Searching for order in disorder: Self-management education for persons with bipolar disorders and their informal caregivers

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Chapter 1

General introduction

INTRODUCTION

1. A historical view on bipolar disorders

Ancient Greek mythology describes many cases of madness, melancholia, and megalomania. For instance, the reckless adventure of Phaeton. The demi-god son of Apollo who, despite all warnings, insisted to steer the sun-chariot that marked his fatal downfall. Alternatively, consider the story of Niobe of Thebe who in her grandiosity (*Hybris* in ancient Greek) had dared to challenge the goddess Leto. Consequently, leading to the dead of her twelve children by Apollo and Artemis. Niobe's deep sorrow and melancholia ultimately transformed her into a rock from which her tears form the fountain that springs the Achelous, the biggest river in Greece (Fry, 2018; Ovid, 2000). Although these great narratives are myths, metaphorically speaking they seem to describe the manic-depressive characteristics of 'bipolar disorder' in present day.

Hippocrates (ca. 400 BC) was the first who medical-systematically reported the pathological mood fluctuations of melancholia and mania, and respectively linked it to excessive black- and yellow bile. Half a decennium later, Soranus of Ephesus (ca. 100 AD) connected both moods. Aretaeus of Cappadocia (ca. 150 AD) claimed that both mood-states occur in the same illness and manifests itself in a two-sided polarity of symptoms. In the slipstream of the enlightenment the pioneers of psychiatry Philippe Pinel (1748-1826) and Dominique Esquirol (1772-1840), and French alienists Jean-Pierre Falret (1794-1870) and Jules Baillarger (1809-1890), described cases of 'folie circulaire' and 'folie double form'. Their systematic reports from clinical observations of circular recurrent polarity of mood disorders cleared the path for a dimensional description. Emil Kreaplin (1856-1926) on his turn distinguished the non-deteriorating manic-depressive disorder from the more disabling illness dementia praecox (Goodwin & Jamison, 2007).

The work of Kreaplin marked a new era of classification and phenomenological descriptions of mental disorders that is still common scientific practice in present day psychiatry (Goodwin & Jamison, 2007). In line of this tradition, this section entails the distinguished (sub)categories of bipolar disorder from a historical perspective (subsection 1.1), and its epidemiology (subsection 1.2). Followed, by an outline of multidisciplinary treatment of bipolar disorder (subsection 1.3.), and ending with the evolution of the Dutch multidisciplinary guideline for treatment of bipolar disorder of which self-management is one of the corner stones of mental health nursing (subsection 1.4).

1.1. Bipolar disorders

In the first two editions of the Diagnostic and Statistical Manual for Mental Disorders (DSM), the bipolar- and depressive disorders were both classified in the category of affective disorders. At first, bipolar disorder was classified as a 'manic-depressive reaction' in the DSM-I, and relabeled as the 'manic-depressive illness' in the DSM-II. Henceforth in the third edition of the DSM, the unipolar- and bipolar affective disorders became distinct categories. Both were relabeled as 'mood disorders' in the DSM-IV to emphasize a persistent affective state without the necessity of an expressive emotional arousal. Finally, bipolar disorder is specified as a mental illness that is characterized by fluctuating emotions and energy levels or activity patterns alternating between euthymic, hypo-manic or manic, major depressive, and mixed mood episodes in the latest, fifth edition of the DSM (American Psychiatric Association, 2013). Nowadays bipolar disorder is distinct in the following subcategories:

1. Bipolar disorder I, when at least one manic episode has occurred somewhere in the history of an individual, that is: an episode of persistently elevated mood with an abnormally high level of activity for most hours of the day and that exists for at least a week;
2. Bipolar disorder II, when an individual suffers primarily from one or more depressive episodes for at least two weeks per episode accompanied by at least one episode of hypomania, i.e. having milder features of mania that are not severe enough for acute hospitalization;
3. Cyclothymic disorder, when a person suffers from alternating episodes of hypomania and depressive mood symptoms for at least two years and is symptom free for less than two months during this period of time that cannot be classified as a feature of bipolar disorder I or II;
4. Substance/medication induced bipolar and related disorder;
5. Bipolar and related disorder due to another medical condition;
6. Other specified bipolar and related disorder, when an individual has short term symptoms without the full features of bipolar disorder I, II or cyclothymia;
7. Unspecified bipolar and related disorder, when an individual has symptoms of a bipolar disorder lacking the features for a specific classification.

The above mentioned subcategories of bipolar- and related disorders can be specified by adding the following characteristics if applicable: mixed features (i.e. having depressive symptoms during a (hypo)manic episode or vice versa), rapid cycling (i.e. at least four episodes in one year classified as bipolar disorder I or -II), melancholia, a-typical features (for instance, weight loss or hypersomnia), psychotic features, catatonia, peri-partum (or four weeks post-partum), or seasonal bound, in line with clinical observations (American Psychiatric Association, 2013).

1.2. Epidemiology

The lifetime prevalence of bipolar disorder for persons between 18 and 65 years of age is 1.3 % in the Netherlands, 1% in the European Union, and 0.8% (0.5–1.1%) worldwide (Ferrari et al., 2016; de Graaf et al., 2012; Pini et al., 2005). Whether or not persons with bipolar disorder seek treatment, being diagnosed with bipolar disorder I or II comes with high morbidity. Bipolar disorder manifests itself in recurrent (hypo-) manic and depressive episodes. During a five year span, persons with bipolar disorder endure full episodes for 60-75% of the time, are symptom free for six months, and endure (sub-)syndromal (hypo)manic or depressive symptoms for 10-35% of the remaining time (Judd et al., 2002; Kupka et al., 2007).

Symptom severity in bipolar disorder is associated with low quality of life, high functional impairment, self-perceived stigmatization, high suicide rates, and decreased autonomy (Gazalle et al., 2007; Goossens et al., 2008b; Robb et al., 1997; Rosa et al., 2010; Sanchez-Moreno et al., 2009). Three in four persons with bipolar disorder report comorbidity, anxiety problems, substance- or alcohol abuse, relational problems, and poor school/work performance; with 48.8 million cases worldwide, bipolar disorders account for 9.9 million (0.4%) of the global disability-adjusted life years (DALYs) (Ferrari et al., 2016; de Graaf et al., 2012).

1.3. Treatment of bipolar disorders

The primary goal in the treatment of bipolar disorders in the acute phase of a manic or depressive episode is symptom reduction, predominantly through pharmacological and behavioral interventions. Subsequently, the focus of treatment shifts toward functional recovery and maintenance pharmacotherapy (Rosa et al., 2010; Vazquez et al., 2011), psychoeducation (Colom et al., 2003; Colom & Lam, 2005), psychosocial support (Crowe et al., 2010), and psychotherapy (Lam et al., 2009). The acute phase often requires hospitalization with psychopharmacological and behavioral interventions to reduce symptoms, provide protection, and prevent recurrences. When a stabilized mood is established, outpatient care delivers maintenance treatment aiming at functional and personal recovery, medication adherence, and self-management to diminish the number of recurrent (hypo-) manic and depressive episodes (Kupka et al., 2015).

1.4. The evolution of multidisciplinary guidelines in the Netherlands

The first Dutch multidisciplinary guideline (Nolen et al., 2001) entailed diagnostics, psycho-education and psychotherapy, and largely emphasized pharmaceutical treatment to prevent recurrence. However, the paragraph, ‘organization of care’ within this guideline described nursing care in just one sentence. The revised multidisciplinary guideline (Nolen et al., 2008) extended the paragraph ‘organization of bipolar care’ and added two aspects: ‘self-management’ and ‘pregnancy and post-partum care’. Influenced by the developments in recovery oriented care (Bonney & Stickley, 2008; Mueser et al., 2002), the nursing role in bipolar treatment was more extensively described in the chapter ‘self-management’. Self-management in the second multidisciplinary guideline entailed symptom-taxation and life-style interventions such as contra-behavior, interpersonal- and social rhythm therapy (Frank, Swartz, & Kupfer, 2000; Frank et al., 2005), and medication adherence (Nolen et al., 2008).

In the third multidisciplinary guideline (Kupka et al., 2015), the advice for bipolar treatment was refined and consolidated by scientific progress on every aspect in bipolar care. Influenced by the recovery oriented care approach, self-management support became a mandatory cornerstone in every phase of treatment, along with medication adherence, psycho-education and psychotherapy (Cook et al., 2012; Morriss et al., 2007; Mueser et al 2002). Consequently, being the largest discipline that delivers self-management education, nursing became a significant part of bipolar care endorsed by a growing body of knowledge (Coster & Norman, 2009; Daggenvoorde, Goossens, & Gamel, 2013; Goossens et al., 2008a).

2. Self-management of bipolar disorder conceptualized

With the number of illnesses pushes healthcare costs up to approximately 3.5-6% of the Gross Domestic Product (GPD) in the EU-countries (OECD, 2018), the demand for active patient involvement in health decision-making processes increases (Holman & Lorig, 2000). Self-management of a chronic illness has become a compulsory component of contemporary healthcare practice, and is recognized as such in both the Chronic Care Model and the definition of health by the World Health Organization (Huber et al., 2011; Wagner, Austin, & VonKorff, 1996). Adequate self-management of a chronic illness is associated with improved outcomes including improved quality of life, symptom reduction, fewer hospitalizations, and reduced costs of healthcare (Newman, Steed, & Mulligan, 2004).

A well-known definition of self-management is that of Barlow et al. (2002), stating that efficacious self-management entails the ability to monitor one's condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life. This view is comparable to other definitions of self-management of chronic illness encompassing active patient involvement in treatment, opting for life style changes, using effective coping strategies to prevent exacerbations, and behavioral change to improve outcomes and maintain a satisfactory quality of life (Holman & lorig, 2000; Trappenburg et al., 2013). But, effect sizes vary and the underlying factors that influence these varying outcomes remain unclear, but suggests that self-management is not a one size fit all approach (Jonkman et al., 2016; Trappenburg et al., 2013).

Pollack (1996) was the first to detect the self-management needs of inpatients with bipolar disorder, additional to clinical management treatment. Followed by Goossens et al.(2008a) who described a set of supporting nursing activities in ambulant bipolar care with self-management of bipolar disorder as a desired outcome. Janney, Bauer, & Kilbourne (2014) synthesized both the patient needs and professional supportive actions, into a set of skills and techniques to master self-management of bipolar disorder. This framework conceptualizes self-management for bipolar disorders, which is further outlined in this section. Starting with an overview of self-assessment instruments to prevent recurrent episodes (subsection 2.1), followed by an outline of life style programs (subsection 2.2.). Subsequently, a characterization of informal caregiver involvement (subsection 2.3.), and closing with a description of professional support to reinforce self-management activities (subsection 2.4).

2.1. Self-assessment

At the core of self-managing bipolar disorder lies 'having a plan' to stay well. A plan to identify trigger events, early warning signs, and an outline of strategies for themselves and others to maintain well (Russell & Browne, 2005). The studies of Daggenvoorde, Goossens, & Gamel (2013) and Goossens et al. (2010) emphasize the importance of recognizing prodromal symptoms and early reaction to counteract (hypo-) manic and depressive episodes. In practice, the relapse prevention plan is often used in conjunction with the prospective-, and retrospective Life Chart Methodology (LCM) respectively for daily assessment of mood, and reconstructing the long term individual episodic course (Denicoff et al., 2000; Denicoff et al., 2002; Honig et al., 2001; Post et al., 2003). The life chart methodology is used in interpersonal and social rhythm therapy to structure the circadian rhythm and sleep-wake cycles (Frank, Swartz, & Kupfer, 2000; Frank et al., 2005). All these instruments support the self-management of bipolar disorder by monitoring, planning, and rapid response to prevent recurrent (hypo-)manic and depressive episodes.

2.2. Life style adjustment

Several self-management interventions for severe mental illnesses were developed in the last decade. These interventions aim at the early recognition of prodromal signs, and increasing self-help or self-care through life style adaptations, either independently or with peer- or professional guidance (Janney, Bauer, & Kilbourne 2014; Jones et al., 2011; Siantz & Aranda, 2014). Examples of these are the Illness Management and Recovery program (Mueser et al., 2002), the Health and Recovery Peer Program (Druss et al., 2010), the Wellness Recovery Action Planning program (Cook et al., 2012), and the Chronic Disease Self-Management Program (Lorig et al., 2014). All of these programs have similar self-regulating ends, such as restoring lost hope, empowering personal recovery, increasing self-determination, lessening the dependence on healthcare professionals, and evoking a sense of control over symptoms (Morton et al., 2018).

