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## Shared decision making in mental health care

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# Chapter 1

## **General introduction**

## Introduction

This thesis focuses on the added value of active involvement of patients in decision making about treatment in specialist mental health care, so-called Shared Decision Making (SDM). We also investigate whether the use of periodic outcome measurements during treatment (Routine Outcome Monitoring, ROM) and electronic health (eHealth) could support patients and clinicians in applying SDM. Until now, in mental health care very little was known about the feasibility and effectiveness of the integration of SDM with ROM and eHealth.<sup>1</sup> To better understand the field of study, first background information on Dutch mental health care is given. Second, the definition, evidence and implementation level of Shared Decision Making, Routine Outcome Monitoring and eHealth are described. Next, the multidimensional construct Decisional Conflict, which assesses the quality of clinical decision making, is explained. Subsequently, the aim of this thesis and the research questions examined are given. This chapter ends with the applied methods and outline of this thesis.

## Background

### Mental health care in the Netherlands

The Dutch mental health care sector consists of different segments of providers. The general practitioner functions as gatekeeper. Almost all Dutch citizens are registered with a general practitioner who deals with most of their medical problems. Patients with mild mental health problems are treated by the primary care providers i.e. the general practitioner assisted by a mental health physician assistant. Patients with mental health problems which are beyond the capability of the primary care provider, are referred to the curative mental health care. Since 2014 the curative mental health care has been divided into two segments. First, the general basic mental health care for people with moderate, non-complex mental health disorders and people with stable chronic problems. Second, specialist mental health care for people with severe, complex mental health conditions.<sup>2,3</sup>

Annually, about 700.000 patients are treated in the curative mental health care by an estimated number of 175 mental health care organisations, varying from large, regional mental health care organisations to small practices.<sup>4</sup> In total,

about 89,000 employees are working in the mental health care sector.<sup>4</sup> This thesis focuses on the patient group above the age of 18 with various mental health disorders treated in specialist mental health care. Most prevalent treated primary diagnoses for adults (18-64 years) are mood (24%), anxiety (15%) and personality (14%) disorders. For elderly (65+ years) cognitive (34%) and mood (29%) disorders are most treated.<sup>4</sup> The mean duration of treatment in curative mental health care is 17.5 months.<sup>4</sup>

### **Shared Decision Making**

In mental health care, attention for the implementation of SDM is increasing.<sup>5-9</sup> Throughout this dissertation SDM is defined as the collaborative approach in which patients, together with their companions, and clinicians share available information about choices in treatment from both perspectives and where patients are supported in participating actively in decision making about treatment.<sup>10</sup> This dialogue aims to take place on an egalitarian footing, involving patients' knowledge from experience, values and wishes, as well as scientific knowledge and clinicians' expertise.<sup>5,10</sup> The SDM method encompasses several steps: 1) introduction of the choice(s), eliciting goals and exploring the roles of patients and their companions; 2) give meaning to available information sources; 3) explore options; 4) weigh options and 5) making a shared decision.<sup>10-14</sup>

Research in mental health care showed that SDM can have a positive influence on the level of informed patients, the degree of actively engaged patients in treatment, patient satisfaction, treatment adherence and treatment outcomes.<sup>5,15-18</sup> Despite these promising insights and the increasing attention for SDM, SDM has not yet been broadly implemented in mental health care, and hence there is much to improve in patients' participation in clinical decision making.<sup>19-24</sup> To bridge the gap between the promising evidence and lagging implementation of SDM, it is important to support clinicians and patients in their switch towards another way of working.<sup>20,25,26</sup> Patients need access to information and tools to prepare themselves for the decision making process about treatment. As described in the sections below, Routine Outcome Monitoring and eHealth are considered to be promising tools to use during this decision making process.<sup>1,13,27,28</sup>

