A GAP BETWEEN THE SCIENCE AND THE ART OF MEDICINE

Understanding and aligning Evidence Based Medicine and Patient Centered Care in bipolar disorder.

Eva Maassen

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Understanding and aligning Evidence Based Medicine and Patient Centered Care
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It is more important to know which individual is suffering the disease, than to know which disease is affecting the individual. – Hippocrates

CHAPTER 1

Introduction

Aim and scope of this thesis

Mental disorders are highly prevalent and are a leading cause of Disability-Adjusted Life Years (DALYs) worldwide (Bloom et al., 2011). These disorders are known to have a major impact on patients and their family (Kohn, Saxena, Levav, & Saraceno, 2004). Bipolar disorder (BD), a chronic and severe mental disorder, is a leading cause of Years Lost due to Disability (YLDs) in nearly all countries (Vos et al., 2015). In the 2013 global burden of disease study, bipolar disorder was the fifth leading cause of DALYs among the mental and substance-abuse disorders and the age-standardized prevalence rates of bipolar disorder in Western Europe are 0.6-0.8 (Ferrari et al., 2016). Bipolar disorder has a tremendous impact on patients and their caregivers (Granek, Danan, Bersudsky, & Osher, 2016; Rusner, Carlsson, Brunt, & Nyström, 2009). Patients often report a low quality of life, functional impairment (Strejilevich et al., 2013; van der Voort et al., 2015), i.e. psychosocial impairment (stigma, relationships) and occupational impairment, and unemployment (Huxley & Baldessarini, 2007; MacQueen, Young, & Joffe, 2001; Yasuyama, Ohi, Shimada, Uehara, & Kawasaki, 2017). In addition, patients with bipolar disorder have a higher than average mortality rate owing to physical comorbidities and suicide (Grande, Berk, Birmaher, & Vieta, 2016). Good care is important in order to overcome these impairments and contribute to a better quality of life (IsHak et al., 2012), but despite the high burden of disease and the importance of treatment, fewer than 70% of WHO member countries have mental health care programs (Bloom et al., 2011).

Most countries struggle with a large gap between the need for treatment and its provision. In low-income countries this treatment gap affects up to 90% of patients (Whiteford et al., 2013), but even in high-income countries between 35 and 50% of the people with severe mental illness do not receive treatment (WHO, 2013), with a median treatment gap for bipolar disorder in European countries of 39.9% (Kohn et al., 2004). This treatment gap could be explained by a lack of human and financial resources, their unequal distribution and inefficient use (Whiteford et al., 2013), and at a more individual level by a lack of knowledge about mental disorders and stigma (Kohn et al., 2004). Even in the Netherlands, where the research on which this thesis is based, despite the relatively good financial support (over 7 billion euros is spent yearly on mental health care) and human resources (WHO, 2014a, 2014b), there is also a treatment gap. It must be acknowledged that in comparison with other countries, the Netherlands has a high quality mental health care system, with an adequate number of trained and specialized health professionals. However, health professionals notice a decline in the accessibility and quality of care (Posma, 2009) and reduced resources create a conflict for providers between the quantity and quality of care (Nestsiarovich et al., 2017). Newspapers frequently report public concerns regarding psychiatric care, e.g. high costs (Trouw, 2017), long waiting times (GGZnieuws, 2017; LHV, 2017; Trouw, 2017) and an increasing number of neglected psychiatric patients (GGZnieuws, 2017; NOS, 2016). In addition to the accessibility of care, the treatment gap could also be explained by the constantly changing views on how to conceptualize and organize psychiatric care. For example, in psychiatric care, health professionals differ in the approach in treatment, where some follow the biological view on psychiatric disorders and treat patients' symptoms, others take a psychosocial approach to illness and focus on recovery beyond the symptoms, resulting in a different approach to patients and their needs (Ghaemi, 2006). Regarding the organization of the provision of care, its fragmentation due to the rapid increase in knowledge and associated specialization, results in inefficient care (Stange, 2009). Moreover, critics argue that the Dutch mental health care is over-regulated by the current quality policy (such as routine outcome monitoring), arising from the market forces, in which observing the rules takes priority over caring for patients (Delespaul, Milo, Schalken, Boevink, & Os, 2018). Subsequently, care becomes standardized and clinical freedom is reduced, resulting in an exclusion of 'complex' patients – e.g. those with comorbidities - that do not fit the standard rules (Delespaul et al., 2018). The standardization of care and the quality policy also resulted in more bureaucratic activities, leading to a focus away from the patient and more towards reporting. Important questions are what underlies these trends in mental health care and how it is possible that, despite the resources attributed to mental health care, patients until now experience unmet needs, e.g. little non-pharmacological treatment (Nestsiarovich et al., 2017) and untimely diagnosis (Goossens, Knoopert-van der Klein, Kroon, & Achterberg, 2014) and may even feel abandoned (Malmström, Hörberg, Kouros, Haglund, & Ramklint, 2016).

An underlying explanation for continuing barriers to mental health care delivery is that what is considered a mental illness and subsequently what is understood as good care has been the subject of debates for many decades if not centuries. Until the mid-twentieth century, the biomedical model of disease predominated. This biomedical approach was a counter-movement against the then dominant psychoanalytical approach to psychiatric disorders. This psychoanalytical approach was criticized since *'psychiatry had become a hodgepodge of unscientific opinions, assorted philosophies and schools of thoughts, mixed metaphors, role diffusion, propaganda and politicking for mental health and other esoteric goals'* (Ludwig, cited by Engel, 1977, p129). The biomedical model required to deal with 'disease' as an entity with a biological origin, left no room for the social and psychological dimensions of illness (Engel, 1977). In the late 1970s, George Engel, a US psychiatrist, introduced the biopsychosocial model, a holistic model, as an alternative, in which he tried '*to reverse dehumanization of medicine*' (Borrell-Carrio, Suchman, & Epstein, 2004, p576) and to encourage health professionals to include psychosocial aspects in treatment as well (Engel, 1977). The biopsychosocial model served as an endeavor to integrate the biomedical and psychoanalytical models (Ghaemi, 2006) and arose in the 1980s in the USA, with the simultaneous rise of the DSM-III and psychopharmacology (Ghaemi, 2009). However, critics of the biopsychosocial model argue that it is too broad to guide clinical practice, resulting in continuing focus on the *bio* part, that still dominates (Ghaemi, 2006). Thus, mental health care as a field, is still *seeking* for the right balance between the biological school and the psychosocial dimensions of illness and to translate this balance into mental health care.

In current mental health care, two paradigms have been widely discussed for more than a decade: Evidence Based Medicine (EBM) and Patient-Centered Care (PCC), both highlighting different aspects of the biopsychosocial model. According to Sackett, Rosenberg, Gray, Haynes, & Richardson (1996), EBM could be defined as *'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients'*. A common definition of PCC is '*health care that establishes 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 require to make decisions and participate in their own care'* (Institute of Medicine, 2001, p. 7). However, the latter still lacks a clear conceptualization (Kitson, Marshall, Bassett, & Zeitz, 2013; Sidani & Fox, 2014). Despite the fact that both paradigms are considered 'good' and 'valuable' (Bensing, 2000), they are often perceived as 'conflicting movements'. EBM is based on a *population approach* and states that 'good care' is based on research evidence, whereas PCC is based on a *personalized approach* and states that 'good care' is based on the individual needs of the patient (Sacristán, 2013). In 2000, Bensing stated that the terms were seldom used by the same author and argued for bringing *'these separate worlds together'* (p. 17). Since then, it is increasingly argued that the paradigms should not be seen as conflicting but as complementary movements, and should be aligned to improve health care (Hasnain-Wynia, 2006; Sacristán, 2013; Wagner et al., 2005).

Both paradigms, EBM and PCC, strive to deliver good quality care. To date, however, little is known about how they could complement each other and so improve quality of care. In addition, there remain many questions what constitutes good mental health care (van der Ham, 2013). According to the EBM paradigm, good quality care is based on the best available evidence, however, what constitutes good mental health care is less clear from the perspectives of patients and from a PCC perspective. This thesis aims to contribute to the improvement of mental health care by systematically aligning the separate worlds of PCC and EBM. It does so by increasing the understanding of what constitutes good quality mental health care from the perspectives of PCC and EBM and by broadening the evidence base. To this end, we conducted a study in the field of bipolar disorder. The high burden of the disease, the treatment gap and its chronic course call for a care approach that is both evidence-based and patient-centered (Miles & Mezzich, 2011; Wagner et al., 2005). Aligning EBM and PCC in order to improve the quality of mental health care might contribute to reducing the treatment gap in bipolar disorder.

CHAPTER 2

Theoretical background

In this chapter, I will elaborate on the concepts that have guided this thesis. First, I will expand on bipolar disorder, after which I will elaborate on the concepts Patient Centered Care and Evidence Based Medicine. This chapter ends with alignment strategies for Evidence Based Medicine and Patient Centered Care.

2.1 Bipolar disorder

Bipolar disorder, previously known as manic-depressive illness, is a complex, chronic and severe psychiatric disorder. It is a mood disorder, characterized by the alternation of mood episodes (mania, hypomania, or depression) and euthymic phases. Globally, the life time prevalence for bipolar I disorder is 0.6% and for bipolar II disorder, 0.4% (Grande et al., 2016). In the Netherlands, the lifetime prevalence for bipolar disorder is estimated at 1.3% (de Graaf, ten Have, van Gool, & van Dorsselaer, 2012). The course of the disorder and the duration and severity of the mood episodes strongly vary. In the following section, I will elaborate on the mood episodes, the course of the disorder, the diagnosis and the treatment.

2.1.1 Mood episodes

Mania and hypomania

Key symptoms of a (hypo)manic mood episode are elevated mood and increased activity and/or energy (see box 1). The episodes differ in severity and in length, but according to the DSM-5, a manic episode has a duration of at least one week, while a hypomanic episode lasts at least four days. A manic episode often leads to functional impairment in a variety of life domains, e.g. social and occupational. It may result in hospitalization and may encompass psychotic symptoms (Grande et al., 2016). A hypomanic episode is a milder state of mania, by definition not leading to significant functional impairment, hospitalization or psychotic symptoms.

Major Depressive episode

A major depressive episode is characterized by symptoms of depressed mood and loss of interest or pleasure (see box 2). The symptoms cause clinically significant functional impairment in a variety of life domains. The DSM-5 criteria for a major depressive episode are the same for bipolar depression as for unipolar depression. However, some clinical features are recognized that could distinguish between those two diagnoses. In bipolar depression the onset and offset are more often abrupt, the episodes are more frequent and shorter, and often have an earlier age of onset (Grande et al., 2016). Moreover, patient more often present with atypical symptoms (e.g. hypersomnia, lability), and psychotic symptoms and it is more often linked to comorbid substance abuse (Grande et al., 2016).

Box 1. Diagnostic criteria of mania and hypomania, according to DSM-5 (APA, 2014)

Diagnostic Criteria
Manic Episode

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy, lasting at least 1 week and present most of the day, nearly every day (or any duration if hospitalization is necessary).
B. During the period of mood disturbance and increased energy or activity, three (or more) of the following symptoms (four if the mood is only irritable) are present to a significant degree and represent a noticeable change from usual behavior:
   1. Inflated self-esteem or grandiosity.
   2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).
   3. More talkative than usual or pressure to keep talking.
   4. Flight of ideas or subjective experience that thoughts are racing.
   5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed.
   6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation (i.e. purposeless non-goal-directed activity).
   7. Excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

C. The mood disturbance is sufficiently severe to cause marked impairment in social or occupational functioning or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.
D. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment) or to another medical condition.

Hypomanic Episode

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity or energy, lasting at least 4 consecutive days and present most of the day, nearly every day
B. During the period of mood disturbance and increased energy and activity, three (or more) of the following symptoms (four if the mood is only irritable) have persisted, represent a noticeable change from usual behavior, and have been present to a significant degree:
   1. Inflated self-esteem or grandiosity.
   2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).
   3. More talkative than usual or pressure to keep talking.
   4. Flight of ideas or subjective experience that thoughts are racing.
   5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed.
   6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation.
   7. Excessive involvement in activities that have a high potential for painful consequences (e.g. engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

C. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the individual when not symptomatic.
D. The disturbance in mood and the change in functioning are observable by others.
E. The episode is not severe enough to cause marked impairment in social or occupational functioning or to necessitate hospitalization. If there are psychotic features, the episode is, by definition, manic.
F. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication, other treatment).

Box 2. Diagnostic criteria of depression, according to DSM-5 (APA, 2014)

Major Depressive Episode

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
    1. Depressed mood most of the day, nearly every day.
    2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.
    3. Significant weight loss when not dieting or weight gain or decrease or increase in appetite nearly every day.
    4. Insomnia or hypersomnia nearly every day.
    5. Psychomotor agitation or retardation nearly every day (observable by others; not merely subjective feelings of restlessness or being slowed down).
    6. Fatigue or loss of energy nearly every day.
    7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
    8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
    9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
C. The episode is not attributable to the physiological effects of a substance or another medical condition.

2.1.2 Subtypes of bipolar disorder

In DSM-5, the following subtypes of bipolar disorder are described:

- Bipolar I disorder: requires at least one manic episode, but this manic episode might alternate with hypomanic or depressive episodes.
- Bipolar II disorder: requires at least one hypomanic episode and one major depressive episode.
- Cyclothymic disorder: requires at least two years of hypomanic and depressive symptoms that never fulfill the criteria for an episode of mania, hypomania or major depression.

2.1.3 Prognosis and impairments

Bipolar disorder is characterized by mood episodes, alternated with euthymic phases. The risk of recurrence is high, compared with other psychiatric disorders; 50% in the first year after a mood episode, which increases to 70% in the four years after a mood episode (Kendall, Morriss, Mayo-Wilson, & Marcus, 2014). On average, patients are euthymic half of the time and find themselves more often in a depressed mood episode than in a (hypo)manic mood episode (Grande et al., 2016; Kupka et al., 2007). Bipolar disorder has been associated with adverse effects in nearly all life domains, among other things due to functional and cognitive impairments in mood episodes and in the euthymic phase, leading to a decrease in quality of life (Bobo, 2017; Grande et al., 2016; IsHak et al., 2012). In addition, people with bipolar disorder are more prone to suffering from medical comorbidities, such as cardiovascular disease, diabetes mellitus, obesity and thyroid problems than the general population (Grande et al., 2016), leading to increased mortality. In addition to physical comorbidities, the risk of premature death is greater due to a 20-times increased risk for suicide compared to the general population (Grande et al., 2016).

2.1.4 The challenges with bipolar disorder diagnosis

Diagnosing bipolar disorder is challenging. There is on average a ten-year gap between the onset of the disorder and the diagnosis (Drancourt et al., 2013), which is problematic since a lack of correct diagnosis leads to delayed or inadequate treatment. Several challenges are recognized that contribute to this gap. First, the diagnosis of bipolar disorder is entirely based on clinical symptoms and course of illness as defined by classification systems DSM-5 or ICD10, since currently there are no pathophysiological tests or distinctive biomarkers, (Mazza, Di Nicola, Janiri, & Bria, 2013). Second, in a majority of cases, bipolar disorder begins with one or more depressive episodes before the manifestation of the first (hypo) mania, inevitably resulting in an initial diagnosis of major depressive disorder. Third, the differentiation between bipolar disorder and unipolar disorder can be challenging since patients often present with a depressive episode and not with (hypo)mania (Phillips & Kupfer, 2013). A majority of the patients (82.5%) recognizes a depressive episode and subsequently consults a health professional, while a minority (22.5%) recognizes (hypo)manic episode and even less (17.5%) consult a health professional (Regeer, Kupka, Have, Vollebergh, & Nolen, 2015). This leads to under recognition of (hypo)manic symptoms (Grande et al., 2016; Phillips & Kupfer, 2013; Regeer et al., 2015). This often results in a delayed diagnosis because the defining features of bipolar disorder are manic symptoms (Berk, Berk, Moss, Dood, & Malhi, 2006). Only 20% of patients with bipolar disorder presenting with depressive episodes are accurately diagnosed in the first year of seeking treatment (Grande et al., 2016). A fourth factor increasing the complexity of diagnosing bipolar disorder is the high prevalence of comorbidity masking the bipolar disorder symptoms (Berk et al., 2006). A fifth challenge in diagnosing bipolar disorder is the presence of episodes with mixed symptoms. Patients can present with both depressive and (hypo)manic symptoms, or rapid alternations between these symptoms (Berk et al., 2006; Phillips & Kupfer, 2013). In this, the predominant complaint is often a depressed mood, unjustly leading to a diagnosis of unipolar depression (Berk et al., 2006). Finally, bipolar disorder symptomatically overlaps with other psychiatric disorders, such as borderline personality disorder, ADHD and schizoaffective disorder, challenging the distinction between those disorders (Mazza et al., 2013).

2.1.5 Treatment

Treatment can help to overcome the symptoms and impairments arising from the disorder. The overall aim of the treatment of bipolar disorder is to achieve clinical and functional remission in order to enhance social and occupational functioning (Morsel, Morrens, & Sabbe, 2018). The Dutch guideline for bipolar disorders makes a distinction between three treatment phases: the acute phase to treat the index mood episode, aiming for symptomatic remission and ensure the patient's safety; the continuation treatment phase, to prevent early relapse; and the maintenance phase to prevent the recurrence of a future episode or to reduce the severity of a new episode and diminish the frequency of episodes (Kupka et al., 2015). The maintenance phase of treatment is especially important due to the high risk of recurrence as mentioned earlier. Each phase and each mood episode has its own specific needs and treatment options (Bobo, 2017; Grande et al., 2016). Overall, the cornerstones of treatment in each phase are pharmacotherapy, psycho-education and self-management strategies (Kupka et al., 2015). In addition, there is a role for psychological treatment and life style approaches (Grande et al., 2016).

Thus, bipolar disorder is associated with a high burden of disease and timely diagnosis and adequate treatment reduces the potential negative consequences of the disorder. Treatment of bipolar disorder strongly benefits from the increase of scientific evidence on effective treatments and nowadays, treatment is to a large extend based on research evidence, translated into clinical guidelines. However, an important characteristic of bipolar disorder needs to be taken into account in treatment: the chronic and recurrent course. It has been argued that a chronic disorder requires a different approach in health care than an acute disorder; it goes beyond 'diagnose, treat and cure' but requires an increased amount of treatment decisions and adjustments to changing circumstances. In addition, self-management has an important role in managing a chronic disorder. Moreover, it must be acknowledged that in bipolar disorder, needs for treatment vary between episodes and between individuals and could concern a wide range of life domains. In addition, these needs could vary in the euthymic phases, where cognitive problems or problems with acceptance could be present. These aspects require treatment to be responsive to the needs of individual patients.

Patient Centered Care strives to deliver good care by focusing on the needs of each individual patient. Evidence Based Medicine strives for delivering good care by providing care to the patient based on the best available evidence. It has been argued that despite its popularity *in principle*, the latter is not always conducive to PCC. So, on the one hand, treatment for bipolar disorder has improved by basing it on the best available evidence, according to EBM; on the other hand, it should be responsive to needs of individual patients, according the PCC. However, as previously mentioned, until recently these paradigms have been understood as two separate worlds. The following section will elaborate on PCC and EBM and why these seem to belong to separate worlds. This chapter ends by elaborating on a strategy that could be supportive to bringing them closer together, so patient with bipolar disorder could profit from the advantages of both paradigms.

2.2 Patient Centered Care

Patient Centered Care (PCC), as framework for care, was actively developed since the mid-1950s (Miles & Mezzich, 2011). It is understood as a response to the biomedical model dominating the medical field at that time (Miles & Mezzich, 2011), as a reaction to the new technologies (Hobbs, 2009) and as a strategy to correct certain tendencies in medicine (Duggan, Geller, Cooper, & Beach, 2006). In 2001, the American Institute of Medicine (IOM) added PCC to its objectives as reaction to the recognition of the value of PCC to quality of care (Institute of Medicine, 2001). Since then, PCC has become more central in health care policies, medical education and the assessment of quality of care (Robinson, Callister, Berry, & Dearing, 2008; Scambler & Asimakopoulou, 2014).

The most often used definition of PCC is the definition of the Institute of Medicine: ‘‘*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 (Institute of Medicine, 2001, p. 7). Despite the apparent agreement on the definition, PCC is often interpreted or understood differently by different people (Wagner et al., 2005). It has been understood as ‘*understanding the patient as a unique human being’* by Balint (1969, p. 152), as ‘*a style of consulting where the doctor uses the patient’s knowledge and experience to guide the interaction*’ by Byrne & Long (1976) and as ‘*an approach where the doctor tries to enter the patient’s world, to see the illness through the patient’s eyes*’ by McWhinney (1989) (cited in Mead & Bower, 2000, p. 1087). These different understandings helped clarify what it was not: doctor-centered, disease centered, technical centered, or medical paternalism (Duggan et al., 2006; Stewart, 2001). Until now, there is no widely accepted conceptual framework for PCC (Scambler &

Asimakopoulou, 2014). It has been described by one school of thought as based on the effect of the illness and how the illness is dealt with by the patient and their caregivers (Miles & Mezzich, 2011). A second school of thought insists that PCC focuses on the patient and their caregivers and their relating values, needs and preferences (Miles & Mezzich, 2011). A third school of thought describes PCC as maintaining the traditional doctor-patient relationship, but additionally ensuring that the patient is informed about, or actively participates in, clinical decision making (Miles & Mezzich, 2011). Despite the lack of clarity about the conceptualization of PCC, a central theme in the definition is a shift from a disease focus towards a focus on patients' feelings and experiences: towards the 'whole person' (Wagner et al., 2005) in order to be able to heal the person (Epstein, 2000; Robinson et al., 2008).

PCC is recognized for its benefits; it is expected to result in better health outcomes, including survival, (Greene, Tuzzio, & Cherkin, 2012; Sidani & Fox, 2014), improved self-management and satisfaction with care (Mills, Frost, Cooper, Moles, & Kay, 2014; Rathert, Wyrwich, & Boren, 2013), improved care processes (Greene et al., 2012), and reduced health care costs (Rathert et al., 2013). Moreover, PCC could result in increased satisfaction among health professionals (Greene et al., 2012; Mills et al., 2014). In addition to these benefits, it is argued that it is the right thing to do (Epstein, Fiscella, Lesser, & Stange, 2010; Greene et al., 2012) and morally desirable to practice PCC (Duggan et al., 2006).

Next to these benefits, there is critique on PCC. The first point of criticism is the continuing lack of clarity about its conceptualization (Bensing, 2000; Mead & Bower, 2000; Sidani & Fox, 2014; Wagner et al., 2005), amongst other since all relevant elements for PCC are not yet adequately characterized (Epstein, 2000). The core concept of PCC is recognized, but it is used differently, depending on the interpretation of the concept (Bensing, 2000). This lack of clarity informs the second point of criticism. PCC is being criticized for not being firmly grounded in scientific evidence. Due to its unclear conceptualization, it is difficult to operationalize in measurable outcomes and to empirically develop a sound evidence-base (Bensing, 2000; Mead & Bower, 2000), hampering its further implementation (Sidani & Fox, 2014).

To conclude, PCC is a relevant paradigm in modern health care. It is understood as a care practice focused on the patient's needs and preferences and on the patient as a whole. However, there is a continuing lack of clarity about its conceptualization. In addition, critics stress the lack of scientific ground of this paradigm. To be able to further implement this paradigm it is important to increase the scientific base of PCC. In chapter 4 of this thesis, we further elaborate on the conceptualization of PCC.

2.3 Evidence Based Medicine

The concept of Evidence Based Medicine (EBM) has its roots more than 150 years ago (Darlenski, Neykov, Vlahov, & Tsankov, 2010), but it has actively developed after being first mentioned by a Canadian physician, Guyatt, in 1990 (Miles & Mezzich, 2011). It was introduced as a new approach to practicing and teaching medicine in 1992. According to Guyatt et al. (1992), this new paradigm was a response to four assumptions clinical practice was based on until then: 1) unsystematic observations are a valid way to build one's knowledge about a patient, 2) studying and understanding basic mechanism and pathophysiology are sufficient to guide clinical practice, 3) thorough medical training and common sense are sufficient to evaluate new tests and treatments, and 4) both content and clinical expertise are sufficient to generate guidelines. These assumptions were firmly criticized by the Evidence Based Medicine Working Group. In 1973, it was documented by Wennberg and colleagues that a wide variation in practice patterns existed. They concluded that the assumption that a health professional always did the right thing based on medical education, journals, individual experience, and exposure to colleagues, was flawed (Eddy, 2005). Moreover, it turned out that only 15% of medical practices were based on clinical trials and that often used clinical practices proved to be ineffective by the same clinical trials (Eddy, 2005). These acknowledgements were reasons to introduce the new paradigm; to de-emphasize intuition and unsystematic clinical experience and to stress the importance of scrutinizing evidence derived by clinical research (Guyatt et al., 1992) and not solely base medical decisions on the 'art of medicine' (Eddy, 2005).

According to Guyatt et al. (1992), the paradigm shift towards EBM started with the development and appreciation of clinical research from the 1960s onwards. EBM is most 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'* (Sackett et al., 1996, p. 71). The objective of EBM was therewith to close the gap between research and clinical practice (Silva & Wyer, 2009). In addition to the statement that clinical practice should be based on the best available research evidence, in EBM it is acknowledged that clinical decision making cannot solely be based on research evidence but also on individual clinical expertise (Guyatt et al., 1992; Miles & Mezzich, 2011; Sackett et al., 1996). Individual clinical expertise is defined as: *'the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care'* (Sackett et al., 1996, p. 71). In other words, the more clinical expertise a health professional has, the more the individual patients' preferences will be compassionately used and taken into account (Sackett et al., 1996). Patients' preferences could therefore be recognized as a separate source of data in decision making (Sackett et al., 1996; Satterfield et al., 2009).

Since its introduction, EBM has been accepted widely and it quickly became a dominant paradigm. This paradigm has supported thousands of guidelines and protocols, used by health professionals in their decision making in managing patients (Weaver, 2015). EBM has been applauded for the support it provides in clinical decision making, the integration between medical education and clinical practice and (Darlenski et al., 2010), the improvement of efficacy and efficiency in health care and the decrease of the use of ineffective clinical practices (Hasnain-Wynia, 2006). However, although conceptually appealing, EBM has been criticized from its introduction onwards (Satterfield et al., 2009). First, EBM has been extended to both health systems and policy-making (Ter Meulen & Dickenson, 2002), despite the notion of Sackett and colleagues that EBM needs to be restricted to the context of individual patient care. This turned EBM into a movement serving cost cutters by excision of non-evidence-based treatments (Hay et al., 2008; Miles & Loughlin, 2011; Sackett et al., 1996) and suppressing clinical freedom (Sackett et al., 1996). Second, research evidence as source of data for decision making got a dominant status over clinical expertise and patients' preferences, and RCTs became most valuable to generate this research evidence. This results in research evidence on population level, instead of individual level (Guyatt et al., 1992; Ter Meulen & Dickenson, 2002), impeding the direct translation from research evidence into clinical practice (Darlenski et al., 2010; Feinstein & Horwitz, 1997) and subsequently, leaving little room to pay attention to individual needs and preferences (Bensing, 2000), resulting in impersonal care (Weaver, 2015). Last, despite the explicit mentioning of the continued importance of the use of clinical expertise and patients' preferences in clinical practice by the Evidence Based Medicine Working Group (Guyatt et al., 1992), neither at the inception of EBM, nor in major articles, a coherent method has been presented to do so, especially when research evidence and clinical expertise and patients' preferences are at odds (Miles & Mezzich, 2011; Satterfield et al., 2009; Tonelli, 2006; Wieringa et al., 2018).

In conclusion, the introduction of EBM has been of great value for improving health care and enabling the provision of the highest quality of care. However, the criticism needs to be addressed in order for EBM to fully comprehend the complexity of clinical practice and to be able to respond to individual needs of patients.

2.4 EBM and PCC

Both EBM and PCC have challenged medicine to move forward in necessary, but different, ways (Miles & Mezzich, 2011). EBM de-emphasized the role of intuition by giving primacy to evidence and assists to deliver high quality mental health care based on this evidence to protect patients from unhelpful and unnecessary treatments. The EBM paradigm provided clinical practice with guidelines and protocols to base clinical decision making on. The current (mental) health care system, strongly encourages adherence to these guidelines by pay-for-performance and other financial incentives and by litigation threats when deviating from these guidelines (Miles & Mezzich, 2011; Weaver, 2015). It has been argued that these factors turn clinical practice into 'cookbook medicine' and 'impersonal care' (Darlenski et al., 2010; Feinstein & Horwitz, 1997; Miles & Mezzich, 2011; Weaver, 2015). Simultaneous to the emphasis on EBM in health care systems, the need for a more PCC approach increased, among other things due to the increase in chronic diseases (Miles & Loughlin, 2011; Wagner et al., 2005). Despite the unclear conceptualization of PCC, the central notion is paying great attention to the needs of the individual (Miles & Mezzich, 2011; Weaver, 2015) and considering these needs in clinical decision making. Due to the differences in views on what should guide clinical practice, until recently, EBM and PCC were considered 'two separate worlds' (Bensing, 2000), however, nowadays, the number of scholars urging for bridging the gap between EBM and PCC increases (Barratt, 2008; Bensing, 2000; Miles & Mezzich, 2011; Sacristán, 2013; Wagner et al., 2005; Weaver, 2015). In EBM as it is seen today, the focus is on the E of EBM, more than on clinical expertise and individual patients' needs, and this prominent role that is attributed to evidence in clinical decision-making seems at odds with PCC. In order to be able to align EBM and PCC, it is important to first fully grasp the problems with the E of EBM for PCC and to understand what *evidence* and *knowledge* actually are.

2.4.1 What is evidence?

According to the English Oxford Dictionary, evidence is *'the available body of facts or information indicating whether a belief or proposition is true or valid'*. Evidence is considered a 'subset of information' by Scott-Findlay & Pollock (2004) and Jones & Higgs (2000) define evidence as '*knowledge derived from a variety of sources that has been subjected to testing and has found to be credible'* (cited by Scott-Findlay & Pollock, 2004, p. 93). A related definition used by Moore, Titler, Kane Low, Dalton, & Sampselle (2015) is: *'information from the scientific literature that is critiqued before it is applied to practice'* (p.2). A central theme in the definition of evidence in health care relates to it being *independently observed and verified,* highlighting the importance of carefully scrutinizing that which passes for evidence (Rycroft-Malone et al., 2004). By some, the concept of evidence is strictly reserved for research findings (Scott-Findlay & Pollock, 2004), while others see experiential knowledge and expertise as evidence as well (French, 2001; Goldenberg, 2006). Currently, politically and hence financially, the primary focus is on generating *research* evidence (Rycroft-Malone et al., 2004), narrowing the definition of evidence to research evidence. The discussion on what could be considered evidence in health care and how it could be generated gained momentum with the introduction of the paradigm of 'Evidence Based Medicine'.

In EBM clinical practice is based on the best available evidence, based on the hierarchy of evidence. On top of this hierarchy are the meta-analyses and systematic reviews, closely followed by RCTs and thence by cohort studies, case control studies, case series, and case reports (Mantzoukas & Watkinson, 2008; OCEBM, 2011; Rosner, 2012). Sackett and colleagues, notified that *'evidence based medicine is not restricted to RCTs'* but *'involves tracking down the best available evidence with which to answer the clinical question'* (Sackett et al., 1996, p. 72). Nonetheless, as mentioned earlier, in the EBM paradigm, RCTs, meta-analysis and systematic reviews are considered the gold-standard when it comes to generating evidence (Rycroft-Malone et al., 2004; Sackett et al., 1996) while clinical observations and experience are placed last in the evidence hierarchy (Isaac & Franceschi, 2008).

Criticisms on basing clinical practice on the best available evidence according to the evidence hierarchy are often directed towards questioning the usefulness of outcomes of RCTs in clinical practice and problematizing their position in the hierarchy. It must be acknowledged that due to RCTs a large number of effective therapies came to light and ineffective therapies could be recognized (Schrevel, 2015). However, research evidence derived from RCTs is not always easily translated into practice (Henry et al., 2013; Newnham & Page, 2010; Rosner, 2012). One reason for this is that these research populations are often homogenous groups, and persons with comorbid disorders or symptoms are excluded (Williams & Garner, 2002). These homogenous groups are only to a limited extend comparable with the majority of the patients in clinical practice (Henry et al., 2013; Newnham & Page, 2010; Williams & Garner, 2002). A second reason is that the outcomes measured in an RCT are not always the outcomes aimed for in clinical practice. Outcomes such as improving life functioning and coping with stress are difficult to measure and therefore often not used in RCTs (Drake et al., 2001; Kazdin, 2008; Newnham & Page, 2010). A third reason is that treatments under research are often not studied under flexible circumstances, while in practice treatment requires flexibility, for example in duration of the treatment or small adaptions to meet the patients' needs (Newnham & Page, 2010). Fourth, people motivated for cooperating in a RCT, are often not 'the average patient' seen in clinical practice (Williams & Garner, 2002). In addition, diagnosis alone is considered a poor predictor for treatment outcomes, as personality and social circumstances play a major role as well (Williams & Garner, 2002). These points of criticism render the problems of using evidence derived by RCTs for treatment of the individual patient and consequently for PCC.

To conclude, although in the EBM paradigm preferably RCTs are conducted to generate scientific evidence there is much debate on the usefulness of this type of evidence in clinical practice for the individual patient. It has been broadly acknowledged that other *factors* or other types of *knowledge* than solely research evidence do influence clinical practice (Scott-Findlay & Pollock, 2004). To understand what influences clinical practice in addition to research evidence, the following section will elaborate on the concept of *knowledge*.

2.4.2 What is knowledge?

The English Oxford Dictionary defines knowledge as '*facts, information, and skills acquired through experience or education; the theoretical or practical understanding of a subject'.* According to Scott-Findlay & Pollock (2004), in the field of knowledge utilization in nursing science, knowledge is a product of knowing and is generated in the human actor by integrating information (i.e. theory, experience, research) with experience. In addition, knowledge is described as being fundamental for clinical decision making (Greenhalgh, Flynn, Long, & Tyson, 2008; Rycroft-Malone et al., 2004). Overall, knowledge is better described by its typology and by its sources than by its definition.

Broadly, two types of knowledge are recognized in Western society: 1) propositional knowledge or codified knowledge, and 2) non-propositional knowledge or personal knowledge and practical knowledge (Higgs, Jones, & Titchen, 2008; Rycroft-Malone & Stetler, 2004). *Propositional knowledge,* also called explicit knowledge (Polanyi (1966) in Greenhalgh et al., 2008) or 'knowing what' (Greenhalgh et al., 2008), is formal knowledge, derived from research. It could be considered as the information part of knowledge, and is transferrable (Caron-Flinterman, Broerse, & Bunders, 2005; Greenhalgh et al., 2008; Rycroft-Malone et al., 2004). *Non-propositional knowledge* or tacit knowledge (Polanyi (1966) in Greenhalgh et al., 2008), could be divided in practical knowledge and personal knowledge. Practical knowledge, also called procedural knowledge (Pearson, Wiechula, Court, & Lockwood, 2007), is acquired by (practical) experience. It is also understood as the 'knowing how' (Higgs et al., 2008), it consists of skills and is considered the competence part of knowledge (Caron-Flinterman, Broerse, & Bunders, 2005). Eraut (2000), a researcher in knowledge development in health care practice, defines personal knowledge as '*the cognitive resource which a person brings to a situation that enables them to think and perform. This incorporated codified knowledge in its personalized form, together with procedural knowledge and process knowledge, experiential knowledge and impressions in episodic memory* (Eraut, 2000, p. 114). This type of knowledge could either be explicit or tacit and is identified by its context and the manner of use (Eraut, 2000). One form of personal knowledge is *experiential knowledge,* a relatively new concept, which is defined as *'the often implicit, lived experiences of individual patients with their bodies and their illnesses as well as with care and cure* (Caron-Flinterman, Broerse, & Bunders, 2005, p. 2576). In contrast with propositional knowledge, non-propositional knowledge is less easy to transfer. However, it could be turned into propositional knowledge, by explicating and debating, contesting and verifying (Rycroft-Malone et al., 2004).

