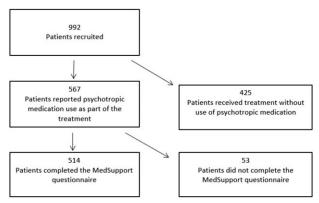


Figure 1. Flow chart of the patients recruited to the study.

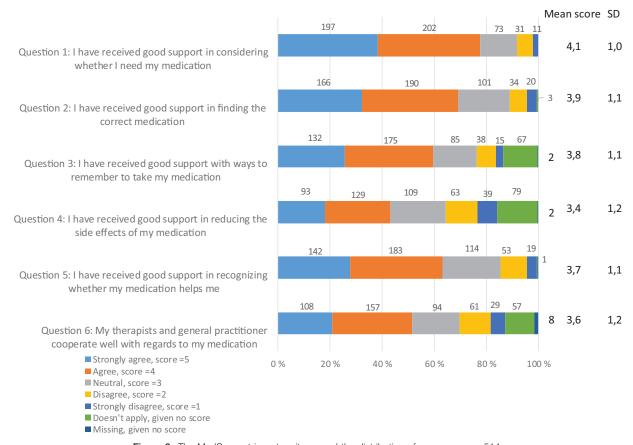


Figure 2. The MedSupport inventory items and the distribution of responses, n=514.

treatments of psychoses; however, it has not been previously validated<sup>[15]</sup> (Fig. 2).

The inventory consists of a 5-point Likert scale, where patients can express how they agree with each statement on a scale with range anchored by 1 (strongly disagree) and 5 (strongly agree), with 3 as a neutral mid-point. An important issue for the task force when constructing the questionnaire was that every item should contain a reasonable alternative for all patients. This premise was fulfilled by providing a "not applicable" box. This is shown as a separate response alternative in Figure 2. A mean score was calculated for the cases where at least 4 questions were answered. A higher mean score indicated that the patients perceived better support for the measured core aspects of using medicines.

The first 5 questions in the MedSupport questionnaire are statements covering core aspects regarding patients' perceived support with medication, including: experienced need for medication, optimizing psychotropic medication, ways to remember to take medication, reducing the adverse effects, and to recognize improvement of symptoms due to medication. The last question discloses the perceived cooperation between the mental health care service and the general practitioner. For publication purposes the MedSupport was translated into English, and then back-translated by a professional translation company. [16]

**2.3.2.** The Beliefs about Medicines Questionnaire (BMQ). The BMQ, developed by Horne and coworkers, is an instrument

for assessing patients' beliefs about their medication. [17] It is available in several version for patients and practitioners, and has been translated into Norwegian and validated for use in psychiatric practice. [1,13,17,18] We applied a part of the BMQ inventory, the BMQ-specific, which concerns patients' present use of medication, and comprises two 5-item factors regarding beliefs about medication prescribed. The factors are the beliefs about the necessity of prescribed medication (BMQ needs), and the beliefs about the danger of dependence and long-term toxicity and the disruptive effects of medication (BMQ concerns). [17] The items are presented as statements and are scored by the patients on a 5-points Likert scale, which ranges from 1 (strongly disagree) to 5 (strongly agree). Calculations of BMQ needs and BMQ concerns were done by summarizing the scores on the 5 corresponding items related to each factor. Higher scores refer to greater beliefs.

#### 2.4. Data analyses

The reliability of the MedSupport inventory was tested with Cronbach alpha coefficient to establish an internal consistency. The latent factor structure was identified by exploratory factor analysis with the maximum likelihood technique to test the dimensionality of the MedSupport. Factors were identified by promax oblige rotation. Kaiser eigenvalue-greater-than-one rule was used to determine the number of factors. Pearson correlation was applied to evaluate the concurrent validity of MedSupport by identifying correlations to the scores on BMQ needs and BMQ

concerns. We explored discriminate validity by comparing means of MedSupport scores between patients subject to compulsory treatment and voluntarily treated patients.

Descriptive analyses were used to describe the patient population and to examine patients' perceptions of the support they received for managing their medications. Results were expressed as frequencies, proportions, and means and standard deviations (SD). Associations between perceptions of support expressed by MedSupport scores, and age, gender, diagnosis, any compulsion, treatment durations, and treatment modalities were explored to examine patient characteristics relevant for extent of support regarding medication. This was performed by univariable and multivariable linear regression models. [19] Results were presented as beta coefficients with 95% confidence intervals and *P* values.