2.3. Informal caregiver involvement

The term “self-management” suggests a solitary quest to battle one’s illness, and therefore the individual might seem to be solely responsible for the outcome (Janney, Bauer, & Kilbourne, 2014; Jones et al., 2011; Trappenburg et al., 2013). However, bipolar disorder has a massive impact on relationships (Goossens et al., 2008c; Granek et al., 2016), and can lead to serious mental problems of informal caregivers too (Perlick et al., 2016; Steele, Maruyama, & Galynker, 2010). Being an informal caregiver of someone with bipolar disorder is associated with high rates of emotional burden, experienced distress (Beentjes, Goossens, & Poslawsky, 2012; Jönsson et al., 2011; Reinares et al., 2006; Van der Voort et al., 2009). Informal caregivers find themselves often balancing between competing needs. They have to cope with feelings of being needed and being rejected at the same time (Lewis, 2015; Rusner et al., 2013).

Although close informal caregiver involvement increases the complexity of the caring process for all collaborating in bipolar care (Chatzidamianos et al., 2015; Peters et al., 2011). Teaching informal caregivers how to support persons with bipolar disorder is essential for the well-being of both (Fiorillo et al., 2016; Fredman et al., 2015; Miklowitz & Chung, 2016; Reinares et al., 2016). Studies have shown that the active involvement of informal caregivers positively affects the episodic course of bipolar disorder (Miklowitz, 2007; Perlick et al., 2010; Scott et al., 2012). Because, informal caregivers are known to detect the prodromal symptoms of upcoming episodes often missed by the person with bipolar disorder (Goossens et al., 2010; Regeer et al., 2015). Therefore, active informal caregiver involvement, together with professional care, is a significant pillar of the ambulant collaborative triad that support persons with bipolar disorder with self-managing their illness (Chatzidamianos et al., 2015).

2.4. Professional support

The clinical management of a bipolar disorder is predominantly pharmaceutical, with nursing interventions aiming on safety, and providing structure in circadian rhythm and daily activities during an acute depressive or (hypo-)manic episode. After the acute phase, professional involvement gradually shifts towards coaching, distant monitoring, and treatment maintenance in ambulant mental healthcare (Goossens et al., 2008a; Kupka et al., 2015). Persons with bipolar disorder and their informal caregivers have to overcome several individual, social and healthcare barriers to cope with the features and consequences deriving from the illness (Blixen et al., 2016). In ambulant treatment both persons with bipolar disorder and their informal caregivers have to learn how to recognize early symptoms, and to counteract occurring mood fluctuations to prevent episodic recurrences (Crowe et al., 2012; Kupka et al., 2015; Robb et al., 1997).

Psychoeducation is one of the professional supporting activities that reduces the number of recurrent (hypo-) manic and depressive episodes by inducing knowledge about the course of the illness (Colom et al., 2003; Colom & Lam, 2005; Reinares et al., 2016), medication adherence, and benefits of therapeutic alliances (Lam et al 2009). Enhanced collaboration between the informal caregivers, the professional, and the person with bipolar disorder works as a mutually supporting network that promotes self-management of bipolar disorder. The purpose of self-management is not solely supporting them how to manage the illness well, but also teach them how to manage well with their disorder (Morgan et al., 2017).

3. Self-management education

Self-management education for bipolar disorders in ambulant psychiatric care is a continuous learning process of self-regulation. In this learning process professionals teach persons with bipolar disorder and informal caregivers about the nature of the illness, how to collaborate, use instruments of mood monitoring, and recognizing and reacting to prodromal symptoms to prevent recurrent episodes (Michalak et al., 2011; Michalak et al., 2016; Morton et al., 2018; Janney, Bauer, & Kilbourne, 2014; Jones et al., 2011). This shift from a healthcare system with expert professionals and passive patient recipients to a collaborative care model that aims at behavioral change, implies that self-management of a chronic illness didactically evolves from passive knowledge-based information provision to active learning of problem solving (Barlow et al., 2002; Lorig & Holman, 2003; Newman, Steed, & Mulligan, 2004; Sackett & Snow, 1979).

This section provides the educational framework of self-management education for chronic illnesses that administers active learning of coping skills (subsection 3.1). Followed by an outline of the educational approaches that are applicable to the context of network learning in ambulant bipolar care (subsection 3.2), and ending with a description of scaffolding as a key concept in network learning towards self-management of bipolar disorder (subsection 3.3).

3.1. Self-management educational approaches

The concept of self-regulation as the pivot point of self-management is closely related to the concepts of self-efficacy and self-determination (Bandura, 1977; Ryan & Deci, 2000). Therefore, the learning approaches commonly used for self-management education are the social learning theory of Bandura (1977); the trans-theoretical model of health behavior change (Prochaska & Velicer, 1997); the health belief model (Rosenstock, Strecher, & Becker, 1988); problem solving models (Bishop & Donovan, 1969), and the theory of planned behavior (Ajzen, 2002). However, the common aspects of these educational theories such as the emphasis on self-determination, autonomy, and active agency, are strongly individualistic and therefore not well suited to provide a framework for the network approach applied in this research.

3.2. Network- and social learning

Contemporary learning theories are, to a large extend, grounded in the constructivism paradigm. Constructivists hold the premises that learning is a self-regulating cognitive process in which learner’s link new knowledge to prior knowledge through abstraction and reflection. The situational context affects learning, as well as the learners’ beliefs and attitudes towards a new idea suggesting that humans construct knowledge and meaning from their experiential background (Bada & Olesugun, 2015; De Laat & Lally, 2003). Constructivism is an answer on philosophical-epistemological problems by claiming that knowledge is a social construct that is constantly changes and evolves on new insights. However, constructivism is not a clear-cut educational theory that explains how people learn, and in which way they should be taught to optimize learning (Colliver, 2002; De Laat & Lally, 2003).

The constructivist educational approach appeals to the underlying rationale of this thesis, which is to unravel how people in ambulant bipolar disorder healthcare learn, and which methods are appropriate to teach people situated in this context. As pointed out before, self-management education in ambulant bipolar care is learned and taught in conjunction with persons with bipolar disorder, their informal caregivers, and professionals. Therefore, self-management education for bipolar disorders can be considered as an implicit social learning activity that needs to be unraveled to become overt. The sociocultural learning theory of Vygotsky (1978) underpins the basic idea that the situational context of a group has a strong mediating effect on the cognitive and conceptual learning processes of all individuals involved. Hence, by describing the collaborative activity of self-management education, the constructing and sharing of knowledge becomes overt (Vygotsky, 1978).

3.3. Expansive learning, and scaffolding

In the slipstream of Vygotsky's sociocultural learning theory, Engeström (2014) developed the Expansive Learning Theory (ELT). The ELT aims on a concept of learning in which individual actions are insufficient to meet the complexity of a new concept. The adaption to this complex new task demands a transformation from individual actions into a collective activity by relabeling the individual actions as being a part of collective activity. In traditional modes of learning wherein the learning content is based on a discrepancy between the 'not –knowing' learner and 'knowing educator'. The ELT states that mastering new complex tasks demands a collective approach of reconceptualization because in this particular case no one exactly knows what needs to be learned, so both the learner and the educator are learners towards a collective activity.

The conceptual framework of expansive learning entails eight basic principles (Engeström & Saninno, 2010): 1) The division of labor, which is the mastery of a task by expanding from singular actions into parts of a common collective activity; 2) The concept of the zone of proximal development (ZPD) refers to the cognitive gap between the problem solving skills of learners and that of peers that are more knowledgeable or educators. Scaffolding, (temporary) stepwise help is an applied technique to promote independent learning in the ZPD (Belland, 2014); 3) The ELT is an object-oriented theory, meaning that the collective conceptualization of a task is the spin-off of individual actions towards the realization of that task; 4) A dialectical concept of contradictions as the driving force of transformation, claiming that questioning is part of learning. Questioning, is a necessary stage for enabling the construction of new knowledge: 'Most importantly, contradictions are the driving force of transformation'; 5) Using this dialectical approach to ascend from the abstract to the concrete, i.e. the question of how to divide a complex (collective) concept into concrete (individual) tasks; 6) Subjective agency, the psychological functioning of providing meaning to a task by reframing actions towards the potential outcome of the action; 7) Being confronted with a task or concept that is too complex to cope with as an individual which consequently demands cooperation with others to comprehend its complexity; and 8) the idea of multi-voicedness meaning that all conflicting and complementary voices (opinions) are a functional part of the learning process. Expansive learning is a multi-voiced process of debate, negotiation, and orchestration of activities (Engeström & Sannino, 2010).

The ELT holds the premise that learning situations are activated, mediated, and expanded by a collaborative network. Expansive learning arises from the contrasting ideas between members of a learning community – e.g. the person with bipolar disorder, the professionals, and the informal caregivers. The contrasting ideas of all individuals participating in the collective ZPD activates the cognitive progress, hence learning by and through participating in a network (Engeström, 2014). The ELT-framework provides an iterative dialectical tool for active learning in a network wherein abstract concepts become clear through collective dialogue. Collective dialogue is an essential network process for mastering new cognitive skills, and literally speaking a new mentality (Engeström, 2014; Engeström & Sannino, 2010). Moreover, the tension between the individual ideas and the concepts of other participants pushes a network towards co-constructed knowledge, meaning and understanding (Engeström, 2014; De laat & Lally, 2003).

4. Aim of the thesis

Self-management education of bipolar disorder is a complex intervention, and mental health nurses are the primary professional discipline up to the task providing it (Clark, 2013; Coster & Norman, 2009; Goossens et al., 2008a; Pollack & Cramer, 2000). But, studies indicate that nurses do not have the didactical underpinning to comprehend the complexity of self-management education (Been-Dahmen et al., 2014; Lawn et al., 2009, Pols et al., 2009), and literature on what skills mental health nurses need to provide efficient self-management education for bipolar disorders is lacking.

The overall aim in this thesis is to overt the underlying mechanisms of network learning to enhance self-management support for persons with bipolar disorder, their informal caregivers, and professionals by providing the stepping stones for further development and testing of this model. More specifically, the general research objectives are:

1. To explore the attitudes of persons with bipolar disorder towards (non-) use of the life chart method, and test the utility of digital mood monitoring instruments in an online patient health record designed to promote self-management of bipolar disorder.
2. To describe and interpret learning experiences in self-management education from a threefold perspective; being that of persons with bipolar disorder, informal caregivers, and mental health nurses.

5. Outline of the thesis and methodology of the studies

This thesis includes nine chapters in two sections based on the research objectives. *Chapter 1* is the general introduction of this thesis, defining the central concepts used in the empirical studies.

Part I contains two studies on mood monitoring to reach objective 1. *Chapter 2*, entails a qualitative inquiry amongst fourteen persons with bipolar disorder, designed to capture their attitudes and motivations for utilizing the Life Chart Methodology. The purpose of this study was to explore the reasons for use or non-use of this well-known method for mood monitoring. To meet this objective, an interpretative phenomenological study was used to examine the perceived value of the LifeChart Method (LCM). Because phenomenology is a philosophical approach without a clear-cut qualitative methodology, we have used the key elements of this approach pragmatically as for reflection to guide qualitative data-collection and data-analysis to detect the attitudes, beliefs and considerations for utilizing the LCM or not (Dowling, 2007; Giorgi, 2005).

In *Chapter 3*, we present a twelve-month follow up pretest-posttest pilot-study to investigate the feasibility of a modified personal health record (PHR-BD). To meet this aim we used a non-randomized, non-controlled, pretest -posttest pilot design with closed- and open ended questionnaires on user experiences to collect information on the utility of the PHR-BD. The primary aim of this study was to explore and detect the utility and usefulness of the PHR-BD as experienced by persons with bipolar disorder, informal caregivers and professionals for further research and development. Secondary outcomes focused on the clinical effects on quality of life, empowerment, symptom reduction, mood, activity, illness burden and severity.

Both studies in chapters 2 and 3 primarily aimed at exploring and describing the use and perceived utility of mood monitoring instruments, either digital or analogue, from two different methodological standpoints.

Part II contains a three-folded perspective on self-management education for bipolar disorders elaborated over three chapters to capture the second aim of this thesis. *Chapter 4* presents the first of the three phenomenological studies. The aim of this study was to describe the learning experiences in self-managing their condition of sixteen persons with bipolar disorder across the population of three specialized outpatient care clinics.