Knowledge derives from a variety of sources. Guided by the typology of sources of knowledge by Rycroft-Malone et al. (2004), four sources of knowledge are recognized as relevant in this thesis. The first source is *research* (Tonelli, 2006). As mentioned earlier, this source is often valued highest, despite the fact that it is not easily translated into clinical practice. Research evidence needs to be used, and therefore translated and particularized in clinical practice. To do so, health professionals need to translate the evidence to the context of the individual patient using the knowledge derived from the second source, namely *clinical knowledge*. This form of knowledge is often tacit knowledge that health professionals gather by *doing* medicine (Greenhalgh et al., 2008; Malterud et al., 2001; Rycroft-Malone et al., 2004; Schrevel, 2015). Clinical knowledge is based on the experience of the clinician who bases his acting on patients' observations and advices in the ongoing process of 'observing, intervening and evaluating' (Pols, 2014) which could be described as 'the art of medicine' (Malterud et al., 2001). The third source is *patients and their caregivers.* They provide two types of knowledge, namely knowledge derived from their previous experience with care and knowledge derived from their knowledge of themselves, their personal life and their knowledge of living with a disorder, e.g. what it is like to go through an illness episode (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998; Pols, 2014; Rycroft-Malone et al., 2004). Pols (2014) suggests that there is immense value in acknowledging patients' knowledge as the equivalent of clinical knowledge. The fourth source is *local context* (Rycroft-Malone et al., 2004) or *system features* (Tonelli, 2006), i.e. the culture of the organization, local and national policy, social or professional networks and economic, logistic and legal factors. Tonelli (2006) states that '*the very system of health care delivery, as well as professional and societal value, may influence decisions regarding the care of individuals'* (p.253). All these sources will be used, either consciously or unconsciously, in clinical decision making (Rycroft-Malone et al., 2004) and it has been argued that it is essential to embrace the value of all of these types of knowledge and not prioritize one source over the others (Tonelli, 2006).

2.4.3 Strategies for the alignment of EBM and PCC

In the previous section, it was explained what the E of EBM entails. Moreover, the evidence hierarchy and its problems for implementing the research outcomes in clinical practice were addressed. In addition, the concept of knowledge and how this influences clinical decision making was elaborated. Overall, the majority of the critics on EBM addresses the threat that the narrow view on evidence poses for PCC. Criticism on PCC mostly entails the lack of clarity of the conceptualization. Both paradigms are considered relevant in health care delivery, however, due to their differences in views on what should guide clinical practice and the value attributed to evidence and knowledge, these paradigms are not supportive to each other. One could argue that it would be beneficial for clinical practice to align EBM and PCC. In this thesis, alignment is understood as strengthening the evidence base of PCC and strengthening the patient centeredness of EBM. Strengthening the evidence base of PCC starts with the improvement of clarity on the conceptualization of PCC. Strengthening the patient centeredness of EBM entails broadening the evidence base. A variety of strategies could be used to contribute to alignment. By conducting these alignment strategies, the predominant points of criticism of both paradigms can be addressed. The following section will elaborate on strategies used to contribute to alignment of EBM and PCC.

Improving clarity on conceptualization PCC

As mentioned earlier, the major point of criticism on PCC is the lack of clarity on what it entails and the vague conceptualization is often described by scholars (Mead & Bower, 2000; Sidani & Fox, 2014; Wagner et al., 2005), despite the numerous attempts (Gabrielsson, Sävenstedt, & Zingmark, 2014; Hobbs, 2009; McCormack, Karlsson, Dewing, & Lerdal, 2010; Mead & Bower, 2000; Mills et al., 2014; Scholl, Zill, Härter, & Dirmaier, 2014). It has been argued that a lack of conceptual clarity hampers the scientific development of the paradigm (Bensing, 2000; Mead & Bower, 2000). A clear conceptualization leads to the possibility to operationalize PCC to conduct systematic research (Bensing, 2000; Mead & Bower, 2000). Subsequently, this could lead to a solid base of evidence (e.g. on the effectiveness) that could be included in the guidelines in order to translate it to clinical practice. To contribute to a better conceptualization, the first step would be to synthesize the literature on the conceptualization of PCC. In chapter 4 of this thesis, we attempt to contribute to clarifying the conceptualization of PCC.

Broadening the evidence base

A first strategy to broaden the evidence base is to take into account clinical experience of the health professional as a source of knowledge contributing to decision making, since health professionals have experience in what actually works in clinical practice. (Hay et al., 2008). A second strategy is including patients in research and health care. Patients are increasingly involved in guideline development (Pittens, Noordegraaf, van Veen, & Broerse, 2013), in health care services (Bagchus, Dedding, & Bunders, 2014) and in health care research (Boote, Baird, & Beecroft, 2010; Elberse, Pittens, de Cock Buning, & Broerse, 2012). One reason for including patients' perspectives is that the knowledge patients have is unique, since they have experiential knowledge on the illness, on living with the illness and on their care needs (Caron-Flinterman, Broerse, & Bunders, 2005; Tait, 2005), that add value to the knowledge of health professionals and researchers (Broerse, Zweekhorst, van Rensen, & de Haan, 2010). This knowledge is often tacit and embedded in day-to day habits (Schrevel, 2015). Explicating patients' perspectives provides unique knowledge and enables the alignment of care and research with the needs of patients. This could improve the quality of health care (Entwistle et al., 1998) and the implementation and dissemination of research findings (Entwistle et al., 1998). Including this 'experiential knowledge' could increase the clinical relevance and implementation of research (Caron-Flinterman, Broerse, & Bunders, 2005), the translation of evidence into health care recommendations (Harding, Pettinari, Brown, Hayward, & Taylor, 2011) and improve the acceptability of both guidelines and research (Caron-Flinterman, Broerse, & Bunders, 2005; Harding et al., 2011), due to a more ‘open-minded approach’ on which treatment outcomes and research questions matter (Faulkner & Thomas, 2002). Including the experiential knowledge of patients is crucial to be able to be more responsive to patients’ needs, and therewith deliver more patient centered care (Elberse et al., 2012). Third, it is argued that producing research closer to the actual circumstances of clinical practice (real time evidence) could result in research that is more relevant, more acceptable, and more tailored for clinical practice (Green, 2009). Sacristán (2013), also acknowledges the relevance for medical practice to become a suitable environment for research, in order to ‘make better use of all the knowledge generated in each medical act’ (p. 463).

In order to broaden the evidence base by means of the above mentioned strategies, scholars urge for participatory research, qualitative research, narratives, and practitioner-based research (Green, 2009; Kazdin, 2008; Misak, 2010; Price, Djulbegovic, Biswas, & Chatterjee, 2015; Rolfe, 1998), i.e. research that is currently placed last in the hierarchy. For example, qualitative research methods gain insight in phenomena and human experiences and therewith providing an understanding of individual patients’ experiences (Kazdin, 2008). With these research designs and methods, non-propositional knowledge could be turned into propositional knowledge, and become distributable so as to benefit other health professionals as well. Thus, the recognition of the influence of multiple sources of knowledge in clinical practice and turning these sources of knowledge into propositional knowledge by means of qualitative research, participatory research or narratives could strengthen the patient centeredness of EBM.

This thesis is a first attempt to align PCC and EBM by using alignment strategies. Applying the alignment strategies to the field of bipolar disorder could provide lessons for clinical practice and research that are expected to enable health professionals to treat patients with bipolar disorder according to the principles of EBM and PCC, and researchers to conduct research relevant for clinical practice.

CHAPTER 3

Research design

The previous two chapters described the concepts on which this thesis is built, the existing gap between EBM and PCC and the recent acknowledgement that these two paradigms are not necessarily belonging to two separate worlds. Creating alignment between these two paradigms could contribute to better health care. This chapter will present the aim and the main research question that guide this thesis, as well as the research approach and methods. This is followed by considerations concerning research validity and research ethics.

3.1 Research aim and research questions

As described in the previous chapter, currently in mental health care EBM and PCC are prominent paradigms, both aimed at delivering good quality care. While both have clear benefits for health care practices, at this moment these paradigms are not always supportive of and complementary to each other. In response to this lacuna, this thesis aims to contribute to the improvement of mental health care by systematically bringing the separate worlds of PCC and EBM together. It does so by increasing the understanding of what constitutes good quality mental health care from the perspectives of PCC and EBM and by broadening the evidence base. We used alignment strategies that contributes to strengthening the evidence base of PCC by providing clarity on the conceptualization and operationalization of PCC and to strengthening the patient-centeredness of EBM by broadening the evidence base with the perspectives of patients and health professionals on care and research for patients with bipolar disorder.

This aim resulted in the following main research question:

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

The following section will introduce the sub-questions that guided the five studies on which this thesis is built.

In order to deliver good quality mental health care, it is important to understand what this entails. Therefore, the following sub-question was formulated:

1. *What constitutes good quality care for patients with bipolar disorder, from the perspective of EBM, PCC and patients?*

According to the EBM paradigm, good quality care bases clinical decisions on the best available evidence. This best available evidence is translated to clinical practice by means of guidelines. Therefore, guidelines are considered as a tool supportive to the EBM paradigm. Thus, the core concept of good care according to the EBM paradigm, is care that complies with guidelines. However, there is less clarity on the perspectives of PCC scholars on good quality care, since there is a lack of clarity on the conceptualization of PCC and consequently on what good quality care entails from this perspective. In addition, little is known on what the perspectives of patients with bipolar disorder are on good care. It is extremely relevant to understand their views on good care in order to be able to deliver care according to their needs and consequently to be able to place patients at the center of clinical practice. Thus, to answer this research question, we studied the perspectives of patients and PCC scholars on good care. This resulted in the following sub-questions:

1a. *What constitutes good quality care for patients with bipolar disorder, from the perspective of patients?*
1b. *What constitutes good quality care for patients with bipolar disorder, from the perspective of PCC scholars?*

To be able to strengthen the patient centeredness of EBM, it is important to align research that is to be conducted with the perspectives of patients and health professionals on relevant research. Therefore, the following sub-question was formulated:

2. *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients and health professionals?*

By studying the research topics relevant for end-users, research evidence is generated that is more relevant for clinical practice. Subsequently, including this evidence in guidelines could result in more PCC, since these guidelines better reflect the needs of end-users - “someone who will consume, use or work in the specific health field under research” (Elberse, Pittens, et al., 2012, p. 232). This could be achieved by understanding the perspectives of end-users on research. Currently, research agendas that steer the direction of research are primarily shaped by researchers, funding agencies, and policy makers. However, it has been increasingly argued that including the perspectives of end-users in the research agenda setting is essential to improve the acceptance of the outcomes. Second, research needs of end-users could be supplementary to those of other stakeholders since end-users have experience with living with the disorder or treating people with the disorder. These additional research needs risk being missed when end-users are not involved in the processes of setting the research agenda. This research question is, therefore, divided into two sub-questions:

2a. *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients?*
2b. What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to health professionals?

In order to fully understand the perspectives of health professionals on relevant research, it is important to understand their views on patients with bipolar disorder and their needs. Therefore, the following sub-question is formulated:

3. Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder and patients' research needs?

Studying the interpretative frames of health professionals, provides insights in how health professionals approach the problems patients encounter in living with bipolar disorder and the knowledge base that is used by health professionals in order to address these problems. This sub-question is answered by studying which interpretative frames are used by health professionals in understanding the research needs from patients. In addition, it is answered by experimenting with conducting research in a real time setting on a complex problem in order to gather real time evidence. From the answers to the previously introduced questions, it becomes clear that diagnosing bipolar disorder is an important complex problem in clinical practice. Therefore, the diagnostic process of bipolar disorder is used as a case to study the interpretative frames in a real time setting. Conducting research in a real time setting could contribute to more relevant research outcomes and broaden the evidence-base of the diagnostic process of bipolar disorder, since the research incorporates a broad range of aspects encountered in clinical practice. This provides health professionals with the possibility to base clinical decision making on evidence that reflects the complex problems they encounter in clinical practice. This question is divided in the following two sub-questions:

3a. Which interpretative frames can be distinguished, used by health professionals in understanding the research needs of patient?
3b. Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder, with a specific focus on the diagnostic process?

3.2 Research approach

In this thesis, we employed qualitative research methods, as well as a mixed-method approach to validate qualitative findings. In general, qualitative research can contribute to the understanding of how people make sense of certain (complex) phenomena, e.g. illness and treatments, incorporating their motivations, emotions, experiences and perceptions (Gray, 2014; Sools, 2013). It provides the opportunity for individuals to elaborate and explore topics that are considered important, in their own words and meaning. Qualitative research methods can be used when relatively little is known about the phenomenon, or to elaborate and gain new perspectives on topics that are often studied (Gray, 2014). It is highly contextual, since data is collected in 'real life' settings.

The rationale behind this research approach, is threefold. First, the qualitative research approach fits the main research question, since this approach provides the possibility to answer the 'what' of a phenomenon (Green & Thorogood, 2009). Second, in health research (and this thesis can be considered as contribution to the field of health research), qualitative methods are used to investigate health, illness or health services, from the perspectives of affected patients or health professionals (Green & Thorogood, 2009), which contributes to answering the main question of this thesis by providing the opportunity to understand what patients consider good quality care and what patients and health professionals consider relevant research. Third, using a qualitative approach is a step towards the alignment of EBM and PCC. It has an added value in terms of broadening the evidence base of medicine with perspectives of patients and health professionals. This research approach in itself, could therefore be considered a strategy that contributes to the alignment of EBM and PCC.

In study 3, a mixed-method approach was used. This approach relies on the combination of qualitative and quantitative research methods and integrating the two forms of data (Creswell & Plano-Clark, 2018). In this particular study, we choose this approach to be able to validate the qualitative findings among a larger sample.

3.3 Methods

The sub-questions were answered by using strategies described in the previous chapter: improving clarity of the conceptualization of PCC and broaden the evidence base by using health professionals' and patients' perspectives and by conducting research in a real time setting. All five studies contain strategies that contribute to reconciling EBM and PCC. Table 3.1 provides an overview of the sub-questions and the used strategies.

Table 3.1 Overview of research questions, used strategies and related studies and chapters.

Sub-question	Alignment strategy	Study	Chapter
What constitutes good quality care for patients with bipolar disorder, from the perspective of PCC?	Clarifying concept PCC	1	4
What constitutes good quality care for patients with bipolar disorder, from the perspective of patients?	Broaden the evidence-base by using patients' perspectives	1,2	4,5
What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients?	Broaden the evidence-base by using patients' perspectives	3	6
What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to health professionals?	Broaden the evidence-base by using health professionals' perspectives	4	7
Which interpretative frames can be distinguished, used by health professionals to understand the research needs of patient?	Broaden the evidence-base by using health professionals' perspectives	4	7
Which interpretative frames can be distinguished, used by health professionals to understand bipolar disorder, with a specific focus on the diagnostic process?	Broaden the evidence-base by using health professionals' perspectives Broaden the evidence by conducting real time research	5 5	8 8

3.3.1 Good quality mental health care

The first sub-question of this thesis was guided by two studies that focused on perspectives of good care. To answer this sub-question a narrative review and two qualitative studies were conducted.

Study 1: Conceptualization of PCC

The aim of this study was to better understand the conceptualization of PCC and refine the conceptualization with perspectives on 'good care' of people with bipolar disorder. This study used two strategies, namely improving clarity of the conceptualization of PCC and using patients' perspectives to further the understanding on 'good care'. We conducted a narrative literature review with a systematic search, including literature reviews on the conceptualization of PCC. The search for literature was conducted in four databases, resulting in an inclusion of 12 literature reviews. We synthesized the existing literature into a model of PCC. Subsequently, we compared patients' perspectives on 'good care', derived from two separate qualitative studies, with the literature and refined the conceptualization of PCC accordingly. Six FGDs with patients with bipolar disorder and nine interviews were conducted. In addition, four FGDs were conducted with patients with ADHD, discussing needs and experiences of these patients with health care. In both studies people with comorbid disorders were included, to acknowledge the complexity of cases health professionals encounter in clinical practice. Data were analyzed using the qualitative software program MAXQDA.

Study 2: Needs regarding mental health from a patient's perspective

This study aimed to explore the challenges patients with bipolar disorder face and explicate what this implies for care and research needs. The strategies 'improving clarity on the conceptualization of PCC' and 'using patients' perspectives' were used. This study contributes to the topic under research in this thesis in two ways. First, it provides a comprehensive understanding on how research and care needs from patients relate to each other. Second, it provides a better understanding of 'good care' from a patient's perspective. Three specific themes were central to the study: diagnosis, treatment and recovery. This study was based on the hypothesizes that 1) the challenges patients experience and the associated care and research needs are interwoven and combining these needs would provide a more complete understanding and that 2) a more complete understanding could contribute to bridging the gap between clinical practice and research when conducting research based on these understanding and therewith conducting research fitting patients' challenges and needs. Data of two separate qualitative studies were compared. The first study focused on challenges and associated research needs, the second study on challenges and associated care needs. The patients' perspectives were derived by means of FGDs (six FGDS with patients on research needs and seven FGDs with patients on care needs). Data were analyzed with the qualitative software program MAXQDA.

3.3.2 End-users' perspectives

The second sub-question of this thesis was answered by two studies focusing on the needs for research of patients and health professionals.

Study 3: Research agenda from a patient's perspective

This study aimed to set up a research agenda from the perspective of patients with bipolar disorder. Explicating the needs of patients regarding research could be considered a necessary condition for research to tie in with the needs of patients and therewith to improve the relevance and patient centeredness of the research. It provides a new base of evidence, by using perspectives of patients. This study consisted of two phases: 1) the consultation phase and 2) the prioritization phase. In the consultation phase, we conducted six FGDs, including patients with bipolar disorder, to discuss the challenges they face in life with bipolar disorder and what these challenges imply for their needs regarding research. All research topics that derived from these FGDs were listed in a questionnaire, for the prioritization phase. The questionnaire aimed to validate the findings from the consultation phase in a larger sample and to prioritize the research topics. Data from the consultation phase were analyzed with the qualitative software program MAXQDA. The research topics were prioritized with descriptive statistics, using quantitative software program SPSS version 23.

Study 4: Relevant research themes for bipolar disorder from a health professional's perspective

This study aimed to explore research needs from clinicians' perspectives and to explore clinicians' perspectives on the research agenda from patient with bipolar disorder. Formulating health professionals' research needs and let them reflect on the explicated research needs of patients provides researchers with a more solid ground to study the topics on the research agenda, since the interest in the topics are widely supported by the end-users of the research, increasing the clinical relevance of the research. This study used health professionals' perspectives as a strategy. This study followed two methodological phases. In phase 1, research needs for a health professional's perspective were derived by means of seven FGDs and two interviews, both guided by a topic list addressing trends in health care, hopes for the future and associated research needs. In phase 2, six interviews were conducted to reflect on the research needs of patients and to get a deeper understanding of the research domains of the researcher-clinicians. Data were analyzed by qualitative software program atlas.ti.

3.3.3 Real time evidence

The third sub-question was answered by study 4 (previously discussed) and study 5.

Study 5: Role clarification in multidisciplinary bipolar disorder health care teams

This study aimed to clarify the roles of different disciplines in multidisciplinary teams (MDTs) in specialized outpatient centers, by elucidating their respective cognitive maps. This study contributes to answering the research question in two ways. First of all, to be able to conduct research relevant for clinical practice, clarifying how clinical practice operates is important. This study contributes to this clarification by gaining insight into multidisciplinary collaboration in a complex problem such as diagnosing bipolar disorder as encountered in clinical practice and in the different perspectives used in a MDT. Second, this study is an example of how research can be conducted to do justice to the actual circumstances of clinical practice. Moreover, it is an example of how clinical expertise of health professionals could be used to clarify a phenomenon commonly occurring in clinical practice. To reach the aim of the study, three methodological phases were followed. In the first phase, the exploration of roles in the diagnostic process of bipolar disorder, we explored the added value of each discipline in a multidisciplinary team, involved in the diagnostic process of bipolar disorder by means of five FGDs and four interviews with psychiatrists, nurses and psychologists. In the second methodological phase, defining tasks and roles in the diagnostic process, we conducted a Delphi study, aiming to reach consensus among experts in the field of bipolar disorder on which tasks should be performed in the diagnostic process and which discipline should primarily perform that task. In the last phase of the study, r*ole clarification using cognitive maps,* cognitive maps were formulated in team setting. Subsequently, the participants used these cognitive maps to differentiate the tasks, to gain insight in the added value of each discipline in the team. In this phase, we conducted two FGDs in two bipolar disorder health care teams.

Table 3.2 summarizes the methods used and the included participants per study.

Table 3.2 Overview of used methods and included participants per study.

Study	Study topic	Method	Participants
1	Conceptualization PCC	Narrative review	12 literature reviews
		6 FGDs + 9 interviews	Patients with BD (n=44)
		4 FGDs	Patients with ADHD (n=30)
2	Care and research needs from patients' perspectives	6 FGDs on research needs	Patients with BD (n=35)
		7 FGDs on care needs	Patients with BD (n=57)
3	Research agenda from patients' perspectives	6 FGDs on research needs	Patients with BD (n=35)
		Questionnaire	Patients with BD (n=219)
4	Relevant research themes from health professionals' perspectives	7 FGDs + 2 interviews	Health professionals (n=18)
		8 Interviews	Researcher-clinicians (n=8)
5	Role clarification in multidisciplinary BD teams	*1st phase* 5 FGDs + 4 interviews	Health professionals (n=18)
		2nd Phase Delphi method	Health professionals (n=27)
		3rd phase 2 FGDs	Health professionals (n=14)

3.4 Validity

Validity often is divided in internal validity and external validity. Internal validity is to be understood as '*how far the constructions of the researcher are grounded in the constructions of those being researched'* (Gray, 2014, p. 182). In other words, the influence the researcher has on the study design, the participation, the data collection and interpretation of the data. External validity is understood as '*the extent to which it is possible to generalize from the data to other cases or situations'* (Gray, 2014, p. 182). A variety of techniques were used to increase the validity of this study and decrease the influence of the researcher on the research.

Techniques to ensure internal and external validity

- *Data triangulation*: In the first four studies, data triangulation was obtained by collecting data on a certain phenomenon (e.g. challenges people with bipolar disorder experience, aspects of good care) using multiple sampling strategies. Methodological triangulation was attained in the mixed-method study where qualitative data were validated with a questionnaire. Moreover, in each research project, multiple researchers were involved to discuss and reflect on the findings and their interpretations, through which researcher triangulation was obtained.

- *Member checks* (Sandeloswki, 1993)*:* All participants included in this study received a summary of the interview or FGDs by email to enable to check the researchers' interpretations of participants' perspectives. Participants were provided with the opportunity to respond in case of misinterpretations.
- *Data management:* All interviews and FGDs were audiotaped and transcribed verbatim to prevent loss of data. Every FGDs was guided by two facilitators, providing the possibility to take notes of every FGDs.
- *Data saturation:* In each study, we opted for data saturation, a state of 'informational redundancy', i.e. no new information appears (Saunders et al., 2017) in the interviews or FGDs. Data collection ended when 2 or 3 interviews or FGDs did not provide new data.
- *Generalization:* The findings and conclusions of each study were compared with findings from other scholars, to be able to embed our findings in the existing literature and to further strengthen our findings beyond our group of study. Comparing our findings with both findings within and outside our field of study increases generalizability.

3.5 Research ethics

In this thesis, several ethical considerations were taken into account. Study 1-3 involved patients with bipolar disorder. According to the Medical Ethical Committee of VU University Medical Center, the Medical Research Involving Human subjects act did not apply for these studies. Study 4 and 5 included health professionals. Due to the non-invasive character of these studies, formal approval from a medical ethical committee was not required, according to the Dutch law. In all studies, participants received information on the length of the study, the aim and the content of the study. They gave verbal or written informed consent on their contribution to the study and on audiotaping, transcribing and analyzing the data. Moreover, it was explained that participation was voluntary and that they could withdraw from the study at any given time, without providing us with a reason and without further consequences. In addition, anonymity was ensured for analysis and publication.

CHAPTER 4

Comparing patients' perspectives of 'good care' in Dutch outpatient psychiatric services with academic perspectives of patient-centred care

Abstract

Background: Over the past six decades, the concept of patient-centred care (PCC) has been discussed in health research, policy and practice. However, research on PCC from a patients' perspective is sparse and particularly absent in outpatient psychiatric services.

Aim: to gain insight into what patients with bipolar disorder and ADHD consider 'good care' and what this implies for the conceptualization of PCC.

Method: A literature review on the different conceptualizations of PCC was complemented with qualitative explorative research on the experiences and needs of adults with ADHD and with bipolar disorder with mental healthcare in the Netherlands using focus group discussions and interviews.

Results: The elements addressed in literature are clustered into four dimensions: 'patient', 'health professional', 'patient-professional interaction', and 'healthcare organization'. What is considered 'good care' by patients coincided with the four dimensions of PCC found in literature and provided refinement of, and preferred emphasis within, the dimensions of PCC.

Conclusions: The study shows the value of including patients' perspectives in the conceptualization of PCC, adding elements, such as 'professionals listen without judgment', 'professionals (re)act on the fluctuating course of the disorder and changing needs of patients', and 'patients are seen as persons with positive sides and strengths'.

This chapter is based on an article that is published in Journal of Mental Health:
E.F. Maassen, S.J.C. Schrevel, C.W.M. Dedding, J.E.W. Broerse & B.J. Regeer (2016). Comparing patients' perspectives of 'good care' in Dutch outpatient psychiatric services with academic perspectives of patient-centred care. *Journal of Mental Health,* 26 (1), 84-94.

4.1 Introduction

The concept of patient-centred care (PCC) has been applied to healthcare policy and healthcare delivery for more than 60 years (Hudon & Fortin, 2011). In 2001, the US Institute of Medicine added PCC to its objectives in recognition of the role of PCC in improving quality of care (Institute of Medicine, 2001). Since then, PCC has become the focus of recent healthcare reform in many Western healthcare systems (Robinson et al., 2008; Scambler & Asimakopoulou, 2014). Reasons for the popularity of PCC are twofold. First, it is grounded in the moral and ethical belief that it is the right thing to do regardless of its influence on health outcomes (Duggan et al., 2006). According to medical ethics, the autonomy of patients should be respected and they should be treated with respect and dignity (Epstein et al., 2010). Second, the delivery of PCC is associated with improved health outcomes, satisfaction with care and reduced healthcare costs (see e.g. Epstein, 2000; Greene et al., 2012; Hudon & Fortin, 2011; Mills et al., 2014; Robinson et al., 2008; Storm & Edwards, 2013).

Since its inception in the 1950s, various efforts have been made to define and conceptualize PCC. Initially, PCC was referred to as “individualized care based on patient-specific information” (Hobbs, 2009, p. 53) because each patient “has to be understood as a unique human-being” (Balint 1969, quoted in Saha et al., 2008, p. 1). A definition of PCC that is commonly used is the one formulated by the US National Academy of Medicine (formerly the Institute of Medicine, IOM) “a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patient’s 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 (Institute of Medicine, 2001, p. 7). Other more instrumental conceptualizations recognize PCC as a measure of the quality of healthcare provided by healthcare organizations (Robinson et al., 2008). Although PCC has a long history of political and academic attention, it is still being criticized for its unclear conceptualization. According to Stewart (2001, p.444-5), “PCC is better understood for what it is not” and definitions are “often oversimplified” and “fail to capture the indivisible whole of a healing relationship.”

In this article we are particularly interested in PCC in the context of mental health. In this context, PCC is mostly described within specific subfields, for example dementia (e.g. Clissett, Porock, Harwood, & Gladman, 2013; Stokes, 2005), forensic psychiatry (e.g.

Encinares & Golea, 2005; Livingston, Nijdam-Jones, & Brink, 2012) or psychiatric education (e.g. McGinthy, Larson, Hodas, & Metz, 2014; Robinson, Bamford, Briel, Spencer, & Whitty, 2010). Most literature concerns inpatient psychiatry which poses a distinct set of problems as compared to outpatient services, such as hospitalization, isolation and coercion (e.g. Gabrielsson et al., 2014; Geller, 2012; Storm & Edwards, 2013). As the majority of the Dutch patients is treated in an outpatient clinic (Trimbos Instituut, 2015), it is important to understand the conceptualization and implications for practice of PCC in this area as well.

However, research that takes a patient's perspective on PCC is sparse. This is striking as the core idea of PCC is that the patient should be placed at the centre of healthcare provision (Robinson, Callister, Berry, & Dearing, 2008). To the best of our knowledge only two qualitative articles have been published about the perspectives of mental health patients on PCC (Corring & Cook, 1999; Williams et al., 1999). Although articles have been published on perspectives of mental health patients on good care, this is not yet linked to PCC (e.g. Johansson & Eklund, 2003). Additionally, no articles have been published that explore PCC from the perspective of patients treated in outpatient psychiatric services. We argue that patients' stories are needed to give meaning to the concept of PCC discussed in the literature and to see if this conceptualization matches the perspectives and experiences of psychiatric patients. Thus, the aim of this study is to gain insight into what patients with bipolar disorder and ADHD consider 'good care' and what this implies for the conceptualization of PCC.

4.2 Methods

A three-step approach was used. First, a narrative literature review with systematic search was conducted to synthesize a model that integrates recent conceptualizations of PCC. Second, qualitative explorative research was conducted on the experiences and needs of adults with ADHD and adults with bipolar disorder with respect to mental healthcare in the Netherlands. Finally, the review findings and the patient perspectives were compared.

4.2.1 Literature review

Search strategy

Empirical research on PCC and its implementation in specific healthcare settings is extensive. However, relatively few articles focus on theoretical or conceptual underpinnings of the concept. As the latter were the focus of our interest, we chose to only include review articles and theoretical articles that used literature as their prime data source. Two researchers (EM and BR) separately performed searches and search strings and results were discussed by the entire research team in order to develop the final search string. The search for relevant literature was performed in four databases: PubMed, CINAHL, PsycInfo and Web of Science. The keywords used were patient/person/user/client centred/oriented/focused care OR patient/person/user/client centeredness OR tailor made care OR individualized care, in the title, in both US and UK spelling, AND dimension OR concept OR principle in the abstract, AND literature OR review, in the abstract.

Conflicting ideas on what to include or exclude were resolved through discussion by the research team. Articles were included if they were (1) about the theoretical conceptualization of PCC, and (2) were literature reviews. Articles were excluded when (1) they were not written in English or (2) they were about PCC in a specific context (e.g. specific disease). Search results from the four databases were imported in endnote and the duplicates were removed resulting in 107 original articles. 78 articles were excluded after screening for eligibility on basis of title and abstract. 18 articles were excluded after reading the full text, resulting in the inclusion of 11 articles. Additionally, 1 more article was included after reference tracking of the included articles. Figure 4.1 shows a flow chart of the systematic search.

Analysis

All elements of PCC derived from literature were studied and discussed by two authors; conflicting ideas were resolved through discussion within the research team. Subsequently, the elements were clustered into core dimensions.

4.2.2 Empirical data

The empirical data of two separate qualitative studies that explored the perspectives of patients on good care for adult ADHD and bipolar disorder, by means of semi-structured interviews and focus group discussions (FGDs), were used. These two patient groups were combined as in both studies the key issues expressed by the participants touched upon the description of PCC.

Participants and data collection

With respect to adult ADHD, participants discussed their experiences with and needs for adult ADHD care in the Netherlands in four FGDs (n=30). Participants were included when they (1) had a primary ADHD diagnosis and (2) were 21 years or older.

People with bipolar disorder participated in six focus groups (n=35) or were interviewed (n=9) about experiences with and needs for mental healthcare[1]. Inclusion criteria were (1) people who were diagnosed with bipolar disorder, (2) were above the age of 18 years old and (3) were stable at the time of the interview or focusgroup.

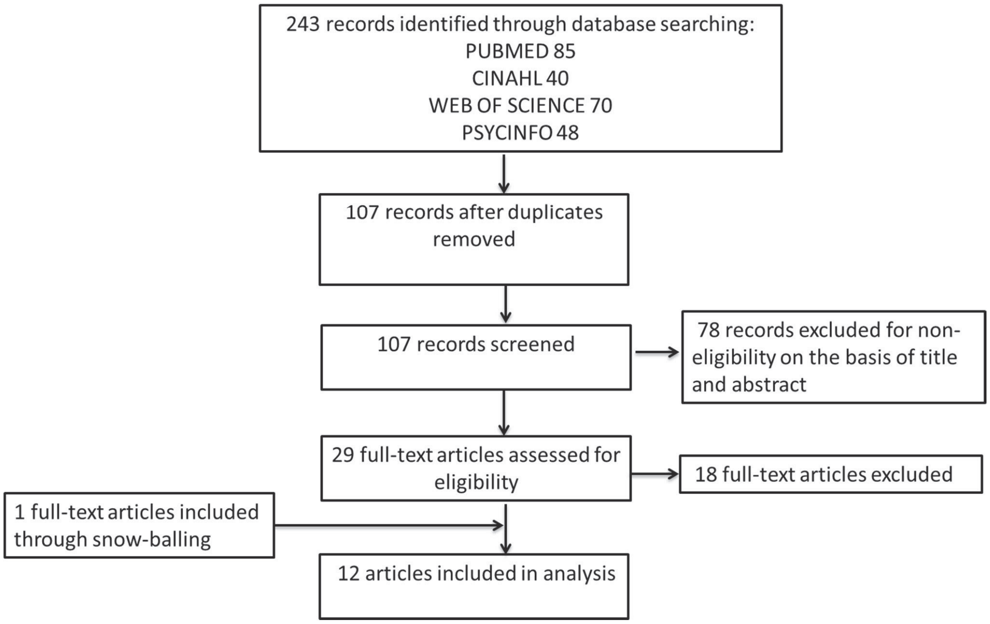

Figure 4.1 Flowchart of study selection.

Since comorbidity is common with ADHD and bipolar disorder, in both studies participants with comorbidities were also included in the study. FGDs took two hours and used a design that guided the discussions to reflect on all stages of care received: accessibility, diagnostic process and treatment. The interview guide had the same structure as the FGDs. FGDs and interviews were recorded and transcribed verbatim; summaries were sent to participants for member check.

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[1] Data collection took place in the context of studies in collaboration with three outpatient clinics for bipolar disorder in The Netherlands (GGZinGeest Amsterdam, GGZinGeest Hoofddorp and Altrecht Bipolair, Utrecht): a) a study on research priorities, in which patients' needs and wishes with regard to health care were discussed; and b) a study on best practices in mental health care.

Data analysis

Data were analysed thematically using a coding sheet based on the integrated PCC model derived from the literature review. Additionally, open coding was done to be able to include elements that were not mentioned in the literature but considered important aspects of good care by patients. The qualitative analysis software program MAXQDA 11.1.2 was used.

Ethical considerations

According to the Medical Ethical Committee of VU University Medical Center, the Medical Research Involving Human Subjects Act does not apply for the current studies with patients with bipolar disorder and ADHD. All participants gave verbal or written informed consent for audiotaping, analysis and publication. Participation was on a voluntary basis and participants could withdraw from the study at any point in time, without giving reasons and without consequence. Anonymity of all participants was ensured in every phase of the research.

4.3 Results

In current literature, PCC is conceptualized in a variety of ways. All reviews included in this study integrated the conceptualization of a variety of studies into a new conceptualization, albeit at different levels of analysis and with a different scope. Some reviews strictly speak about the theoretical dimensions (or components or themes) of the concept of PCC, while others include a discussion of required skills, factors contributing and barriers to PCC as part of the conceptualization. An overview of the included articles and the core dimensions by which PCC is described is provided in Table 4.1.

The elements addressed in literature were clustered into four dimensions (Figure 4.2): ‘patient’, ‘health professional’, ‘patient-professional interaction’, and ‘healthcare organization. The ‘patient’ is conceptualised as a human being and has the right to be heard and receive tailor-made care and treatment (see Figure 4.2, A). The implications of this view for the interaction between health professionals and patients is also discussed by all articles, calling for a new style of communication and shared responsibility (see Figure 4.2, B). Furthermore, many articles argue that not only the person behind the patient but also behind the health professional, and his/her role and attitude, is essential for PCC, as the person behind the health professional influences the interaction (see Figure 4.2, C). Although a conceptualization including patients, health professionals and their interaction is widely recognized and used, some scholars have argued that a greater focus needs to be placed on the organizational level of PCC, and not solely on its constituent parts (see

Figure 4.2, D). The dimensions of PCC are closely intertwined. For analytical purposes we will discuss each dimension separately, juxtaposing what was found in literature with our empirical data, in order to understand how patients' perspectives of good care align with these conceptualizations of PCC.

