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Perspective on shared decision-making for depression and anxiety disorders in clinical practice: a qualitative and quantitative exploration

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Perspectives on shared decision-making for
depression and anxiety disorders in clinical practice:
a qualitative and quantitative exploration

A MATTER OF CHOICE



Sumayah Rodenburg-Vandenbussche

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Perspectives on shared decision-making for depression and anxiety disorders in clinical practice: a qualitative and quantitative exploration

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To be, or not to be

To be, or not to be; that is the question;
Whether 't is nobler in the mind to suffer
The slings and arrows of outrageous fortune,
Or to take arms against a sea of troubles,
And by opposing, end them. To die, to sleep –
BY WILLIAM SHAKESPEARE (HAMLET)

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Chapter 1

General introduction

BACKGROUND

Depression and Anxiety disorders

Worldwide many people suffer from mental health disorders, that have a large impact on their daily functioning.

According to the World Health Organization (WHO), one in every eight persons was living with a mental illness in 2019. Of these mental illnesses anxiety- and depressive disorders were the most common ones¹. Mental disorders can be defined as a health condition involving changes in an individual's thinking, feelings, and/or behavior¹.

DEPRESSION (depressive disorder) is a serious psychiatric illness, that can be characterized by the presence of depressed mood and/or loss of interest or pleasure in almost all activities during most of the day. Depressive symptoms can vary from mild to severe and can lead to emotional and physical problems, disabling everyday functioning². To be diagnosed with depression, according to the Diagnostic Statistical Manual (DSM-5), a person must have 5 symptoms of depression, including 1. depressed mood or 2. loss of interest or pleasure, for a consecutive period of at least two weeks³⁻⁵.

ANXIETY DISORDERS are a group of disorders characterized by fear and anxiety as most important symptoms marked as excessive or out of proportion to the actual threat posed, persistent, and associated with impairments in social, occupational, or other important areas of functioning^{6,7}. The DSM-5 used to distinguish different anxiety disorders. The most important disorders in this group are: panic disorders, specific phobia, social phobia, and generalized-anxiety disorder. Obsessive compulsive disorder (OCD) and related disorders is separated from the 'pure' anxiety disorders. The various anxiety disorders and OCD share several clinical features and often have similar behavioral manifestations, such as avoidance of fearful stimuli, and anticipation anxiety but underlying beliefs usually differ⁸.

International research shows that about one in five persons (18%) experiences a common mental disorder within a 12-month period, with anxiety disorders affecting one in fifteen and depressive disorders affecting one in twenty persons annually. The aggregated lifetime prevalence of common mental disorder was estimated at 29%, with highest prevalence rates for anxiety disorders (12%) and mood disorders (10%)⁹. It is known that prevalence estimates show some regional variation. For example, according to one of the WHO's World Mental Health Surveys (WMH surveys), the estimated lifetime prevalence of having one or more of the disorders varied from 12% in Nigeria to 32% in the Netherlands and 47% in the United States¹⁰.

In the Netherlands the mental health status of the Dutch general population was assessed in two nationally prospective studies: NEMESIS-1 (1996-1999) and NEMESIS-2 (2007-2018). Both studies showed that the lifetime prevalence for mental disorders in adults was approximately 40%, with highest prevalence rates of approximately 20% for both depressive disorders and anxiety disorders¹¹. The 12-month prevalence for mental disorders

was estimated at approximately 20%, with anxiety disorders (10%) and depressive disorders (6%) being the most common^{12,13}. These prevalence rates are comparable to those in other Western European countries^{10,13}. Furthermore, of the people with a lifetime mental disorder, 46% had at least one other comorbid disorder¹².

Most recent results of the Dutch NEMESIS study (NEMESIS-3, 2019-2022) also show an increase of the prevalence rates, with a 12-month prevalence of 26%, anxiety disorders (15%) and mood disorders (10%) being the most common¹⁴.

Mental health disorders, such as anxiety- and depressive disorder are not only highly prevalent, they also cause a high degree of burden on patients and their relatives, and come with high societal costs¹⁵. Due to the chronic nature of the illnesses, long-term disability and dependency, a substantial part of the burden of disease worldwide is attributed to mental disorders, of which depressive disorder is the major contributor^{16–18}.

Treatment of Depression and Anxiety Disorders

Following international and national (Dutch) guidelines the most important treatments for depression and/or anxiety disorders include talking therapy (psychotherapeutic interventions), drug therapy (pharmacological interventions) or a combination of both^{19–23}.

For the treatment of depression in adults, the recommended psychotherapeutic interventions are Behavioral Therapy, Cognitive Therapy, Cognitive-Behavioral Therapy (CBT), Interpersonal Psychotherapy (IPT), Mindfulness-Based Cognitive Therapy (MBCT), Psychodynamic Therapy and Supportive Therapy. Of these, CBT is the first choice. Recommended pharmacological interventions are second-generation antidepressants, such as selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitors (SNRIs) and norepinephrine/dopamine reuptake inhibitors (NDRIs). For anxiety disorders, CBT is the first-choice psychological treatment. Effective pharmacological interventions for anxiety disorders are SSRI's and SNRI's.

The effectiveness of these interventions, especially of CBT and second generation antidepressants (SSRI's and SNRI's) have been widely investigated in randomized controlled trials, systematic reviews and meta-analysis^{24–27}. There is no doubt that both types of treatment are effective and, when compared, they are considered equally effective for most patients^{24,26,28}. In addition, at least similar effects were found when both CBT and pharmacological treatment were combined and their combination may even be superior to mono treatments^{28–30}.

Although both types of treatment have comparable effects, the long-term effectiveness in real-world setting seems modest^{29,31}. It is partially unclear whether all advised types of antidepressants and all advised types of psychotherapy have comparable effects. Furthermore, different kinds of treatment have different degrees of efficacy for depressive disorders and anxiety disorders, and efficacy varies for the different types and severity of these disorders²⁴. In addition, individuals vary widely in response to treatment and this variability remains unpredictable. Finally, not all people with mental problems seek or find

help and not all treatment options are equally accessible to them, e.g., due to waiting lists or availability of CBT therapists²⁶.

Treatment Selection and the concept of Shared Decision Making

Selecting the treatment that is most suitable for an individual patient is the outcome of a complex process interplay between the clinician and the patient. In psychiatry, for clinicians, clinical decision-making involves the collection of information, the identification of patient's symptoms and an integration of these with the latest medical evidence to establish treatment decisions which are in the best interest of the patient^{32,33}. Treatment guidelines have been developed to help clinicians and patients with the decision-making, by offering practical suggestions and step by step instructions with respect to diagnostic and treatment options. International and national clinical practice guidelines recommend that clinicians conduct a comprehensive assessment, not only taking into account the symptoms, but also the severity of symptoms, previous psychiatric and somatic history, duration and course of the illness, and functional impairment and /or disability associated with the illness^{22,34,35}. Specific treatments should be selected based on previous experience with the treatment, side effects, and costs. The presence of comorbid psychiatric or general physical conditions may influence treatment choices. Furthermore, treatments should be delivered in a stepped care approach with set evaluation moments, as is also described in the guidelines^{7,21,22,35,36}. Last but not least, the current clinical guidelines explicitly suggest to involve patients, to make shared decisions with their patients, taking patient preferences into account^{34,37}. Placing patients in the center of treatment, patient-centered care (PCC) and patient involvement in the decision-making have become an important part of healthcare policy and healthcare quality over the last decades. It is now the common standard in contemporary health care³⁸⁻⁴⁰. Patient-centered care has been described as: "Treating patients as individuals and as equal partners in the business of healing; it is personalized, coordinated and enabling" and "Care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient's values guide all clinical decisions"^{41,42}. In shared decision-making (SDM), patients and clinicians work together to reach a treatment decision⁴³⁻⁴⁶. SDM is a way to achieve patient-centeredness, it ensures that individuals are supported to make decisions that are right for them, centering patient's preferences, values, and priorities during the decision-making process⁴⁷. Shared decision-making can therefore be defined as a process in which decisions are made in a collaborative way between patients and health care professionals, based on reliable information about different options, provided in an accessible way, taking the concerns, personal circumstances and context of patients and their families into account⁴⁸.

Over the last decade SDM has increasingly been advocated as the preferred approach to making healthcare decisions and the concept SDM has become indispensable in almost all healthcare settings. Reasons to support SDM arise from an ethical and clinical justification.

SDM respects and facilitates patient autonomy and can be seen as a human right^{43,44,49}. From a clinical perspective SDM can reduce practice variation and the provision of unwanted treatments. Furthermore, SDM can lead to better engagement, better decision making, and may increase treatment adherence, improving outcome⁴⁴.

In the Netherlands SDM is advocated by the Federation for Medical Specialists (FMS) (<https://demedischspecialist.nl/themas/thema/samen-beslissen-0>). SDM has been an emerging area of interest in mental health^{45,47,50–56}, but it is still less developed compared with other settings such as primary care and oncology^{53,57–60}. However, research on SDM and its potential in mental healthcare is promising^{44,45,47,55}.

In psychiatric care SDM has the potential to strengthen patient-centered care and to empower patients to be involved in treatment decisions⁴⁷. The evidence-based recommended treatments for depressive- and anxiety disorders are considered equally effective for most patients, and it is difficult to predict which patient will benefit from which treatment. In this already complex decisional process clinicians unfortunately must deal with uncontrolled external factors, such as time pressure, costs, availability and accessibility of resources, and certain levels of risk and uncertainty regarding treatment outcomes. There is little evidence to guide clinicians in this process regarding the (initial) treatment selection. They often need to rely on their intuition and experience. When no ‘best’ treatment exists, decisions may depend on how patients weigh the benefits and the harms of treatment options and on other factors important to them in the decisional process. Therefore, the reliance on SDM in this setting becomes all the more important⁵¹. Furthermore, SDM can lead to improved treatment adherence. In daily practice, the efficacy of treatments is negatively affected by low patient adherence rates and premature discontinuation, contributing to increasing relapse risk, developing chronic disorders, and increasing morbidity and mortality⁴⁵. Studies in mental health care settings suggest that patient involvement using SDM leads to better informed patients and improves treatment adherence, patient satisfaction, and outcomes^{61,62}. However, despite the increased interest in SDM, SDM interventions and the promising effects of patient-centered care in mental healthcare, patient involvement in clinical practice is still not optimal and the effects of SDM interventions are inconclusive⁵⁶. Studies on actual patient involvement suggest that most patients still play a passive role in the decision-making, in all settings, despite their willingness to be involved. Moreover, preferences are seldom incorporated in treatment decisions^{44,46,55,59,63}.

AIMS AND OUTLINE

Aims and Research Questions

The process to determine treatment selection for depressive and anxiety disorders in clinical practice remains largely unexplored and is still poorly understood. Scientific knowledge about how treatment decisions are made in clinical practice and which factors play a role,

will illuminate the process of treatment decision-making, and can propel the development and implementation of (future) decision-making interventions and SDM. Therefore, the main objective of this thesis was to gain insight in the different aspects of the treatment decision-making process regarding the treatment of depression and anxiety disorders in a clinical specialized mental health care setting, by investigating treatment preferences and treatment choices, (shared) decision-making and its influencing factors.

This leads to the central research question of our thesis:

What factors are important in the treatment decision-making process of depression and anxiety disorders and how do they determine the decision outcome, i.e., the decision to opt for: pharmacotherapy, psychotherapy, or a combination of both?

And sub questions:

- *What preferences do patients and clinicians have regarding the treatment of depression and anxiety disorders? Which factors are involved and how do they play a role in the formation of treatment preferences and treatment decisions?*
- *What preferences do patients and clinicians have regarding their role in the decision-making process regarding the treatment of depression and anxiety disorders? And to what extent is there SDM in clinical practice?*
- *How can we improve shared decision-making?*

Outline

We used a multimethod research design, i.e., a combination of qualitative and quantitative methods to answer our research questions and gain a more complete picture of (shared) treatment decision-making in clinical practice.

First, in **Chapter 2**, we report on a quantitative retrospective cohort study that we conducted with chart review data combined with Routine Outcome Monitoring (ROM) data of MDD (Major Depressive Disorder) outpatients. We measured associations between treatment choices and patients' sociodemographic- and clinical characteristics, using multinomial logistic regression analyses.

We used focus groups to investigate treatment preferences, treatment decisions and relevant influencing factors concerning the formation of treatment preferences and decisions to start (or (dis)continue) CBT and/or medication (**Chapter 3**). We conducted the focus groups with outpatients and professionals in a clinical specialized mental health care setting. For the focus groups we recruited outpatients of GGZ Rivierduinen (RD), a Dutch mental health care provider, and the Department of Psychiatry at the Leiden University Medical Centre (LUMC) in the Netherlands. Participating patients were diagnosed and treated for depression and anxiety disorder(s). We composed a separate focus group consisting of patients with OCD, because we expected a difference in (treatment) decision-making between these

patients and in their perspectives on SDM because of their obsessions. Additionally, the goal was to identify key elements of the decision-making process and to investigate the views of clinicians and outpatients on SDM in treatment decisions, i.e. decisions to start (or (dis)continue) CBT and/or medication, for depression, anxiety disorders, and OCD. We also explored suggestions for potential interventions (decision aids) for this population (**Chapter 4**).

In **Chapter 5** we report a survey among outpatients in a specialized mental health care setting to measure aspects of the decision-making process for depression and anxiety disorders before and after the consultation. Patients' preferred and experienced decision-making role, patients' treatment preferences and treatment choices, and associated factors were measured. For this study, we used the findings from our focus group study to select the existing measurement instruments (validated questionnaires) and to develop additional items, included in the survey questionnaire booklet (**Chapter 5**).

Finally, in **Chapter 6**, we present the Dutch translation and psychometric testing of the SDM-Q-9 and SDM-Q-Doc, two self-report instruments developed to measure the process of Shared Decision Making (SDM) as perceived by the patients and physicians respectively. This validation study was conducted in several clinical settings.

Chapter 7 provides an overview and discussion of the results of our studies and an answer on the predefined questions and sub questions of this thesis. This chapter ends with directions for further research and recommendations for clinical practice.

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Chapter 2

Clinical and sociodemographic associations with treatment selection in Major Depression

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ABSTRACT

Objective: To investigate treatment selection in a naturalistic sample of MDD outpatients and the factors influencing treatment selection in specialized psychiatric care.

Method: Multinomial Logistic Regression analysis investigated associations between treatment selection and patients' sociodemographic and clinical characteristics, using retrospective chart review data and Routine Outcome Monitoring (ROM) data of MDD outpatients.

Results: Of the patients included for analyses ($N = 263$), 34% received psychotherapy, 32% received an antidepressant (AD) and 35% received a combination. Men were more likely than women to receive AD with reference to psychotherapy ($OR_{AD} = 5.57$, 95% CI 2.38–13.00). Patients with severe depression and patients with AD use upon referral, prescribed by their general practitioner, were more likely to receive AD ($OR_{severe\ depression} = 5.34$, 95% CI 1.70–16.78/ $OR_{AD\ GP} = 9.26$, 95% CI 2.53–33.90) or combined treatment ($OR_{severe\ depression} = 6.32$, 95% CI 1.86–21.49/ $OR_{AD\ GP} = 22.36$, 95% CI 5.89–83.59) with respect to psychotherapy. More severe patients with AD upon referral received combined treatment less often compared to psychotherapy ($OR = 0.14$, 95% CI 0.03–0.68).

Conclusion: AD prescriptions in primary care, severity and gender influenced treatment selection for depressive disorders in secondary psychiatric care. Other factors such as the accessibility of treatment and patient preferences may have played a role in treatment selection in this setting and need further investigation.

INTRODUCTION

Worldwide, major depressive disorder (MDD) is highly prevalent in general populations¹⁻³. In the Netherlands, the overall lifetime prevalence of MDD is approximately 20%. Of these patients, almost half (46%) suffers from a comorbid psychiatric disorder and only 30% receive some form of treatment⁴. Patients with anxiety and/or depressive complaints consult their general practitioner (GP) first, and may be treated in primary care (with either antidepressants by their GP or CBT by a psychologist/psychotherapist) before they are referred to specialized psychiatric care, i.e. secondary care and, in case of therapy resistance tertiary care.

To treat MDD, treatment guidelines recommend a stepped-care approach that uses a range of effective therapy options, in a specific order, depending on patient severity profiles and their response to previous treatments⁵⁻⁷. Clinical guidelines recommend psychotherapy, for example, Cognitive Behavioral Therapy (CBT) or Interpersonal Psychotherapy (IPT), Medication/antidepressants (ADs) or a combination of both. These treatments are considered equally suitable and efficacious for MDD³⁻⁷, but they are not effective for all patients⁸. The guidelines mention that psychotherapy is effective for mild to moderate depression, medication is suggested for moderate to severe depression and combined treatment is more effective and indicated for severe or chronic forms of depression, suggesting that pharmacological treatment (with or without psychotherapy) is more appropriate in more severe forms of depression. Current clinical guidelines explicitly advise to involve patients and to gain their consent in treatment. In this context, important factors are interpersonal or psychosocial problems, patient preferences, results of previous treatments of the patient, side-effects of medication, family history of MDD or pragmatic issues, such as waiting lists for treatment⁷. However, guidelines cannot stipulate completely how treatment decisions should be made⁹⁻¹¹.

Diagnosing and treating psychiatric disorders can be complex because clinicians must balance biological-, psychological- and social factors¹². Considering that no 'best' treatment exists and that both treatments are recommended in the guidelines, decisions regarding how to treat MDD are 'preference sensitive', that is, the best choice depends on how patients value the benefits versus the harms and on other factors important to the decisional process^{13,14}. There is little evidence to guide clinicians in this process and the initial choice to treat a patient with AD, psychotherapeutic treatment or a combination of both¹⁵.

The process to determine treatment selection for depressive disorders in clinical practice is still poorly understood, and research on this topic in secondary psychiatric care is scarce. Little is known about actual treatment selection of patients and clinicians in routine clinical practice; the same is true for the specific clinical and sociodemographic factors associated with this selection¹⁶. Such information would illuminate the process of making treatment decisions in clinical practice; it would also propel the development and implementation of

future decision-making interventions and the development of new (international) treatment guidelines for MDD.

Aims of the study

The aim of the present study was to analyze patients' socio- demographic and clinical factors in relation to treatment selection in a naturalistic sample of outpatients with MDD in a secondary mental health care setting.

MATERIALS AND METHODS

Overview

For this retrospective cohort study, we used an existing dataset from psychiatric outpatients treated at the Dutch Mental Health Care Provider GGZ Rivierduinen. We captured diagnostic and socio- demographic data from routine clinical practice from the Routine Outcome Monitoring (ROM) baseline assessment¹⁷. Next, we combined ROM data with clinical data, i.e. primary diagnosis (made by the clinician) and treatment modalities, captured from an earlier retrospective chart review by van der Lem et al. (2011)¹⁸⁻²⁰. Based on the literature and the availability in our database, we selected the following sociodemographic and clinical variables for our analyses: age, gender, ethnic background, education, marital status, living situation and employment status, i.e. personal characteristics of the patient; co- morbidity, symptom severity and AD use upon referral (medical history), i.e. clinical characteristics of the patient. We investigated the association between these independent variables and the treatment modalities of psychotherapy, medication, or both to determine the influence of specific sociodemographic and clinical factors on treatment selection.

Data sources

ROM

The Leiden Routine Outcome Monitoring Study is a naturalistic study among adult (age 18 to 65 years) outpatients at GGZ Rivierduinen. General practitioners (GPs) in primary care refer patients for specialized treatment of mood-, somatoform- and/or anxiety disorders. Reasons for patient referral to GGZ Rivierduinen are (i) more severe, recurrent, or refractory depression, (ii) the presence of comorbid psychiatric or somatic disorders and (iii) sometimes a preference for psychotherapy. As part of routine clinical practice, all patients are asked to complete an extensive battery of psychometric measures. De Beurs et al.¹⁷ describe the procedure in more detail. All patient data from the Leiden Routine Outcome Monitoring Study are stored anonymously in the Psychiatric Academic Registration Leiden (PAREL) database and are accessible for research purposes only.

Retrospective chart review

We captured data on treatment modalities and primary diagnoses made by clinicians from a chart review conducted by van der Lem et al.¹⁹ as part of a study assessing the generalizability of AD and psychotherapy efficacy trials¹⁸⁻²⁰. The study included all adult (18–65 years) outpatients with a DSM-IV diagnosis of a current MDD, according to MINI-Plus 5.0.0²¹ who sought treatment at GGZ Rivierduinen between January 2002 and January 2007. Of this population, van der Lem et al.¹⁹ selected all patients with at least one ROM follow-up assessment (N=626). Next, an extensive chart review was conducted to collect additional information, such as patients' primary clinical diagnoses and treatment modalities.

The medical ethics committee of the Leiden University Medical Centre (LUMC) approved both studies, and informed consent was obtained from all participants.

Patients

Between 2002 and 2007, the ROM baseline assessment included a standardized diagnostic interview, the Mini-International Neuropsychiatric Interview Plus (MINI-Plus; Dutch version 5.0.0)²¹, a questionnaire on sociodemographic and socioeconomic data, disease specific severity scales and generic questionnaires. All patients with sufficient mastery of the Dutch language who were able to complete computerized and written questionnaires were eligible for ROM. Our study population was selected based on the MINI-Plus, that is, all patients meeting the diagnostic criteria of a current MDD diagnosis. The MINI-Plus has good psychometric properties: interrater reliability between 0.88 and 1.00, test–retest reliability between 0.76 and 0.93. In order to investigate a homogenous group of patients, we further restricted the sample to patients who were also given a primary diagnosis of MDD by their clinician, independently from the results of the MINI-Plus. This variable was captured from the retrospective chart review. In the current sample, a clinician (a psychiatrist or resident in training supervised by a psychiatrist or psychotherapist) determined the clinical/primary diagnosis – the most relevant diagnosis and the main focus of treatment according to that clinician- using his or her clinical skills, via a clinical interview in order to determine the presence/absence of a DSM-IV diagnosis²².

Outcome

Patients in the study population received different types of treatment for their depression of which most (85%) were in line with ((in)ternational) guidelines²⁰. We captured three major categories of the treatment modalities from the chart review^{18,19}: 1) 'psychotherapy' (mostly cognitive behavioral therapy (CBT) only or interpersonal psychotherapy (IPT) only, as recommended in the guidelines); 2) 'AD' (antidepressant only, which were: selective serotonin reuptake inhibitor (SSRI), serotonin norepinephrine reuptake inhibitor (SNRI) or tricyclic antidepressant (TCA), accordant with clinical guidelines for pharmacological treatment of depression in secondary care. Adequacy of the dosage was not included in the study.); and 3) 'combined treatment' (combination of an AD and CBT or IPT).

Patient characteristics

The sociodemographic variables were available from a self-report questionnaire in ROM that assessed age, gender, ethnic background, education, marital status, living situation and employment status. A Dutch background was assumed when the patient and both parents were born in the Netherlands. Education was categorized into two levels: 'low' (no education and primary education – up to and including junior general secondary education or preparatory secondary vocational education) and 'high' (senior secondary general education or senior secondary vocational education – up to and including higher education, pre-university education, higher professional education, or higher academic education, i.e., university). Marital status was categorized into 'married/cohabitating' and 'not married/not cohabitating'. Living situation was categorized into two categories: 'alone' or 'with partner and/or family'. Employment status was categorized into 'job' (employed full- or part-time) and 'no job' (unemployed, retired or on sick leave).

We captured clinical variables from ROM measurements and the retrospective chart review. We used other diagnoses on the MINI-Plus 5.0.0 to assess comorbidity, which was divided into two categories: 'no' (depression only) and 'yes' (depression and one or more Axis I diagnosis – mostly anxiety disorder). Depression severity was assessed using the revised Beck Depression Inventory (BDI-II)²³. The BDI-II, a widely used self-report instrument, measures the severity of depression, and reflects the diagnostic criteria for MDD described in the DSM-IV²⁴. The BDI-II has shown good internal consistency, reliability, and validity²⁵. For our analyses, we used the BDI-II total score, which was composed of the summation of 21 questions, each answer being scored on a scale value of 0–3. According to clinical practice guidelines, BDI-II total scores were divided into two categories: 'severe depression' (BDI-II total score of > 28 points) or 'mild to moderate depression' (BDI-II total score of < 29 depressive symptoms).

We captured information on AD use (at or prior to referral) from the chart review and divided it into yes/no categories.

Statistical analyses

Data are presented as N (%) or mean ($\pm$ SD), as appropriate. Sociodemographic and clinical characteristics of patients in the three treatment groups were compared using univariable multinomial logistic regression analysis. Independent associations of treatment groups were assessed using multivariable multinomial logistic regression analyses, with individual psychotherapy as a reference category. Odds Ratios (OR) represent the odds that a certain treatment modality was selected given the occurrence of a sociodemographic or clinical categorical variable or one unit increase in the value of a continuous variable: age (in years). For the multivariable analyses, all candidate determinants achieving significance levels of $p \leq .25$ in the univariable analyses were selected. This P-value criterion reduces the initial number of variables in the model but also minimizes the risk of missing important variables^{26,27}. Failure to achieve significance ($p \geq .05$) in the resulting multivariable model

prompted removing variables, except for age and gender, which were forced into the model as possible confounders. Statistical analyses were performed using IBM SPSS Statistics Version 25.0²⁸.

Post Hoc analyses

Because of the findings regarding treatment from the GP upon referral and severity, post hoc analyses were performed to investigate whether treatment prescribed by the GP was continued in secondary care, using crosstabs. In addition, interactions of AD upon referral with gender, age and severity respectively were added to univariable and multivariable analyses.

RESULTS

Sample characteristics

Fig. 1 shows the flow chart of patients included in the study. Of the 263 patients that were included for analyses, 34% received psychotherapy, 32% AD and 35% received a combined treatment. The study population had a mean age of 40 years (SD = 11) and consisted of mostly women (65%). Patients were primarily Dutch (86%), 50% were married/cohabitating, 51% lived alone, 60% were highly educated and 64% were unemployed. Slightly more than half of patients (55%) had a comorbid psychiatric disorder according to the MINI-Plus 5.0.0, 58% suffered from a severe depression according to the BDI-II. 58% of the patients were using and AD upon referral, in 61% of these cases, medication was continued in secondary care as monotherapy (36%) or combination therapy (61%).

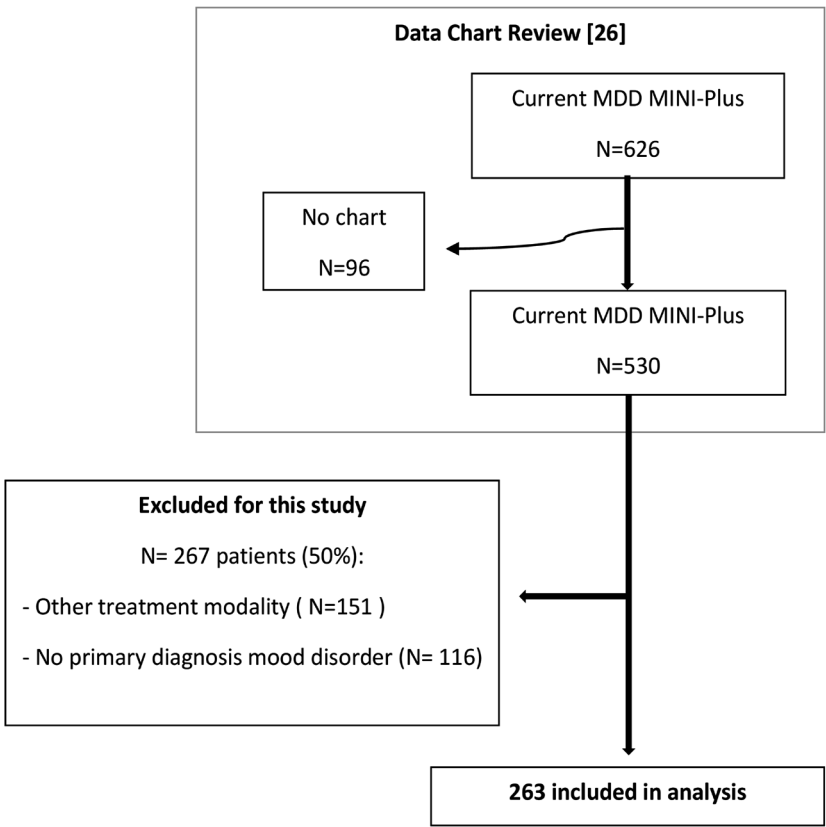


Figure 1 Flowchart of inclusion.

Table 1 shows the characteristics of our study population according to treatment selection. Patients who exclusively received psychotherapy had a lower mean age, almost half had a mild to moderate depression and more than half (57%) were not using an AD upon referral. Half of the patients who exclusively received an AD (51%) were male.

Table 1 Sample characteristics of $N = 263$ patients with Major Depression.

	Total N = 263	Psychotherapy N = 88 (34%)	Antidepressant N = 83 (32%)	Combination N = 92 (35%)
<i>Personal Characteristics</i>				
Age (years $\pm$ SD)	40 $\pm$ 11	36 $\pm$ 11	42 $\pm$ 10	41 $\pm$ 11
Gender (n, %)				
Male	93 (35%)	24 (27%)	47 (56%)	22 (24%)
Female	170 (65%)	64 (73%)	36 (43%)	70 (76%)
Ethnicity (n, %)				
Dutch	199 (86%)	70 (89%)	60 (83%)	69 (85%)
Non Dutch	33 (14%)	9 (11%)	12 (17%)	12 (15%)
Marital Status (n, %)				
Married/cohabitating	116 (50%)	38 (48%)	37 (51%)	41 (51%)
Not married/ cohabitating	116 (50%)	41 (52%)	35 (49%)	40 (49%)
Living Situation (n, %)				
Alone	118 (51%)	43 (54%)	35 (49%)	40 (49%)
With partner / family	114 (49%)	36 (46%)	37 (51%)	41 (51%)
Education (n, %)				
High	138 (60%)	50 (63%)	37 (51%)	51 (63%)
Low	94 (41%)	29 (37%)	35 (49%)	30 (37%)
Employment (n, %)				
Job	84 (36%)	31 (39%)	26 (36%)	27 (33%)
No job	148 (64%)	48 (61%)	46 (64%)	54 (67%)
<i>Clinical Characteristics</i>				
Comorbidity ^a (MINI-Plus)				
Comorbidity	144 (55%)	45 (51%)	46 (55%)	53 (58%)
No Comorbidity	119 (45%)	43 (49%)	37 (45%)	39 (42%)
Severity ^b				
Severe depression	149 (58%)	39 (45%)	55 (68%)	55 (62%)
Mild to moderate depression	107 (42%)	48 (55%)	26 (32%)	33 (38%)
AD upon referral ^c (n, %)				
Yes	151 (58%)	26 (30%)	55 (68%)	70 (78%)
No	108 (42%)	62 (70%)	26 (32%)	20 (22%)

^a One or more comorbid diagnosis on Axis I according to the MINI-Plus.

^b Symptom severity assessed with the Beck Depression Inventory (BDI-II). Total scores > 29 points indicate severe depression, total scores < 29 indicate mild to moderate depression.

^c Patients using an antidepressant upon referral, prescribed by the General Practitioner.

Associations with treatment selection

Table 2 shows the results of the univariable and multivariable multinomial logistic regression, expressed as the odds that a patient received an AD or combined treatment with respect to psychotherapy. Univariable analyses revealed significant differences between treatment groups for age, gender, severity, and AD upon referral. The ORs of the univariable analyses show that older patients were slightly more likely than younger patients to receive an AD or a combined treatment with respect to psychotherapy ($OR_{AD} = 1.05$, 95% CI 1.02–1.08 per year; $OR_{combined\ treatment} = 1.04$, 95% CI 1.01–1.07 per year). Male patients were more likely to receive an AD with respect to psychotherapy ($OR_{AD} = 3.48$, 95% CI 1.84–6.60). Patients with severe depression were more likely than patients with mild to moderate depression to receive an AD or combined treatment with respect to psychotherapy ($OR_{AD} = 2.60$, 95% CI 1.39–4.89; $OR_{combined\ treatment} = 2.05$, 95% CI 1.12–3.75). With respect to psychotherapy, patients who already used an AD upon referral were more likely to receive an AD than patients not using an AD upon referral ($OR_{AD} = 5.04$, 95% CI 2.62–9.70); they were even more likely than patients not using an AD upon referral to receive combined treatment with respect to the exclusive use of psychotherapy ($OR_{combined\ treatment} = 8.35$, 95% CI 4.25–16.41). To reveal possible interaction between the effects of age with gender and severity with age and gender, respectively, we also entered the interaction terms for these variables into the univariable analyses, which were significantly associated with treatment selection, see Table 2.

Based on the results of the univariable analyses, post hoc univariate analyses for the interaction of AD upon referral with age, gender and severity were performed. These analyses showed significant associations with treatment selection (see Table 2). The variables age, gender, education, severity and AD upon referral and interaction terms were entered in the multivariable analysis. This multivariable nominal logistic regression analysis revealed significant associations between male gender, severity, AD upon referral and the interaction of severity and AD upon referral with treatment selection. Men were more likely than women to receive an AD with respect to psychotherapy ($OR_{AD} = 5.57$, 95% CI 2.38–13.00). Patients with severe depression were more likely than patients with mild to moderate depression to receive AD ($OR_{AD} = 5.34$, 95% CI 1.70–16.78) or a combined treatment ($OR_{combined\ treatment} = 6.32$, 95% CI 1.86–21.49) with respect to psychotherapy. Patients who used an AD upon referral were more likely than patients not using an AD upon referral to receive either AD ($OR_{AD} = 9.26$, 95% CI 2.53–33.90) or a combined treatment with respect to psychotherapy ($OR_{combined\ treatment} = 22.36$, 95% CI 5.89–83.59). Patients with severe depression and AD upon referral were less likely to receive combination therapy with respect to psychotherapy ($OR_{combined\ treatment} = 0.14$, 95% CI 0.03–0.68). Despite statistical significance in the univariable analyses, age was not significantly associated with treatment selection in the multivariable model and no interactions were found.

