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Introduction

Bipolar disorder is a psychiatric disorder characterized by episodes of depression and (hypo)mania. It has a tremendous impact on patients and their caregivers and calls for good treatment. Despite the relatively good financial support for mental health care in the Netherlands, there remains a treatment gap: a gap between the needs for treatment and its provision. High costs and long waitlists hamper the accessibility of psychiatric care. In addition, the fragmentation of care due to rapid increase of specialized knowledge, and the market forces resulting in overregulation and an increase of bureaucracy further increase the treatment gap.

An underlying explanation of this treatment gap is the constantly changing views on how to conceptualize and organize psychiatric care. The concepts of 'mental illness' and 'good care' have been subject to debate for many decades. In current mental health care, two paradigms are widely discussed: Evidence Based Medicine (EBM) and Patient Centered Care (PCC). Both paradigms are recognized for being valuable, however, they are often perceived as 'conflicting movements'. EBM is considered a movement based on a population approach that is guided by research evidence, whereas PCC is based on a personalized approach, guided by the needs of individual patients. More recently, it has been argued that these two paradigms could be complementary movements, both striving for good quality care. However, little is known on how they could complement each other. Therefore, the aim of this thesis is to contribute to the improvement of mental health care by systematically aligning the separate worlds of EBM and PCC. This thesis specifically focuses on the field of bipolar disorder, since it has been argued that the high burden of the disease, an existing treatment gap and its chronicity call for a care approach that is both evidence-based and patient-centered. This is more elaborately explained in chapter 1 of this thesis.

Theoretical background

In chapter 2 of this thesis, the concept PCC and EBM are explained. PCC is a framework for care that has actively been developed since the 1950s. A central theme in the framework is a shift from a disease focus towards a focus on patients' feelings and experiences. The Institute of Medicine defines PCC as: *"A partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients' wants, needs and preferences and that patients have the education and support they need to make decisions*

and participate in their own care” in every stage of healthcare from entry to discharge. On the one hand, PCC is praised for its positive effect on health outcomes, self-management, satisfaction of care, care processes and satisfaction among health professionals, but at the same time, PCC is criticized for the lack of clarity about its conceptualization, resulting in a lack of scientific grounding of PCC.

EBM is often understood as *‘the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research’*. EBM has been applauded for supporting clinical decision making, integrating medical education and clinical practice, improving the efficacy and efficiency in health care and decreasing the use of ineffective clinical practices. At the same time it has been criticized for excising non-evidence-based treatments and impeding the direct translation from research evidence into clinical practice, leaving little room for individual needs and preferences.

Due to the different views on what should guide clinical practice, PCC and EBM seem to belong to separate worlds. In EBM, clinical practice is predominantly guided by research evidence, whereas PCC is guided by the experiential knowledge of health professionals and patients. However, it has increasingly been argued that aligning these paradigms would be beneficial for clinical practice. In this thesis, alignment is understood as strengthening the evidence base of PCC and strengthening the patient centeredness of EBM. Alignment strategies that address the predominant points of criticism on both paradigms are used for that purpose. The first strategy strengthening the evidence base of PCC is, to contribute to the improvement of the conceptualization of PCC, and therefore remove criticism concerning the lack of clarity of what PCC entails. The second strategy, to strengthen the patient centeredness of EBM, is to broaden the evidence base by 1) including the perspectives of health professionals and patients in health care and research and 2) producing research that is closer to the actual circumstances of clinical practice (real time evidence), that results in more acceptable and relevant research for clinical practice. Applying the alignment strategies to the field of bipolar disorder could provide lessons for clinical practice and research, which could enable health professionals to treat patients with bipolar disorder according to the principles of both EBM and PCC, as well as researchers to conduct research relevant for clinical practice.

Methods and research questions

The main research question that guided this thesis is:

What does aligning Evidence Based Medicine and Patient Centered Care imply for clinical practice and research in the field of bipolar disorder?

In order to answer this research question, three sub-questions are formulated.

1. What constitutes good quality care for patients with bipolar disorder, from the perspective of EBM, PCC and patients?
2. What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients and health professionals?
3. Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder and patients' research needs?