## **Routine Outcome Monitoring**

Clinical feedback from outcome measurements in everyday practice, so-called Routine Outcome Monitoring (ROM), could be helpful for both patients and clinicians in decision making about treatment.<sup>29-31</sup> ROM is a personalized source of information and implies regular measurements of clinical outcomes during treatment. ROM has the primary goal to provide feedback on the patients' progress during treatment<sup>29,30</sup>, and consequently has the potential to be a useful tool involving patients in their treatment process and to be used as a source of information while choosing appropriate treatment options.<sup>1,13,31,32</sup> Research pointed out that ROM can enhance the communication between patients and clinicians, and, when patients and clinicians both are provided with this feedback information, ROM can have beneficial effects on mental health status, especially for patients who are not responding to treatment favourably.<sup>30,32-35</sup>

In addition to the primary, original goal of ROM i.e. 1) Giving feedback to patients and clinicians targeting to evaluate treatment, ROM could also be used for other purposes i.e. 2) learning and improving within teams with ROM feedback on an aggregated level; 3) research with naturalistic ROM data, and 4) external use for performance measurement and accountability.<sup>36-38</sup> Since the nationwide dissemination of ROM from 2010 onwards<sup>36</sup>, attention has been especially focused on the last mentioned fourth goal of ROM. Therefore, clinicians experienced ROM as a tool for management and external control, which led to resistance and hampered the use of ROM by clinicians and patients in day-to-day practice.<sup>39-43</sup> This has given ROM in the Netherlands a negative connotation, which is unfortunate as ROM, if tailored to the patient group and used as feedback instrument during treatment, is still a promising tool for patients and clinicians to evaluate the progress and communicate about treatment.<sup>1,13,30-32,44</sup>

In 2011 GGz Breburg developed and implemented a model for SDM using ROM in a centre for patients with combined physical and mental disorders. This approach was evaluated in a pilot study, which showed the feasibility of the implementation and the utility of ROM as a personalized source of information during decision making about treatment.<sup>1,13</sup> A Randomised Controlled Trial was recommended aimed to test the effectiveness of SDM combined with ROM

more thoroughly.<sup>1</sup> Regarding the opportunities of ROM and the, in general, suboptimal use in clinical practice, in 2014 in Dutch mental health care a government sponsored National Quality Improvement Collaborative (QIC)<sup>45</sup> was initiated aiming to enhance the nationwide uptake of ROM in routine clinical practice. In this QIC initiative ROM was embedded in a SDM framework. In this dissertation the implementation of ROM and the effectiveness of SDM using ROM has been evaluated.

### **Electronic Health (eHealth)**

In this thesis we also investigate whether electronic health (eHealth) could foster SDM. EHealth is a very broad concept; several definitions have been used to describe eHealth activities.<sup>46</sup> In our research eHealth implies an internet-supported intervention, which focuses on the intake process and includes educational and therapeutic interventions aimed at exploring treatment needs, expectations and preferences of patients intended to prepare patients for the intake consultations and to give them the opportunity to play an active role in decision making about treatment.<sup>46,47</sup> This so-called blended eHealth intervention is self-guided and human-supported as well. This means that patients follow eHealth partly independent with some degree of automated feedback, while it also incorporates human interventions for support, guidance and feedback.<sup>46</sup> Nowadays, there is increasing attention for the implementation of eHealth in mental health care.<sup>46,48,49</sup> EHealth interventions are promising to stimulate active patient participation<sup>27,28,50</sup> and to enhance treatment outcomes.<sup>51-53</sup> Despite these promising results of studies investigating eHealth interventions, until now the amount and quality of the evidence is low.<sup>51-53</sup> Therefore, more studies are needed to establish these findings.<sup>51-53</sup>

### **Quality of clinical decision making**

With the implementation of SDM, there is an increasing need to evaluate the quality of its application in clinical practice.<sup>54,55</sup> A construct that may be helpful is Decisional Conflict. Decisional Conflict is a multi-dimensional and transactional construct that covers both the decision making process and the quality of the decisions made and is related to the way of collaboration between patients and clinicians. Decisional Conflict gives insight into the degree in which patients are engaged in and also whether patients feel comfortable about important clinical decisions that are made about their treatment.<sup>56,57</sup>