Table 2 Univariable and multivariable odds ratios^a of sociodemographic and clinical determinants of treatment choice in *N* = 263 MDD patients.

Medication	Univariable Analyses			Multivariable Analyses		
	Odds Ratio	95% CI	p value	Odds Ratio	95% CI	p value
<i>Base case: Individual Psychotherapy</i>						
<i>Personal Characteristics</i>						
Age ^{**}	1.05	1.02–1.08	0.001	1.03	0.99–1.07	0.20
Male gender ^{***}	3.48	1.84–6.60	<0.001	5.57	2.38–13.00	<0.001
Non Dutch ethnicity	1.56	0.61–3.95	0.35			
Not married/cohabitating	0.88	0.46–1.66	0.69			
Living alone	0.79	0.42–1.50	0.48			
Low education	1.63	0.85–3.13	0.14			
Unemployed	1.14	0.59–2.21	0.69			
<i>Clinical Characteristics</i>						
Comorbidity ^b	1.19	0.65–2.17	0.58			
Severe depression ^{c**}	2.64	1.39–4.89	<0.01	5.34	1.7–16.78	<0.01
<i>Medical History (previous experience)</i>						
AD upon referral ^{d***}	5.04	2.24–9.70	<0.001	9.26	2.53–33.90	0.001
<i>Interactions</i>						
Age*Male gender	1.07	1.03–1.10	<0.001			
Age*Female gender	1.03	1.00–1.07	<0.05			
Age*Severe depression	1.06	1.03–1.10	<0.001			
Age*Mild-moderate depression	1.04	1.01–1.07	<0.05			
Male gender*Severe depression	18.09	5.58–58.58	<0.001			
Male gender*Mild-moderate depression	4.10	1.48–11.40	<0.01			
Female gender*Severe depression	3.17	1.25–8.03	<0.05			
<i>Post Hoc^e</i>						
AD upon referral*Age	1.06	1.03–1.09	<0.001			
AD upon referral*Male gender	21.26	6.97–64.88	<0.001			
AD upon referral*Female gender	5.72	2.32–14.08	<0.001			
No AD upon referral*Male gender	3.91	1.50–10.23	<0.01			
AD upon referral*Severe depression	10.20	4.06–25.60	<0.001			
AD upon referral*Mild-moderate depression	7.22	2.40–21.68	<0.001			
No AD upon referral*Mild-moderate depression	2.96	1.11–7.86	<0.001			
Combined Treatment						
<i>Personal Characteristics</i>						
Age ^{**}	1.0	1.01–1.07	<0.01	1.01	0.98–1.05	0.46
Male Gender	0.84	0.43–1.64	0.61	1.65	0.69–3.97	0.38
Non-Dutch ethnicity	1.35	0.54–3.42	0.52			
Not married/cohabitating	0.90	0.49–1.68	0.75			
Living alone	0.82	0.44–1.52	0.52			
Low education	1.01	0.53–1.93	0.97			
Unemployed	1.29	0.68–2.46	0.44			

Clinical Characteristics						
Comorbidity ^b	1.30	0.72–2.34	0.40			
Severe Depression ^{c*}	2.05	1.12–3.75	<0.05	6.32	1.86–21.49	<0.01
Medical History (experience)						
AD upon referral ^{d***}	8.35	4.25–16.41	<0.001	22.36	5.89–83.59	<0.001
Interactions						
Age*Male gender	1.04	1.00–1.07	<0.05			
Age*Female gender	1.04	1.01–1.07	<0.01			
Male gender*Severe depression	2.78	0.94–8.27	0.07			
Male gender*Mid-moderate depression	0.49	0.18–1.37	0.17			
Female gender*Severe depression	1.48	0.74–2.97	0.27			
Severe depression*Age	1.05	1.02–1.08	<0.01			
Mild-moderate depression*Age	1.03	1.00–1.06	0.33			
Post Hoc ^e						
AD upon referral*Age	1.04	1.01–1.0	<0.05			
AD upon referral*Male gender	8.31	2.77–24.96	<0.001			
AD upon referral*Female gender	7.77	3.56–16.95	<0.001			
AD upon referral*Severe depression	15.68	5.60–43.86	<0.001	0.14	0.03–0.68	<0.05
AD upon referral*Mild-moderate depression	18.78	5.97–59.07	<0.001			
No AD upon referral*severe depression	3.84	1.28–11.53	<0.05			

^a Odds ratio, 95% CI and *p* value by univariable and multivariable multinomial logistic regression (stepwise method); forward entry:

age, gender (forced), education, severity, medication upon referral and interaction terms.

^b One or more co morbid diagnosis on Axis I according to the MINI-Plus

^c > 29 points on the Beck Depression Inventory (BDI-II).

^d Patients using an antidepressant upon referral, mostly prescribed by the General Practitioner.

^e Post Hoc univariable multinomial logistic regression for interaction terms with AD upon referral
p* value <.05, *p* value <.01, ****p* value <.001.

DISCUSSION

Our study is one of the few that identifies specific factors associated with treatment selection for MDD in routine clinical practice in a secondary psychiatric care setting. Treatment selection for MDD seemed mostly in line with clinical guideline recommendations. We found a variation in selected treatments that can be partly explained by severity. We found no evidence for distinct sociodemographic patient profiles to explain this variation, but we found a few factors that might be noteworthy.

First, we found a strong association between treatment selection and AD use upon referral. Patients who already used an AD when referred by their GP were most likely to continue this treatment in secondary mental health care—exclusively or in combination with psychotherapy. Often the same medication was continued, but in almost 40% of the cases it was switched to another AD. In the Netherlands, patients with depression visit their GP first. Patients may be treated with AD by their GP in primary care and are referred to secondary care when they do not respond well to this treatment^{7,29} or when psychotherapy is recommended. As there are waiting lists for psychotherapy, an AD can be prescribed to bridge the delay. Often, the

patients referred to secondary mental health care are more severely ill, have comorbidity, do not respond to first-step treatment options and/or are difficult to treat; therefore, they may need pharmacological therapy, which is also suggested in the guidelines. Our results do show that patients with severe depression are more likely to be treated exclusively with AD or combination therapy – compared to psychotherapy only. However, because we assessed the association independent of symptom severity and comorbidity, our finding may also be explained by other factors. It is possible that the medication was continued because it takes up to six weeks for ADs to attain a therapeutic effect, and they had not been prescribed/used for such a period⁷. Sometimes when patients are already on an AD (prescribed by their GP), doses require adjusting or patients must switch to another AD. Discontinuation of an AD is known to cause withdrawal effects, which in addition to relapses, could influence future effectiveness of ADs in the same patient³⁰. Psychiatrists and patients likely hesitate to abruptly discontinue an AD to avoid the adverse effects of medication withdrawal. Our results also show that patients with severe depression, who already use ADs upon referral, are more likely to receive psychotherapy only, compared to combination therapy. Possibly, because these patients have too little response and/or may experience too many side – effects from the AD therapy. Our results indicate that decisions to treat patients with an AD in primary care significantly impact future treatment options and selection in secondary psychiatric care.

Second, we found that men were less likely to receive psychotherapy – a result found in one other study in primary care³¹. Studies that investigated gender differences in relation to offered or received treatments are rare and results are inconclusive³¹. Clinical guidelines do not suggest that pharmacological treatment is especially more effective in men, nor is there unequivocal evidence that men respond better to medication or less to psychotherapy compared to woman^{7,32}. Studies suggest that men and women show different symptom profiles and that men often exhibit the same symptoms more severely than women, or seek help later, which might explain why men and women receive different treatments^{31,33,34}. In which case being male itself does not necessarily leads to pharmacological treatment, but this treatment selection is indirectly based on severity. Van Noorden et al.³⁵ found no gender differences in MDD outpatients regarding disease severity based on a clinician-rated severity scale, the Montgomery Asberg Depression Rating Scale (MADRS), and found slightly higher severity ratings for women on a patient-rated severity scale (BDI-II)³⁵. Another explanation could be that men preferred being treated with medication and not with psychotherapy. Several studies on patient preferences report that men more readily accept pharmacological therapies and that women showed a preference for psychotherapy^{36,37}. However, in a recent review paper on patient preferences for psychological versus pharmacological treatment of depressive and anxiety disorders, the authors found no significant differences in treatment preference between men and women³⁸. In this context, Sierra Hernandez et al.³⁴ suggested that there is a common unfounded (yet persuasive) belief that men dislike psychotherapy. They studied the treatment preferences of male and female psychiatric outpatients and

found that men had either a preference for psychotherapy over pharmacological treatment or for no treatment. Furthermore, men and women's preference patterns did not differ significantly³⁵. The assumption of a clinician that men are more responsive to or have a preference for ADs, because they are less 'talkative' than women, may explain our finding. Patient preferences and personal aspects of patients are considered to be deciding factors in the treatment selection according to clinical guidelines. The patients in our study more often received an AD (exclusively or in combination with psychotherapy). It is possible that the patients in our population preferred to be treated with ADs or that the setting, specialized secondary care, is explaining this finding. However, studies on patient treatment preferences for MDD showed that patients often prefer psychotherapy to pharmacotherapy³⁸⁻⁴⁰. Several studies in primary and psychiatric care identified several sociodemographic influencing factors associated with patient treatment preferences for depression, such as age, ethnicity, social/cultural background, education and income^{34,36,37,41}. If patient preferences played a substantial role, we would expect more patients' sociodemographic characteristics to be significantly associated with treatment selection.

Clinicians' preferences may have directed the decisional process. In routine clinical practice, the clinical judgment of the clinicians determines the main focus of treatment and consequently the treatment options offered. Our results indicate that previous treatments prescribed by the GP and ratings of severity – often made by the psychiatrist – are leading when selecting a treatment in secondary care. Studies on treatment variations in different settings indicated that physicians' preferences and practice styles influenced clinical practice⁴² and that physicians often made unilateral decisions that were based on their own preferences rather than patient preferences⁴³⁻⁴⁵. Furthermore, the importance of clinician factors in treatment decisions was found in studies on treatment decision-making for psychiatric problems – mostly primary care settings³¹⁻⁴⁶. In many cases, clinicians' treatment decisions are based on personal life experiences and attitudes rather than professional characteristics⁴⁶.

Strengths and limitations

A strength of our study was that we used data from a naturalistic treatment-seeking population in a secondary mental health care setting. Additionally, our use of ROM data provided us with a variety of sociodemographic and clinical information.

Some limitations. First, variables were dichotomized because of their skewed distributions, which adversely affected statistical power. Second, the study population was relatively small, which explains the wide confidence intervals. We divided the outcome variable, treatment modality, into three treatment groups, which resulted in low frequencies in some cells. Consequently, our sample size was too small to perform subgroup analyses for comorbidity and ethnicity. Third, due to our study design, our findings are not generalizable to a broader population nor is it possible to say anything about causal relationships. Finally, information on patient treatment preferences and data on clinician characteristics were not available.

As a result, it was not possible to investigate associations of these factors with treatment selection, and it is therefore not possible to draw any conclusions about if and how patient preferences, nor how clinicians played a role in the decisional process. At the time of our data collection, Shared Decision Making (SDM) was in its infancy, and to this date, SDM is not yet widely implemented in mental health care^{42,47,48}. Future research should explore the specific clinician characteristics that influence treatment selection as well as the role of clinician and patient preferences in treatment decision-making for depressive disorders in secondary care.

Conclusions

Treatment selection for MDD in secondary care is according clinical guidelines and severity seems a deciding factor. Our study also indicates that when referred patients already use an AD upon referral, their medication is not stopped or changed to non-pharmacological treatment, reflecting the impact of treatment decisions made in primary care. Accessibility and availability of CBT/psychotherapy in primary and secondary care are likely to play a part. Current ((in)ternational) clinical guidelines emphasize combination therapy for severe MDD⁴⁹⁻⁵¹, which can only be offered to patients, when psychotherapeutic treatments are accessible, without waiting lists. Furthermore, to include patients' personal characteristics and preferences in the decisional process, as (Dutch) clinical guidelines highly recommend, efforts must be made to make all treatment options equally available to all patients.

Conflict of interest

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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Chapter 3

Treatment decision-making for Depression, Anxiety disorders, and Obsessive-Compulsive disorder in specialized psychiatric care:

Patients' and clinicians' perspectives on treatment preferences, treatment decisions and influencing factors.

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ABSTRACT

Objective: To explore patients' and clinicians' decision-making regarding the choice of treatment (psychotherapy and/or pharmacotherapy) for depression, anxiety- and obsessive-compulsive disorders, with the aim to identify key elements of the decision-making process and influencing factors considered important in secondary psychiatric care.

Methods: Seventeen psychiatric outpatients and 33 clinicians participated in eight focus group interviews. We audiotaped, transcribed, and coded the interviews. Data were analyzed using thematic analysis.

Results: Patients and clinicians discussed similar key elements that play a role in the decision-making process: 'communication', 'information/knowledge', 'preferences' and 'decisions'. Relevant influencing factors were related to 'values and attitudes', 'contextual factors' and 'the decision-making process itself'. Contextual factors were categorized into: 'patient', 'illness', 'treatment', and 'clinician' characteristics. Values and attitudes described by patients and clinicians differed, leading to differences in (treatment) preferences and decisions. Contextual factors overlapped but differed in importance and relevance between patients and clinicians. Additional constructs related to the decision-making process were: having treatment options ('choice'); 'weighing' of pros and cons of these options with often 'uncertain' outcomes, 'the patient-clinician relationship', and 'who decides?'.

Conclusion: Treatment decision-making processes of patients and clinicians are characterized by similar key elements and influenced by values/attitudes and contextual factors that are only partly overlapping. Differences in these factors and consequently preferences, could lead to a discrepancy between what patients want and what clinicians (can) offer, thus choice. Clarifying such issues in the clinical encounter could improve collaborative decision-making and optimize treatment decisions.

INTRODUCTION

Depression and anxiety disorders are highly prevalent in general populations worldwide and have substantial personal, social and economic impact^{1–3}. Providing patients with the most advantageous and best fitting treatment is essential. To treat depression and anxiety disorders, including obsessive compulsive disorders (OCD), the first steps recommended by multidisciplinary guidelines are psychotherapy (behavioral therapy, cognitive behavioral therapy (CBT)), pharmacotherapy, or a combination of both^{3–7}. Clinical research shows that CBT/psychotherapy and pharmacotherapy are equally efficacious in many patients^{5,8}, but for some patients, clinicians consider these treatments as less suitable and/or outcomes remain suboptimal. In clinical practice, it remains uncertain which patients will benefit from which treatment⁹.

Considering that no ‘best’ treatment exists, decisions regarding how to treat patients with depression, anxiety disorders or OCD are often complicated and regarded to be ‘preference sensitive’. This means that the best choice is the treatment that best suits the patient, depending on how patients value the benefits versus the harms, and other factors important to them in the decisional process^{10–12}.

Interest in Patient Centered Care (PCC) and Shared Decision Making (SDM) has therefore grown in mental health during recent years and their relevance is now widely recognized. Research has shown that patients in mental health have identifiable treatment- and decision-making preferences^{13–15}. Furthermore, incorporation of such preferences in decisions regarding treatment seems positively related to satisfaction, treatment adherence and possibly also health outcomes^{15–18}. Studies in primary and secondary care have identified influencing factors of treatment preferences and/or treatment decisions^{19–23}. Current clinical guidelines for depression and anxiety disorders explicitly suggest involving patients and their preferences in treatment decision-making^{6,7,24,25}. Still, in clinical practice, the treatment decision-making process is frequently not systematically guided by patient preferences^{13,22,26–31}.

Only few studies have investigated the process of treatment decision-making in routine psychiatric care, especially in secondary care^{28,32–34}. Current research mainly focuses on evaluating interventions to incorporate patient preferences, to deliver or promote PCC, and to implement SDM as well as specific SDM tools (decision aids)³⁵.

More insight in the decisional process and possible target points might be valuable to improve treatment decision-making and support implementation of PCC and SDM in clinical practice. To attain this goal, we need to know more about how treatment decisions are actually made in secondary psychiatric care (i.e. about key elements of the decision-making process such as treatment preferences) as well as the role of influencing factors on patients’ and clinicians’ treatment decision-making for depression, anxiety disorders and OCD³³.

In this qualitative study, we organized focus groups (FGs) in a secondary care setting with the aim to explore outpatients’ and clinicians’ decision-making processes and influencing

factors regarding the choice (start or (dis)continuation) of treatment (psychotherapy and/or pharmacotherapy) for depression, anxiety disorders, and OCD.

METHODS

Sample and recruitment

Recruitment of patients took place at GGZ Rivierduinen (RD), a regional mental health care provider, and the Department of Psychiatry at the Leiden University Medical Centre (LUMC) in the Netherlands. Inclusion criteria to participate in the patient focus groups (PFGs) were: diagnosed with and treated for depression and/or anxiety disorder(s)/OCD, command of the Dutch language, and the ability (mentally and physically) to participate in a focus group (FG).

As depression and anxiety disorders/OCD often co-occur and treatment courses tend to converge, especially in the secondary care setting, we set out to compose two mixed PFGs for patients diagnosed with depression and/or anxiety disorders and a third PFG for patients diagnosed with OCD. We considered the possibility that OCD patients might differ in making (treatment) decisions due to their obsessions^{26,36}.

Clinicians (psychiatrists and psychologists) were asked to identify patients meeting the inclusion criteria. Eligible patients were informed about the study and invited to participate by the researcher (SR) in a consecutive manner, until four to eight patients for each PFG signed up.

Clinicians were recruited at RD and LUMC and at the Invitational Conference 2012 of the Dutch Knowledge Centre for Anxiety Disorders, OCD, and Depression (NedKAD) [<https://nedkad.nl/voor-professionals/invitational-conference/invitational-conference-2012/>]. The inclusion criteria to participate in the clinicians' focus groups (CFGs) were employment at RD/LUMC as psychiatrist, psychiatric residents, being a health/clinical psychologist or psychotherapist working in a secondary mental health care setting; and involved in the decision-making processes regarding the treatment of depression, anxiety disorders, OCD. We held two mixed CFGs and three mono disciplinary CFGs for psychiatrists, residents, and psychologists, respectively. For more detailed information on sample and recruitment: see Rodenburg-Vandenbussche et al. (2019)³⁵.

The study was approved by the Medical Ethics Committee of LUMC (P12.003).

Procedures and data collection

The FGs featured a semi-structured approach, following an interview guide (see *Appendix A*, Electronic Supplementary Material 1 (ESM) 1), with fairly broad open-ended questions, in line with the explorative nature of our study. All FGs were moderated by the first author (SR), with assistance of a second researcher, taking notes, the observer (VK, see

acknowledgements), both trained in conducting and analyzing FG interviews. The group interviews were audiotaped and transcribed verbatim.

Based on the literature, the following elements were used as topics in our interview guide: a) knowledge of the illness and indicated treatment options; b) attitudes towards treatments; c) (formation of) treatment preferences; d) (making) treatment decisions; and e) factors that influence preferences and the decisional process.

Participants were welcomed and received information about the topics of the focus group. They were encouraged to respectfully share and discuss their opinions with other members of the group. We informed participants that the interview was audiotaped, ensured confidentiality of the data use and that participation was voluntary, explaining that they could stop and withdraw from the study at any time without consequences regarding their treatment. Participants signed the informed consent and filled out a short background information questionnaire. The CFG started with a personal introduction round. The PFG started with a general opening question to get acquainted, yet to give the patients the opportunity to stay anonymous. The duration of the FG-interviews was approximately 90 minutes, including a 10-minute break.

Data coding and analysis

Atlas ti.7.5 (Scientific Software Development GmbH, Berlin, Germany)³⁷ was used to code and analyze the qualitative data of the FGs. First, the researcher (SR and VK) independently coded the transcripts of the first PFG and the first two CFGs, where open coding was used to label the relevant fragments within the texts³⁸. Both researchers compared their codes and grouped the corresponding codes into clearly defined categories. This process resulted in a working thematic codebook that was used to code subsequent transcripts (for the codebook see *Appendix B*, ESM 2). We used a concept map (see paragraph 3.2 and *Appendix C*, ESM 3) and our research questions as a frame, to group the data and to identify similarities and differences across the data^{38–41}. The analysis focused on the content and relevance of participants' responses, rather than on actual frequencies⁴².

RESULTS

Demographics

We conducted eight FGs on treatment decisions between June 2012 and December 2013³⁵. Patients' and clinicians' characteristics of each FG are shown in *Table 1*. Three six, and eight participants, respectively (total N=17 outpatients) participated in the three PFGs that we conducted. Clinicians participated in five different CFGs, ranging from three to nine participants (total N=33 clinicians). Three psychiatric nurses joined a CFG by mistake, although they did not meet our inclusion criteria. Their statements were therefore not included in the analyses³⁵.

Table 1 Characteristics of focus groups' participants: patients and clinicians

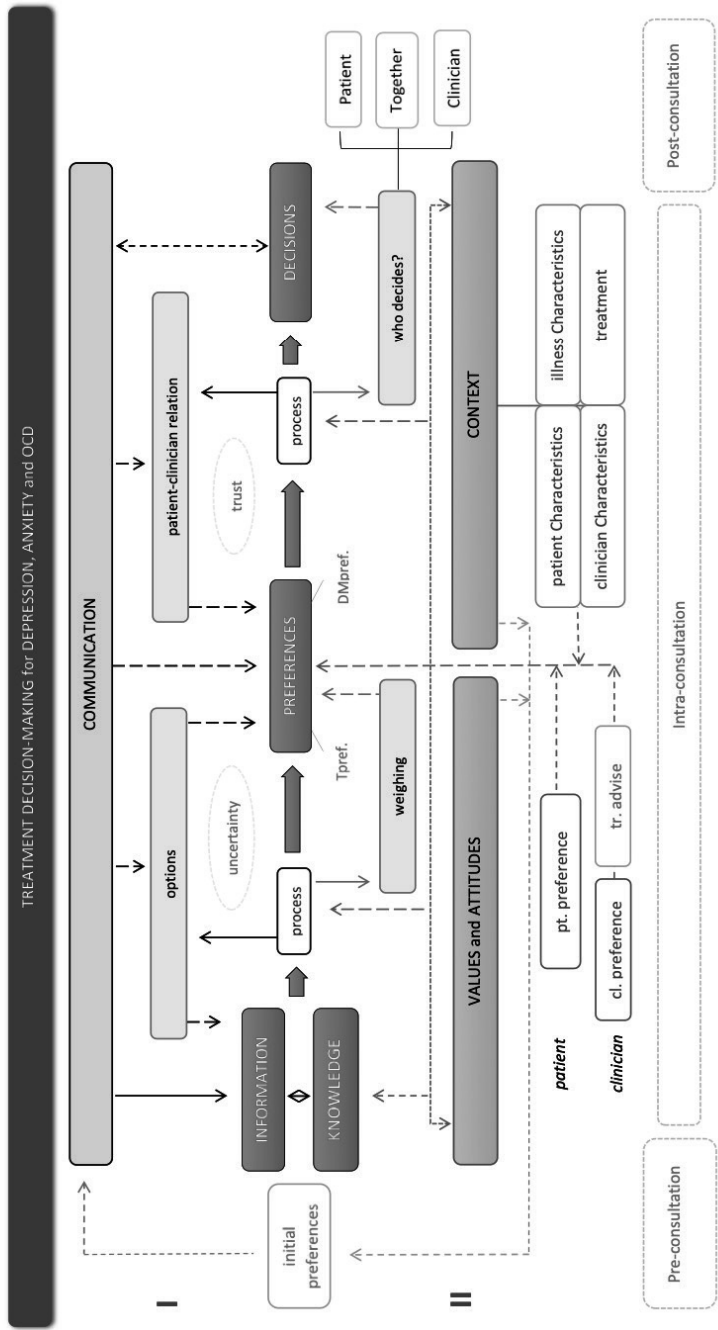
Patients	Total N= 17
Disorder	
Depression and/or anxiety disorder [†]	11
Obsessive–compulsive disorder	6
Gender	
Male	9
Female	8
Age	
Mean years $\pm$ SD (range)	44 $\pm$ 16 (20–75)
Education	
Middle to high	15
Low	2
Employment	
Yes	9
No	8
Professionals	Total N = 30
Profession	
Psychiatrist	11
Resident in psychiatry	8
Clinical psychologist	7
Psychologist/psychotherapist	4
Gender	
Male	15
Female	15
Age	
Mean years $\pm$ SD (range)	47 $\pm$ 12 (27–69)
Professional experience in psychiatry	
Mean years $\pm$ SD (range)	19 $\pm$ 12 (2–40)

[†]Specific information on diagnosis and previous treatments were not available because of the anonymous nature of the focus groups. We gave patients the chance to share this specific information at the beginning of the focus groups, but no one did. Some patients mentioned it during the discussion on specific topics.

Model of treatment decision-making

We used the topic guide to group the codes extracted from the FG interviews into a concept map (Appendix C), and new elements (themes) emerging from the data were added. Based on our concept map, a model of treatment decision-making for patients and clinicians was developed (see *Figure 1*). See Appendix D for supporting quotations.

Fig. 1 Model of the decision-making process for patients and clinicians, regarding the choice of treatment (psychotherapy and/or pharmacotherapy) for depression, anxiety disorders, and obsessive compulsive disorder.



solid arrow/line = involves (being part of); dotted arrow/line = influence

The model shows that decision-making regarding the treatment of depression, anxiety disorders and OCD in secondary care is a process that involves key elements (I) and influencing factors (II): I) 'communication' (between patients and clinicians), information, preferences (treatment and/or decision-making) and decisions; II) values and attitudes and contextual factors. This process is further influenced by additional constructs related to these elements and influencing factors (I & II): "having treatment options (choice)", "uncertainty", the "weighting of variables", the "patient-clinician relationship", "trust" and "who decides".

Key-elements of the decision-making process: Communication, Information/Knowledge, Preferences and Decisions (Fig.1 part I)

Communication: According to patients and clinicians, communication was an important element of the decisional process. This involved not only the content of what was communicated, but also the way in which relevant information is shared (i.e., clear explanation, how personal information is discussed). According to most patients, communication with a clinician should involve a conversation about their illness, relevant treatments, attitudes, experiences, and expectations from both the patients' and the clinicians' perspectives.

Clinicians found it important to provide adequate and complete information and to check if the patient has understood the information, so that the patient is equipped to make a good treatment decision. They also recognized the importance of including the patient perspective. Yet, participating professionals also said that the communication often involved steering and negotiating with the patient.

Information/Knowledge: Receiving the right information about their illness and the different treatment options, including effectiveness and side-effects, was very important to patients. Patients said to value the information from their clinician most. Other sources of information patients tended to rely upon included: experiences from family/friends, educational material, and online information. All this information together (knowledge) was found an important element in the decision-making process.

For clinicians, it was also important to receive information from the patient about symptoms, medical history, personal values, and context, in order to give the best fitting treatment recommendation. The clinicians considered it as their responsibility to give their patients adequate and relevant information, this involved the diagnosis, treatment options (effectiveness and side-effects), and the prognosis.

Preferences: Patients' and clinicians' preferences could be divided in treatment preferences (e.g., what therapy) and decision-making preferences (e.g., who decides).

Treatment preferences: many patients had an explicit dislike for medication, which was also recognized by the participating clinicians. OCD patients seemed to have a firmer dislike for medication than patients with anxiety and/or depressive disorders, and they more strongly believed that medication was a last resort. Most patients said they already had formed initial preferences before seeing a clinician in secondary care (pre-consultation). These initial preferences could be modified during the consultation, based on new information and the treatment recommendation of the clinician, and the communication between patient and clinician (*intra-consultation*). After the consultation, patients sometimes discussed the treatment recommendation with family/friends or checked (online) educational material, before deciding (*post-consultation*).

Most of the participating clinicians mentioned that many patients already have a preference when they first visit their clinician and that those preferences (sometimes based on wrong

information and misconceptions) are difficult to change. Clinicians said of themselves that they do not have initial preferences and that they base their professional preference on clinical factors, personal characteristics of the patient, and external/circumstantial factors (e.g., waiting lists, availability). However, some clinicians said that clinician preferences were also influenced (biased) by the clinician's personal characteristics (see paragraph 3.2.2 contextual factors) (Fig.1 part II).

Decision-making preferences: most patients wanted to make the decision about their treatment together with their clinician. Clinicians thought it was their task to prepare the patient to make the decision autonomously.

Decisions: Patients had difficulty differentiating between factors that influenced preferences and factors that influenced the final decision specifically. Indicating that this is a gradual process. Patients thought that they often made the final decision because they could refuse or stop treatment. Most patients did not have the feeling of being forced into a decision. Clinicians agreed that the final decision was often made by the patients and that patients should decide autonomously.

Influencing factors of the decision-making process: Values, attitudes, and contextual factors (Fig.1 part II)

Values: Patients placed most importance on the severity/burden of their illness and the harms (fear of side effects) of the different treatment options, in relation to their own wellbeing (recovery and quality of life) and that of their relatives.

Clinicians placed most importance on the clinical aspects (diagnosis, symptomatology, and its severity) and the indicated treatments according to clinical guidelines (focused on relieving symptoms and recovery of a patient).

Attitudes: The pros and cons of treatment options and participants' attitudes towards them were an important topic in the FGs. *Table 2* shows the pros and cons of CBT/psychotherapy and medication, mentioned in all focus groups. Most participants said that medication could be an effective treatment: it can reduce suicidal thoughts and makes patients less depressive and more susceptible to CBT/psychotherapy. On the other hand, patients were more negative about possible side effects, expected dependency, and effects of discontinuation. Many patients described medication as a last resort or a "necessary evil".

Clinicians recognized the cons of patients but did not have a negative attitude towards medication in general. They also mentioned the placebo-effect as a positive (side) effect of medication.

In contrast to medication, participants were generally more positive towards CBT/psychotherapy. Psychotherapy was said to offer patients useful skills to prevent relapses. Some clinicians mentioned that CBT/psychotherapy could also have side effects for some patients (such as feelings of distress and undermined self-efficacy). In addition, CBT/psychotherapy was considered to require a certain amount of cognitive capacity of patients.

Table 2 Pros and Cons of available treatments from a patients and clinicians' perspective, mentioned by patients and/or clinicians (X).

TREATMENTS		PATIENTS	CLINICIANS
Medication			
Harms			
- Side effects:		X	X
Weight gain		X	X
Sexual dysfunction		X	x
Change of personality (blunted affect)		X	X
Possible dependency (addiction)		X	X
Sweating		X	X
(Unknown) long term effects on physical development (fertility)		X	
Effects of discontinuation (withdrawal symptoms, relapse)		X	X
Feeling disabled in normal functioning when on medication		X	
- Fear of having to use it the rest of their lives		X	
- Interaction effects with other medication			X
- Contra-indications (other illness, pregnancy)			X
- Tapering costs time, with possible withdrawal and relapse	X		X
- Long build up period, with possible deterioration or even suicidality			X
- Possible medicalization and undermining of autonomy and self-worth	X		X
- Only relieves symptoms			
Benefits			
- Effectiveness:		X	X
Can be very effective,		makes patients	stops suicidal
Works (relatively) fast and easy		feel better,	thoughts and
Makes patients more susceptible to CBT/psychotherapy		stronger, easier to be around.	relieves depressive symptoms.
CBT/Psychotherapy			
Harms			
- Often in groups (most patients are anxious in groups and do not want to deal with problems of others)	X		
- Practical issues	X		
Waiting lists	X		X
Planning appointments into schedule	X		X
Financial costs			X
Costs energy and time			X
- Requires a certain amount of intelligence, insight, active attitude and motivation			
	X		X
- Teaches certain coping skills			X
Benefits			
- Can prevent relapse			

Table 3 Influencing factors of the decisional processes of patients and clinicians, regarding the choice of treatment (psychotherapy and/or pharmacotherapy) for depression, anxiety disorders, and obsessive-compulsive disorder.

CATEGORIES		PATIENTS	CLINICIANS
Illness (clinical)	Diagnosis	x	x
	Symptomatology	symptoms	symptomatology
	Severity	perceived need for help	risk, vital signs
	Cause	biological/circumstances	explanatory model
Treatment (clinical)	Cons	mostly side-effects	contra-indications, side-effects
	Effectiveness	experience self/others	according to clinical guidelines
	Other benefits	x	x
	Effect on quality of life	x	
	Personal fit	x	
	Accessibility (planning schedule)	x	
	Clinical guidelines	x	x
	Treatment availability		waiting lists/need to refer
	Evidence Based Medicine	x	x
Patient (personal)	Costs (time/effort/financial)	financial	time/effort
	Background	social/cultural	ethnicity
	Experience with illness	personal	medical history
	Experience with treatment	personal	effectiveness previous treatment
	Perceived cause of illness	x	explanatory model
	Preconceptions about illness and treatment	experience, information from others	misinformation, expectations
	Motivation	extrinsic (for someone else)	intrinsic of patient
	Capacity	due to illness	intelligence and insight
Clinician (personal)	Person	personality traits	personal background
	Knowledge	knowledge, experience	expertise/ knowledge
	Background	social/cultural	education
	Professional experience	profession	professional experience
	Personal experience	age	Professional experience
	Personal agenda	x	x
	Department culture		x
	Steering behavior		x
	Prescribing practice		x
Communication	Patient-clinician relation	seen, treated as a person, trust	constructive treatment relation
	Information /	educational material	information exchange
	Continuity	x	x

X: mentioned by patients and/or clinicians in the FGs, with the same meaning.

Contextual: Patients and clinicians described many factors influencing the decisional process, linked to the context. We grouped them in four categories: ‘patient characteristics’, ‘illness characteristics’, ‘treatment’ characteristics’, and ‘clinician characteristics. Regarding influencing factors, we did not find differences between the patients with anxiety and/or depressive disorders versus OCD. *Table 3* shows an overview of the influencing factors mentioned by participating patients and clinicians.

Half of the participating patients said to have past experience with medication treatment, thus having made the decision to start medication. Important influencing factors in this context were: previous treatment experience, severity of symptoms, treatment recommendation (according to clinical guidelines), and information from and the relation with the clinician. Participating clinicians believed the most important determining factors regarding the treatment chosen were diagnosis and severity of the illness as well as (in)effectiveness of a previous specific treatment. They also said that for any treatment to work, it was important that there was a constructive patient-clinician relation, and that the patient gave informed consent and adhered to the treatment (compliance). Therefore, the treatment chosen needed to be a good fit with the patient’s expectations, experiences, and beliefs regarding ‘causes’ of the illness (explanatory model).