The first sub-question contributes to strengthening the evidence base of PCC by clarifying the conceptualization of PCC and to strengthening the patient centeredness of EBM by broadening the evidence base by using patients' perspectives. The second sub-question searches the strengthening of the patient centeredness of EBM by aligning research with the perspectives of patients and health professionals on relevant research. For this purpose, the strategy to broaden the evidence base by using patients' and health professionals' perspectives was used. The third sub-question also strives to strengthening the patient centeredness of EBM by broadening the evidence base by producing real time evidence.

To answer these sub-questions, qualitative research methods and mixed-methods were employed, presented in chapter 4-8 of this thesis. Methods include a narrative review (chapter 4), semi-structured interviews (chapter 4 and 7), focus group discussions (chapter 4-8), a questionnaire (chapter 6) and the Delphi method (chapter 8). The methods are more elaborately explained in chapter 3 of this thesis.

Results

To strengthen the evidence base of PCC, it is important to clarify its conceptualization. **Chapter 4** describes the results of a literature review on the conceptualization of PCC. The elements relevant for PCC according to literature are clustered into four dimensions: 'patient-

professional interaction', 'patient', 'health professional', and 'healthcare organization'. The patient-professional interaction is described as an interaction in which the patient and health professional have shared power and responsibility and discuss their experiential knowledge. This could result in a therapeutic alliance and individualized care. In order to achieve this interaction, in PCC 'the patient' and 'the health professional' are also conceptualized. The patient is conceptualized as a person with his/her own knowledge about living with a disease, who is able to participate in his/her own care, has the right to autonomy, dignity and privacy and has unique preferences, needs, and values. The health professional is conceptualized as a person with a biopsychosocial perspective, a caring attitude and knowledge and expertise. Furthermore, the health professional should be able to apply rule flexibility to respond to the unique needs of the individual patient. The patient and the health professional need to have the support of the health organization. A health organization that is facilitating PCC focuses on the coordination and integration of care, transition and continuity of care, the accessibility of care and is supportive to multidisciplinary teams.

To strengthen the patient centeredness of EBM, it is relevant to systematically study patients' perspectives on good care in order to be able to deliver care according to their needs. In **chapter 4 and 5** these perspectives are described. The perspectives of patients on good care are comparable with the perspectives of PCC. According to patients, 'good care' implies acknowledging, and being sensitive to, different forms of uniqueness. Patients generally desire to be treated with dignity and respect, value the exchange of knowledge with their health professionals, and have a preference for a health professional who is attuned to their personal needs, preferences and values, with a focus on their individual strengths. Patients' unique desires are not stable per se; they can be situational and may change over time. In addition, it is important that a healthcare professional has clinical knowledge and expertise, is able to balance between being directive and being supportive, takes a holistic approach, and is considered as a person, rather than just a health professional. A good relationship is necessary to reach therapeutic alliance and consists of feeling comfortable and having trust in the health professional. It can be influenced by the behaviours and skills of health professionals, but also depends on personal preferences and a connection.

In addition, to strengthen the patient centeredness of EBM, it is important to conduct research that is relevant for clinical practice according to patients and health professionals. **Chapter 6 and 7** answer the sub-question which research-topics are relevant for clinical practice as well as the scientific field of bipolar disorder by explicating patients' and health professionals'

perspectives. This resulted in a research agenda for bipolar disorder. Relevant research topics according to patients could be clustered into five themes: cause of disorder (etiology of disorder; triggers of an episode), diagnosis (recognition of early warning signs; knowledge improvement of general practitioners; development of diagnostic tools; a correct referral system), pharmacological treatment (effectiveness of medication; mechanism of action of medication; the necessity of medication; research on side-effects; development of better targeted medication with less side-effects; the effect of lithium on sport performances), non-pharmacological treatment (the effectiveness of non-pharmacological treatments; the development of new treatment including the treatment for caregivers) and recovery and recovery-oriented care (the knowledge of society on bipolar disorder; strategies to increase acceptance by society; self-management strategies; positive aspects of bipolar disorder; impact of bipolar disorder on the patient; treatment options for comorbid disorders; designing a PCC system; collaboration between health professionals). The perspectives of health professionals on research needs for bipolar disorder often overlapped with the needs of patients, but health professionals have also added research topics to the research agenda of patients. In the theme 'cause of disorder' health professionals added the topic 'clarifying the psychological explanation of the disorder'. In the theme 'diagnosis', they added the need for research to the role of psychologist and the distinction between bipolar disorder and personality disorder and in the theme 'pharmacological treatment' the need for research to factors that predict which medication will be effective and to better pharmacological treatment of bipolar depression. The theme 'non-pharmacological treatment' was enriched with the topics 'non-pharmacological interventions for bipolar depression' and 'development of e-health'. In the theme recovery and recovery-oriented care, the topics 'functional impairments of bipolar disorder', 'the quality of care from a patient's perspective', 'strategies to better integrate science and clinical practice', and 'the use of all expertise available in clinical practice' were added by health professionals to the research agenda of patients.

