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

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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, costs[4]. 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 studies[7–9], 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 care[8].

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 depression[10], 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 adherence[17]. 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 psychotherapy[27]. 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 lists[28], 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 depression[31].

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 proposals[35]. 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 practice[38], and that clinicians often make unilateral decisions that were based on their own preferences rather than patient preferences[31]. Differences in these processes and eventually preferences could lead to a discrepancy between what patients want, expect and what clinicians (can) offer, thus choice[1]. 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 them[48]. This may be related to the patient's education, assertiveness, and state of health[48]. In addition, the results indicate that the process of eliciting personal perspectives is not often carried out[48].

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 style[49]. 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 symptomatology[50].

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 settings[52–54]. 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 SDM[51]. 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 literacy[56]. Patients in our population were likely less severely ill, with better health literacy and self-efficacy as a result[56].

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' capacities[58]. 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-9[63] 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 original[63] 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 disorders[67]. 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 construct[38].

We can assess SDM from several viewpoints, using an external observer, the patient, or the physician[69]. 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) scale[70], 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 separately[47]. 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 identified[74]. Subsequently, these variables were assessed in quantitative research[74]. 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 time[59]. 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 reality[1]. 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 SDM[78]. 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. ASK3[79], 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 process[81]. 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 settings[82–84]. 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 consultation[87]. 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-making[91]. Additional SDM guidelines, on how to apply SDM, in clinical practice may be useful[92].

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 investigation[93].

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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