Influencing decision-making constructs:

Treatment Choice, the Patient-Clinician relationship and trust (Fig. 1, part I), uncertainty, weighing and who decides (Fig.1, part II)

During the FGs, additional aspects were discussed that determined the decision-making process and were related to communication, information, values, attitudes, and contextual factors (Fig.1).

The patient-clinician relationship (trust) was very important according to both patients and clinicians, as it determined the quality and effect of the treatment. In addition, patients need to like and trust their clinician (there needed to be a fit), especially when CBT/psychotherapy was the treatment of choice.

Having treatment options and thus choice, emerged as an important theme in all focus groups. Some patients in the mixed PFGs mentioned not having been offered a choice, i.e., only one treatment option was offered, or it was not clear that the patient could be involved in the treatment decision. OCD patients felt they had been offered a clear choice between CBT/psychotherapy and medication, where CBT/psychotherapy was recommended first. Overall, clinicians said that clinical factors (e.g., diagnosis and severity) determined the indicated treatments and that they followed Evidence-Based Medicine and clinical guidelines (see table 3). Perceived previous effectiveness of treatments was also of clinical relevance, as were the departmental culture and availability of a certain treatment (e.g., waiting time for CBT). Additionally, the capacity and motivation of a patient influenced the treatment recommendation of the clinician to the patient.

The role of uncertainty in the decisional process was described by both patients and clinicians. Patients often mentioned that they were unsure about their diagnosis (psychiatric illnesses are vague and cannot be visualized) and the (side) effects of their treatment. Clinicians said that in many cases they also are uncertain what the best treatment will be.

The weighing of all variables was according to most participating patients and clinicians an important aspect of treatment decision-making. Patients weigh what they know and what is important to them against the severity of their symptoms (perceived need for help) and quality of life. Many patients also said that, in the end, they just followed their 'gut feeling'. Participating clinicians said to weigh the effectiveness and side effects of one treatment against those of other treatments for a particular patient (considering patient preferences, but also their own professional experience).

Finally, *who decided* influenced the decisional process and final treatment decision. Patients preferred making the decision together with their clinician, but this was not always the case. Clinicians thought that patients should decide autonomously, although clinicians often steered patients and treatment decisions in the direction of their own preference.

DISCUSSION

Main findings

The results of this FG study on treatment decision-making in patients with depression, anxiety disorder, or OCD in secondary psychiatric care show that the decisional processes of patients and clinicians are characterized by similar key elements and influencing factors (Fig.1). Yet, the meaning, value, and relevance of these factors differed considerably between patients and clinicians: patients placed more importance on personal factors (e.g., values and attitudes, gut-feeling), while clinicians placed more importance on clinical factors (e.g., diagnosis, illness severity, guidelines). Most often, individual perceptions and values of patients and clinicians colored the connotation of factors (individual context). For example, patients based severity on their own perceptions of their illness and perceived need for help, while clinicians based severity on their clinical impression and assessment of symptoms and risks. Furthermore, patients weigh the effective and affective aspects of a treatment against the severity of their symptoms and quality of life, while clinicians weigh the pros and cons of a treatment against those of another treatment.

The fact that psychotherapy, pharmacotherapy, and its combination have been found to be about equally effective for mild to moderate depression and anxiety disorders, might imply there is an equal choice between these treatment options. Our findings suggest otherwise. First, for many patients this choice is not an equal one. To them, the benefits of medication (even in combination with CBT/psychotherapy) do not outweigh its harms, especially compared to CBT/psychotherapy only. In contrast with this, professionals have a less negative attitude regarding medication, and they consider CBT/psychotherapy not suitable for all

patients. As our results show, OCD patients had the same attitudes towards the treatment as patients with depression or anxiety disorders, although they more often were offered a choice between all treatment options. Second, sometimes certain treatments (such as CBT/psychotherapy only) seem not an option, because of clinical and personal experiences of patients or clinicians find this treatment unsuitable. These different perceptions could lead to a discrepancy between a patient's preferred treatment and a clinician's treatment recommendation. As a result, patients may experience limited choice, contributing to less optimal treatment decisions, lower treatment satisfaction, lower adherence, and potentially poorer treatment outcomes.

Comparison to previous literature

Our findings fit other descriptive models of patient decision-making such as the one introduced by Wills and Hovner³³. Following the same key elements, we identified congruent interrelationships, and found similar influencing factors (individual-level variables). In addition to these results, we found that the same model applies to clinician decision-making, although attitudes, values and contextual factors between patients and clinicians may differ. For both patients and clinicians, the context plays an important role in the decisional process, and we were able to identify several contextual factors.

Our findings regarding a preference for CBT/psychotherapy over medication or a general dislike of medication are consistent with the literature on treatment preferences in other psychiatric services and primary care^{9,13,22,26,43–45}. Some authors suggested that this preference against medication may be specific to those suffering from chronic forms of depression. Medication might be perceived as an aid to survive a crisis, but when patients have to use it for a longer time period, some become more ambivalent about medication^{9,45,46}. This is in line with the importance patients in our study laid on the negative influence of it on their quality of life.

Also consistent with the literature, our results showed the importance of patients' experiences with previous treatments and specific characteristics of the treatment modalities^{8,47}. Many of our patients have already experienced (sometimes ineffective or inadequate) treatment in primary or secondary care, which determines their further treatments preferences. Additionally, we found that these experiences influenced the treatment recommendation of the clinician in secondary care. This is in line with results of another study which indicates that previous treatments in primary care were significantly associated with subsequent treatment decisions in secondary care²³.

Strengths and limitations

To our knowledge, this is the first study exploring treatment decision-making for depression, anxiety disorders and OCD for both patients and clinicians in a secondary psychiatric care setting. Most studies have focused on depression and anxiety disorders in primary care, or on severe mental illness (e.g. schizophrenia) in secondary care, and did not investigate

both the patient and the clinician perspective^{13,19–21,44,48}. The results of this qualitative study provide an overview of the most important elements of treatment decision-making and influencing factors (context) in clinical practice and give insight into the decisional processes of both patients and clinicians.

This study also comes with limitations. Although the FGs and analysis of the transcripts were executed by two independent and qualified researchers, participants' and researchers' pre-existing knowledge of the topic may have influenced the conclusions. Since our inclusion criteria required patients to be capable of participating in a FG discussion, only patients with less severe disorders (following the recommendations of patients' attending clinicians) were included. Also, participating patients were possibly, talkative persons, who have a preference for psychotherapy/CBT, which could have biased our results. In addition, some of our eight FGs were rather small. Moreover, clinicians may have selected patients based on their preference for a certain patient, as the recruitment process involved the selection of patients by the clinicians, thus depended highly on the clinicians' limited time and effort³⁵. However, data saturation was attained in both patients' and clinicians' FGs³⁵. It is difficult to draw conclusions about specific differences between patients suffering from a depression, anxiety disorder, or OCD, because we used mixed PFGs. This and the use of a convenience sample from a limited number of sites, could endanger generalizability. Lastly, since the time of our data collection, there have been further developments in PCC and SDM. However, to this date, studies on the decisional process regarding treatment remain limited, and the concepts of PCC and SDM are scarcely implemented in mental health care^{12,49,50}. Therefore, we think that our findings are still relevant for the development and implementation of interventions to improve treatment decision-making.

CONCLUSION

A broad range of factors influence the treatment decision-making process, according to patients and clinicians in secondary psychiatric care. Although seemingly overlapping, many of these influencing factors are of different value for patients and clinicians. This can lead to different attitudes towards treatments, different treatment- and decision-making preferences, and eventually to a discrepancy between what a patient wants (or expects) and what a clinician (can or will) offer, and thus choice. Having a choice is essential in treatment decision-making. Building a good patient-clinician relationship with trust, and creating choice awareness (i.e., make clear to patients that there are two or more relevant options, where having no treatment can also be an option [47]) can further improve communication. Such collaborative decision-making may integrate the decisional processes of patients and clinicians and optimize treatment decisions.

"I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story."

ACKNOWLEDGEMENTS

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ETHICAL DECLARATIONS

Funding

This research was funded by the mental health care provider GGZ Rivierduinen

Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The trial has been approved by the Medical Ethics Committee of Leiden University Medical Center (P12.003).

Informed consent

Informed consent was obtained from all individual participants included in the study.

SUPPLEMENTARY MATERIAL

Appendix A. Interview Guide Focus Groups

PATIENTS:

Opening round: "Did you feel you had a choice regarding your treatment and why?"

Treatment options

I) Knowledge and attitudes

- What do you think about the available treatment options (i.e. medication and/or CBT/ psychotherapy) for your complaints?

II) Preferences

- Personal preferences for medication and/or CBT/psychotherapy.
- Personal opinion on the different treatments (harms and benefits).
- Ideas about treatment preferences of professionals (treatment provider).

Decision-making process

III) Forming treatment preferences

- Factors determining/influencing own preferences. (values)
- Ideas on factors influencing preferences of professionals (treatment providers).

IV) Making treatment decisions

- The way (process) final decisions are made (who makes the final decision, did you feel there was a choice).
- Factors influencing own decisions. (values)
- Ideas on factors influencing decisions of professionals (treatment providers).

CLINICIANS:

Opening round: introduction

Treatment options

I) Knowledge and attitudes

- What do you think about the available treatment options (i.e. medication and/or CBT/psychotherapy) for depression, anxiety disorders and OCD?
- Personal treatment preferences for medication and/or CBT/psychotherapy.
- Personal opinion on the different treatments (harms and benefits).

II) Preferences

- Ideas about own treatment preferences.
- Ideas about the treatment preferences of patients.

Decision-making process

III) Forming treatment preferences

- Factors determining/influencing own preferences. (values)
- Ideas on factors influencing preferences of patients.

IV) Making treatment Decisions

- The way (process) final decisions are made (who makes the final decision).
- Factors influencing own decisions. (values)
- Ideas on factors influencing decisions of patients.

Appendix B: Codebook Focus groups

Level 1	Level 2	Level 3 (4)
A Decisions		
	A.1 Decision Making Process (DM)	A.1.1 Aspect Decision Making
		A.1.1.1 Discussion/Negotiation
		A.1.1.2 Weighing
		A.1.1.3 Explanation model
		A.1.2 DM in Clinical Practice
	A.2 Who decides	
		A.2.1 Patient
		A.2.1.1 Patient makes decision
		A.2.1.2 Noncompliance/ drop out
		A.2.1.3 Motives for compliance
		A.2.2 Clinician
		A.2.2.1 Clinician makes decision
		A.2.2.2 Steering Clinician
		A.2.3 Together
B Preferences		
	B.1 Formation of Preferences	
		B.1.1 Pre-consultation
		B.1.2 Intra-consultation
		B.1.3 Post-consultation
	B.2 Preference Patient	
	B.3 Preference Clinician	
C Information		
	C.1 Content	
	C.2 Communication	
D Values		
E Context		
F Factors		
	F.1 Patient	
		F.1.1 Patient Characteristics
		F.1.1.1 Ethnicity
		F.1.1.2 Age
		F.1.1.3 Gender
		F.1.1.4 Social status
		F.1.1.5 Personality (coping style)
		F.1.1.6 Intelligence

- F.1.1.7 Illness Insight
- F.1.1.8 Capacity
- F.1.1.9 Attribution
- F.1.1.10 Background/ values
- F.1.1.11 personal environment
(family/friends)
- F.1.1.12 Previous experiences
with treatment
- F.1.1.13 Knowledge of treatment
- F.1.1.14 Bias/ preconceptions
medication
- F.1.1.15 Experience (versed)
- F.1.1.16 Assertiveness
- F.1.1.17 Expectations

F.1.2 Treatment preference

- F.1.2.1 Medication
- F.1.2.2 CBT
- F.1.2.3 Combination
- F.1.2.4 No preference

F.1.3 Decision making preference

- F.1.3.1 Shared Decision making
- F.1.3.2 Follow patient wishes

F.1.4 Decisions

- F.1.2.1 Medication
- F.1.2.2 CBT
- F.1.2.3 Combination
- F.1.2.4 No preference

F.2 Factors Clinician

F.2.1 Characteristics Clinician

- F.2.1.1 Personal agenda
- F.2.1.2 Experience
- F.2.1.3 Attitude/ working style
- F.2.1.4 Uncertainty
- F.2.1.5 Department culture
 - F.2.1.5.1 hierarchy
 - F.2.1.5.2 team communication
 - F.2.1.5.3 discussion psychiatrist-
psychologist
- F.2.1.6 Experience (versed)
- F.2.1.7 Knowledge of treatment
(expertise)

F.2 Factors Clinician (cont.)

F.2.1.8 Prescribing practice

F.2.1.9 Steering behaviour

F.2.2 Treatment preference

F.2.2.1 Match preference/wishes patient

F.2.2.2 Weighing pro's and cons

F.2.3 Tasks Clinician

F.2.3.1 Diagnostics

F.2.3.1.1 Obtaining info

F.2.3.1.2 Reconsruction illnes

F.2.3.1.3 Explanation model

F.2.3.2 Providing information

F.2.3.2.1 Provision of information

F.2.3.2.2 Explaining illness

F.2.3.2.3 Discussing progression

F.2.3.2.4 Discussing pro's/cons

F.2.3.2.5 Explain treatment options

F.2.3.2.6 Giving treatment advise

F.2.3.3 Giving treatment

F.2.3.3.1 Constructive relation

F.2.3.3.2 Building trust

F.2.3.3.3 Giving advise

F.2.3.3.4 Formulating goals

F.2.3.3.5 Continuous adaptation

F.2.3.3.6 Evaluation/ check effects

F.2.3.4 Communication

F.2.3.4.1 Negotiate

F.2.3.4.2 Enticing

F.3 Factors Illness

F.3.0 Diagnosis

F.3.0.1 Depressive disorder

F.3.0.2 anxiety disorder

F.3.0.3 Psychotic disorders

F.3.1 Characteristics Illness

F.3.1.1 Symptomatology

F.3.1.2 Severity

F.3.1.2.1 Vital signs

F.3.1.2.2 Perceived need for help

F.3.1.3 Etiology/ explanation model

- F.3.1.3.1 Biological cause
- F.3.1.3.2 Psychological cause

F.4 Factors Treatment

F.4.0 Treatment Options

- F.4.0.1 CGT
- F.4.0.2 Medication
- F.4.0.3 Combination
- F.4.0.4 Other

F.4.1 CGT

- F.4.1.1 Characteristics CGT
 - F.4.1.1.1 works preventive
 - F.4.1.1.2 locus of control with patient
 - F.4.1.1.3 more expensive
 - F.4.1.1.4 requires homework
 - F.4.1.1.5 requires more effort of clinician
 - F.4.1.1.6 requires more time to full recovery
 - F.4.1.1.7 costs more energy / time
 - F.4.1.1.8 effects last loner
 - F.4.1.1.9 requires more effort patient
 - F.4.1.1.10 need to refer
 - F.4.1.1.11 effects in other area's
- F.4.1.2 Cons CGT
- F.4.1.3 Pro's CGT
- F.4.1.4 Requirements CGT

F.4.2 Medication

- F.4.2.1 Characteristics Medication
 - F.4.2.1.1 Effectiveness, easy and quick
 - F.4.2.1.2 Effectiveness, takes time to work
 - F.4.2.1.3 Effectiveness, relieves symptoms
 - F.4.2.1.4 Effectiveness, no effect after stop
 - F.4.2.1.5 Placebo effect

- F.4.2.1.6 Side effects
 - F.4.2.1.6.1 Withdrawal effects
 - F.4.2.1.6.2 Sexual dysfunction
 - F.4.2.1.6.3 Kinetic disorders
 - F.4.2.1.6.4 Weight gain
- F.4.2.1.7 Dependence
- F.4.2.1.8 Less effort for clinician
- F.4.2.1.9 Less effort patient
- F.4.2.1.10 Makes CBT possible
- F.4.2.1.11 Legitimation of illness
- F.4.2.1.12 Undermines intrinsic motivation
- F.4.2.1.13 Medicalization illness
- F.4.2.1.14 Externalization illness
- F.4.2.2 Cons Medication
- F.4.2.3 Pro's Medication

F.4 Factors Treatment (cont.)

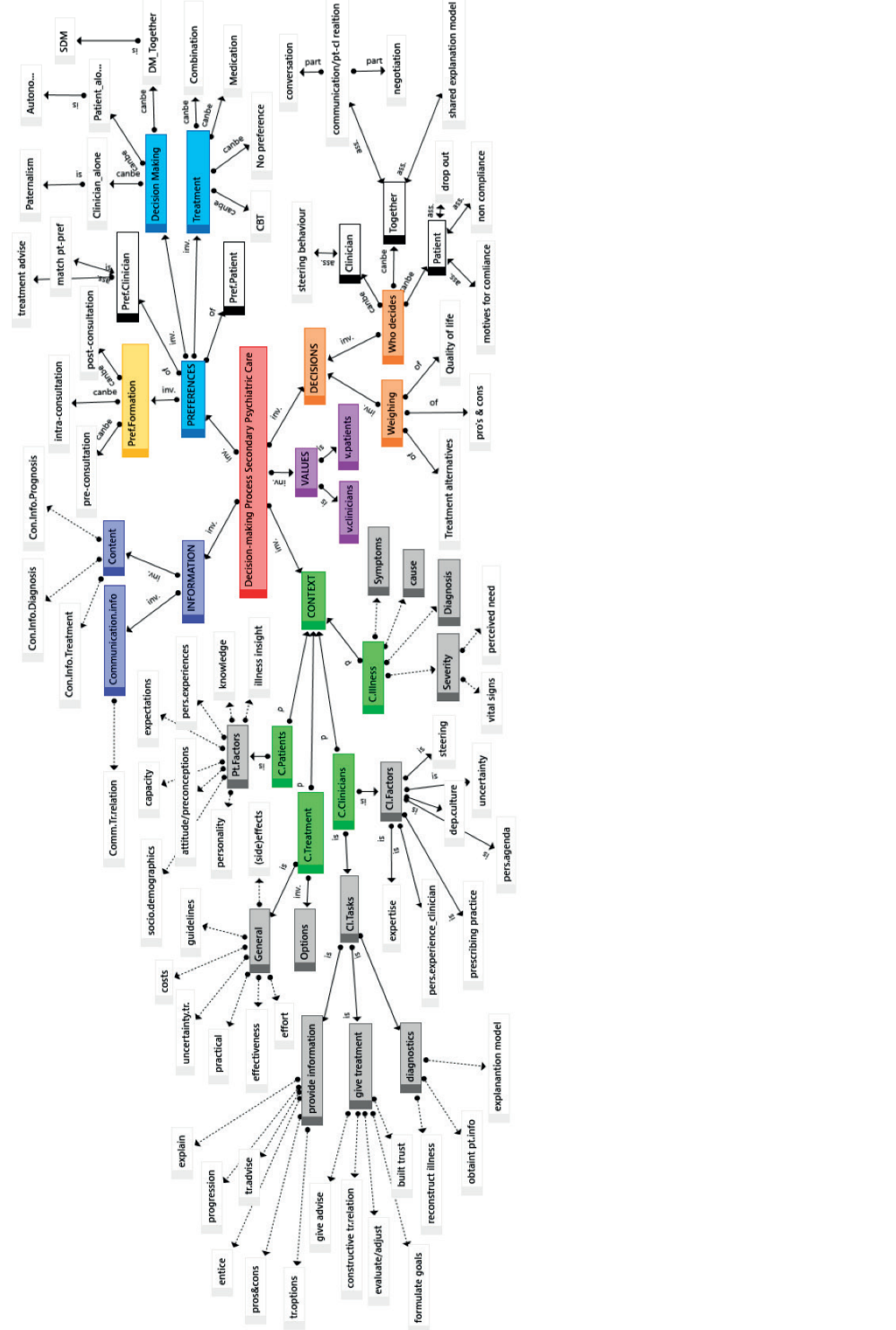
F.4.3 Combination therapy

- F.4.3.1 Characteristics
 - Combination
 - F.4.3.1.1 Holistic approach
- F.4.3.2 Cons Combination
- F.4.3.3 Pro's Combination

F.4.4 General Characteristics

Treatment

- F.4.4.1 Options
- F.4.4.2 Indication
- F.4.4.3 Practical aspects
- F.4.4.4 Availability
- F.4.4.5 Treatment effect
 - (effectiveness)
- F.4.4.6 Legislation
- F.4.4.7 Guidelines
- F.4.4.8 Financial costs (insurance)
- F.4.4.9 Logistics
- F.4.4.10 Evidence based
- F.4.4.11 Patient-clinician
 - relationship
- F.4.4.12 Uncertainty



Appendix D: Supporting Quotations

Box a. Communication

"I am all for a dialogue, in liaison with your clinician. It is about the input you provide; they can work with that." (PFG RD Resp.6)

"The difficulty is, that diagnostics and treatment can hardly be separated. During the first consultation you need to compromise, create trust, that is more than just getting information, other factors play a role." (CFG Psych. Resp. 1)

Box b. Information/Knowledge

"I would like to know what they are going to do, because I have not started yet and I am not sure what exactly is understood by behavioral therapy" (PFG OCD Resp. 5)

"It is also important that the clinician, at least takes into account evidence-based medicine and stays up to date with regard to the latest guidelines and is able to inform the patient about this." (CFG Res. 1)

Box c. Preferences

"But there is not always one preference better than the other right? Then, you should be able to choose the treatment that suits you." (PFG OCD Resp. 1)

"Knowledge in general, knowledge helps and experience. For instance, I have less experience with interpersonal therapy (IPT) than with CBT and I tend to go for CBT because of that." (CFG Psych. Resp. 4)

Box d. Decisions

"For me, it started with the choice, what do you want? We talked about that, what the pros and cons were. She [clinician] left it up to me, so not really an advice what I should do, I was allowed to make my own choice." (PFG OCD Resp. 1)

"Recurrence, severity, familial, fails or successes of previous treatments, these are important criteria". (CFG Mixed Resp.3)

Box e. Values and Attitudes

“I felt it was too easy. You want to try to solve it yourself and it felt like the easy way to take medication before I tried the other options.” (PFG OCD Resp.2)

“Clinicians discard that too easily, I think, “it is just gaining weight”, it is a big deal when you gain 10-20 kg.” (CFG Ther. Resp. 4)

Box f. Contextual factors

“It does feel as a sacrifice every time, another few hours off work” (PFG OCD Resp. 2)

“When we prescribe medication, we can treat patients ourselves, when we prescribe CBT we have to refer. I see referral as a disadvantage, it is customer-unfriendly and often patients are put on a waiting list.” (CFG Res. Resp.6)

Box g. Having treatment options and Uncertainty

“The options are offered by clinicians, that know about it, preferably not too many options, but at least an option. You need to be able to trust your clinician. It is a complex matter; you cannot do it all by yourself that is the problem. (PFG RD Resp. 2)

“I find it disappointing that it is difficult to predict what will be the best treatment for an individual.” (CFG Mixed Resp.5)

Box h. Weighing and who decides.

“Weighing everything, 123 and hope for the best, you try to think it all over, do it in a cognitive matter, but in the end it is on good luck, because you really don’t know” (PFG LUMC Resp. 2)

“In most cases, we, clinicians, make a proposal and the patient agrees, I think.” “It is a continuum, but a lot depends on the persuasiveness of the clinician, I think.” (CFG Psych. Resp. 2)

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Chapter 4

Patients' and clinicians' perspectives on shared decision- making regarding treatment decisions for Depression, Anxiety disorders, and Obsessive-Compulsive disorder in specialized psychiatric care.

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ABSTRACT

Rationale, aims, and objectives: People worldwide are affected by psychiatric disorders that lack a “best” treatment option. The role of shared decision-making (SDM) in psychiatric care seems evident yet remains limited. Research on SDM in specialized mental health is scarce, concentrating on patients with depressive disorder or psychiatric disorders in general and less on patients with anxiety and obsessive-compulsive disorder (OCD). Furthermore, recent research concentrates on the evaluation of interventions to promote and measure SDM rather than on the feasibility of SDM in routine practice. This study investigated patients’ and clinicians’ perspectives on SDM to treat depression, anxiety disorders, and OCD as to better understand SDM in specialized psychiatric care and its challenges in clinical practice.

Methods: Transcripts of eight focus groups with 17 outpatients and 33 clinicians were coded, and SDM-related codes were analyzed using thematic analyses.

Results: Motivators, responsibilities, and preconditions regarding SDM were defined. Patients thought SDM should be common practice given the autonomy they have over their own bodies and felt responsible for their treatments. Clinicians value SDM for obtaining patients’ consent, promoting treatment adherence, and establishing a good patient-clinician relationship. Patients and clinicians thought clinicians assumed the most responsibility regarding the initiation and achievement of SDM in clinical practice. According to clinicians, preconditions were often not met, were influenced by illness severity, and formed important barriers (e.g., patient’s decision-making capacity, treatment availability, and clinicians’ preferences), leading to paternalistic decision-making. Patients recognized these difficulties but felt none of these preclude the implementation of SDM. Personalized information and more consultation time could facilitate SDM.

Conclusions: Patients and clinicians in specialized psychiatric care value SDM but adapting it to daily practice remains challenging. Clinicians are vital to the implementation of SDM and should become versed in how to involve patients in the decision-making process, even when this is difficult.

INTRODUCTION

Many adults worldwide suffer from depressive and/or anxiety disorders^{1–3}. According to (inter)national guidelines, the treatments for these disorders include pharmacotherapy, psychotherapy, or a combination of both. These evidence-based treatment methods are considered equally effective for most patients^{3–5}. Some patients benefit from psychotherapy, such as cognitive behavioral therapy (CBT), whereas other patients benefit from medication only or a combination of both. In most cases, it is difficult to predict which patient will benefit from a treatment; sometimes, patients may not benefit from any of these treatments. Besides clinical characteristics (e.g., severity and psychiatric history), other relevant factors that might be considered in treatment decisions are personal characteristics, (previous) experiences, and patients' personal preferences. Therefore, a shared approach to decision-making between patient and professional seems appropriate^{6–8}. Recent studies suggest that involving patients in their own treatments using shared decision-making (SDM) leads to more informed patients, better treatment adherence, higher patient satisfaction, and possibly better outcomes^{9–16}.

In SDM, patients and clinicians work together to reach a treatment decision, by discussing both the available evidence and patients' preferences^{17,18}. Although views on SDM vary and a clear set of steps to implement this approach is lacking, most descriptions of SDM overlap¹⁹ and similar elements of SDM have been deemed important. Stiggelbout et al.²⁰ identified SDM as when (a) the professional informs the patient that a decision is to be made and that the patient's opinion is important; (b) the professional explains the options and the pros and cons of each relevant option; (c) the professional and patient discuss the patient's preferences, and the professional supports the patient in deliberation; and (d) The professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow-up²⁰. Recently, shared goal-setting has become a focus in SDM regarding chronic or complex care (e.g., mental health care^{21,22}).

In the Netherlands, all health care professionals act within the regulatory frameworks of the Medical Treatment Agreement Act (*Wet Geneeskundige Behandelingsovereenkomst*, WGBO, article 7: 453 of the Civil Code); important aspects include "the right to information" and the "right to give consent to treatment" (informed consent), implying that the patient and the health care provider decide together²³. Additionally, current clinical guidelines explicitly suggest involving patients and gaining their consent for treatment^{24–26}. Important factors include interpersonal or psychosocial problems, patient preferences, results of patients' previous treatments, side effects of medication, family history of psychiatric disorders, and practical issues (e.g., treatment waiting lists)^{25–27}. Patient preferences are a significant aspect of the psychiatric consultation; however, many clinical health care practices have yet to integrate SDM (as described above) in secondary psychiatric care^{18–21,28–33}.

Given the important role of patients' treatment preferences, other personal aspects in treatment selection, and the suggested benefits of SDM in psychiatric care, efforts are

underway to implement and to promote SDM in clinical practice. SDM interventions and tools, varying in design and delivery, have been developed or customized to support patients in treatment decision-making, to promote their understanding of the issues, and/or to guide them in asking relevant questions^{34–40}. These interventions/tools are mostly based on the theoretical SDM construct and related steps as described above or inspired by existing initiatives in other clinical fields. Interventions include traditional decision aids (DAs) for use before the consultation that contain information about treatment options and ask patients about experiences and preferences (and can also be taken to the consultation)³⁷; shorter versions for use by patients and clinicians together (e.g., Option Grids³⁴); web-based decision support systems (e.g., Common Ground web application³⁸ computerized clinical decision support tool [CDST]³⁹ and e-health programs using routine outcome monitoring [SDM-DI]^{35,36,41}. Most SDM interventions resulted in better informed patients, showed an increase of consumer involvement facilitated by the clinician, an increase of consumer satisfaction and treatment adherence, and often resulted in less decisional conflict (DC)^{18,35–37,41,42}. Yet effects on SDM and health service outcomes remain inconclusive, and SDM is not yet widely implemented across mental health care settings¹⁸. Some authors suggested that the effects of decision aids are weak, because of a less than optimal uptake of interventions/tools in current clinical practice, and that incentives might be needed to stimulate SDM and the use of DAs and other SDM interventions^{36,42,43}. In addition, Metz et al.³⁵ found an effect only for mood disorders and not for other diagnoses, suggesting that their SDM intervention might have been too generic. Tailoring interventions to patient groups and decision topics may be necessary to improve results⁴¹.

To better adapt existing SDM interventions and/or develop tailor-made interventions for secondary mental health care, there is need for more insight into SDM in routine clinical practice for specific patient groups in this setting (i.e., the position of SDM in the treatment of depression, anxiety disorders, and obsessive-compulsive disorder [OCD] in specialized psychiatric care), SDM's challenges in clinical practice, and ways to address these.

Research on SDM in mental health, especially in specialized psychiatric care, remains scarce⁴⁰ and concentrates on patients with depressive disorder or psychiatric patients in general and less on patients with other mental disorders, such as anxiety and OCD⁴⁴. In addition, current research mainly focuses on evaluating the SDM interventions and tools, mentioned above, by measuring their feasibility and effects on treatment outcomes, SDM, patient satisfaction, and decisional conflict (DC) rather than the general feasibility of SDM in practice or influencing factors.

The aim of our study was to investigate the views on SDM in treatment decision-making—in the context of decisions to start (or (dis)continue) CBT and/or medication—for depression, anxiety disorders, and OCD as perceived by clinicians and outpatients with depression, anxiety disorders, and OCD in specialized psychiatric care. Suggestions for potential interventions (decision aids) for this population were also explored.

METHODS

Sample and recruitment

Between June 2012 and December 2013, we held eight focus groups on treatment decisions for depression and/or anxiety/OCD in specialized psychiatric care. We used consecutive sampling to recruit patients and purposive sampling on clinicians⁴⁵.

In the Netherlands, patients with depression, anxiety, and OCD consult their general practitioner (GP) first and may be treated in primary care before they are referred to specialized psychiatric care (i.e., secondary, or tertiary care). Patients referred to secondary care tend to have more experience with different treatments, may be more severely ill, have comorbidity, and/or do not respond to first-step treatment options. Patients were recruited at GGZ Rivierduinen (RD), a Dutch mental health care provider, and the Department of Psychiatry at the Leiden University Medical Centre (LUMC) in the Netherlands. Patients who were diagnosed and treated for anxiety and/or depressive disorder(s), who spoke Dutch fluently, and who possessed the mental and physical ability to participate in a focus group were eligible for inclusion in the patient focus groups.

We held two mixed focus groups including outpatients with anxiety and/or depressive disorder(s)—one with patients from RD and one with patients from LUMC. A third focus group consisted of patients with OCD (GGZ RD/LUMC); we expected these patients might differ in making (treatment) decisions and in their views on SDM given their obsessions^{44,46}. We evaluated patients' inclusion criteria by their psychiatrist/psychologist and approached them consecutively until we had achieved commitment from five to eight patients for each focus group.

Clinicians eligible for inclusion in our focus groups included psychiatrists, psychiatric residents (i.e., junior doctors in specialty training), and psychologists (health psychologists and psychotherapists) who worked in a specialized care setting and who were actively involved in the decision-making process regarding the treatment of anxiety and depressive disorders. Clinicians in the first focus group were recruited at the Dutch Knowledge Centre for Anxiety Disorders, OCD, and Depression (NedKAD) Invitational Conference 2012 [<https://nedkad.nl/voor-professionals/invitational-conference/invitational-conference-2012/>]. For the other focus groups, clinicians were recruited at RD and LUMC.

We held two mixed professional focus groups and three mono-disciplinary groups for psychiatrists, residents, and psychologists, respectively. Up to 12 clinicians attending the NedKAD conference signed up for the first mixed focus group at the start of the conference. Psychiatrists for the mono-disciplinary group were recruited using the mailing list for the monthly scientific lectures at RD/LUMC. The heads of the participating departments (locations) of RD recruited participants for the second mixed focus group and other mono-disciplinary focus groups (psychiatric residents and psychologists). Professionals attending the NedKAD conference were all working in specialized mental health care institutions similar to RD and LUMC and involved in the treatment (decision-making) of secondary care

patients with depression, anxiety, and OCD. The Medical Ethics Committee of the LUMC approved our study (P12.003).

Procedures and data collection

The focus groups featured a semi-structured design. All focus groups were moderated by the first author (S.R.) and assisted by a second researcher, the observer (V.K., see Acknowledgements). Both researchers were trained in conducting and analyzing focus group interviews. Participants were informed of the focus group topics and encouraged to share and discuss their opinions, while respecting the opinions of the other members.

At the beginning of the focus group, participants were informed that the group interview was being audio recorded and that each focus group transcript would be de-identified and coded, assuring them of the confidentiality of data and their anonymity. We informed participants that their participation was voluntary and that they could withdraw from the study at any time without repercussions regarding their treatment. Each participant signed the informed consent and received an identification number. Participants were also asked to fill out a short background information questionnaire. At the end of the focus group, patients received a €25 gift card for their participation. Clinicians could accept the gift card or could donate the amount to charity by the researcher on their behalf.