Chapter 5 describes the learning experiences of ten informal caregivers with self-management support for persons with bipolar disorder in a phenomenological study. The aim of this study was to describe how informal caregivers have learned to overcome the impact of emotional burden and distress, and how they have developed a personal way of providing efficient self-management support to persons with bipolar disorder. The descriptive phenomenological method used in chapter 4 and 5 was chosen for its philosophical claim to 'go back to the things themselves' emphasizing on the construction of meaning given to a phenomenon from the different perspectives of lived-through experiences of subjects (Husserl, 1973; Husserl, 1984).

Chapter 6 captures the teaching experiences of nine mental health nurses to unravel the tacit knowledge from their practical experiences. For this purpose we used a hermeneutic-phenomenological approach in the tradition of Heidegger (1957) and Gadamer (1986), in which the analysis was iteratively repeated in accordance with the hermeneutical premise that each preunderstanding (*Vorstehen*) leads to an affirmed understanding (*Verstehen*), until data saturation is obtained (*Hermeneutische Zirkel*). We chose this method, because the experiences of two researchers who were nurses with experience in bipolar disorder care themselves, would made ‘bracketing’ of prejudgments impossible. Instead, we deliberately made use of the knowledge and experiences of all researchers during the iterative process of data collection and -analyses as a ‘pre-understanding’ according the hermeneutical-phenomenological philosophy (Heidegger, 1957; Gadamer, 1986; Thirsk & Clark, 2017).

In all three studies in chapters 4-6, we used a topic list with themes based on a general model for an activity system from the Expansive Learning Theory, to guide the interviewees when narrating beyond the scope of our study (Engeström & Sannino, 2010).

Chapter 7 is the closing chapter of this thesis. Here we present a general discussion in order to reflect on the findings of our research project, the research methods used, and the implications of our results for the clinical practice of mental health nurses who provide self-management education to persons with bipolar disorder and their informal caregivers.

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Part I

Mood monitoring at the heart of self-managing bipolar disorder

Chapter 2

Attitudes of patients with a bipolar disorder towards the Life Chart Methodology: a phenomenological study

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ABSTRACT

Background: The Dutch guideline for bipolar disorder [BD] recommends the use of the Life Chart Methodology [LCM] to help patients to monitor fluctuating mood patterns. But in practice patients show ambivalent attitudes towards this instrument.

Objective: To describe attitudes and motivations of patients with BD for (non-) using the LCM.

Design: A phenomenological study with unstructured in-depth interviews of 14 patients with BD. Patient narratives were audiotaped, transcribed verbatim, analyzed, and coded inductively.

Results: The results show that despite variability in perceptions and willingness to work with the LCM, the general attitude towards this instrument was a recognized value for using the LCM. However, the emotional impact of daily mood charting was experienced as a substantial burden, particularly during the early stages of diagnosis.

Conclusion: The impact of the diagnosis of BD needs to be taken in account when introducing the instrument for the first time to a patient.

BACKGROUND

Bipolar disorder [BD] is a chronic psychiatric illness that often develops in early adulthood and usually lasts a lifetime. BD causes unusual shifts in mood, energy, activity levels, and the ability to carry out daily tasks (American Psychiatric Association, 2000). Episodes of mania, hypomania, and depression typically recur of over time. Between episodes or during a so-called euthymic mood state, some people with BD are completely free of symptoms but many experience subsyndromal symptoms that can negatively influence the patient's quality of life (Goossens, Hartong, Knoppert-van der Klein, & van Achterberg, 2008b).

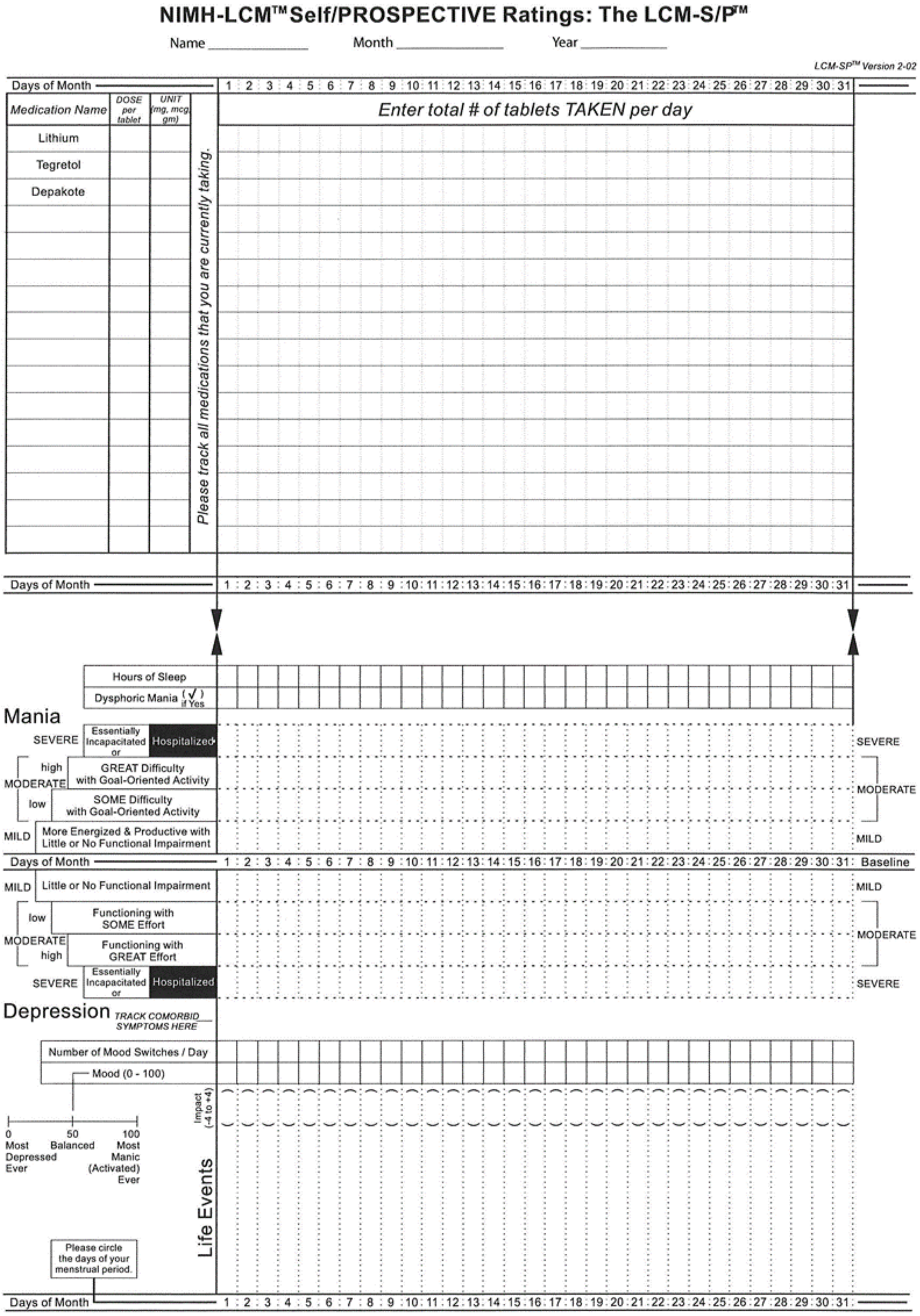
The lifetime prevalence of BD is estimated to be 1.3 % for types I and II in the Netherlands. In 75% of the cases of BD in the Netherlands, patients are also reported to suffer from comorbid behavioral or anxiety problems, abuse of alcohol or substances, and relationship problems; they may also perform poorly at school and work (de Graaf, ten Have, & van Dorselaar, 2010).

In the Netherlands, the treatment of BD is described in a guideline that recommends a number of interventions: pharmacotherapy, psychotherapy, public relations material, psycho-education, and self-management training (Nolen et al., 2008). Self-management is defined as the individual capacity to cope with symptoms, treatment consequences, physical consequences, psychological consequences, and lifestyle changes that are inherent to living with a chronic health problem. Effective self-management includes opportunities to assess one's own health and the skills needed to strengthen the cognitive, behavioral, and emotional reactions needed to maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Self-management in BD thus involves learning about BD, developing a capacity to recognize early warning signs of recurrence, and taking action as quickly as possible to prevent recurrence.

The Life Chart Method™ Self Rating scale (LCM) is one of the validated instruments recommended in the Dutch National Guideline for Treatment of Bipolar Disorders to promote patient self-management (Kupka, Akkerhuis & Nolen, 1997). Using the LCM, retrospective or prospective day-by-day data on the course of one's illness is recorded. Each Life Chart can provide a graph of mood fluctuations above and below a line that represents an euthymic mood state. An example is presented in figure 1. More information and manuals can be downloaded on http://bipolarnews.org/?page_id=175. Treatment, medication, comorbid symptoms, hours of sleep, and significant life events are also recorded on a daily basis. Community psychiatric nurses in the Netherlands often help patients work with the LCM (Goossens, Beentjes, de Leeuw, Koppert-van der Klein, & van Achterberg, 2008a).

Daily mood charting offers patients insight into current and previous conditions. It helps patients to detect early signs and symptoms of manic or depressive episodes, co-morbidities and stressful life events (Hörn, et al., 2002). Early detection of prodromal symptoms can help patients gain control over their illness allowing them to undertake early interventions to prevent exacerbations and thus promote self-management of illness (Daggenvoorde, Goossens, & Gamel, 2013).

In actual clinical practice, however, it has been shown that many patients find it difficult to work with the LCM. Kupka, Akkerhuis, and Nolen (1997), for example, found that patients need several weeks of practice to properly complete a daily mood chart. In other studies, the LCM has been shown to not only be a reliable and valid instrument for mood charting but to also take more information about the severity of symptoms into account than other rating scales. Denicoff et al (1997, 2000, 2002) and Maeden, Daniels, and Zajecka (2000) similarly consider the LCM a useful instrument for retrieving data from patients, but stated that patients tend to underestimate the severity of their illness during manic and hypomanic episodes. It is therefore recommended that patients should be coached during their initial use of the LCM and particularly on the recording of their mood states and functioning.



NIMH-LCM™ Self/PROSPECTIVE Ratings: The LCM-S/P™

Name ____________ Month ____________ Year ___________

LCM-SP™ Version 2-02

Days of Month 1 : 2 : 3 : 4 : 5 : 6 : 7 : 8 : 9 : 10 : 11 : 12 : 13 : 14 : 15 : 16 : 17 : 18 : 19 : 20 : 21 : 22 : 23 : 24 : 25 : 26 : 27 : 28 : 29 : 30 : 31

Medication Name	DOSE per tablet	UNIT (mg, mcg, gm)	Enter total # of tablets TAKEN per day
Lithium			
Tegretol			
Depakote			

Please track all medications that you are currently taking.

Days of Month 1 : 2 : 3 : 4 : 5 : 6 : 7 : 8 : 9 : 10 : 11 : 12 : 13 : 14 : 15 : 16 : 17 : 18 : 19 : 20 : 21 : 22 : 23 : 24 : 25 : 26 : 27 : 28 : 29 : 30 : 31

Hours of Sleep

Dysphoric Mania (✓ if Yes)

Mania

SEVERE Essentially Incapacitated or Hospitalized SEVERE

MODERATE high GREAT Difficulty with Goal-Oriented Activity MODERATE

low SOME Difficulty with Goal-Oriented Activity

MILD More Energized & Productive with Little or No Functional Impairment MILD

Days of Month 1 : 2 : 3 : 4 : 5 : 6 : 7 : 8 : 9 : 10 : 11 : 12 : 13 : 14 : 15 : 16 : 17 : 18 : 19 : 20 : 21 : 22 : 23 : 24 : 25 : 26 : 27 : 28 : 29 : 30 : 31 : Baseline

MILD Little or No Functional Impairment MILD

low Functioning with SOME Effort

MODERATE high Functioning with GREAT Effort MODERATE

SEVERE Essentially Incapacitated or Hospitalized SEVERE

Depression TRACK COMORBID SYMPTOMS HERE

Number of Mood Switches / Day

Mood (0 - 100)

0 Most Depressed Ever

50 Balanced

100 Most Manic (Activated) Ever

Impact (-4 to +4)

Life Events

Please circle the days of your menstrual period.

