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

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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' prefeences[17,18]. Although views on SDM vary and a clear set of steps to implement this approach is lacking, most descriptions of SDM overlap[19] 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-up[20]. 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 Behandel Overeenkomst, 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 together[23]. 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 Grids[34]); web-based decision support systems (e.g., Common Ground web application[38] 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 settings[18]. 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 results[41].

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 scarce[40] and concentrates on patients with depressive disorder or psychiatric patients in general and less on patients with other mental disorders, such as anxiety and OCD[44]. 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 clinicians[45].

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 texts[48].

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

4

B

impacts
impacts
decision making capacity
insight
want to take responsibility for treatment
precondition
precondition
precondition
assertiveness
precondition
impacts
SEVERITY
impacts
waiting lists
grey zone
CHOICE
PSYCHIATRY
choice
complexity
PATIENT
improves patient satisfaction
improves therapeutic relation
precondition
impacts
uncertainty
let patient decide
motivators
supports treatment
knowledge
lack
challenges
Role
DEFINING SDM
REALITY
weighing pro's and cons of treatment
improves treatment effect
lack
creates
interdisciplinairy consultation
give professional advise
SDM
clinicians' perspective
patient as SDM partner
decision tree
improves
not
resolve waiting lists
improves
ask patient preferences and expectations
precondition
psycho education
equipoise
DEFINING SDM
IMPROVE SDM
inform patients
motivators
Role
give relevant information
better INFORMATION
solutions
time
give best treatment
responsibility
DVD/ VIDEO
responsibility
relevant treatment
short information leaflet
INFORMED CONSENT
responsibility
pros and cons of
extra consultation
CLINICIAN
illness
getting consent
responsibility
SDM education clinicians
involve family
persuasion techniques
continious evaluation of treatment
responsibility
short questionnaires before intake
improves
make a treatment plan together
own preferences
clinician as SDM partner

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 data[48–51]. 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.

	THEMES MENTIONED IN FOCUS GROUPS	
Categories	**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

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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 opinions[44].

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 advise" (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 decision[52]. 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

treatment[21]. 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 processes[53]. Although informed consent and SDM overlap, SDM may be applied to a wider range of clinical decisions and emphasizes the needs of the individual patient[54].

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 oncology[56]. 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 researchers[21]. 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 setting[55]. 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 capacity[59].

Practical implications

Our results indicate that clinicians assume most of the responsibilities regarding the initiation and achievement of SDM in clinical practice[56]. 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 illness[56]. However, such interventions do not guarantee that decisions will be shared, and they are not a substitute for the discussion/communication between patient and clinician[60]. 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).

<u>Decision-making process</u>

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.

<u>Decision-making process</u>

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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