The topics of the SDM focus groups included (a) participants' own definition of and attitude towards SDM, (b) SDM in routine clinical practice, and (c) ways to improve SDM and the implementation thereof, particularly the potential of SDM interventions (Box 1). See Appendix A for the complete guide of the focus group interviews.

Box 1. Topics and example questions of the focus group

Opening Questions:

Did you feel you had a choice regarding your treatment? (patients)

What is your own definition of SDM? (professionals)

SDM Related Topics:

Attitudes to SDM/SDM in clinical practice

"Do you have a clear personal treatment preference?"

"What role do they play in the decision-making?"

"Who makes the final decision and why?"

"How do you think treatment decisions are made?" /

"How do you think treatment decisions should be made?"

"Is SDM suitable in specialized psychiatric care?"

Decision Aids

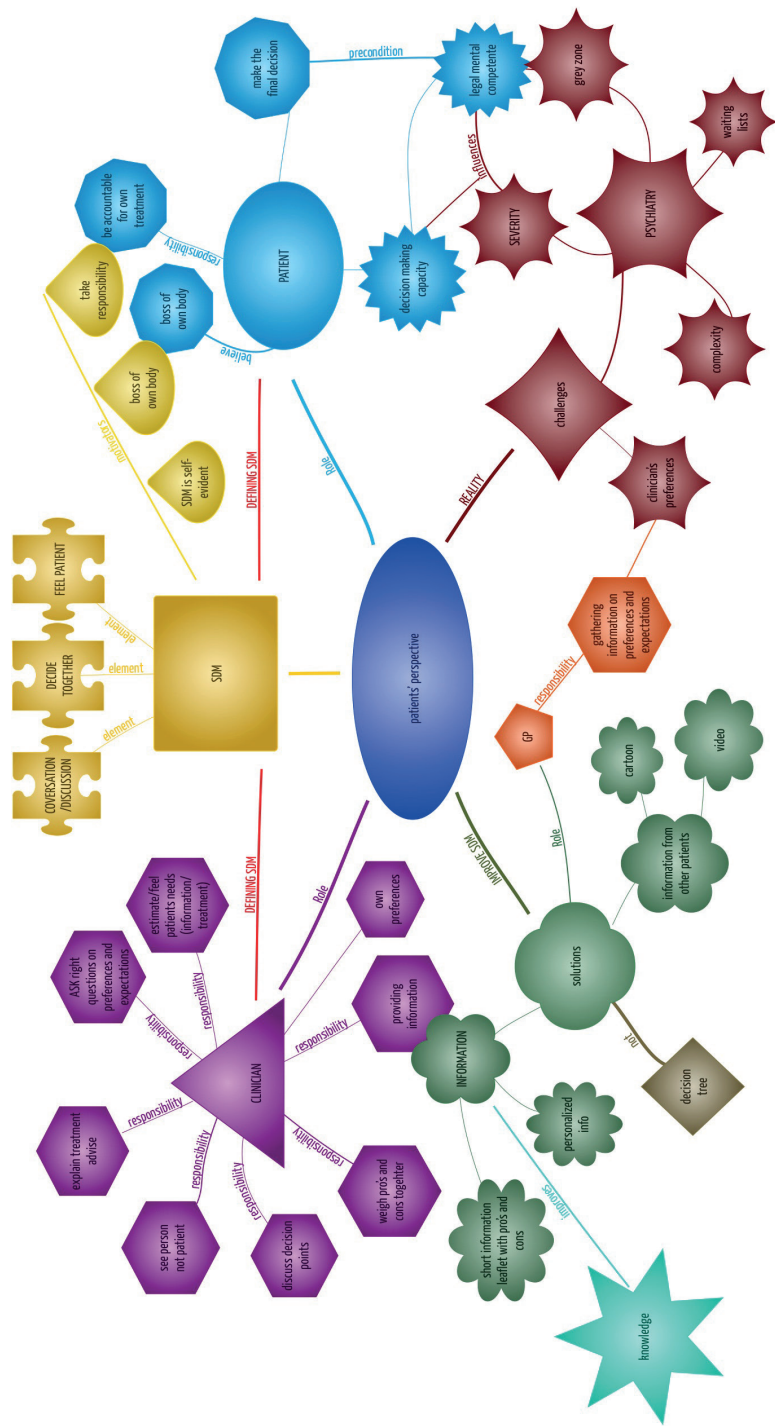
"What can help to make better decisions (together with the patient/clinician)?"

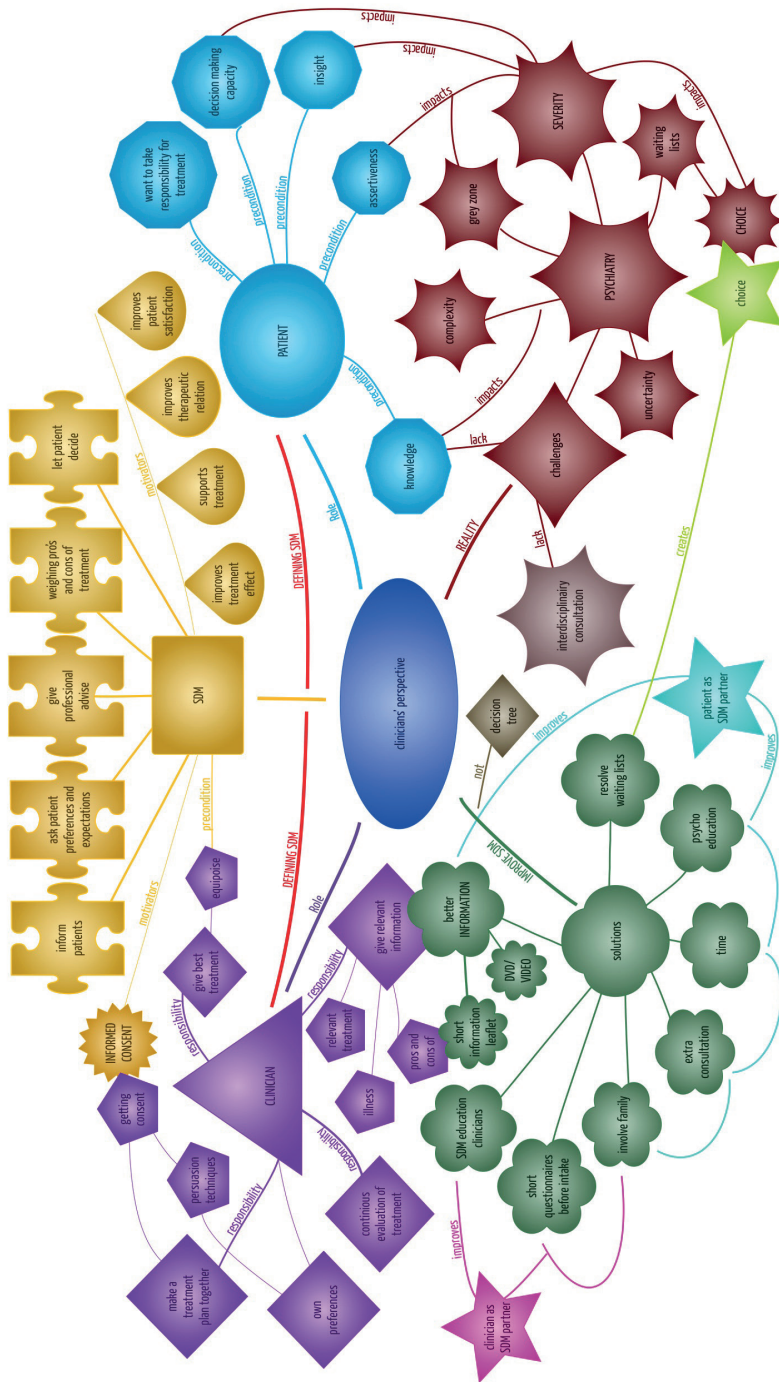
Data coding and analysis

We transcribed audiotapes verbatim. We used Atlas ti.7.5 (Scientific Software Development GmbH, Berlin, Germany)⁴⁷ to analyze the qualitative data, to code, and to thematically analyze the transcripts of the focus groups. First, two researchers (S.R. and V.K.) independently coded the transcripts of the first two professional focus groups and the first patient focus group; the researchers used open coding to label the relevant fragments within the texts⁴⁸.

FIGURE 1 Concept map of the most important themes and their relationships that emerged from SDM codes in (A) all patient’s focus groups and (B) all clinicians’ focus groups. Related codes were grouped together by topic; their relationships to each other and to other groups were visualized using different shapes and colors.

A



B

They compared their codes and grouped the codes they agreed upon into clearly defined categories. In this process, a working thematic codebook emerged that was used to code subsequent transcripts. Each new transcript was systematically compared with prior ones, to ensure that characteristics of and differences between the data were identified and incorporated into the analysis. We used concept maps, with our research questions as a framework, to group the data and to look for similarities and differences across the data⁴⁸⁻⁵¹. The most important themes regarding SDM (mentioned in all focus groups) and their relationships are displayed in concept maps shown in Figure 1A,B (patient and professional perspectives, respectively).

RESULTS

Table 1 shows the characteristics of the patients and the clinicians who participated in each focus group (FG). A total of 17 outpatients took part in three different patient focus groups consisting of three, six, and eight participants. In total, 33 clinicians participated in five different clinician focus groups ranging from three to nine participants. The focus groups lasted approximately 90 minutes and included a 10-minute break.

Four patients registered to attend the first patient focus group, but one participant did not show up. The remaining patient focus groups had an attendance rate of 100%. In total, 11 patients with anxiety and/or depressive disorders and six patients with OCD participated in the patient focus groups (see Table 1).

There was a 50:50 male to female ratio, and the participating patients covered a wide range with respect to age (20-75 y). Of the participating patients, most patients had middle to higher education (88%), and half of them were employed. Most participating clinicians were psychiatrists (N = 11) or residents in psychiatry (N = 8); other participants included seven clinical psychologists and four psychotherapists. Three psychiatric nurses unwittingly joined a clinician focus group; the psychiatric nurses are very relevant for the treatment of mental disorders and play an important role for patients and SDM in this setting. However, we chose not to include their statements in our analyses as they did not meet our inclusion criteria (i.e., they are not involved in the decision-making process to start medication and/or CBT and are not part of the consultation regarding the actual treatment decisions for these illnesses). There was a 50:50 male to female ratio, and the participating professionals covered a wide range with respect to age (27-69 y) and years of experience (2-40 y).

The codes extracted from the focus group interviews could be grouped into specific themes emerging from the data “Defining, the conceptualization of SDM in specialized psychiatric care” (“Motivators,” “Responsibilities,” and “Preconditions”) as well as themes regarding “Reality, SDM in routine clinical practice” (“Barriers,” “Illness severity,” and “Facilitators [Solutions]”). See summary in Table 2.

Table 1 Characteristics of focus groups' participants: patients and clinicians

Patients		Total
		N= 17
Disorder		
Anxiety and/or depressive disorder [†]		11
Obsessive–compulsive disorder		6
Gender		
Male		9
Female		8
Age		
Mean years ± SD (range)		44 ± 16 (20–75)
Education		
Middle to high		15
Low		2
Employment		
Job		9
No job		8
Professionals		Total
		N = 30
Profession		
Psychiatrist		11
Resident in psychiatry		8
Clinical psychologist		7
Psychologist/psychotherapist		4
Gender		
Male		15
Female		15
Age		
Mean years ± SD (range)		47 ± 12 (27–69)
Professional experience in psychiatry		
Mean years ± SD (range)		19 ± 12 (2–40)

[†] Specific information on diagnosis and previous treatments were not available because of the anonymous nature of the focus groups. We gave patients the chance to share this specific information at the beginning of the focus groups, but no one did. Some patients mentioned it during the discussion on specific topics.

TABLE 2 Views on SDM in specialized psychiatric care as perceived by patients and clinicians.

Categories	THEMES MENTIONED IN FOCUS GROUPS	
	Patients	Clinicians
CONCEPTUALIZATION OF SDM		
Defining shared decision making (SDM)	X	X
Patient		
	decides -	x
Together		
	weigh pros and cons of treatment x	x
	conversation/discussion x	x
	decide together x	
Clinician		
	informs patient x	x
	asks preferences x	x
	gives professional advise x	x
	allows patient to decide x	x
	has a sense of the patient x	
Motivators (believes)	X	X
Patient		
	SDM improves patient satisfaction	x
	SDM improves treatment outcome	x
	SDM empowers patients x	x
	patient is boss of own body x	
Together		
	importance SDM x	x
	SDM improves patient–clinician relationship x	x
Clinician		
	SDM supports treatment x	x
Responsibilities (tasks)	X	X
Patient		
	takes responsibility x	x
Together		
	make treatment plan together (shared goal setting) x	x
	weigh pros and cons of treatment x	x
Clinician		
	gives (relevant) information x	x
	gives best treatment	x
	asks the right questions (preferences, expectations) x	
	formulates decision points x	
	estimates information needs patient x	
	sees person behind the patient x	
	explains treatment advise x	
Preconditions	X	X
	Patient	
	has legal mental competence x	x
	has some knowledge (is informed) x	x

Categories	Patients	Clinicians
CONCEPTUALIZATION OF SDM (cont.)		
	wants to participate	x
	has some illness insight	x
	has some assertiveness	x
Together		
	Patient–clinician relationship x	x
Clinician		
	has treatment options available	x
	equipoise	x
SDM IN CLINICAL PRACTICE		
Barriers	X	X
Patient		
	illness insight x	x
	decision-making capacity x	x
	assertiveness x	x
Together (general)		
	uncertainty x	x
	treatment choice	x
	complexity x	x
Clinician		
	own preferences (opinions) x	x
Severity (affects)	X	X
Patient		
	decision-making capacity x	x
	assertiveness x	x
	illness insight x	x
	trust in self x	
Together		
	treatment options x	x
Clinician		
	paternalistic approach	x
Facilitators	X	X
Patient		
	gives information (fills in short questionnaire)	x
	gets psycho education	x
	gains knowledge x	x
Together		
	involve family x	x
	check assumptions x	x
	take time/extra consultation x	x
Clinician		
	gives better information x	x
	resolves waiting lists	x
	learns (about) SDM	x

Note. Themes and categories identified in the focus groups. The bold and Capital X, means this are the big topics

We found no specific differences between the mixed anxiety and/or depressive focus groups and the OCD focus group regarding the SDM topics discussed. However, OCD patients seemed to encounter less barriers with regard to availability and choice. They were almost always offered CBT or a combination of CBT and medication and seemed to have more time (given by the clinician) in their treatment trajectory to discuss, to gather information, and to overthink the decision to begin medication. As expected, OCD patients expressed having difficulties making decisions and focused more on information gathering and verifying their preconceived opinions⁴⁴.

Conceptualization of SDM

When asked about their own definition of and attitude towards SDM, most patients and clinicians responded positively and described an ideal conceptualization of SDM, which included support for SDM, specific roles and responsibilities of patients and clinicians involved in SDM, and preconditions to achieve SDM (see Table 2).

Motivators

Patients strongly advocated SDM, stating that they were “the boss of their own body” and should be accountable for their own treatment. Therefore, patients regarded being involved in their treatment as important and self-evident. “We [patients] should have the final responsibility” (FG patients RD, Respondent 2 [Resp. 2]). Most clinicians also advocated SDM in mental health care, especially in the treatment of depression, anxiety disorders, and OCD. Clinicians argued that biological, psychological, and social factors are important aspects of the illness and that the effectiveness of treatment highly depends on patient participation. Simply stated, clinicians believe that SDM should be the starting point of every treatment. It helped them to establish a good treatment relationship with their patients, to obtain consent to treat a patient, and to promote treatment adherence. “Getting the patient to go along with the treatment is a benefit of including the patient in the decision” (FG residents, Resp. 7).

Responsibilities

According to most patients, SDM included sharing the treatment decision and sharing responsibility. In this context, SDM comprises important elements: (a) the clinician and the patient engage in a conversation about all relevant treatment options, including pros and cons and the expected treatment course, and (b) then the clinician and the patient decide together. “Having an open dialogue is essential” (FG patients RD, Resp. 6). However, patients also mentioned several responsibilities (tasks) of the clinician in the decisional process, such as giving information, asking the right questions, and recognizing the person behind the patient (see Table 2/Figure 1A). “Clinicians should really see the person in front of them. It needs to become personal, because every individual is different” (FG patients RD, Resp. 1).

Clinicians' definitions of SDM varied in phrasing and/or meaning. For instance, some believed it was about weighing pros and cons together, shared goal setting, or finding common ground. Some clinicians thought that, in SDM, clinicians make treatment decisions together with the patient, and others thought the patient should decide. There were no distinct differences between specific groups of professionals regarding their definitions. Most definitions included the following overlapping elements: (a) The clinician presents information about the disease to the patient as well as relevant treatment options (including pros and cons), (b) so that he or she is well informed. (c) The clinician asks the patient's preferences and expectations and (d) interjects professional advice regarding the relevant treatment(s) available and their effectiveness, (e) so that the patient can decide (see Table 2/Figure 1B). "In SDM you give information about available treatment options, explore what the benefits and harms are and weigh these with the patients" (FG mixed NedKAD, Resp. 10). Similarly, clinicians listed their numerous responsibilities in the decisional process and mainly discussed their own tasks. Many clinicians stated that the final responsibility with respect to the treatment choice rested with them, but that patients should be involved in the decision-making process and should also take responsibility with regard to their treatment. "To inform a patient from a professional's perspective about diagnosis and treatment, because this is your primary role and then, in the context of informed consent, try to make a treatment decision together with the patient" (FG mixed RD, Resp. 4). "According to the law (WGBO), there needs to be consent, unless it is a dangerous situation, then you have to revert to forced treatment, but in principle a patient needs to agree to your treatment advice" (FG psychiatrists LUMC, Resp. 3). A few clinicians stated that many patients want the professional to decide, because "the doctor knows best" or because some patients simply "do not want the responsibility to decide."

Preconditions

Both patients and clinicians mentioned that a good patient-doctor relationship was an important prerequisite for SDM; for example, patients should trust (and like) their clinicians. Patients preferred a range of treatment options and to be well informed thereof. Clinicians also described certain preconditions or requirements for SDM. Patients should have the mental capacities to make treatment decisions. SDM also requires that a patient has enough knowledge of (and experience with) the illness and its treatment options. "A prerequisite for SDM is that a patient understands how severe his illness is, understands the situation and what can be accomplished with treatment" (FG psychiatrists LUMC, Resp. 1). Furthermore, patients need to have some amount of assertiveness. The availability of relevant treatments was also an important precondition for SDM, according to clinicians (see Table 2/Figure 1B).

SDM in clinical practice

Patients and clinicians advocated the concept of SDM, but in reality, they faced several challenges. Specific barriers and facilitators to SDM in clinical practice were identified on

an illness, patient, professional, and system levels, and the role of illness severity in this medical setting was discussed. Solutions to tackle the challenges of applying SDM in routine clinical practice were also explored.

Barriers

According to patients and clinicians, treatment decision-making in (specialized) psychiatric care was different from other medical specialties and more difficult.

Decision-making capacity

According to participants, because psychiatric illnesses are located in the brain, patients may be incapable of understanding the information or making sound treatment decisions. So, although a patient may be considered legally competent, he or she may not choose the best treatment option identified by the attending clinician. “In psychiatry cognitive capacity is impaired by the illness” (FG psychiatrists LUMC, Resp. 1).

Complexity and uncertainty

Patients in specialized psychiatric care often have chronic, more complex disorders, resulting in uncertainty regarding treatment outcomes. Psychologists/psychotherapists also mentioned that the content and quality of the treatment (ie, CBT and its effectiveness) depend on the experience and quality of the therapist and his or her personal characteristics. The difference between psychiatry and other medical specialties was an important theme in all focus groups. Participating patients compared their mental illness to other illnesses such as angina, a broken leg, or diabetes. Patients asserted that their illnesses are vague and intangible and cannot be visualized (e.g., via X-ray). Similarly, clinicians stated that incorporating SDM into specialized psychiatric care was challenging, compared with anxiety and/or depressive disorders in primary care, because patients in specialized psychiatric care are more severely ill, may have less insight into their illness, and have fewer treatment options.

Treatment choice

Another important barrier to SDM was having only one treatment option. Patient and clinicians stated that CBT was not an option in more severe cases; instead, patients are treated with medication (sometimes in combination with CBT), following clinical guidelines. A patient’s treatment choice was also impeded by a lack of availability (waiting lists), absence of indication, or the (in)effectiveness of previous treatments. “I had a choice, but on the other hand, everything (examination, diagnosis, previous treatments) added up to something so obvious, that it was clear what the decision would be” (FG patients OCD, Resp. 1).

Clinicians' preferences

Finally, patients and clinicians believed that the clinician's own treatment preferences determined the options offered to patients and the amount of steering behavior exhibited by the clinician (Table 2/ Figure 1B). "We [clinicians] steer more than we think. Clinicians steer towards what they think is best for the patient" (FG mixed NedKAD, Resp. 3).

Illness severity

Both patients and clinicians thought that illness severity was an important factor in successfully incorporating SDM into psychiatric care, because it influences all the barriers mentioned above. Severity affects a patient's capacity to understand information and to make (treatment) decisions. Moreover, patients should include insights into their illnesses, feelings of empowerment, and assertiveness in the discussion with their clinician (see Table 2/Figure 1A, B). Some patients mentioned that their illness sometimes hampered their ability to make treatment decisions and to trust their own judgement. Patients agreed that illness severity could affect patients' ability to make treatment decisions and that the clinician should sometimes take the lead. "I think there are different phases. In the first phase you are fully aware of your symptoms and able to assess the situation. Then, there is a grey phase in which you are not aware of how bad it really is. And when you go further, e.g., not coming out of bed, not taking care of personal hygiene, thinking about suicide, you know that it's bad and you are not capable of assessing the situation and making treatment decisions" (FG patients LUMC, Resp. 2). However, patients also thought that, despite illness severity, they were ultimately responsible for making the decision and were uncomfortable with the idea of clinicians taking over. "In the grey phase patients cannot make a treatment decision, but it is the best alternative, because even when that is probably not the right decision, they [the patients] are the only ones who can make it (with their family/friends)" (FG patients LUMC, Resp. 2).

Clinicians agreed that if there were two or more equally effective and available treatment options (i.e., the clinician has no preference or the patient and clinician have found a state of equipoise), the patient could decide—provided he or she was capable of doing so. However, clinicians often expressed doubt that patients could make these decisions or that they could oversee the consequences of their choices due to their illnesses, limited intelligence, and/or lack of sufficient information/knowledge. In these instances, clinicians assumed control (i.e., became more paternalistic) and admitted to using techniques (e.g., tempting, negotiating, or persuading) to entice patients to follow their recommended treatment. Some clinicians described SDM as a continuum, depending on disease severity. At the high end of SDM use, the clinician allows the patient to decide. At the low end of SDM use, the clinician feels compelled to decide for the patient (sometimes including family and friends) and leaves the patient out of the decision entirely. "When the decision-making is shared, in the 'white area' so to say, we [clinicians] can negotiate with the patient. In the 'grey area' we have a preference, and our main goal is to get the patient to do it. But when it comes to psychosis

and suicidality it changes to dark grey and we take over. Then, there is no choice” (FG psychiatrists LUMC, Resp. 4). According to clinicians, most patients in specialized psychiatric (secondary) care fell somewhere in between the two ends of the spectrum.

Facilitators Information (personalized)

Patients and clinicians thought that too much information and complex tools (e.g., decision trees) would overwhelm most patients and that many existing tools were too difficult. “I think, especially the group of depressive patients have little empowerment. So, I am not that optimistic with regard to decision making tools. I doubt they will use it” (FG mixed RD, Resp. 5). Participants were familiar with existing educational material and online information sites but thought there was room for improvement.

Many patients consulted the internet for information and for experiences from other patients—even though they knew that such information is based on individual cases and distorted by personal experiences. Most patients believed that having information based specifically on their individual situation could improve SDM in clinical practice and could help patients decide on the best treatment. According to patients, written information should be short and easy to read because their illness could make it difficult to concentrate and to understand large amounts of information. One patient wished to be informed about when treatment decisions were to be made and what kind. Patients valued the treatment recommendations of the professionals but thought that the professionals should also explain why a particular treatment is advised.

Clinicians stated that current patient information material was insufficient and overwhelmingly technical and often composed by professionals who favored a particular treatment. Accordingly, patient information material should be limited to one page and written clearly by a neutral author. Many clinicians suggested improving the information on websites or using video material to show patients what treatments entail and to share the experiences of others. Regarding this kind of material, however, clinicians cautioned that patients (tend to) see themselves in the characters of a video, so videos should be kept neutral.

Time

Patients suggested that extra time to think and to make a decision—an extra consultation with the clinician or an appointment to ask questions—would be helpful to make the “right” decision. “A short assessment, did you receive all the information you need, did you have time to think, are there any questions? Maybe at a different moment, with another professional. That, in combination with the clinician sensing the needs of the patient, could help making better treatment decisions” (FG patients LUMC, Resp. 3).

Psycho education

Many clinicians mentioned that a form of psycho education could be useful by providing patients with more information regarding their psychiatric condition and coping abilities, which could help them to gain insight into their situation and (treatment) needs. This could also help patients and professionals to establish a shared explanatory model and to set treatment goals together. “I think it is better to have a conversation with patients about their resistance, preferences and their doubts and fears” (FG mixed RD, Resp. 4). Patients also valued the therapeutic alliance and thought that clinicians should strive to see the person behind the patient.

DISCUSSION

Summary

The results of this focus group study on SDM in patients with a depression, anxiety disorder, or OCD in specialized psychiatric care show that patients and clinicians share a positive attitude towards SDM. However, their definitions of SDM and their motivations for applying SDM differ. Patients believed that SDM is self-evident and that they should assume responsibility for their treatments. Furthermore, clinicians should inform patients, discuss the pros and cons with them, and involve them in a conversation about their treatment to make a shared decision. Patients did mention a few barriers regarding SDM; however, none of these barriers preclude the implementation of SDM.

Clinicians asserted that the ultimate goal of SDM is to facilitate patients’ autonomous decision-making and that a clinician is responsible for informing the patient, deliberating the pros and cons, and helping them to make a decision⁵². Most clinicians stated that they already use SDM at the starting point of the treatment process in clinical practice, because it helps clinicians obtain a patient’s consent to treatment and to promote treatment adherence. At the same time, however, clinicians highlighted several preconditions and barriers to SDM that are difficult to overcome. Clinicians stated that illness severity could determine the feasibility of SDM in clinical practice, because it affects many preconditions. In this context, clinicians described situations in which they believe the clinician must become more paternalistic. In these situations, clinicians tend to motivate their patients to consent to their preferred (advised) treatment but may also (unintentionally) provide biased information on treatment options.

Both patients and clinicians think specialized psychiatric care is different from other specialties due to the complexity and intangibility of psychiatric disorders, the uncertainty of treatment outcome, the chronicity of many disorders, and because symptoms of the illness might interfere with the decision-making process.

The concept of informed consent exists worldwide; clinicians must inform patients about the pros and cons of their treatment options and persuade patients to consent to a particular

treatment²¹. The participating clinicians in our study described these aspects; however, clinicians do not have a clear uniform definition of SDM that addresses all elements of the SDM concept (such as making clear that a decision is to be made and that the patient's opinion is important and exploring the patient's role preferences)²⁰. This indicates that many clinicians still resort to informed consent and lack the necessary knowledge of SDM to go beyond the established informed consent processes⁵³. Although informed consent and SDM overlap, SDM may be applied to a wider range of clinical decisions and emphasizes the needs of the individual patient⁵⁴.

Strengths and limitations

To our knowledge, this is the first qualitative study to explore patients' and clinicians' views on SDM (in the context of decisions to start [or (dis)continue] CBT and/or medication) in the treatment of depression, anxiety disorders, and OCD in a specialized psychiatric care setting. This study, however, has some limitations. Although measures were taken to minimize bias and interviews and analysis of the transcripts were executed by two independent researchers, conclusions can be influenced by participants' and researchers' experience/knowledge of the topics. Patients also had to be capable of participating in a 90-minute long group discussion, so we only included patients who had moderately severe disorders based on the recommendations of their attending clinicians. We conducted eight focus groups, with different compositions, but some groups were rather small. Moreover, because clinicians selected patients, the recruitment of patients depended highly on the clinicians' limited time and effort. Thus, clinicians may have selected patients based on their preference for a certain patient. The recruitment of clinicians was more straightforward, but this led to an imbalance between the two groups, which could have influenced our results. Despite these limitations, we attained data saturation in both patients' and clinicians' focus groups. Furthermore, we believe that clinicians play a large role in the decision-making process, which increases the scope and value of their information. To be clear, the topics of our focus groups concentrated on SDM in treatment decision-making in the context of decisions to start (or (dis)continue) CBT and/or medication. SDM can and should of course also be applied in a broader context (e.g., shared goal-setting and shared evaluations and feedback during treatment trajectories). In addition, the composition of mixed patient focus groups makes it difficult to draw conclusions about specific differences between patients suffering from a depressive disorder, anxiety disorder, or OCD. This, along with our use of a convenience sample from a limited number of sites, should be considered before applying our conclusions to a broader population. At the time of our data collection, SDM was in its infancy. Although this could have influenced our results, research shows that to this date, SDM is still not widely implemented in mental health care^{18,20,21}. Furthermore, recent literature shows that the difficulties we identified regarding the implementation of SDM in clinical practice seem similar across different patient groups and health care settings^{18,36,42,43}. This suggests that despite SDM developments in recent years, our findings are still relevant,

and our conclusions may be applicable in a wider range of health care area's in the Netherlands and internationally.

Comparison with other literature

Many of our findings are supported by recent literature on SDM in general and specifically in mental disorders in primary and secondary care^{18,33,41,55}. One finding to underline is the fact that patients and clinicians have a shared commitment to generic values with regard to SDM, but do not have shared interpretations of those values in clinical practice. Another important finding, relating to the conceptualization of SDM, is the prime role of the clinician and responsibilities of patients and clinicians in the decisional process (from patients' and clinicians' perspectives), which resemble the findings of a recent study on SDM in oncology⁵⁶. Contrary to what participants in our study suggested, the challenges encountered in clinical practice are not unique to specialized psychiatric care. Other medical fields have documented similar barriers, such as lack of accurate information regarding diagnosis or prognosis, effectiveness and side effects, the (un)availability of treatment options, and patients' (in) capacity to engage in the decisional process^{57,58}. The way clinicians described the fluctuating use of SDM in clinical practice, by patient and by context, corresponds to the complex-care models described by other researchers²¹. Steering behavior towards what clinicians' believe is the best (available) treatment option was also identified by Engelhardt et al (so-called [implicit] persuasion techniques) as a potential barrier to SDM in an oncological setting⁵⁵. However, an important difference we found in this setting is the fact that clinicians believed patients' capacity to make sound treatment decisions, and therefore, SDM is impaired by the mental disorder and directly relates to illness severity. Coinciding with this, a recent study on psychiatrists' conceptions of decision-making capacity in psychiatry found that psychiatrists, as opposed to clinicians in somatic care, have a tendency to regard patients' imprudent decisions as a lacking in decision-making capacity⁵⁹.

Practical implications

Our results indicate that clinicians assume most of the responsibilities regarding the initiation and achievement of SDM in clinical practice⁵⁶. Indeed, because clinicians identify most barriers, clinicians are well equipped to learn how to overcome these barriers and to apply SDM in daily practice^{53,57,58}. This familiarization process includes imparting clinicians with the importance and ethical obligation to involve patients in the treatment decision-making process, making them aware of the impact of their unintended (and sometimes unnecessary) influence on treatment decisions, and training them to engage their patients in SDM as part of the clinical encounter—even when this is difficult. Other interventions should focus on overcoming the specific barriers that we identified for this setting. Short personalized SDM tools, which are designed to share information about an illness and to promote informed decisions about treatments, can be useful to improve patients' knowledge and can encourage patients to engage in the discussion, making them better SDM

partners (and fulfilling the SDM requirements)⁴⁰. The same applies for extra (consultation) time, which was also identified as an important facilitator in oncology, and forms of psycho-education—an evidence-based therapeutic intervention that provides patients and their families with information and support to better understand and cope with illness⁵⁶. However, such interventions do not guarantee that decisions will be shared, and they are not a substitute for the discussion/communication between patient and clinician⁶⁰. On a system level, SDM can be improved by developing clinical guidelines that describe more explicitly how patients and clinicians can engage in a conversation to help share knowledge, experience, and preferences. Patients' personal characteristics and preferences must be weighed and integrated in treatment decisions.

CONCLUSION

Based on the results of our focus groups, which are supported by recent literature, it can be concluded that patients and clinicians are motivated to apply a shared approach to treatment decision-making for depressive and anxiety disorders and OCD in specialized psychiatric care, but many patients and clinicians find it difficult to carry out SDM in clinical practice. Patients and clinicians both seem ill equipped (e.g., they both lack sufficient skills and/or knowledge) to overcome the challenges that come with SDM. Specific barriers that were identified are related to patient characteristics, the illness (severity), and treatment options. Unless patients are legally incapable, these barriers should not block patients' involvement in the decision-making process because many of these are inherent to the patient population in specialized psychiatric care. By educating patients on SDM and by giving them relevant information and time to think, ask questions, and to make decisions, clinicians can empower patients to become equal SDM partners. Clinicians play a vital role in putting SDM into practice; therefore, they should be educated and trained to involve patients in the decisional process, even when this seems difficult.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

SUPPLEMENTARY MATERIAL

Appendix A. Interview Guide Focus Groups

Interview Guide Focus Groups

PATIENTS:

Opening round: "Did you feel you had a choice regarding your treatment and why?"

A) Treatment options: preferences and attitudes

- What do you think about the available treatment options (i.e., medication and/or CBT/ psychotherapy) for your complaints?
- Personal preferences for medication and/or CBT/psychotherapy.
- Personal opinion on the different treatments (harms and benefits).
- Ideas about treatment preferences of professionals (treatment provider).