Days of Month 1 : 2 : 3 : 4 : 5 : 6 : 7 : 8 : 9 : 10 : 11 : 12 : 13 : 14 : 15 : 16 : 17 : 18 : 19 : 20 : 21 : 22 : 23 : 24 : 25 : 26 : 27 : 28 : 29 : 30 : 31

Figure 1: Example Life Chart Method

Despite the promise of the LCM for managing BD, keeping track of illness, and monitoring response to treatment, daily mood charting is not found to occur with sufficient consistency in actual practice. The question is why patients are hesitant for not completing their mood charts, despite efforts to keep them motivated to do this? The purpose of the present study was therefore to describe attitudes and motivations of patients with BD for (non-) using the LCM based on their own experiences with the LCM. A clear description of patients' perceived ambivalent attitude towards the LCM will provide insight in the underlying motivations for (non-)using the LCM.

METHOD

Study approach

An interpretative, phenomenological approach was chosen to examine the perceived value of the LCM for patients. Phenomenology is the study of both the description of life experiences and the meaning given to the experiences i.e., phenomena (Groenewald, 2004).

Ethical considerations

According the regulations set by the Dutch Central Committee Involving Research on Human Subjects, full medical-ethical review was not necessary (CCMO, 2011). Ethical approval of the study and access to respondents was granted by the executive board of the institution where the study was conducted. All participants also signed an informed consent form prior to their interview. Information from the interviews was treated confidentially by both the interviewer and the research team.

Participants

Participants were recruited from an outpatient clinic specialized in the treatment of BD within a large mental health care institution in the eastern part of the Netherlands. Inclusion was set to acquire a quota sample of 15 respondents meeting the DSM-IV criteria for BD I and/or II and diagnosed as such, currently being in a euthymic mood state at the time of the interview based at glance of the interviewer's clinical experience. We also aimed to have a heterogeneous sample and thereby different perspectives on the LCM: Case managers were asked to recruit patients with variable experiences in the use of the LCM. Final selection resulted in 14 participants who met the inclusion criteria and had different attitudes towards the LCM as outlined in Table 1.

Patients from the first author's own caseload or patients seen by her in times of crises where excluded from the sample in order to prevent any bias. All of the participants were interviewed at the outpatient clinic with the exception of two who were interviewed in their homes.

Table 1: Variation in study population

Participant	Sex	Age	Diagnosis (set in)	Working with LCM	Attitude towards LCM
R. 1	W	46	Bipolar I, 2008	2 year, sometimes	+
R. 2	W	58	Bipolar I, 2010	1 year, not anymore	-
R. 3	W	28	Bipolar I, 2007	1,5 year, sometimes	+
R. 4	M	23	Bipolar II, 2011	6 months, continuously	+
R. 5	M	45	Bipolar I, 2010	2 months, not anymore	+/-
R. 6	W	36	Bipolar I, 2002	2 months, continuously	+
R. 7	W	55	Bipolar I, 2006	4 months, continuously	+/-
R. 8	M	60	Bipolar I, 2009	3 years, continuously	+
R. 9	M	49	Bipolar I, 2006	3 years, sometimes	+/-
R. 10	W	21	Bipolar I, 2010	8 months, sometimes	+
R. 11	M	51	Bipolar I, 2006	never	-
R. 12	W	56	Bipolar I, 2005	3 years, sometimes	+/-
R. 13	M	30	Bipolar I, 2010	5 months, 1 x per 2,3 weeks	+/-
R. 14	M	23	Bipolar I, 2010	1 months, not anymore	-

Data collection

Individual, unstructured, in-depth interviews were conducted with all participants. The interviewer started every interview with the opening question: “Can you tell me about your experiences with working with the LCM?” The interviewer tried to create a sphere of trust that allowed the patient to speak freely. This open interview technique is well-suited for gaining insight in personal experiences (Evers, 2007).

All of the interviews were conducted by the same interviewer, audio taped, and transcribed verbatim. Prior to the start of the interview process, two pilot interviews were held with patients from the interviewer’s own caseload. The interviewer used a checklist of interview techniques such as introduction, formulation of questions, probing, use of non-verbal responses and the interviewers’ attitude to reflect upon, to guide the first eight interviews (Groenewald, 2004). Revisions in the interview guide were discussed with peers during the interviews until saturation of topics was reached. All participants received a summary of their interview and asked to check the interviewer’s interpretation on recognizability, i.e. a confirmation that the essence of what the respondent meant to say during the interview was interpreted correctly by the interviewer. Three of the 14 participants confirmed the findings; non-response by the other 11 participants was considered as confirmation that the interpretation was accurate. After 10 interviews, virtually no new information was added to what was already known. Saturation of information about attitudes towards the LCM was attained at the twelfth interview; two additional interviews were held to confirm saturation.

Data analysis

In qualitative research, gathering and analysis of data are intertwined. Analyses of available data shaped the interview guide used in subsequent interviews until saturation of themes was reached. The objective of the phenomenological method was gaining rigor in the inductively collected data, by reading and re-reading each transcript before coding the responses of the interviewee.

Every interview was transcribed verbatim, and the experiences with regard to the LCM were analyzed from the perspective of the respondent. Open coding was done by the interviewer and two peers. The interview transcripts were divided into fragments and labeled independently of each other. Fragments of text concerned with the experiences of the patients and an audit trail of memos during the interview and the analysis provided in-depth insight into the value of the LCM for the patients useful for further coding. Premature coding was avoided by formulating tentative interpretations for checking and discussion by the interviewer and peers. Peer debriefing was used to create consensus on the coded fragments. Experiences that were explicitly mentioned by a patient were marked as so called in vivo codes, i.e. the code had the same term as actually said by the respondent (Boeije, 2005). This information played an important role in the coding and interpretation of the data. The concepts revealed during the coding procedure were linked to existing literature, creating density in the conceptual meaning through a ‘thick description’ of phenomena.

FINDINGS

The coded fragments were reduced to four interrelated categories that described the general attitude of patients with BD in working with the LCM following a chronological order that represents an authentic process of how patients are taught to work with the LCM in actual clinical practice; introduction of the instrument, using the instrument, the role of the professional in working with the instrument and the perceived utility of the instrument.

Experiences with the introduction of the LCM

Different perceptions emerged when the patients were asked about what they thought and felt when the LCM was first introduced. Some participants stated that the introduction of the LCM came too soon within the process of accepting a diagnosis of BD. Being in denial made it virtually impossible to motivate yourself to use the LCM.

> “[…] She [the nurse] handed over the life chart… exactly at a time when I was just thinking things over....‘what do you mean…by me, being diagnosed with BD!?’ You know, I'm definitely NOT going to use...that! [LCM]” (Resp.13)

The data clearly show that using the LCM is influenced at least in part by the stage of grief and recovery. Five of the 14 participants indicated that they were not ready for the introduction of the

LCM. Respondents explicitly pointed out that therapists should consider their client's stage of grief as opposed to simply introducing the LCM immediately following determination of the diagnosis.

"No. I wasn't quite ready for it, I think. I had already received so much information. I had so many things to think over, and my mind wasn't in the right mode to register my mood in that booklet. And to do that all over again the next day, every day! [...] I still hadn't reached that stage in my process of grieving, you know […]" (Resp.1)

The analyses of the interviews made it clear that working with the LCM has to be the patient's own choice. The patients in general stated that being forced to fill in the LCM led to non-adherence of therapeutic goals and they explicitly wanted to be able to decide for themselves on whether or not using the LCM, and how to realize this in daily live.

"[…] eventually I made a clear choice… okay, I'm going to fill in this booklet… I had some thoughts and decided what was important enough to write down, you know, to do it my own way. So, it's not as if you have to do it in one particular way. It's mainly, what I… what do I want to see, what do I want others to see. […] If you have second thoughts about something you have to do, you might honestly say, you'll end up not doing it." (Resp.4)

People who already kept a diary or had plans to do so thought more positively about the LCM. In sum, motivation appeared to play a critical role in deciding to use the LCM or not. Patients found it hard to work on something that they couldn't "feel." They had doubts about what goals to set and which strategy to follow. Despite being given guidelines and the therapist emphasizing the importance of using the LCM, patients seemed they had to convince themselves before they could show commitment.

"If you don't accept having the disease, you won't notice the booklet at all and you won't acknowledge its utility. Then it just lies there somewhere. At that point you're probably still in the middle of a grieving process. Acceptance is very important!" (Resp. 6)

Experiences with using the LCM

Just as the introduction of the LCM, using it on a daily basis elicited many different emotions; almost all of the patients in our study indicated that use of the LCM had a major impact on them. A recurring keyword was "confrontation": a daily confrontation with the illness and the limitations that the illness entails.

"It wasn't the design of the instrument; no… it was purely and only, the confrontation. Writing down how you feel, every day […].I found it very confronting and sometimes it still feels that way." (Resp. 1)

The patients' reactions to the confrontation that they experienced in connection with the LCM varied widely and appeared to relate to their individual characteristics and coping styles. Six of the 14 participants indicated that the confrontation with their limitations made them feel worse and increased resistance in using the LCM.

"Yes, yes. Maybe I'm just worried that filling in the booklet triggers something inside me. It sounds weird, […], I know, being fixated on…on my depression. By writing down how depressed I feel every time, I get preoccupied with all these other feelings, what else do I feel besides depressed? You know? And maybe, I realize that I'm strongly opposed to it. Maybe I really don't want to know about it in the end! By knowing about it and listening to it, it only feels worse! " (Resp. 2)

Some of the participants nevertheless mentioned that the confrontation raised their awareness and increased their motivation to make behavioral changes. Knowledge, understanding, and awareness all play an important role in the use of the LCM, and 6 of the 14 participants in our study reported that they first had to reach rock bottom (i.e., experience a depressive episode) before they finally sought help and decided to try the LCM. An important precondition for working with the LCM and completing the forms on a daily basis is having insight into your disease.

"Yes. I found it very difficult. What is a manic episode? And is it possible to be a little manic or a lot? And then I even had to give this feeling a number, you know! I found that extremely difficult! Is it a one or a two? And what is the difference between a one and a two? For instance, does the nurse use the same criteria for a zero as I do? What is my zero? Do you get what I'm trying to say? (Resp. 5)

On the other hand, "working with the LCM" was considered a precondition by some patients for increased disease awareness. According to some, filling in the daily mood chart made it clear that there was really something going on with their mood. Nevertheless, illness awareness and the individual course of the emotions evoked by use of the LCM did not prevent some respondents from using the LCM occasionally and not on a daily basis. These patients completed the LCM at times when they felt good or at times when the use of the LCM could be expected to help them. The patients could, for example, use the LCM when experiencing an unstable mood, to recover from a major depressive episode, to evaluate the effect of a lifestyle change, or to monitor treatment response. One factor that played an important role in complying with the use of the LCM was, not wanting to always be reminded of one's illness.

"Yes. It, it might make you behave or feel sicker than you actually are because you're diagnosed with a chronic illness that can preoccupy your mind on almost every day. Occasionally, it's very good to get some distance from the booklet...having this disease, I think ...and try to live an ordinary life." (Resp. 13)

The frequency of using the LCM varied widely among the patients who completed it. Some used it occasionally; some used it on a daily basis. Some reused the LCM during particular episodes; some used it at the recommendation of their therapist to monitor unstable mood; and some used it to monitor treatment results.

The general opinion of the interviewees was that the scoring of a specific mood state was difficult and that the LCM lacked "reference points." Stated differently, the graph was perceived as too general and not sufficiently reflecting one's personal situation or personal concerns. The general complaint was that the LMC is not "custom made." Ease of use was also mentioned as being important with a call for a digital version of the LCM for use on the computer or smartphone among the participants' wishes.

The recurrence of a manic or depressive episode also influenced the use of the LCM. Some respondents stated that during a depressive episode they weren't able to motivate themselves and during a manic episode they didn't feel the need to work with the LCM. In contrast, some respondents said that filling in the life chart and seeing the graphed results right before their eyes was very helpful during an episode of depression. In addition, external motivational factors were reported by some to encourage working with the LCM. These included responsibilities towards family such as children and partners. Almost none of the respondents with family completed or discussed the LCM together with their loved ones, however. The LCM was only shared with the therapist and kept away from others. Nevertheless, the LCM was occasionally used to start a conversation with the partner and thereby indicate that things were not going well.

"I'm not keeping a secret, but the booklet is my personal property." (Resp. 8)

Patients sometimes did not talk about the LCM because the life chart was regarded as a private diary, they did not want to burden their families, or they did not want to be perceived as ill.