Age at inclusion was found to have a linearity relationship with MedSupport, and was presented per 10 years in the regression analyses. Gender (male/female) and compulsory treatment (yes/ no) were considered as dichotomized variables. The median treatment duration was used as a cut-off value to distinguish longer- from shorter- term treatments. Treatment was categorized into 4 different modalities: ambulatory care, day care, inpatient care, and out-patient care. Out-patient treatment was set as the reference category as the majority of the included patients were in this group. The main diagnoses were categorized according to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision classification system (ICD-10). [20] The diagnoses were classified as: F10-19 (Mental and behavioral disorders, due to psychoactive substance use), F20-29 (Schizophrenia, schizotypal, and delusional disorders), F30-39 (Mood disorders), F40-48 (Neurotic, stressrelated, and somatoform disorders), F60-69 (Disorders of adult personality and behavior), and F90-98 (Behavioral and emotional disorders, usually with childhood and adolescence onsets). The Mood disorder group (F30-39) was set as reference diagnostic group in the regression analyses, as it was regarded as a principal diagnosis group among the mental health disorders, and was the most frequent diagnosis group among the included patients. The 2 factors of BMQ-specific, needs and concerns, were analyzed separately in the regression models, as 2 independent continuous variables.

All analyses were performed with Statistical Package for the Social Sciences (SPSS) version 23.<sup>[21]</sup>

#### 3. Results

#### 3.1. Population characteristics

Among the 992 patients recruited, 567 patients (57%) reported regular use of 1 or more psychotropic medications, and 514 (91%) of these completed the MedSupport questionnaire and were included in the analyses this paper.

The included patients had a mean age of 38.1 years (SD 13.6), and 56% were women. No information about ethnicity was acquired from the patients, but more than 90% were white. The most frequent diagnosis was *Mood disorders* (F30-39) (n=130 patients; 25%), followed by *Neurotic, stress-related and somatoform disorders* (F40-48) (n=123; 24%). Only 23 patients (5%) were subjected to compulsory treatment. The mean treatment duration was 6.4 years (SD 7.6, range 0–40 years), with a median of 3.0 years. Out-patient treatment was received by 348 (68%), ambulatory treatment by 57 (11%), day care treatment by 22

(4%), and 82 (16%) were inpatients. The BMQ-specific need score was mean 17.8 (SD 4.5), and the concern score was mean 13.3 (SD 4.3).

## 3.2. MedSupport scores and evaluation of the MedSupport inventory

The mean MedSupport score was 3.8 (SD.9). Question 1 (I have received good support in considering whether I need my medication) had the highest mean score (4.1, SD 1.0); 78% of patients agreed (agree or strongly agree) with the statement. Question 4 (I have received good support in reducing the side effects of my medication) had the lowest mean score (3.4, SD 1.2). Only 43% of patients agreed (agree or strongly agree) with this statement (Fig. 2). The correlation between the items included in the MedSupport were.32 to.73, with the best correlation between the questions 1 (I have received good support in considering whether I need my medication) and 2 (I have received good support in finding the correct medication), and the weakest between questions 1 and 3 (I have received good support with ways to remember to take my medication) ().

The MedSupport questionnaire showed an adequate internal consistency, with a reported Cronbach alpha coefficient of .87 (95% CI.86-.89). From factor analysis the largest Eigenvalue was 3.3 and the second largest was .5, yielding a ratio greater than 3. Thus, the factor structure was in favor of uni-dimensionality. The first factor explained 73% of the variation of the items. As hypothesized, we found a positive correlation between the MedSupport and BMQ needs (.28, P<.001) and a negative correlation between the MedSupport and BMQ concerns (-.34, P<.001). The mean MedSupport score was 7 lower for compulsory treated patients than for patients receiving voluntary treatment (3.1 and 3.8, respectively, P<.001). Data is shown in the univariable regression analysis in Table 2.

## 3.3. Associations between MedSupport and patient related factors

We found a significant association between the MedSupport and BMQ-specific responses. Reports of a greater belief in the needs of medication were associated with higher MedSupport scores (beta.05, 95% CI.03 to.06, P < .001). In contrast, greater concerns about medication use were associated with lower MedSupport scores (beta -.06, 95% CI -.07 to -.04, P < .001) (Table 2). Patients at higher age reported more perceived support with their medication than younger patients; an increase of 10 years yielded an average of.06 higher score of MedSupport (P = .03).