Decision-making process

B) Forming treatment preferences

- Factors determining/influencing own preferences.
- Ideas on factors influencing preferences of professionals (treatment providers).

C) Making treatment decisions

- The way (process) final decisions are made (who makes the final decision, did you feel there was a choice).
- Factors influencing own decisions.
- Ideas on factors influencing decisions of professionals (treatment providers).
- How can we improve (shared) treatment decision making (possibilities decision tools).

PROFESSIONALS:

Opening round: introduction + personal definition of SDM

A) Treatment options: preferences and attitudes

- Personal treatment preferences for medication and/or CBT/psychotherapy.
- Personal opinion on the different treatments (harms and benefits).
- Ideas about treatment preferences of patients.

Decision-making process

B) Forming treatment preferences

- Factors determining/influencing own preferences.
- Ideas on factors influencing preferences of patients.

C) Making treatment Decisions

- The way (process) final decisions are made (who makes the final decision).
- Factors influencing own decisions.
- Ideas on factors influencing decisions of patients.
- How can we improve (shared) treatment decision making (possibilities decision tools).

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Chapter 5

Decision-making and the role of preferences in the treatment of Depression and Anxiety disorders: *A cross-sectional survey in specialized psychiatric care*

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ABSTRACT

Objective: To investigate treatment decision-making and the role of preferences in depression and anxiety disorders in specialized mental health care.

Methods: A survey study among 99 patients attending a specialized outpatient clinic for mood- and anxiety disorders using a two-part questionnaire (pre-post consultation). Part I included pre-consultation questions on the patients' treatment preferences, preferred decisional role, and baseline characteristics (e.g., health literacy, decision-making participation self-efficacy). Part II included post-consultation questions on experienced decisional role, treatment choice made, and aspects of the consultation/decision-making process (e.g., treatment options and -recommendations provided, trust in the clinician, decisional conflict).

Results: Most of the patients (83%) preferred a collaborative or autonomous decisional role, 37% experienced their preferred decisional role. Higher perceived self-efficacy in decision-making participation was associated with a stronger preferred and experienced collaborative decision-making role. An experienced collaborative decision-making role was associated with higher trust in the clinician and less decisional conflict. Treatment choices made were mostly associated with information on treatment options, but also treatment recommendations, and trust in the clinician, but not with patients' a priori treatment preferences. Concordance between treatment preferences and treatment choice was associated with patients' health literacy and self-efficacy.

Conclusions: Treatment decisions seem mostly based on the communication/information provided by the clinician within the consultation. The low concordance between preferred and experienced decision-making role and between treatment preferences and treatment choice, shows room for improvement with respect to collaborative decision-making. Patients' decision-making self-efficacy can be an important target to improve shared deliberation and decision-making.

INTRODUCTION

Depressive and anxiety disorders are highly prevalent in the general population and can cause a high degree of burden on patients and their relatives, as well as high societal costs¹⁻⁴. Selecting the optimal treatment for patients is an important first step in a patients' treatment course.

The recommended treatment options for these disorders are psychotherapy (e.g., Cognitive Behavioral Therapy (CBT)), medication (antidepressants), or a combination of both. Clinical guidelines describe a stepped-care approach that uses the range of these equally effective therapy options, depending on factors such as patient preference, illness severity, first episode or recurrence, and the response to previous treatments⁵⁻⁸.

Complying with the principles of patient-centered care and Evidence Based Medicine (EBM), current clinical guidelines advise clinicians to involve patients in the decisional process, to consider patient preferences, to respect patients' choices and thus to improve therapy adherence and treatment outcome⁵. However, guidelines do not stipulate how the most optimal treatment is selected for or with a patient in clinical practice and how clinicians (and patients) make treatment decisions⁹⁻¹³. Research shows, however that perceived patient involvement is not optimal and that concordance between preferred and experienced decision-making role and between preferred and received treatments is still low in clinical practice¹⁴⁻²⁰. Barriers to patient involvement that have been identified include: poor information exchange between patients and clinicians^{15,18}, patients' lack of self-confidence to engage in a conversation with the clinician about their treatment (decision-making participating self-efficacy), and patients' perceived poor ability to perform basic reading of health care information (health literacy)^{14,17,21-25}.

Research also shows that patients have preferences for involvement in the decision-making process (decisional role preferences) and identifiable treatment preferences^{4,26-34}. Collaborative decision-making, the congruence between preferred and perceived decision-making role, and the congruence between preferred treatment and selected treatment, have been suggested to be associated with higher treatment satisfaction, better treatment adherence, less drop-out from treatment, and consequently better treatment outcomes^{15,35-39}. Furthermore, meeting patients' desires with respect to their preferred decision-making role is associated with higher trust in the therapist and less decisional conflict, i.e. the personal uncertainty about which treatment option to choose^{37,40-42}.

Research on the extent to which clinicians involve their patients in the decision-making process is mainly performed in a heterogenous medical specialist setting^{25,43,44}. Relevant studies performed in mental health care are few, as are studies of determinants of low concordance between preferred and experienced decision-making role and between preferred and received treatments and its impact on patients' experience of the decision-making process (including treatment decisions).

Treatment decision-making in mental health care is a complex process and seems different from other settings^{16,45}. To improve patient involvement in decision-making in mental health care, more insight in the decisional process in this setting is needed.

We used a naturalistic sample of outpatients with depression and/or anxiety disorders in specialist psychiatric care to investigate: the decision-making process underlying treatment decisions in the context of decisions to start or (dis)continue CBT/psychotherapy and/or medication; and the role of treatment- and decision-making preferences in the decisional process. The aims of this study were to explore:

1. Determinants of preferred and experienced decision-making role, and of their concordance, divided over three sub aims:
 - 1.1. Associations of **preferred decision-making role** with baseline patient characteristics (age, gender, patients' health literacy, decision-making participation self-efficacy) and baseline treatment preferences.
 - 1.2. Associations of **experienced decision-making role** with baseline patient characteristics, preferred decision-making role, treatment preferences, and characteristics of the decision-making process (trust in the clinician, and decisional conflict).
 - 1.3. Associations of the **concordance** between preferred and experienced decision-making role with baseline patient characteristics, preferred decision-making role, treatment preferences and characteristics of the decision-making process.
2. Determinants of treatment preferences and treatment choices, and of their concordance, also divided over three sub aims:
 - 2.1. Associations of baseline **treatment preference** with baseline patient characteristics.
 - 2.2. Associations of **treatment choices** with baseline patient characteristics, baseline treatment preferences, provided information (treatment options discussed and treatment recommendations of the clinician during the consultation), and with characteristics of the decision-making process.
 - 2.3. **Concordance** between treatment preferences and treatment-choice and its associations with baseline patient characteristics, provided information, experienced decisional role, and characteristics of the decision-making process.

MATERIALS AND METHODS

Study population and procedure

The study population consisted of adult psychiatric outpatients, aged 18 to 65 years, referred to a secondary care outpatient clinic for mood- and anxiety disorders at the Dutch Mental Health Care Provider GGZ Rivierduinen, between October 2014 and December 2015. Most patients visiting this clinic are referred by their general practitioner for specialized treatment and often received treatment in a primary care setting before referral²⁴. As part of the intake procedure, the clinician determines the primary clinical diagnosis and main focus

of treatment, and discusses treatment options⁴⁶. Patients were informed about the study by the researcher (SR) in the waiting room and were invited to participate. Patients eligible for this study were approached consecutively, until we included a total of 99 patients. All participants provided Informed Consent and were requested to complete a questionnaire (see Measures). The clinician could be a psychiatrist, a resident-in-training supervised by a psychiatrist, or a psychologist/psychotherapist.

The Medical Ethics Committee of the Leiden University Medical Centre (LUMC) approved the current study (P12.003).

Measures

For this survey study, we used a self-report questionnaire booklet, that consisted of two parts, administered before (Part I) and after (Part II) the intake-consultation (before treatment started). Variables were selected based on the results of a previous qualitative focus group study on this topic in a similar population^{24,47} and on relevant literature^{17,48}.

Part I of the questionnaire measured baseline patient characteristics (gender, age, Health Literacy [Set of Brief Screening Questions (SBSQ)]²², Self-efficacy in participating in decision-making [Decision Making Participating Self-Efficacy Scale (DEPS: “process” and “decision-making” scales)]²¹, Preferred decision-making role [Control Preference Scale (*CPSpre*)]³⁰ and Treatment Preference (CBT/Psychotherapy vs Medication, Combination vs CBT/Psychotherapy, Combination vs Medication, No Preference).

Part II of the questionnaire measured characteristics of the decision-making process (Trust in the clinician [Wake Forest Trust Scale (WF-D)]⁴⁹, Decisional Conflict [Decisional Conflict Scale (DCS)]^{42,50,51}, Experienced decision-making role [Modified Control Preference Scale (*CPSpost*)], Provided Information (Treatment Options Discussed and Treatment recommendations/advice of the clinician during the consultation), and Treatment Choice. Treatment Options discussed and Treatment choices were CBT/Psychotherapy, Combination, Medication, None. See Box S1 in the Supplemental Materials for more detailed information on the instruments.

Statistical analyses

Data are presented as *N* (%) or Mean ($\pm$ SD), as appropriate. For the analyses, answering categories of the *CPSpre* and *CPSpost* were recoded into three categories regarding decision-making role: “Patient’s decision” (active), “Shared decision” (collaborative), and “Clinician’s decision” (passive)^{14,52}. Concordance between preferred - and experienced decision-making role and Concordance between treatment-preference and treatment choice were only computed for patients who had a preference and for/with whom a treatment decision was made, respectively.

1. Baseline characteristics of patients were compared between the answering categories - “active”, “collaborative”, “passive”- for preferred (1.1) and experienced (1.2) decision-making role and answering categories -“yes/no”- for decisional role concordance (1.3).

Chi-square tests and univariable logistic (binary or multinomial) regression analyses were used to analyze associations of: preferred decision-making role with preferred treatment (1.1); experienced decision-making role with preferred decision-making role, preferred treatment, trust in the clinician and decisional conflict (1.2); decisional role concordance with preferred decision-making role, preferred treatment, trust in the clinician and decisional conflict (1.3).

2) Baseline characteristics of patients were compared between the answering categories, -“CBT/psychotherapy”, “Combination”, “Medication”, “no preference/no decision- for treatment preference (2.1) and treatment choice (2.2) and between the answering categories -“yes/no”- for treatment choice concordance (2.3). Chi-square tests and univariable and (binary or multinomial) logistic regression analyses were used to analyze associations of treatment choices with: preferred treatment, treatment options discussed, treatment advice, trust in the clinician, and decisional conflict (2.2); and of treatment choice concordance with: experienced decision-making, treatment options discussed, treatment recommendation/advice, trust in the clinician, and decisional conflict (2.3). Statistical analyses were performed using IBM SPSS Statistics Version 26.0⁵³.

RESULTS

Part I. Pre-consultation patient characteristics and preferences.

Results of the pre-consultation measurements are shown in Table S1 and Box S1 provides information for the interpretation, see Supplemental Materials. The mean age of participants was 35,5 years (SD=13.5), range 18-63 years and 54% were female. Mean Health Literacy was 2.40 (0.5), range 0.7 – 3.3, and mean Decision-making participating Self-efficacy (in short Self-efficacy) was 76.6 (12.2), range 40 -100 Most patients (47%) preferred a collaborative decision-making role, 36% preferred an active role, and 13% preferred a passive role. Most patients preferred Combination therapy (42%) or CBT/psychotherapy (34%), 6% preferred Medication, and 10% had no (clear) treatment preference.

Part II. Post-consultation provided information, characteristics of the consultation, decision-making process, experienced roles, and treatment choices.

Results of the post-consultation measurements are shown in Table S2, see Supplemental Materials. Seventy-seven patients (77%) completed Part II of the questionnaire. Reason for not completing was a lack of energy or motivation after the (long) consultation (intake procedure) in combination with the length and/or difficulty of the second part of the questionnaire.

Regarding experienced involvement in the decision-making, patients mostly experienced: a passive role (41%) or a collaborative role (40%), followed by an active role (19%).

Regarding treatment options discussed with and provided treatment recommendations by the clinician during the consultation, patients discussed: "Combination therapy" (30%), "CBT/Psychotherapy" (20%), "Medication only" (16%), "No treatment options" (13%), "Medication only and CBT/Psychotherapy separately" (12%), "All treatment options" (7%), "Medication only and combination separately" (1%) or "CBT/Psychotherapy only and combination separately" (1%). Patients were recommended "CBT/psychotherapy" (32%), followed by "Combination therapy" (29%) and "Medication" (20%).

Regarding treatment choices, selected treatments were: "CBT/psychotherapy" (28%), "Combination" (22%), "Medication" (16%), "Another treatment" (12%) or no decision was made yet (22%).

On average, patients reported medium trust in the clinician (in short Trust) (Mean = 3.4 (SD=0.57)) and reported little decisional conflict (Mean = 35.4 (SD = 13.82)).

Preferred and Experienced decision-making roles, Concordance, and associated variables (1)

Table 1 shows associations of Preferred and Experienced decision-making role with baseline patient characteristics and experienced decision-making role with characteristics of the decision-making process. No significant associations were found between patients' preferred decision-making roles and patient characteristics (age, gender, Health Literacy, Self-efficacy), except for Self-efficacy ($\chi^2=10.86$, $p<.01$), with highest scores for patients preferring an active role, and lowest for patients preferring a passive role. No significant associations were found between patients' experienced decision-making roles and patient characteristics, except again for Self-efficacy ($\chi^2=7.60$, $p<.05$), with highest scores for an experienced active role, and lowest for a passive role.

Experienced decision-making roles were significantly associated with trust ($\chi^2= 13.38$, $p<.01$) and decisional conflict ($\chi^2= 8.61$, $p<.05$). The highest trust scores were seen for a collaborative experienced decision-making role, the lowest for a passive role. The highest decisional conflict score was seen for a passive role.

Concordance of preferred-decision-making-role-with-experienced-decision-making-role was 37%. Most of the discordance occurred in the cases that patients experienced a passive role.

Table 2 shows associations of Concordance of Preferred and Experienced decision-making roles with baseline patient characteristics and characteristics of the decision-making process. No significant associations were found.

Table 1 Baseline patient characteristics by Preferred Decision-making role*. [1.1]
Baseline patient characteristics and decision-making characteristics by Experienced Decision-making role*. [1.2]

PATIENT CHARACTERISTICS		Preferred Decision-making role (N=95, missing 4**)				Experienced Decision-making role (N=75, missing 24**)					
		Active	Collaborative	Passive	X ²	p	Active	Collaborative	Passive	X ²	p
Gender (N [†])											
male		18	16	5	1.51	0.47	10	16	12	3.45	0.18
female		18	28	7			4	14	17		
Age (Mean (SD))		36.4 (12.2)	34.5 (14.3)	32.5 (4.0)	0.92	0.63	34.1 (13.0)	34.9 (14.3)	34.7 (13.3)	0.03	0.99
Health Literacy ¹ (Mean (SD))		2.4 (0.4)	2.4 (0.5)	2.3 (0.4)	0.44	0.80	2.4 (0.5)	2.4 (0.5)	2.4 (0.4)	0.63	0.73
Self-efficacy ² (Mean (SD))		76.0 (13.4)	76.6 (11.8)	76.4 (12.0)	0.09	0.96	74.9 (12.4)	77.4 (10.6)	74.3 (13.0)	1.11	0.57
DEPS process		68.1 (17.1)	71.3 (14.9)	75.0 (16.4)	2.23	0.33	67.0 (14.6)	71.6 (14.0)	68.8 (16.8)	1.01	0.61
DEPS decision		75.0 (17.9)	68.5 (19.2)	52.5 (21.9)	10.86	<0.01	75.0 (21.9)	72.4 (18.1)	60.8 (18.2)	7.60	<0.05
PREFERENCES											
Role preference ³ (N)										9.12	0.06
active							8	13	6		
collaborative							6	13	17		
passive							0	3	7		
Treatment Preference (N)					5.75	.452				4.13	.659
CBT/psych.		17	13	4			5	11	10		
combination		13	21	7			5	11	16		
medication		3	3	0			2	1	1		
no. pref		3	9	2			2	6	4		
DECISION-MAKING CHARACTERISTICS											
Trust ⁴ (Mean (SD))							3.5 (0.3)	3.6 (0.4)	3.1 (0.7)	13.38	<0.01
Decisional Conflict ⁵ (Mean (SD))							29.9 (10.7)	32.3 (12.9)	41.1 (14.4)	8.61	<0.05

*Using Chi-square and univariable multinomial regression analyses. **Missing values may vary in combination with different variables.

¹Set of Brief Screening Questions (SBSQ), ²Decision-making Participation Self-efficacy (DEPS), ³Control preference scale (CPSpre), ⁴Wake Forest Trust Scale (WF-D), ⁵Decisional Conflict Scale (DCS).

Table 2 Associations with Decisional Role Concordance* (using univariable binary logistic analyses). [1.3]

BASELINE CHARACTERISTICS	Concordance preferred – experienced decision-making role (N=73)*		
	Univariable Analyses		
	OR	95% CL	p
<i>male</i>	1.10	0.43 - 2.84	0.84
<i>female (ref)</i>			
Age	0.97	0.94 - 1.01	0.16
Health Literacy¹	0.38	0.12 - 1.15	0.09
Self – Efficacy²	0.99	0.96 - 1.04	0.92
<i>DEPS process</i>	1.00	0.97 - 1.03	0.88
<i>DEPS decision</i>	0.88	0.97 - 1.02	0.68
PREFERENCES			
Treatment preference			
<i>psych</i>	0.53	0.13 - 2.13	0.37
<i>med.</i>	1.00	0.10 - 9.61	1.00
<i>combi</i>	0.52	0.14 - 2.01	0.35
<i>no pref. (ref)</i>			
DECISION-MAKING CHARACTERISTICS			
Trust in clinician⁴	1.62	0.66 - 3.98	0.29
Decisional Conflict⁵	0.98	0.94 - 1.01	0.20

* Concordance was calculated with only the patients with a preferred and experienced decision-making role (N=73).

¹ Set of Brief Screening Questions (SBSQ), ²Decision-making Participation Self-efficacy (DEPS), ³Control preference scale (CPSpre),

⁴ Wake Forest Trust Scale (WF-D), ⁵Decisional Conflict Scale (DCS).

Preferred Treatment, Treatment Choices, Concordance, and associated variables (2)

Table 3 shows associations of treatment preferences with baseline characteristics, and associations of treatment choices with baseline characteristics, provided information and decision-making characteristics. Analyses showed no associations of baseline characteristics (age, gender, Health Literacy, Self-efficacy) with treatment preferences or treatment choices. Associations were found for treatment choices with treatment options discussed ($\chi^2= 96.98$, $p<.001$) and TA ($\chi^2= 131.71$, $p<.001$), with most patients receiving the treatment that was discussed/recommended. Also, associations were found for the decision-making characteristic trust ($\chi^2= 11.8$, $p<.01$), with lowest trust scores for patients receiving combination therapy.

Concordance could only be calculated for patient with an identifiable a priori treatment preference and if a treatment choice was made. In 23 patients (57%), treatment preferences

and treatment choices were concordant ($N=40$). Disconcordance was highest when the resulting treatment choice was “Medication”.

Table 4 shows associations of concordance between treatment-preferences-and-treatment-choice with baseline patient characteristics and with characteristics of the decision-making with. Associations were found for Health Literacy ($OR= 7.06, p<.05$) and Self-efficacy ($OR= 1.04, p<.05$): patients with high Health Literacy scores and patients that scored high on the DEPS were more likely to receive their preferred treatment (concordance between treatment-preferences-and-treatment-choice).

Table 3 Baseline patient characteristics by Treatment Preferences^{*}: [2.1]
Baseline patient characteristics provided information and decision-making characteristics by Treatment Choices^{*}: [2.2]

PATIENT CHARACTERISTICS	Treatment Preferences (N=96)**				Treatment Choices (N=67)**							
	CBT/Psych.	Comb.	Med.	No pref.	χ ²	p	CBT/Psych	Comb.	Med.	No dec.	χ ²	p
Gender (N)					2.32	0.51					2.77	0.43
male	15	15	4	6			8	7	7	10		
female	19	26	2	6			13	9	4	7		
Age (Mean (SD))	33.3 (11.6)	35.7 (14.9)	35.2 (11.1)	36.4 (14.4)	0.83	0.84	32.9 (11.3)	33.8 (14.8)	40.8 (10.7)	34.8 (15.4)	2.52	0.47
Health Literacy ¹ (Mean (SD))	2.4 (0.4)	2.4 (0.4)	2.2 (0.5)	2.4 (0.7)	1.42	0.70	2.4 (0.6)	2.5 (0.3)	2.3 (0.5)	2.4 (0.4)	2.15	0.54
Decision-making Participation Self-efficacy ² (Mean (SD))	76.9 (14.7)	75.3 (11.3)	80.7 (8.5)	77.9 (9.3)	1.35	0.71	75.8 (12.2)	76.0 (12.7)	75.3 (13.8)	77.2 (9.0)	0.22	0.98
DEPS process	71.1 (18.2)	69.4 (15.0)	76.0 (10.8)	72.8 (13.1)	1.33	0.72	68.45 (16.7)	69.92 (16.7)	70.31 (16.7)	72.4 (11.1)	0.68	0.88
DEPS decision	71.3 (23.9)	66.1 (18.2)	75.0 (15.8)	69.2 (15.0)	1.99	0.58	70.23 (15.0)	70.00 (19.4)	64.6 (24.9)	67.7 (23.0)	0.75	0.86
PREFERENCES												
Treatment Preferences ³											13.26	.15
CBT/psychotherapy							10	1	4	6		
combination							8	11	3	7		
medication							1	0	2	1		
no preference							2	4	3	3		

PROVIDED INFORMATION

Treatment Options Discussed

CBT/psychotherapy
medication
combination
psych.& med.
psych. & combi
combi. & med.
all
none

11	0	0	0	3	96.98	<.001
0	1	9	0	0		
4	13	0	4	4		
5	0	2	2	2		
0	1	0	0	0		
0	0	1	0	0		
1	2	0	1	1		
0	0	0	0	7		

Treatment Advice

CBT/psychotherapy
combination
medication
no advice
none/else

21	0	0	0	2	131.71	<.001
0	15	1	4	4		
0	2	11	1	1		
0	0	0	9	9		

Trust⁴ (Mean (SD))

3.5 (0.3)	3.0 (0.8)	3.6 (0.1)	3.6 (0.5)	11.8	<0.01
33.8 (10.5)	38.4 (13.1)	27.1 (17.1)	38.9 (11.9)	6.86	0.08

Decisional Conflict⁵ (Mean (SD))

⁵Using Chi-square analyses and univariable multinomial regression analyses. ⁶Missing values may vary due to the combination of variables.

¹Set of Brief Screening Questions (SBSQ), ²Decision-making Participation Self-efficacy (DEPS), ³Control preference scale (CPSpre), ⁴Wake Forest Trust Scale (WF-D), ⁵Decisional Conflict Scale (DCS).

Table 4 Associations with Concordance of treatment preference and choice (using univariable binary logistic analyses). [2.3]

BASELINE CHARACTERISTICS, PREFERRED TREATMENT, EXPERIENCED ROLE & DECISION-MAKING CHARACTERISTICS	Concordance treatment preferences – treatment choices (N=40) *		
	OR	Univariable Analyses 95% CL	p
Gender	0.57	0.16-2.03	0.39
Age	0.96	0.91-1.01	0.15
Health Literacy¹	7.06	1.10-45.34	<0.05
Self – Efficacy²	1.03	0.98-1.08	0.29
<i>DEPS process</i>	1.02	0.98-1.06	0.36
<i>DEPS decision</i>	1.04	1.00-1.08	<0.05
Preferred treatment			
<i>psych</i>	2.00	0.51 – 7.80	0.32
<i>Med.</i>	2.00	0.16 – 25.40	0.59
<i>Combi (ref.)</i>			
Experienced decisional role ³			
<i>active</i>	1.67	0.29 – 9.71	0.57
<i>collaborate</i>	3.44	0.79 – 15.02	0.10
<i>passive (ref.)</i>			
Trust in clinician⁴	0.60	0.19-1.87	0.38
Decisional Conflict⁵	0.97	0.92-1.02	0.25

* Concordance was calculated with only the patients with a defined treatment preference and treatment decision (N=40).

¹ Set of Brief Screening Questions (SBSQ), ²Decision-making Participation Self-efficacy (DEPS), ³ Modified Control preference scale (CPSpost), ⁴Wake Forest Trust Scale (WF-D), ⁵Decisional Conflict Scale (DCS).

DISCUSSION

To our knowledge, this study is the first to investigate treatment- and decision-making preferences in relation to experienced decision-making role and actual treatment choices, measured before and after the intake-consultation, in the context of decisions to start (or (dis)continue) treatment for depression and anxiety disorders in an adult patient group in specialist mental health care. Our study shows that most patients preferred a collaborative decision-making role, and that they were confident about their ability to understand medical information and to engage in a conversation with their clinician. An experienced collaborative decision-making role was associated with trust in the clinician and less decisional conflict. Yet, many patients experienced a passive decision-making role, i.e., the decision was made by the clinician alone. Additionally, our study shows that patients have a priori treatment preferences. Treatment choices seemed mostly according to clinical guideline recommendations and were not significantly influenced by patients' a priori treatment preferences. Furthermore, treatment choice was only associated with the information provided by the clinician during the intake-consultation, i.e., treatment options and treatment recommendation. These findings reflect the substantial role that clinicians have in the treatment decision-making process.

Our findings support the results of a previous qualitative study on shared decision-making we conducted in the same setting²⁴, which found that most patients and clinicians want to engage in collaborative decision-making but its implementation in daily practice remains challenging. According to both patients and clinicians in that study, collaborative decision-making required a good patient-clinician relation, having treatment options, and patients to have the capacity to understand information and make treatment decisions. Our previous findings on treatment selection in the same setting⁴⁷ indicated that treatment choices were explained not so much by patient characteristics but by clinical factors (i.e. symptom severity and previous experiences/prescriptions), indicating that clinicians' professional preferences played an important role in treatment selection. By providing selective information on treatment options, clinicians can also (unintentionally) steer the decision in the direction of their treatment advice^{16,47,54,55}.

The concordance between preferred and experienced decision-making role and between treatment preferences and treatment choice was poor in our study. Concordance of decisional roles was reported in less than half of the cases. Concordance of treatment preferences with treatment choices was seen in approximately 6 out of 10 cases, mostly in patients with higher perceived ability to understand medical information and to take responsibility for the treatment decision, which may also reflect assertiveness and prior knowledge of or experience with the available treatment options.

These findings regarding concordance of preferred and experienced decision-making role are partly consistent with other studies^{20,44}, including a study in an outpatient psychiatric care setting³². In most studies, patients also preferred a collaborative decision-making role,

but they often experienced less involvement^{32,48}. De las Cuevas et al.³² found that patients least preferred an active role (patient decides alone), as opposed to our finding that patients want an active or collaborate role and least preferred a passive role (clinician decides). This could possibly be explained by population differences between studies and the fact that De las Cuevas et al.⁽³²⁾ did not study the a priori preferences and the consultation directly. Moreover, they included patients with different psychiatric disorders and found that diagnosis influenced concordance²⁰.

In our study, patients who wanted an active role were less likely to get what they preferred. This could mean that decisional role concordance has more to do with the patient's role preferences matching the decision-making style of the clinician instead of the other way around, i.e., the clinician actually adapting his decision-making style to the wish of the patient. Driever et. al. ((2022) found that clinicians' self-reported usual decision-making style in different secondary care settings was not associated with the (actual) observed patient involvement. Also, clinicians tend to overestimate the extent to which they apply shared decision-making⁴³. Concordance between preferred and chosen treatment was associated with patients' self-efficacy pre-consultation. This seems to imply that patients who believe that their own behavior can influence outcome, seek a collaborative role which may in turn influence the clinician's acceptance of this collaboration, as seen by de las Cuevas³². Self-efficacy was found to be a precondition for shared decision-making from a clinicians' perspective²⁴. Clinicians' often revert to paternalistic decision-making, because of their perception that patients are incapable of making the decision²⁵. The severity of the illness and associated symptoms, such as doubting and indecisiveness, can influence this perception. The willingness/attitude of patients to take responsibility for their treatment might influence the way clinicians evaluate the patient's decision-making capacity in a positive way and motivate clinicians to accept patients' treatment preferences as an appropriate treatment option. Thus, become more receptive towards patients' preferences. A strength of the present study is that we used data from a naturalistic treatment-seeking patient population in a secondary mental health care setting, measured before and after the intake consultation. In addition, we were able to measure several variables that are important in treatment decision-making according to previous qualitative research in the same setting.

There are also limitations. First, our study population was relatively small given the number of variables we examined, resulting in small subgroups for analyses. Some of our outcome variables consisted of three or more categories, which resulted in low frequencies in some cells. This explains the wide confidence intervals, and therefore some outcomes should be interpreted with caution. Moreover, concordance between choice and preference could only be determined in less than half of the patients, due to missing values and because the treatment decision had not been made yet in one in five patients. Also, 20% of the patients did not complete the second part of our questionnaire, which could have biased our results (e.g., these patients might have had more severe symptoms, or were less assertive).

However, post hoc analyses to compare pre- and post- consultation groups did not reveal significant differences. Second, due to our study design, we don't know whether our findings are generalizable to another health care setting. Nor is it possible to draw conclusions on causal relationships regarding provided information and decision-making characteristics (measured post-consultation). Third, information on clinical factors (e.g., diagnosis, illness severity, treatment history) and clinician characteristics was not available. As a result, we do not know for certain if and how these factors influenced treatment decision-making. Fourth, our data were collected in 2014–2015 and our findings may be somewhat outdated. However, until this date no additional research on the specific topic (and population) of our study has been published. From recent research in the Netherlands, we know that the situation regarding collaborative decision-making has not changed much. Studies on shared decision making and patient involvement in different settings show that patient involvement is still limited in clinical practice, and that care is rarely adjusted to patient preferences^{15,25,43,44,56,57}. Therefore, our results can make a valuable contribution to patient involvement and (shared) decision-making in mental health care.

CONCLUSION

In conclusion, this study highlights that patients' decision-making role- and treatment preferences are rarely incorporated in the treatment decision-making process in an outpatient mental health care setting. Our study indicates that in patients with higher health literacy and higher self-efficacy, treatment decisions are more often shared. Therefore, patients' self-efficacy regarding decision-making participation may be an important factor in improving collaborative deliberation and decision-making in a mental health setting. This study also underlines the importance of targeting clinicians' communication and (shared) decision-making skills to improve the implementation of collaborative treatment decision-making in clinical practice in this setting.

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SUPPLEMENTARY MATERIAL

Measures

For this survey study, we used a self-report questionnaire booklet, that consisted of two parts, administered before (Part I) and after (Part II) the intake-consultation (before treatment started).

The following widely used (validated) questionnaires were included to measure:

Health Literacy, the Set of Brief Screening Questions [SBSQ]

Self-efficacy in participating in decision-making, the Decision Making Participating Self-Efficacy Scale [DEPS], divided into two dimensions: “process” and “decision-making” scales]

Preferred decision-making role, the Control Preference Scale [*CPSpre*]

Trust in the clinician, the Wake Forest Trust Scale [WF-D]⁴⁹

Decisional Conflict, the Decisional Conflict Scale [DCS]

Experienced decision-making role, the Modified Control Preference Scale [*CPSpost*]

Box S1 provides more detailed information on the instruments used in this survey, including references of the original scales.

RESULTS

Table S1 shows the results of the pre-consultation measurements, consisting of baseline patient characteristics of N=99 participants, i.e., gender, age, Health Literacy, and decision-making self-efficacy and patients’ preferences regarding their decision-making role and treatment modality. For some variables categories were calculated.

Table S2 shows the results of the post-consultation measurements of N=77 participants consisting of provided information (i.e., treatment options discussed and treatment recommendation from the clinician) and characteristics of the consultation (i.e. trust in the clinician and decisional conflict, experienced decision-making role and selected treatment (treatment choices)).

Box S1 Overview of (validated) instruments included in the questionnaire booklet.

Instrument	Measure	Items	Scale	Score
<i>PART I pre-consultation</i>				
SBSQ	Health Literacy Set of Brief Screening Questions(1)	3	5-point Likert scale from 0 to 4. An average score of two indicates “inadequate health literacy”, and a score higher than two indicates “adequate health literacy”	Mean score
DEPS	Decision Making Participating Self-efficacy Scale(2)	5	5 response options “not at all” to “completely” confident A higher score indicates higher self-confidence. Two separate indicators of self-efficacy: participating in the deliberation process (items 1–4) and taking responsibility for the final decision (item 5) were also created.	Mean score, linearly transformed 0–100 metric
CPS	Control Preferences Scale(3)	1	5-point Likert scale, with different roles “patient alone” to “clinician alone”	categorical
<i>PART II post-consultation</i>				
CPSpost	Modified Control Preference Scale(4)	1	5-point Likert scale, with different roles “patient alone” to “clinician alone”	categorical
DCS	Decisional Conflict Scale(5–7)	16	5-point Likert scale, “completely agree” to “completely disagree” Scores under 25 (no to little DC), from 25 up to and including 37.5 (some degree of DC), and scores higher than 37.5 (clinically significant or high degree of DC).	Mean score, multiplied by 25; 0–100 metric
WF-D	Wake Forest Physician Trust Scale(8)	10	5-point Likert scale “totally agree” to “totally disagree” A higher score indicates more trust.	Mean score

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Table S1 Pre-consultation measurements (N=99): Baseline patient characteristics & preferences.