"I don't share it with other people, no.…Because, um, I prefer that my mother is my mother and my brother is my brother. They are my family and not my care providers. Sometimes there is friction which puts our relationship under pressure. It bothers me, for instance, when I feel good, more stable, or in an euthymic phase, they still treat me like someone who is depressed…Obviously, they have some difficulties seeing things right, and their intentions are good, but it still bothers me that they treat me like a patient…My friends, they know about it. But I hardly mention it and they don't ask about it....I like that, especially because it allows me to do the things I want to do at that particular moment, which is, not think about it too much." (Resp. 13)

Respondents experiences with professionals in working with the LCM

The respondents frequently mentioned that the professional did not seem to be aware of the impact of a diagnosis of BD for the patient. Professionals must keep in mind that the moment of introducing the LCM can be very delicate. Times from diagnosis, knowledge of the disorder, and sensitivity to the implications of the diagnosis for the patient's life were all cited by respondents as factors to consider in choosing the right moment to introduce the LCM.

Patients also reported difficulties connecting to their feelings and recording these on the life chart; more detailed guidance from the professionals was therefore mentioned as a necessity.

"I would like you to ask, before we start working with the life chart… Give me a good explanation, some good instructions! This is crucial! Because… I've received the booklet with the remark: 'Just start with it, give it a try.' No, no, that isn't how it works! […] How often and in what way do I need to fill in that booklet? Please, take some time to explain it to me before I start using it! (Resp.5)

The LCM was often mentioned by respondents as a tool for getting into a conversation with the professional about how the recent period has gone. Discussion of the LCM with the professional provided more insight in the respondents' daily mood and the respondents mentioned learning to recognize early warning signs of recurrence as a result of this discussion. The discussion of the life chart provided an overview of the course of the disease and thereby something for the respondent to take action on.

The respondents nevertheless experienced the role of the professional differently. Some participants found it convenient to have the clinician take a look at the life chart. Others experienced the professional looking at the life chart as a means of control; as a means of "checking" something that was more or less imposed on the participant; as judgmental. And some of the respondents mentioned that they gave the life chart a try in order to please the therapist; they would otherwise felt guilty for not exerting every effort to get well despite all efforts of the professional.

"Well, that I, umm, how should I put it? Um, […] I don't want to leave the impression that I'm not willing to work towards my recovery. Because that isn't what this is about." (Resp. 3)

The perceived utility of the instrument

Almost all of the participants underlined the added value of the instrument for treatment, even when they had not yet experienced it themselves. Probably because it is a well-known instrument and almost every patient with BD might have heard about it at some time during treatment. Despite difficulties in working with the LCM and even stopping with its use at times, many positive aspects were mentioned during the interviews: greater understanding of one's own mood, better overview of disease course, additional guidance and structure, signaling function, mnemonic to warning signals and things for preventive action, tool for dialogue with the therapist, and stimulant for behavior change.

Two of the three respondents who quit working with the LCM indicated that they had done so because they couldn't see the added value for themselves. It is important that the LCM must be customized to the individual needs of the patient. And the patient must be helped to determine reference points for themselves. Respondents commented on the impersonal character of the instrument: "I'm not this booklet" or "A piece of paper doesn't feel anything." When participants worked to personalize the LCM, this appeared to increase their motivation to use it and their perceptions of its value.

One of the respondents indicated that sometimes recovery expectations — which may or may not have been unrealistic to start with — were undermined by the unpleasantness of working with the LCM. Although statements made were reformulated by the therapist later on, the aftermath was that an unpleasant feeling of false hope, being cured from a chronic illness, remained.

> "Everything will be all right, I'll get healthy again. Yes, I thought if I do what they tell me to, if only I use this booklet, take my medicine, visit my therapist on a regular basis, then […] umm, then my mood will stabilize." (Resp. 2)

Finally, the patients noted that clinicians should avoid reliance on only patients' judgments of their mood and functioning and therefore include the judgments of relatives as well. Particularly when an episode of mania or hypomania is emerging, participants experienced the limitations of the LCM as a self-assessment tool and that are therefore needed the backup of relatives and others.

DISCUSSION

The results of our study of the use of the LCM by 14 patients with BD show that patients experience its use differently but acknowledge the potential value of the instrument in supporting their recovery. While the patients *knew* that commitment to the use of the LCM was needed to contribute to their self-management skills and personal recovery, this knowledge did not necessarily correspond to its use of the LCM. It is clear that use of the LCM entails more than simply completing the daily record. Use of the LCM evokes emotions related to having to cope with a chronic and often unpredictable psychiatric illness. The use of the LCM touches upon one's identity, which has been threatened by the loss of the "healthy self." These findings are consistent with recovery oriented literature for persons with chronic mental illnesses. Buck, et al. (2013) for instance, stated that one of the challenges of professionals working with persons with schizophrenia is acknowledging a patients' grief of the loss of one's self. Although schizophrenia has different features than bipolar disorder we have found some similarities, such as loss of control (to manage mood and activities) and loss of the meaning of one's own live. Our findings show that in general the LCM is a helpful tool for patients in reconstructing their life, providing meaning to previous episodes and regaining control.

The results of our research show that professionals should acknowledge and recognize the impact of being diagnosed with BD on the individual patient's life. Further, the process of coping with the disease and its symptoms must be considered when working with an individual patient and the LCM by tuning into the story of each patient. This is consistent with the so-called attendance approach, which states that professionals must listen to and join patients in their recovery process (Baart, 2002). Professionals must dare to let go of guidelines and interventions when a more individualized approach is called for. The professional should then, at least temporarily, focus on the patient and how they are dealing with the situation at the moment.

Among the factors found to influence the use of the LCM was the degree of “customization.” This relates — at least in part — to the professional and their attitudes towards working with the LCM. Standardization of care was repeatedly mentioned in the stories of the patients we interviewed. Introducing the instrument at the beginning of treatment without consideration of the patient’s grieving process (Kübler-Ross & Kessler, 2005) was repeatedly mentioned as a possibly limiting factor. Patients indicate that they should acquire a certain degree of acceptance and disease comprehension before the LCM can be put to use. Acceptance of the disorder (by the patient) and recognition of the consequences of the disorder for the patient (by the professional) should be occurred before the LCM can provide a deeper insight into the emotions of the patient. The phase of mourning and recovery from a mood episode represents important motivational or obstructive information that is individually determined.

Customizing the LCM and thereby allowing it to relate to the needs and coping styles of individual patients can maximize coping and self-management although some patients still feel that the LCM does not sufficiently capture their desires, needs, and possibilities. They feel that their self-management ability is limited as opposed to enhanced by working with the LCM. Clearly the use of the LCM alone is not enough to manage one’s own illness; it has to be considered as one of the instruments with an adding value in the treatment of BD.

One of the keywords that stood out during several interviews was “confrontation.” Some respondents wanted to avoid confrontation with their health problems while others needed exactly this in order to learn to cope more actively with the disorder. In other research, Goossens, Knoppert-van der Klein, and van Achterberg (2008c) found patients with BD to often have a more avoidant than active style of coping when compared to other people in the general population. Seven of the 14 patients in the present study showed an active attitude towards the development of strategies to stay well and avoid relapse into depression, hypo-mania, or mania by also working with the LCM. Others deliberately opted not to do this because they could not see how using the LCM could help them cope with BD. They do not see their reaction as avoidant, moreover.

“Leading my life in such a manner that the disorder is not an ever-present factor ruling my life.”(Resp.13)

The question is to what extent this style of coping can be considered inadequate. Patients who consciously choose to not work with the LCM because they do not see the value of doing this are entitled to their decision. And it is possible that using the LCM can make patients feel worse at times. It can be counterproductive when the professional still urges a patient to work with the LCM under such circumstances.

In addition to the phase of mourning and recovery, the mood episode can also play a role in the decision to use or not use the LCM. Both a depressive episode and manic episode can be a demotivating factor for using a tool like the LCM. Patients in an euthymic phase sometimes found it difficult to maintain charting because of a loss of interest and lack of urgency. Daily use of the LCM during a manic episode was also felt to be useless by many of the patients in our study, which confirms the findings of the study of Pollack(1996).

The respondents in our study questioned the reliability of their completion of the LCM at times and particularly the reported seriousness of their symptoms and the limitations on their functioning. They implied that the professional should not always rely on input from the patient alone, particularly during an episode as one’s ability to look at their self can be limited and therefore limiting the LCM as a self-assessment tool. Lysaker, et al. (2002) showed that patients might not be aware of their symptoms and a patient's story might be incoherent with actual history due to cognitive impairments. Metacognitive impairments such as a low capacity of being self-reflective are found in patients with schizophrenia (Lysaker, et. al., 2010) and might be similar to the difficulties patients with BD experienced when reflecting on a previous manic episode. These findings are consistent with the lack of insight that is found in bipolar patients with lifetime psychotic features and cognitive impairments (van der Werf-Eldering, et al., 2011). The findings of the study of van der Werf-Eldering, et al. (2011) clearly showed that better insight is associated with lower processing speed, better memory performance, increased emotional learning, higher level of depressive symptoms, and longer duration of illness. The retrospective LCM has showed to be a useful instrument for guiding a patient's personal narratives through the reconstruction of previous episodes of acute mania by filling the lacunae in memory, whereas reconstructive use of the LCM during euthymic or mild depressive episodes might actually increase insight through self-reflection.

Sometimes patients did not complete their life charts with full honesty because they feared there might be negative consequences such as a hospital admission, that don't reflect their personal needs and ideas of that time. It was further noted that patients sometimes complete the LCM retrospectively, which raises questions about the reliability of their reporting. Some respondents expressed their concern that one might be judged negatively for *not* completing the life chart. Consistent with, what Urquhart (1991) called the 'parking lot effect' some respondents reported completion of the LCM before meeting with the therapist in order to claim that they had done their homework whilst the chart was completed in retrospect which decreased the reliability of the measurements.

Relatives play a limited role in the use of the LCM. The majority of respondents do not share information from or about the LCM with relatives in order to protect them, in order to not feel like a patient all the time, or in order not to burden their relatives (van der Voort, Goossens, & van der Bijl, 2009). Others report working with the LCM out of a sense of responsibility towards their relatives and a sense that they must undertake all effort to prevent a relapse. Professionals and relatives might otherwise judge them as uncommitted to getting well.

Scope and limitations of the study

The present study is a qualitative study with a relatively small number of participants. Almost all of the respondents were diagnosed with a BD, type I, therefore statements following from this study is limited to this specific patient category.

Despite these shortcomings, we have shed light on the variability of the experiences of patients working with the LCM and been able to provide insight into the initiation and use of the LCM by care providers. Future research should aim to include an equal number of patients diagnosed with BD, type II, and thereby provide insight into the generalizability of the phenomena found in the present study.

Conclusion and recommendations for future practice

We conclude that both patient and professional must recognize the consequences of BD for the individual patient, the implications of the stage of mourning or recovery, and the mood episode as important impeding and motivational factors for use of the LCM. Professionals ought to reconsider whether or not strict adherence to guidelines and recommendations is appropriate in individual cases. Professional care providers should listen to the stories of their patients more often to gain insight into the significance of the experiences of a patient.

Further attention should be paid to pressure to use the LCM as a self-assessment instrument and when this may be counterproductive. Instead of requiring use, we suggest that possibilities to personalize the LCM be explored and methods to customize the tool to the needs and desires of the individual patient be explored. Such customization and personalization can maximize motivation. And the introduction of a digital version of the LCM might also better fulfill the needs of some patients. The participants in our study asked for greater explanation of how to complete the life chart and support from a professional while working with the LCM.

Finally, the LCM is a self-assessment tool and should be regarded as such. Professionals should constantly be aware of the possibility of distortion of the mood state of the patient or responding in a socially-desirable as opposed to therapeutic manner. The results of our research show that professionals should recognize the course of coping with, and impact of a diagnosis of, BD on the individual patient’s life by personalizing and tailoring working with the LCM. Despite the marked variability in perceptions and willingness to work with the LCM, in general the attitude towards this instrument was the recognized value of using the LCM. But the emotional impact of daily mood charting was experienced as a substantial burden, particularly during the early stages of diagnosis and need to be taken in account, especially when the instrument was introduced for the first time to a patient.

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Chapter 3

The user experiences and clinical outcomes of an online personal health record to support self-management of bipolar disorder: A pretest-posttest pilot study.

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ABSTRACT

Background: Self-management comprises knowledge, behavior, activities and resources providing people with bipolar disorder (BD) control over fluctuating mood and activity-patterns. The 'Self-management and Dialogue in Bipolar Disorder' project entailed the tailoring of an online personal health record (PHR) originally designed for the chronically ill to monitor condition and share information with their clinician to people with BD (PHR-BD). The aim of this study was to evaluate the feasibility, utility and user-experiences of participants with BD, relatives, and healthcare professionals who worked with the PHR-BD.