The patients with *Mood disorders* reported MedSupport scores of mean 3.9 (SD.8, range 1.7–5.0). Explorative analysis showed that this group was the most suitable comparator group for MedSupport scores among the different diagnostic groups. Patients diagnosed with *Behavioral and emotional disorders with onset usually occurring in childhood and adolescence* (F90–98) reported more support than patients with *Mood disorders* (F30–39) (beta.34, 95% CI.04 to.64, P=.03). We found no significant association between the other diagnostic groups and the MedSupport scores. There were no significant differences in perceived support between males and females, treatment duration shorter or longer than 3.0 years or between patients subjected to the different treatment modalities (Table 2).

Table 1

Characteristics of patients included in MedSupport evaluations, n=514.

	N	%	mean	SD
Age, years			38.1	13.6
Gender				
Female	287	55.8		
Male	227	44.2		
Main diagnosis, in accordance with ICD-10				
F10-19 Mental and behavioral disorders due to psychoactive substance use	74	14.4		
F20–29 Schizophrenia, schizotypal and delusional disorders	65	12.6		
F30–39 Mood disorders	130	25.3		
F40-48 Neurotic, stress-related and somatoform disorders	123	23.9		
F60-69 Disorders of adult personality and behavior	37	7.2		
F90-98 Behavioral and emotional disorders with onset usually occurring in childhood and adolescence	39	7.6		
Other diagnosis or missing information	46	8.9		
Compulsory treatment				
Yes	23	4.5		
No	491	95.5		
Treatment duration				
Mean, years			6.4	7.6
≤ median 3.0 years	262	51.0		
> median 3.0 years	252	49.0		
Treatment modality				
Ambulatory care	57	11.1		
Day-care Day-care	22	4.3		
In-patient care	82	16.0		
Out-patient care	348	67.7		
Missing information	5	.1		
BMQ sum scores*				
Needs			17.81	4.47
Concern			13.26	4.32

<sup>\*</sup>Sum scores are the sum of the scores on the items in the BMQ. Scores range from 5 to 25 for the needs and concern factors (each 5 items), with higher scores indicating greater beliefs. BMQ = Beliefs about medications questionnaire; ICD-10 = World Health Organization International Classification of Diseases, 10th Revision; SD = standard deviation.

#### 4. Discussion

#### 4.1. Main findings

We found that the MedSupport inventory had an adequate internal consistency for assessing patients' perceptions of support from mental health services. It showed a uni-dimensional feature with 1 factor explaining a high proportion of the variance. The convergent validity showed a significant positive correlation between MedSupport scores and BMQ needs although weak, and a significant moderate negative correlation between MedSupport scores and BMQ concerns. The correlation between the questions was significantly moderate to high.

The cross sectional study population showed a diverse pattern with regard to age, diagnosis, compulsion, treatment duration, and treatment modality; reflecting the daily treatment situation at the different clinical units at our hospital. Most of the patients received out-patient treatment, and half of the patients in the study had received treatment for at least 3 years. Good clinical practice implies that such long treatment series include psychoeducation containing information of their medication. Therefore, we expected the included patients to have received information about their medication. However, we could not demonstrate better MedSupport scores among patients with longer treatment durations.

The study sample perceived reasonable support for medication issues, with mean scores on all items above the neutral mid-point on the scale ( $\geq$ 3.4). The lowest score was for the question concerning support in reducing medication adverse effects.

Adverse effects are an important reason for discontinuing medication treatments in general, [22] and psychotropic medications might be encumbered with troublesome adverse effects. The lowest score on this question indicates that the service should emphasize focus on reducing the adverse effect burden as much as possible for the individual patients. On the other hand, the question also showed the highest proportion of scores "doesn't apply". We suggest an interpretation that this score explains a straightforward experience without problematic side effects from many of the patients. If side effects never was an issue for them, the patients may view the question as irrelevant. Taken together, the variation in the responses to this question may reflect a diverse situation in the clinics, where the majority of patients do not experience adverse effects, but for the patients who do, the service may not take sufficient initiatives and follow-ups, and this group of patients should be a target for closer attention. These patients were identified through the MedSupport, and the inventory may target groups in need for relevant initiatives. Further, the higher proportion of patients reporting "doesn't apply" to the questions concerning support with remembering to take the medicines and the cooperation between the therapist and the general practitioner, respectively, can also be explained by the patients' lack of experience of any problem regarding the subjects. Not all patients struggle with remembering their medicines, and a number of patients do not visit their general practitioner on a regular basis.