Table 4.1 Overview of the included papers.

Author(s) *'Title'* Journal	Year	Type of review	Core dimensions of PCC described
Hobbs **'*A dimensional analysis of patient-centered care'*** **Nursing research**	2009	Dimensional analysis (n=69)	Describes 5 dimensions of PCC. *Perspective*: alleviating vulnerabilities *Context*: fragmentation of service provision; patient acuity; staffing; centralized and decentralized decision making; efficiency; effectiveness *Condition*: heterogeneous response to illness; needs exceed capacity; suffering; disease condition; approach of health professional to patient; caring presence of health professional; characteristics of health professional; rule orientation of health professional *Process*: therapeutic engagement *Consequences*: lessen suffering; needs of patient met; effective care; minimize erosion of individual identity; address complexity by health professional; broadening explanatory perspective of illness by health professional
Kitson et al. **'*What are core elements of patient-centered care? A narrative review and synthesis of the literature form health policy, medicine and nursing'*** **Journal of advanced nursing**	2012	Narrative review (n=60)	Describes 3 themes. *Patient participation and involvement:* patient participating as a respected and autonomous individual; the care plan is based on the patient's individual needs and the care addresses the patient's physical and emotional needs *Relationship between the patient and health professional*: a genuine health professional-patient relationship; open communication of knowledge, personal expertise and clinical expertise between the patient and the professional; health professional having appropriate skills and knowledge; having a cohesive and co-operative team of professionals *The context where care is delivered*: access to care; policy practice continuum/language used; barriers to PCC; supportive organizational system; therapeutic environment
Leplege et al. **'*Person-centeredness: conceptual and historical perspectives'*** **Disability and rehabilitation**	2007	Conceptual and historical analysis (n=10)	Describes 4 concepts. PCC means: Person as expert: participation and empowerment; Respect the person behind impairment or disease; Addressing the person's difficulties in life; Addressing the person's specific and holistic properties

Lusk &Fater ***´A concept analysis of patient-centered care’*** **Nursing forum**	2013	Concept analysis (n=24)	Describes attributes, antecedents and consequences of PCC. *Attributes*: encouraging patient autonomy; caring attitude of health professional; individualizing patient care by the health professional *Antecedents*: the need for healthcare intervention, the ability of the patient or significant other to participate in his/her own care *Consequences*: experience of power; shared decision-making; caring; self-care ability; patient satisfaction
McCormack et al. ***‘Exploring person-centeredness: a qualitative meta-synthesis of four studies’*** **Scandinavian Journal of Caring Science**	2010	Qualitative meta-synthesis (n=4)	Describes PCC on the basis of prerequisites, care environment, care processes and outcome. *Prerequisites:* professionally competent; developed interpersonal skills; commitment to the job; clarity of beliefs and values; knowing ‘self’ *The care environment:* appropriate skills mix; shared decision making systems; effective relationships; supportive organizational systems; power sharing; potential for innovation and risk taking *Care processes:* working with patient’s beliefs and values; engagement; sharing decision making; having sympathetic presence; providing for physical needs *Outcome:* satisfaction with care; involvement with care; feeling of well-being; creating a therapeutic culture
Mead & Bower **‘*Patient-centeredness: a conceptual framework and review of the empirical literature’*** **Social science & Medicine**	2000	Narrative review (n=41)	Describes 5 dimensions. Biopsychosocial perspective; patient-as-person; sharing power and responsibility; therapeutic alliance; doctor-as-person
Morgan **‘*A concept analysis of person-centered care’*** **Journal of holistic nursing**	2011	Concept analysis (n=50)	Describes PCC on the basis of attributes, antecedents and consequences. *Attributes*: holistic; individualized; respectful; empowering *Antecedents*: vision and commitment; organizational attitudes and behavior; shared governance *Consequences:* improves quality of care; increased satisfaction with healthcare; improved health outcomes
Pelletier & Stichler ***‘Patient-centered care and engagement. Nurse Leaders’ Imperative for Health Reform.***	2014	Narrative review (n=40)	Describes PCC on the basis of attributes. Attributes: considerate and respectful of patients’ beliefs, values and personal meanings associated with their state of wellness or illness; inclusive of patients’ personal and social support system; delivered in the context of caring, therapeutic partnership between patient and provider; integrated and coordinated across a continuum of services, providers and settings; enables with the education, information and

The journal of Nursing Administration			evidence necessary to engage patients in their own healthcare; activating and facilitating use of internal and external resources to manage their own care.
Pelzang ***'Time to learn: understanding patient-centered care'*** **British Journal of nursing**	2010	Narrative review (n=17)	Describes two models; a systems model introduced by Flarey (1995) and a process model, consisting of 7 dimensions introduced by Gerteis et al., 1993. *Process model:* respect of patients' values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; transition and continuity of care *Systems model:* Organizational self-care: development; retention/recruitment; image Masters of change: planning; research; adaptation Partners in care: collaboration; coordination; communication Patient-centered environment: values; empowerment; advocacy
Scholl et al. ***'An integrative model of patient-centeredness- A systematic review and concept analysis'*** **PLOS ONE**	2014	Systematic review (n=417)	Describes 15 dimensions. Essential characteristics of health professional; health professional-patient relationship; patient as unique person; biopsychosocial perspective; health professional-patient communication; integration of medical and non-medical care; teamwork and teambuilding; access to care; coordination and continuity of care; patient information; patient involvement in care; involvement of family and friends; patient empowerment; physical support; emotional support
Sidani& Fox ***'Patient-centered care: clarification of its specific elements to facilitate interprofessional care*** **Journal of Interprofessional Care**	2014	Integrative literature review (n=178)	Describes 3 components and 1 non-specific element of PCC. ***Components:*** *Holistic care:* attend to all patient's needs at the time of particular healthcare encounter or experienced over time; target the totality of patients' condition; all patients' needs i.e. physical care, comfort, emotional care; education; development and enactment of a care plan that incorporates health promotion, illness prevention and behavioral change strategies *Collaborative care:* patients' involvement in decision making; encouraging independence and self-directed care; developing an effective partnership; offering and respecting patients' choices; finding common ground on what the problem is; collaborating on problem solving by understanding patients' problem; negotiating treatment goals; sharing information in complete, accurate and timely way; educating patient; sharing power and responsibility *Responsive care:* maintaining consistency between intervention and patients' needs, values and preferences; individualizing care; acknowledging the patient as an individual by concentrating on

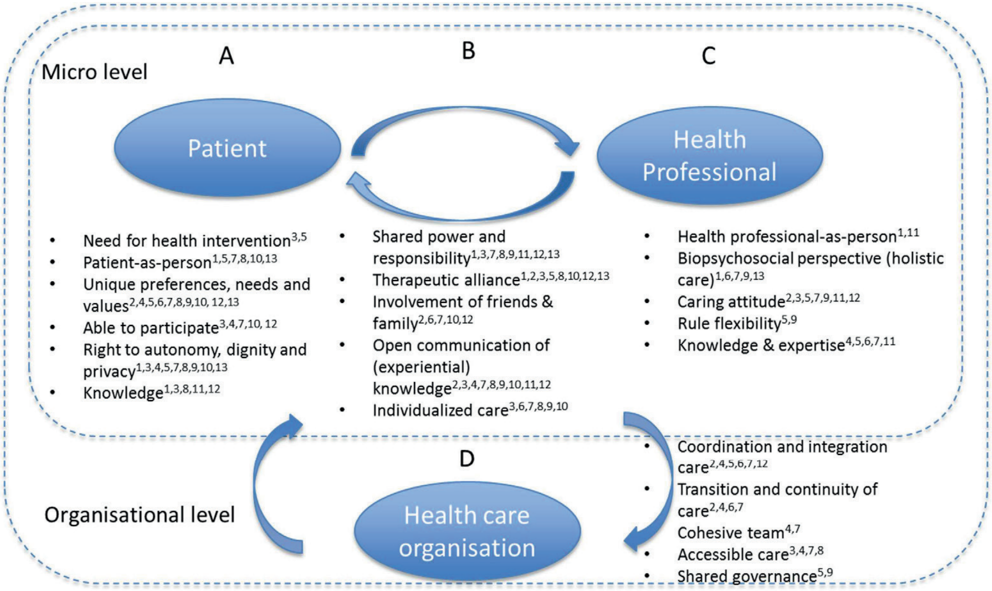
			patient's circumstances rather than the disease; understanding and respecting patients' perspectives, feeling and needs; right for autonomy; providing flexible, personalized care ***Non-specific element:*** *The therapeutic relationship*: patients respect professionals' expertise; healthcare professionals are personable, open to and respectful of patients' knowledge and experiences; health professionals have competent communications skills; health professionals listen; health professionals share information; health professionals communicate effectively; health professional provides technical and emotional support
Slater ***'Person-centredness: a concept analysis'*** ***Contemporary Nurse***	2006	Concept analysis (n=19)	Describes 7 attributes: Recognition of personhood; evidence of a therapeutic relationship between person and health provider; respect for the individuality of the person; provision of care that reflects professional ethical standards; identification and reinforcement of the person's strengths and positive aspects rather than the weaknesses and problems; acknowledgement of the person's lived world; empowerment for the person to make their own decisions about their own health

4.3.1 Patient

In PCC the patient is first and foremost seen as a *unique person* – as "an experiencing individual" (Mead & Bower, 2000b, p.1089), with his or her "own way of perceiving and experiencing" (Pelzang, 2010, p.913). As a consequence, patients have "a heterogeneous response to illness" (Hobbs, 2009, p.55). Thus, as opposed to the commonly held belief that all patients with the same diagnosis should receive the same treatment, in the PCC discourse it is emphasized that patients have *unique preferences, needs and values* in relation to their illness (Kitson, Marshall, Bassett, & Zeitz, 2013; Mead & Bower, 2000; Morgan & Yoder, 2012; Pelletier & Stichler, 2014; Pelzang, 2010; Scholl, Zill, Härter, & Dirmaier, 2014; Sidani & Fox, 2014; Slater, 2006). Moreover, fully respecting the unique preferences of patients also implies that patients decide whether they even need or want care (Lusk & Faber, 2013; Hobbs, 2009). In addition to being unique, in PCC a patient is seen as *able to participate* in his/her own care (Pelletier & Stichler, 2014), and has the *right to autonomy, dignity and privacy* (Lusk & Fater, 2013; Slater, 2006).

In the stories of people with ADHD and bipolar disorders many examples of 'being unique' and the desire to be treated accordingly appear. Prominent in these stories is the conviction that a person is more than his or her diagnosis:

> *[The therapist] should treat me as a person. That's the most important: treat me as a human being and not as a problem. (Female, 51, bipolar disorder)*
>
> *Really look at who you are as a person, and place the ADHD next to that person, because everyone has different problems with which he struggles or another history that troubles him. (Female, 33, ADHD)*



1. Mead & Bower 2. Gerteis (in Pelzang, 2010) 3. Lusk & Fater 4. Kitson et al. 5. Hobbs 6. Pelzang 7. Scholl et al. 8. Sidani & Fox 9. Morgan, 10. Leplege et al. 11. McCormack et al. 12. Pelletier & Stichler 13. Slater

Figure 4.2 The integrative model of PCC.

A diagnosis, whether bipolar disorder or ADHD, is just one aspect of human life and coincides with other aspects such as family life, professional life and the person's place as an individual human being in society. In addition to support for each of the elements of PCC regarding the patient that were found in literature, our data provides more in-depth insights into some of the elements.

First, an important aspect of considering 'patients-as-persons', not explicitly discussed in the studied literature, is that many patients stressed that they have a variety of *strengths and competences*, in addition to merely deficits associated with mental disorders, which can be used in the treatment trajectory. According to these patients, their strengths are hardly addressed in current healthcare practice:

> *It’s always like oh you are diagnosed with ADHD so you can’t study and you can’t concentrate (…). Turn that around and approach it more positively: you’re more creative, you’re more intelligent, you hear and see more, you’re better suited for a think-tank. (Female, 50, ADHD)*

> *Sometimes they only speak about bipolar, and you think, I am more than just bipolar. I am a great reader, or speak my languages fluently, etcetera. (Female, 69, bipolar disorder)*

The patients do not just ask for recognition of these strengths, but also for awareness that these strengths could act as a source for personalised treatment.

Second, many stories shared by patients support the idea that the way in which the diagnosed disorder works out for individual patients and their context is unique. There are differences between individuals in both their personal characteristics (I am a different person from you) and their experiences of illness (my ADHD is different from your ADHD). The symptoms, the severity of the symptoms and the problems that these symptoms cause vary from one individual to another, and can have a very different impact on the daily lives of persons living with it. In addition to the current conceptualization, patients stress that preferences, needs and values are not just individually determined but are, to a certain extent, situational and can change over time. For the delivery of PCC, this means that personal desires and contexts help to fine-tune treatment to maximize effectiveness and satisfaction *within* that context:

> *When I am in nature I am in a flow. A lot is context dependent; at a different place on earth I am fine without medication. (Male, 57, bipolar disorder)*

Third, patients appreciate the ability to share experiential knowledge with their health professional and thereby being appreciated as a person with knowledge about their disorder. This is often not the case as illustrated by the following quote:

> *“Once I was given the wrong pills and became very manic. When I said that I thought something was wrong, they said: ‘Nah, just keep on going, let’s finish this first’. (Female, 34, bipolar disorder)*

Thus, 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, attuned to their personal needs, preferences and values, with a focus on their individual strengths, and value the exchange of knowledge with their health professionals. Patients' unique desires are not stable per se; they can be situational and may change over time.

4.3.2 Health professional

Just as the 'patient' was re-conceptualized as a unique person PCC demands a new conceptualization of the health professional as person, implying an additional set of characteristics. According to Steward (cited by Mead & Bower, 2000b, p. 1088), a patient-centred health professional adopts a biopsychosocial perspective on illness and is "willing to become involved in the full range of difficulties patients bring to their doctors and not just their biomedical model". In addition to knowledge and professional expertise essential to medical practice (Hobbs, 2009; McCormack, 2004; Pelzang, 2010; Scholl et al., 2014), the health professional is a person with a caring attitude which is understood as being respectful, empathic, honest and, above all, being present (Hobbs, 2009; Lusk & Fater, 2013; McCormack, 2004; Scholl et al., 2014). Furthermore, the patient centred health professional is aware of and reflective to their own emotional responses (McCormack, 2004; Mead & Bower, 2000b; Scholl et al., 2014). Rule flexibility is needed to determine "when and how to deviate from established norms and standards when the patient situation dictates" (Hobbs, 2009, p.55). This means that the health professional needs to be assertive, rather than dominant or compliant, in relation to both the patient and their healthcare organization.

Almost all patients acknowledged that their health professionals should – of course – have a caring attitude, including being empathic and listening carefully, but they also emphasized the importance of being knowledgeable and competent as this is essential for a valid diagnosis and obtaining the right treatment. Many patients value a healthcare professional who finds a balance between active and open listening and, as a professional with knowledge and expertise, is able to be directive when necessary.

> *He should also just ask the right questions, because he is still the therapist; it is important that the therapist gives a certain direction. (Male, 25, bipolar disorder)*

Furthermore, several patients mentioned that health professionals seemed to have a preference for pharmacotherapy over non-pharmacological treatment, while patients rather preferred a broader perspective, including attention to lifestyle change, sports and nutrition.

> *A consultation with the psychiatrist is short. I would say, just try once to spend only half of the time on the pharmaceutical aspects, make it 50/50. (Male, 68, bipolar disorder)*

Additionally, in the stories of patients it came forward that it is important that not just the patient but also the health professional is considered to be a person, with his or her own background and experiences in life which could be expressed by time for self-disclosure or small talk.

> *At a certain moment, I reached the point with the psychiatrist that he was talking about his vacation and his sailboat. (Male, 25, bipolar disorder)*

Thus, according to patients, 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 only as a health professional.

4.3.3 Interaction between patients and health professionals

As PCC demands a reconceptualization of 'patients' and 'health professionals', this inherently implies a different relationship between them. The paternalistic doctor-patient relationship has to be transformed into a more personal relationship between the patient and the health professional in order to enact therapeutic change in patients (Mead & Bower, 2000). According to Hobbs (2009, p. 57), this therapeutic alliance develops through a "cyclical process based on the development of trust" and "involves availability and responsiveness of health professional and patient to one another". Both the health professional and the patient are acknowledged as knowledgeable actors (Slater, 2006). The former should provide accurate and tailored information concerning the disease and treatment and the latter should be stimulated to share personal knowledge about his or her health condition and illness experience (McCormack, 2004; Mead & Bower, 2000; Pelletier & Stichler, 2014; Pelzang, 2010; Scholl et al., 2014; Sidani & Fox, 2014). In other words, PCC demands "mutual participation" wherein power and responsibility are shared, an open exchange of knowledge is possible and where both the doctor and the patient reflect on their affects and how they mutually influence each-other (Mead & Bower, 2000; Pelletier & Stichler, 2014). Together these aspects should result in an individualized care plan for each patient.

Many people with ADHD and bipolar disorder stressed the importance of a conducive therapeutic environment and therapeutic alliance. Especially a good relationship between the health professional and the patient was often mentioned to be of major importance. In our study, several patients described this good relationship as feeling comfortable with and having trust in the healthcare professional, not only in his or her knowledge and skills but also in the willingness to listen without judgments, creating the possibility of open communication.

> *You only tell someone like that your deepest secrets if [you trust them] (…) there should be the right sort of feeling. It's to do with your relationship, otherwise you wouldn't do it that easily. (Male, 25, bipolar disorder)*

For other patients, an important attribute to reach a good relationship was the ability to share decision-making power and responsibility, in both treatment and diagnostics. These participants felt they were mostly on the receiving end of the process where professionals distributed labels. Rather, they would like to see the diagnostic process to be a joint venture:

> *I am one of those people who for 10 years had to convince people I have ADHD but to them I was a hyperactive woman with returning depressions because of my hyperactivity … only later the diagnosis [ADHD] was given. (Female, 47, ADHD)*

Despite the fact that a good relationship with the health professional could be influenced by the skills of the health professionals and the participation of the patient in his or her own care, having a connection with the health professional may also be based on personal preferences:

> *I was just about to say that (…), there is also something as having a "click" with a doctor, and I think I have been really lucky for having that with my psychiatrist. (Female, 34, ADHD)*

Thus, according to patients, a good relationship is necessary to reach therapeutic alliance and consist 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.

4.3.4 Healthcare organization

The organizational structure and culture sets boundaries to the interaction, treatment options, and overall *patient-centeredness*. As Saha, Beach, & Cooper (2008) argue: "there is a great deal more to fix in the healthcare system than the interaction style of its practitioners" (p.2). They argue that the healthcare organization needs: (1) to have a committed and engaged board, (2) to empower health professionals to respond to patients' needs, and (3) to facilitate health professionals to 'bend' the rules, if necessary, to deliver tailor-made care (Hobbs, 2009; Morgan & Yoder, 2012; Pelzang, 2010). Patient-centred healthcare organization should deliver coordinated and integrated care, continuous care and accessible care (Kitson et al., 2013; Lusk & Fater, 2013; Pelzang, 2010; Scholl et al., 2014). Coordination and integration, refers to the collaboration within teams and between specialisms or different types of services, so that care for patients flows smoothly and is not fragmented (Hobbs, 2009; Pelzang, 2010; Scholl et al., 2014). Fragmentation of care creates discontinuity and prevents healthcare professionals from gaining full understanding of the patient's illness or following his or her progress (Morgan & Yoder, 2012; Pelzang, 2010). According to Scholl et al. (2014), integrated care also entails the integration of medical and non-medical care, such as alternative care or spiritual care and support services.

When reflecting on the organizational level of mental healthcare, patients mainly addressed the importance of a well-coordinated healthcare where different aspects of care are integrated to reach an individualized treatment plan. First, many patients put forward that a healthcare organization needs to be equipped to deal with the fluctuating course of mental disorders. For example, several participants with ADHD explained that sometimes they were off treatment for a period of time. When they started to experience impairment again, or changes occurred that affected their functioning, they desired supervision by a therapist. However, most institutes have long waiting lists and, after some time, treat returning patients as new patients for financial reasons. This means the whole treatment process has to start all over again.

> *Say I stopped with my medications and I want to come back, I have to reapply, I have to wait for a couple of weeks and I get a whole new therapist (…) isn't that weird? I find it hardly accessible and that I find a real pity. (Female, 50, ADHD)*

The fluctuating course of bipolar disorder requires healthcare that is accessible at any time, as illustrated in the following quote:

> *Yeah, the accessibility is very problematic, especially outside of office hours, you know, the disease also doesn't keep to a nine to five schedule. But the system is not designed for that. (Female, 34, bipolar disorder)*

Second, most patients stressed that good collaboration within and between disciplines is important. In particular, many participants pointed at the beneficial aspects of alternative therapies. Even though these therapies may not have been proven effective as treatment for their disorder, these participants themselves experienced the positive effects of these therapies. They desired the integration of alternative therapies, or certain parts thereof, in their own treatment plan:

> *Listen, if the therapies aren't compatible I can understand [that it's difficult], but I don't see why an alternative therapist can't call a normal therapist so that they can talk about it. (Female, 34, bipolar disorder)*

A third element that was regularly mentioned by patients is the continuity of care between various sectors in the healthcare system. For example, the time between a referral by a GP and the first meeting with a psychiatrist in specialist care should be short and referral between professionals from different disciplines, for example from a psychologist to a psychiatrist, should be smooth. However, many participants report that the time between seeking help and getting adequate care can be substantial, often referred to as 'a long quest', which may lead to dangerous situations.

> *But the GPs also don't have a guideline how to treat someone with bipolar disorder, they rather refer you to someone else. But then you end up on a waiting list for a couple of months before you can have your first conversation with a psychiatrist. (Female, 51, bipolar disorder)*

Some participants criticized that their professionals for financial reasons did not refer them to a specialist better equipped to address (parts of) their problems:

> *They should not be focused on running their own business, you know, I find*

> *it terrible when a psychologist or a psychiatrist treats you they just want to keep you, because you are a golden goose and they are not prepared to refer you to someone who is better for you. (Female, 33, ADHD)*

In short, according to patients, a healthcare organization should provide the possibility for cooperation with therapist/coaches within and outside the system, to act and react to the fluctuating needs of patients. This entails better accessibility outside office-hours and ensures continuity of care, even after having left the system for while.

4.4 Discussion and conclusions

This narrative literature review integrated all elements of PCC as described in literature in one model of PCC. In addition, the perspectives of people with ADHD and people with bipolar disorder on what constitutes ‘good care’ were investigated. Next, we analysed to what extent their stories on ‘good care’ align to current conceptualizations of PCC. The core elements most elaborated upon in the reviews relate to the interaction between patients and health professionals, and the role of the health professional and the skills the health professional needs to deliver PCC, which primarily entails treating patients as unique individuals with their own experiences. Other scholars extend this discourse and argue that organizations play an important role as well, by either hampering or facilitating PCC.

Listening to the stories of patients provided no new core dimensions, but they helped in (1) understanding what the dimensions entail for people with ADHD and bipolar disorder, and (2) verifying and refining these dimensions. First, where in literature listening is described as an important aspect of a caring attitude of a health professional, our results add the importance of listening *without judgment*, which is only mentioned by Slater (2006). This is important because sometimes patients feel ashamed of their own behaviour, more often they have experiences of not being accepted because of it. A second refinement is the acknowledgement of a *personal connection* with the health professional, in addition to the conceptualization of the patient-professional relationship as described in literature. This is of great importance as personal and sensitive experiences and feelings are topics of conversation. A third refinement, in relation to the organization, is that the need for flexibility is stressed, to be able *to act and react on the fluctuating course of the disorders* and the *changing needs of patients*. Patients ask for improvements in the accessibility of services, by extending office hours and easier re-admission into mental health clinic facilities when necessary. Fourth, the current conceptualization refers to ‘patient-as-person’: patients stress the importance of seeing the patient as a person with *positive sides and strengths*, and not merely as a person with deficits, which is only scarcely described in literature (e.g. Slater, 2006) Finally, patients indicate that, next to the health professional’s expertise, they highly appreciate their own experiential knowledge to be taken serious too. After all, patients gain knowledge about their disorder, and even though each person’s trajectory is unique, patients feel that their individual stories on how to cope with the disorder are helpful in care.

A comparison of the perspectives of people with ADHD and people with bipolar disorder with other studies on patients’ perspectives on care, shows many similarities. The wishes of patients ‘to be listened to non-judgmentally’ and ‘to pay attention to the possible change in needs’ are also described in a study of (Billsborough et al., 2014) on support needs during periods of mania and depression for people with bipolar disorder. The desire of adults with ADHD for more accessible and continuous care, which includes treatments not typically offered for ADHD, have also been described in the UK in a study on patients’ experiences of impairment, service provision and clinical management (Matheson et al., 2013). The importance, as well as the potential problems, of a health professional acting professionally and demonstrating empathy as a person is also described by a study of Eliacin, Salyers, Kukla, & Matthias (2015) on the patients’ understanding of shared decision making in mental health setting and Williams et al. (1999) on the user perspectives on person-centeredness in social psychiatry.

Addressing the patient as ‘knowledgeable’ or as an expert is mentioned by some scholars in the context of PCC (e.g. Corring & Cook, 1999; Eliacin et al., 2015; Leplege et al., 2007; Lusk & Fater, 2013; McCormack et al., 2010; Mead & Bower, 2000; Pelletier & Stichler, 2014; Sidani & Fox, 2014), but is more extensively and explicitly evident in the area of patient participation in healthcare and health research (Caron-Flinterman et al., 2005; Entwistle et al., 1998; Epstein et al., 2010). Acknowledging these other discourses on patients’ experiential knowledge within the PCC discourse could strengthen the epistemic position of patients in medical practice and challenge the dominant biomedical approach.

Few studies pay attention to the system in which healthcare professionals have to act. To move beyond the incidental patient-centred interaction between health professional and patient, we suggest that ‘patient-centeredness’ should be perceived as a characteristic of a health system, which is responsive and adaptive to the needs of patients – a health system in which (organizational) structures and cultures are conducive to patient-centred practices. Such a health system "adapt(s) to the often unexpected and context-dependent requirements" (Epstein et al., 2010, p. 1492). This requires a move from the intentions of (groups of) individuals to structural change around patient-centred care. Combining the present PCC discourse with a multilevel perspective (e.g. Essink, 2012; Shields, 2013) and that of complex adaptive systems (e.g. Minas, 2014) could enrich endeavours to understand and scale-up patient-centred care. Such a process would add attention to system-wide cultures and structures to the current narrow focus on patient-centred practices (encompassing primarily patients and health professionals in their interaction).

4.4.1 Strength and limitations

This study has several strengths. First, it increases our understanding of the conceptualization of PCC from a patient's perspective in the field of mental health (outpatient psychiatric services) and contributes to reducing the gap in literature about this topic. Second, a narrative literature review was conducted using literature about the conceptualization of PCC – providing the most current and relevant insights into the topic. A third strength is that we included perspectives of people with ADHD and people with bipolar disorder on healthcare.

In this study we focused on the conceptualization of PCC in mental health, using two psychiatric disorders as exemplary. A limitation of our study is that, although there were many similarities in the accounts of both patient groups on what constitutes 'good care', further research into the extent to which the identified refinements are applicable to other psychiatric disorders and somatic diseases is warranted. Furthermore, our analysis could be enriched by including and integrating theories and approaches of closely related developments in mental health, like recovery-oriented care, collaborative care, and service-user participation.

In sum, this innovative study shows that what is considered 'good care' by patients with ADHD and bipolar disorder resonates with key dimensions of PCC as found in literature. Furthermore, the study demonstrates the value of patients' perspectives in the refinement of, and preferred emphasis in, the conceptualization of PCC.

CHAPTER 5

Challenges of living with bipolar disorder: implications for health care and research

Abstract

Background: In mental health care, clinical practice is often based on the best available research evidence. However, research findings are difficult to apply to clinical practice, resulting in an implementation gap. To bridge the gap between research and clinical practice, patients' perspectives should be used in health care and research.

Aim: Understand the challenges people with bipolar disorder (BD) experience and examine what these challenges imply for health care and research needs.

Method: Two qualitative studies were used, one to formulate research needs and another to formulate healthcare needs. In both studies focus group discussions (FGDs) were conducted with patients to explore their challenges in living with BD and associated needs, focusing on the themes *diagnosis, treatment* and *recovery.*

Results: Patients' needs are clustered in 'disorder-specific' and 'generic' needs. Specific needs concern preventing late or incorrect diagnosis, support in search for individualized treatment and supporting clinical, functional, social and personal recovery. Generic needs concern health professionals, communication and the healthcare system.

Conclusion: Patients with BD address disorder-specific and generic healthcare and research needs. This indicates that disorder-specific treatment guidelines address only in part the needs of patients in everyday clinical practice.

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E.F. Maassen, B.J. Regeer, E.J. Regeer, J.F.G. Bunders-Aelen, R.W. Kupka (2018). Challenges of living with bipolar disorder: implications for health care and research. *International Journal of Bipolar Disorders.*

5.1 Introduction

Bipolar disorder (BD) is a major mood disorder characterized by recurrent episodes of depression and (hypo)mania (Goodwin & Jamison, 2007). According to the Diagnostic and Statistical Manual 5 (DSM-5), the two main subtypes are BD-I (manic episodes, often combined with depression) and BD-II (hypomanic episodes, combined with depression) (APA, 2014). The estimated lifetime prevalence of BD is 1.3% in the Dutch adult population (de Graaf et al., 2012), and BD is associated with high direct (health expenditure) and indirect (e.g. unemployment) costs (Fajutrao, Locklear, Priaulx, & Heyes, 2009; Michalak et al., 2012), making it an important public health issue. In addition to the economic impact on society, BD has a tremendous impact on patients and their caregivers (Granek et al., 2016; Rusner et al., 2009). Even between mood episodes, BD is often associated with functional impairment (Strejilevich et al., 2013; van der Voort et al., 2015), such as occupational or psychosocial impairment (Huxley & Baldessarini, 2007; MacQueen et al., 2001; Yasuyama et al., 2017). Apart from symptomatic recovery, treatment can help to overcome these impairments and so improve the person's quality of life (IsHak et al., 2012).

Evidence Based Medicine (EBM), introduced in the early 1990s, is a prominent paradigm in modern (mental) health care. It strives to deliver health care based on the best available research evidence, integrated with individual clinical expertise (Sackett et al., 1996). EBM was introduced as a new paradigm to *'de-emphasize intuition'* and '*unsystematic clinical experience'* (Guyatt et al., 1992, p. 2420). Despite its popularity *in principle* (Barratt, 2008), EBM has also been criticized. One such criticism is the ignorance of patients' preferences and healthcare needs (Bensing, 2000). A second criticism relates to the difficulty of adopting evidence-based treatment options in clinical practice (Bensing, 2000), due to the fact that research outcomes measured in 'the gold standard' randomized-controlled trials (RCTs) seldom correspond to the outcomes clinical practice seeks and are not responsive to patients' needs (Newnham & Page, 2010). Moreover, EBM provides an overview on population level instead of individual level (Darlenski et al., 2010). Thus, adopting research evidence in clinical practice entails difficulties, resulting in an implementation gap.

To bridge the gap between research and clinical practice, it is argued that patients' perspectives should be used in both health care and research. Patients have experiential knowledge about their illness, living with it in their personal context and their care needs (Tait, 2005). This is valuable for both clinical practice and research as their knowledge complements that of health professionals and researchers (Broerse, Zweekhorst, et al., 2010; Caron-Flinterman, Broerse, & Bunders, 2005; Tait, 2005). This source of knowledge can be used in the process of translating evidence into clinical practice (Schrevel, 2015). Moreover, patient participation can enhance the clinical relevance of and support for research and the outcomes in practice (Abma & Broerse, 2010). Hence, it is argued that these perspectives should be explicated and integrated into clinical guidelines, clinical practice, and research (Misak, 2010; Rycroft-Malone et al., 2004).

Given the advantages of including patients' perspectives, patients are increasingly involved in healthcare services (Bagchus et al., 2014; Larsson, Sahlsten, Sjöström, Lindencrona, & Plos, 2007), healthcare quality (e.g. guideline development) (Pittens et al., 2013) and health-related research (e.g. agenda setting, research design) (Boote et al., 2010; Broerse, Zweekhorst, et al., 2010; Elberse, Pittens, et al., 2012; Teunissen, Visse, Boer, & Abma, 2011). However, patients' perspectives on health care and on research are often studied separately. We argue that to be able to provide care focused on the patients and their needs, care and research must closely interact.

We hypothesize that the challenges BD patients experience and the associated care and research needs are interwoven, and that combining them would provide a more comprehensive understanding. We hypothesize that this more comprehensive understanding would help to close the gap between clinical practice and research. For this reason, this study aims to understand the challenges people with BD experience and examine what these challenges imply for healthcare and research needs.

5.2 Methods

To understand the challenges and needs of people with BD, we undertook two qualitative studies. The first aimed to formulate a research agenda for BD from a patient's perspective, by gaining insights into their challenges and research needs. A second study yielded an understanding of the care needs from a patient's perspective. In this article, the results of these two studies are combined in order to investigate the relationship between research needs and care needs. Challenges are defined as 'difficulties patients face, due to having BD'. Care needs are defined as that what patients 'desire to receive from healthcare services to improve overall health' (Asadi-Lari, Tamburini, & Gray, 2004, p.2). Research needs are defined as that what patients 'desire to receive from research to improve overall health'.

5.2.1 Study on research needs

In this study, mixed-methods were used to formulate research needs from a patient's perspective. First six focus group discussions (FGDs) with 35 patients were conducted to formulate challenges in living with BD and hopes for the future, and to formulate research needs arising from these difficulties and aspirations. These research needs were validated in a larger sample (n=219) by means of a questionnaire. We have reported this study in detail elsewhere (Maassen, Regeer, Bunders, Regeer, & Kupka, 2018).

5.2.2 Study on care needs

This study was part of a nationwide Dutch project to generate a practical guideline for BD: a translation of the existing clinical guideline to clinical practice, resulting in a standard of care that patients with BD could expect. The practical guideline (Netwerk Kwaliteitsontwikkeling GGZ, 2017) was written by a taskforce comprising health professionals, patients. In addition to the involvement of three BD patients in the taskforce, a systematic qualitative study was conducted to gain insight into the needs of a broader group of patients.

Participants and data collection

To formulate the care needs of people with BD, seven FGDs were conducted, with a total of 56 participants, including patients (n=49) and caregivers (n=9); some participants were both patient and caregiver. The inclusion criteria for patients were having been diagnosed with BD, aged 18 years or older and euthymic at time of the FGDs. Inclusion criteria for caregivers were caring for someone with BD and aged 18 years or older. To recruit participants, a maximum variation sampling strategy was used to collect a broad range of care needs (Kuper, Lingard, & Levinson, 2008). First, all outpatient clinics specialized in BD affiliated with the Dutch Foundation for Bipolar Disorder (Dutch: Kenniscentrum Bipolaire Stoornissen) were contacted by means of an announcement at regular meetings and by email if they were interested to participate. From these outpatient clinics, patients were recruited by means of flyers and posters. Second, patients were recruited at a quarterly meeting of the Dutch patient and caregiver association for bipolar disorder. The FGDs were conducted between March and May 2016.

The FGDs were designed to address challenges experienced in BD health care and areas of improvement for health care for people with BD. The FGDs were structured by means of a guide and each session was facilitated by two moderators. The leading moderator was either BJR or EFM, having both extensive experience with FGD's from previous studies. The first FGD explored a broad range of needs. The subsequent six FGDs aimed to gain a deeper understanding of these care needs, and were structured according to the outline of the practical guideline (Netwerk Kwaliteitsontwikkeling GGZ, 2017). Three chapters were of particular interest: diagnosis, treatment and recovery. These themes were discussed in the FGDs, two in each session, all themes three times in total. Moreover, questions on specific aspects of care formulated by the members of the workgroup were posed. The sessions took 90–120 minutes. The FGDs were audiotaped and transcribed verbatim. A summary of the FGDs was sent to the participants for a member check.