Methods: Post-test online closed- and open-ended questionnaires were used to collect information on utility, and user-experiences with PHR-BD. A pre-posttest design to evaluate clinical effects on quality of life, empowerment, symptom reduction, changes in mood and activity, and illness burden and severity at baseline and at 12-months follow-up.

Results: Sixty-six participants with BD logged in at baseline. At study endpoint thirty-nine participants with BD, eleven professionals and one family caregiver filled out the evaluations. No significant differences in the clinical outcomes from baseline were found. Qualitative evaluations showed a frequent utility of the mood chart modules, improved communication between clinician and participant with BD and, increased insight in influencing factors of mood fluctuations.

Limitations: Small convenience sample, no controls.

Conclusions: The option to alternate the interface from a prospective to a retrospective mood chart , and integration with the personal crisis plan was considered to be of added value in self-managing BD. The findings of this study will guide the future implementation of the PHR-BD.

INTRODUCTION

Bipolar disorder (BD) is a chronic illness characterized by recurrent depressive, manic, hypomanic, or mixed episodes (American Psychiatric Association, 2013). The primary goal of treatment in the acute phase of a manic or depressive episode is symptom reduction, predominantly by pharmacological and behavioral intervention. Subsequently, the focus of treatment shifts toward functional recovery and maintenance pharmacotherapy for relapse prevention (Rosa et al., 2010; Vazquez et al., 2011). Since BD is predominantly treated on an outpatient basis, people with BD and their informal caregivers have to recognize and manage early symptoms to gain control over mood fluctuations (Crowe et al., 2010; Kupka et al., 2015; Robb et al., 1997). Self-management refers to self-induced interventions of actively involved people with BD and informal caregivers to overcome the negative consequences of living with a chronic condition and to maintain a satisfactory quality of life (Barlow et al., 2002; Lorig & Holman, 2003; Pollack et al., 1996).

Adequate self-management of a chronic illness is associated with improved outcomes and reduced costs of healthcare (Newman et al., 2004). Several self-management interventions improve functional and therapeutic outcomes of BD (Janney et al., 2014; Jones, et al., 2011; Siantz et al., 2014). A recent study shows that self-management of BD induces patient empowerment by increasing self-determination, lessen the dependence of healthcare professionals, and evoking a sense of control over symptoms (Morton et al., 2018). Psychoeducation reduces the number of recurrences by enhancing knowledge about the course of the illness (Colom et al., 2003; Colom & Lam, 2005; Reinares et al., 2016), the benefits of therapeutic alliances, and medication adherence (Lam et al., 2009). Meanwhile, structuring circadian rhythms and sleep-wake cycles is the main focus of interpersonal and social rhythm therapy (Frank et al., 2000; Frank et al., 2005).

Alongside patient education, self-management of BD entails the recognition of prodromal symptoms and early reaction to counteract (hypo-) manic and depressive episodes (Daggenvoorde et al., 2013; Goossens et al., 2010). The retrospective and prospective Life Chart Methodology (LCM) can be used to monitor and reconstruct the individual course of mood and activity (Denicoff et al., 2000; Honig et al., 2001; Post et al., 2003). Van Bendegem et al. (2014) found that people with BD favored a digital Life Chart over a paper version because they believed that a present-day instrument would increase the usage of the LCM and, therefore, enhance self-management of BD.

Recent technological developments in eHealth promise to connect separate interventions through a single coherent system, thereby enhancing patient self-management, but evidence of the feasibility and the effectiveness of online applications for BD is still sparse (Hidalgo-Mazzei et al., 2015; Karasouli & Adams, 2014). As a result of technological developments and use of mobile technology the needs for online self-management of BD possibilities (mHealth) such as, applications for daily mood monitoring, quick response on prodromal symptoms, and rapid communication via voice over internet protocol (VoIP) or message functions to counteract upcoming episodes at an early stage, are largely unmet (Nicholas, Boydell, & Christensen, 2017; Schwartz et. al., 2016). However, although the possibilities of mHealth are numerous and diverse, it does not provide the coherence of more programmatic self-management (eHealth) approaches for people with BD (Gliddon et, al., 2017; Naslund et al., 2016).

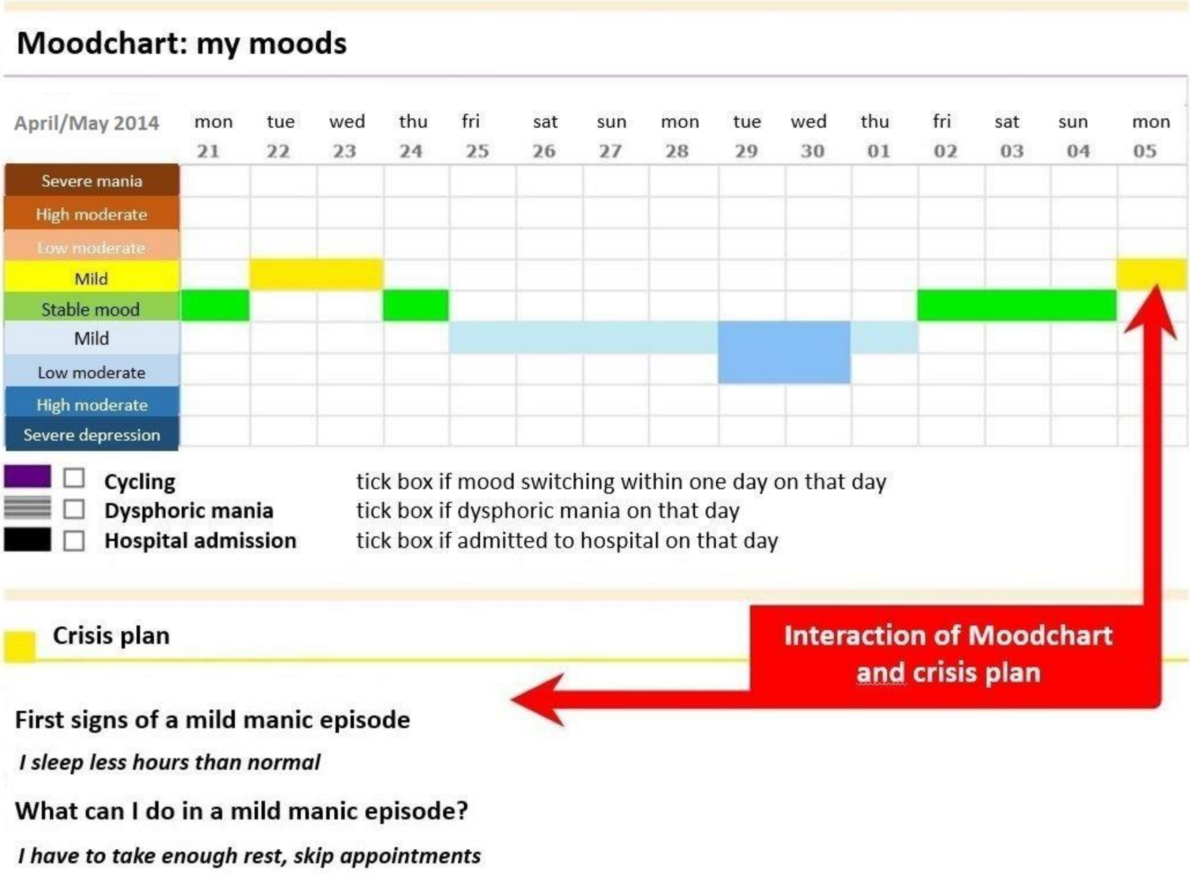
To address the need for a coherent eHealth program to enhance self-management of BD, the Self-management and Dialogue pilot project was developed by a collaboration between the Dutch patient association for BD, clinicians, and informal caregivers. It was an online personal health record (PHR) originally designed for chronically ill persons with BD to monitor changes in their condition and share information with their clinician and, through this project, it was tailored to bipolar disorder (PHR-BD).

The primary objective of this study was to test the feasibility of the PHR-BD and to evaluate the user experiences of persons with BD, involved informal caregivers, and clinicians (Craig et al., 2013). The secondary objective was to examine changes in quality of life, empowerment, symptom reduction, changes in mood and activity, and illness burden and severity.

METHOD

Materials and methods

The standard PHR interface includes four modules: medical record (condition, operations, in case of emergency, clinical measurements, reports, and collaborating clinicians), medication, treatment, and medical passport. For the modified PHR-BD, five additional modules were designed: 1) general information about the features of BD, protocols and the Dutch multidisciplinary guidelines for BD (Kupka et al., 2015), 2) laboratory results and reports, 3) a personal messages module to communicate with the appointed clinician, and 4) a mood chart on which the participant with BD filled out their current daily mood with a hyperlink to 5) a personal crisis plan (Daggenvoorde et al., 2013), as well as a mood graph interface that displayed the fluctuations in mood over a period of time as based on the retrospective and prospective Life Chart (Denicoff et al., 2002; Honig et al., 2001). The interaction between the mood chart and crisis plan is displayed in figure 1. The mood graph interface is illustrated in figure 2.



Moodchart: my moods

April/May 2014	mon 21	tue 22	wed 23	thu 24	fri 25	sat 26	sun 27	mon 28	tue 29	wed 30	thu 01	fri 02	sat 03	sun 04	mon 05
Severe mania															
High moderate															
Low moderate															
Mild		🟨	🟨												🟨
Stable mood	🟩			🟩								🟩	🟩	🟩	
Mild					🟦	🟦	🟦	🟦	🟦	🟦	🟦				
Low moderate									🟦	🟦					
High moderate															
Severe depression															

■ ☐ **Cycling** tick box if mood switching within one day on that day
▤ ☐ **Dysphoric mania** tick box if dysphoric mania on that day
■ ☐ **Hospital admission** tick box if admitted to hospital on that day

Crisis plan

Interaction of Moodchart and crisis plan

First signs of a mild manic episode

I sleep less hours than normal

What can I do in a mild manic episode?

I have to take enough rest, skip appointments

Figure 1. Mood chart and crisis plan interaction.

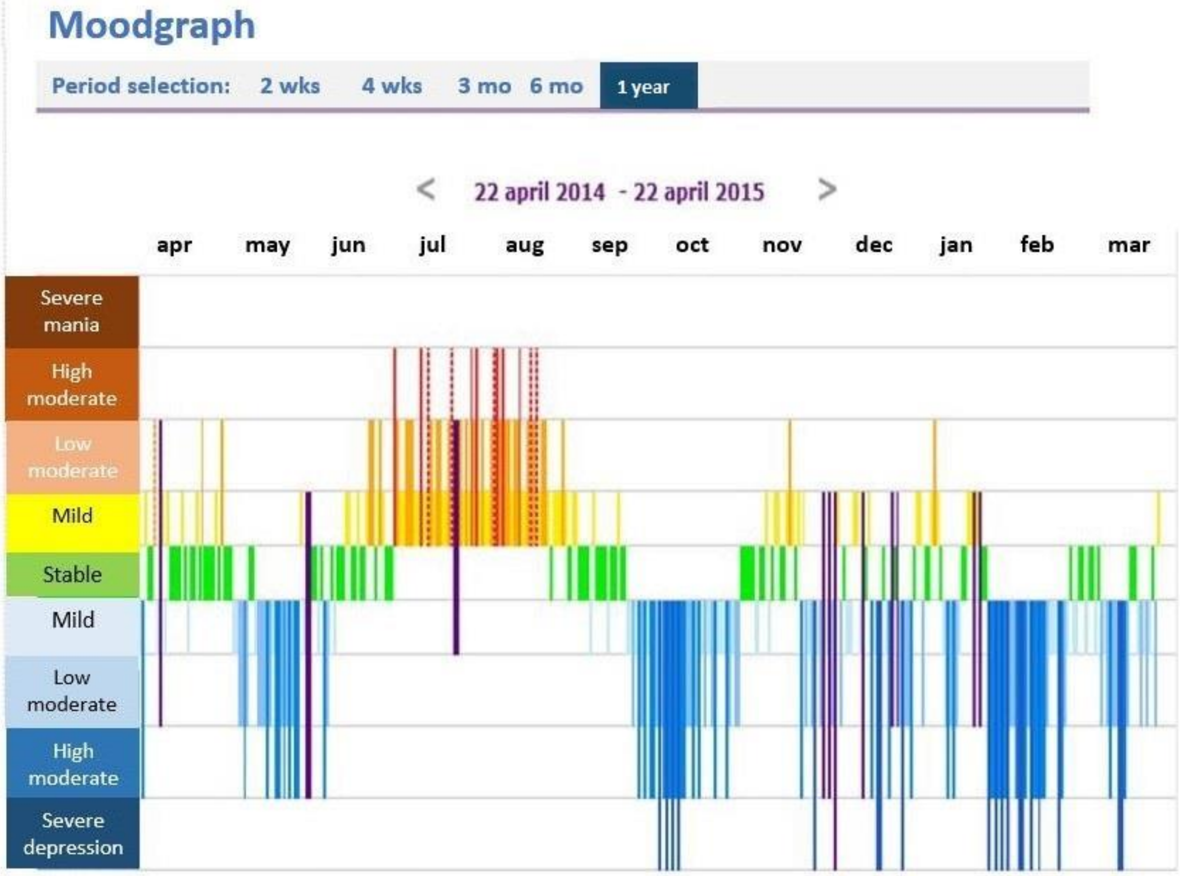


Figure 2. Mood graph interface.