A low level of Decisional Conflict is very important, because when patients experience less Decisional Conflict, their adherence to treatment and health outcomes are likely to improve, whereas more Decisional Conflict could have negative consequences such as drop-out, dissatisfaction with the treatment, poorer health outcomes and reduced quality of life.<sup>57,58</sup> SDM can improve the decision-making process and reduce Decisional Conflict.<sup>17,18,54,59</sup>

## General aim and research questions

This thesis contributes to the field of knowledge on the quality of clinical decision making in specialist mental health care, and subsequently encompasses how and whether Shared Decision Making (SDM) using Routine Outcome Monitoring (ROM) and eHealth could optimise patient participation and the quality of clinical decision making. Overall we hypothesized that the application of SDM using ROM and eHealth should lead to less Decisional Conflict, more patient participation in decision making, a better working alliance, more treatment adherence and better treatment outcomes. As illustrated in Figure 1, we argued that a better application of SDM first might lead to positive effects on the proximal dependent outcome and process parameters, which were closely related to the SDM construct, i.e. Decisional Conflict, process of Shared Decision Making, patient participation and working alliance.<sup>17,18,54,59-61</sup> Subsequently, we expected that, if patients are satisfied about the collaboration with their clinician, they had the opportunity to participate actively in decision making and experienced less Decisional Conflict, this might in turn influence the secondary, distal dependent outcome parameters higher treatment adherence and better treatment outcomes.<sup>57,58,62-67</sup> Although, better scores on the proximal dependent outcome variables would be a benefit per se<sup>62,68,69</sup>, achieving better results on the distal dependent outcome parameters treatment adherence and outcome, which were indirectly related to a higher level of SDM, would be the most important final outcomes of our interventions.<sup>69</sup>

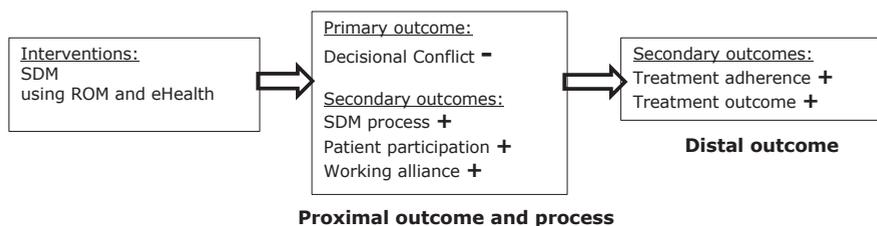


Figure 1. Initial model: the influence of SDM on primary and secondary outcomes.

The general research question of this thesis ‘Does the implementation of SDM using ROM and eHealth lead to less decisional conflict, more patient participation in clinical decision making, better working alliance, more treatment adherence and better treatment outcomes’ is divided into the following sub-questions:

1. What is the relevance and usefulness of Decisional Conflict to evaluate clinical decision making in daily practice, and how can it be described, illustrated in a model and measured?
2. Whether are patients in specialist mental health care experiencing Decisional Conflict and what is the influence of socio-demographic and clinical characteristics?
3. What are the effects of the National Quality Improvement Collaborative on the actual use and perceived utility of ROM in routine clinical practice?
4. What are the effects of the implementation of SDM using ROM, facilitated by the National Collaborative, on Decisional Conflict, working alliance and treatment outcome?
5. What are the effects of a multi-faceted blended eHealth intervention during the intake process supporting SDM on Decisional Conflict, patient participation, applying SDM, working alliance, treatment adherence and treatment outcome?