Data analysis

To analyze the data on challenges and needs, a framework for thematic analysis to identify, analyze and report patterns (themes) in qualitative data sets by Braun & Clarke (2006) was used. First, we familiarized ourselves with the data by carefully reading the transcripts. Second, open coding was used to derive initial codes from the data. These codes were provided to quotes that reflected a certain challenge or care need. Third, we searched for patterns within the codes reflecting challenges and within those reflecting needs. For both challenges and needs, similar or overlapping codes were clustered into themes. Subsequently, all needs were categorized as ‘specific’ or ‘generic’. The former are specific to BD and the latter are relevant for a broad range of psychiatric illnesses. Finally, a causal analysis provided a clear understanding of how challenges related to each other and how they related to the described needs.

To analyze the data on needs regarding recovery, four domains were distinguished, namely clinical, functional, social and personal recovery (Lloyd, Waghorn, & Williams, 2008; van der Stel, 2015). Clinical recovery refers to symptomatic remission; functional recovery concerns recovery of functioning that is impaired due to the disorder, particularly in the domain of executive functions; social recovery concerns the improvement of the patient’s position in society; personal recovery concerns the ability of the patient to give meaning to what had happened and to get a grip on their own life. The analyses were discussed between BR and EM. The qualitative software program MAX QDA 11.1.2 was used (MaxQDA, 2018).

5.2.4 Ethical considerations

According to the Medical Ethical Committee of VU University Medical Center, the Medical Research Involving Human Subjects Act does not apply to the current study. All participants gave written or verbal informed consent regarding the aim of the study and for audiotaping and its use for analysis and scientific publications. Participation was voluntary and participants could withdraw from the study at any time. Anonymity was ensured.

5.3 Results

This section is in three parts. The first presents the participants' characteristics. The second presents the challenges BD patients face, derived from both studies, and the disorder-specific care and research needs associated with these challenges. The third part describes the generic care needs that patients formulated.

5.3.1 Characteristics of the participants

In the study on care needs, 56 patients and caregivers participated. The mean age of the participants was 52 years (24-75), of whom 67.8% were women. The groups varied from four to sixteen participants, and all groups included men and women. Of all participants 87.5% was diagnosed with BD, of whom 48.9% was diagnosed with BD I. 3.5% was both caregivers and diagnosed with BD. Of 4 patients the age was missing, and from 6 patients the bipolar subtype.

5.3.2 Diagnosis

Despite the fact that participants acknowledge the inevitable diagnostic difficulties of a complex disorder like BD, in both studies they describe a range of challenges in different phases of the diagnostic process (Figure 5.1). Patients explained that the general practitioner (GP) and society in general did not recognize early-warning signs and mood swings were not well interpreted, resulting in late or incorrect diagnosis. Patients formulated a need for more research on what early-warning signs could be and on how to improve GPs' knowledge about BD. Formulated care needs were associated with GPs using this knowledge to recognize early-warning signs in individual patients. One participant explained that certain symptoms must be noticed and placed in the right context:

> *I call it, 'testing overflow of ideas'. [....] When it happens for the first time you yourself do not recognize it. Someone else close to you or the health professional, who is often not involved yet, must signal it.*

Moreover, these challenges are associated with the need to pay attention to family history and to use a multidisciplinary approach to diagnosis to benefit from multiple perspectives.

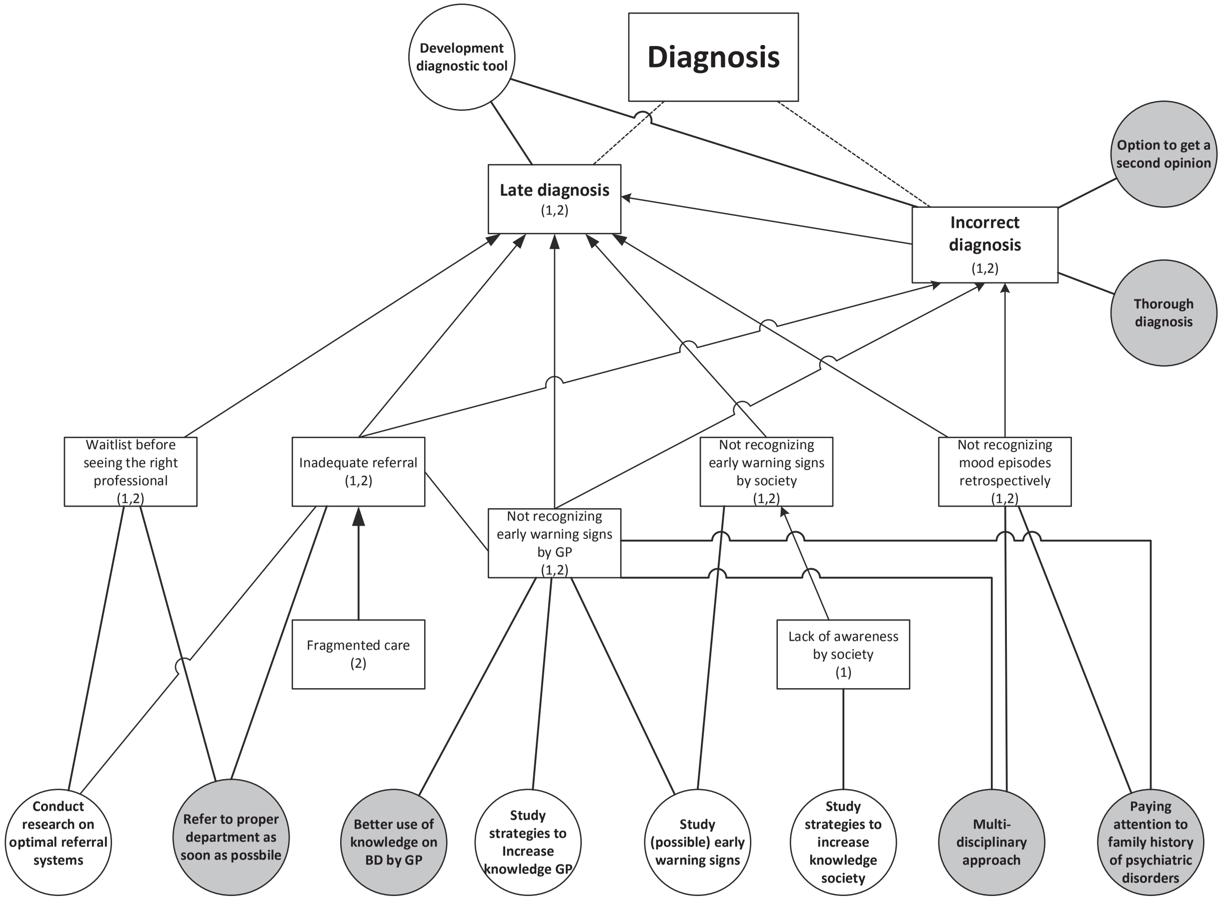

Figure 5.1 Challenges with diagnosis (squares) including relating research needs (white circles) and care needs (grey circles) (1): mentioned in study on research needs; (2): mentioned in study on care needs. Dotted lines: division of challenges into sub challenges. Arrows: causal relation between challenges.

The untimely recognition of early symptoms also results in another challenge: inadequate referral to the right specialized health professional. After referral, people often face a waiting list, again causing delay in the diagnostic process. These challenges result in the need for research on optimal referral systems and the care need for timely referral. One participant described her process after the GP decided to refer her:

> *But, yes, at that moment the communication wasn't good at all. Because the general practitioner said: 'she urgently has to be seen by someone'. Subsequently, three weeks went by, until I finally arrived at depression [department]. And at that department they said: 'well, you are in the wrong place, you need to go to bipolar [department*]'.

The challenge of being misdiagnosed is associated with the need to be able to ask for a second opinion and to have a timely and thorough diagnosis. On the one hand, it is important for patients that health professionals quickly understand what is going on, on the other hand that health professionals take the time to thoroughly investigate the symptoms by making several appointments.

5.3.3 Treatment

From both studies, two main challenges related to the treatment of BD were derived (Figure 5.2). The first is finding appropriate and satisfactory treatment. Participants explained that it is difficult to find the right medication and dosage that is effective and has acceptable side-effects. One participant illustrates:

> *I think, at one point, we have to choose, either overweight or depressed.*

Some participants said that they struggle with having to use medication indefinitely, including the associated medical checks. The difficult search for the right pharmacological treatment results in the need for research on long-term side-effects, on the mechanism of action of medicine and on the development of better targeted medication with fewer adverse side-effects. In care, patients would appreciate all the known information on the side-effects and intended effects. One participant explained the importance of being properly informed

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[2] Care farm: farms that combine agriculture and services for people with disabilities (Iancu, 2013, p. 6). These farms are used as interventions in mental care throughout Europe and the USA to facilitate recovery (Iancu, Zweekhorst, Veltman, Van Balkom, & Bunders, 2014).

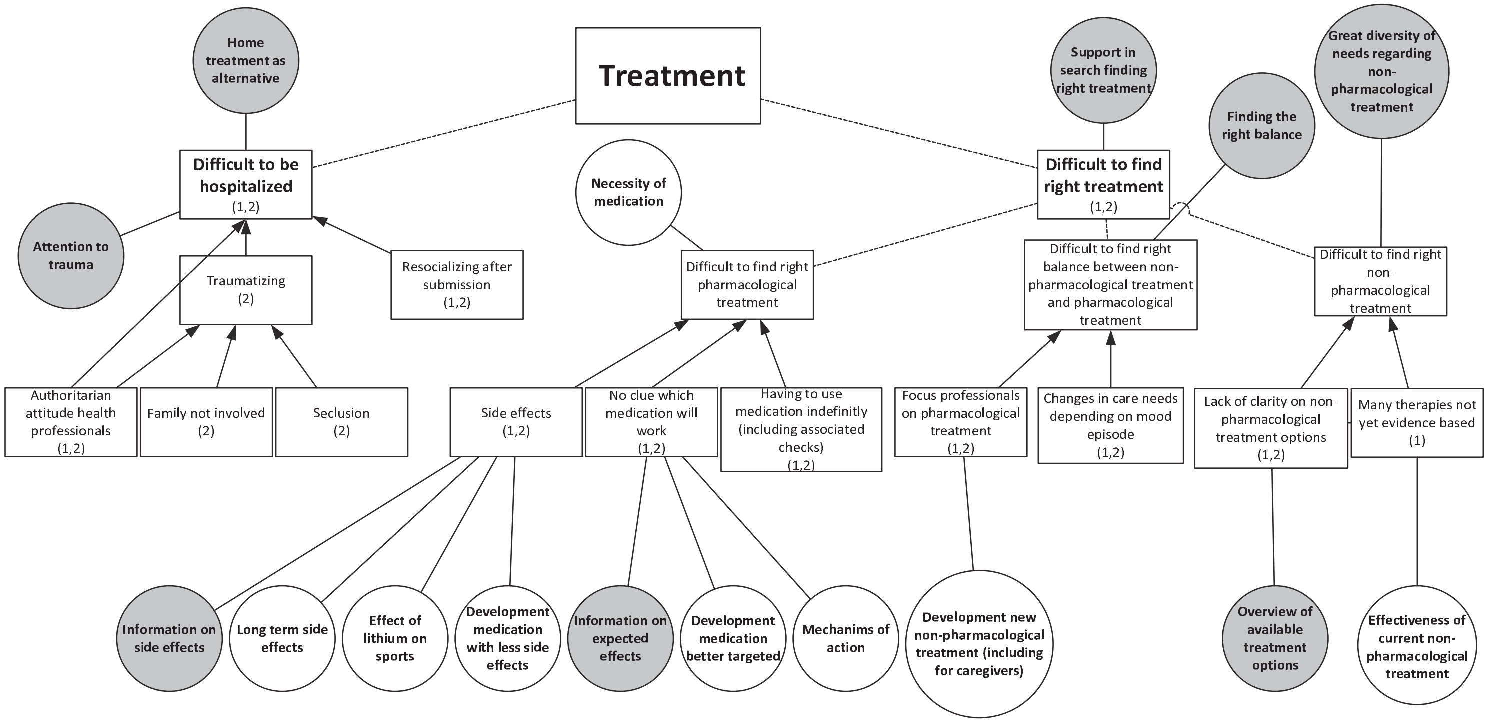

Figure 5.2. Challenges with treatment (squares) including relating research needs (white circles) and care needs (grey circles) (1): mentioned in study on research needs; (2): mentioned in study on care needs. Dotted lines: division of challenges into sub challenges. Arrows: causal relation between challenges.

> *I don't read anything [about medication], because then I wouldn't dare taking it. But I do think, when you explain it well, the advantages, the disadvantages, the treatment, the idea behind it, that would help a lot in compliance.*

A second aspect is the challenge of finding non-pharmacological therapies that fit patients' needs. They said they and the health professionals often do not know which non-pharmacological therapies are available and effective:

> *But we found the carefarm ourselves*[2] *[….]. You have to search for yourself completely. Yes, I actually hoped that that would be presented to you, like: 'this would be something for you'.*

Participants mentioned a variety of non-pharmacological therapies they found useful, namely cognitive behavior therapy (CBT), EMDR, running therapy, social-rhythm training, light therapy, mindfulness, psychotherapy, psychoeducation, and training in living with mood swings. They formulated the care need to receive an overview of all available treatment options in order to find a treatment best suited to their needs. They would appreciate research on the effectiveness of non-pharmacological treatments.

A third aspect within this challenge is finding the right balance between non-pharmacological and pharmacological treatment. Participants differed in their opinion about the need for medication. Whereas some participants stated that they need medication to function, others pointed out that they found non-pharmacological treatments effective, resulting in less or no medication use. They explained that the preferred balance can also change over time, depending on their mood. However, they experience a dominant focus on pharmacological treatment by the health professionals. To address this challenge, patients need support in searching for an appropriate balance.

Next to the challenge of finding appropriate and satisfactory treatment, a second treatment-related challenge is hospitalization. Participants often had a traumatic experience, due to seclusion, the authoritarian attitudes of clinical staff, and not involving their family. Patients therefore found it important to try preventing being hospitalized, for example by means of home treatment, which some participants experienced positively. Despite

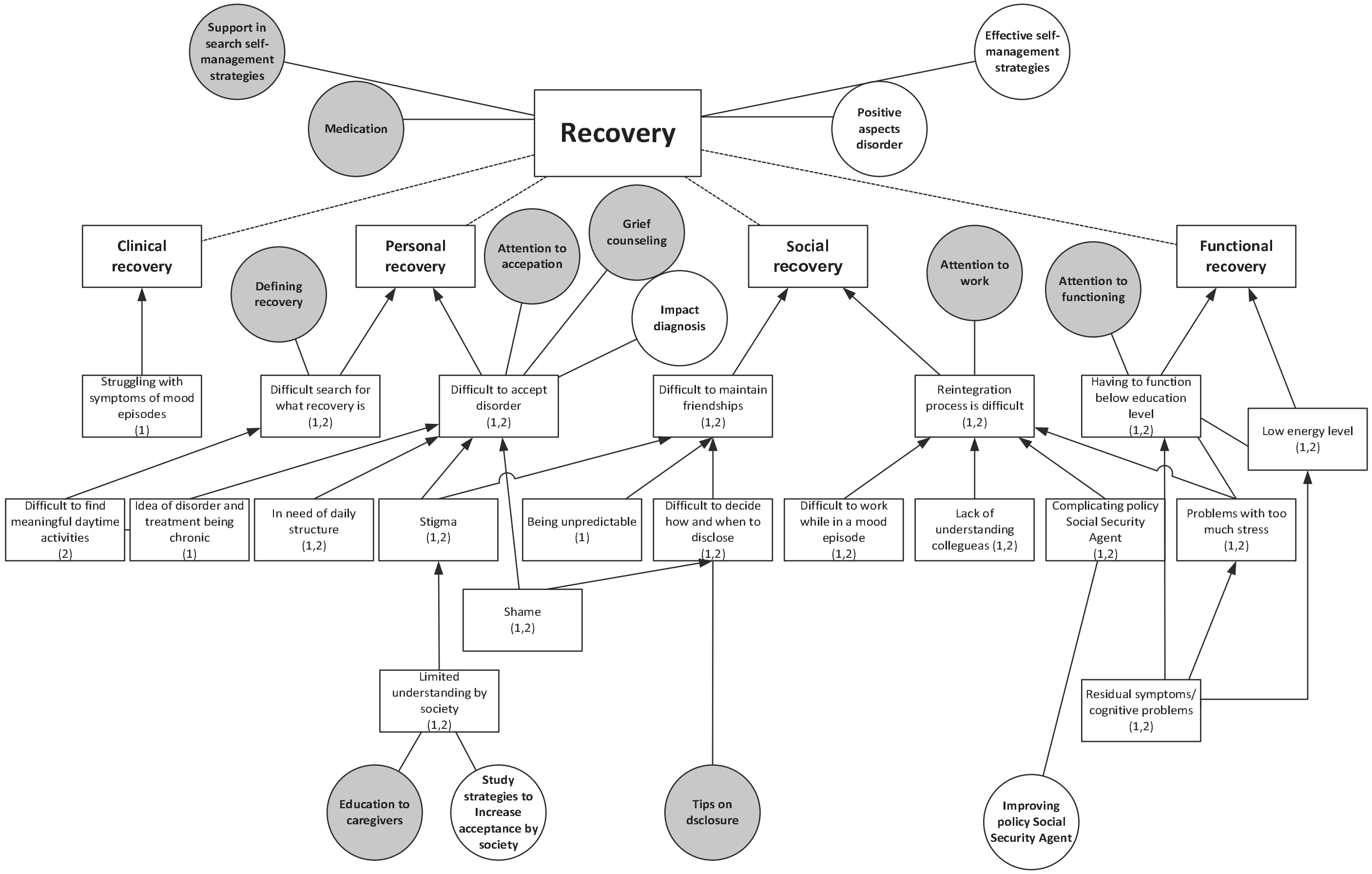

Figure 5.3 Challenges with recovery (squares) including relating research needs (white circles) and care needs (grey circles) (1): mentioned in study on research needs; (2): mentioned in study on care needs. Dotted lines: division of challenges into sub challenges. Arrows: causal relation between challenges.

the challenges relating to hospitalization, participants did acknowledge that in some cases it cannot be avoided, in which case they urged for close family involvement, open communication and being treated by their own psychiatrist. Still, in the study on research needs, hospitalization did not emerge as an important research theme.

5.3.4 Recovery

In both studies, participants described challenges in all four domains of recovery: clinical, functional, social and personal (Figure 5.3). In relation to clinical recovery, participants struggled with the symptoms of mood episodes, the psychosis and the fear of a future episode. In contrast, some participants mentioned that they sometimes miss the hypomanic state they had experienced previously due to effective medical treatment. In the domain of functional recovery, participants contended with having to function below their educational level due to residual symptoms, such as cognitive problems, due to the importance of preventing stress in order to reduce the risk of a new episode, and because of low energy levels. This leads to the care need that health professionals should pay attention to the level of functioning of their patients.

In the domain of social recovery, participants described challenges with maintaining friendships, due to stigma, being unpredictable and with deciding when to disclose the disorder. The latter resulted in the care need for tips on disclosure. Moreover, patients experienced challenges with reintegration to work, due to colleagues' lack of understanding, problems with functioning during an episode, the complicating policy of the (Dutch) Employee Insurance Agency[3] in relation to the fluctuating course of BD and the negative impact of stress. These challenges are associated with the care need that health professionals should pay attention to work and the need for research on how to improve the Social Security Agency's policy.

For their personal recovery, participants struggled with acceptance of the disorder, due to shame, stigma, having to live by structured rules and disciplines, and the chronic nature of BD. This results in care needs for grief counselling and attention to acceptance and the need for research on the impact of being diagnosed with BD. Limited understanding within society also causes problems with acceptance, corresponding with the care need for education for caregivers and for research on how to increase social acceptance. Another challenge in

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[3] A government agency involved in the implementation of employee insurance and providing labor market and data services.

personal recovery was discovering what recovery means and what constitute meaningful daily activities. Patients appreciated the support of health professionals in this area. One participant described the difficult search for the meaning of recovery:

> *I have been looking to recover towards the situation [before diagnosis] for a long time; that I could do what I always did and what I liked. But then I was confronted with the fact that I shouldn't expect that to happen, or only with a lot of effort. (…) Then you start thinking, now what? A compromise. I don't want to call that recovery, but it is a recovered, partly accepted, situation. But it is not recovery as I expected it to be.*

In general, participants considered frequent contact with a nurse or psychiatrist supportive, to help them monitor their mood and help them find (efficient) self-management strategies. Most participants appreciated the involvement of caregivers in the treatment and contact with peers.

5.3.5 Generic care needs

We have described BD-specific needs, but patients mentioned also mentioned several generic care needs. The latter are clustered into three categories. The first concerns *the health professionals*. Participants stressed the importance of a good health professional, who carefully listens, takes time, and makes them feel understood, resulting in a sense of connection. Furthermore, a good health professional treats beyond the guideline, and focuses on the needs of the individual patient. When there is no sense of connection, it should be possible to change to another health professional. The second category concerns *communication between the patient and the health professional*. Health professionals should communicate in an open, honest and clear way both in the early diagnostic phase and during treatment. Open communication facilitates individualized care, in which the patient is involved in decision making. In addition, participants wanted to be treated as a person, not as a patient, and according to a strength-based approach. The third category concerns needs at the level of *the healthcare system*. Participants struggled with the availability of the health professionals and preferred access to good care 24/7 and being able to contact their health professional quickly when necessary. Currently, according to the participants, the care system is not geared to the mood swings of BD, because patients often faced waiting lists before they could see a health professional.

> *Is adequate treatment also having a number from a mental health institution you can always call when you are in need, that you can go there? And not that you can go in three weeks, but on a really short notice. So at least a phone call.*

Participants were often frustrated by the limited collaboration between health professionals, within their own team, between departments of the organization, and between different organizations, including complementary health professionals. They would appreciate being able to merge their conventional and complementary treatment, with greater collaboration among the different health professionals. Furthermore, they would like continuity of health professionals as this improves both the diagnostic phase and treatment, and because that health professional gets to know the patient.

5.4 Discussion and conclusions

We hypothesized that research and care needs of patients are closely intertwined and that understanding these, by explicating patients' perspectives, could contribute to closing the gap between research and care. Therefore, this study aimed to understand the challenges patients with BD face and examine what these imply for both healthcare and research. In the study on needs for research and in the study on care needs, patients formulated challenges relating to receiving the correct diagnosis, finding the right treatment, including the proper balance between non-pharmacological and pharmacological treatment, and to their individual search for clinical, functional, social and personal recovery. The formulated needs in both studies clearly reflected these challenges, leading to closely corresponding needs. Another important finding of our study is that patients not only formulate disorder-specific needs, but also many generic needs.

The needs found in our study are in line with the current literature on the needs of patients with BD, namely for more non-pharmacological treatment (Malmström et al., 2016; Nestsiarovich et al., 2017), timely recognition of early-warning signs and self-management strategies to prevent a new episode (Goossens et al., 2014), better information on treatment and treatment alternatives (Malmström et al., 2016; Neogi, Chakrabarti, & Grover, 2016) and coping with grief (Goossens et al., 2014). Moreover, the need for frequent contact with health professionals, being listened to, receiving enough time, shared decision-making on pharmacological treatment, involving caregivers (Fisher, Manicavasagar, Sharpe, Laidsaar-Powell, & Juraskova, 2017; Malmström et al., 2016; Skelly et al., 2013), and the urge for better access to health care and continuity of health professionals (Nestsiarovich et al., 2017; Skelly et al., 2013) are confirmed by the literature. Our study added to this set of literature by providing insights in patients' needs in the diagnostic process and illustrating the interrelation between research needs and care needs from a patient's perspective.

The generic healthcare needs patients addressed in this study are clustered into three categories: *the health professional*, *communication between the patient and the health professional* and *the health system.* These categories all fit in a model of patient-centered care (PCC) by Maassen, Schrevel, Dedding, Broerse, & Regeer (2016). In their review, patients' perspectives on good care are compared with academic perspectives of PCC and a model of PCC is created comprising four dimensions: *patient, health professional, patient–professional interaction* and *healthcare organization.* All the generic needs formulated in this study fit into these four dimensions. The need to be treated as a person with strengths fits the dimension 'patient', and the need for a good health professional who carefully listens, takes time and makes them feel understood, resulting in a good connection with the professional, fits the dimension 'health professional' of this model. Furthermore, patients in this study stressed the importance of open communication in order to provide individualized care, which fits the dimension of 'patient–professional interaction'. The urge for better access to health care, geared to patients' mood swings and the need for better collaboration between health professionals and continuity of health professionals fits the dimension of 'health care organization' of the model. This study confirms the findings from the review and contributes to the literature stressing the importance of a patient-centered care approach (Mills et al., 2014; Scholl et al., 2014).

In the prevailing healthcare paradigm, EBM, the best available evidence should guide treatment of patients (Darlenski et al., 2010; Sackett et al., 1996). This evidence is translated into clinical and practical guidelines, which thus facilitate EBM and could be used as a decision-making tool in clinical practice (Skelly et al., 2013). For many psychiatric disorders, treatment is based on such *disorder-specific* clinical and practical guidelines. However, this disease-focused healthcare system has contributed to its fragmented nature. Stange (2009) argues that this fragmented care system has expanded without the corresponding ability to integrate and personalize accordingly. We argue that acknowledging that *disorder-specific* clinical and practical guidelines address only parts of the care needs is of major importance, since otherwise important aspects of the patients' needs will be ignored. Because there is an increasing acknowledgement that health care should be responsive to the needs of patients and should change from being disease-focused towards being patient-focused (Mead & Bower, 2000; Sidani & Fox, 2014), currently in the Netherlands generic practical guidelines are written on specific care themes (e.g. co-morbidity, side-effects, daily activity and participation). These generic practical guidelines address some of the generic needs formulated by the patients in our study. We argue that in addition to disorder-specific guidelines, these generic practical guidelines should increasingly be integrated into clinical practice, while health professionals should continuously be sensitive to other emerging needs. We believe that an integration of a disorder-centered and a patient-centered focus is essential to address all needs a patient.

5.4.1. Strengths and limitations

This study has several strengths. First, it contributes to the literature on the challenges and needs of patients with BD. Second, the study is conducted from a patient's perspective. Moreover, addressing this aim by conducting two separate studies enabled us to triangulate the data.

This study also has several limitations. First, this study reflects the challenges, care needs and research needs of Dutch patient with BD and caregivers. Despite the fact that a maximum variation sampling strategy was used to derive a broad range of challenges and needs throughout the Netherlands, the Dutch setting of the study may limit the transferability to other countries. To understand the overlap and differences between countries, similar research should be conducted in other contexts. Second, given the design of the study, we could not differentiate between patients and caregivers since they participated together in the FGDs. More patients than caregivers participated in the study. For a more in-depth understanding of the challenges and needs faced by caregivers, in future research separate FGDs should be conducted. Third, due to the fixed outline of the practical guideline used to conduct the FGDs, only the healthcare needs for diagnosis, treatment and recovery of BD are studied. Despite the fact that these themes might cover a broad range of health care, it could have resulted in overlooking certain needs in related areas of well-being. Therefore, future research should focus on needs outside of these themes in order to provide a complete set of healthcare needs.

5.5. Conclusion

Patients and their caregivers face many challenges in living with BD. Our study contributes to the literature on care and research needs from a patient perspective. Needs specific for BD are preventing late or incorrect diagnosis, support in search for individualized treatment, and supporting clinical, functional, social and personal recovery. Generic healthcare needs concern health professionals, communication and the healthcare system. This explication of both disorder-specific and generic needs indicates that clinical practice guidelines should address and integrate both in order to be responsive to the needs of patients and their caregivers.

CHAPTER 6

A research agenda for bipolar disorder developed from a patients' perspective

Abstract

Background: Diagnosis and treatment of bipolar disorder is complex. Health care is supported by clinical guidelines, which are highly based on scientific evidence. However, such care does not necessarily correspond to preferred care according to patients. In order to narrow the gap between scientifically based guidelines and the patient's perceptions of the best clinical practice, additional research is needed. The aim of this study was to create a patient based research agenda for bipolar disorder to enhance the alignment between patients' needs and care system.

Methods: A mixed method study design was employed consisting of two phases: consultation and prioritization. In the consultation phase, six focus group discussions (FGDs) with patients (n=35) were conducted to explore research needs according to patients, resulting in 23 research topics. Subsequently, these topics were prioritized by means of a questionnaire with patients (n= 219).

Results: Patients with bipolar disorder mentioned a variety of research topics covered by the following five themes: causes of disorder; pharmacotherapy; non-pharmacological treatment; diagnosis; and recovery & recovery oriented care. 'Etiology' was the topic with highest priority.

Discussion: The theme 'causes of disorder' is prioritized highest. We argue that this can be explained by the added value of an *explanatory framework* for appropriate treatment and recovery. The theme 'recovery & recovery oriented care' is currently underrepresented in actual research. It is argued that in order to bridge the knowledge and implementation gap, social science and health system research is needed in addition to biomedical research.

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E.F. Maassen, B.J. Regeer, J.F.G. Bunders-Aelen, E.J. Regeer, R.W. Kupka (2018). A research agenda for bipolar disorder developed from a patient's perspective. *Journal of Affective Disorders.* 239 (15), 11-17.

6.1 Introduction

Bipolar disorder (BD) is a psychiatric disorder characterized by episodes of depression and (hypo)mania. The estimated lifetime prevalence across Europe is 1.5-2%, with a lifetime prevalence of 1.3% for bipolar I disorder in the Netherlands (de Graaf et al., 2012). Globally, bipolar disorder is ranked sixth among the causes of Disability-Adjusted Life Years (DALY) between the ages of 15 to 44 years, is an important cause of a decline in the health-related quality of life (IsHak et al., 2012), and is associated with a high burden of social and occupational stress (Pini et al., 2005; Renes, Regeer, van der Voort, Nolen, & Kupka, 2014). Furthermore, it is a serious public health concern, as bipolar disorder often leads to hospitalization and therefore to high healthcare expenditure (Michalak et al., 2012). To limit these adverse consequences, timely diagnosis and adequate treatment are essential.

Clinical guidelines aim to optimize diagnosis and treatment and to improve outcomes. However, the underlying scientific evidence is not based on samples that represent the heterogeneous patient groups in real-life clinical practice (Concato, Shah, & Horwitz, 2000; Henry et al., 2013; Newnham & Page, 2010; Williams & Garner, 2002). Moreover, interventions recommended in guidelines may not always be applicable in individual cases (Bensing, 2000; Henry et al., 2013), e.g. guidelines recommend monotherapy as maintenance therapy, while in practice many patients receive polypharmacy (Henry et al., 2013). Research agendas for increasing scientific evidence in health care are shaped primarily by clinical or pre-clinical researchers, policy-makers, national funding agencies, charitable foundations and the pharmaceutical industry (Broerse, et al., 2010; Caron-Flinterman et al., 2007). Although these agents have much expertise to make decisions on relevant research topics, those that patients consider to be important may be unknown or neglected. It is increasingly argued that patients' involvement is essential in order to gain a full understanding of research needs for clinical practice (e.g. Abma & Broerse, 2010; Boote et al., 2002).

Three arguments for including patients in research are often mentioned – normative, instrumental and substantial (Broerse, Zweekhorst, et al., 2010). The normative argument maintains that it is the right of end-users (e.g. patients) (Elberse et al., 2012) to be involved in (discussions on) research (Boote et al., 2002; Broerse, Zweekhorst, et al., 2010; Entwistle et al., 1998; Patterson, Trite, & Weaver, 2014). The instrumental argument concerns greater support for research (Broerse et al., 2010), the acceptance of decisions and outcomes

(Elberse et al., 2012), and improved clinical relevance (Abma & Broerse, 2010; Boote et al., 2002; Brett et al., 2014), therefore contributing to better outcomes for patients (Boote et al., 2002; Telford & Faulkner, 2004). The substantial argument considers that patients are experts on their illness, their needs for care, and their navigation of the mental healthcare system (Tait, 2005), while health professionals are experts on the disease, resulting in a different focus (Boote et al., 2002). Patients' experiential knowledge about their illness can complement that of health professionals (Broerse, Zweekhorst, et al., 2010), and lead to different research priorities (Banfield, Barney, Griffiths, & Christensen, 2014; Caron-Flinterman et al., 2007; Elberse, Laan, et al., 2012; Tallon, Chard, & Dieppe, 2000).

Currently, despite a substantial volume of research on health care in the field of bipolar disorder, there is still a gap between research outcomes and clinical practice. In everyday clinical practice, questions commonly arise that research-based evidence cannot answer (Buckley, Grant, & Glazener, 2013), e.g. which type of treatment to offer to different subpopulations or which medication will be effective for an individual patient. This may result in treatment choices that are not evidence based. We argue that in order to enrich clinical practice with scientific knowledge, it is important to include patients in the agenda-setting process. In the Netherlands, a number of research agendas have been designed in collaboration with patients, researchers and health professionals, e.g. for asthma/COPD, burn wounds, congenital heart disease, and neuromuscular diseases (Broerse, Zweekhorst, et al., 2010; Caron-Flinterman, Broerse, Teerling, & Bunders, 2005; Elberse, Laan, et al., 2012; Nierse, Abma, Horemans, & van Engelen, 2013). In the field of mental health, there have been initiatives to set research agendas that are general (e.g. Davison, D'Andreamatteo, Mitchell, & Vanderkooy, 2017; Rose, Fleischman, & Wykes, 2008; Wykes et al., 2015) or specific to a disorder (e.g. Banfield et al., 2014; Jacobson, Östlund, Wallgren, Österberg, & Tranæus, 2016), but to date there is no shared research agenda specifically for bipolar disorder. The aim of this study was to develop a research agenda for bipolar disorder from the perspective of patients.

6.2 Methods

The agenda-setting process consisted of two phases: consultation and prioritization (Abma & Broerse, 2010).

6.2.1 Phase 1. Consultation

To create a research agenda, both the research needs and the arguments for them are of interest. For this purpose, focus group discussions (FDGs) were conducted. This qualitative method was chosen to make it possible to gather data on participants' narratives (Green & Thorogood, 2005) and group norms, to generate feelings, experiences, and beliefs, and to facilitate the possibility of triggering the participants by the views and experiences of their peers (Gray, 2014).

To recruit participants, questionnaires were sent to 100 randomly selected from a group of patients with BD who were treated at a specialized Dutch outpatient clinic (A) based at a large mental health institution, and who had indicated at an earlier occasion that they would be interested in participating in research. If they expressed an interest for this particular study, they were contacted to participate in a FGD. In addition, participants were recruited via the website of the Dutch patients' organization for Manic Depressive Patients and their Caregivers (VMDB). Inclusion criteria were: being diagnosed with bipolar disorder, being at least 18 years of age, and not currently in a severe mood episode.

The FGDs lasted 90–120 minutes and were facilitated by experienced moderators (BR & EM) to assist in formulating research themes. The structure of the FGDs was based on a guide, consisting of three parts. In the first part, the question addressed the challenges of living with BD and discussed among the participants. In the second part, aspirations for the future with regard to BD were discussed, based on a fictitious case of a young woman with BD who had not yet been diagnosed. Participants were asked to write down everything they hoped for this young woman in all life domains and for health care, after which these ideas were discussed among all participants. Using a 'vignette' offers a space to think outside the participants' own situation and so broaden the findings. This provided insight into possible needs for changes in health care, society and personal surroundings and stimulated solution-oriented thinking as the introduction for the third part, in which participants were asked to formulate research topics or questions they considered important in the field of BD. After each FGD a summary in which the research topics were clustered into themes was sent to the participants as a member check, to verify our interpretations of the discussions and our analysis.

The FGDs were transcribed and analyzed using the qualitative analysis software program MAXQDA 11.1.2. To identify and report patterns (or themes), a framework for thematic analysis by Braun & Clarke (2006), consisting of six phases, was used. First, we familiarized ourselves with the data by carefully reading the transcripts. Second, open coding was used to generate initial codes (i.e. research needs) from the data. Third, we looked for patterns throughout these codes and the themes as formulated in the summaries of the FGDs. These themes were further refined by looking for patterns throughout all the FGDs. Finally, the themes were named. The analyses were discussed by EM and BR. These analytical phases resulted in a list of 23 topics for research, clustered into five themes.