PART I PRE-CONSULTATION MEASUREMENTS (N= 99)			
Patient Characteristics & Preferences		N (%) / M(SD)	Categories
Gender N (%)		N (%)	
Age	male	53 (54%)	
	female	43 (43%)	
	Mean (SD) Range	35,5 (13,5) 18-63	
		Age cat.*	
		1. <26 yrs	33 (33.3%)
		2. 26-40 yrs	28 (28.3 %)
		3. >40yrs	33 (33.3%)
Health Literacy [SBSQ] ¹		HL cat.* (adequacy)	
	Mean (SD)	2,40 (0,5)	adequate 71 (71,7%)
	Range	0,7 – 3,3	inadequate 24 (24,2%)
Decision-making Participation Self-efficacy [DEPS] ²			
Process	Mean (SD)	76,6 (12,2)	
	Range	40 – 100	
	Mean (SD) range	70.9 (15,7) 25-100	
Decision	Mean (SD)	68,9 (19,9)	
	range	25-100	

Categorised variable of Age, Health Literacy, Preferred decision-making role, Treatment preferences, respectively.

Set of Brief Screening Questions (SBSQ).² Decision-making Participation Self-efficacy (DEPS),³ Control preference scale (CPSpre).⁴ Categorised variable of Age, Health Literacy, Perceived decision-making role, Treatment preferences, respectively.

Table S2 Post-consultation measurements (N=77, 22 missing): Provided Information and characteristics of the decision-making process.

PART II POST-CONSULTATION MEASUREMENTS (N=77, missing N=22*)	
Provided information	N (valid %) / M (SD)
Treatment options discussed	
CBT/psychotherapy medication combination	15 (19.7%)
medication and psychotherapy/CBT separately	12 (15.8%)
psychotherapy and combination separately	23 (30.3%)
medication and combination separately	9 (11.8%)
all options separately	1 (1.3%)
none	1 (1.3%)
(missing N=23)	5 (6.6%)
10 (13.2%)	
Treatment Recommendation from clinician	
medication	15 (19.7%)
CBT/psychotherapy/combination	24 (31.6%)
no advice	22 (28.9%)
other	10 (13.2%)
(Missing N=23)	5 (6.6%)
Decision-making characteristics	M (SD)
Experienced DM role [CPS_{post}]¹	
A- I made the decision myself	9 (11.8%)
B- I made the final decision after seriously considering my clinician's opinion	5 (6.6%)
C- My clinician and I made the decision together	30 (39.5%)
D- My clinician made the final decision, but seriously considered my opinion	17 (22.4%)
E- My clinician made the decision	14 (18.4%)
(Missing N=24)	
CPS_{post} cat.²	
active	14 (18.7%)
collaborative	30 (40.0%)
passive	31 (41.3%)
Concordance³ CPS_{Spre} – CPS_{post}	
yes	28 (37.3%)

Treatment Choices

medication
CBT/psychotherapy
combination
no decision
other
(Missing N=23)

12 (15.8%)
21 (27.6%)
17 (22.4%)
17 (22.4%)
9 (11.7%)

Concordance TC – Tp^d 23 (57%)**

Trust in physician [WF-D]⁵

Mean (SD)
Range
(Missing N=23)

3,4 (0,57)
1,4 – 4,4

Decisional Conflict [DCS]⁶

Mean + SD
Range
(Missing N=32)

35,4 (13.82)
1,6 - 68,8

* seventy-seven patients completed part II of the questionnaire. ** concordance was calculated with only the cases that had a clear preference and a decision was made (N=40).
¹Modified control preference scale (CPSpost), ²Categorical variable of experienced decision-making role and preferred decision-making role respectively, ³Computed variable concordance of preferred and experienced decision-making, ⁴ Computed variable concordance of treatment choice with preferred treatment, ⁵Wake Forest Trust Scale (WF-D), ⁶Decisional Conflict Scale (DCS).

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Chapter 6

Dutch translation and psychometric testing of the 9-Item Shared Decision Making Questionnaire (SDM-Q-9) and Shared Decision Making Questionnaire-Physician Version (SDM-Q-Doc) in primary and secondary care

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ABSTRACT

Purpose: The SDM-Q-9 and SDM-Q-Doc measure patient and physician perception of the extent of shared decision making (SDM) during a physician-patient consultation. So far, no self-report instrument for SDM was available in Dutch, and validation of the scales in other languages has been limited. The aim of this study was to translate both scales into Dutch and assess their psychometric characteristics.

Methods: Participants were patients and their treating physicians (general practitioners and medical specialists). Patients (N = 182) rated their consultation using the SDM-Q-9, 43 physicians rated their consultations using the SDM-Q-Doc (N = 201). Acceptability, reliability (internal consistency), and the factorial structure of the instruments were determined. For convergent validity the CPSpost was used.

Results: Reliabilities of both scales were high (alpha SDM-Q-9 0.88; SDM-Q-Doc 0.87). The SDM-Q-9 and SDM-Q-Doc total scores correlated as expected with the CPSpost (SDM-Q-9: $r = 0.29$; SDM-Q-Doc: $r = 0.48$) and were significantly different between the CPSpost categories, with lowest mean scores when the physician made the decision alone. Principal Component Analyses showed a two-component model for each scale. A confirmatory factor analysis yielded a mediocre, but acceptable, one-factor model, if Item 1 was excluded; for both scales the best indices of fit were obtained for a one-factor solution, if both Items 1 and 9 were excluded.

Conclusion: The Dutch SDM-Q-9 and SDM-Q-Doc demonstrate good acceptance and reliability; they correlated as expected with the CPSpost and are suitable for use in Dutch primary and specialized care. Although the best model fit was found when excluding Items 1 and 9, we believe these items address important aspects of SDM. Therefore, also based on the coherence with theory and comparability with other studies, we suggest keeping all nine items of the scale. Further research on the SDM-concept in patients and physicians, in different clinical settings and different countries, is necessary to gain a better understanding of the SDM construct and its measurement.

INTRODUCTION

In recent years, there has been an increasing emphasis on the role of patients' preferences and of shared decision making (SDM) in treatment decision making. There is a growing recognition that this sharing is important. In partnership with their clinicians, patients are encouraged to consider the likely harms and benefits of available treatment options, communicate their preferences, and select the option that best fits these¹. SDM helps to ensure that treatment decisions reflect patient preferences so that patient experiences of care as well as treatment outcomes may improve². Thus, SDM is a critical part of quality care and should be one of the principles for good clinical practice³⁻⁵. Although great efforts are made to promote shared decision making, the measurement of its construct is challenging⁶ and evidence on its impact remains sparse⁷. Reliable and valid instruments are needed for studies that assess the effectiveness of SDM. In addition, these can help gain a better understanding of the concept of SDM and its correlates. Furthermore, such instruments will help to facilitate the development, implementation, and evaluation of decision-making interventions in clinical practice.

An important self-report instrument developed to measure the process of shared decision making as perceived by the patient is the nine-item Shared Decision-Making Questionnaire (SDM-Q-9)⁶. The original German SDM-Q was developed building on Elwyn's model of competences for involving patients, and on additional psychological theories^{6,8}. This 24-item questionnaire underwent a major revision and was reduced to a 9-item scale, the SDM-Q-9. The scale had a high internal consistency, high item discriminations, and showed high face and factorial validity⁶. In addition to this patient version a German physician-version, the SDM-Q-Doc, was constructed as well, by rephrasing the questions of the original SDM-Q-9. The SDM-Q-Doc showed good internal consistency and acceptable to good item discriminations, indicating a good reliability of the scale⁹.

Over the last years the SDM-Q-9 has become a frequently used instrument to measure SDM in clinical practice, and has been translated into several languages, including English^{6,10}, Spanish¹¹, and French, Italian, Chinese, Japanese, Korean, Persian and Hebrew (I Scholl, personal communication, 2014). Until now, no Dutch version was available. However, validation of the various translations was limited, and little has been done to establish the convergent validity of the scale^{10,12}. To our knowledge, only the Spanish SDM-Q-9 was officially translated, validated (mostly with respect to internal consistency) and published¹¹. It showed some differences in the factor structure with the original German scale. Furthermore, most of the validation studies of the SDM-Q-9 have been carried out using patients in primary care. The internal consistency of the German SDM-Q-Doc was tested in a primary and a specialized care sample, but there has been no further validation of this scale yet. Therefore, the present study set out to translate the SDM-Q-9 and the SDM-Q-Doc into Dutch and to evaluate their psychometric properties using Dutch primary and specialized care samples of patients and their treating physicians from different medical specialties.

METHOD

Ethics statement

The study was approved by the Medical Ethics Committee of the University Medical Centre Utrecht, the Medical Ethics Committee of Maastricht University and Medical Ethics Committee of the Leiden University Medical Centre (Reference number P12.043). All participants provided their written consent before filling in the questionnaires.

Sample

The study sample was composed of outpatients and their treating medical specialists at the Departments of Psychiatry and of Ophthalmology of Leiden University Medical Centre; the Departments of Gynecology and of Oncology (breast cancer) of the Maastricht University Medical Centre, and Type 2 Diabetes patients and their general practitioners, participating in the OPTIMAL study of the Julius Centre for Health Sciences and Primary Care, Utrecht University Medical Centre.

We aimed at a sample of 180 patients, based on the heuristic of 15–20 patients per item of the questionnaire. We intended to recruit five physicians from every department and each participating physician was asked to collect data from 10 patients who met the following eligibility criteria: a) above 17 years of age; b) able to speak and read Dutch; and c) facing a decision regarding the health problem for which they visited their physician.

Procedures

To establish the study sample, the heads of each participating department agreed to inform and recruit physicians of their own departments (GPs, specialists, and residents).

Physicians were informed about the project and asked to recruit 10 of their consulting outpatients. Physicians were instructed to inform their eligible patients about the study and to ask informed consent for their participation. For each participating patient, physicians were asked to complete after the consultation: the SDM-Q-Doc, including two open-ended questions on what health problem was the subject of the consultation and which decision was made⁶, and Kasper et al.'s single-item modification of the Control Preferences Scale (CPS), CPS_{post}¹³ (see Measures, paragraph 2.3.3). Physicians also completed a (once only) short questionnaire on their demographic characteristics.

Patients willing to participate first signed an informed consent form. Immediately after the consultation, patients were asked to rate the extent to which they felt involved in decision making by filling out the SDM-Q-9 (including the two open-ended questions), the CPS_{post}, and questions on demographic characteristics.

Both patients and physicians were asked to fill in their own name and the name of their patient/physician. This information was only used to link patient and physician data.

Measures

SDM-Q-9 and SDM-Q-Doc. The SDM-Q-9 and the SDM-Q-Doc measure the views of respectively the patient and physician on the decision-making process in a consultation. The nine items of the scale each describe a different step of the SDM process, for example “My physician made clear that a decision needs to be made” and “My physician and I selected a treatment option together”⁸. All items are scored on six-point Likert scales ranging from 0 (“completely disagree”) to 5 (“completely agree”). The aggregated scores over all items of the SMD-Q-9 lead to a total raw score between 0 and 45, with 0 indicating the lowest and 45 indicating the highest level of perceived SDM.

Translation of the questionnaires. First, two native Dutch speakers with fluent command of the German language independently translated the original German versions of the SDM-Q-9 and SDM-Q-Doc into Dutch. These translations were then discussed in a consensus meeting, consulting the English version⁶ in case of ambiguity (see S1 Appendix). The agreed upon Dutch versions were then back translated into German by two native German speakers with fluent command of the Dutch language. The original questionnaires and the back-translations were compared, and discrepancies were resolved between four members of the research team (among whom IS and AS). At the end of the translation process, both versions were presented to several clinicians for their opinion. Because the clinicians found that the phrasing of the words “ausdrücklich mitgeteilt” (“uitdrukkelijk medegedeeld”) was too strong in Dutch, and that they are seldom used in Dutch clinical practice, we preferred to use “made clear” (“duidelijk gemaakt”). In addition, “mitgeteilt” sounds too formal in Dutch, therefore we chose “told” (“verteld”), as in the English translation. This was discussed and agreed upon by the research team, resulting in the final version. See S1 Appendix for the description of the items of the SDM-Q-9 and SDM-Q-Doc in English.

CPS_{post} As a gold standard for measuring the perceived level of involvement is lacking, we chose a modified version of the Control Preferences Scale, the CPS_{post} for comparison. The CPS_{post} is a five-point Likert scale formulated to measure the experienced role in the final decision, which has a good reliability and validity¹³. The original Control Preferences Scale was developed by Degner¹⁴ to measure preference for involvement and is one of the most commonly used instruments to assess someone’s preferred decisional role. Modifications of the CPS as a single five-point Likert scale to measure someone’s experienced role have been used in different studies, showing good reliability and validity^{13,15,16}. An example is Kasper et al’s¹³ CPS_{post}, which was used in a validation study on inter-relating measures for SDM. The authors reported a moderate association between the CPS_{post} and SDM-Q-9, a more autonomous role (CPS_{post}) was associated with more involvement as reported on the SDM-Q-9. For this study a physician’s version was made by rephrasing the CPS_{post} item. The CPS_{post} presents subjects with a choice of five alternative decisional roles. Patients/physicians were asked to indicate who made the decision: 1: “I made the decision alone”, 2: “I made the decision alone considering my physician’s opinion /patient’s preferences”,

3: "I shared the decision with my physician /patient", 4: "My physician /patient decided considering my opinion/preferences" and 5: "My physician /patient made the decision".

Statistical analyses

As the summated SDM-Q-9 and SDM-Q-Doc raw scores have an unfamiliar range (0–45), we followed Kriston et al.⁶ and rescaled this range to 0–100; the rescaled version is used throughout this paper. First, we investigated the characteristics of the frequency distributions of the total scores (mean, standard deviations, skewness and kurtosis). In addition, acceptance rates of the questionnaire items were assessed as the percentage of participants who were willing to fill out a particular item.

Item difficulties were determined by calculating the mean total score of each item. Low mean scores, below the midpoint (2.5 on a 6-point Likert scale ranging from 0 to 5), can be interpreted as a generally difficult aspect of SDM behavior to achieve in a consultation. Secondly, we assessed the internal consistency of the SDM-Q-9 and SDM-Q-Doc with Cronbach's- α ¹⁷. We also determined whether all items were contributing sufficiently to the scales by computing both corrected item-total correlations and the value of Cronbach's α if the item were deleted. Considering that both questionnaires (SDM-Q-9 and SDM-Q-Doc) have proven to be psychometrically sound instruments in several other samples, we expected to find good internal consistency (Cronbach's $\alpha > .70$) for both scales, comparable to other studies.

We evaluated the SDM-Q-9 for dependencies within consultations by means of intraclass correlation coefficients (ICCs), to determine if we needed to take the hierarchical nature of the data into account (some patients were treated by the same physician). We then evaluated convergent validity of the SDM-Q-9 and the SDM-Q-Doc by using Spearman's correlation coefficient to assess the association of the total (standardized) SDM scores with the CPS_{post} item treated as an ordinal variable. We also used the CPS_{post} as a variable with five nominal categories and compared the mean SDM scores between the categories using an analysis of variance.

With regard to convergent validity, our hypothesis was that the SDM-Q-9 / SDM-Q-Doc would have a significant moderate to good correlation ($r = 0.40$ – 0.60) with the CPS_{post}, based on Kasper et al.'s¹³ findings. Furthermore, we expected the mean scores of the SDM-Q-9 and SDM-Q-Doc to be highest on the CPS_{post} when the decision was considered to be shared. Next, we carried out a principal component analysis (PCA) to assess the scales' dimensionalities. We assessed whether additional components could be extracted that would call into question the appropriateness of the single-component hypothesis. To this end, the eigenvalues and the scree plot, as well as the amount of variance accounted for were used.

Given that earlier studies on the SDM-Q-9 and the SDM-Q-Doc showed a one-dimensional structure based on confirmatory factor analyses (CFA)[6, 9], we also performed such analyses using EQS software (Multivariate Software Inc., Encino, California, USA). Since

the χ^2 statistic used to test model fit is highly sensitive to conceptually unrelated technical conditions (like violation of the normality assumption and sample size), the fit of the models was also evaluated by means of descriptive fit indices, such as the comparative fit index (CFI), root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR)^{18,19}. The CFA models were regarded as acceptable to good when the fit indices met the following cut off criteria: RMSEA 0.06; CFI > 0.95 and SRMR 0.08^{19,20}. Apart from the confirmatory factor analyses, the statistical analyses were performed using IBM SPSS Statistics Version 20 (IBM, Chicago, IL, USA).

Post-hoc analyses

As the distribution of the scores on both SDM questionnaires was clearly non-normal, it was decided to carry out a variety of tests, all requiring different assumptions for the dependent variables. Moreover, taking the observed sample distributions as the best approximation to the population distributions, 1000 bootstrap samples were taken from the observed sample distribution, and their associated confidence intervals for the means were calculated.

RESULTS

Sample characteristics

A total of 182 patients rated their consultations with 44 physicians. Two-thirds (65%) of the patient sample was female. Their mean age was relatively high, 61 years (SD = 15.5), with a range from 19 to 88 (Table 1).

Forty-three different physicians (23 specialists and 20 general practitioners) rated 213 consultations with their patients (see Table 2 for numbers by specialty). The physician sample consisted of slightly more men than women (58%). Due to a different procedure for the general practitioner sample, no demographic data other than gender were available for the latter group. The mean age of the specialists was 34 years, ranging from 24 to 60 years. The mean number of patients rated by each physician was five, with values ranging from 1 to 15.

Missing questionnaires of both patients and physicians caused differences in the numbers of participants in the analyses. In some cases, patients completed their questionnaires, but their physician did not or vice versa. The reliability analysis and principal component analyses were based on datasets with complete data for all of the nine items (Npat = 160 and Ndoc = 201). It was not feasible to obtain rates on how many physicians were asked to participate but declined, because physicians were informed and asked to participate by the head of their department. Additionally, because it was already difficult to get physicians to participate, we did not ask them to register how many of the eligible patients did not participate.

Table 1. Sample Characteristics of the Patients.

		N=182*	in %
Gender	Male	61	34
	Female	119	65
Age**	Mean (SD; range)	60.9(15.5; 19-88)	-
Health problem	Type 2 diabetes	74	41
	Psychiatric	36	20
	Ophthalmic	36	20
	Gynaecologic	24	13
	Breast Cancer	12	7

* The sample size varies between 177 and 182 due to missing values.

** As reported on the SDM-Q-9 by participating patients.

Table 2. Sample Characteristics of the Physicians.

		N=43*	in %
Gender	Male	23	58
	Female	17	43
Age	Mean (SD; range)	34(10.8; 24-60)	-
Profession	General practitioner	20	36
	Psychiatrist	11	28
	Gynaecologist	7	18
	Ophthalmologist	4	18
	Surgeon (oncologic)	1	1

* The sample size varies between 40 and 43 due to missing values.

Psychometric properties

In this result section, we will first discuss the acceptance rates of the questionnaire items and their reliabilities. Then the dimensional structures are discussed, followed by the convergent validation using the CPSpost item.

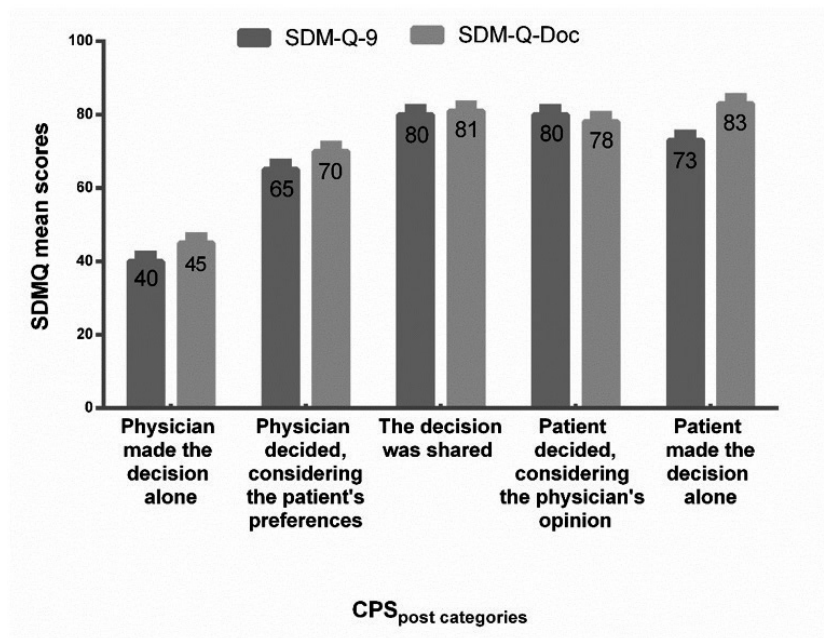
Acceptance and internal consistency. Completion rates of the patient version of the scale (SDM-Q-9) exceeded 95% for all items. Item difficulties were substantially above the midpoint of the 0–5 scale ranging from 3.5 to 4.3. Reliability analyses of the scale showed a high Cronbach's α of 0.88. Corrected item-total correlations were substantial, i.e., above 0.40 (ranging from 0.43–0.75) except for Item 1 (0.38). Inter-item correlations ranged from 0.16 to 0.78, with a mean of 0.44. The lowest correlation of 0.16 was between Item 5 and Item 7. Similar results were found for the physician version of the scale (SDM-Q-Doc). Completion rates for the physicians exceeded 98% for all items. Item difficulties were above the midpoint

of the 0–5 scale ranging from 3.3 to 4.5. Reliability analyses also showed a high Cronbach's α of 0.87. Corrected item-total correlations were substantial, i.e., above 0.40 (ranging from 0.43–0.79) except for Item 9 (0.26). Inter-item correlations ranged from 0.08 to 0.70 with a mean of 0.41. The lowest correlation of 0.08 was between Item 3 and Item 9 (Table 3).

Table 3. Item Characteristics of the SDM-Q-9 and SDM-Q-Doc.

Item	Acceptance (completion rates in %)		Discrimination (corrected item-total correlations)		Difficulty (mean range 0-5)		Cronbach's alpha if item deleted	
	SDM-Q-9	SDM-Q-Doc	SDM-Q-9	SDM-Q-Doc	SDM-Q-9	SDM-Q-Doc	SDM-Q-9	SDM-Q-Doc
1	98.4	99.1	0.38	0.43	3.7	3.9	0.88	0.87
2	96.7	99.5	0.58	0.63	3.5	3.25	0.87	0.86
3	96.2	98.6	0.66	0.69	3.5	3.6	0.86	0.85
4	96.7	99.1	0.70	0.73	3.7	3.6	0.85	0.85
5	95.6	100.0	0.63	0.47	4.2	4.1	0.86	0.87
6	95.6	99.5	0.73	0.73	3.6	3.6	0.85	0.85
7	96.7	99.5	0.71	0.79	3.5	3.4	0.85	0.84
8	95.6	98.6	0.75	0.70	3.7	3.6	0.85	0.85
9	97.3	99.1	0.43	0.27	4.3	4.5	0.88	0.88
Scale							0.88	0.87

Fig 1. Mean SDM-Q-9 and SDM-Q-Doc scores by category of the CPSPost



Convergent validity. Since the Intra-class coefficient for the SDM-Q-9 was only 0.06, we did not use a hierarchical analysis.

The SDM-Q-9 and SDM-Q-Doc total scores were significantly correlated with the CPSpost ($r = 0.29$ (SDM-Q-9) and $r = 0.48$ (SDM-Q-Doc), both $p < 0.001$). Fig 1 shows the mean SDM-Q-9 and SDM-Q-Doc scores per CPSpost categories for the two samples (Fig 1).

Notwithstanding the non-normality, the bootstrap analysis of both questionnaires showed that the violations of the normality assumption were of little influence on the detailed results. All confidence intervals and all tests came to essentially the same results, be it slightly more variable for the patient than for the physician questionnaire. All overall tests indicated that there were significant differences in total scores of both the SDM-Q-9 and the SDM-Q-Doc between the CPSpost categories (Table 4).

Table 4. Significance tests for the SDM-Q-9 and the SDM-Q-Doc using CPS_{post} categories.

Test	SDM-Q-9			SDM-Q-Doc		
	df	Value	p	df	Value	p
ANOVA F	(4,123)	8.8	<0.001	(4,155)	25.0	<0.001
Welch test	(4,38)	8.4	<0.001	(2,101)	20.9	<0.001
Brown-Forsyth	(4,60)	7.6	<0.001	(2,146)	27.2	<0.001
Kruskal-Wallis	4	22.1	<0.001	4	50.7	<0.001
Median test	4	11.9	0.018	4	30.6	<0.001
Jonckheere-Terpstra test	-	3.3	0.001	-	6.2	<0.001

Overlapping intervals indicate non-significant differences between the means of the CPSpost categories. Table 5 shows the total SDM-Q-9/SDM-Q-Doc scale scores as well as the confidence intervals for the five categories of the CPSpost item (Table 5). As can directly be seen from the confidence intervals, all multiple comparison tests (both equal and unequal variances) indicated homogeneous subsets for the SDM-Q-9: (1,2,5) and (2,3,4,5) and for the SDM-Q-Doc (1), (2,4) and (3,4,5). Thus, as expected, category 1 ("Physician decided") had a significantly lower mean SDM-Q-9 score than categories 3 and 4 in the patient sample. The mean of category 2 ("Physician decided considering the patient's preferences") and category 5 ("Patient decided") were not significantly different from any of the other categories. For the SDM-Q-Doc the mean of category 1 ("Physician decided") was significantly lower than the means of all other categories. The mean of category 2 ("Physician decided considering the patient's preferences") was significantly lower from that of category 3 ("Shared Decision") and 5 ("Patient decided"). Categories 3, 4 and 5 were not significantly different from each other (Fig 2).

Table 5. Means and confidence intervals for assessing the convergent validity of the SDM-Q-9 and SDM-Q-Doc using the CPS_{post}*

CPS _{post}	SDM-Q-9						
	N	Mean	S _e	Bootstrap S _e	Confidence Interval	Bootstrap Confidence Interval	
Physician decided	11	39.4	7.2	7.1	23.3 – 55.5	26.1 – 55.2	
Physician decided, considering patient's preferences	25	64.9	5.4	5.5	53.7 – 76.0	54.0 – 75.5	
Shared decision	55	81.1	2.6	2.6	75.9 – 86.3	75.8 – 85.8	
Patient decided, considering physician's opinion	20	80.1	3.3	3.3	73.2 – 87.1	73.7 – 86.4	
Patient decided	17	72.5	8.0	7.7	55.5 – 89.5	56.9 – 87.2	
Total	128	73.1	2.3	2.3	68.6 – 77.6	68.5 – 77.6	
SDM-Q-Doc							
Physician decided	19	44.7	3.9	4.0	36.4 – 52.9	36.9 – 52.4	
Physician decided, considering patient's preferences	44	69.0	2.5	2.6	64.0 – 74.1	63.7 – 73.7	
Shared decision	55	80.6	1.7	1.7	77.1 – 84.1	77.2 – 84.0	
Patient decided, considering physician's opinion	24	77.5	3.0	3.1	71.2 – 83.8	71.5 – 83.3	
Patient decided	18	82.6	2.4	2.4	77.4 – 87.7	77.8 – 87.5	
Total	160	73.0	1.5	1.5	70.0 – 75.8	69.8 – 75.7	

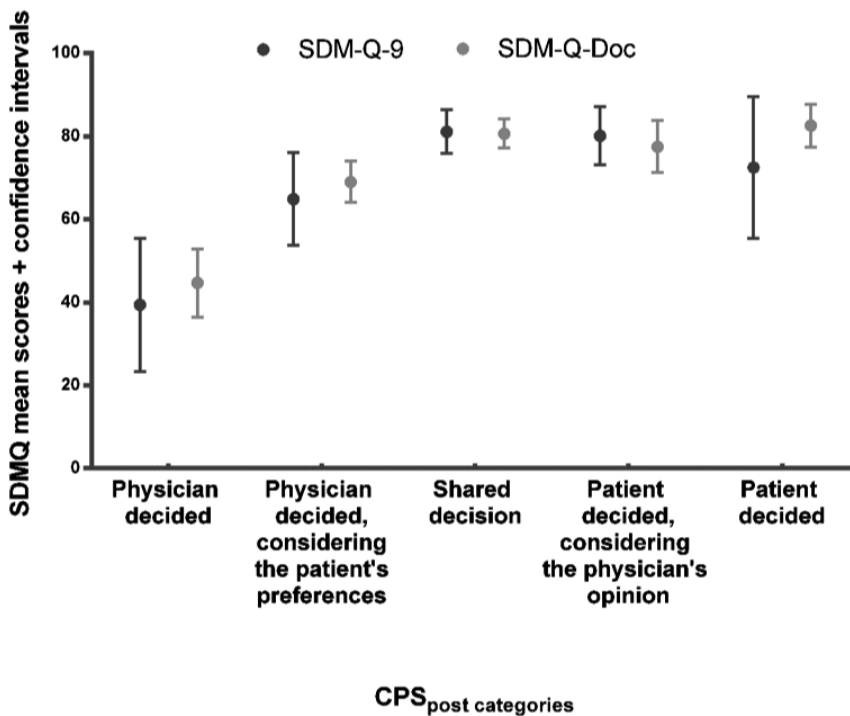
Fig 2. Mean scores and confidence intervals of the SDM-Q-9 and SDM-Q-Doc by category of the Control Preferences Scale

Table 6. Results of the Principal Factor Analysis (PCA) for the SDM-Q-9 and SDM-Q-Doc.

SDM-Q-9 (patients)				SDM-Q-Doc (physicians)		
Item	Component 1	Component 2	h^2	Component 1	Component 2	h^2
1	-0.14	0.94	0.80	0.14	0.65	0.52
2	0.22	0.72	0.70	0.73		0.54
3	0.45	0.47	0.60	0.86		0.68
4	0.81		0.67	0.75	0.14	0.67
5	0.67	0.12	0.53	0.19	0.63	0.53
6	0.85		0.72	0.89	-0.10	0.74
7	0.94	-0.16	0.78	0.85		0.76
8	0.90		0.77	0.73	0.13	0.62
9	0.46	0.13	0.28	-0.15	0.81	0.58

Factor structure. To assess whether a single component would account for sufficient variance to confirm the original single scale based on the nine items, we carried out a principal component analysis (PCA). The Kaiser-Meyer-Olkin measures verified the sampling adequacy for the analyses: KMO was > 0.85 for both samples, and almost all KMO values for individual items were above 0.8 in both samples, except for Item 1 in the patient sample (0.67), which was still above the acceptable limit of 0.5. This means that the patterns of correlations are relatively compact and factor analyses should yield distinct and reliable factors²¹. Bartlett's test of sphericity was significant for both scales, indicating sufficient correlations between the items for a factor analysis to be appropriate ($\chi^2 (36) = 724$, $p < 0.001$ (SDM-Q-9) and $\chi^2 (36) = 795$, $p < 0.001$ (SDM-Q-Doc)). In both samples two components had eigenvalues over Kaiser's criterion of 1.0, with component 1 explaining 51.4% of the variance for the SDM-Q-9 and the second component explaining 13.5%. For the SDM-Q-Doc the first component explained 50.1% of the variance, the second 12.4%. Inspection of the scree plots suggested a two-component solution in both samples. After oblimin rotation, items 3 through 9 of the SDM-Q-9 loaded reasonably to highly on the first component (range 0.45–0.94), items 1 and 2 had loadings < 0.4 on the first component (-0.14 and 0.22) and loaded highly on the second component (0.94 and 0.72). For the SDM-Q-Doc all items except three had high loadings on the first component. Item 9 had the lowest loading (-0.15), followed by Items 1 (0.14) and 5 (0.19). These items loaded reasonably high (range, 0.63–0.81) on the second component (Table 6). These results point to a possible second component for both forms of the questionnaire.

Since the German SDM-Q-9 showed a one-dimensional structure based on a PCA and this was confirmed in the Spanish version of the patients' scale and the German SDM-Q-Doc scale as well, we also conducted a confirmatory factor analysis (CFA) on our patient and physician data.

Based on the results of the other studies we tested: 1) the one-factor model (Model 1); 2) a one-factor model excluding Item 1 (Model 2), because this model obtained the best fit

in the Spanish SDM-Q-9 and Item 1 had low factor loadings and low corrected item-total correlations in both our samples; 3) a one-factor model excluding Item 9 (Model 3), because of the low corrected item-total correlations of Item 9 in both our samples, especially in the physician sample; and 4) a one-factor model excluding both Items 1 and 9 (Model 4).

Because our data followed a non-normal distribution, we used maximum likelihood (LM) as well as robust statistics in our analysis; the latter are resistant to errors in the results produced by deviations from assumptions (e.g., of normality)^{22,23}.

Results showed that two cases in the physician sample accounted for too much of the kurtosis, so these were excluded from the analysis²².

For the patients, Model 1 did not meet any of the cut-off criteria of the fit indices, and Model 2 yielded acceptable fit indices, meeting the cut-off criteria for two of them (RMSEA and SRMR) and improving the others (χ^2 and CFI) (Table 7). The best indices of fit were obtained with Model 4. For the SDM-Q-Doc Model 1 only met the cut-off criterion of the SRMR. All other models had an acceptable fit, meeting the cut-off criteria of the CFI and the SRMR. However, the best solution was obtained with Model 4 (Table 7).

Table 7. Results of the Confirmatory Factor Analysis (CFA) for the SDM-Q-9 and SDM-Q-Doc: Maximum Likelihood (ML) and Robust statistics.

	df	χ^2	CFI		RMSEA		SRMR	
		ML	Robust	ML	Robust	ML	Robust	ML
SDM-Q-9								
Model 1	27	137.4***	76.5***	0.84	0.88	0.16 (0.13-0.19)	0.11 (0.08-0.14)	0.09
Model 2	20	77.8***	41.9 *	0.91	0.94	0.14 (0.10-0.17)	0.08 (0.05-0.12)	0.06
Model 3	20	106.8***	55.5***	0.88	0.91	0.17 (0.13-0.20)	0.11 (0.07-0.14)	0.09
Model 4	14	56.2***	27.4 *	0.93	0.96	0.14 (0.10-0.18)	0.08 (0.03-0.12)	0.06
SDM-Q-Doc								
Model 1	27	74.8***	56.9***	0.94	0.93	0.09 (0.07-0.12)	0.08 (0.05-0.10)	0.06
Model 2	20	49.7***	35.2 *	0.96	0.96	0.09 (0.06-0.12)	0.06 (0.03-0.09)	0.05
Model 3	20	57.9***	40.7 **	0.95	0.95	0.10 (0.07-0.13)	0.07 (0.04-0.10)	0.05
Model 4	14	33.9 **	21.3	0.97	0.98	0.08 (0.05-0.12)	0.05 (0.00-0.09)	0.04

Recommended values: CFI(comparative fit index) >0.96, RMSEA (root mean square error of approximation) ≤ 0.06 and SRMR (root mean square residual) ≤ 0.08. Values meeting cut off criteria are in bold.