We accepted questionnaires with at least 4 of the 6 items answered. By doing this we obtained reports also from patients who wished to express their opinion about some of the topics, but

Table 2
Univariable and multivariable linear regression analyses of MedSupport scores among the included patients, n=415.

	Univariable linear regression			Multivariable linear regression*			
Independent variables	Beta	95% confidence interval	P value	Beta	95% confidence interval	<i>P</i> value	
Age							
per 10 years	.04	02 to.09	.17	.06	.01 to.11	.03	
Gender							
Female	.05	.01 to.30	.04	.05	10 to.21	.47	
Male	Ref			Ref			
Diagnosis †							
F10-19	36	59 to $13$	.002	22	46 to.02	.07	
F20-29	−.15	39 to.09	.23	23	05 to.51	.10	
F30-39	Ref			Ref			
F40-48	.01	19 to.20	.93	.07	12 to.26	.48	
F60-69	29	59 to.01	.06	28	58 to.01	.06	
F90-98	.37	.08 to.66	.01	.34	.04 to.64	.03	
Compulsory treatment							
Yes	70	-1.05 to $34$	<.001	37	77 to.02	.06	
No	Ref			Ref			
Treatment duration							
> 3.0 years	−.15	30  to 01	.04	12	27 to.03	.12	
$\leq$ 3.0 years	Ref			Ref			
Treatment modality							
Ambulatory care	23	47 to.01	.06	14	42 to.13	.31	
Day-care	05	41 to.32	.80	−.01	36 to.35	.96	
In-patient care	26	47 to $06$	.01	16	37 to.05	.14	
Out-patient care	Ref			Ref			
BMQ <sup>‡</sup> score							
Needs	.05	.04 to.07	<.001	.05	.03 to.06	<.001	
Concern	06	08 to $05$	<.001	06	07 to04	<.001	

<sup>\*</sup> n=415 patients with information about all the variables in the model.

not necessarily all topics presented. As more than 90% of the eligible patients answered at least 4 out of the 6 items in the MedSupport, we got a wider basis for exploring their attitudes. The 53 patients who did not complete the MedSupport reported weaker BMQ- specific beliefs about needs and concerns. As they report less need for medication as well as less concerns about negative consequences of medication, we suggest that medication issues are less important to them, and they did not have any motivation to express their opinion with regard to their medication. However, as the patients not completing the MedSupport were more frequently receiving out-patient treatments than the patients who completed the inventory, we suggest the bias was probably partly caused by different inclusion efforts in the different parts of the service.

We found that a greater belief in medication as a necessity correlated positively to the perception of better support. This was in line with our hypothesis: if patients perceive adequate support with their medication and have been educated sufficiently, they will to a greater degree agree on the medication. The finding was supported in a previous study by Horne and Weinman, who found that believing in medication as a necessary part of the treatment promoted adherence, and conversely, concerns about medications hindered adherence. <sup>[13]</sup> Our findings also indicate that patients' concern beliefs about medication issues. This finding is consistent with previous studies, which found patient understanding and acceptance of the treatment (e.g., how to use

the medicines) important for medication adherence<sup>[12,23,24]</sup> and thus, treatment outcome.<sup>[1,5,25]</sup>

Patients diagnosed with F90-98 Behavioral and emotional disorders with onset usually occurring in childhood and adolescence reported higher MedSupport scores than the reference population (the patients with F30–39 Mood disorders). We propose that there might be a difference in the way the treatment is organized. As the medications frequently used for these conditions are stimulants and categorized as narcotics in the Norwegian prescription system, thorough reviews and tight control are claimed by the authorities. This leads to a more tight follow-up and regular assessments of medication use, which presumably includes all patient medications, and that have a positive effect on the patients' perceptions of support. Higher patient age was also associated with higher MedSupport scores. This could be an expression of different expectations from older, compared to younger patients to the health care service. Additionally, we would assume that service related factors are involved in this finding as well, i.e. treatment context and practitioner skills.