6.2.2 Phase 2. Prioritization

The 23 research topics were used to design a questionnaire, which focused on (1) demographic characteristics, (2) prioritization, and (3) additional comments. To prioritize the topics, patients could distribute 25 points over the 23 topics as they wished, with no restrictions. A pilot questionnaire was tested by seven patients, who were recruited by random selection from patients who consecutively visited another specialized Dutch outpatient clinic (B) for routine appointments. This pilot study resulted in small adjustments, particularly of language, to clarify the research topics. The resulting questionnaire was then completed by two patient groups. The first group was recruited from patients who routinely attended the two specialized outpatient clinics (A and B) over a period of two weeks. Questionnaires could be anonymously returned either in print, or filled out online. For recruiting a second group, a link to the online questionnaire was posted on the website, Facebook page and in the newsletter of the Dutch patients' organization (www.vmdb.nl). For the online version we used SurveyMonkey, an online survey development software. The questionnaire was then open for eight weeks, results were received anonymously. Seventy-three percent of the people who started the online survey completed the questionnaire.

Statistical analyses were performed using SPSS version 23. The research topics were prioritized using descriptive statistics (total attributed points, means). For each topic, the total attributed points were calculated, enriched with the mean attributed points (total points divided by *all* respondents) and the range. In addition, the research themes were prioritized based on their total score, divided by the number of topics.

6.2.3 Ethical considerations

According to the Medical Ethical Committee of the VU University Medical Center, the Medical Research Involving Human Subjects Act does not apply for this study. All participants confirmed their understanding of the aim of the research and approved the FGDs being audio-taped. Anonymity of all participants was ensured.

6.3 Results

6.3.1 Characteristics of the participants

Consultation phase

In total, 35 participants (22 from outpatient clinics and 13 via the patients' organization) attended the six FGDs. The mean age of the participants was 51.6 years (27–66 years), of whom 48.5% were women. The groups varied from three to eight participants, and all groups included women and men.

Prioritization phase

In total, 219 patients completed the questionnaire. The characteristics of respondents of the questionnaire are shown in Table 6.1. The average age of the respondents was 48.3 (SD 11.3), of whom women account for 71% (n=157). Almost all (96.3%) study participants are receiving some form of treatment – 90.4% of the respondents use medication for BD, and 49.7% have been diagnosed for less than 10 years.

Table 6.1. Characteristics of respondents of the questionnaire

Characteristics		Values
		Mean (SD)
Age		48.3 (1.3)
		N (%)
Sex	Men	62 (28.3)
	Women	157 (71.7)
Years of diagnosis	0-4 year	64 (29.2)
	5-14 years	81 (37.0)
	>15 years	70 (32.0)
	I don't know	4 (1.8)
Treatment	No	8 (3.7)
	Yes, general practitioner	9 (4.1)
	Yes, psychiatric clinic	165 (75.3)
	Yes, independent practitioner	18 (8.2)
	Other	19 (8.7)
Medication	Yes	198 (90.4)
	No	21 (9.6)

6.3.2 Prioritization of the research agenda

Table 6.2 presents the research agenda for BD from the patients' perspective. All 23 research topics are presented in order of prioritization, based on the total attributed points. The research topic 'etiology' is most prioritized, with a total of 605 points and a mean score of 2.76. In total, 142 respondents attributed points to this topic, more than any of the other research topics. Furthermore, it is notable that both research topics addressing the side-effects of medication are ranked second and third and that both research topics clustered as 'cause of disorder', are in the top four.

Table 6.2 Research agenda for bipolar disorder according to patients, presenting research topic and corresponding research theme; prioritization is based on total attributed points. The mean is calculated by total points divided by all participants (n=219). The number of attributed points is the number of respondents that attributed to that topic.

Top	Topic	Research Theme	Total Points	Mean	Range	SD	Number of attributed points
1	Etiology	Causes of disorder	605	2.76	0-25	3.68	142
2	Development of medication with fewer side-effects	Pharmacological treatment	415	1.89	0-20	2.58	124
3	Long-term side-effects of medication	Pharmacological treatment	388	1.77	0-25	2.67	125
4	Triggers for onset of mood episode	Causes of disorder	365	1.67	0-10	2.08	122
5	Recognition early warning signs of BD	Diagnosis	342	1.56	0-10	1.96	122
6	Development of medication that is better targeted	Pharmacological treatment	335	1.53	0-20	2.35	110
7	Re-integration in society	Recovery & recovery-oriented care	305	1.39	0-10	2.14	107
8	Development of new non-pharmacological therapies	Non-pharmacological treatment	295	1.35	0-10	1.91	113
9	Effectiveness current non-pharmacological therapies	Non-pharmacological treatment	263	1.20	0-15	1.90	106
10	Increase of social acceptance	Recovery & recovery-oriented care	235	1.07	0-10	1.70	99
11	Designing a patient-centered care approach	Recovery & recovery-oriented care	215	0.98	0-25	2.12	92
12	Knowledge improvement GP	Diagnosis	209	0.95	0-10	1.66	88
13	Self-management strategies	Recovery & recovery-oriented care	191	0.87	0-10	1.58	88
14	Positive aspects BD	Recovery & recovery-oriented care	181	0.83	0-10	1.63	90
15	Development diagnostic tool	Diagnosis	162	0.74	0-8	1.54	76
16	Collaboration system practitioners (incl. alternative medicine)	Recovery & recovery-oriented care	145	0.66	0-10	1.56	75
17	Development therapies to support caregivers	Non-pharmacological treatment	140	0.64	0-10	1.31	79
18	Impact of diagnosis	Recovery & recovery-oriented care	135	0.62	0-5	1.15	82
19	Mechanism of action of medication	Pharmacological treatment	132	0.60	0-7	1.24	73
20	Treatment options for co-morbidity	Recovery & recovery-oriented care	130	0.59	0-10	1.39	69
21	Need for medication	Pharmacological treatment	121	0.55	0-6	1.17	73
22	Adequate referral system	Diagnosis	98	0.45	0-10	1.36	58
23	Effect of lithium on sports	Pharmacological treatment	68	0.31	0-5	0.99	52

BD: bipolar disorder; GP: general practitioner

The 23 research topics were clustered into five themes. The five themes in order of importance are: cause of disorder, pharmacological treatment, non-pharmacological treatment, diagnosis and recovery, and recovery-oriented care. In the top seven most important research topics, all five themes are represented. The emphasis (top four), however, is on the causes of disorder and pharmacological treatment.

In the following section the research themes are presented in order of prioritization.

6.3.3 Understanding the research themes

Causes of disorder

This research theme was seen as the greatest priority by patients with bipolar disorder. When discussing the causes of the illness, two aspects for research were of particular importance, namely the *etiology* and *the triggers* responsible for developing a depressive or manic episode. Many participants indicated that they would appreciate research on genetic influences and brain processes to increase their understanding of the mechanisms underlying the symptoms they experience and because it will have a positive influence on pharmacological treatment, the process of diagnosis, and developing interventions to prevent relapse. In addition to the pathophysiological mechanisms behind the disorder, many participants wanted research on the triggers for a depressive or manic episode:

> *… you can also look at the external causes. So, what are the triggers? I really want research done on what you can do [to prevent or respond to triggers], to decrease the use of medication. If we know what the triggers are for developing a depressive or manic episode, you can work on those triggers. That is only possible if you recognize them in time.* (Woman, aged 49)

Some participants gave examples of triggers that might influence a relapse, namely stress, travelling, lifestyle, and the effects of physical illnesses. They wanted research on the influence of these aspects on developing a depressive or manic episode.

Pharmacotherapy

The research theme pharmacotherapy was ranked second. Participants of the FGDs formulated six research topics that were clustered as ‘pharmacotherapy’. First, they believed that finding the right medication that effectively treats the individual patients can be timeconsuming and so called for research on the development of new medication that is better targeted. One participant explained:

> *Research on medication. There is a wide variety of medicines […]. You need to wait three months for a pill to start working. Then I think, come on, I am depressed now, I just want it to work quickly. After three months you come back because it still doesn't work and then you get another pill and again you have to wait three months before [you know if] it starts working. And then it is six months later. I think come on. So I believe it to be important to do research so that the effect is known sooner.* (Man, aged 50)

The side-effects of pharmacotherapy were a second major issue. Many of them had struggled to find medication in which the positive effects outweigh the negative, resulting in the need for research on medication with fewer side-effects. One of the participants indicated this as follows:

> *Medication and side-effects. I am searching [for the right medication] and sometimes it drives me crazy. I once gained 12 kg and sex is changing due to medication. Sometimes you start to think that you can solve it by taking [illicit] drugs.* (Woman, aged 27)

These challenges were experienced by the majority of the participants, leading them to doubt the usefulness of and need for medication, which resulted in a need for research on the value of medication:

> *Yes, yes, of course there is a huge aversion to medication, mainly because of the side-effects. And maybe taking medication is inescapable. If that is the case, it would be nice to know.* (Man, aged 51)

In addition, some participants wanted research on the medication's mechanism of action, and of the effect of lithium on sport performance.

Non-pharmacological treatment

The research theme 'non-pharmacological treatment' was ranked third and comprised three research topics. The need for non-pharmacological treatment came out clearly in discussing aspirations concerning treatment for a fictitious woman who will be diagnosed with BD in 2025:

> *I would advise her to do mindfulness training. It helped me a lot. I am really sad that 20 years ago it did not exist.* (Woman, aged 50)

> *Yes, me too [had use of mindfulness]. And I did cognitive behavioral therapy, that was really important for me as well. I would advise her to start with that.* (Man, aged 55)

> *What I do believe is important, is that she can talk, therapeutically, with a psychologist, so that you can talk about the fears and shame you experience.* (Man, aged 51)

Most participants wanted research to be conducted on the effectiveness of a variety of non-pharmacological treatments. Second, they wanted that new treatments focus more on non-pharmacological than on pharmacological interventions. Third, they would appreciate research on the development of therapy focused on caregivers.

Diagnosis

The research theme ‘diagnosis’ was ranked fourth. Four research topics fitted this theme. In the FGDs, participants described the process of timely recognition and diagnosis as problematic. For them, the problem is the considerable delay between seeking help and being correctly diagnosed with bipolar disorder. According to participants, reasons for this delay are the presence of co-morbidity, the fact that BD often starts with depressive episodes, and limited knowledge about the disorder. As one participant said:

> *Yes, I have been with my general practitioner for a long time. He prescribed pills himself, which he should never have done. It was the wrong medication. He did not diagnose me correctly.* (Man, aged 55)

For some participants this delay meant not receiving any diagnosis for 10 to 20 years, for others it meant being misdiagnosed before being correctly diagnosed with BD and hence receiving inadequate or no treatment during that period. The following quote illustrates a severe consequence of delay in diagnosis:

> *I have been sick for three years, because I could not be diagnosed. It was cyclic, rapid cycling. I did not function at my job and because of that, I had a nervous breakdown.* (Man, aged 64)

Thus, the shared opinion was that research should improve the diagnostic process; research needs to be conducted on early warning signs of BD, a diagnostic test that is more effective in detecting BD, how to improve the knowledge of general practitioners and how to develop an adequate referral system to reduce the delay in diagnosis.

Recovery and recovery-oriented care

The last theme is ‘recovery and recovery-oriented care’. Eight research topics addressing this theme emerged from the FGDs. Participants struggled with self-acceptance and social acceptance. Self-acceptance was described as accepting their own limitations and of being chronically ill and in need of medication. According to most participants, self-acceptance is linked with social acceptance. Acceptance is important for social recovery, for example being able to return to work. According to participants, the complexity of the re-integration process is exacerbated by the fluctuating course of the disorder. This challenge is explained by a participant:

> *If you are diagnosed with bipolar disorder and you are not able to work, you are declared unfit for work. […] when you are declared fit for work again and a year later something happens that makes you stressed again you can go back to the UWV*[4] *to apply for sickness benefit again. [….] I have sort of a trauma due to all this hassle at the UWV. Only looking at the forms makes me nauseous.* (Woman, aged 34)

To recover, participants advocated a recovery-oriented care system, with better collaboration between various disciplines and departments and between the standard and alternative care systems, especially for those who suffer from co-morbid disorders. Second, some patients struggled with the limited availability of emergency services when they are in crisis. Third, the system could be improved if it was focused on customized care and the stimulation of self-management rather than focused primarily on the illness.

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[4] UWV (Uitvoeringsinstituut Werknemersverzekeringen) is a Social Security Agency in the Netherlands

> *What happens is, you get a diagnosis and then the illness will be treated, while I would benefit a lot more from solving the problems that I experience at that moment.* (Man, aged 46)

Customized care entails making patients' needs the starting point of the treatment and could result in tailor-made support regarding lifestyle, psychological treatment, sport, nutrition and the social environment.

These challenges resulted in associated research needs on (1) topics that contribute to their personal, social and functional recovery, and (2) ways to design a recovery-oriented healthcare system. For the first, participants explained the need for research on awareness programs and school programs to increase public acceptance and on the policy of the social security agent regarding the re-integration process, but also on the impact of the diagnosis on the patients and their social environment and on the positive aspects of bipolar disorder. The second includes research on a patient-centered healthcare system, the organization of a flexible care system for people with co-morbid disorders, the attention to self-management in treatment and collaboration in order to improve cooperation between a range of (alternative) practitioners.

6.4 Discussion

In order to bridge the knowledge gap (Elberse et al., 2012) and the implementation gap (Tallon et al., 2000) between research and clinical practice, it is important to include patients in the agenda-setting process. In this study, patients with bipolar disorder currently treated in specialized outpatient mental health facilities and/or being a member of the patients' organization set a research agenda including 23 topics covering five major research areas.

Our results are confirmed by a mental health research agenda established by service users from the UK (Rose et al., 2008) and an Australian research agenda for mood disorders (Banfield et al., 2014). Patients in both the UK and Australian project preferred topics that resemble our theme of recovery-oriented care, namely improving re-integration, accessibility of care, social understanding of mental illness and customized care (Banfield et al., 2014). Other topics are similar too, namely the impact of the diagnosis (Banfield et al., 2014; Rose et al., 2008), the GP's knowledge (Banfield et al., 2014), side-effects of medication (Banfield et al., 2014), effectiveness of complementary therapies and the need for medication (Banfield et al., 2014; Rose et al., 2008) and causes, such as genetic and environmental factors (Banfield et al., 2014; Rose et al., 2008). Due to the similarities with the UK research agenda for mental health service users in general, it could be suggested that these themes are important for the broader mental health field, as stated by Banfield et al. (2014).

It is interesting to see whether the research themes prioritized in this project correspond to the current European research agenda for bipolar disorder. To stimulate European-wide research on BD, to improve its management and to gain understanding of the underlying mechanisms, centers from six European countries joined forces in a European Network of Bipolar Research Expert Centre (ENBREC) (Henry et al., 2013), and its research program can be seen as a current European research agenda on bipolar disorder. In this network, special attention is paid to diagnostic tools, cognitive functions, biomarkers, genetics, treatment optimization, and neuro-imaging. These research topics fit the categories 'diagnosis', 'causes of disorder' and 'pharmacotherapy' in our study. In addition, ENBREC will address the implementation of psycho-education, which fits our category of non-pharmacological treatment. Interestingly, recovery and recovery-oriented care initiatives are not mentioned in the ENBREC research projects. This particular gap between current research and patients' priorities is confirmed by Michalak et al. (2016), who found that in the field of BD, the focus of current research is mainly on 'genetics', 'neurobiology' and 'clinical phenomenology', despite patients' need for research on recovery, lifestyle and psychosocial factors. In addition, a similar gap was found in the British ROAMER project on mental health priorities in Europe, where service users emphasized social rather than biomedical interventions, e.g. the research priorities on the quality of health services and the development of alternative therapies (Robotham et al., 2016; Wykes et al., 2015), and in an Australian initiative that found research topics highly prioritized by patients with BD (e.g. individualized care, effective coping strategies and evidence on effective therapies), were underrepresented in the literature (Banfield, Griffiths, Christensen, & Barney, 2011).

In the research agenda for bipolar disorder set out in this study, the themes most prioritized are 'causes of disorder' and 'pharmacological treatment' and the topic most prioritized is 'etiology'. We hypothesize there are two reasons for this. First, that generating an understanding of the etiology contributes to more acceptance and recovery. Schrank & Slade (2007) describe in their study on the concept of recovery in psychiatry that two components of recovery, 'self-identity' and 'symptom management', both benefit from 'knowing the illness' and 'developing an explanatory framework to understand the experience'. In addition, in a study about how patients successfully manage their bipolar disorder, Suto, Murray, Hale, Amari, & Michalak (2010) found that one of the six strategies on managing BD was understanding the disorder, including its etiology. Second, we argue that it is prioritized highly because of the belief that understanding the etiology might provide patients with a clear direction towards the appropriate form of treatment. From the FGDs it became clear that participants are often struggling with making sense of their treatment trajectory and deciding on its focus (pharmacological or non-pharmacological treatment), which for some participants depends on the etiology. We could therefore state that insights into the etiology of BD is supportive of the first step into the recovery process.

To further the previous discussion, we argue that it is relevant to acknowledge that the high ranking of research topics such as 'etiology', 'triggers for onset of episode', 'development of new medication with fewer side-effects' and 'long-term side-effects' could also be explained by the public view on what research entails; 'research' is often associated with basic science and interventional science and not with health system research. However, we would argue that the topics clustered in the theme 'recovery and recovery-oriented care' are indeed research topics, and that they may not currently be on e.g. the ENBREC agenda because they represent complex, unstructured, and often interdisciplinary issues, for which it is not clear which types of knowledge are needed (Schuitmaker, 2012). This makes it difficult to identify specific research questions related to these issues. Moreover, it may not be only biomedical research that is needed, but also social science research and health system research, fostering a more integrated perspective.

6.4.1 Limitations and recommendations for further research

Our study has some limitations. First, there was an overrepresentation of women and it is not known to what extent this could have influenced the results. Due to the sampling approach via Dutch outpatient clinics and the patient organization most of the sample received specialized treatment. More research is needed among untreated BD patients. Second, a patient-informed research agenda may contain topics that have been researched but of which patients are not aware. Some topics could, therefore, reflect implementation gaps of existing research rather than true research gaps, a phenomenon also described by Owens (2008) and Banfield (2014). In order to make this distinction, further research to compare previous research with the research topics prioritized by patients could provide insight. Third, it will also be relevant to include caregivers and health professionals in the agenda-setting process, since their perspectives could complement the patients' research agenda. Therefore, for future research we focus on including *all* end-users in order to obtain a shared research agenda for bipolar disorders.

In conclusion, our study contributes to the field of research agenda setting by including the perspectives of patients with bipolar disorder. This research agenda could steer funding agencies and researchers to conduct research that is relevant to end-users. The next step in this process is to narrow the formulated research topics into specific research questions, without detracting from the complexity of topics addressed by patients. It will require a close collaboration between patients and researchers to increase our understanding and thereby effective diagnosis and treatment of bipolar disorder.

CHAPTER 7

Research needs for bipolar disorder from a health professionals' perspective: Narrowing the research-practice gap

Abstract

*Introduction***:** Research evidence is incompletely translated into clinical practice. This study aimed to explore research needs from health professionals' perspectives in the field of bipolar disorder and their reflections on patients' research needs as well as to unravel the potential role of researcher-clinicians.

Methods: Using focus group discussions (FGDs) and interviews, research needs according to psychiatrists, psychologists, and nurses working with bipolar disorder were explored. Subsequently, we interviewed researcher-clinicians to gain insights into their views on patients' research needs.

Results: The health professionals' research needs were clustered as: causes, diagnosis, pharmacotherapy, non-pharmacological treatment, recovery, and care system, and overlapped with the research needs formulated by patients. Researcher-clinicians were able to translate patients' needs into feasible research questions.

*Discussion***:** Researcher-clinicians can serve as intermediaries between research and practice, and can both integrate their practical experience into research and their research experience into practice.

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7.1 Introduction

Bipolar disorder (BD) is a complex psychiatric disorder, characterized by recurrent episodes of (hypo)mania and depression alternating with euthymic intervals. It affects more than 1% of the population worldwide (Grande et al., 2016). In the Netherlands, the estimated lifetime prevalence is 1.3% (de Graaf et al., 2012). BD is disabling due to its early onset, severity and chronicity (Ferrari et al., 2016), and the functional impairment even in euthymic phases. Moreover, BD leads to a reduced quality of life for patients and their caregivers (Granek et al., 2016). These consequences could be partly overcome by treatment, which is considered to reduce symptoms and improve functioning and the quality of life (IsHak et al., 2012; Sylvia et al., 2017). However, it remains challenging to diagnose and treat BD (Henry et al., 2013), due to the complex course and the heterogeneity of the disorder.

In modern mental health care, care is often provided according to the prevailing paradigm of Evidence Based Medicine (EBM). The cornerstone of EBM is practicing health care based on the best available research evidence (Sackett et al., 1996) in order to *'de-emphasize intuition'* and '*unsystematic clinical experience'* (Guyatt et al., 1992, p. 2420). In this paradigm, Randomized Controlled Trials (RCTs) are central in acquiring this evidence (Darlenski et al., 2010) and are, along with meta-analysis and systematic reviews, considered the gold standard of research (Rycroft-Malone et al., 2004). These research findings are often translated into treatment guidelines, which are a tool to support clinical decision making based on research evidence (Hay et al., 2008; Weaver, 2015). Research has resulted in a greater understanding of the disorder. However, the effect of this understanding on the effectiveness of mental health care is considered questionable (e.g. Henry et al., 2011) and the evidence is not always easily translated into clinical practice (Green, 2009; Kazdin, 2008; Rosner, 2012), leading to a gap between research and practice (Henry et al., 2011).

It is increasingly acknowledged that to bridge the gap between research and practice, it is beneficial for several reasons to include patients in research as end-users - as 'someone who will consume, use or work in the specific health field under research' (Elberse et al., 2012, p. 232). First, it improves the clinical relevance of research and the acceptance of the research outcomes (Abma & Broerse, 2010; Elberse, Laan, et al., 2012) and second, it contributes substantive new knowledge, owing to patients' experience of living with the illness and their need for care (Broerse, Zweekhorst, et al., 2010; Tait, 2005). In a previous study, we explored the research needs of patients with BD (Maassen et al., 2018). As health professionals are also end-users of the research, the same argument can be made to include them in the research process. Involving health professionals would be advantageous for numerous reasons. They could complement the patients' experiential knowledge with their clinical expertise by adding relevant research topics and by indicating which research results are (un)likely to be used in clinical practice (Newnham & Page, 2010). Therefore, we argue that one step into bridging the research–practice gap is to unravel relevant research needs according to health professionals and the overlap with patients' research needs. Moreover, health professionals, and in particular researcher–clinicians, could play an intermediary role between research and practice, and potentially narrow the gap between the two (Kluijtmans, de Haan, Akkerman, & van Tartwijk, 2017). They are close to patients, and hence in a good position to understand patients' needs and preferences. In their role as health professionals, they use the results of research in clinical practice by applying guidelines, while being at the same time actively involved in research processes. Many health professionals are involved in research projects, whether through collecting data about their patients or through setting up and conducting entire research projects. Thus, in order to contribute to bridging the research–practice gap, our study seeks to explore research needs from health professionals' perspective in the field of BD and their reflections on the research needs of patients.

7.2 Methods

A qualitative research approach was used to gain insights into health professionals' perspective (Green & Thorogood, 2009) on research needs and to elaborate on topics (Gray, 2014) to deepen the understanding of their motivations and views. Our study consists of two phases.

7.2.1 Phase 1: research needs from a health professional's perspective

This phase aimed to gain insights into the research needs according to health professionals. For this purpose, we recruited health professionals from three teams specialized in treatment of BD at two Dutch outpatient clinics. In each team, separate Focus Group Discussions (FGDs) were conducted with psychiatrists, psychologists and nurses to derive a broad range of research needs. In two teams, there was only one psychologist. We therefore conducted interviews instead of FGDs. In total, 18 health professionals participated: seven psychiatrists, seven nurses and four psychologists. The FGDs and interviews were based on a preliminary guide, comprising three parts: trends in health care, hopes for the future and associated research needs. The sessions took 60–90 minutes. The FGDs and interviews were audio-taped and transcribed verbatim. A framework for thematic analysis ('identifying, analyzing and reporting patterns and themes within data') by Braun & Clarke (2006) was used for the analysis, supported by the qualitative software program Atlas.ti. Open coding was used to derive all research needs formulated by health professionals. Subsequently, we sought patterns to cluster these codes into themes, after which these themes were named. In addition, the research needs of health professionals were compared with the research agenda according to patients with BD.

7.2.2 Phase 2: reflections of researcher-clinicians on patients' research needs

As previously explained, including end-users in setting a research agenda has been shown to contribute to narrowing the gap between research and practice. In addition, narrowing this gap could benefit from the potential intermediary role researcher–clinicians could play, since they use research in their clinical practice, are actively involved in research, and are in a position to understand patients' needs and preferences. We therefore conducted a pilot study to gain insights into the views of researcher–clinicians on patients' research needs. As a discussion tool, the 23 research needs according to patients with BD was used. First, two pilot interviews were conducted with two researcher–psychiatrists to fine-tune the interview guide. Before the start of the interview, participants were asked to reflect on each of the 23 topics formulated by patients, considering *if* and *in which phase of research* they see a role for their discipline to contribute to the research topic. Four phases of research were distinguished: 1) formulating a problem statement; 2) conducting the research; 3) interpretation of the results; and 4) implementation of the results in clinical practice. In total, six interviews were conducted, two with psychiatrists, two with psychologists, and two with nurses. Participants were included in this phase of the study if they had experience with treating patients with BD and if they were conducting research in this field. The interviews took approximately 45 minutes. The interviews were audio-taped and transcribed verbatim. The first step in the analysis was to familiarize ourselves with the data. Second, open coding was used to code all segments that described factors that play a role in the view of researcher–clinicians on the research needs of patients. Third, all codes were listed and comparable codes were merged into the same code. Subsequently, we looked for patterns throughout all codes, using the Atlas.ti qualitative software program.

7.2.3 Ethical consideration

According to the Medical Ethical Committee of the VU University Medical Center, the Medical Research Involving Human Subjects Act does not apply to the first part of this study. Given the non-invasive character of the second part of the study, formal approval from a medical ethical committee was not required, according to Dutch law. All participants gave verbal consent before the start of the FGD or interview for audio-taping, transcribing and analyzing the FGDs and interviews. Anonymity of all participants was ensured. Participants were informed that they could withdraw from the study at any time.

7.3 Results

7.3.1 Research needs from a health professional's perspective

The research needs formulated by health professionals could be clustered into six themes: causes of BD, diagnosis, pharmacological treatment, non-pharmacological treatment, recovery, and care system. In the following section, these research themes are further explained.

Causes of BD: including the psychological perspectives

Health professionals formulated research needs on the etiology and the triggers for a mood episode. They called for more research on genetic influences and neurobiological processes, but also indicated the relevance of a psychological explanation for the manifestation of BD. This would include research on the influence of personality traits on the onset of BD, the psychological explanation for the symptoms and the question of whether certain personality traits could be more frequently recognized in patients with BD. This research need is explained by a psychologist:

> *But also if people with BD have different premorbid characteristics … That they are different than people who are not diagnosed with BD.*

Research on these fundamental questions would provide health professionals with a better understanding of (the causes of) the disorder.

Diagnosis: detection and distinction

According to health professionals, diagnosing BD is challenging. This is expressed by one psychiatrist:

> *There is an average ten-year gap, between the early signs and the moment the patient is diagnosed with BD. If we would find more [information] on that, we would win the Nobel prize! So early detection, that is what it is about.*

Health professionals set out a diverse set of research needs involving the diagnostic process, aiming to increase the early detection of BD and enable the distinction between BD and other psychiatric disorders. According to health professionals, this requires research on the early warning signs of BD, greater knowledge among general practitioners (GPs) about BD, the validity of diagnostic tools and the distinction between BD and personality disorders. In addition, there is a need for more research on the role of psychologists in the diagnostic process.

Pharmacological treatment: increasing the efficacy

health professionals stressed challenges in the process of finding effective and acceptable pharmacological treatment, and being able to predict which medication will be most effective. The following quote from a psychiatrist addressed this challenge:

> *Sometimes, people are stabilized by the medication, but they experience side-effects. And sometimes persistent side-effects. With lithium, kidney failure. Then you have found a treatment that is effective, but at the same time harmful.*

These challenges featured a focus on research on increasing the efficacy of medication, while also developing medication with fewer side-effects and improving the ability to predict which pharmacotherapy will be most effective for an individual patient, e.g. by research on biomarkers. In line with these research needs, health professionals recognized the relevance of improving the treatment of BD , since this is more difficult to treat than a manic episode.

Non-pharmacological treatment: broadening the treatment options

A variety of research needs in the theme non-pharmacological treatment were highlighted, and were aimed at broadening the options for treatment. Health professionals formulated needs for research on the efficacy of non-pharmacological treatments and the development of eHealth. The former includes research on the efficacy of non-pharmacological biological treatment options, e.g. light therapy, but also entails research on psychological treatment. The need for more research on the role of psychological treatment in treating BD has been highlighted, to gain insight into effective psychological treatments, and when and in what circumstances these are appropriate. Research on the efficacy of treatments could also include studying the effectiveness of treatments that are currently used in other disorders for treatment of BD. Within broadening the treatment options, the improvement of non-pharmacological treatment for bipolar depression was particularly stressed. In addition, health professionals would appreciate research on which elements of a treatment might influence effectiveness. As one psychologist explained:

> *Look, we now start a cognitive behavioral therapy group, but also from this therapy it is not exactly clear what the effectiveness is and for whom it would be effective, because that is depending on the mood.*

Recovery: reducing the impairments

Health professionals called for more research to contribute to reducing impairments in a variety of life domains caused by BD. They formulated the need for research on the nature of functional impairments due to BD, such as cognitive impairments or over-stimulation, and on the influence of these impairments on occupational functioning. In addition, research needs on increasing knowledge in society and decreasing stigma to reduce social impairments were formulated. One nurse explained why this is important:

> *Increasing the understanding by society. We often notice, that when patients tell others they have a manic-depressive disorder, automatically they are branded as crazy. People think these patients always suffer from psychosis or have multiple personality disorder (…). And the term bipolar disorder is often unknown. If you say manic depressive disorder, they know, but then a negative result comes in.*

Another research need to contribute to reducing impairments was to gain knowledge on effective self-management strategies. Overall, health professionals advocated research on factors influencing the patients' quality of life.

Care system: towards a dynamic system

Health professionals expressed research needs that would contribute to establishing a dynamic care system. These needs include research on improving the continuity of care, the question on how to use everyone's expertise in clinical practice to improve efficiency and collaboration systems among a variety of health professionals. One psychiatrist explained:

> *Look, as a bipolar care team, you cannot offer everything, but since it is a disorder that often deals with comorbid disorders… it is about improved collaboration within the mental health institution but also*

> *child welfare and family therapists […], but also in the field of physical health, including neurologists, doctors of internal medicine […]. To find an efficient way of collaborating.*

In addition, health professionals expressed interests in research on how science and practice could be better integrated, to be able to use scientific results and conduct research that is relevant for clinical practice. Furthermore, they would appreciate research on the quality of care from a patient's perspective.

Reflecting on the research–practice gap, it is important to focus on the overlap and differences between the research needs formulated by patients and health professionals. There is a considerable overlap between the health professionals' research needs, as identified above, and the research agenda formulated by patients with BD (see Table 7.1) (Maassen et al., 2018). Both end-user groups call for research aiming to provide a clearer understanding of the underlying cause of the disorder, with a focus on the etiology and triggers of BD. Both patients and health professionals formulate the need to study the effectiveness of pharmacological treatment and the development of effective new medication, as well as for the need for research on the effectiveness of non-pharmacological therapies, early warning signs, (the validity of) diagnostic tools and the improvement of GPs' knowledge of BD. Moreover, both end-user groups formulated the need for research on enhancing social acceptance and knowledge, effective self-management strategies and the improvement of the care system to provide continuity, flexible care and an adequate collaboration system among health professionals. Overall, health professionals' and patients' research needs address the same research themes, but their specification varies slightly, with patients and health professionals emphasizing both overlapping and distinct topics within the themes. For instance, health professionals did not mention the needs formulated by patients related to recovery, e.g. positive aspects of BD, the impact of BD on patients and caregivers and strategies for social reintegration. Therefore, it would be interesting to understand the view of researcher–clinicians on research topics mentioned by patients, if they see potential in these topics and if they consider them eligible for research.

7.3.2 Reflections of researcher-clinicians on patients' research needs

From the interviews it became clear that researcher–clinicians saw potential in, and understood, all the research topics formulated by patients, including those not formulated by health professionals. This finding was strengthened by the fact that the

Table 7.1 Research agenda for bipolar disorder according to patients (Maassen et al. 2018)

	Topic	Research Theme
1	Etiology	Cause of disorder
2	Development of medication with less side effects	Pharmacological treatment
3	Long term side effects of medication	Pharmacological treatment
4	Trigger for onset mood episode	Cause of disorder
5	Recognition early warning signs of BD	Diagnosis
6	Development of medication that is better targeted	Pharmacological treatment
7	Reintegration in society	Recovery & recovery oriented care
8	Development new non-pharmacological therapies	Non-pharmacological treatment
9	Effectiveness current non-pharmacological therapies	Non-pharmacological treatment
10	Increase of acceptance by society	Recovery & recovery oriented care
11	Designing a patient centered care approach	Recovery & recovery oriented care
12	Knowledge improvement GP	Diagnosis
13	Self-management	Recovery & recovery oriented care
14	Positive aspects BD	Recovery & recovery oriented care
15	Development diagnostic tool	Diagnosis
16	Collaboration practitioners (incl. alternative medicine)	Recovery & recovery oriented care
17	Development therapies to support caregivers	Non-pharmacological treatment
18	Impact of diagnosis	Recovery & recovery oriented care
19	Mechanism of action of medication	Pharmacological treatment
20	Treatment options for comorbidity	Recovery & recovery oriented care
21	Necessity of medication	Pharmacological treatment
22	Correct referral system	Diagnosis
23	Effect of lithium on sports	Pharmacological treatment

BD: bipolar disorder; GP: general practitioner

researcher–clinicians not only affirmed they could contribute in (phases of) research on these topics, but also made concrete suggestions for research approaches.

These suggestions provided a better insights into the role of interpretative frames of researcher–clinicians in translating patients' research needs into research they could conduct and the conditions in which they would be able to conduct the research.

Interpretative frames

From the findings, it became clear that researcher–clinicians used an interpretative frame to interpret the research needs of patients and translate these into research. This interpretative frame is formed by their role in clinical practice, their disciplinary background and the multidisciplinary nature of clinical practice.

The first aspect that plays a role in the interpretation and translation is the *reasoning from a clinical viewpoint* by researcher–clinicians. The research topics were approached from a clinical perspective rather than from a solely scientific perspective. These approaches reflected the clinical actions of the researcher-clinicians and the problems they experienced in clinical practice. One psychologist explained how a research question can be derived from clinical practice:

> *For me it [reason why I would conduct research] is way more clinical when I am treating patients and I think: for this I would want a solution, because I run into a problem in the treatment and it would be nice if we would have something to offer or that we can do something about it.*

A nurse illustrated why a research topic would be suitable for their research domain, based on their role in clinical practice:

> *Well, I think triggers for a new episode. The triggers, that are just the things you try to capture in for example an alert plan, so I think research in that area would really fit nurses.*

A second aspect is the specific disciplinary background of the researcher–clinicians. Nurses would focus primarily on *the consequences* for the patient, *the influence on functioning* and *the impact*. Psychiatrists would approach the research topics from a *medical* frame, focusing on *physical aspects*, *biological aspects*, *medication* and *symptomatology* and the psychologists from a *psychological* frame which entails a focus on *psychological mechanisms*, *behavior*, *cognition* and *experiences.* Table 7.2 illustrates the differences in perspectives between disciplines on the basis of three research topics that clearly address these differences.