Research design

To test the feasibility of the PHR-BD, we used a non-randomized, non-controlled, pretest-posttest pilot design with post-test online closed- and open ended questionnaires on user experiences.

Participants

Seventy-five potential candidates with BD, and eleven appointed clinicians (e.g., psychiatrists, advanced nurse practitioners, and community psychiatric nurses) from three specialized outpatient treatment facilities for BD in the Netherlands were asked to participate in this study. At baseline, sixty-six potential candidates with BD and eleven clinicians agreed to participate in this study. The inclusion criteria were as follows: (a) 18 years of age or older, (b) a diagnosis of bipolar disorder I (BD I) or bipolar disorder II (BD II) according to DSM-IV-TR criteria (American Psychiatric Association, 2000), (c) an illness history of three or more recurrent (hypo-) manic or depressive episodes, at least one of which occurred in the past 12 months, (d) receiving outpatient treatment for at least six months prior to participating in the study and visiting the clinic at least once in six weeks, (e) speaking and understanding the Dutch language, (f) having basic computer skills and access to a personal computer or laptop with email and internet, and (g) willing to use the PHR-BD for a 12-month period. Participants with BD in a current and severe major depressive or manic episode (CGI-

BP ≥6) were excluded. The Clinical Global Impression - Bipolar Version scale (CGI-BP) on a seven-point Likert scale (Spearing et al., 1997) was used by the clinician to evaluate the severity of manic and depressive symptoms at every face-to-face contact.

Ethical approval

The study was approved by the Medical Ethics Committee of the VU University Medical Center, Amsterdam, Netherlands. All participants gave written informed consent.

Procedure

The clinicians from collaborating institutes screened their caseloads for potential participants. These were informed about the procedure and aim of the study by their appointed clinician before consent was reached. The study started with participants with BD updating their crisis plan, medication list, retrospective Life Chart, and filling out self-rating questionnaires before accessing the PHR-BD. After the first measurements, participants with BD logged in and used the PHR-BD for 12 months consecutive next to treatment as usual (TAU) during the period of January 2014 to July 2015. Considered to be the main user and according the principles of self-management the participants with BD could choose whether or not they granted access to informal caregivers. Thus, involvement of informal caregiver in this study was based on a convenience sample. The utility of modules and login frequencies were monitored during the time of participating in the study.

Measurements of the user experiences with the PHR-BD

Online closed- and open ended questionnaires were used to evaluate the user experiences of participants with BD, informal caregivers and clinicians post-intervention. The online closed-ended questions captured themes such as: frequency of login and utility of modules, past use of instruments on paper, insight on symptoms, activity and mood, communication with clinician, opinions about the email-alert function, granting access to significant others, and an overall judgement of the PHR-BD. In the online open-ended questions all participants had the opportunity to elaborate their opinions for choosing a particular answer in the online closed-ended questions and were asked to suggest future applications of the PHR-BD.

Clinical measurements

An adapted Dutch version of the Questionnaire for Bipolar Illness (QBP-NL), divided in parts A (clinician) and B (patient), was used at baseline to collect sociodemographic data, illness history (including age of onset, duration of illness, number of episodes, and hospitalizations), medication use, comorbid substance abuse, and family history of psychiatric disorders (Leverich et al., 2001; Suppes et al., 2001). Pre- and post-intervention participants with BD filled out the 45-item Outcome Questionnaire (OQ-45.2) on a five-point Likert scale to measure general psychological functioning over four dimensions: psychological symptomology, interpersonal relationships, social functioning, and both fear and somatic symptomatology (Lambert et al., 2001; Lambert et al., 2004). The symptomatology of manic episodes was measured with the Altman Self-Rating Mania Scale (ASRM) on five items (Altman et al., 1997). The severity of depressive symptoms was measured by the 30-

items Inventory of Depressive Symptomatology Self-Rating Scale (IDS-SR) on a four-point Likert scale (Rush et al., 1996). The Manchester Short Assessment of Quality of Life (MANSA) was used to measure quality of life over 16 items on a seven-point Likert scale (Priebe et al., 1999). Empowerment was assessed by the 40-item Dutch questionnaire on patient empowerment (NEL) on a five-point Likert scale (Boevink et al., 2008).

Statistical analysis

Analyses were carried out with IBM SPSS 22 for Windows. Descriptive statistics were used to analyze the frequency of login and module utility. The data collected post-intervention from the online closed-ended questionnaires were analyzed in crosstabs. The data from the online open-ended questionnaires were categorized by two analysts into thematically related opinions and future recommendations of participants per utilized module. Paired t-tests were used to detect effects in clinical outcomes pre- and post-test with a significance level of $p \leq 0.05$.

RESULTS

Sociodemographic characteristics of the participants with BD

Sixty-six participants with BD logged-in on the PHR-BD at baseline (T0) and had a mean age of 45.2 (±10.7) years, were predominantly female (66.7 %), and were diagnosed with BD I (76.7%). At the study's endpoint, a total of 39 participants with BD (M = 47.2 (±9.6) years of age, 59% female, and 76% diagnosed with BD I) filled out the evaluations and the online closed- and open ended questionnaires. Sociodemographic characteristics are shown in table 1.

Table 1. Sociodemographic characteristics

Group (mean ±SD)	**T0 (n=66)**	**T1 (n=39)**
Age (years)	45.17 (±10.67)	47.17 (±9.57)
Gender (% female)	66.7	59
Educational level (%)		
Elementary education	1.5	--
Lower vocational education	9.1	10.3
Intermediate vocational education	22.7	17.9
Higher vocational education;	37.9	41.0
University	22.7	23.1
Post-doctoral education	6.1	7.7
Marital status (% in relationship)	60.6	59
Employment (% unemployed)	31.8	33.3
Diagnosed (% BD I)	76.7	76

Utility of the participants with BD

Descriptive analyses indicate that the 66 participants with BD who had logged-in at baseline, utilized the PHR-BD a total of 5,962 times (M = 90.3, 0-1,385), or approximately one to two times a week, as presented in table 2. Overall, the mood chart module was utilized the most with 4,778 logins (M = 72.4, 0-538). The crisis plan (login = 326, M = 4.9, 0-242) and the mood graph interface (login = 160, M = 2.4, 0-53) were visited less.

Table 2. Login frequencies

Login	% (at T1, n=39)	% (drop-out, n=27)	Total % (n=66)
Never	---	7.4 (n=2)	3 (n=2)
Once	5.1 (n=2)	51.9 (n=14)	24.2 (n=16)
1-5 times a month	25.6 (n=10)	22.2 (n=6)	24.2 (n=16)
6-10 times a month	41 (n=16)	14.8 (n=4)	30.3 (n=20)
> twice a week	23.1 (n=9)	3.7 (n=1)	15.2 (n=10)
Daily	5.1 (n=2)	---	3 (n=2)

User experiences of the participants with BD

At the study's endpoint, 39 participants with BD filled out the questionnaires. Of all the modules, the mood chart (88.9%) and mood graph interface (66.7%) were used most. Half of all who responded (50%) used the crisis plan, messages module, and laboratory and reports module. The general information, guideline and protocol module was used the least (≤ 25%). The majority of the 39 participants with BD (84.6%) recommended use to others and reported continuing use after the study. The overall valued judgment (87%) of the PHR-BD was positive with a mean of 7.0 on a 0-10 scale.

The 39 participants with BD stated they gained more insight into their mood and activity fluctuations when they used the mood chart and graph (74.4%), monitored hours of sleep (71.8%), and detected prodromal symptoms (69.2%). They also stated that communication with the appointed clinician was more efficient (61.5%). Participants with BD reported that the PHR-BD improved insight into trigger events (61.5%), which resulted in an increased subjective feeling of control over mood swings and activities (53.9%). Approximately half (51.6%) of them preferred the online module above the previously used paper version of the Life Chart. Interestingly, only 23.1% found an informal caregiver's access to the PHR-BD preferable, while 25.6% found it to be adverse. Instead of caregiver involvement, 59% of the participants with BD found the possibility of an automatic notification of an impending episode, as detected by the mood chart, being sent to the appointed clinician to be preferable.

The informal caregiver experiences with the PHR-BD

Surprisingly, only one family caregiver was given access to the PHR-BD; she filled out the evaluations and participated in the online closed- and open ended questionnaires. Being granted access to the PHR-BD increased her insight in, the current mood, alcohol and drug usage, hours of sleep, trigger events of mood fluctuations, general psychological wellbeing, and medication adherence of the participant with BD. The informal caregiver believed that using the PHR-BD to self-manage BD helped her partner to increase control over his illness and live in general. The automatic connection between the LCM and crisis plan was not of added value to her as an informal caregiver, nor did she believe that the message module increased the responding time of the clinician and improved communication. Instead, in the future an email-alert function to the clinician when mood fluctuated was seen as more useful option. Her overall appreciation of the PHR-BD was a 3 on a 0-10 scale, largely because accessing and navigating the website could be better. A separate access code or user-interface for the informal caregiver to the PHR-BD was not found necessary, because access to the PHR-BD by her and her partner was based on mutual trust.

User experiences of the clinicians

Ten out of eleven clinicians (psychiatrists [n = 3], advanced nurse practitioners [n = 4], and community psychiatric nurses [n = 3]) utilized the PHR-BD to fill out questionnaires about their user experiences. The majority of clinicians (56.7%) used the PHR-BD regularly. The modules they visited the most were: the mood graph that displayed an adjustable overview of mood over a period of time (92.5%), general mental condition of the participants with BD (71.7%), the crisis plan to detect trigger events (67.9%), and the mood chart that displayed the current mood of the participants with BD (47.2%).

More than half of the clinicians (52.8%) reported that participants with BD who used the PHR-BD experienced increased control over mood swings (52.8%) and life in general (34%) and that they experienced increased positive attitudes toward the use of instruments to monitor mood and activity. For instance, nearly a quarter of the participants with BD (24.5%) who used the mood chart and graph modules did not use a paper version of the Life Chart before this study. Use of the PHR-BD increased the clinician's insight into mood and activity patterns (73.6%), sleep rhythms (69.9%), trigger events (60.3%), general psychological functioning (58.5%), medication adherence (66.1%), alcohol usage (43.3%), whether he did or did not respond to prodromal symptoms (37.8%), and what prodromal symptoms were specific for a particular participant with BD (35.9%).

Almost a third of the clinicians (32.1%) found that the communication between them and the participants with BD improved. However, they did not attribute this improvement solely to the messages module (71.7%). Opinions differed (26.4% in favor versus 26.4% not in favor, with a majority of 47.2% that was in doubt) as to whether or not participants with BD were persuaded by the PHR-BD to contact their clinician in case their mood changed significantly. There was similar disagreement about whether or not it would be preferable to develop an automatic email alert when mood changes occurred. Most (63.7%) found that this might increase rapid response. However, over a third of the clinicians (36.3%) disagreed. In their opinion, email alerts distorted open communication and decreased the responsibility of the participant with BD to get in contact for appropriate help; direct telephone contact was favored instead.

Most clinicians (69.8%) agreed that the PHR-BD enhances open communication with participants with BD'. However, opinions differed on whether informal caregivers should be granted open access to the PHR-BD. Some clinicians (28.3%) favored informal caregiver access to speed up rapid response, stimulate dialogue between partners, and increase informal caregiver involvement. Others (32.1%) disagreed because giving open access to informal caregivers might impair the privacy of the participant with BD', might be patronizing, and might complicate communication between partners about the illness at a premature stage. The rest (39.6%) did not have a fixed opinion on this matter.