Mental health care continues to struggle in promoting attitudes and structures that enable patient voices to be heard and acted upon. [26,27] Many of the patients in mental health care are long-term patients, and their experiences with previous treatments were likely to influence experiences with current treatments, which is also mentioned by Mestdagh and Hansen in a qualitative study. [28] Therefore, even though this was emphasized to the

<sup>†</sup> According to the World Health Organization International Classification of Diseases, 10th Revision (ICD-10). F10-19: Mental and behavioral disorders due to psychoactive substance use, F20-29: Schizophrenia, schizotypal and delusional disorders, F30-39: Mood disorders, F40-48: Neurotic, stress-related and somatoform disorders, F60-69: Disorders of adult personality and behavior, F90-98: Behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

<sup>\*</sup> BMQ: Beliefs about Medicines Questionnaire.

patients, the reports were not necessarily related solely to the current treatment, but might include patients' earlier experiences as well.

Hawkins and co-workers have suggested that PROM evaluations are not limited to the statistical features of the instrument; they include empirical evidence that support its intended use. [29] Due to this, patients reports gain empirical evidence as a supplement to validity exploration of PROMs. Therefore, our patient reports at the MedSupport inventory support the reliability and validity testing to determine application.

Coercion did not affect the perceived support with medication in this study. In the literature patients subjected to compulsory treatment usually differ from voluntarily treated patients in their attitude towards treatment. We do not know the reason behind this unexpected finding, but it could perhaps be coinsidential due to the rather small patient subgroup (n=23; 4.5%). As we did not perform assessments of adherence or satisfaction in this study, it remains unknown if responses on the MedSupport are directly related to those factors.

#### 4.2. Strengths and limitations

A strength of the MedSupport questionnaire is that it is short and easy to apply. Additionally, the MedSupport questionnaire contains global items, i.e. not specific to a specific medicine, diagnosis, or treatment course. Thus, it has a broad applicability for assessing the health care service's ability to support patients who use medicines. As patients differ in education levels, social functioning levels, and illnesses, they require individualized treatment approaches. Another strength is that we included a real world patient population in our study. We will therefore argue the cohort to be considered typical for the population at specialist-level mental health services. Consequently, we suggest our results to be considered valid for the population, despite the limitations.

The psychometric properties examined showed adequate features of the MedSupport inventory. However, it limits the investigation of the MedSupport instrument that this was an explorative study and we did not accomplish a complete validation. We were not able to perform a test-retest to affirm the reliability of the MedSupport. This would have strengthened the reliability of the scale. Additionally, more variables available for comparison to explore construct validity were wanted.

The study had a cross-sectional design from which we cannot draw conclusions about causality, which is a limitation. However, it is likely that the direction of the influence is mainly that support can alter beliefs. Greater support would likely change patient beliefs in a positive direction and conversely, less support would strengthened preexisting negative beliefs (e.g. concern about the medication). Mental health care professionals should preferably conduct explorations of both beliefs and perceived support perspectives, and address revealed issues.

During data collection, we only requested the patients' main diagnoses. At this demarcation, we missed any secondary diagnoses of potential importance for understanding the patients' level of functioning, including illicit substance use. The negative influence of comorbid illicit substance use or addiction on patient behavior is well documented for many mental disorders. [31,32] Further, we did not request any assessments of the current severity of the patients' disorder, which could have provided additional information relevant for the understanding of the concept.

#### 4.3. Implications

The MedSupport inventory showed an adequate internal consistency and validity regarding the available variables. It is a brief and easily applicable instrument, which provides knowledge on the perceived support from health care service. We postulate from our findings that by supporting the patients adequately regarding medication issues, their concerns regarding medication can be decreased, and their experience of needs can be increased. Such alterations in beliefs are associated to treatment adherence and treatment outcome. By assessing the patients' perception of support regarding medication issues, the health care service can tailor their efforts to achieve optimal treatment courses. Further investigation of the inventory would be beneficial to expand the exploration of the associations found in this study.

#### **Author contributions**

KD, VØH and TR composed the MedSupport. KD, JKV, VØH, YLH and HR planned and run the study. YLH collected the data, KD, JKV, YLH and RSF analyzed the data, All authors interpreted the data. KD, JKV, VØH and TL wrote the manuscript. All authors gave contributions, and approved the final manuscript.

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