The third aspect is the interdisciplinary nature of clinical practice. Researcher–clinicians recognized their role as member of a multidisciplinary team, which was considered relevant both in addressing patients' needs in clinical practice and in research. They emphasized the importance of an interdisciplinary approach to benefit from all the available knowledge and expertise and to do justice to the complexity of the research topics. They were able to recognize and appreciate the research needs of patients that were not directly related to their own discipline and should primarily be studied by another discipline. However, even when participants attributed the research need of patients to another discipline, they recognized a role for themselves in one of the research phases, for example in formulating the problem statement or implementing the results.

Moreover, they mentioned that some research could be conducted *within* a team of researcher–clinicians, but other research requires collaboration with experts from other fields (e.g. public administrators, pharmacologists). In the latter, researcher–clinicians could function as a source of knowledge, while other experts take the lead in the research. According to the participants, an interdisciplinary approach would prevent a narrow approach to the research topics.

> *I think, by definition, everything should be interdisciplinary. […] Yes, because I think otherwise, by definition, you conduct bad research, because you already steer it [the research] in a certain direction.*

Research conditions

As mentioned earlier, researcher–clinicians expressed an interest in the research needs formulated by patients, and even formulated practical conditions under which they would conduct the research with the resources at their disposal. Based on the findings, three important aspects related to resources can be distinguished.

The first aspect mentioned by participants is the *research setting*, e.g. academic setting or mental health clinics. This influences the available techniques (e.g. laboratories, MRI-scans) that are necessary to, and expertise (e.g. neuroscientists, pharmacologists) that could be supportive in, conducting research and therefore shapes the research approach. One psychiatrist illustrated the relevance of the research setting:

> *Biological [triggers] are of course also very important, but then you need large institutions. That is not very practical from a general institution. […..] We can join, but academic centers will be leading*.

The second aspect mentioned is *patient population*. For some research topics a certain patient population is required that is does not exist in every setting, e.g. a certain age group or population that could be followed up over time. This could mean that the research topic is either completely incompatible, or would require a different approach, focused on the available patient population. For example, early warning signs could be studied in a group of young children who are not being treated at an adult outpatient clinic. To study early warning signs in a distinct setting would require a different approach.

Table 7.2 Illustration of differences in perspectives of psychiatrists, psychologists and nurses on three research topics

Research topic	**Discipline**	**Frame**	**Illustrative quote**
Long-term side-effects of medication	Psychiatrist	Physical aspects	*That would fit, because we have patients with chronic disorder, so in other words, we could describe the side effects of medication, and it would be relatively easy to study metabolic syndrome.* *Indeed the more hard medical variables, like kidney failure and that kind of things.*
	Psychologist	Experience aspect	*“Side-effects always have a strong experience aspect. Look, you have the side-effect in a narrow sense, but also how it is experienced by people and how the side-effect is reported. Yes and with these experience aspects [of long-term side-effects], I think a psychologist can contribute.*
		Identity	*Then I would look at what the effects are on wellbeing or for example identity. People often have problems with apparently needing pills to be normal. So, if that would be the focus, then I think you need psychologists in the research project.*
	Nurse	Consequential aspects	*And for the nurses, I think, what are the consequences of these long-term side-effects on peoples’ lives? And on their functioning?* *Because that is something we talk about with patients on a daily basis, about the effects and side--effects and where they suffer from. So that would fit us [nurses]. Also because side-effects have a major influence on the quality of life.*
Development diagnostic tool	Psychiatrist	Symptomatology	*When you talk about a diagnostic tool that would map the clinical information, like a screening instruments for, for example, general practitioners.*
		Biological	*But you could also use a biological approach. Research with MRI-scans and CT-scan. That we further develop that.*
	Psychologist	Validity aspects	*Psychologists often work with a questionnaire. So, in the development of a more valid questionnaire. For example, I think that psychologists, by definition, are trained to think along in the development [of a new questionnaire].*

	Nurse	Functioning	*When you want to get a better overview of the patient's functioning, than you need to develop a tool that helps to map the functioning of each individual bipolar patients. And that would be something for a nurse.*
		Self-management	*That you collect the right information for the nursing discipline. Something we can work with, is the development of an instrument to measure self-management needs of patients.*
Triggers for onset of mood episode	Psychiatrist	Biological	*Most important outcome according to us is, as little episodes as possible. So carefully understand what triggers [the episode], provides us with a site of action in treatment. For example, biological.* *That you really look from a biological point of view, like is there a more sensitive stress system. Could that be the cause that people relapse? Because with little stressors they already relapse [in a new mood episode]. So that would be a more biological approach.*
	Psychologist	Psychological make-up	*But also certain events that have a special meaning for people for the sake of their personal style and development. And yes, that is eminently something a psychologist should conduct research on. I think on the basis of how a person developed, there are certain sensitivities in the psychological make up that could contribute to the development of a mood episode.*
		Behavioral aspects; cognitive aspects	*You also see that in clinical practice, that environmental factors are playing a role. But then in terms of cognition, or behavior. So, I think, with these research question a psychologist should be involved, to study what psychological triggers are in the emergence of psychopathology.*
	Nurse	Life events	*What a nurse could do is, for example, in families where many people have bipolar disorder, to study, like, how about that? How is such a family structured? And who is getting sick and who is not? Which factors are of influence? That kind of thing. [….] So, I would choose a kind of multiple case study design and you select a couple of people from such a family and you completely reconstruct the course of life. From a mixed method design, and you collect qualitative and quantitative data to see if there is a certain trend [in life events].*

The third aspect mentioned is *population size.* Some research topics, e.g. the genetic influences on the disorder, require a population size that transcends the borders of the institutions and even countries, which makes this type of research incompatible with the research environment of researcher–clinicians.

> *That [genetic research] really must be done from the NIMH [The National Institute of Mental Health] and otherwise it is less than a drop in the ocean.*

To conclude, based on this pilot study, researcher–clinicians can play an intermediary role between research and practice. They are able to understand the research needs of patients based on their clinical experience and at the same time offer concrete suggestions on how to conduct the research based on these needs, including the conditions in which this could be done.

7.4 Discussion

The importance of involving end-users' perspectives in formulating research agendas in order to improve the clinical relevance and increase acceptance of the research, and thus narrow the research–practice gap, is increasingly acknowledged (e.g. Elberse, Laan, et al., 2012; Newnham & Page, 2010). Therefore, this study aimed to explore the research needs from health professionals' perspectives and to complement it with a comparison with previously studied patients' needs as well as to unravel the potential intermediary role of researcher–clinicians. Research needs as perceived by patients largely overlap with health professionals' research needs. Health professionals view patients' research needs as relevant and researchable and suggest concrete ways of doing the research. In this way they can act as intermediaries.

In the first phase of this study, six categories of research needs were derived: causes, diagnosis, pharmacological treatment, non-pharmacological treatment, recovery, and care system. Even though health professionals' research needs regarding BD had not yet been systematically studied, several studies have included health professionals' perspectives on research priorities for mental health in general (Forsman et al., 2015; Griffiths, Jorm, Christensen, Medway, & Dear, 2002; Michalak et al., 2016; Owens, Ley, & Aitken, 2008) and in mental health, justice and safety issues (Crocker et al., 2015). The findings of these initiatives partly overlap with our findings, such as research on pharmacological treatments (Forsman et al., 2015; Griffiths et al., 2002), (genetic) causes (Forsman et al., 2015; Griffiths et al., 2002), cognitive processes (Griffiths et al., 2002) and improving society's mental health literacy (Crocker et al., 2015; Fiorillo et al., 2013; Griffiths et al., 2002). In addition, health professionals' research needs on helpful components of psychological interventions (Fiorillo et al., 2013; Forsman et al., 2015; Michalak et al., 2016; Owens et al., 2008), the quality of services (Fiorillo et al., 2013), early detection and the social impact and stigma (Fiorillo et al., 2013; Michalak et al., 2016) were also found in other initiatives on mental health in general. This overlap suggests that these research topics are not only relevant for BD, but for other psychiatric disorders as well.

Interestingly, the health professionals' research needs can be positioned between the research needs according to patients and the current European research agenda formulated by the European Network of Bipolar Research Expert Centre (ENBREC) (Henry et al., 2013; Maassen et al., 2018) Patients' research topics relating to recovery and recovery-oriented care were underrepresented in this European agenda. Health professionals and researcher–clinicians not only formulated topics relating to recovery and recovery-oriented care but were also able to translate these topics into research questions. By recognizing the relevance of these topics and formulating research approaches to address them, the underrepresentation of this theme could be reduced with the support of researcher–clinicians. Hence, health professionals (and researcher–clinicians) can play a role in developing meaningful research based on their experiences in practice (and in research).

In the past decades there have been many efforts to bridge the gap between research and practice under labels such as transdisciplinary research (Darbellay, 2015; Enengel et al., 2012; Klein, 2015), implementation sciences (Damschroder et al., 2009; Proctor et al., 2009), and translational medicine (Drolet & Lorenzi, 2011; Woolf, 2008). A core feature of these approaches is that they emphasize the role of actors being part of several contexts. These actors, labeled for example as brokers or boundary spanners, and familiar with settings on the ground and research or policy contexts, are regarded as promising in narrowing the research–practice gap. According to recent literature, researcher–clinicians can play this intermediary role for several reasons. First, they have the ability to translate research findings into clinical practice (Gunasekaran, Krishnadevarajan, & Lawrence, 2017; Kluijtmans et al., 2017; Roberts, Fischhoff, Sakowski, & Feldman, 2012; van Oostveen, Goedhart, Francke, & Vermeulen, 2017), Second, they are directly confronted with patients' reactions and can thus lead information from practice into research by creating new hypotheses (Roberts et al., 2012). This resonates with our study, where we found that health professionals understand patients' needs and can translate them into research questions. They showed that patients' clinically relevant questions could be translated into a research question that fit their setting. In this study it emerged that the interpretative frame and the research conditions of the researcher–clinicians play an important role in this translation process. For example, respondents indicated that research topics that could be approached by studying a patient population who would fit their perspective, whereas research topics that could be approached with studies that required a laboratory would not. This finding is confirmed by Cleary, Hunt, Walter, & Jackson (2010), who stated that academic researchers often have scientific projects 'ready to go', but need health professionals to investigate the effectiveness of treatments. Third, they have the ability to both conduct research and disseminate their results to other researchers and health professionals, thereby bridging a gap in perspective between researchers and health professionals (Smith & Wilkins, 2018). Fourth, researcher–clinicians can play an intermediary role between research and practice because they have a broader perspective on care than either researchers or health professionals. Kluijtmans et al. (2017) found that health professionals who became skilled as scientists '*evoked reflection with regard to their clinical profession as they developed broader perspectives on patient care and the organization of care'* (p. 651). Our study also found that researcher–clinicians had a broad perspective on patient care. They were not only able to translate the research needs of patients into research questions that would fit their own interpretative frame but could also recognize research questions that would fit other disciplines.

7.4.1 Limitations and recommendations for future research

Our study has some limitations. First, this study explored research needs from the perspectives of health professionals and the researcher-clinicians' perspectives on the research needs of patients. However, we did not study patients' perspectives on the research needs of health professionals. To deepen the understanding of the clinical relevance of these research needs, further research is needed to study patients' perspectives on the health professionals' research needs. Second, to generalize the findings of our study, research needs from the perspective of health professionals should be verified by a larger group. Third, we studied the views on the research needs of patients in a small group of researcher–clinicians. To further the understanding of the potential intermediary role of researcher–clinicians, this study needs to be extended.

7.5 Conclusion

In conclusion, our study contributes to the field of research agenda setting by studying the research needs of health professionals in the field of BD. The research needs formulated by health professionals largely overlapped with those of patients with BD, but in addition both health professionals and patients raised specific topics. Research topics formulated by patients could be translated by researcher–clinicians into study approaches that fit existing research domains. Therefore, researcher–clinicians could play an intermediary role between clinical practice and research in order to narrow the research-practice gap.

CHAPTER 8

Role clarification: a qualitative study on interprofessional bipolar disorder teams using cognitive maps

Abstract

In order to cope with increasing complexity in health care and provide more patient-centered care, it becomes more important to work in interprofessional teams (IPTs). However, IPT work can be difficult because of differences in cognitive maps between disciplines. This study aims to clarify the roles of different disciplines in interprofessional care teams in specialized outpatient centers, by elucidating their respective cognitive maps. The process of diagnosing bipolar disorder is studied in three mental health care teams, comprising psychiatrists, psychologists and nurses, all experienced with diagnosing bipolar disorder. The study followed three methodological phases, an exploration phase, a Delphi study and a differentiation phase. According to our findings, there is a lack of clarity in distributing tasks among disciplines. Formulating cognitive maps offers insights into how disciplines could complement each other by differentiating tasks. We distinguish two types of differentiation; *leading to deepening* and *leading to broadening.* We hypothesize that by going through this process with an IPT, it will improve the use of expertise of each discipline resulting in knowledge-enriched decision-making and, hence, better and more efficient care.

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8.1 Introduction

Providing health care has become more complex (Mickan & Rodger, 2005) and demanding (MacDonald et al., 2010). One reason is the rapid expansion of knowledge and treatment options, which has resulted in greater specialization of health professionals (Fay, Borrill, Amir, Haward, & West, 2006) and in fragmented care (Fleissig, Jenkins, Catt, & Fallowfield, 2006; Hall & Weaver, 2001; Mickan & Rodger, 2005). A second reason is the ongoing shift in focus of health care from a disease-centered approach towards one that is more patient-centered (Maassen et al., 2016). This shift demands that health professionals possess more knowledge and skills, because they need to pay attention not only to diagnosing and addressing symptoms, but also to a broader range of needs, such as quality of life, levels of functioning and coping of both patients and caregivers (Hall & Weaver, 2001; Maddock, 2015). Both factors underlie the increased complexity of providing health care and make it unlikely that one health professional might meet all patients' needs (Hall & Weaver, 2001; Suter et al., 2009). In consequence, the increase in necessary skills and available knowledge and the complexity of a patient's problem have led to a renewed interest in the concept of interprofessional teamwork in the context of health care (Madge & Khair, 2000).

In the literature on teamwork in health care, a variety of concepts is used to designate collaboration between different health care professionals in care teams (e.g. multidisciplinary teamwork, interprofessional collaboration). In this article we will refer to this type of teamwork as interprofessional teamwork (IPT), which is defined as "a type of work which involves different health and/or social professions who share a team identity and work closely together in an integrated and interdependent manner to solve problems and deliver services (Reeves, Lewin, Espin, & Zwarenstein, 2010). IPT as a concept was first described in the field of mental health care in the early 1970s and in diabetic care in the 1980s (Madge & Khair, 2000; Ryan, 1996). The renewed research focus is mainly on the effectiveness of teams (Fleissig et al., 2006; Lemieux-Charles & McGuire, 2006), characteristics or organizational structures of effective teams (Bélanger & Rodríguez, 2008; Fennell, Das, Clauser, Petrelli, & Salner, 2010; Mickan & Rodger, 2005) and patients' and health professionals' experience with IPTs (Schwartz, Wright, & Lavoie-Tremblay, 2011; Vitale & Mannix-McNamara, 2013).

IPT work is increasingly promoted because of its benefits, which have been studied particularly in the field of cancer care. In a review by Fleissig et al. (2006) on the effectiveness of IPTs in cancer care, they describe them as ensuring 'high quality diagnosis, evidence-based decision making, optimum treatment planning and delivery of care' (p. 936), contributing to better continuity of care. Furthermore, it has been shown that interprofessional care significantly increases the survival rate of cancer patients (Ruhstaller et al., 2006), as well as reducing costs, improving the quality of care and enhancing patient and professional satisfaction (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005; Macnaughton, Chreim, & Bourgeault, 2013; McInnes, Peters, & Bonney, 2015). Scholars commonly argue that 'joint decisions are more accurate than the sum of all individual opinions' (D'Amour et al., 2005; Ruhstaller et al., 2006, p. 2490).

Notwithstanding the benefits of working in an IPT, it can also be fraught with difficulties. Some scholars explain these difficulties partly by the differences in values and beliefs among disciplines, due to their educational backgrounds and a socialization process in which professionals adopt a discipline-based vision on patients' problems and the interventions that can be offered (Bélanger & Rodríguez, 2008; D'Amour et al., 2005; Hall & Weaver, 2001; Orchard, Curran, & Kabene, 2005). Similarly, scholars describe a difference in the 'cognitive map', which means that disciplines have their own ways of conceptualizing problems and interventions (D'Amour et al., 2005; Hall & Weaver, 2001), and can '*look at the same thing and not see the same thing*' (Petrie (1976) cited in Hall, 2005, p. 190). Thus, the development of a strong culture or identity might hinder the ability to understand others' frameworks and hamper collaboration (D'Amour et al., 2005; Orchard et al., 2005), among other things due to differences in vocabulary and approaches to problem-solving (Hall & Weaver, 2001).

According to scholars in the field of interprofessional collaboration, one way to overcome this barrier is role clarification or role understanding (Orchard et al., 2005; Petri, 2010; Suter et al., 2009). Orchard (2005) describes role clarification as gaining an understanding of the roles assumed by each member. Understanding the role, knowledge and skills of each discipline, including their own, enhances collaboration in an IPT (McInnes et al., 2015; Petri, 2010; Ruhstaller et al., 2006; Suter et al., 2009). Moreover, it could increase confidence among team members (Petri, 2010), maximize skills by allowing disciplines to focus (Macnaughton et al., 2013), improve patient outcomes (Suter et al., 2009) and prevent duplication (Suter et al., 2009; Brown, Crawford, & Darongkamas, 2000). Thus, role clarification could contribute to a more efficient IPT.

Currently, mental health care is often provided by an IPT. For example, in bipolar disorder (BD), care is provided using a multidisciplinary guideline (Kupka et al., 2015). Still, despite the carefully formulated guideline, diagnosing a complex and heterogeneous illness such as BD remains challenging. There is an average 10-year gap between the onset of the disorder and the diagnosis (Drancourt et al., 2013). This could partly be explained by the lack of pathophysiological tests (biomarkers), which results in an entirely clinical diagnosis (Mazza et al., 2013), in which clinical expertise and experience gain importance. We built on the assumption that by clarifying the roles of each IPT member each person's skills could be maximized and duplication could be reduced, contributing to more efficient teamwork and an improved diagnostic process. To this end, this study sought to clarify the roles of different disciplines in interprofessional care teams in specialized outpatient centers, by elucidating their respective cognitive maps.

8.2 Methods

Qualitative research methods were used to deepen our understanding of differences in cognitive maps and to demonstrate how such understanding could contribute to role clarification. Cognitive maps are discipline-specific ways of seeing and conceptualizing problems and interventions; approaches to problem-solving; and vocabulary. In this study, cognitive maps are operationalized as the articulation of discipline-specific approaches to a particular task in the diagnostic process. The study does not examine how the different disciplines approach problem-solving in clinical practice. Rather, it focuses on their views of what needs to be done, not on what they do.

8.2.1 Case description

In comparison with, for example, a surgical team, whose members operate alongside each other, in mental health care, professionals often work in parallel, not seeing what other professionals are doing. Furthermore, the multidisciplinary guideline for BD (Kupka et al., 2015) states that the diagnostic process is a challenging interprofessional task. For these reasons, this study was conducted in Dutch outpatient health care teams specialized in the diagnosis and treatment of patients with BD. Three teams were studied, comprising psychiatrists, psychologists and nurses, as well as psychologists from other teams, due to some underrepresentation of psychologists in the originally selected teams.

Data were collected in three phases: an exploration phase, a Delphi study and a differentiation phase. Phases 1 and 2 supported phase 3, when cognitive maps were used to contribute to role clarification.

8.2.2 Data collection and analysis

Phase 1. Exploration of roles in diagnostic process

In this phase, we studied insights into the added value of each discipline compared to the other disciplines in an IPT in diagnosing BD. To gain these insights, focus group discussions (FGDs) and interviews were conducted with psychiatrists, psychologists and nurses. Three sessions were planned in each clinic, one with each discipline, using FGDs or interviews depending on the number of professionals per discipline. In total five FGDs (two with psychiatrists, two with nurses and one with psychologists) and four interviews (three with psychologists and one with a nurse) with a total of 18 participants took place. The FGDs and interviews addressed the same topics: 1) the added value of each discipline and 2) the focus of each discipline in the diagnostic process.

All FGDs and interviews were audiotaped and transcribed verbatim. First, the transcripts were carefully read and open coding was used to derive all the tasks important for the diagnostic process. Second, when the codes addressed the same task, they were merged and formulated into one task. This resulted in a list of 34 tasks.

Phase 2. Defining tasks and roles in the diagnostic process: a Delphi consensus study

After exploring the relevant tasks in the diagnostic process of BD in phase 1, an online Delphi study was conducted. The Delphi method is used to collect the opinions of experts, reach consensus on a certain topic (Yousuf, 2007) and as a tool for 'expert problem solving' (Okoli & Pawlowski, 2004). A Delphi study consists of three rounds. Each successive round copies and includes the results from the previous one to allow for anonymous interaction between experts (Hsu & Sandford, 2007; Yousuf, 2007). The aim of the Delphi method in this study was to reach consensus on which tasks should be performed primarily by which discipline to prevent overlap and improve efficiency. Participants were recruited via the Dutch Foundation for Bipolar Disorder , a nation-wide professional expertise network. Twenty-seven experts in the field were selected for this study, ten psychiatrists, nine nurses and eight psychologists. For each of the three rounds of the Delphi study participants received an email with the link to the survey. The survey was created in SurveyMonkey, an online survey development software.

In the first round, open questions on the added value of each discipline were asked (similar to phase 1). A total of 25 participants responded, which resulted in an additional

19 tasks. Combined with the results from phase 1, this resulted in 53 diagnostic tasks as the basis of the second round. Participants were asked to decide which discipline should primarily perform each task. They were allowed to provide only one answer in order to force them to choose. They were also asked if the task was essential or optional for the diagnostic process. Twenty-six of the participants responded. In the third round, once more the survey was send to the participants. All 53 tasks were included in the survey, provided with the scores from the second round. The participants were again asked to assign each diagnostic task to one discipline, whereby they could either confirm or change their previous answer. Furthermore, when in great doubt, participants had the chance to explain why a certain task could also be assigned to a second or even third discipline. A total of 25 experts responded. All responses were collected anonymously and entered into an Excel spreadsheet. In the analysis, it was calculated what percentage of the participants assigned a task to a specific discipline, to see if consensus could be reached. Consensus was defined as reaching a certain cut-off point. As cut-off points for consensus are widely discussed in literature, the one that should be used depends on the importance and the consequences of the consensus (Keeney, Hasson, & McKenna, 2006). Percentages used for consensus generally range between 51% and 100% (Keeney et al., 2006; Powell, 2003). Often, consensus is decided when 70% or 80% is reached (Hsu & Sandford, 2007; Jorm, 2015). In this study, we defined consensus on a topic when there was 80% agreement. We argued that when the cut-off point is too low, health professionals might disagree on how the roles are clarified. When it is too high, too few tasks will reach consensus, resulting in no role clarification and continued duplication. This phase resulted in one list of tasks on which participants reached consensus and another where no consensus could be reached.

Phase 3. Role clarification using cognitive maps: a differentiation of the tasks

The aim of this phase was to demonstrate how cognitive maps could contribute to role clarification. First, we conducted two FGDs in two of the three mental health care teams from phase 1. This time, all disciplines sat together. The first team comprised two psychiatrists, two psychologists (one in training) and three nurses. The second team comprised four psychiatrists (one in training), two nurses and a psychologist. The FGDs started with formulating key descriptions that would be characteristic of each discipline. Subsequently, participants discussed the differences between disciplines, focusing on the tasks on which no consensus was reached in phase 2, resulting in insights into the differentiation of the tasks.

To formulate the cognitive maps, we analyzed all the data. First all tasks were clustered into categories important for the diagnostic process. These categories could contribute to better understanding the cognitive maps as they provided insights into which 'part' of the diagnostic process should be conducted by which discipline. In addition, the FGDs and interviews from phase 1 and the FGDs from phase 3 were all coded on cognitive maps, i.e. approaches to a particular task, first by use of open coding. When a new code was formulated, the other transcripts were re-read to see if that code could be also attributed to a statement in the FGDs/interviews. This analysis resulted in a characterization of the cognitive maps of each discipline. Subsequently, the differentiation of the tasks of team 1 and team 2, formulated in phase 3, were compared.

8.3 Results

This section consists of four parts. The first presents characteristics of the participants, and the second sets out the tasks formulated in the Delphi study, combined with (when consensus was reached) the discipline which, according to the participants, should be primarily responsible for that specific task. In the third part, the cognitive map of each discipline is presented, which is used in the fourth part to clarify roles in tasks where there was no consensus on the responsible discipline.

8.3.1 Participants' characteristics

Table 8.1 presents the characteristics of the participants who participated in the different rounds of the Delphi study.

Table 8.1 Characteristics of participants in the Delphi study

Characteristics		Values round 1	Values round 2	Values round 3
Discipline, n (%)	Psychiatrist, N (%)	10 (40)	10 (38,5)	9 (36)
	Psychologist, N (%)	6 (24)	7 (26,9)	7 (28)
	Nurse, N (%)	9 (36)	9 (34,6)	9 (36)
Years of experience with BD, years	Total average	12,5	12,3	11,5
	Psychiatrist	18,9	18,9	17,7
	Psychologist	6,6	6,5	6,5
	Nurse	9,3	9,3	9,3

8.3.2 Tasks

In total, 53 tasks were formulated that participants considered important in diagnosing BD. These tasks were clustered in eight categories: integration, symptomatology, physical state, co-morbidity, causes, psychosocial, personality and additional data gathering. Table 8.2 shows these clusters with associated tasks and disciplines on which there was consensus, and also illustrates whether the task always needs to be performed in the diagnostic process (essential) or only when indicated (optional).

As presented in Table 8.2, there was consensus on who should primarily be responsible for a majority of the tasks. The tasks in the cluster 'integration', 'symptomatology' and 'physical

Table 8.2 Results Delphi study: tasks considered important in diagnosing bipolar disorder, disciplines on which there was consensus and whether the task is essential or optional for the diagnostic process.

Cluster	Task	Discipline / No consensus	Essential/optional
Integration	Documentation of DSM classification	Psychiatrist	Essential
	Final decision	Psychiatrist	Essential
	Integrate all available information	Psychiatrist	Essential
Symptomatology	Assessment suicide risk	Psychiatrist	Essential
	Psychiatric medical history	Psychiatrist	Essential
	Systematic anamnesis to gain insights in symptoms	Psychiatrist	Essential
	Carefully describe symptomatology	Psychiatrist	Essential
	Assessment current psychiatric state	Psychiatrist	Essential
	Recognize pattern BD	Psychiatrist	Essential
Physical state	Enquire current medication use	Psychiatrist	Essential
	Assessment current physical condition and medical history	Psychiatrist	Essential
	Enquire effects medication	Psychiatrist	Essential
	Gain insight in possible physical conditions that influence mood state	Psychiatrist	Essential
	Family history of medication	Psychiatrist	Optional
Co-morbidity	Attention for possible co-morbidity	Psychiatrist	Essential
	Set up a differential diagnosis	Psychiatrist	Essential
	Systematically examine co-morbidity	No consensus	Essential
	Differentiate between personality disorder and BD	No consensus	Essential
	Differentiate between ADHD and BD	No consensus	Essential
	Enquire substance abuse	No consensus	Essential
	Inventory presence trauma	No consensus	Optional
	Differentiate autism and BD	No consensus	Optional
Causes	Gain insight in underlying psychological mechanisms	Psychologist	Optional
	Inventory of psychological factors that maintain depressive symptoms	Psychologist	Optional
	Map factors contributing to onset of disorder	No consensus	Essential
	Map factors contributing to onset first episode	No consensus	Essential
	Psychiatric family history	No consensus	Essential
Psychosocial	Gain insight into daily functioning	Nurse	Essential
	Gain insight in psychosocial consequences	Nurse	Essential
	Gain insight in psychosocial factors	Nurse	Essential
Personality	Diagnosis personality disorder	Psychologist	Optional
	Gain insight in personality structure	Psychologist	Optional
	Relationship between personality, coping and mood	Psychologist	Optional
	Relationship between biography, development personality and coping	Psychologist	Optional
	Gain insight in coping mechanisms	Psychologist	Optional
	Gain insight in self-management strategies	Nurse	Optional
	Gain insight in the level of illness 'awareness and understanding'	No consensus	Essential

Additional data gathering	Map normal state versus hypomanic state	No consensus	Essential
	Gain insight in what kind of person the patient is, how s/he is in life and what s/he experienced in life	No consensus	Essential
	Map patient in context (holistic)	No consensus	Optional
	Enquire meaning previous episodes	No consensus	Optional
	Development history	Psychologist	Optional
	Usage of screening instruments	Psychologist	Optional
	Gain insight in intelligence level	Psychologist	Optional
	Neuropsychological assessment	Psychologist	Optional
	Gain insight in cognitive damage due to mood episode	Psychologist	Optional
	Gain insight in course of disorder by life chart	Nurse	Optional
	Network analysis	Psychologist	Optional
	Heteroanamnesis	No consensus	Essential
	Child-rearing history	No consensus	Optional
	Cognitive functioning	No consensus	Optional
	Biography	No consensus	Optional

state' were all assigned to the psychiatrist and the tasks in the cluster 'psychosocial' were assigned to the nurses. Tasks in the clusters 'co-morbidity', 'causes', 'personality' and 'additional data gathering' on which consensus is reached were particularly assigned to the psychologist.

In exploring task distribution, it is striking that 15 of the 16 tasks assigned to the psychiatrists were considered essential in the diagnostic process. This in contrast to the 14 tasks assigned to the psychologist, which, according to the participants, all need to be done only in specific circumstances. In total five tasks were assigned to the nurses, three of which were considered essential in each diagnostic process.

There was no consensus on 18 diagnostic tasks. For teamwork however, it is interesting to identify if these tasks have the risk of not being performed since all disciplines assigned them to another discipline, or if the tasks are performed twice since more than one discipline assigned the task to themselves. Psychologists agreed among themselves that nine of these 18 tasks should be assigned to their own discipline, while psychiatrists and nurses reached consensus among themselves on four of the 18 tasks. In only three tasks no discipline reached consensus who should perform them, however, in none of these did they all point towards each other. Overall, disciplines had the tendency to assign tasks to themselves rather than to the other disciplines.

From this part of the study, it became clear that there is a lack of clarity among disciplines for some tasks. To be able to understand the specific contribution of each discipline on the tasks where no consensus could be reached, it is useful to understand the cognitive map each discipline uses to address the task. In the following part, we take a closer look at these cognitive maps.

8.3.3 Cognitive maps

The data revealed an overlap between the roles of psychiatrists, psychologists and nurses in diagnosing BD in some of the tasks. Participants could not always attribute a task to one specific discipline and commented that it could equally be done by two or even all three disciplines. However, it was also recognized that there are significant differences between these disciplines, which became even clearer when participants explained these differences in a team setting in phase 3. The second part of the results will focus on the differences in cognitive maps between the disciplines and the consequences for role clarification.

Psychiatrist

The cognitive map of psychiatrist could be termed a '***symptom evaluation frame***'. According to the participants, this frame consists of several aspects. The first characteristic could be described as 'disease focused'. Psychiatrists concentrate on *symptoms* and *patterns* within them, and *cluster* these symptoms to confirm a diagnosis. Second, participants suggested that the *clinical way of reasoning* is distinct from other disciplines. As one psychiatrist explained:

> *We think from behavior towards symptoms towards always something like where does it come from, physiology, towards a solution. That is, sort of, the line of thinking of a doctor.*

Closely related to the previous two aspects is the *differential diagnostic way of thinking*, whereby psychiatrists interpret symptoms in order to formulate an appropriate classification, keeping in mind other potential explanatory diagnoses. A psychologist described this 'interpreting' as being an added value of the psychiatrist:

> *Well, I think, where I mostly need the psychiatrist, is in these complex cases like 'is this a schizophrenic development or is the symptom atypical. How should I understand it. […] Which 'color' does this psychosis have. That. So the whole mental status.*

A fourth aspect that psychiatrists bring to an IPT is the *focus on physical state*, including medication, and use that focus to explain the patient's symptoms. In the words of a psychologist:

> *Of course, the medical part is the most important added value of the psychiatrist. So, the real knowledge about the influence of the physical state [of the patient] on the symptoms and the influence of medication… the effect... Now and in the medical history [of the patient]. I think that is a very important added value.*

Lastly, especially when dealing with severe psychiatric disorders, *final responsibility* has hitherto been considered an important aspect attributable to the psychiatrists, which is embedded in their cognitive map as it influences how and when the psychiatrist is involved in the diagnostic process. In this sense the psychiatrist acts as the team 'captain', has an overview, prioritizes tasks and takes the final decision.

Psychologist

The cognitive map of the psychologist could be termed ***'personality-focused frame'***. First, they aim to understand who the person is and how their personality relates to their symptoms. They concentrate on psychological mechanisms, personality traits and (coping) styles and aim to differentiate between illness and character. As one nurse said about the frame of psychologists:

> *And of course, that also needs specific diagnostics. What is the illness, what is character and what is personality? To differentiate between that. And are there things in the personality that frustrate the illness? Things that prevent progress in treatment.*

In line with this comment, psychologists focus on *the patients' development* throughout life to gain insight into their background and place this in light of the personality traits and symptoms. Third, according to participants, psychologists have a *broader view* on the diagnosis and have added value in determining possible co-morbidity. As one psychiatrist mentioned:

> *The psychologist has a broader view. We are very much focused on the bipolar disorder and the psychologist sees completely different things that often have a huge added value. And besides the formal diagnostics, he also has an eye on psychological mechanisms and things*

> *in the personality that are of importance. So it is really good to have a psychologist sitting around the table.*

Moreover, psychologists use a more *systematic approach* in the diagnostic process, meaning that they more systematically and comprehensively examine the patients and their problems, and analyze the findings to reach a conclusion. As one psychologist said:

> *The added value of the psychologist is that they are able to scientifically approach it [the patient], so that you hypothesize, gather information and that you therewith can answer the questions. That you… yes, and that you use test materials [screening instruments]. That of course is an important one.*

In conclusion, findings showed that psychologists bring added value in diagnosing BD as they broaden the view on the patient and do not primarily focus on the disorder, seeing a patient as a person that has evolved over time, resulting in certain behaviors and values.

Nurse

According to the participants, nurses have a *'**psychosocial frame**'* on patients and their problems. Among other things, this frame implies a focus on 'the patient's life' and how he or she is organizing that, paying attention to work, finances and living. Nurses especially focus on how patients function in these aspects of life and how functioning is influenced by the disorder. Next to *'functioning'*, the focus on the patient's life also entails mapping the patient's social context. As one nurse said:

> *The difference is that nurses focus more on the social context […] well, especially that. So, work, hobbies, spare time, relationships, question more about all of that.*

The second aspect of nurses' cognitive map is the ability *to connect with a patient*, as they often have more time to do so. Participants said this was particularly helpful in *gathering information*, to create an overall picture of the patient. Nurses could gather additional information on, among other things, symptoms, which is then used by psychiatrists or psychologists to make a diagnosis, thus contributing by exploring and pointing out problems. The importance of connecting with a patient is stressed in the following quote:

> *I think that nurses are really good in connecting [with a patient]. That is an added value... that's why… people maybe tell about themselves much more easily. Diagnosing becomes more easy.*

In addition, nurses often use a strength-based approach, which is highly appreciated, resulting in insights into patients' strengths, which could be used in formulating a treatment plan. In the words of a psychologist:

> *And what I really appreciate, is that they [nurses] clearly have insights in the strength of the patient. I think more than the psychiatrists and psychologists.*

To sum up, nurses' frame involves focusing on the social and functional context of a patient and on the patient's strengths, creating a supportive connection to be able to gather more (personal) information.

8.3.4 Role distribution

From these cognitive maps, it can be concluded that patients and their problems are approached from different angles by different disciplines. Knowledge of the differences in cognitive maps could be used to prevent care duplication by gaining insight into the different results these maps could yield. From the data, it became apparent that there were two types of task differentiation: 1) level of acting and 2) information being gathered. The following section illustrates these types of differentiation. Three tasks where there was no consensus on who should primarily focus on them are used as examples. At first, participants stated that these tasks could be performed by any of the disciplines. However, when taking a close look at the differences in approach and frames between disciplines, it became clear that different results will come to light depending on which discipline performs the task.

