



**Universiteit  
Leiden**  
The Netherlands

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

Rodenburg-Vandenbussche, S.

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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 ones<sup>1</sup>. Mental disorders can be defined as a health condition involving changes in an individual's thinking, feelings, and/or behavior<sup>1</sup>.

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 functioning<sup>2</sup>. 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 weeks<sup>3-5</sup>.

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<sup>6,7</sup>. 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 differ<sup>8</sup>.

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%)<sup>9</sup>. 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 States<sup>10</sup>.

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 disorders<sup>11</sup>. The 12-month prevalence for mental disorders

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

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 common<sup>14</sup>.

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 costs<sup>15</sup>. 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<sup>16-18</sup>.

### **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<sup>19-23</sup>.

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<sup>24-27</sup>. There is no doubt that both types of treatment are effective and, when compared, they are considered equally effective for most patients<sup>24,26,28</sup>. 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<sup>28-30</sup>.

Although both types of treatment have comparable effects, the long-term effectiveness in real-world setting seems modest<sup>29,31</sup>. 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 disorders<sup>24</sup>. 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 therapists<sup>26</sup>.

### **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<sup>32,33</sup>. 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<sup>22,34,35</sup>. 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<sup>7,21,22,35,36</sup>. 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<sup>34,37</sup>. 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 care<sup>38-40</sup>. 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"<sup>41,42</sup>. In shared decision-making (SDM), patients and clinicians work together to reach a treatment decision<sup>43-46</sup>. 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 process<sup>47</sup>. 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 account<sup>48</sup>.

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<sup>43,44,49</sup>. 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 outcome<sup>44</sup>.

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<sup>45,47,50-56</sup>, but it is still less developed compared with other settings such as primary care and oncology<sup>53,57-60</sup>. However, research on SDM and its potential in mental healthcare is promising<sup>44,45,47,55</sup>.

In psychiatric care SDM has the potential to strengthen patient-centered care and to empower patients to be involved in treatment decisions<sup>47</sup>. 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 important<sup>51</sup>. 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 mortality<sup>45</sup>. 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<sup>61,62</sup>. 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 inconclusive<sup>56</sup>. 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<sup>44,46,55,59,63</sup>.

## 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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