## Methods and outline of this thesis

To answer the research questions, described above, we conducted a review of literature, a nationwide and a regional study. The nationwide data collection was part of the National Quality Collaborative and took place in order to

gain knowledge about the use of ROM in daily practice and get insight into the effectiveness of applying SDM using ROM in routine clinical practice. In addition to this national initiative, where especially the clinician was supported in applying SDM during treatment, GGz Breburg, a specialist mental health care organisation in the southern part of the Netherlands, takes a step forward in improving SDM by developing a multi-faceted blended eHealth intervention in the intake process. In this initiative, both patients and clinicians were supported in SDM. This regional study at GGz Breburg evaluated this multi-faceted intervention in the intake process.

The outline of this thesis, which consists of three parts, and the designs of the different studies are described in brief below. For further details on the research methods the reader is referred to the various chapters of this thesis.

### **Part I: Decisional Conflict: a concept to assess the quality of clinical decision making**

**Part I** focuses on the concept Decisional Conflict, a construct which evaluates the quality of clinical decision making and gives insight into patients' engagement in and satisfaction with clinical decisions.

**Chapter 2** answers research question 1, and provides insight from a literature study covering a description of the multi-dimensional construct Decisional Conflict and illustrated this concept in a model. We also described the usefulness and measurement of Decisional Conflict in clinical practice.

In **Chapter 3** research question 2 is answered. This chapter describes the results of a cross-sectional study exploring the level of DC experienced by patients in specialist mental health care and the influence of patients' characteristics on Decisional Conflict. This study was performed on the baseline data of the RCT aimed to investigate the added value of Shared Decision Making using Routine Outcome Monitoring.

### **Part II: The impact of the National Quality Collaborative on improving Shared Decision Making using ROM.**

In **Part II** we focus on the National Quality Collaborative aiming to implement ROM in a SDM framework. In this second part research questions 3 and 4 are answered. **Chapter 4** provides the results of an implementation study

investigating the actual use and perceived utility of ROM in clinical practice, which was assessed by a survey for clinicians participating in 21 intervention and 14 control teams. Clinicians of the intervention and control teams completed this survey at the beginning and end of the National Collaborative. This study included a parallel group design with matched pairs of participating teams in which a cluster randomised controlled trial (RCT) was embedded.

**Chapter 5** describes the study protocol and **Chapter 6** the results of the nationwide RCT investigating the effectiveness of SDM using ROM. This two-arm matched-paired cluster RCT was performed to investigate the effects of this SDM-ROM approach primary on patients' perception of Decisional Conflict, and secondary on working alliance and treatment outcomes. In total, 186 patients (94 intervention, 92 control) and 57 clinicians (25 intervention, 32 control) from 4 organisations (matched pairs; 7 intervention and 7 control teams) across the Netherlands participated in this trial.

**Part III: The effectiveness of supporting Shared Decision Making using a multi-faceted blended eHealth intervention during intake: a regional initiative.**

In **Part III** research question 5 is answered. This part describes the development and evaluation of a regional, multi-faceted blended eHealth intervention supporting SDM during intake. **Chapter 7** describes the study protocol and **Chapter 8** the results of the RCT investigating this regional, multi-faceted initiative in the intake process of GGz Breburg. In order to gain insight in the effectiveness of this intervention, we conducted a two-arm matched-paired cluster RCT. The primary outcome was Decisional Conflict. Secondary outcomes were patient participation, SDM-process, working alliance, treatment adherence and symptom severity. In total, 8 teams (matched pairs; 4 intervention and 4 control), 56 couples of intake clinicians, who jointly performed the intake (29 intervention, 27 control), and 200 patients (94 intervention, 106 control) participated in this trial.

Finally, in **Chapter 9** the main findings of this thesis are presented and discussed from a broader perspective. This chapter also describes the contribution of this entire dissertation to our understanding of the implementation of SDM using ROM and eHealth and its added value for patients and clinicians. In addition, implications for clinical practice and further research are suggested. The thesis ends with a summary and acknowledgements in Dutch.

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