The first example concerns the task of 'enquire substance abuse'. According to participants, psychiatrists categorically question the patient on substance abuse to gain insight into whether and what kind of substances a patient is using. This could be explained from their *focus on physical state* were a link is made between physical state or medication and the psychiatric symptoms the patient experiences. A psychologist focuses on the function of substance abuse and how and for what it is a coping mechanism. Moreover, according to participants, psychologists aim to understand substance abuse in the context of personality development and assess whether the patient is willing to be treated for the addiction. This could be explained by their knowledge of psychological mechanisms and coping styles. Nurses, on the other hand, use their psychosocial frame and their connection with the patient to gain insight into the actual use and the consequences of substance abuse on functioning and social life. Thus, in this case, the differences in cognitive maps result in *supplemental information being gathered*.

The second task demonstrated here, is '*differentiating between ADHD and BD'.* Within this task, participants explained that while the psychiatrist will focus on symptoms and disorders (both mental and physical) and screen in response to symptoms if there is a need for additional diagnostic research, nurses use another angle, because they start from daily functioning, and observe if there is any struggle in patient's daily life which could suggest the presence of Attention Deficit Hyperactivity Disorder (ADHD). When psychiatrists or nurses formulate suspected ADHD, psychologists systematically approach these symptoms and use questionnaires in order to gain a deeper understanding of whether the symptoms could be explained by ADHD. In this task, it becomes clear that the *level of acting* varies between disciplines, as the psychiatrist screens, the nurse signals the possible presence of ADHD and the psychologist systematically probes. This type of differentiation could result in formulating new *sub*tasks, i.e. 'screening for presence of ADHD', 'signaling the presence of ADHD' and 'systematically investigate presence of ADHD'.

The third task is '*gain insight in the level of illness awareness and understanding'.* Participants explained that the psychiatrists gain such insights to anticipate the likelihood of compliance and interpret it as part of the psychiatric disorder, and confront the patient with a possible lack of awareness and understanding of their illness. Nurses will observe how a patient is dealing with the disorder and how this influences daily functioning. Psychologists gain insight into the patient's ability for self-reflection and the possibility of developing this competence. After the different focus resulting in different information, participants said that psychologists are asked to systematically examine how a possible lack of 'illness awareness and understanding' could be explained, when it clearly influences functioning and treatment. This example illustrates that the differences in cognitive maps results in both types of differentiation of tasks, i.e. '*Supplemental information being gathered'* and '*different level of acting'.*

Table 8.3 shows all tasks where no consensus was reached, but which were essential in the diagnostic process, including the type of differentiation each discipline brings to the task, i.e. different level of acting or supplemental information being gathered or both.

Table 8.3 Type of differentiation between disciplines, based on essential, non-consensual tasks

Task	Type of differentiation
Systematically examine co-morbidity	Both
Differentiate between personality disorder and BD	Different level of acting
Differentiate between ADHD and BD	Different level of acting
Enquire substance abuse	Supplemental information being gathered
Map factors contributing to unset of disorder	Supplemental information being gathered
Map factors contributing to unset first episode	Supplemental information being gathered
Psychiatric family history	Supplemental information being gathered
Gain insight in the level of ‘illness awareness and understanding’	Both
Map normal state versus hypomanic state	Both
Gain insight in what kind of person the patient is, how s/he is in life and what s/he experienced in life	Supplemental information being gathered
Heteroanamnesis	Both

8.4 Discussion

In order to cope with the increasing complexity in health care and provide more patient-centered care, it becomes more important to work in IPTs. One aspect of efficient teamwork is understanding the specific role of each discipline in IPTs. This study aimed to clarify roles of each discipline by contributing to a better understanding of their respective cognitive maps and demonstrating how these could contribute to further role clarification. Although it could be concluded from this study that there is considerable overlap between the disciplines of psychiatrist, psychologist, and mental health nurse, it is argued that looking at the differences in cognitive maps could contribute to better and more efficient teamwork. When looking at the cognitive maps, we found that the psychiatrists’ ‘symptom evaluation frame’ is characterized by: a disease focus, a clinical way of reasoning, a differential diagnostic way of thinking, a physical perspective and final responsibility. The ‘personality-focused frame’ of psychologists is characterized by: a person focus, focus on person’s development, a broader view and a systematic approach. The nurses’ frame could be described as ‘psychosocial’: focused on patients’ lives, on functioning, ability to connect to patients and a strength-based approach.

The literature shows that traditionally the psychiatrist has a medical frame on patients (Herrman et al., 2002; Kingsbury, 1987; Wyatt & Livson, 1994), which often correlates with more decision-making power (Mead & Bower, 2000). This phenomenon is still described in more recent literature (McNeil & Mitchell , 2013) and is confirmed in this study. This poses the risk that the contributions of other disciplines are less recognized or undervalued. For example, in a literature review conducted by McNeil (2013) on interprofessional practice and professional identity, it is mentioned that often interprofessional teams fail to acknowledge the importance of the 'caring-for-the-patient contribution' nurses provide in a team. This contrasts with the findings in our study, where the participants recognize the importance of the ability to connect with the patients, a characteristic assigned to the nurses.

In our study, it was suggested that some tasks could be assigned to a specific discipline, while others could be performed by two or three disciplines. This separation of tasks could be compared with the findings of MacNaughton et al. (2013) in a study on role construction and role boundaries in primary health care teams. They describe the concepts of *interchangeable roles* and *differentiated roles*, whereby the former are roles where the responsibilities of team members overlap and the latter is where responsibilities are distinctive for a certain discipline. Our study explored these interchangeable roles to understand if these are indeed interchangeable or whether the outcomes of the task might differ depending on the acting discipline, resulting in a gain when these outcomes are integrated. What we found is that some tasks appeared to be interchangeable, but team discussions on those tasks brought to light different aspects, which could be explained by the differences in cognitive maps. These differences should be integrated to contribute to a full understanding of the patient.

A failure to integrate different disciplinary frames is a barrier for interprofessional collaboration as interprofessional care refers to 'a deeper level of collaboration (…) by pooling together their specialized knowledge and expertise' (Schadewaldt, McInnes, Hiller, & Gardner, 2014). We argue that disciplines could complement each other by integrating the outcomes of the differentiated tasks. We distinguished two types of differentiation (Table 8.4). The first is differentiation '*leading to deepening'.* This type could be explained as follows: one discipline 'screens' for certain problems and refers to another discipline to unravel these further. Both disciplines work on the same task, but in extension of each other, resulting in different outcomes. This type of differentiation might be easier to recognize and to consciously use as implementing the task is at another level. The second is differentiation '*leading to broadening'*, i.e. different disciplines approach a problem from a different angle and produce distinct information. This results in a more complete view of the patient. It is argued that this type of differentiation is harder to consciously use as it not always acknowledged that it will yield different outcomes when the task is performed by multiple disciplines. In order to gain a full understanding of the patient and to use the team's expertise, the differentiation of the tasks needs to be recognized and the outcomes integrated.

Table 8.4 Typology of differentiation between disciplines

Types	Characteristics
Leading to deepening	• disciplines work in extension of each other; • one discipline 'signals' or 'screens' and refers to the second discipline, which further 'unravels'; • different level of acting; • easier to recognize.
Leading to broadening	• approach of patient by different angle; • distinct information comes to light, depending on implementing discipline; • more complete view of patient; • more difficult to recognize.
Both	• a combination of both leading to deepening and leading to broadening.

A further finding of our study is that participants considered it often difficult to assign tasks to one specific discipline. We hypothesize that one explanation might be that differences in cognitive maps are not well acknowledged. This hypothesis is strengthened by the methodological finding that formulating the cognitive maps of each discipline in a team setting is beneficial for recognizing differences between disciplines when performing a certain task. A second explanation is protection of *professional identity.* In a study by Baxter & Brumfitt (2008) on professional differences in interprofessional working, it emerged that practitioners feel responsible for their team but also for their profession and their professional identity. The feeling of being underused leads to frustration and could result in the urge to protect one's own role (Brown, Crawford, & Darongkamas, 2000). A third hypothesis is that by working together for a long time, cognitive maps might become closer, a concept more often described in literature as *role blurring.* This concept could result in the inability to identify the added value of different disciplines and to assign tasks to a specific discipline.

The literature describes both the benefits and disadvantages of role blurring. While it is seen as an opportunity to expand responsibilities, reduce workload and contribute to a more flexible team (Brown et al., 2000; Macnaughton, Chreim, & Bourgeault, 2013), it might also cause confusion, tension and underused skills (Brown et al., 2000; Hall, 2005; MacDonald et al., 2010). Schönfelder & Nilsen (2016) describe in a study on comparing interprofessional relations and skill mix in health care an ideal–typical framework with three types of teamwork: ‘single track hierarchical systems’, ‘transitional hierarchical systems’ and ‘diversified hierarchical systems’. The latter is a type of teamwork that would be best suitable to deliver holistic care, as several professional frames focus on providing care to help the patient. This could be explained by role blurring. According to Schönfelder and Nilsen (2016), the risk of this system is ‘causing competition instead of coordination’.

In line with these observations, we argue that both role blurring and role clarification could be beneficial if they happen deliberately and in the right order. To benefit from the positive consequences of role blurring while aiming to pre-empt its negative consequences, IPTs should first acknowledge the differences between the disciplines. It would be supportive for IPTs to use parts of the method used in this study as a means to clarify roles. The first step would be to formulate tasks that need to be performed for a specific process (in this study: diagnostic process). The second step towards more role clarification would be to assign these tasks to a specific discipline. After that it would be useful to find a common denominator for assigning these set of tasks to a certain discipline (examples from this study: symptomatology, broader view). The next step would be to formulate the cognitive map for each discipline, making use of both each IPT member’s own experience and the common denominators, which could be explained as elements of the cognitive maps. The last step is to use these cognitive maps in order to look how these might influence the outcomes of a task and understand the type of differentiation (leading to deepening or leading to broadening) that need to occur. We hypothesize that by going through this process with an IPT, it will improve the use of expertise of each discipline, resulting in an increased ability to provide efficient patient-centered care.

8.4.1. Limitations

This study has some limitations. The first is that, even though participants were explicitly told to try to think outside their current way of working and about the preferred way of working, it sometimes proved difficult to think outside the existing paradigm and daily routines of providing health care. This might have resulted in a more ‘traditional’ or so-called ‘medical’ way of assigning tasks. However, we argue that the cognitive maps formulated in this study represent the differentiation between disciplines, because the IPTs could use the results for thinking about restructuring their diagnostic process, and there were no differences in cognitive maps found between the teams. The second limitation relates to a point described earlier, namely the protection of professional identity. This may have affected the results because disciplines might have assigned more tasks to themselves than to other disciplines in order to assert the importance of their discipline. We hypothesize that more tasks would have reached consensus without this phenomenon. A third limitation is that the role of psychologists in the care of people with BD is relatively new, so fewer psychologists work in this field, resulting in a smaller group of psychologists included in this study.

CHAPTER 9

Conclusions and discussion

This thesis started with the elaboration on two prominent paradigms in mental health care, Patient Centered Care (PCC) and Evidence Based Medicine (EBM). These paradigms reflect different values and visions, and their lack of alignment hampers being able to provide care according to the needs of patients. Various scholars have reported on suggestions to align these dominant paradigms (Barratt, 2008; Bensing, 2000; Miles & Mezzich, 2011; Sacristán, 2013; Wagner et al., 2005; Weaver, 2015). This thesis aimed to contribute to the improvement of mental health care by systematically bringing the separate worlds of PCC and EBM together, which has been done by increasing the understanding of what constitutes good quality mental health care from the perspectives of PCC and EBM and by broadening the evidence base.

This thesis was guided by the following research question:

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

To answer this research question, three sub-questions were formulated:

1. *What constitutes good quality care for patients with bipolar disorder, from the perspective of EBM, PCC and patients?*
    a. *What constitutes good quality care for patients with bipolar disorder, from the perspective of patients?*
    b. *What constitutes good quality care for patients with bipolar disorder, from the perspective of PCC scholars?*

2. *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients and health professionals?*
    a. *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients?*
    b. *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to health professionals?*

3. *Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder and patients' research needs?*

a. *Which interpretative frames can be distinguished, used by health professionals in understanding the research needs of patient with bipolar disorder?*
b. *Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder, with a specific focus on the diagnostic process?*

In this chapter, the sub-questions will be answered and the findings will be embedded in the existing literature. Considerations regarding the research validity and future research will then be discussed.

9.1 Reflections on the findings and conclusion

This section will present a summary of the findings and a reflection on these results to answer the sub-questions. This will be followed by an overall conclusion.

9.1.1 Good mental health care from the perspective of EBM, PCC and patients

As explained in Chapter 3 of this thesis, there is a knowledge gap regarding what entails good mental health care according to PCC scholars and patients. According to the EBM paradigm, good quality care is based on the best available evidence, according to the hierarchy of evidence (OCEBM, 2011). Depending on the availability of the evidence, the highest form of available evidence according to this hierarchy should guide clinical practice. However, little is known about the perspectives of patients and PCC scholars on what constitutes good mental health care. To strengthen the evidence base of PCC, it is important to clarify its conceptualization and to understand patients' perspectives on what constitutes good care. In the following section, the first sub-question will be answered: *What constitutes good quality care for patients with bipolar disorder, from the perspective of EBM, PCC and patients?*

Comparison of patients' perspectives with the PCC paradigm

The perspectives of patients with bipolar disorder on good care derived from studies 1 and 2, are presented in Chapters 4 and 5. Their perspectives closely resemble the perspectives on good care according to the PCC paradigm, since they address similar 'attributes' of good care. However, studies 1 and 2 added to the current literature by including the perspectives of patients with bipolar disorder, resulting in refinements of the attributes for the specific context of bipolar disorder. According to patients with bipolar disorder and the PCC paradigm, good care *focuses on the unique needs and preferences* of patients (e.g. Kitson et al., 2013; Mead & Bower, 2000; Morgan & Yoder, 2012). Patients added that needs are not only person-specific, but also situation-specific, and could therefore change over time. In addition, patients formulated both disorder-specific needs (e.g. timely diagnosis and adequate treatment, balancing pharmacological and non-pharmacological treatment) and generic needs (e.g. caring health professionals who listen non-judgmentally, and a sense of connection with the health professionals), both of which need to be acknowledged in treatment. Thus, good care requires being sensitive to a broad range of needs and to integrate disorder-specific and generic care needs for each individual patient. A second overlapping attribute is the *focus on the patient* and not merely on the symptoms (e.g. Hobbs, 2009; Mead & Bower, 2000; Scholl et al., 2014). The patients want to be considered as individual human beings with an acknowledgement of all the aspects of their life, e.g. their social life and occupational functioning, and not just be seen as a person with bipolar disorder. Third, patients added the *focus on strength*, which is underrepresented in the PCC paradigm, and the relevance of including these strengths in the individual treatment plan. The fourth attribute of good care according to patients, and not explicitly addressed by the PCC paradigm, is that good care provides *practical tips*, such as strategies to support the development of a daily structure and how to disclose the disorder to friends and colleagues. Fifth, patients consider *multidisciplinary* care as good care, so that they can benefit from multiple perspectives and approaches to diagnosis and treatment; an attribute of care that is scarcely described in the PCC paradigm (Pelzang, 2010).

To provide good care that meets these attributes, patients and the PCC paradigm describe a variety of facilitating factors. The first shared facilitating factor is *a caring health professional* who is respectful and honest (e.g. Lusk, Fater, & Care, 2013; Pelzang, 2010). Patients refine this by emphasizing the relevance of a health professional who listens non-judgmentally, is sensitive to the patient’s need, takes time, makes the patient feel understood and balances between being directive and being open. Second, both patients and the PCC paradigm emphasize the importance of a knowledgeable health professional for a valid diagnosis and obtaining the right treatment (e.g. McCormack, 2003; Scholl et al., 2014). The third shared facilitating factors is *a good relationship* with the health professional, with shared power and responsibility, in order to reach therapeutic alliance (e.g. Sidani & Fox, 2014; Slater, 2006). A good relationship consists of feeling comfortable and having trust in the health professional. Patients acknowledge that this relationship is not only influenced by the attitude and skills of the health professional but also depends on the patient's personal preferences on what is considered a good health professional. They add the importance of being able to switch health professional when there is no sense of connection. Fourth, patients' *experiential knowledge* needs to be acknowledged, by conceptualizing a patient as knowledgeable expert, with knowledge on living with bipolar disorder. This facilitating factor is barely addressed in the PCC paradigm (Slater, Mccance, & Mccormack, 2015). Last, the patients' perspectives added the facilitating role of the health care organization, which is only recently acknowledged in the literature (e.g. Kitson et al., 2013; Scholl et al., 2014), and further refine this facilitating role by addressing the importance of the organization's flexibility and accessibility, to be able to act on and react to the fluctuating course of the disorder and the corresponding changing needs.

Comparison of patients' perspectives with the EBM paradigm

The core dimensions of good care according to PCC scholars and patients with bipolar disorder, differ from the EBM paradigm, according to which good care is based on the best available evidence, translated into guidelines (Guyatt et al., 1992; Sackett et al., 1996). In other words, good care is defined by adhering to guidelines. When closely looking at the description of guidelines, namely, '*systematically developed statements to assist practitioners and patients in choosing appropriate care for specific clinical conditions'* (Hasnain-Wynia, 2006, p. 3), and taking the frequent criticism that guidelines induce 'cookbook medicine' (Hasnain-Wynia, 2006; Weaver, 2015) into account, one could argue that it is difficult to capture the uniqueness of a patient by solely following the guidelines. Guidelines are used to standardize care rather than to individualize care (Hasnain-Wynia, 2006; Price et al., 2015) and with this overlook the complexity of clinical practice (Bal, 2017). The definition of a guideline includes providing statements for dealing with a *specific clinical condition*. This results in a predominantly disease-focused approach to care, which does not fully correspond to the needs-focused, person-focused and strength-focused approach that patients prefer. At first sight, the patients' perspectives on what constitutes good care do not correspond to the perspectives of the EBM paradigm, due to the tension between standardized and individualized care. However, an important overlapping attribute is that good care is *informative,* providing the patients with the information on their diagnosis and treatment that is currently available, e.g. expected side-effects of medication, non-pharmacological treatment options and early warning signs.

Thus, this first step in the alignment of EBM and PCC showed that there are opportunities to bring them closer together. As described, elements of the patients' perspectives on good care closely relate to concepts of PCC. Therefore, good care for people with bipolar disorder could be understood as a 'patient-centered care' practice, in which PCC is broadened and refined by people with bipolar disorder. Moreover, patients emphasized the importance of a knowledgeable health professional who is up to date with knowledge regarding the disorder and its treatment. This need is not ignored in the PCC paradigm (e.g. Kitson et al., 2013), however, given the importance of this element of care in the EBM paradigm, and the criticism of PCC that it lacks a scientific base (Bensing, 2000; Weaver, 2015), this need of patients is specifically referred to as 'an evidence-informed care' practice, a term that is increasingly used in literature (e.g. Miles & Loughlin, 2011; Weaver, 2015). This attribute of good care is translated into evidence-informed, rather than evidence-based, due to the acknowledgement that clinical practice is informed by a variety of knowledge sources, and the role of these sources in translating available evidence to the individual needs of patients. Thus, based on the perspectives of patients with bipolar disorder, in this thesis good mental health care is defined as an 'evidence-informed, patient centered care' practice.

9.1.2 Perspectives of end-users on relevant research topics for bipolar disorder

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. Studies 3 and 4, presented in Chapters 6 and 7 of this thesis, studied the research needs of patients and health professionals in the field of bipolar disorder. In the following section the second sub-question that guided this thesis will be answered – *What research topics are seen as relevant for the clinical and scientific field of bipolar disorder, according to patients and health professionals?* In addition, the research needs of patients and health professionals are compared with literature. Subsequently, the likelihood of the implementation of the research agenda according to patients is discussed in the light of the literature.

Patients' perspectives

Patients formulated 23 research topics, which could be clustered in the five themes: *causes of disorder, diagnosis, pharmacological treatment, non-pharmacological treatment* and *recovery and recovery-oriented care*. The theme *causes of disorder* included the research topics 'etiology of disorder' and 'triggers of an episode'. The theme *diagnosis* included the research topics 'recognition early warning signs', 'knowledge improvement of GPs', ‘development of diagnostic tools’ and ‘a correct referral’. The theme *pharmacological treatment* included the research topics ‘effectiveness of medication’, ‘mechanism of action of medication’, ‘the necessity of medication’ and addressed the need for research on ‘side-effects’, ‘development of new medication with less side-effects and better targeted’ and ‘the effect of lithium on sport performances’. *Non-pharmacological treatment* included topics focused on ‘the effectiveness of non-pharmacological treatments’ and ‘the development of new treatments’, including ‘treatment for caregivers’. In the last theme, *recovery and recovery-oriented care,* the topics ‘the knowledge of society on bipolar disorder’, and ‘strategies to increase acceptance by society’ were included. Furthermore, this theme involved research on ‘self-management strategies’, ‘positive aspects of bipolar disorder’, ‘impact of bipolar disorder on the patient’ and ‘treatment options for comorbid disorders’, ‘designing a PCC system’ and ‘collaboration between health professionals’. Of all topics, research on the etiology of the disorder was given highest priority.

Comparison of perspectives

The perspectives of health professionals on research needs for bipolar disorder overlapped with the needs of patients, but there were also some differences. Health professionals added the research need to clarify the psychological explanation of the disorder and the role of psychologists in both diagnosis and treatment. They also formulated the need for research on factors that predict which medication will be effective. In addition, they added research needs on better treatment options (pharmacological and non-pharmacological) for bipolar depression and on the development of e-health. Furthermore, they added research on the distinction between bipolar disorder and personality disorder, the use of all expertise available in clinical practice, strategies to better integrate science and clinical practice, the quality of care from a patient’s perspective and on functional impairments of bipolar disorder. Patients added research on the need for medication, the development of new non-pharmacological treatments for themselves and their caregivers, support for caregivers, positive aspects of bipolar disorder, the impact of bipolar disorder, strategies for social reintegration, an adequate referral system and treatment options for comorbidity. The differences in research topics reflect nuances. For example, health professionals appreciate research on the functional consequences of bipolar disorder on several life domains, i.e. problem-oriented research, whereas patients emphasized the relevance of research on adequate solutions for the problems, such as how to reintegrate into society despite the impairments, and which self-management strategies would help to deal with these impairments, i.e. solution-oriented research. In other words, health professionals formulated the need for research on *consequences* while patients formulated the need for research on *how to deal with the consequences*.

The importance of including end-users in setting a research agenda becomes clear when comparing the perspectives of patients with bipolar disorder with current research agendas in the field of bipolar disorder, in which research on 'genetics', 'neurobiology' and 'clinical phenomenology' predominate (Henry et al., 2013; Michalak et al., 2016). This is illustrated by the European Network of Bipolar Research Expert Centres (ENBREC), which aims to develop personalized medicine by using behavioral and neurobiological measures (Henry et al., 2013). In addition, Michalak et al. (2016), recognized that the current treatment trial designs often focus on side-effects and use the outcome measure 'symptom reduction' and do not address the core questions of patients with bipolar disorder, which relate to functional and quality of life outcomes. Despite the fact that end-users acknowledge the relevance of more biomedical research, studies 3 and 4 clearly show the need for research on psychosocial aspects of bipolar disorder (e.g. the impact of the disorder on the patients and caregivers and reducing stigma in society) and research that focuses on a broader range of recovery domains than merely reducing the symptoms. This gap between the research needs of end-users in the field of bipolar disorder and current research initiatives has also been found in research agenda-setting projects for mental health in general (Robotham et al., 2016; Wykes et al., 2015). Thus, the perspectives of end-users on research could contribute to more acceptable and more relevant research for the end-users of the research outcomes.

To further understand the overlap with the research agenda set in this thesis and general mental health research agendas, the findings of this thesis are compared with general mental health research agendas: the European ROAMER project (ROAMER, 2015) and the Dutch research agenda for mental health (GGZ Nederland, 2016). The theme 'cause of disorder' shows close resemblance with research topics on the Dutch research agenda for mental health (e.g. mechanisms that explain why used interventions work; new mechanisms that could be used for new interventions; identification of bio- and sociomarkers to personalized care) and with research topics in the theme 'causal mechanisms' of the ROAMER project (e.g. functional characteristics of neurobehavioral mechanisms; social and biological factors underlying risk or resilience factors; the influence of vulnerabilities and stress to poor health and specific mental disorders). These research topics of the two projects also show overlap with the research topics in the themes 'pharmacological treatment' and 'non-pharmacological treatment' described in this thesis, since the identification of mechanisms, and bio- and sociomakers, are supportive to the development of new pharmacological and non-pharmacological treatments. In addition, the research topics 'efficiency of interventions aiming at improving personal and social recovery' and 'effectivity of symptom-focused and competency-reinforcing interventions' on the Dutch research agenda for mental health*,* relate to the research topic 'development of new non-pharmacological treatments'. The research topic 'understanding why some individuals do not respond to treatment' formulated in the ROAMER project correlates with the research topic of health professionals 'predicting which medication will be effective'. Furthermore, all three projects have formulated research topics on eHealth. In the theme 'diagnosis', end-users described the importance of early diagnosis. This urge for early diagnosis strongly correlates with research topics (risk profiles for early detection, personal risk factors and personal competencies) on the Dutch research agenda for mental health, and the research theme 'research to mental disorder prevention, mental health promotion and intervention for mental disorder in children, adolescents and young adults' formulated in the ROAMER project. The theme 'recovery and recovery-oriented care' described in this thesis shows considerable overlap with the topic 'social participation' on the Dutch research agenda for mental health and with research topics in the theme 'reducing stigma' of the ROAMER project (e.g. experience of caregivers with stigma, cost-effective elements of anti-stigma interventions, establishing better national or local interventions to address stigma and social exclusion and discrimination). In addition to the overlap, the research agenda for bipolar disorder also refines research topics of the general mental health research agendas. For example, according to end-users, new pharmacological treatment most be developed with specific focus on medication with *fewer side-effects*, and special attention must be paid to *psychological* mechanisms in the etiology of bipolar disorder. Furthermore, end-users add research topics, e.g. positive aspects of bipolar disorder, and triggers for the onset of a mood episode. Therefore, it is argued that it is relevant to set both a disorder specific research agenda and general mental health research agenda, in order to do justice to the full range of research needs. In addition, to fully understand which research topics on a general mental health research agenda are particularly relevant for a specific mental disorder, setting a disorder specific research agenda according to end-users is valuable.

Implementation of a research agenda from an end-user's perspective

In addition to the value of eliciting the research needs according to end-users, implementation of the research agenda is important in order to actually conduct the research. Therefore, it is relevant to look at factors that influence the implementation of the research agenda.

According to the literature, the implementation of the patients' research agenda can be challenging, due to a variety of contextual and process factors, e.g. willingness to cooperate, time, representation (Pittens, Elberse, Visse, Abma, & Broerse, 2014). In literature it has been recognized that the uptake of research topics depends on the scope of the commissioning organizations or funding agencies, in which the medical model often dominates (Pittens et al., 2014; Telford & Faulkner, 2004). This could hamper the uptake of the patients' research needs, since these are often more related to solution-oriented research, quality of life and psychosocial aspects (Banfield et al., 2014; Broerse, Zweekhorst, et al., 2010; Pittens et al., 2014; Rose et al., 2008). Furthermore, researchers often chose topics that are promising for publication or have *scientific* relevance (Elberse, 2012). As found in study 4, the complexity of the research topics formulated by patients could benefit from a qualitative and multidisciplinary research approach, while topics being researched often have a single disciplinary focus (Elberse, 2012). Despite the increasing acceptance of qualitative methods in the field of social science and nursing science, publishing studies using qualitative methods is still challenging in medical science. In addition, multidisciplinary research is less often cited than monodisciplinary research (Levitt & Thelwall, 2008).

Next to these factors described in literature, study 4 showed that the research setting, patient population, available population size and disciplinary frame influence the ability to address the topic on the research agenda. Another factor is based on the attitude of researchers towards patient participation. In literature, it has been described that researchers might see themselves as more 'objective' than patients (Boote et al., 2002; Broerse, Zweekhorst, et al., 2010), since their knowledge is based on science (Elberse, 2012) and consider patients 'unable' to formulate research questions. It has been argued by scholars that instead of research questions, patients formulate implementation gaps of research that has been conducted but not (yet) implemented (Owens et al., 2008) or service needs rather than research needs (Banfield et al., 2014). These attitudes relate to researchers devaluing patients' experiential knowledge. In response to the criticism that patients formulate service needs rather than research needs, study 4 showed that the researcher-clinicians do not consider the research needs of patients with bipolar disorder as merely service needs but rather consider them as topics that could be studied. It has been argued in study 4 that researcher-clinicians could play an intermediary role between research and practice in narrowing the research-practice gap, because of their ability to translate research topics formulated by patients into study approaches that fit existing research domains.

9.1.3 Interpretative frames of health professionals

Studies 4 and 5, presented in Chapters 7 and 8 of this thesis, studied the perspectives of health professionals on patients with bipolar disorder and their research needs. Based on these studies, the third sub-question of this thesis could be answered: *Which interpretative frames can be distinguished, used by health professionals in understanding bipolar disorder and patients' research needs?*

In the literature on mental health care, the importance of multidisciplinary teams (MDTs) to address the complexity of the needs of patients has been recognized (Maddock, 2015; Vitale & Mannix-McNamara, 2013). However, it was unclear what this actually entails in care for people with bipolar disorder. From study 5, we concluded that health professionals from different disciplines use different frames in task performance in the diagnostic process of bipolar disorder. This difference in approaches could be understood by considering the differences between cognitive maps in different disciplines. A cognitive map, or interpretative frame, is defined as 'a discipline-specific way of conceptualizing problems and interventions' (D'Amour et al., 2005; Hall & Weaver, 2001). In study 5, the cognitive maps of each type of health professional were explored and named. The cognitive map of psychiatrists is termed 'symptom evaluation frame'. This frame includes a disease focus, concentrating on symptoms and patterns, the interpretations of which results in presenting the most appropriate DSM-5 classification. This disease focus also includes the physical state of the patient. The psychologists' cognitive map is termed 'personality focused frame'. This frame 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 cognitive map of the nurses is termed the 'psychosocial frame'. This frame implies a focus on the practical aspects of a patient's life, their functioning in the different domains of life and on their social context. In addition, participants stated that nurses often apply a strength-based frame on which a treatment plan can be established. Insights into the cognitive maps of health professionals resulted in insights into task differentiation, leading to broadening and to deepening. In the first, health professionals complement each other by gathering different information about the same topic (e.g. substance abuse), while in the latter, health professionals have a different level of acting (e.g. the psychiatrist 'screens', the psychologist 'systematically investigates' and the nurse 'signals'). Through this insight, the cohesion between the outcomes of the task performances of each discipline is articulated. Subsequently, one could argue that this could be beneficial for a move from a multidisciplinary approach, in which disciplines work in parallel and approach the patients from their own (autonomous) perspective (Jessup, 2007; Körner, 2010), towards more interdisciplinary teamwork, in which the separate disciplinary approaches are integrated into the treatment plan for the individual patient (Jessup, 2007) and in which the team becomes more effective (Körner, 2010).

In addition to these different interpretative frames between disciplines in care, in the pilot study described in study 4, we found that these differences are also present in the field of research. Nurse-researchers approached the research topics by considering the consequences, the influence on functioning and the impact for the patients, while 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. For example, the research topic 'long-term side-effects of medication' could be studied by focusing on physical aspects (e.g. lithium and kidney failure), on how side-effects are experienced by the patients and on the consequences of the side-effects for the patient's functioning. These approaches yield different information. This could be compared with task differentiation leading to broadening in care, which results in 'gathering different information', described above. In addition, some research topics require a different academic field than researcher-clinicians, e.g. health scientists, biomedical scientist or public administrators. It could be hypothesized that in addition to the differentiation 'gathering different information', on certain research topics, different academic fields have a 'different level of acting', comparable with the task differentiation leading to deepening in care. In order to move from multidisciplinary research towards interdisciplinary research, this needs to be further studied.

Thus, study 5 contributed to the existing literature by creating more insights into what multidisciplinary care entails for care for people with bipolar disorder and study 4 provided a deeper understanding of what evidence a multidisciplinary research approach would yield. Insights into these various interpretative frames contribute to the alignment of PCC and EBM by revealing how different disciplines could contribute to broadening of the evidence base in the field of bipolar disorder.

9.1.4 Evidence-Informed Patient Centered Care Practice

The strategies used in this thesis aiming to contribute to the alignment of EBM and PCC in care for people with bipolar disorder resulted in the introduction of 'the evidence-informed, patient centered care' practice. In this care practice, the conceptualization of the PCC paradigm is broadened and refined to the context of bipolar disorder. Furthermore, based on the findings of this thesis, the meaning of 'evidence-informed' could be further understood. The model for an 'evidence-informed, patient centered care practice' is presented in Figure 9.1.

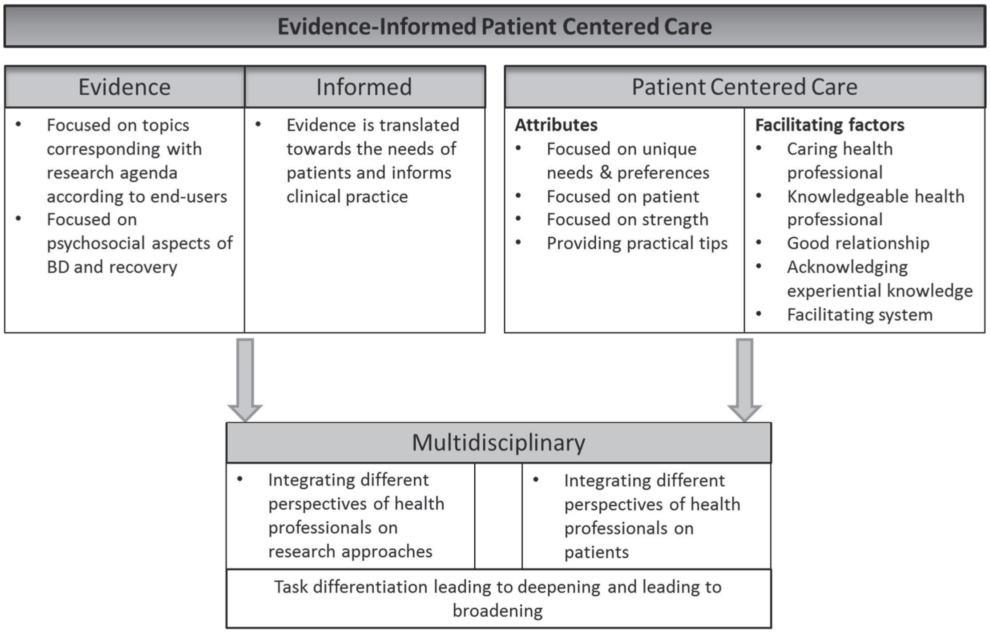

Figure 9.1 An Evidence-Informed Patient Centered Care practice for the context of bipolar disorder

9.2 Implications for clinical practice and research

This thesis contributed to the alignment of PCC and EBM. This alignment resulted in the description of an 'evidence-informed patient centered care' practice. In addition, the alignment resulted in a research agenda for bipolar disorder from the perspectives of end-users and in insights into the perspectives of health professionals on patients and their needs. To further inspect the meaning of the alignment of PCC and EBM for clinical practice and research, the findings of this thesis are placed in the context of scientific literature, which will be discussed at different levels: *the professional level, the organizational level, the research system and the health system.*

9.2.1 Practitioners level

In literature, it has been recognized that to be responsive to patients' needs, the health professional needs to reflect on the clinical decisions made and monitor whether the provided care meets the needs of the patient and whether the advice given by the guideline fits the patient's (complex) situation (Rycroft-Malone et al., 2004). To use the evidence generated by research and translate this to the needs of individual patients, health professionals use knowledge from a variety of sources, e.g. clinical expertise, practical knowledge and personal knowledge (Salter & Kothari, 2016) and so integrate explicit knowledge derived from research with tacit experiential knowledge. It has been argued that this integration may be applied by health professionals via reflection and a process of learning, and could benefit from a *reflective practice* (Salter & Kothari, 2016)*,* a concept introduced by Schön in 1983. Schön described reflective practice as critically assessing one's own actions and consequently developing one's own professional abilities (Kinsella, 2010). He makes a distinction between two phases of reflection: *in action* and *on action*. The former entails reflection on the, often tacit, 'knowledge-in-action' while being in action means being able to change thinking and action (Ng, 2012; Schön, 1983). The latter concerns the reflection after the actual action (Schön, 1983). Through this process of reflection in and on action, health professionals are able to learn from their own actions and so create new knowledge (Eraut, 2000), by turning tacit knowledge into explicit knowledge. However, it has been argued that this process of learning is not an individual process, but a social one, and requires interaction between health professionals (Salter & Kothari, 2016). One could argue that the findings from the studies conducted in this thesis refine the aspects of care that health professionals should primarily reflect on, in and on action (e.g. on integrating disorder-specific and generic needs and on listening non-judgmentally) to provide good quality mental health care, as patients with bipolar disorder underlined.