* p-value < .05 ; ** p-value < .01; *** p-value < .001

DISCUSSION AND CONCLUSION

Discussion

This study translated Shared Decision-Making Questionnaire for patients (SDM-Q-9) and physicians (SDM-Q-Doc) into Dutch and describes the psychometric evaluation of both scales. Good acceptance, internal consistency, and acceptable-to-good convergent validity were demonstrated.

The Dutch SDM-Q-9 and SDM-Q-Doc have similar psychometric properties as the original instruments and the Spanish SDM-Q-9 and they showed somewhat higher acceptance than the original German version (> 80%- 88% (SDM-Q-9) and > 93% (SDM-Q-Doc)).

Based on the literature¹⁷ a Cronbach's α coefficient higher than 0.7 is desirable, which was the case for both versions. Corrected item-total correlations were lower than the original German patient version (corrected-item-total scores >.7), but in accordance with the Spanish version of the SDM-Q-9. The Spanish study also found a low corrected item-total score for Item 1 ("My physician / I made clear to me/my patient that a decision needs to be made"), meaning that this item correlates poorly with the other items. In our study, the item-total correlation of Item 9 ("My physician and I reached an agreement on how to proceed") of the patient version, was also relatively low compared to those of the other items, but this was not seen in the German and Spanish versions of the SDM-Q-9.

Corrected-item-total scores of the Dutch SDM-Q-Doc are similar to those of the original German version, with lowest scores on Items 1 and 9. The discrimination of 0.27 of Item 9 of the Dutch scale was much lower than that of the German version (0.44).

Besides the four limited investigations regarding the validity of the SDM-Q-9 and SDM-Q-Doc, mentioned in the Introduction, there has been little further study of the validity of the scales. Convergent validity of the SDM-Q-9 was tested by Scholl and colleagues¹² by comparing it to an observer rating scale measuring the extent to which physicians involve patients in decision making, the OPTION (observing patient involvement) scale, but no substantial correlation was found and convergent validity of the SDM-Q-9 could not be established. In a study on the interrelatedness of SDM measures, Kasper et al.¹³ could not find any significant correlation between the same OPTION scale and the SDM-Q-9 but did find a moderate correlation between the SDM-Q-9 and their CPSpost. Perception of a more autonomous role of the patient (CPSpost) was associated with more involvement as reported on the SDM-Q [12]. In line with Kasper et al.'s findings, we also found a significant albeit low correlation of the SDM-Q-9 ($r = 0.29$) and a significant moderate correlation of the SDM-Q-Doc ($r = 0.48$) with the CPSpost. The shared category of the CPSpost is in the middle, therefore an association of the SDM-Q-9 /SDM-Q-Doc with the CPSpost would not be linear, according to our hypothesis, which makes the interpretation of a Spearman's correlation coefficient difficult. Still, in case of non-linearity (SDM-Q-9), a significant Spearman's correlation coefficient tells us that an

association exists. Furthermore, we did not expect very strong associations, since the scales do not exactly measure the same construct: the SDM-Q-9/SDM-Q-Doc measures the process of SDM and the CPSpost item only assesses the final decision. However, our results do support the hypothesis that the scales are related, especially when we look at the categorical analyses. Patients and physicians both had the lowest scores on the SDM-Q when they felt the physician had decided. In addition, patients also had the highest SDM-Q scores when they perceived their consultations as more shared as based on the CPSpost. For physicians SDM-Q scores were highest when the patient decided alone or together with the physician, likely reflecting that an active role of the patient fits a shared process more than a consumerist or informed process, because in general participation of patients is low. The differences between the other categories on the CPS (2,4,5) are less clear and seem to carry different meanings for patients and physicians. More research on this topic might provide insight into what SDM actually means to different stakeholders.

Results of our PCA and CFA were similar to the findings of De Las Cuevas et al.¹¹. In our study, the PCA yielded a two-component solution for the SDM-Q-9, with factor loadings above 0.6 on the second component for Items 1 and 2. In addition, for the SDM-Q-Doc Items 1, 5 and 9 showed low loadings on the first component and loaded above 0.6 on the second component. The PCA on the Spanish version of the SDM-Q-9 also showed a two-component solution, with factor loadings above 0.5 on the second component for the same items, Items 1 and 2. Furthermore a CFA showed that the best solution was obtained for a one-factor model without Item 1¹¹. For the SDM-Q-Doc results of our CFA were comparable to the German version. For the original German SDM-Q-Doc, a CFA showed factor loadings of Items 1 and 9 below 0.4, but the items were retained based on their coherence with theory of the SDM construct⁹.

Although the psychometric results of our study on the Dutch SDM-Q-9 and SDM-Q-Doc are largely concordant with the results of the original German scales, and the scales thus are suitable for use in a primary and specialized hospital care sample, there are some differences. Incongruity between the SDM-Q-9 questionnaires might be explained by factors like age and gender, since our sample consisted of relatively older patients (mean age of 61 years old) and a slightly smaller percentage of women (60%) compared to the samples in the Spanish study (mean age 45 years and 70% of women). We also had younger physicians (34 years of age) compared to the German physician sample (50 years of age)^{6,8,9}. Differences might also be caused by the fact that we chose for less strong statements in some items, following the English version, or by cross-cultural differences between Germany and the Netherlands regarding the physician-patient relationship. However, in case of translation problems, the difficulties with certain items should have been the same in both Dutch versions (SDM-Q-9 and the SDM-Q-Doc), but this was not the case.

The main strength of this study is the fact that we examined both the patient (SDM-Q-9) and the physician versions (SDM-Q-Doc) of the 9-item Shared Decision-Making Questionnaire in the same diverse clinical settings. However, since this was not the case for the original German- and the Spanish validation studies, comparison of the Dutch versions with (and between) the other versions is difficult. The fact that our sample consisted of physician and patient groups in primary and specialized hospital (secondary) care, could have played an important role in the differences we found.

These differences may also reflect the discussion in the literature on the conceptualization of SDM. There is no consensus yet between different parties on what constitutes the SDM-process^{24,25}. The SDM-Q-9 was based on theoretically defined steps of physician behaviors in a shared decision-making process⁶. Possibly, Item 1 does not necessarily relate to a role of the patient in making the decision. That is, the physician could make explicit that a decision needs to be made but implicitly assume that it is the role of the physician to make that decision, which might especially be the case in specialized care. Furthermore Items 1 and 9 may be seen not as part of the shared decision-making process itself, but as facilitators to engage patients in (Item 1) or to conclude the process (Item 9).

The psychometric results of the original SDM-Q-Doc were similar to the results for both our SDM-Q-9 and SDM-Q-Doc. All of these scales were tested in both a primary and a secondary care sample (both including Type 2 diabetic and psychiatric (depression) health problems) and found that Item 9 ("My patient and I reached an agreement on how to proceed") had low corrected item-total correlations⁸ with the scale scores. This could mean that this aspect of SDM is less relevant or more complicated in specialized care or even different for specific specialties, which was also found in another study of De Las Cuevas and colleagues²⁶. Their findings suggest that the process to come to a shared decision may have a distinctive profile, depending on the type of diagnosis/health problem²⁶. More research on the German, Spanish, and Dutch scales together and comparison of the different study populations may shed light on this. Such research can be useful to improve the instruments and will tell us more on the shared decision-making concept, between patients and physicians, in different cultures and different specialism. In addition, mixed methods research can provide insight in how patients, physicians and observers view SDM and will help further define what SDM is at its core.

The main limitation of this study is the fact that there are no comparable instruments, which are necessary for the proper assessment of the convergent validity. Even though the total sample sizes were sufficient for our analyses, we did not recruit enough participants of every specialty to compare mean scores or test for differences in internal consistency between primary and specialized care or the different medical specialties.

Another limitation is the fact that we included a convenience sample of patients with different backgrounds. We have no information on non-participants and cannot evaluate if and if so, to what extent, participant selection may have biased our results.

Finally, there were potential differences in procedures between centers. All participating departments received the same instructions, information, and questionnaires, but we cannot verify if participating physicians complied with the instruction to complete the questionnaire immediately after consultation. Delayed responses could have led to recall errors and imprecise ratings⁸, but this was also true for the procedures in the other countries.

CONCLUSION

Taken together, our findings suggest that the Dutch versions of the SDM-Q-9 and SDM-Q-Doc questionnaires are suitable for use in Dutch primary and specialized care. The scales are acceptable to participants, demonstrate good reliability and are related as expected with the CPSPost.

The questionnaires show an acceptable (patients) to good (physicians) model fit with a one-dimensional structure. Results of this validation study call into question Item 1, and Item 9, and thus the concept used. However, we believe these items address important aspects of SDM. Based on the coherence with theory and comparability with other studies, we therefore suggest keeping all nine items of the scale, until more light is shed on this issue. Still further testing of the validity of the questionnaires in different clinical settings and more research on the concept of SDM is necessary.

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SUPPLEMENTARY MATERIAL

S1 Appendix.

Item content of the Shared Decision Questionnaire for Patients (SDM-Q-9) and Physicians (SDM-Q-Doc) in English. For Dutch version, please email a.m.stiggelbout@lumc.nl. (DOCX)

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Chapter 7

Summary and general discussion

In this thesis, we used qualitative and quantitative research methods to gain insight in treatment decision-making for depression- and anxiety disorders in specialized mental health care. We identified what factors are important in the decisional process, to both patients and clinicians, and how they determine decision-making outcomes, i.e., the decision to opt for: pharmacotherapy, psychotherapy, or a combination of both. We determined what preferences patients and clinicians have regarding the treatment of depression and anxiety disorders, which treatments are selected, and which factors are involved in the formation of such treatment preferences and treatment selection. Additionally, we determined what preferences patients and clinicians have regarding their role in the decisional process, their experienced decision-making roles, and the level of concordance between preferred and experienced role of patients. Finally, we examined the extent of Shared Decision-Making (SDM) in clinical practice and explored possible target points to improve SDM.

This final chapter summarizes the key findings of our studies, discusses these findings in the context of the research literature, considers the strengths and limitations of our research, and ends with implications for clinical practice and suggestions for further research.

SUMMARY

After a general introduction leading to the research questions of this thesis (**Chapter 1**), we report in **Chapter 2** on a quantitative retrospective chart review, that we used to measure associations of patients' baseline and clinical characteristics with treatment decisions for Major Depressive Disorder (MDD). We present our findings on treatment choices for MDD in a specialized psychiatric outpatient care setting, as well as clinical and sociodemographic factors associated with these treatment choices. We found a significant association of (self-reported) severity of the illness and gender with treatment choice. In addition, we found that the use of an antidepressant at referral, usually prescribed by the General Practitioner (GP), was associated with the decision to continue the antidepressant (with or without Cognitive Behavioral Therapy (CBT)/psychotherapy) in specialized care. This demonstrates the impact of previous treatment decisions made in primary care on future treatment courses.

In **Chapter 3** and **Chapter 4**, we present the results of the eight focus groups we conducted. We used focus groups with patients and with clinicians, to discuss the aspects of the treatment and the decision-making process that they considered most relevant for the treatment of depression, anxiety disorders, and obsessive-compulsive disorders (OCD) in specialized mental health care. We further assessed the perspective on SDM of both patients and clinicians. First, in **Chapter 3**, we describe patient's and clinicians' attitudes towards treatments, their treatment preferences, factors that according to them influenced the origin of these preferences, and the actual treatment selection (decision-making). Four key elements of the decisional process emerged: 'communication', 'information/knowledge', 'preferences', and 'decisions'. We identified a diversity of influencing factors related to these

elements: values and attitudes, contextual factors (patient, illness, treatment, and clinician characteristics) and the decision-making process itself (i.e., treatment choice, the patient-clinician relationship and trust, uncertainty, the weighing process, and who decides). Patient characteristics that were mentioned, by patients and clinicians, were: age, gender, mental capacity, previous experiences (medical history), and personal traits (e.g., having a general (dis)like for medication, being a talkative person). The most important characteristics of the illness were: beliefs on what causes the illness (i.e., biological factors, psychological factors or both (explanatory model)), and ideas about the severity and chronicity of the illness. Treatment characteristics that were mentioned were aspects such as side-effects, efficacy, evidence/guidelines, duration, intensity, availability, waiting lists, costs, and location. Clinician characteristics were: age, gender, knowledge, professional experience, and personal characteristics and traits (e.g., daring to deviate from guidelines, steering behaviors). We found that patients with OCD mention the same elements and influencing factors, they also had the same attitudes towards the treatment as patients with depression or anxiety disorders. However, they more often were offered a choice between all treatment options. In conclusion we found that the decisional processes of patients and clinicians were characterized by similar key elements and influencing factors, but the meaning, value, and relevance of these factors differed considerably between patients and clinicians.

In **Chapter 4**, we describe the conceptualization of SDM, motivators, and responsibilities with respect to SDM and the decision-making from patients' and clinicians' perspectives, but also preconditions and experienced barriers to SDM in clinical practice. Because of the qualitative nature of this study, our observations provide an insight in the SDM process in clinical practice, with patients and clinicians reflecting on what SDM means to them and how they think it works from their experiences in this setting. Our results highlight the influence of communication and trust, values/beliefs, contextual factors, and the importance of the availability of treatment options, when making treatment-decisions in this context. We found that patients and clinicians both advocate SDM, but there are barriers that influence its realization. Important barriers that they both mentioned were the complexity and uncertainty related to making treatment decisions in psychiatry, severity of the illness, and patients' decision-making capacity. Although patients mention these issues and acknowledge the difficulties regarding SDM, they thought these barriers should not preclude SDM. Patients thought that, despite illness severity and possible impaired decision-making abilities, they were ultimately responsible for making the decision, thus should get the opportunity to be involved in the decision-making about their own treatment. Patients with OCD and patients with depression and/or anxiety disorder discussed similar SDM topics, that were important to them and had similar point of views. Yet, patients with OCD seemed to have less difficulties regarding the availability of CBT or a combination of CBT and medication. It also seems these patients were given more time to overthink the decision to start medication. As expected, patients with OCD more often mentioned

to have difficulties with making decisions. Overall, our findings underscore the fact that patients and clinicians share some of the generic values of SDM, such as “patients should be involved in decisions about their own treatment”, “the elicitation of values and preferences is important” and, “SDM should be the main starting point of treatment”. However, their motivations, interpretations of SDM and its barriers in clinical practice differed. For example, patients felt it is their basic ethical right to be involved in their treatment and that they should be accountable for their own treatment, while clinicians thought the responsibility regarding the final decision rested with the clinician. Furthermore, most clinicians advocated SDM, because they thought that the effectiveness of treatment depended on patient participation, SDM established a good treatment relation with patients and promoted treatment adherence. Patients and clinicians thought clinicians should inform patients, discuss treatment options, including pros and cons with patients, and involve patients in a conversation about their treatment to make a shared decision. However, many other clinicians also thought that SDM meant informing the patient and letting the patient decide. To patients, SDM meant sharing information, preferences and values and make a treatment decision together with the clinician. Both patients and clinicians thought clinicians had an important task and responsibility with respect to informing patients, involving the patients, the patient-clinician relation, and treatment selection. Therefore, clinicians seem to play a vital role in the initiation/achievement of SDM in clinical practice.

Chapter 5 reports on a cross sectional survey we conducted among outpatients with depressive and/or anxiety disorders, to measure relevant aspects of the decision-making process (as identified in our focus groups). In the survey, we measured treatment- and decision-making- preferences, actual treatment decisions and experienced decision-making roles. We investigated associations of these variables with patient characteristics (age, gender, health literacy, decision-making participation self-efficacy), characteristics of the consultation (information provision, treatment recommendation) and decision-making characteristics (trust in the clinician, decisional conflict). We also studied the relationships between patient’s preferred and experienced decision-making role, their preferred and selected treatments, as well as the concordance thereof. We found that concordance between preferred and experienced decision-making role was low, as was the concordance between preferred and selected treatment. Thus, integration of patients’ decision-making role preferences and treatment preferences is limited in the treatment decision-making process in this outpatient mental health care setting. Our observations suggest that supporting health literacy and patients’ self-efficacy regarding decision-making participation may be important factors in improving collaborative deliberation. The results of this study further underscore the importance of targeting clinicians’ communication and SDM skills.

Finally, in **Chapter 6**, we report on the translation and validation of the 9-Item Shared Decision-Making Questionnaire for patients (SDM-Q-9) and Shared Decision-Making

Questionnaire-Physician Version (SDM-Q-Doc) in Primary and Specialized Care. The SDM-Q-9 and SDM-Q-Doc are two self-report instruments developed to measure the process of Shared Decision-Making (SDM) as perceived by the patients and physicians, respectively. The SDM-Q-9 is a widely used instrument in the SDM field. However, the validation of its various translations was limited. Furthermore, the physician version was only available and tested in Germany and there was no further validation of this scale yet. Therefore, we translated both instruments in Dutch and determined their acceptability, reliability (internal consistency) as well as the factor structure of the new scales (SDM-Q-NL and SDM-Q-NL doc) in a diverse primary and specialized care sample (General Practice (Diabetic 2 patients), Ophthalmology, Psychiatry, Gynecology and Oncology). The Dutch SDM-Q-9 and SDM-Q-Doc demonstrated good acceptance and reliability; they correlated as expected with a questionnaire assessing a similar construct (the modified Control Preference Scale (CPSpost)). They both are suitable for measuring SDM in Dutch primary and specialized care.

GENERAL DISCUSSION

The central research question of this thesis was as follows: *What factors are important in the treatment decision-making process of depressive and anxiety disorders and how do they determine the decision outcome, i.e., the decision to opt for: pharmacotherapy, psychotherapy, or a combination of both?*

Overall, we can conclude from our results that clinical factors (such as severity and previous treatment experiences) are important in the treatment decision-making for depression and anxiety disorders (including obsessive compulsive disorders(OCD)). Patient characteristics and preferences are considered important, but they seem scarcely incorporated in the decisional process. Treatment decisions follow (international) practice guidelines from a clinical perspective, but the proposed patient involvement and SDM fall short. We found that patients had a priori treatment preferences, which were based on multiple factors. Furthermore, patients indicated they want to be involved in the decision-making, and most of them thought they had the capacity to do so. Patients and clinicians both valued patient-centered care and were motivated to apply SDM. However, both patients and clinicians face several challenges in applying SDM and they seemed ill-equipped regarding SDM knowledge, tools, and communication skills. We found that clinicians played a crucial role in making patient-centered treatment decisions, going beyond informed consent, and putting SDM into practice. By initiating SDM at the beginning of the clinical encounter and actively involving patients in the decisional process, clinicians can build a shared understanding of the illness (explanatory model, i.e. what causes it, what is the core problem, what is the objective of the treatment), with the patient as a basis for shared treatment decisions^{1,2}. Based on the results of the studies in this thesis, as summarized before, we will now further discuss our most important findings by means of our sub-research questions.

What are patients' and clinicians' treatment preferences for depressive and anxiety disorders, which factors are involved and how do they play a role in the formation of treatment preferences and treatment decisions?

Patients' treatment preferences

According to our results, most patients have identifiable a priori treatment preferences, that were formed before the encounter with the clinician, and which are based on personal values, knowledge of the illness and beliefs about the cause of their illness, treatment options and the knowledge and beliefs about them, previous treatment experiences (in general practice and sometimes in secondary care), how treatment options suit them and assumptions that are sometimes based on information from family/friends/patient organizations (Chapter 3 and Chapter 5). Patients indicate that such initial preferences can change during the consultation, based on new information about their illness and treatment options, the treatment recommendation of the clinician, the communication between patient and clinician, and sometimes deliberation with family/friends. Clinicians mentioned however that these patient preferences are not so easy to change and are sometimes based on wrong information and misconceptions (Chapter 3). The finding that patients already have strong and rather persistent preferences before their encounter with a clinician has previously also been found in a study on treatment preferences for PTSD (post-traumatic stress disorder)³. Tünneßen et al.⁴ identified various attributes of treatment preferences similar to our influencing factors, i.e. side-effects, efficacy, treatment duration, costs⁴. Furthermore, we found that having treatment options and thus the information from the clinician (about the treatment options and a recommendation) are not only important to patients in forming preferences (Chapter 3), but also influence treatment decisions. Our retrospective chart review showed that treatment decisions were directly related to the treatment options discussed, treatments recommended by the clinician, and trust in the clinician (in terms of the clinicians' competence, honesty, and fidelity) (Chapter 5). The role of clinicians' treatment recommendation in the decision-making process was also found in earlier conversation analytic research, showing that the treatment recommendation is a distinct phase of the medical consultation^{5,6}. In addition, Bolden et al.⁶ found that psychiatric treatment discussions with patients with serious and persistent psychiatric disorders seemed built to elicit acceptance rather than to invite patients' views.

Our results of both the focus group study and the survey show that many patients preferred combination therapy or CBT/psychotherapy and that only few patients preferred pharmacotherapy alone (Chapter 3 and Chapter 5). This is in line with results from other studies⁷⁻⁹, including a meta-analytic review, indicating that about 75% of participants preferred psychological treatment to pharmacological treatment for depressive and anxiety disorders. This preference was observed independently across heterogeneous settings, both in primary and specialty care⁸.

We found conflicting evidence about factors that could influence patients' treatment preferences. Several patient characteristics (such as age, gender, health literacy and decision-making self-efficacy) that were mentioned in our focus group studies (Chapter 3) were not found to be associated with preferences in our survey study (Chapter 5). One explanation may be, that what patients' and clinicians' think plays a role in the formation of preferences, is not in line with what actually influences their preferences. Participants also indicated that they found it difficult to differentiate between factors that influence preferences and factors that influence decisions. Some of the few earlier studies on this topic found associations of female gender and educational level with preference for psychotherapy for patients with a first episode depression¹⁰, but this finding remains inconsistent in the literature^{2,10,11}. Lokkerbol et al.¹² found individual level variation in preferences in patients with an anxiety disorder, but this study focused on treatment characteristics only (i.e. waiting time, treatment intensity, face to face, digital, group size), and not on the nature of the treatment/modality itself (pharmacotherapy versus psychotherapy). In our study population, most of the outpatients with depression and/or anxiety disorders had already experienced previous treatment in primary or secondary care, which was likely to influence their treatment preferences (Chapter 3). In this respect they differ from patients in primary care and possibly also from patients with other diagnoses (such as first episode depression), which can explain the inconsistency and diversity of associations of influencing factors with patient treatment preferences in the literature and in our study^{7,10,11,13}. Preferences not only vary between patients based on different factors, but patients' individual preferences also were stated to tend to fluctuate over time, depending on different phases of patients' lives and context (Chapter 3). Furthermore, preferences of patients vary in levels of strength and how they value them^{4,7}.

In our focus group study, we found that patients' personal values, attitudes towards the illness, treatments, experiences with previous treatments, and specific characteristics of the treatment modalities were important influencing factors for preferences and treatment choices (Chapter 3). This was also found in previous studies^{2,3,12-16}. A substantial number of patients in our focus group study expressed an explicit dislike for medication, which according to them influenced their preferences (Chapter 3). Some studies investigated people with a fear of medication and negative attitude toward medication ('pharmacophobia') as opposed to people who have a liking for medication ('pharmacophilia'), in relation to treatment adherence^{17,18}. These studies found that pharmacophobia was common among patients with psychiatric disorders and significantly reduced medication adherence¹⁷. To our knowledge, the relation between pharmacophobia and treatment preferences and decisions has not been investigated in this setting but might be relevant. Other studies show that health beliefs and locus of control were associated with patients' attitudes towards treatment^{2,14,16}. Furthermore, preferences for treatment seem strongly influenced by a personal evaluation of the treatment (i.e., effectiveness, indication, suitability, adherence and convenience, side-effects, and experience with the treatment)¹⁰. Patients' previous

(negative) experiences with the treatment were also associated with the preference for and selection of non-pharmacotherapeutic interventions^{19,20}. Additionally, patients in our focus groups mentioned the fear of side effects of pharmacotherapy, becoming dependent on it, having to take medication for the rest of their lives, and possible changes of personality due to medication (Chapter 3).

Clinicians' treatment preferences

Most clinicians in our focus groups indicated they do not have a priori treatment preferences, but that they form their professional treatment preference for an individual patient according to treatment guidelines/protocols (based on clinical factors such as diagnosis, severity of the illness and (in)effectiveness of a previous treatment). In addition, patients' personal preferences/characteristics and external/circumstantial factors (such as costs, waiting lists, availability) play a role (Chapter 3). In line with this, we found that actual treatment selection was mostly based on severity (self-reported by patients) and medical history (antidepressant use upon referral) (Chapter 3), which is according clinical guideline recommendations^{21–26}. Some clinicians mentioned that clinicians' professional preferences can be biased by the clinicians' own personal style (Chapter 3). Results of the focus groups show that clinicians do not share the negative attitude of patients regarding pharmacotherapy. Furthermore, clinicians felt that psychotherapy required a certain amount of cognitive capacity of patients (Chapter 3). We also found that male patients were less likely to receive psychotherapy for their treatment for depression (Chapter 3), although we did not find men to prefer pharmacological therapy over psychotherapy. A study on treatment preferences of male psychiatric patients found that men had a preference for psychotherapy²⁷. This might mean that clinicians think/assume that men prefer medication. Possibly, treatment decisions may also be based on assumptions of the clinician and also on practical considerations such as availability and waiting lists²⁸, rather than patient preferences. The influence of factors such as life experience and attitudes regarding treatment of clinicians on treatment decisions has previously been found in other studies on treatment decision-making for psychiatric problems in primary care^{29,30}. A review by Himmerich et al. found that treatment decisions regarding antidepressants were influenced by knowledge, experience and beliefs of the treating physician and the patient-physician relationship, guidelines, treatment properties, demographic characteristics, co-morbidity, patient preferences (and his/her family), and severity and/or subtype of the depression³¹.

Clinicians in our focus groups also mentioned that, for any treatment to be successful, it is important that there is a constructive patient-clinician relationship, and that the chosen treatment should have a good fit with the patient's expectations/experiences/beliefs regarding 'causes' of the illness, i.e., the explanatory model (Chapter 3). Since the relation between the patient and the clinician is asymmetric, clinicians can (un)intentionally frame encounters and determine the options that patients have or steer the decisional process, as was also mentioned by the clinicians in the focus groups (chapter 4)^{5,32–37}. Thompson et al.³⁶

describe formulations for psychiatrists' recommendations as pronouncements, suggestions or proposals. Recommendations seemed most frequently formulated as pronouncements and less often as suggestions or proposals³⁵. Furthermore, psychiatrists pronouncements implied that the treatment decision was 'completed' and that further actions were communicated as directives^{35,36}. Additionally, a study by Valenti et.al.³⁴ shows that persuasion and leverage are often used in mental health care to influence patient behavior and improve treatment adherence. However, they can negatively affect patient satisfaction and quality of care.

Based on our results, it seems that the formation of treatment- preferences and decision-making of patients and clinicians are separate and individual processes that should preferably be more integrated starting early in the process. Studies on practice variations in different settings indicated that clinicians' preferences and practice styles influence clinical practice³⁸, and that clinicians often make unilateral decisions that were based on their own preferences rather than patient preferences³¹. Differences in these processes and eventually preferences could lead to a discrepancy between what patients want, expect and what clinicians (can) offer, thus choice¹. This in turn may negatively affect the clinician-patient relation, trust, and satisfaction.

Concordance between treatment preferences and treatment decisions

The patients in our focus groups found it difficult to distinguish factors that influence treatment *preferences* from factors that influence or determine the treatment *decision* (Chapter 2). This may be because preferences and treatments are inextricably intertwined in the decisional process, especially during the short clinical encounter patients have with their clinician. Not surprisingly, therefore, in our focus group study the influencing factors of treatment selection that were mentioned by patients and clinicians were similar to the factors influencing preferences. These were: clinical characteristics (such as severity and what has worked before); patients' characteristics (such as mental capacity); external factors (such as availability); clinicians' characteristics (such as experience with the treatment); and the patient-clinician relationship (Chapter 2). This is mostly in line with other studies^{4,25,39}. Alang et al.³⁹ found that severity of mental illness, pathway into care, race/ethnicity, residential area, and age were associated with treatment modality (medication, counseling, or both medication and counseling).

Most patients in the focus groups indicated that, although they preferred psychotherapy, they had been treated with pharmacotherapy only or in combination with psychotherapy (Chapter 2)⁴⁰. In line with this, results of our survey study showed that concordance of treatment preferences with treatment choices was seen for about 60% of the patients. Discordance was highest when the resulting treatment choice was Medication. We found no association between patients' treatment preferences and treatment selection in our survey study, indicating that preferences themselves had no influence on treatment decisions.

Concordance was associated with higher perceived ability to understand medical information and to take responsibility for the treatment decision (Chapter 5). Patient characteristics (such as age, gender, health literacy and self-efficacy) were not associated with the treatment selection. However, health literacy and self-efficacy did determine if patients received their preferred treatment (i.e., concordance). Clinicians in our focus groups indicated that there were some requirements for patients to be able to make treatment decisions, in particular their mental capacity. This included, that patients should be able to comprehend the information provided, understand the severity of their illness and the effectiveness of treatments. This may explain our findings that patients with high health literacy and self-efficacy scores were more likely to receive their preferred treatment (Chapter 5). The problem with such requirements is that, related to illness severity, mental illness can (temporarily) affect patients' capacities (Chapter 3 and Chapter 4). This may affect treatment decisions in some cases, for example patients with severe anxiety may not be able to participate in (group) therapy. Clinicians also indicated that they expected assertiveness from patients, so they may therefore be more open to the engagement and preferences of patients with high health literacy and self-efficacy. This can also imply that patients who believe that their own behavior can influence outcome, actively seek a collaborative role which may in turn influence the clinician's acceptance of the collaboration^{41,42}.

Perspectives of patients and clinicians on Shared Decision-making (SDM)

What preferences do patients and clinicians have regarding their role in the decision-making process regarding the treatment of depressive and anxiety disorders? And to what extent is there SDM in clinical practice?

Results of our survey study show that most patients prefer a collaborative decision-making role or an active role in the decision-making about their treatment, but many experience a passive role. We found concordance of preferred and experienced decision-making role to be low (37%), and most discordance occurred when patients experienced a passive role (Chapter 5). This was also found in our focus group study (Chapter 4) and in other studies found in the literature^{41,43–47}. In a study among psychiatric outpatients, De las Cuevas et al.⁴¹ found a minimum of concordance for the patients preferring a collaborative role, with only 20% of them reporting such a role. We did not find significant associations between patient characteristics and decisional role concordance in our study, which may be explained by the small number of patients for whom concordance could be calculated (Chapter 5). We did, however, find an association between lower self-efficacy and a preferred and experienced passive decision-making role (Chapter 5). De las Cuevas et al.⁴¹ found concordance between psychiatric patients' preferred and experienced roles to be associated with variables such as age, gender, health locus of control and self-efficacy.

These findings may indicate the importance of patients' self-efficacy in the implementation of SDM. Patients' self-efficacy may be a possible target point for SDM interventions, empowering patients to engage in the conversation about their treatment. In a review on

patient-reported barriers and facilitators to SDM in a broader patient care setting, Joseph-Williams et al.⁴² suggested that being able to perceive the opportunity and personal ability to be involved is an essential first step in the SDM encounter. Furthermore, a review on the elicitation of the patient's perspective in a general health care setting showed that patients do not often volunteer or disclose information related to the patient's personal preferences, values and/or context if the clinician does not explicitly ask them⁴⁸. This may be related to the patient's education, assertiveness, and state of health⁴⁸. In addition, the results indicate that the process of eliciting personal perspectives is not often carried out⁴⁸.

Results of our focus group study showed that clinicians felt responsible for the decisional process and that achieving SDM was always the goal in their consultations (Chapter 4). However, clinicians indicated that there were barriers to SDM. These were patient's decision-making capacity, treatment availability, and the clinicians' own preferences. These barriers could be influenced by illness severity and lead to paternalistic decision-making (Chapter 4). In line with our findings, a study on preferred decision-making styles of clinicians in mental health services across different regions of Europe showed that SDM was the preferred decision-making style⁴⁹. A study with outpatients with severe mental illness found that clinicians mostly adopted a shared decision-making style, but also found that this was associated with higher functioning patients with higher levels of interpersonal relationship skills and less severe symptomatology⁵⁰.

Congruent with the literature in other fields, clinicians in our focus group study thought they applied SDM in their practice (Chapter 4), but evidence from this thesis and other research shows that SDM is often inadequate^{47,51}. It may be that clinicians in our study had a different perspective on or definitions of SDM (Chapter 4). Coinciding with other studies that also found varieties of how SDM is defined and practiced in clinical practice among health care professionals in different medical settings⁵²⁻⁵⁴. Moleman et al.⁵⁵ suggested that these varieties were a response to the limitations posed by the barriers that clinicians encounter and not a lack of consensus. They describe three definitions, i.e. SDM as a negative right, that stems from the notion that patients cannot be forced into a treatment against their will; SDM as informed decision-making and SDM as a tailored partnership similar to definitions found in our focus group study (Chapter 4)⁵⁵. Driever et al.⁵¹ studied the gap between consultants' perceived and actual decision-making behaviors in consultations in different clinical settings. They found that clinicians tended to overestimate the extent to which they apply SDM and may be unconsciously incapable of SDM⁵¹. Another study by Driever et al.⁴⁷ investigated the steps of SDM by clinicians in clinical practice using the SDM-Q-9. They found that the SDM process focused more on discussing treatment options than on the steps actually involving patients (for example making clear that a decision needed to be made, elicitation of how patients want to be involved in decision-making, and weighing the pros and cons of different options together with the patient). These findings underline the importance of training (future) clinicians, specifically on the key steps of SDM^{47,51}.