In order to fully understand the perspectives of health professionals on relevant research, it is important to understand their views on the research topics of patients. Systematically studying the interpretative frames of health professionals, broadens the evidence base of bipolar disorder. In research, different frames could be distinguished, as described in **chapter 7**. Nurse-researchers approached the research topics by considering the consequences, the influence on functioning and the impact for the patients, whereas the psychiatrist-researchers approached the topics from a medical perspective, and considered

physical and biological aspects, medication and symptomatology in the formulation of a research question. The psychological perspective on research focused on the psychological mechanisms, behavior, cognition and experiences of patients. These different frames often result in research approaches that address different aspects of the topics. To further the understanding of the interpretative frames of health professionals and to strengthen the patient centeredness of EBM by producing real time evidence, interpretative frames were further studied in a specific health care setting: the diagnostic process, described in **chapter 8**. The interpretative frame of psychiatrists is termed ‘symptom evaluation frame’. This frame has a disease focus, concentrating on symptoms and patterns, including the physical state of the patient — the interpretations of which results in presenting the most appropriate DSM-5 classification. The psychologists’ frame is termed ‘personality-focused frame’, which entails systematically concentrating on psychological mechanisms, personality traits, coping styles and on a patients’ development and how these aspects relate to the patient’s symptoms. The frame of the nurses is termed the ‘psychosocial frame’, implying a focus on the practical aspects of a patient’s life, their functioning in the different domains of life including their social context, and on the patient’s strength.

Discussion and conclusion

This thesis contributed to the alignment of EBM and PCC in the field of bipolar disorder. The strategies used to contribute to the alignment resulted in the introduction of an ‘evidence-informed, patient centered care’ practice. This model emphasized the need to conduct research on topics corresponding with the research needs of patients with bipolar disorder and health professionals, with special focus on psychosocial aspects of bipolar disorder and recovery. Subsequently, the research outcomes should be translated to the needs of patients, using a variety of knowledge sources, in order to deliver individualized care that is focused on the patient as a person with unique strengths, needs and preferences. Furthermore, this model recognizes the importance of a multidisciplinary approach in both health care and research, to integrate different perspectives of health and benefit from all expertise available.

The alignment of EBM and PCC, that resulted in the description of an ‘evidence-informed patient centered care’ practice, a research agenda for bipolar disorder and insights into the perspectives of health professionals on patients and their needs, has implications for clinical practice and research on four different levels. At practitioner-level, the ‘evidence-

informed patient centered care' practice implicates that health professionals use a variety of knowledge sources to translate evidence to the individual needs of patients. This integration may be applied by health professionals via reflection and a process of learning, and could benefit from a reflective practice. At the organizational level, care for people with bipolar disorder could benefit from a learning organization in order to support the reflection process of the health professional. At the research system level, the findings of this thesis implicate that the research topics of patients with bipolar disorder and health professionals would benefit from a research approach using experiences and practices of health professionals and patients and therewith benefit from a practice-based research approach, resulting in practice-based evidence. At the health system level, the findings of this thesis implicate that both the health care system and the health research system would benefit from an integrated system rather than a fragmented system, to grasp the complexity of patients' problems.

Thus, by aligning EBM and PCC in the field of bipolar disorder this thesis provides insights into how the science of medicine and the art of medicine could be combined in order to improve the quality of mental health care.