9.2.2 Organizational level

In line with the reflective practitioner at the professional level, one could argue that care for people with bipolar disorder would benefit from a *learning organization*. According to literature, a learning organization supports the reflection process of the health professional (Handley, Sturdy, Finchman, & Clark, 2006; McCormack, Dewing, & McCance, 2011; Salter & Kothari, 2016). When this reflective practice is understood as a social process, the social context (i.e. the health care organization) becomes a key influential factor (Salter & Kothari, 2016). It has been suggested that for a reflective practice, *learning* should be an integrated component of practice (McCormack et al., 2011), supported by '*a learning organization'* (Salter & Kothari, 2016; Senge, 1990; van Veelen, 2017). According to Senge (1990), a learning organization could be defined as one *'where people continually expand their capacity to* *create the result they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning to see the whole together'.* In practice this could mean that the health care organization acknowledges the relevance of informal and formal learning and provides health professionals with possibilities to do so (Salter & Kothari, 2016). Moreover, as previously mentioned, reflective practice is not an individual process, but requires interaction among health professionals (Salter & Kothari, 2016). This emphasizes the importance of working in a team, since one can learn from the experiential knowledge and reflections of others (Handley et al., 2006) and integrate this knowledge into one's own clinical decision making as a new source of knowledge (D'Amour et al., 2005). Owning to the constant learning, the organization is able to respond and adapt to the support needs of health professionals in the practice of providing evidence-informed patient-centered care.

9.2.3 Research system

As explained in Chapter 2, it has been acknowledged that including end-users in setting the research agenda improves the acceptance of the outcomes and the relevance of the research for clinical practice. We found that in addition to research topics that require a biomedical approach (e.g. what is the etiology of the disorder) or an RCT approach to study the effectiveness of therapies (e.g. what is the effectiveness of non-pharmacological therapies), end-users formulate research topics that, according to our findings, would benefit from a research approach using experiences and practices of health professionals and patients (e.g. impact of diagnosis, self-management strategies). According to literature, these approaches could benefit from a practice-based research approach, resulting in practice-based evidence. Practice-based research could be understood as '*research conducted within the context of real world practice*' (Brownson & Jones, cited by Leeman & Sandelowski, 2012, p. 171) and as 'research *in* practice and research *on* practice (Smith & Wilkins, 2018). Practice-based evidence is increasingly recognized as valuable in generating evidence that is more relevant and more tailored to clinical practice (Bekemeier & Ensign, 2017; Green, 2009; Leeman & Sandelowski, 2012; Smith & Wilkins, 2018). Thus, in addition to including end-users in the process of setting the research agenda to create more evidence that is relevant for clinical practice, practice-based research in itself could contribute to creating evidence that is more suitable for use in clinical practice (Green, 2014; Rolfe, 1998), which could contribute to an evidence-informed patient-centered practice. This approach was used in study 5 of this thesis to generate evidence close to the real world. Second, the complexity of the topics formulated by end-users, and the associated variety of approaches that could be used to study the topic, confirms the call for more multi-, inter- or transdisciplinary research (Aboelela et al., 2007; Darbellay, 2015). The findings of studies 3 and 4 show that research topics formulated by patients are often too complex to approach from one discipline. The research topics they formulated are not always discipline-focused, but instead, require a multidisciplinary approach in order to do justice to the complexity of problems that arise in the daily lives of people with bipolar disorder and in clinical practice.

9.2.4 Health system

The alignment of PCC and EBM also has implication for the health system. Based on the WHO definition of a health system: *'all these activities whose primary purpose is to promote, restore or maintain health'* (WHO, 2000, p. 5), the health system is understood as both the health care system and health research system. First, the findings of this thesis illustrate that patients struggle with aspects of the health care organization, e.g. regarding collaboration among health professionals and continuity of care, which hamper the ability to address both their disorder-specific and generic care needs. These problems could partly be explained by the fragmented health care system. Fragmentation in health care means *'the systematic misalignment of incentives or lack of coordination*' (Enthoven, 2009, p. S284). The fragmentation of the health system arose with the rapid increase of knowledge, resulting in specialized information (Stange, 2009). More specialized care based on this specialized information was provided, but without expansion of the ability to integrate and personalize this information (Stange, 2009). This is problematic, especially for people with severe mental illnesses, who often experience a complex range of needs (Nicaise, Dubois, & Lorant, 2014), which is confirmed in this thesis for people with bipolar disorder. According to Enthoven (2009), a fragmented care system is the opposite of integrated care. He described an integrated care system as an '*organized, coordinated and collaborative network, that links various health professionals […] to provide a coordinated, vertical continuum of services to a particular patient population and is accountable for the clinical outcomes and health status of the population*' (p. S285). In addition, a fragmented health system is considered a barrier to PCC (Greene et al., 2012; Lusk et al., 2013; Pelzang, 2010). In line with the needs of patients, the relevance of care continuity, and the more recent acknowledgement that understanding complex problems is more than understanding the sum of their parts (Stange, 2009), it could be argued that a fragmented care system will not be adequate to grasp the complexity of patients' problems and support an evidence-informed patient-centered care practice. Conversely, an evidence-informed patient-centered care practice would benefit from an integrated care system.

In addition, it became clear from the research agenda for bipolar disorder, described in Chapters 6 and 7, that the research field relevant for bipolar disorder, is broader than merely the research field of researcher-clinicians. Indeed, the research topics formulated by end-users could also benefit from other academic fields. The research topics that require attention from other academic fields could be considered generic research needs, since these are not disorder-specific. Examples of generic research needs are ‘improving collaboration between health professionals or ‘increasing knowledge of the GP’. Care for people with bipolar disorder would therefore benefit from a close collaboration with researchers who conduct research on these generic topics. One could argue that, similar to the health care system, the health research system would also benefit from an integrated system rather than a fragmented research system. An integrated research system, that is responsive to both disorder-specific and generic research needs, would contribute to broadening the evidence base for bipolar disorder.

To conclude, this thesis provided a set of coherent strategies that was beneficial for the alignment of PCC and EBM in the field of bipolar disorder. This set of strategies consists of 1) using patients’ perspectives to specify what constitutes good quality care; 2) setting the research agenda from the perspectives of end-users; and 3) drawing upon the different interpretative frames used to understand care and research. This set of strategies could be used for the alignment of PCC and EBM, in order to contribute to the improvement of care for other complex health problems as well. One might think of other psychiatric disorders, such as schizophrenia or ADHD, but this set of strategies could also be used in other chronic, complex health problems, e.g. obesity, chronic obstructive pulmonary disease (COPD) and inflammatory bowel disease (IBD), to gain insights into *what* kind of care needs to be provided, *how* this could be provided and gain insights into what evidence is relevant to broaden the evidence base.

9.3 Research validity

In section 3.4 of this thesis the techniques that were used in the conducted studies to increase the internal and external validity of the research were discussed: 1) triangulation of data, methods and researchers; 2) member checks; 3) data saturation; and 4) generalization. In this section, I will reflect on my role as researcher throughout the thesis, on the inclusion process of the participants and on the generalizability of the research.

9.3.1 Internal validity

Role of the researcher

In qualitative research, the researcher is the major instrument in the data collection (Shenton, 2004) and analysis. Therefore, the researcher's role needs to be considered when interpreting the results of the study.

Developing an early familiarity with the organization under study is beneficial to increase internal validity (Shenton, 2004).During the PhD trajectory, I started working as a psychiatrist in training. Although, I am only just starting to work as a health professional in mental health care, I began to be familiar with the disorder under study, and the struggles one might encounter in treating people with bipolar disorder. In addition, I worked in a multidisciplinary team and faced some of the challenges of the health care system. On the one hand, the conducted research benefited from my dual role as researcher and psychiatrist in training. I was able to understand the context and the participants. However, there is also a danger in this dual role. Especially in study 5, on the roles of psychiatrists, psychologists and nurses, I needed to stand back from assumptions based on my experience in working in a multidisciplinary team and, let the data speak for itself. Another risk could be that I too quickly thought I understood the participants and used probing questions insufficiently or with limited curiosity (Chenail, 2011). One strategy we used in studies 3 and 4 to reduce the possible researcher's bias was conducting a pilot study. Pilot studies help identifying potential bias by means of a 'test run', since the researcher can ask the participants for feedback to identify ambiguous or difficult questions and determine whether the questions provide the answers sought for and provide an adequate range of answers (Chenail, 2011). In all studies, we used the strategy of triangulation of data, methods and researchers to reduce the potential researcher bias. In addition, the research design, data collection and data analysis were discussed between researchers and member checks were sent to the participants of studies 1, 2 and 3 in order to check our interpretations of the findings.

Inclusion of participants

To be able to value the exploration of perspectives, it is also relevant to reflect on the selection process of participants. Patients were selected via two sources: health care organizations and the patient organization. By selecting patients through health care organizations, only patients who received care for bipolar disorder could be included. All patients who had a consultation with their health professional within a certain period of time received an information letter about the research and how to participate if interested. To broaden the variety of patients' characteristics, patients were also recruited through the patient organization. However, it should be taken into account that patients who were included in the studies were not suffering a major manic or depressive episode at time of the FGD or interview; their accounts could, however, enrich the findings emphasizing the non-medical aspects of care. Moreover, patients who were willing to participate might be further in their recovery process, which could result in the same bias towards the non-medical aspects of care. In addition, in all studies involving patients, more women were included, which could result in different findings. To increase internal validity, it was aimed to make a full exploration of perspectives among others by opting for data saturation in each of the studies. In addition, the risk of the selection bias influencing the findings was reduced by data triangulation in studies 1 and 2.

For the inclusion of the health professionals in study 4, three teams specialized in bipolar disorder from two outpatient clinics were included. To be able to include health professionals from other clinics as well, for study 5 we recruited health professionals via the national knowledge center for bipolar disorder. Due to the relatively new role of psychologists in the field of bipolar disorder, few psychologists could be recruited via the pre-selected outpatient clinics and in the knowledge center for bipolar disorder. Therefore, the psychological perspective is slightly underrepresented in the findings of this thesis.

9.3.2 External validity

External validity is concerned with the generalizability of this thesis to a broader context. The research on which this thesis is based took place in Dutch outpatient clinics involving patients with bipolar disorder and health professionals experienced with treating these patients. It should be taken into account that bipolar disorder is unique in the sense that patients experience mood disorders in two opposite poles, each leading to their own unique specific challenges and care needs. However, as presented in studies 1, 2 and 3 of this thesis, many of the patients' care and research needs are generic and not disorder-specific, thus addressing the patient–professional relationship and the health care system as a whole. In study 3, the research agenda for bipolar disorder from a patient's perspective was compared with a research agenda for mental health in general and many similarities were found. Moreover, study 1 already addressed the similarities in perspectives on good care between patients with ADHD and bipolar disorder. In that sense, it is reasonable to generalize to a broader range of psychiatric disorders and even to chronic health disorders, since benefits of the specific notion to deliver care according to the individual's needs accounts for all chronic health disorders. Further research needs to explore to what extent our findings can be applied to other chronic (psychiatric) disorders.

In relation to the generalizability of the research to other countries, it must be taken into consideration that the health care system, and the mental health care system specifically, is organized differently throughout Europe and worldwide. Therefore, it must be carefully considered if the findings could be generalized to other countries. However, the care needs and research needs found in studies 1, 2, 3 and 4 were compared with studies conducted in other countries, and considerable similarities were found. In addition, in the US and in European countries, PCC is also sought and the same challenges regarding reconciling EBM with PCC are present. In addition, as in the Netherlands, the core value of mental health policy is reducing institutionalization and enhancing the integration of mental health patients into the community by improving community-based services. This could result in similar challenges in providing mental health care. Moreover, the value of delivery of multidisciplinary care, or even interdisciplinary care, is increasingly recognized worldwide. Owing to the same ongoing trends in mental health care changes, it could be argued that this study is relevant for other countries as well.

9.4 Future research

This thesis presented the first steps in the alignment of PCC and EBM for bipolar disorder. It leads to new questions that could be addressed in future research.

This thesis has shown that patients with bipolar disorder consider an evidence-informed, patient-centered care practice, as good care. It has been discussed that this care practice has implications for health professionals. To further contribute to the improvement of care for people with bipolar disorder, and to be able to provide care accordingly, future research is needed on the perspectives of health professionals on an ‘evidence-informed, patient-centered care’ practice. By understanding their perspectives on good care, through qualitative research, and through facilitating the reflection of health professionals on the care needs of patients, possible barriers and facilitating factors for embedding an evidence-informed, patient-centered care practice can be established.

Furthermore, this thesis focused on patients and health professionals that are treated or work in an outpatient setting. The insights derived from the alignment of PCC and EBM could therefore primarily be used in this setting. However, psychiatric patients could also be treated in an inpatient setting in which research shows that the experiences of both staff and patients are often reported as negative (Beckett et al., 2013). This thesis showed that patients in an outpatient setting prefer a patient-centered care practice, but one could argue that the inpatient setting is subject to a tension between PCC, including ‘shared power’ and ‘being an autonomous person’ on the one hand, and the concept of ‘pressure’ and ‘coercion’ on the other. The negative experiences of patients treated in an inpatient setting as found in literature (e.g. Beckett et al., 2013), and this described tension, are reasons to further explore patients’ and health professionals’ perspectives of care in inpatient settings. In order to do so, the set of strategies used in this thesis could be applied to inpatient settings.

In order to have evidence available that is relevant for clinical practice, the topics on the research agenda according to end-users need to be investigated in future studies. To further contribute to the relevance of research for clinical practice, relevant outcome measures need to be identified. It has been discussed in literature that often research outcomes (e.g. symptom reduction) do not correspond to the outcomes patients seek in clinical practice, which impedes the implementation of the research outcomes in clinical practice (Kazdin, 2008; Newnham & Page, 2010). In this thesis, the perspectives of health professionals on the patients’ research agenda were explored and suggestions for research approaches and outcome measures were formulated. Future research is needed to specify the outcome measures that are useful for clinical practice and simultaneously do justice to the research needs as formulated by patients.

9.5 Conclusion

The aim of this study is to contribute to our understanding of improving mental health care by systematically bringing the separate worlds of PCC and EBM together. This thesis provides a set of coherent strategies that may be beneficial for the alignment of PCC and EBM in the field of bipolar disorder. The first strategy is to explicate patients’ perspectives on what constitutes good quality care to provide a direction for care and research. The second strategy is to include the perspectives of end-users (both patients and health professionals) to formulate a needs-based research agenda for bipolar disorder. The third strategy is to distinguish the different interpretative frames, used by health professionals in understanding care and research to optimize the use of multiple sources of knowledge.

These strategies resulted in a new model of care: ‘an evidence-informed, patient-centered care practice’. This model emphasizes the need to conduct research relevant for clinical practice, using a variety of sources of knowledge to translate the research outcomes to the individual patient, and providing individualized care, focused on the patient as a person with unique strengths, needs and preferences. In addition, this model recognizes the importance of multidisciplinary care and research to benefit from all expertise available. In this way, this thesis provides insights into how the science and the art of medicine could be combined in order to improve the quality of mental health care.

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SUMMARY

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.

SAMENVATTING

Introductie

Bipolaire stoornis is een psychiatrische aandoening, die gekarakteriseerd wordt door episodes van depressie en (hypo)manie. Deze aandoening heeft een grote impact op patiënten en hun naasten. Goede behandeling is daarom van belang. Ondanks de relatief ruime financiële middelen kampt Nederland met een behandelingskloof: een kloof tussen de behandelbehoeftes van patiënten en de zorgaanbieding. Hoge kosten en lange wachtlijsten belemmeren de toegankelijkheid van de psychiatrische zorg. Bovendien zorgen de fragmentatie van de zorg door een snelle toename van kennis, en de marktwerking in de zorg, die resulteert in overregulatie en een toename van de bureaucratie, voor een verdere toename van deze kloof.

Een onderliggende verklaring voor deze behandelingskloof is dat de visies op hoe de psychiatrische zorg geconceptualiseerd en georganiseerd moet worden voortdurend veranderd. De inhoudelijke betekenis van de concepten 'geestesziekte' en 'goede zorg' wordt al tientallen jaren bediscussieerd. In de huidige geestelijke gezondheidszorg, worden twee paradigma's het meest besproken: Evidence Based Medicine (EBM) (geneeskunde op basis van bewijs) en patiëntgerichte zorg. Beide paradigma's worden waardevol bevonden, echter, worden ze vaak als 'conflicterende paradigma's' beschouwd. EBM is een paradigma gebaseerd op een benadering op populatie niveau, waarin onderzoeksresultaten centraal staan, terwijl patiëntgerichte zorg is gebaseerd op een individuele benadering, waarin de behoeftes van de individuele patiënt centraal staan. Tegenwoordig wordt beargumenteerd dat de beide paradigma's ook complementair aan elkaar kunnen zijn, omdat ze beide streven naar goede kwaliteit zorg. Er is echter weinig bekend over hoe ze elkaar kunnen aanvullen. Daarom is het doel van dit proefschrift om bij te dragen aan het verbeteren van de geestelijke gezondheidszorg door EBM en patiënt gerichte zorg op een systematische manier op één lijn te brengen. Dit proefschrift focust zich specifiek op het veld van bipolaire stoornis, in verband met de hoge ziektelast die deze stoornis met zich meebrengt, de hierboven gesignaleerde behandelingskloof en het chronische beloop dat vraagt om zowel EBM als patiëntgerichte zorg. Dit wordt verder toegelicht in hoofdstuk 1 van dit proefschrift.

Theoretische achtergrond

In hoofdstuk 2 van dit proefschrift worden de concepten EBM en patiëntgerichte zorg uitgewerkt. Patiëntgerichte zorg is een behandelkader dat zich sinds 1950 heeft ontwikkeld.

Het centrale thema is een verschuiving van een ziekte-focus naar een patiënt-focus, met aandacht voor diens gevoelens en ervaringen. Het 'Institute of Medicine' definieert patiëntgerichte zorg als: '*een relatie tussen behandelaren, patiënten en familie (indien gepast) om er zeker van te zijn dat beslissingen de behoeften en voorkeuren van patiënten respecteren en dat patiënten de educatie en steun krijgen die zij nodig hebben om een beslissing te nemen en deel te nemen aan hun eigen zorg, in elke fase van de zorg, van binnenkomst tot ontslag'.* Aan de ene kant wordt patiëntgerichte zorg geprezen voor de positieve effecten op gezondheidsresultaten, zelfmanagement, tevredenheid met de zorg, zorg processen en tevredenheid van behandelaren, maar tegelijkertijd wordt patiëntgerichte zorg bekritiseerd vanwege de onduidelijke conceptualisatie, waardoor er sprake is van een gebrek aan wetenschappelijke gronden voor patiëntgerichte zorg.

EBM wordt vaak begrepen als *'het nauwkeurige, expliciete en oordeelkundige gebruik van het best beschikbare bewijs in het maken van beslissingen in de zorg voor een individuele patiënt. Het beoefenen van Evidence Based Medicine houdt in dat individuele klinische expertise geïntegreerd wordt met het best beschikbare externe klinische bewijs van systematisch onderzoek*'. EBM wordt geprezen voor het bieden van steun bij klinische besluitvorming, het integreren van onderwijs en klinische praktijk, het verbeteren van de efficiëntie en werkzaamheid in de zorg en het verminderen van het gebruik van ineffectieve behandelingsvormen. Tegelijkertijd wordt het bekritiseerd vanwege het wegzetten van niet-wetenschappelijke behandelingen en het bemoeilijken van het vertalen van wetenschappelijk bewijs naar de klinische praktijk, door de dominante status van onderzoek, waardoor er weinig ruimte is voor individuele behoeftes en voorkeuren.

Door de verschillende visies op wat leidend moet zijn in de klinische praktijk, lijken EBM en patiëntgerichte zorg tot verschillende werelden te behoren. In EBM wordt de klinische praktijk voornamelijk geleid door wetenschappelijk bewijs, terwijl patiëntgerichte zorg wordt geleid door ervaringskennis van behandelaren en patiënten. Toch wordt het tegenwoordig meer en meer erkend dat het op één lijn krijgen van deze paradigma's gunstig kan zijn voor de klinische praktijk. In dit proefschrift wordt met op één lijn krijgen bedoeld: het versterken van de 'evidence base' van patiëntgerichte zorg en het versterken van de patiëntgerichtheid van EBM. Om dit te bereiken worden strategieën gebruikt die de punten van kritiek van beide paradigma's adresseren. De eerste strategie, om de 'evidence base' van patiëntgerichte zorg te versterken, is het bijdragen aan de verbetering van de conceptualisatie van patiëntgerichte zorg, waarmee de kritiek op de onduidelijke conceptualisatie wordt geadresseerd. De tweede strategie, ter versterking van de patiëntgerichtheid van EBM, is het verbreden van de ‘evidence base’ door 1) de perspectieven van behandelaren en patiënten te includeren in de zorg en in onderzoek en 2) het uitvoeren van onderzoek dat dichter bij de daadwerkelijke context van de klinische praktijk staat, wat zal resulteren in acceptabeler en meer relevant onderzoek voor de klinische praktijk. Het toepassen van deze strategieën in het veld van bipolaire stoornis kan lessen voor de klinische praktijk en voor onderzoek opleveren, die 1) behandelaren in staat stellen om patiënten met een bipolaire stoornis te behandelen volgens de principes van zowel EBM als patiëntgerichte zorg en 2) onderzoekers in staat stellen om onderzoek te verrichten dat relevant is voor de klinische praktijk.

Onderzoeksopzet

De hoofdvraag die in dit proefschrift wordt beantwoord is:

Wat impliceert het nader tot elkaar brengen van EBM en patiëntgerichte zorg voor de klinische praktijk en het onderzoek in het veld van bipolaire stoornis?

Om deze onderzoeksvraag te beantwoorden, zijn er drie subvragen geformuleerd.

1. Wat houdt goede kwaliteit zorg in voor mensen met een bipolaire stoornis, vanuit het perspectief van EBM, patiëntgerichte zorg en patiënten?
2. Welke onderzoeksonderwerpen zijn, volgens patiënten en behandelaren, relevant voor het klinische en wetenschappelijke veld van bipolaire stoornis?
3. Welke perspectieven, die door behandelaren worden gebruikt om de bipolaire stoornis en onderzoeksonderwerpen die volgens patiënten relevant zijn te begrijpen, kunnen worden onderscheiden?

Het antwoord op de eerste subvraag draagt bij aan het versterken van de ‘evidence base’ van patiëntgerichte zorg door het verhelderen van de conceptualisatie van patiëntgerichte zorg. Ook draagt het bij aan het versterken van de patiëntgerichtheid van EBM door het verbreden van de ‘evidence base’ door het gebruiken van de perspectieven van patiënten. Het antwoord op de tweede subvraag draagt bij aan het versterken van de patiëntgerichtheid van EBM door enerzijds onderzoek dat wordt uitgevoerd en anderzijds de perspectieven van patiënten en behandelaren op wat relevant onderzoek is, op één lijn te brengen. Voor dit doel wordt de strategie om de ‘evidence base’ te verbreden met de perspectieven van patiënten en behandelaren gebruikt. De derde subvraag streeft ook naar het versterken van de patiëntgerichtheid van EBM door de ‘evidence base’ te verbreden door onderzoek uit te voeren die dichter bij de klinische praktijk staat.

Om deze subvragen te beantwoorden zijn kwalitatieve onderzoeksmethoden en gemengde onderzoeksmethoden gebruikt. De resultaten hiervan worden gepresenteerd in hoofdstuk 4-8 van dit proefschrift. Er is gebruik gemaakt van de volgende onderzoeksmethoden: literatuurreview (hoofdstuk 4), semi-gestructureerde interviews (hoofdstuk 4 en 7), focusgroep discussies (hoofdstuk 4-8), een vragenlijst (hoofdstuk 6) en de Delphi methode (hoofdstuk 8). De methode wordt verder toegelicht in hoofdstuk 3 van dit proefschrift.

Resultaten

Om de ‘evidence base’ van patiëntgerichte zorg te versterken is het van belang dat de conceptualisatie hiervan wordt verhelderd. In **hoofdstuk 4** worden de resultaten van een literatuurreview over de conceptualisatie van patiëntgerichte zorg beschreven. De elementen die volgens de literatuur relevant zijn voor patiëntgerichte zorg worden geclusterd in vier dimensies: ‘patiënt-behandelaar interactie’, ‘patiënt’, ‘behandelaar’, en ‘zorgorganisatie’. De patiënt-behandelaar interactie wordt beschreven als een interactie waarbij de patiënt en de behandelaar de macht en de verantwoordelijkheid delen en waarbij beiden hun ervaringskennis inbrengen. Dit kan leiden tot een goede behandelrelatie en tot geïndividualiseerde zorg. Om deze vorm van interactie te bereiken, worden in patiëntgericht zorg de ‘patiënt’ en de ‘behandelaar’ ook geconceptualiseerd. De patiënt wordt geconceptualiseerd als een persoon met zijn/haar eigen kennis over het leven met een ziekte, die in staat is om deel te nemen aan zijn/haar eigen zorg, die het recht heeft op autonomie, waardigheid en privacy, en die zijn/haar eigen unieke voorkeuren, behoeftes en waarden heeft. De behandelaar wordt geconceptualiseerd als een persoon met een biopsychosociaal perspectief, een zorgzame houding, en met kennis en expertise. Verder moet de behandelaar in staat zijn om flexibel te kunnen omgaan met regels om de unieke behoeftes van de individuele patiënt centraal te kunnen stellen. De patiënt en de behandelaar hebben de steun nodig van de zorgorganisatie. Een zorgorganisatie die patiëntgerichte zorg faciliteert, focust zich op de coördinatie en integratie van zorg, transitie en continuïteit van zorg, toegankelijkheid van zorg en faciliteert multidisciplinaire teams.

Om de patiëntgerichtheid van EBM te versterken, is het van belang om onderzoek uit te voeren dat relevant is voor de klinische praktijk volgens patiënten en behandelaren, de eindgebruikers. **Hoofdstuk 6 en 7** beantwoorden de subvraag welke onderzoeksonderwerpen relevant zijn voor de klinische praktijk door de perspectieven van patiënten en behandelaren te expliciteren. Dit resulteerde in een onderzoeksagenda voor bipolaire stoornis. Relevante onderzoeksonderwerpen volgens patiënten konden worden geclusterd in vijf thema's: oorzaken van de stoornis (etiologie van de stoornis; triggers voor een stemmingsepisode), diagnose (herkennen van vroege signalen; kennisverbetering van de huisarts; ontwikkeling van diagnostische hulpmiddelen; een adequaat doorverwijssysteem), medicamenteuze behandeling (effectiviteit van medicatie; werkings-mechanisme van medicatie; noodzaak van medicatie; bijwerkingen; ontwikkeling van medicatie die beter gericht is en minder bijwerkingen heeft; het effect van lithium op sportprestaties), niet-medicamenteuze behandeling (de effectiviteit van niet-medicamenteuze interventies; de ontwikkeling van nieuwe interventies, inclusief interventies voor naasten), en herstel en herstelgerichte zorg (de kennis van de maatschappij over bipolaire stoornis; strategieën om acceptatie in de maatschappij te vergroten; zelfmanagement strategieën; positieve aspecten van bipolaire stoornis; impact van bipolaire stoornis op de patiënt; behandelopties voor comorbide stoornissen; ontwikkeling van een patiëntgericht zorgsysteem; samenwerkingsvormen tussen behandelaren). De perspectieven van behandelaren op relevante onderzoeksonderwerpen voor bipolaire stoornis overlappen met de perspectieven van patiënten. Aan het thema 'oorzaken' voegen behandelaren nog het onderzoeksonderwerp 'verhelderen van psychologische verklaring voor de stoornis' toe. Aan het thema 'diagnose' voegen behandelaren toe dat ze onderzoek willen naar de rol van de psycholoog bij de diagnostiek en naar het onderscheid tussen een bipolaire stoornis en een persoonlijkheidsstoornis en aan het thema 'medicamenteuze behandeling' voegen ze de onderwerpen 'voorspellende factoren voor effectieve medicatie' en 'betere medicamenteuze behandeling voor de bipolaire depressie' toe. Het thema 'niet-medicamenteuze behandeling' werd door behandelaren verrijkt door de onderzoeksonderwerpen 'niet-medicamenteuze interventies voor de bipolaire depressie' en 'de ontwikkeling van eHealth'. Aan het thema 'herstel en herstelgerichte zorg', voegden behandelaren de onderwerpen 'functionele beperkingen van de bipolaire stoornis', 'de kwaliteit van zorg vanuit het patiënten perspectief', 'strategieën om wetenschap en klinische praktijk beter te integreren', en 'het gebruik van alle aanwezige expertise in de klinische praktijk' toe.

Om de perspectieven van behandelaren op relevant onderzoek volledig te begrijpen, is het van belang om hun visies op de onderzoeksonderwerpen van patiënten te begrijpen. Het systematisch onderzoeken van de perspectieven van behandelaren verbreed de 'evidence base' van bipolaire stoornis. In onderzoek konden verschillende perspectieven worden onderscheiden, welke in **hoofdstuk 7** worden beschreven. Verplegingswetenschappers benaderen de onderzoeks-onderwerpen door consequenties, invloed op functioneren en de impact voor de patiënt in ogenschouw te nemen, terwijl psychiater-onderzoekers de onderwerpen benaderen vanuit een medisch perspectief, en met name fysieke en biologische aspecten, medicatie en symptomatologie in ogenschouw nemen bij het formuleren van een onderzoeksvraag. Het psychologische perspectief op de onderzoeksonderwerpen focust met name op psychologische mechanismes, gedrag, cognitie en ervaringen van patiënten. Deze verschillende perspectieven resulteren in verschillende onderzoeks-benaderingen die verschillende aspecten van een bepaald onderzoeksonderwerp belichten. Om deze perspectieven verder te begrijpen en om de patiëntgerichtheid van EBM te versterken door onderzoek uit te voeren die dichter bij de klinische praktijk staat, worden deze perspectieven verder onderzocht in een specifiek zorgproces: het diagnostisch proces. Dit wordt beschreven in **hoofdstuk 8.** Het perspectief van psychiaters wordt het 'symptoom evaluatie perspectief' genoemd. Dit perspectief omvat een ziektefocus, waarbij psychiaters zich concentreren op symptomen en patronen, inclusief de fysieke toestand van patiënt. De interpretatie van deze focus resulteert in de meest passende DSM-5 classificatie. De psychologische benadering wordt het 'op persoonlijkheid gefocuste perspectief' benoemd. Dit omvat een systematische benadering van psychologische mechanismes, persoonlijkheidskenmerken, coping stijlen en de ontwikkeling van de patiënt en hoe deze aspecten relateren aan de symptomen van de patiënt. Het perspectief van verpleegkundigen wordt het 'psychosociale perspectief' genoemd. Dit omvat een focus op praktische aspecten in het leven van de patiënt, hun functioneren in verschillende levensdomeinen en hun sociale context, en op sterke punten van een patiënt.

Discussie en conclusie

Dit proefschrift draagt bij aan het dichter bij elkaar brengen van EBM en patiëntgerichte zorg in het veld van bipolaire stoornis. De strategieën die worden gebruikt om hieraan bij te dragen resulteren in de introductie van een 'evidence-informed, patiëntgerichte zorg' praktijk. Dit model benadrukt de behoefte aan het onderzoeken van onderwerpen die corresponderen met de onderzoeksbehoeften van eindgebruikers van dit onderzoek, met een specifieke focus op psychosociale aspecten van bipolaire stoornis en herstel. Vervolgens moeten deze onderzoeksuitkomsten worden vertaald naar de behoeften van de patiënt, waarbij er gebruik wordt gemaakt van verschillende kennisbronnen, zoals bijvoorbeeld ervaringskennis, om geïndividualiseerde zorg te kunnen leveren, die focust op de patiënt als een persoon met unieke krachten, behoeften en voorkeuren. Verder wordt in dit model het belang van multidisciplinaire benaderingen in zowel de zorg als in onderzoek herkend, om op deze manier de verschillende perspectieven te integreren en gebruik te maken van alle expertise die aanwezig is.

Het nader tot elkaar brengen van EBM en patiëntgerichte zorg, dat heeft geresulteerd in de beschrijving van een 'evidence-informed, patiëntgerichte zorg' praktijk, een onderzoeksagenda voor bipolaire stoornis en inzichten in de perspectieven van behandelaren op patiënten en hun behoeften, heeft implicaties voor de klinische praktijk en voor het onderzoek op vier verschillende niveaus. Op het behandelaarsniveau impliceert het 'evidence-informed, patiëntgerichte zorg' model dat de behandelaar verschillende kennisbronnen moet gebruiken om het wetenschappelijke bewijs te kunnen vertalen naar de behoeften van de individuele patiënt. Deze verschillende kennisbronnen kunnen door de behandelaar worden geïntegreerd via reflectie en een leerproces. De behandelaar kan hierbij baadt hebben bij een reflectieve behandelpraktijk. Op het organisatieniveau kan de zorg voor mensen met een bipolaire stoornis baadt hebben bij een leerorganisatie om het reflectieproces van behandelaren te ondersteunen. Op het onderzoekssysteemniveau, impliceren de bevindingen van dit proefschrift dat de onderzoeksonderwerpen van de eindgebruikers baadt hebben bij een onderzoeksbenadering die ervaringen van behandelaren en patiënten gebruikt, ook wel een op praktijk gebaseerde onderzoeksbenadering, wat resulteert in op praktijk gebaseerde onderzoeksresultaten. Op het gezondheidssysteemniveau impliceren de bevindingen van dit proefschrift dat zowel het zorgsysteem als het onderzoekssysteem baadt hebben bij een meer geïntegreerd systeem in plaats van een gefragmenteerd systeem, om grip te kunnen krijgen op de complexiteit van de problemen van de patiënten.

Concluderend, door EBM en patiëntgerichte zorg dichter bij elkaar te brengen in het veld van bipolaire stoornis biedt dit proefschrift inzichten in hoe de wetenschap en de kunst van de geneeskunde kunnen worden gecombineerd om de kwaliteit van de geestelijke gezondheidszorg te verbeteren.

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Curriculum Vitae

Eva Maassen werd geboren op 26 juni 1987 te Nijmegen. Na het behalen van haar VWO-diploma ging ze geneeskunde studeren aan de Universiteit van Maastricht. In 2012 startte ze aanvullend met de master International Public Health aan de Vrije Universiteit te Amsterdam. Ze schreef haar afstudeerscriptie over de perceptie op depressie van twee San gemeenschappen in Kimberley, Zuid Afrika. Aansluitend aan deze master startte ze als junior onderzoeker en docent aan het Athena Instituut van de Vrije Universiteit te Amsterdam. Hier startte zij haar promotietraject, in samenwerking met GGZinGeest en Altrecht, instellingen voor geestelijke gezondheidzorg in Amsterdam en Utrecht. Na 2 jaar begon ze naast haar promotie als arts-assistent psychiatrie bij Altrecht, op de behandelpoli bipolaire stoornissen. In april 2017 begon zijn aan de opleiding tot psychiater bij Altrecht, waar zij op dit moment nog werkzaam is.