The patient-clinician relationship and perceived acceptability of patient involvement were identified as influencing factors of SDM in our focus group results (Chapter 4)⁴². In general, patients in our focus groups indicated that they want to be involved in decisions about their own treatment (Chapter 3 and Chapter 4). Additionally, many patients of the focus groups thought that they were confident that they could understand the (medical) information about their illness and treatment options, and that they want to take responsibility for the treatment decision (Chapter 3 and Chapter 4). This was also measured in our survey study that showed adequate health literacy and moderate self-efficacy scores in patients (Chapter 5). In contrast, some previous studies found that health literacy was low in the general population and that health literacy may be even lower in patients with severe mental illness (schizophrenia, inpatient psychiatric care)^{47,56–58}. A study by Bacon et al. (2017) found that 71% of their population had inadequate health literacy in an inpatient psychiatric population, although the treatment providers believed 100% of their patients had inadequate health literacy⁵⁶. Patients in our population were likely less severely ill, with better health literacy and self-efficacy as a result⁵⁶.

Similar to our focus group findings (Chapter 4), Joseph-Williams et al.⁴² reported key themes regarding barriers and facilitators to SDM. Factors were related to ‘how the healthcare system is organized’ (i.e. factors that are largely outside of patients’ and clinicians’ control, such as time), and ‘what happens during the decision-making interaction’ (i.e. factors more influenced by the participants taking part in the decision-making interaction, such as the presence of cognitive impairments, i.e. a predisposing factor)⁴². A scoping review by Keij et al.⁵⁹ on reported patient-related characteristics associated with the occurrence of SDM, found a large variety of patient-related characteristics, but for many the association with the actual application of SDM remains unclear. We found that an experienced passive decision-making role was associated with lower trust in the clinician and higher decisional conflict scores. This confirms the importance of a trustworthy patient-clinician relationship and the role of SDM in making sustainable treatment decisions, found in other studies^{42,60–62}.

Based on our results, it seems clear that both patients and clinicians value SDM, but its realization is difficult. Patients and clinicians share the idea that the responsibility for initiating and applying SDM lies with the clinician (Chapter 4). However, SDM seems to also rely on patients’ capacities⁵⁸. Patients and clinicians want to work together to share treatment decisions, but they have different conceptualizations of SDM and its barriers (Chapter 4), which may hinder SDM in clinical practice. In line with this, Joseph-Williams et al.⁴² pointed out the importance of understanding patient-reported barriers as they are distinct from those of clinicians.

Evaluation of SDM

As the interest in the SDM construct and its implementation in clinical practice grow, reliable and valid instruments to measure the SDM process and its effectiveness on treatment

outcome are needed. Furthermore, such instruments are necessary in the development, implementation, and evaluations of decision-making interventions. We translated both versions of the SDM-Q-9⁶³ and validated the new scales in a diverse primary and specialized care sample. Because there was no gold standard for measuring the perceived level of involvement, a modified version of the Control Preferences Scale, the CPSpost, was used to determine the convergent validity of the SDM-Q-9. The CPSpost is a five-point Likert scale formulated to measure the experienced role in the final decision, which is a commonly used scale and has a good reliability and validity^{64,65}. Similar to the original⁶³ and other language validation versions, we found that the Dutch SDM-Q-9 and SDM-Q-Doc (SDM-Q-NL and SDM-Q-NL doc) demonstrated good acceptance and reliability; they correlated as expected with the CPSpost and are suitable for use in Dutch primary and specialized care^{63,66–68}. Recently, the SDM-Q-9 was translated and validated (using the OPTION scale to determine convergent validity) in an Italian sample of patients affected by major psychiatric disorders⁶⁷. The results of this study were largely equivalent to our findings, demonstrating that the SDM-Q-9 is a useful tool to investigate SDM in a clinical mental health care setting. The SDM-Q-9 is a widely used reliable instrument, which measures more specific steps of the SDM process, related to the construct³⁸.

We can assess SDM from several viewpoints, using an external observer, the patient, or the physician⁶⁹. However, SDM can also be measured combining the patient's and the physician's points of view, by using the 9-item Shared Decision Making Questionnaire (SDM-Q-9)⁶³ or other instruments such as the dyadic OPTION (observing patient involvement) scale⁷⁰, and the MAPPIN'SDM measure^{71,67}. SDM or patient involvement has also been investigated by comparing patient or clinician self-reported and observed patient involvement. Studies in a general specialized medical setting found significant differences between intended or preferred and actual (observed) level of patient involvement^{51,72}. Furthermore, the SDM-Q-9 can be used to evaluate the key steps of SDM separately⁴⁷. Studies in oncology settings, for example, show that the first steps of the process (in which the clinician makes clear that a decision needs to be made and that the patients' opinion is important, and discussing treatment options) were perceived at a suitable level of SDM. However, the level of "decision talk", in which preferences should be explored, was low^{47,73}. In addition, further investigation of the level of SDM key steps in clinical mental health care settings is needed, as patients in our focus group study expressed that choice is essential in decision-making, but often experienced little choice (Chapter 2 and Chapter 3).

Strengths and Limitations

The strength of this thesis is that we used qualitative and quantitative research designs to answer our research questions, combining patients' and clinicians' perspectives. By combining qualitative and quantitative methods and addressing several aspects of preferences, treatment decisions and the decisional process, we could gain a broad and more complete picture of (shared) treatment decision-making in specialized mental health

care practice. To our knowledge, this is one of the few studies to investigate the actual process and underlying factors of forming preferences, making treatment decisions and involving patients in depression and anxiety disorders in this setting. However, the studies described in this thesis also have limitations, most of which were discussed in detail in the individual chapters of this thesis. We used a sequential exploratory design in which qualitative data was collected first and relevant variables were identified⁷⁴. Subsequently, these variables were assessed in quantitative research⁷⁴. Although we integrated the results of our studies to form a complete picture, we conducted and analyzed the studies separately and therefore the results are complementary rather than convergent. As qualitative research is more subjective, it is prone to certain biases, such as moderator bias (in focus groups) and for example biased reporting. Furthermore, given the explorative character of our study and the large number of variables we identified in our focus group studies, it was not possible to assess all variables in our quantitative studies. In addition, we had small sample sizes. Some of our focus groups had only few participants and sample sizes of our quantitative studies were too small to perform subgroup analyses. Nevertheless, most of our study findings are in line with similar studies on the same topics in different settings^{45,46,58,72,75}. Therefore, this thesis gives insight in the treatment decision-making process and underlying factors. Since, our data were collected in 2012–2015 they may be somewhat outdated. However, until this day little additional research on this specific topic and in the population of our study has been published. Recent research shows that interest in patient involvement and shared decision making in different settings is still growing and its importance is widely recognized^{45,58}. Yet, results of these studies also show that patient involvement was limited in the given time period and likely still is limited in clinical practice, that care is modestly adjusted to patient preferences, and that efforts must be made to improve SMD and its implementation^{37,51,72,75}. Therefore, we expect that our results can still make a valuable contribution to the improvement of treatment decisions, patient involvement and (shared) decision-making in mental health care.

Implications for Clinical Practice and Future research

How can we improve patient centered care (the integration of patient preferences) and shared decision-making in clinical practice?

Because treatment selection in mental health problems is complex, a decision-making approach that integrates the interaction of biological, psychological, social and cultural factors is needed^{37,76}. Evidence shows a wide variety of (inconclusive) factors to be influencing the formation of (treatment and decision-making role) preferences of patients. Additionally, preferences may differ in strength and change over time⁵⁹. Therefore, these preferences cannot be predicted for individual patients and can only be known when elicited by the clinician during the clinical encounter. To involve patients, incorporate preferences and improve outcomes, the decision-making process must be focused more on relationships, building trust, reducing decisional conflict, and strengthen patients' self-confidence and self-

efficacy. Clinical practice demands a shared explanatory model (i.e., beliefs) and a treatment plan based on patient and physician perspectives, incorporating the diversity of patients, problems, and beliefs. Clinicians should view the world through patient's perspectives to understand their reality¹. True Shared Decision-making, initiated and implemented by the clinician can help clinicians and patients to find a common ground to build from and reach patient centered decisions^{37,77}.

Implementing Shared Decision-Making in clinical practice

Evidence is making clear that Shared Decision-making is not easy to achieve in clinical practice, possibly because clinicians and patients are insufficiently equipped, lacking SDM knowledge, skills and tools^{42,47,51,58,72}. Based on our findings, we believe the following suggestions can help improve (the implementation of) SDM and treatment decision-making.

Decision aids, varying in design and delivery, have proven to be useful in empowering patients in SDM⁷⁸. These interventions/tools assist patients in treatment decision-making, often promoting their apprehension of the choices and formulating relevant questions. In addition, they are mostly based on the theoretical SDM construct. Traditional Decision aids can be used before the start of (and during) the consultation. These explore experiences and preferences of patients and provide information about treatment options. However, many of them demand much effort (homework) and skills, and place responsibility with the patient. This may be too much to ask, especially in this mental health care setting. However, patients should and can be empowered by public education campaigns (e.g. 'Samen beslissen', (<https://demedischspecialist.nl/themas/thema/samen-beslissen-0>)) and patient activation campaigns (e.g. ASK3⁷⁹, <https://3goedevragen.nl/>). Furthermore, since the decision-making seems mostly directed by the clinicians, the focus of these Decision aids should be supportive of the decisional process, e.g., strengthening patients' confidence and self-efficacy, supporting the healthcare professional in the provision of objective information (e.g., comprehensive and appropriate information regarding treatment options)⁸⁰.

Since clinicians seem vital to treatment decision-making in clinical practice and the implementation of SDM, they should become versed in how to gain insight into patients concerns and preferences and how to involve patients in the decision-making process⁸¹. Therefore, SDM training should be considered for clinicians already working in a mental health care setting, to create awareness, educate them on the concept of SDM and teach them how to apply the different steps of SDM in the clinical encounter. Relevant educational programs or workshops have been successfully developed in different settings⁸²⁻⁸⁴. Overall, such programs focus on improving knowledge of SDM, the principles of collaboration and the importance of patients' values and preferences^{82,85}. Training activities may also be aimed at SDM skills, using instructional methods, such as demonstrations, small group discussions or role play^{82,83,85}. Additionally, feedback sessions and (audio/video) reflections

can be used^{86,87}. Although limited and of low quality, evidence shows positive effects of training programs on knowledge, attitudes and comfort with SDM^{82,88}. Furthermore, SDM deserves much more attention in medical education, embedded in training plans and quality visitations. Students, junior doctors and medical specialists in training should not only learn theoretical principles of patient centered care and SDM, but should also be taught practical communication skills and strategies to involve patients in the decision-making^{58,62,81,89}. These skills should be practiced and continuously evaluated^{51,90}. For instance, instruments such as the SDM-Q-9 and OPTION-5 can be used as an evaluation tool, to gather feedback on the different SDM steps that were addressed during an individual consultation⁸⁷. This will provide the clinician insight in which steps of SDM they already sufficiently apply, and which steps need further practice.

Clinical practice guidelines play an important role in treatment decisions for depression and anxiety disorders in specialized mental health care and can be an important target point to improve SDM. Clinical practice guidelines support patient centered care by explicitly addressing the patient perspective and promoting elicitation of preferences and applying SDM. However, clinical practice guidelines focus on evidence to inform and guide clinicians (and patients) with respect to treatment selection and are not developed to completely stipulate how treatment decisions should be made or when and how to apply SDM in clinical practice. They may even hinder SDM in clinical practice by being seen as prescriptive. The motivation and phrasing of recommendations may limit choice awareness and thus shared decision-making⁹¹. Additional SDM guidelines, on how to apply SDM, in clinical practice may be useful⁹².

Future Research

Scientific knowledge on the decision-making process regarding the treatment of depressive and anxiety disorders remains scarce and needs expanding. Treatment preferences, treatment decisions and concordance should be investigated in a larger study population, including more patient characteristics (such as educational level and ethnicity) and clinical characteristics (such as diagnosis and severity) to draw useful conclusions about the factors involved in treatment decisions for these disorders. Further research is needed on patients' and clinicians' definition of SDM, differences in attitudes toward and perspectives on SDM. This may clarify issues regarding the conceptualization of SDM and can help to overcome barriers to SDM in clinical practice. Furthermore, more evidence on factors involved in the decisional process and how these determine the shared decision-making process is needed. This can be used to develop shared decision-making interventions, which can improve patient centered care and can optimize treatment decisions. Severity was an important influencing clinical characteristic of treatment preferences, decisions and SDM in our study. More research is needed on the role of illness severity in the decisional process for depressive and anxiety disorders. Furthermore, more research is needed on patients'

health literacy and self-efficacy as these may be important target points to improve SDM. Additionally, research on the specific steps of SDM during the clinical encounter can advance and improve SDM in clinical practice. Finally, the quality of the evidence on the effect of SDM educational programs on SDM outcomes is low, and research is still limited^{83,88}. Therefore, the possibilities and effects of SDM training programs in a mental health care setting and SDM education in the medicine program in general need further investigation⁹³.

General conclusion

The results of this thesis show that treatment preferences, treatment decisions, communication and personal values are important elements of treatment decision-making for depression and anxiety disorders. Characteristics of the patient, illness, treatments, clinicians, and contextual factors may influence treatment- preferences and decisions. We found that patients already have strong treatment preferences before the clinical encounter and that these are difficult to change. Furthermore, clinical factors (such as illness severity and previous treatment experiences) determine patients' preferences and treatment decisions. Clinicians' professional and personal characteristics also seem to play a role, specifically in the communication of treatment options and the treatment recommendations. Although patient characteristics and preferences were considered important, these seemed scarcely incorporated in the decisional process and treatment decision. Additionally, we found concordance between preferred and experienced decision-making role to be low. Clinicians and patients value SDM, but find it difficult to achieve, mainly because they seem to have different perceptions on SDM and experience different barriers. The most important barriers were the patients' lack of decision-making capacity and treatment availability. In addition, patients' health literacy and self-efficacy seem to play an important role. Furthermore, clinicians may lack sufficient knowledge of the key steps of SDM and the skills to apply these in clinical practice. Therefore, better education and training on how to involve patients in the decision-making, taking the barriers into account, is needed for clinicians. In addition, decision aids supporting the decisional process or enhancing patients' self-efficacy can be useful.

Based on the theoretical concept of SDM and results of this thesis, we think the use of SDM in mental health care has the potential to enhance patient-centered care and improve treatment decision-making, thus optimize treatment decisions.

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Addendum

Nederlandse samenvatting

Curriculum vitae

List of publications

Dankwoord

NEDERLANDSE SAMENVATTING

In dit proefschrift beschrijven we de uitkomsten van het ‘Pillen en/of Praten’ onderzoek. Dit onderzoek richt zich op behandelbeslissingen voor depressie, angststoornissen en Obsessieve Compulsieve Stoornis (OCS) in de specialistische Geestelijke Gezondheidszorg (2^e/3^e lijns GGZ). Met dit onderzoek wilden we inzicht krijgen in verschillende aspecten van de besluitvorming over de behandeling van depressie en angststoornissen in de klinische praktijk, en meer specifiek de beslissing om te kiezen voor: farmacotherapie (medicijnen), psychotherapie of een combinatie van beide. Hiervoor gebruikten we zowel kwalitatieve als kwantitatieve onderzoeksmethoden.

We identificeerden factoren die belangrijk zijn in de besluitvorming, voor patiënten en klinici (psychiaters (i.o), psychologen, verpleegkundigen) en we onderzochten hoe deze factoren de uitkomst van het besluitvormingsproces bepalen, d.w.z. de keuze voor ‘Pillen en/of Praten’.

We onderzochten:

1. welke voorkeuren patiënten en klinici hebben met betrekking tot de behandeling van depressie en angststoornissen én voor welke behandeling er uiteindelijk wordt gekozen; en welke factoren een rol spelen bij de vorming van dergelijke behandelvoorkeuren en -keuzes.
2. welke voorkeuren patiënten en klinici hebben met betrekking tot hun rol in het besluitvormingsproces én hoe zij die rol (hebben) ervaren; de mate van overeenstemming tussen de voorkeurs- en ervaren rol van patiënten; en de mate van Gezamenlijke Besluitvorming (Shared Decision-Making, SDM) in de klinische praktijk.

Tenslotte exploreerden we:

3. mogelijke aangrijpingspunten om de (gezamenlijke) besluitvorming rondom de behandeling van depressie en angststoornissen te verbeteren.

Hoofdstuk 1 geeft een algemene inleiding op het onderwerp en de onderbouwing van de onderzoeksvragen. Hierin belichtten we de hoge prevalentie, co-morbiditeit, hoge ziektelast en sociaaleconomische lasten van depressie en angststoornissen. Ook gaan we verder in op de beschikbare behandelingen voor deze aandoeningen. Volgens (inter)nationale richtlijnen ten tijde van dit onderzoek zijn de meest effectieve behandelingen: psychotherapie, medicatie, of een combinatie van beide. Deze behandelingen blijken uit onderzoek even effectief, maar voor veel patiënten toch nog niet optimaal. De keuze hiervoor hangt o.a. af van het ziektebeeld en eerdere ervaringen. Echter, er spelen ook verschillende andere factoren mee, waaronder de persoonlijke voorkeuren van patiënt en behandelaar. Tenslotte bespreken we het concept Patient Centered Care (PCC) en gezamenlijke besluitvorming, ook wel Shared Decision-making (SDM) of Samen Beslissen genoemd. De laatste jaren

komt er vanuit de medische wereld steeds meer een accent te liggen op betrokkenheid van patiënten bij behandelbeslissingen. Daarnaast groeit in het kader hiervan de interesse in voorkeuren van patiënten. Ook patiënten zelf willen actiever betrokken worden bij medische beslissingen. Door middel van SDM, kan dat. Onderzoek naar SDM heeft in de Geestelijke Gezondheidszorg (GGZ) een duidelijke achterstand vergeleken met andere disciplines. Desondanks is juist in de psychiatrie een belangrijke rol weggelegd voor deze manier van besluitvorming.

Hoofdstuk 2 beschrijft de associaties tussen de sociaal demografische en klinische kenmerken van patiënten met een ernstige depressieve stoornis (MDD) en de keuze voor een behandeling met een van de drie hoofdcategorieën van de behandeling van depressieve stoornissen: farmacotherapie (antidepressiva); psychotherapie (cognitieve gedragstherapie, CGT); een combinatie van beide. Voor dit retrospectieve cohortonderzoek gebruikten we klinische data van poliklinische patiënten van GGZ Rivierduinen, een aanbieder van specialistische geestelijke gezondheidszorg in Leiden e.o. Deze gegevens werden verzameld in een naturalistische setting met behulp van Routine Outcome Monitoring (ROM) en aanvullende gegevens werden verkregen uit medische patiëntendossiers. De resultaten van dit onderzoek laten zien dat de keuze voor behandeling in deze setting over het algemeen in lijn is met de toenmalige behandelrichtlijnen. We vonden dat bij patiënten met een meer ernstige depressie vaker een behandeling met antidepressiva (al dan niet in combinatie met CGT/psychotherapie) werd ingezet. Daarnaast vonden we een significant verband tussen de behandelkeuze en de (zelf-gerapporteerde) ernst van de stoornis en het geslacht van de patiënt: mannen werden minder vaak dan vrouwen behandeld met psychotherapie (ten opzichte van antidepressiva). Bij patiënten die al een antidepressivum gebruikten op het moment van verwijzing naar de specialistische GGZ (veelal voorgeschreven door de huisarts) werd vaker besloten deze behandeling in de gespecialiseerde zorg voort te zetten, dus te 'kiezen voor pillen'.

In **hoofdstuk 3 en hoofdstuk 4** doen we verslag van de acht focusgroepen die we hielden met patiënten en met clinici van GGZ Rivierduinen en de afdeling Psychiatrie van het Leids Universitair Medisch Centrum (LUMC). Allereerst beschrijven we de mening en houding van patiënten en clinici ten opzichte van behandelingen; daarna hun behandelvoorkeuren en factoren die volgens hen het ontstaan van deze voorkeuren en de daadwerkelijke keuze voor een behandeling (pillen en/of praten) beïnvloeden (hoofdstuk 3). We identificeerden vier centrale elementen van het besluitvormingsproces: 'communicatie', 'informatie/kennis', 'voorkeuren' en 'beslissingen'. Kennis en (ontvangen) informatie bepaalden via voorkeuren de uiteindelijke beslissing.

Dit proces konden we onderverdelen in verschillende fasen:

1. Voor een deel werden à priori voorkeuren bepaald nog voor het consult (de ontmoeting tussen patiënt en de psychiater/psycholoog), gebaseerd op eerdere ervaringen, informatie van familie/vrienden en andere informatiebronnen.
2. op basis van bestaande kennis en aanvullende informatie (een uitwisseling tussen patiënt en psychiater/psycholoog) werden gedurende het consult nieuwe voorkeuren gevormd of de à priori voorkeuren versterkt.
3. Tenslotte werd er een uiteindelijke beslissing genomen, veelal op basis van een behandeladvies van de psychiater.

Naast kennis en informatie speelden de relevantie en beschikbaarheid van behandelopties, normen en attitudes van patiënten en klinici een belangrijke rol, maar ook een verscheidenheid aan contextuele factoren, onder te verdelen naar eigenschappen van de patiënt, ziekte, zorgprofessional en behandeling. Communicatie was op verschillende niveaus en in verschillende fases in dit proces essentieel. Daarbij speelden concepten zoals vertrouwen, onzekerheid, het 'wikken en wegen' en 'wie beslist?' een belangrijke rol. Alhoewel besluitvormingsprocessen van patiënten en klinici werden gekenmerkt door vergelijkbare elementen en beïnvloedende factoren, verschilden deze aanzienlijk in betekenis en waarden tussen patiënten en klinici.

In **hoofdstuk 4** beschrijven we de conceptualisering van SDM, stimulerende factoren en verantwoordelijkheden met betrekking tot SDM en de besluitvorming vanuit het perspectief van patiënten en klinici, alsook randvoorwaarden en ervaren barrières voor SDM in de klinische praktijk. Onze observaties gaven inzicht in het SDM-proces, waarbij we patiënten en artsen lieten nadenken over wat SDM voor hen betekende en hoe zij dachten dat het werkte in de klinische praktijk op basis van hun eigen ervaringen in deze setting. De resultaten benadrukken de invloed van communicatie en vertrouwen, waarden/overtuigingen, contextuele factoren en het belang van de beschikbaarheid van behandelopties bij het nemen van behandelbeslissingen, en dus de uiteindelijke keuze. Zowel de patiënten als de klinici waren voorstander van SDM, maar de uitvoering van SDM in de praktijk vonden beiden moeilijk en zij liepen daarbij tegen een aantal belemmeringen aan. Patiënten en klinici deelden de generieke waarden van SDM, zoals "patiënten moeten betrokken worden bij beslissingen over hun eigen behandeling", "uitvragen/achterhalen van waarden en voorkeuren is belangrijk" en "SDM zou het belangrijkste startpunt van de behandeling moeten zijn". Belemmeringen die beide partijen noemden waren de complexiteit en de onzekerheid gerelateerd aan het nemen van behandelbeslissingen in de psychiatrie; de ernst van de ziekte; en de besluitvaardigheid van patiënten. Hoewel patiënten deze punten wel noemden en zij erkenden dat dit effect kon hebben op SDM, vonden zij niet dat deze belemmeringen hun deelname aan het besluitvormingsproces, dus SDM, volledig zouden mogen uitsluiten. Zij waren van mening dat, ondanks de ernst van de ziekte en mogelijk een verminderde besluitvaardigheid, patiënten uiteindelijk verantwoordelijk zijn voor het

nemen van de beslissing en daarom de mogelijkheid moeten krijgen om betrokken te zijn bij de besluitvorming over hun eigen behandeling. Ook de redenen om SDM toe te passen in de klinische praktijk verschilden tussen patiënten en klinici. Patiënten vonden dat het fundamenteel een ethisch recht is van patiënten om betrokken te worden bij hun eigen behandeling en dat ze zelf verantwoordelijk zijn voor de keuze van hun behandeling. Clinici vonden dat de verantwoordelijkheid voor de behandeling en de uiteindelijke beslissing bij de professionals ligt. SDM was volgens hen meer een middel om een goede behandelrelatie met patiënten op te bouwen en therapietrouw te bevorderen. Patiënten en klinici waren het er wel over eens dat klinici een aantal duidelijke taken hebben in het proces: 1. de patiënten informeren en de behandelingsopties bespreken, inclusief de voor- en nadelen en 2. patiënten betrekken bij het gesprek over hun behandeling om zo tot een gezamenlijk besluit te komen. Echter, een deel van de klinici meende dat SDM betekende: de patiënt informeren, zodat de patiënt daarna zelf kon beslissen. Voor patiënten betekende SDM: het delen van informatie, voorkeuren en waarden en samen met de zorgverlener/clinicus een besluit nemen.

Hoofdstuk 5 doet verslag van een onderzoek dat we uitvoerden om de hierboven genoemde relevante aspecten van het besluitvormingsproces te meten. Met behulp van een vragenlijst onder poliklinische patiënten met een depressie en/of angststoornis onderzochten we voorafgaand aan het consult o.a. de voorkeuren ten aanzien van de behandeling en de gewenste besluitvormingsrol, en vervolgens achteraf de daadwerkelijke behandelkeuzes en de ervaren besluitvormingsrol van patiënten. We onderzochten de relatie tussen de verschillende variabelen. Uit de resultaten blijkt dat de meeste patiënten een voorkeur hadden voor de combinatie van CGT en een antidepressivum of CGT alleen ('Praten'). Slechts enkele patiënten gaven de voorkeur aan een behandeling met alleen een antidepressivum ('Pillen'). Verder bleek dat de meeste patiënten de voorkeur gaven aan een gedeelde besluitvormingsrol (een actieve patiëntenrol) en dat zij vertrouwen hadden in hun eigen vermogen om medische informatie te begrijpen en om een gesprek aan te gaan met hun arts of psycholoog (gezondheidsvaardigheden/'health literacy'). Patiënten die gezamenlijk hadden besloten en een actieve rol ervaarden hadden meer vertrouwen in de clinicus en rapporteerden minder beslissingsambivalentie ('decisional conflict'). Toch ervaarden veel patiënten achteraf dat ze de beslissing ofwel alleen hadden genomen of dat de clinicus deze had genomen. De resultaten laten zien dat patiënten al een voorkeur voor een behandeling hadden vóór het consult met de clinicus. En dat uiteindelijke keuzes voor een behandeling wel grotendeels in overeenstemming waren met de aanbevelingen van de klinische richtlijnen, maar niet werden beïnvloed door de à priori behandelvoorkeuren van patiënten. Deze keuzes hielden voornamelijk verband met de informatie die de clinicus tijdens het intakegesprek had verstrekt, de beschikbaarheid van de behandelingsopties en het advies van de clinicus. We vonden dat de overeenstemming tussen voorkeuren en de ervaringen van patiënten ten aanzien van de besluitvormingsrol laag was; hetzelfde gold

voor de overeenstemming tussen hun voorkeuren voor een behandeling en de uiteindelijke keuze. Patiënten die hoger scoorden op zelf-gerapporteerde gezondheidsvaardigheden kregen vaker de behandeling waar zij ook een voorkeur voor hadden (overeenstemming tussen voorkeur en keuze).

Tenslotte rapporteren we in **Hoofdstuk 6** over de validatiestudie van de naar het Nederlands vertaalde 9-Item Shared Decision Making Questionnaire voor patiënten (SDM-Q-9) en artsen (SDM-Q-Doc) in de eerstelijns- en gespecialiseerde zorg. De SDM-Q-9 en SDM-Q-Doc zijn twee veelgebruikte (oorspronkelijk Duitse) instrumenten, die zijn ontwikkeld om het proces SDM te meten, zoals waargenomen door respectievelijk patiënten en artsen (zelf-rapportage). We vertaalden beide instrumenten naar het Nederlands en voerden een validatiestudie uit in verschillende klinische settings. We concludeerden dat beide Nederlandstalige instrumenten geschikt zijn om SDM in de Nederlandse eerstelijns- en gespecialiseerde zorg te meten.

Concluderend laten de resultaten van dit proefschrift zien wat de belangrijkste elementen zijn van het besluitvormingsproces en welke factoren allemaal een rol spelen bij beslissingen rondom de behandeling van depressie en angststoornissen in de specialistische GGZ. Patiënten hebben al vóór de klinische ontmoeting sterke behandelvoorkeuren en deze zijn moeilijk te veranderen. Vooral klinische factoren (zoals de ernst van de ziekte en eerdere behandelervaringen) en eerder gemaakte keuzes lijken van invloed op voorkeuren en behandelbeslissingen (en daarmee toekomstige behandeltrajecten) van patiënten. De professionele en persoonlijke kenmerken van klinici kunnen daarnaast ook een rol spelen, specifiek in de communicatie over behandelopties en het behandeladvies. Hoewel eigenschappen en voorkeuren van de patiënt belangrijk worden gevonden, lijken deze niet genoeg meegenomen te worden in het besluitvormingsproces en de uiteindelijke behandelkeuze. Daarnaast is de overeenstemming tussen de voorkeursrol en de ervaren besluitvormingsrol van patiënten laag. Clinici en patiënten waarderen SDM, maar vinden het moeilijk om uit te voeren. Ze hebben verschillende opvattingen over SDM en ervaren andere belemmeringen. Ze hebben daarnaast verschillende houdingen ten opzichte van behandelingen, (en o.a. daardoor) verschillende voorkeuren. Al deze verschillen kunnen uiteindelijk leiden tot een discrepantie tussen wat een patiënt wil (of verwacht) en wat een clinicus kan of wil bieden, dus keuze. Belangrijke belemmeringen voor SDM zijn de beschikbaarheid van behandelingen en het gebrek aan besluitvaardigheid van de patiënten. Daarnaast lijken patiënten met betere gezondheidsvaardigheden meer te worden betrokken bij behandelbeslissingen, daarom kan het stimuleren van bijvoorbeeld 'health literacy' en 'participating self-efficacy' een belangrijk aangrijpingspunt zijn om SDM in deze setting te verbeteren. Clinici hebben nog te weinig kennis van de belangrijkste stappen van het SDM-proces en bezitten soms onvoldoende (SDM) vaardigheden om deze toe te passen in de klinische praktijk. Vanwege de substantiële rol die klinici hebben in het

besluitvormingsproces zijn zij cruciaal bij de initiatie en vervolgens de realisatie van SDM in de klinische praktijk. Daarom is het van belang om de communicatie- en SDM-vaardigheden van clinici te verbeteren, bijvoorbeeld door ze beter op te leiden, c.q. te trainen in SDM, zodat ze patiënten kunnen betrekken bij de besluitvorming, ook als dit soms moeilijk lijkt. Daarnaast zijn er meetinstrumenten zoals de SDM-Q-9 die de mate en stappen van SDM kunnen monitoren en keuzehulpen die het besluitvormingsproces ondersteunen of de patiëntervaring kunnen verbeteren.

Gebaseerd op het theoretische concept van SDM en de resultaten van dit proefschrift, denken we dat SDM het potentieel heeft om patiëntgerichte zorg in de gespecialiseerde GGZ te verbeteren en behandelbeslissingen te optimaliseren.

CURRICULUM VITAE

Sumayah Vandebussche was born on October 13th, 1974, in Leiden, the Netherlands. After her pre-university education, Sumayah started her academic career in Psychology at Leiden University in 1993. After completing her propaedeutic phase in one year, she moved to Amsterdam in 1994 to study Communication sciences. Soon she realized that her interests lay in the human mind and behavior, and she enrolled at the faculty of Social Sciences to finish Psychology, specializing in Social Psychology (track Consumer Behavior and Decision Sciences). At the end of her studies, she became more and more interested in decision-making and medicine (medical health care). This resulted in a master's thesis on genetic counseling and a scientific internship at GGZ Engedeest (Rijngestgroep, now GGZ Rivierduinen), where she conducted a patient experience and satisfaction study. After finishing her Master's (doctoraal), she worked at GGZ Rivierduinen as a Junior Care counselor and worked on a project to strengthen primary mental healthcare, "SPV in de huisartsenpraktijk", evaluating the effect of consultations by a specialized psychiatric nurse in general medical practice to support general practitioners and patients with mental health problems. She realized she wished to study Medicine, and via the decentralized selection procedure, she was accepted at the faculty of Medicine of Utrecht University/UMC Utrecht. During her medical studies, her interest continued to lie in the psychology behind illness and its treatment. Psychiatry fascinated her the most.

In the meantime, Sumayah had started a family and her home situation changed. She had to make new choices regarding her career. She completed her BSc but decided not to finish the MSc programme in medicine. With some regret but ultimately grateful for the knowledge she gained: a unique combination of psychology, human behavior, the human body, clinical decision-making, with clinical experience and scientific research, she started her PhD project ('Kiezen voor Pillen en/of Praten') [in Dutch] at the department of Psychiatry of the Leiden University Medical Center. During her PhD project she took part in various courses focusing on quantitative and qualitative research methodology and epidemiology. As part of her PhD project, she attended and presented at several meetings and conferences, and she started teaching.

In December 2016 Sumayah started working as a postdoctoral researcher at the department of Social Medicine, Youth Health (J&G) of the VU medical center. She conducted research on the work activities and stakeholders' and users' experiences with a consultation and advice expert team, to support general practitioners (GP's), youth professionals and youths with mental health problems. During this post-doc project Sumayah was involved in several educational activities, one of which was being a tutor for students of the Bachelor of Medicine at the VU. Shortly after finishing her post-doctoral research project Sumayah returned to the J&G department to be appointed as an academic lecturer.

Currently Sumayah is still working at J&G, now Child and Adolescent Public Health Research & Innovation (Social Medicine), where she is involved in many different facets of education at the Amsterdam UMC (VUmc and AMC) and the VU, faculty of Behavioral Sciences and faculty of Movement Sciences. Her teaching activities focus on Youth Public Health Care, Prevention and Clinical Scientific Methodology, as a lecturer, course coordinator and thesis supervisor. Sumayah is also still a tutor for first, second-, and third-year medical students, and a mentor for medical interns of the Master of Medicine at the VU. As part of her own ongoing learning activities, she is now finalizing her University Teaching Qualification (BKO) and recently took part in a leadership development and team development program in the educational context (BASOT).

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