Clinical outcomes

We found no statistically significant differences in quality of life, patient empowerment, general psychological features, symptom reduction, or illness burden in the 39 participants with BD at the study's endpoint when compared to the baseline. Clinical outcomes are presented in table 3.

Reasons for non-use and post hoc subgroup analyses

As a reminder during the study to fill out a questionnaire about the reasons for non-use, clinicians were alerted when participants with BD did not login to the PHR-BD for one month. Nevertheless, thirty-nine persons with BD remained in the study and did complete the questionnaires at study endpoint.

Table 3. Clinical outcomes at baseline (T0) and study endpoint (T1)

	Mean T0 (SD)	**Mean T1 (SD)**	***t***	**95% CI**	**P-value**
Quality of Life (MANSA)	58.97 (±10.7)	57.6 (±13.62)	.748	(-2.05 - 4.46)	.46
Empowerment (NEL)	142.71 (±15.35)	140.20 (±18.12)	.940	(-2.89 - 7.92)	.35
Severity of depressive symptoms (IDS-SR)	20.82 (±11,04)	22.21 (±13,00)	1.38	(-2.44 – 5.20)	.47
(hypo)manic symptomatology (ASRM)	1.92 (±3,04)	1.67 (±2,04)	.547	(-.64 - 1.16)	.57
General psychological features (OQ-45)	125.23 (±15.43)	124.33 (±15.94)	.423	(-3,39 - 5,19)	.67
Symptom severity mania (CGI-BD)	1.44 (±.87)	1.40 (±.82)	.196	(-.381 - .461)	.84
Symptom severity depression (CGI-BD)	1.88 (±1.01)	1.56 (±1.00)	1.554	(-.105 - .745)	.13
Symptom severity general BD (CGI-BD)	2.04 (±1.27)	1.88 (±1.27)	.609	(-.382 -.702)	.55
GAF score last week	63.64 (±15.61)	66.76 (±10.78)	-.952	(-9.88 - 3.64)	.35
GAF score best week past year	71.8 (±6.75)	72.16 (±7.38)	-.293	(-2,89 - 2.18)	.77
GAF score worst week past year	52.28 (±9.65)	54.64 (±10.81)	-1.07	(-6.90 - 2.18)	.29

From all participants who non-responded at study's endpoint (n=27), 81.5% gave the following reasons for dropping-out: the PHR-BD was not user-friendly (20.8%), too much work (17%), too much effort (11.3%), too complex to log into (11.3%), they did not perceive the added value (9.4%), were too busy (5.6%), and felt too confronted when monitoring the course of their illness (3.8%). Other reasons for non-use (18.9%) were being hospitalized, being transferred or moved to another region, technical issues, or a preference for mood monitoring on paper. Five of the 27 participants with BD who dropped-out did not provide a reason for doing so.

To explore the clinical reasons for non-use, we conducted a post hoc analysis by splitting the baseline dataset of the 66 participants with BD into two subgroups based on who did and who didn't filled out the questionnaires at study endpoint: completers (n = 39) and dropouts (n = 27). Our secondary analysis revealed that the 27 who dropped-out (M = 24.6, ±35.2) logged-in significantly less to the PHR-BD (M = 87.8 ±182.8, t = 3.9, P<0.001) then the 39 completers (M = 135.9, ±227.7).

A baseline analysis of the sample revealed that 60% of all the 66 participants with BD suffered from recurrent depressive (M = 6.3, 3-20+, 95% CI [5.6, 6.9]) and manic (M = 6.1, 95% CI [5.3, 6.8]) episodes. Therefore, subgroup analyses were conducted to determine whether or not lifetime illness characteristics, as measured by the QBP-NL, were correlated with Kendall's tau to user-frequency. We found that remaining in the study (n=39) was significantly correlated with a higher number of past suicide attempts (*t*= .306, p = 0.001) and rapid cycling (*t* = .28, p = 0.009), as well as fewer past psychotic events (*t*= -.297, p = 0.004). No other significant correlations were found between sociodemographic characteristics and the illness severity of completers (n=39) and dropouts (n=27). Subgroup analyses are presented in table 4.

Table 4. Lifetime illness characteristics and dropouts

	Drop-outs(n)	Completers (n)	Kendall's *tau*	SE	P-value
Frequency past hypomanic/manic episodes	27	39	.209	.135	.121
Frequency of hospitalizations for mania	27	39	-.118	.126	.349
Frequency of past depressive episodes	27	39	.057	1.35	.673
Frequency of hospitalization for depression	27	39	-.074	.129	.563
Number of past suicide attempts	**27**	**39**	**.306**	**.09**	**.001***
Severity current episodes ^{b}	5	18	-.219	.196	.171
Rapid Cycling past 12 months	**27**	**39**	**.280**	**.103**	**.009***
Past psychotic episodes	**27**	**39**	**-.297**	**.097**	**.004***
Insight in illness during euthymic period ^{b}	5	18	-.112	0.61	.324

Recommendations for improvement

At the study's endpoint, the participants with BD (n = 39), who remained in the study reported that they used a laptop (59%), a tablet/e-reader/smartphone (25.6%), or a desktop computer (15.4%) to access the PHR-BD. All responding clinicians (n =10) used a desktop computer at work. However, in the future all participants preferred the possibility of an application ('app') for mobile devices to improve user-friendliness, as it would ease access, be beneficial for website navigation, optimize the layout of the interface, remove unnecessary information, and simplify medication tracking. An important barrier to clinicians for using the messages function was the lack of compatibility with existing hospital electronic medical record systems. As a result, clinicians had to copy and paste reports from the records system into the PHR-BD and vice versa, which was considered too time-consuming and unfeasible for daily practice. A future integration with existing electronic patient record systems or a connection through email or WhatsApp was recommended by clinicians.

The 39 participants with BD who filled in the online open ended questionnaires suggested adding modules to measure changes in weight, concentration, activity, energy level, stress, and the menstrual cycle, as well as adding the option to record bed- and wake-times in the sleep rhythm module. Furthermore, the responding participants with BD mentioned that the PHR-BD was not always a topic of conversation during clinician visits. Some of them stated that using the PHR-BD sometimes felt time-consuming, and they felt they lacked a proper introduction course.

Both clinicians (n=10) and participants with BD (n=39) emphasized that the dynamic connectivity between the mood chart and the personal crisis plan (see figure 1) was a valuable improvement that exceeded the clinical value of the paper versions of both instruments. The mood chart gave a clear overview and distinguished various moods by colors. Another added value of the BD self-management tool was the switch function, which allowed users to alternate the interface of the mood graph (see figure 2) between different time sequences (overviews of two weeks, four weeks, six months, or one year). The only suggestion of the participants with BD for improvement was the option of a dropdown menu to simplify the interface and reduce the amount of visible detailed information.

DISCUSSION

The present pilot study was designed to develop, test, and evaluate a complex self-management intervention, and to determine the feasibility of conducting a possible follow-up study (Anderson et al., 2008; Craig et al., 2013). The primary aim was to evaluate the user experiences of participants with BD, and clinicians, and if, informal caregivers were granted access to the PHR-BD, they were also included in this study. The secondary goal was to detect major clinical changes at the study's endpoint as compared to baseline.

The most obvious finding that emerged from the analysis was the frequent use of the mood chart. Both clinicians and participants with BD were very positive about the 24/7 online availability of the multiple functions of the mood chart for all users and, especially, the connection with the personal crisis plan that indicates early warning signs and actions to take to prevent further progression. The integration of these often-used instruments exceeded the clinical value of the paper versions and was considered by most to be of added value in self-managing BD. They also emphasized the clinical value of being able to alter the interface from the current mood chart into a graph that displays the longitudinal illness course over different time sequences. These interacting modules of the PHR-BD largely meet the needs of people with BD to provide coherence in functions when designing a self-management enhancing eHealth technology (Gliddon, et al., 2017; Murnane et al., 2016).

Self-management of BD is largely based on insight into trigger events, problem-solving, and coping with prodromal and early symptoms of alternating moods, activities, and disturbances of sleep patterns (Frank et al., 2000; Goossens et al., 2010; Janney et al., 2014). Our findings revealed that both clinicians and participants with BD gained more insight into the course of the illness, and participants with BD experienced an increased perceived control when using the mood chart and graph in combination with a personal crisis plan. These findings are in line with studies that found that the perceived control of counteracting prodromal symptoms of recurrent episodes is a key empowering element in self-management of BD (Morriss et al., 2007; Perry et al., 1999; Morton et al., 2018).

Another interesting finding that emerged from our study was the improved communication between clinicians and participants with BD. Still, although evidence shows that improved communication between people with BD and clinicians enhances therapeutic alliance and contributes to patient outcomes (Fisher et al., 2016), from the perspective of self-management, informal caregiver involvement is also an important factor to improving outcomes (Fredman et al., 2015; Reinares et al., 2016).

A possible explanation for the underrepresentation of informal caregivers in our study might be that participants with BD fear overinvolvement of informal caregivers if they granted access to the PHR-BD. These findings are in line with studies that marked the ambivalence of people with BD toward informal caregiver involvement (Granek et al., 2016; Scott et al., 2012). However, the sole informal caregiver who participated in this study also mentioned the importance of mutual trust between persons with BD and their informal caregivers, instead of having a separate access code or user-interface to the PHR-BD. Mutual trust is found to be an essential part of informal caregiver support in self-management of BD (van den Heuvel, et. al., 2018). From the clinician's perspective, caution must be taken when there is an improved therapeutic alliance with caregiver involvement, since the professional might be caught in the crossfire of inter-relational quarrels and ethical issues concerning dual loyalty (Beentjes et al., 2016; Reinares et al., 2006).The study's high attrition rate of 41% raised the question of whether or not illness history was a possible influencing factor to continuing or stopping the use of the PHR-BD. A subgroup analysis found small, but significant, correlations where there were more past suicide attempts, more rapid cycling, and less past psychotic events in the 39 participants with BD who remained in the study as compared to those who dropped out (n=27). In general, these findings suggest that people with BD who suffer from a higher illness burden but face less psychotic events may be more motivated to self-manage BD. However, caution must be applied to generalizing these findings as a result of the *post hoc* analysis and the small sample size.

Limitations of this study

This study has some important limitations. Although it was not our primary study target, the use of a small, non-randomized convenience sample was not appropriate to find significant clinical effects. Post-intervention measurements were conducted on 59% of the number of participants with BD at baseline, making this study vulnerable to attrition bias. Furthermore, the measurements took place only at baseline and at 12-months post-intervention, which provides no information on clinical changes in between nor is TAU taken in account as a possible effect modifier. Finally, there was no control group.

Implications for practice

Notwithstanding its limitations, this study offers valuable insights into user experiences that can be transferred to support the implementation of the PHR-BD and similar instruments in daily practice. Users specifically mentioned that some adjustments have to be made to promote implementation, such as a simplified login procedure, the option to send an automatic email alert when the mood chart detects changes, and the development of an application for mobile devices to improve navigation. These recommendations on access and navigation are valuable suggestions for improving the successful implementation of the PHR-BD.

Based on the time spent implementing this first version of the online PHR-BD, we recognize that it is not feasible to conduct a randomized controlled trial in its current form. The rapid development of e-health applications would probably outdate the results of a one-year, follow-up, randomized clinical trial. Instead, after necessary revisions based on the evaluations of this pilot study, which include access via a mobile app, we will implement the online PHR-BD on a short-notice basis and monitor clinical outcomes to compare it to patient groups of non-users.

Overall, we conclude that despite several technical difficulties and content issues, respondents who completed the study were generally positive about the features, utility, and potential of the PHR-BD as an online instrument for promoting self-management of BD. The results of this pilot study generated input to guide further development of self-management tools and future studies on this topic. The PHR-BD can be seen as an online platform where all stakeholders can meet each other, monitor mood changes, and respond at an early phase. We recommend people with BD to use the PHR-BD when they feel a need to gain more control over their illness, are conscientious of reporting changes, feel confident in their computer-skills, have accepted their diagnosis, tend to decompensate very quickly, and are motivated to take part in the treatment of their condition.

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Part II

A threefold perspective on self-management education for bipolar disorders

Chapter 4

Identifying and describing patients' learning experiences towards self-management of bipolar disorders: a phenomenological study.

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ABSTRACT

Background: Existing evidence suggest that self-management education of bipolar disorder (BD) is effective. However, why outcomes differ across the full range of service users has not been examined. This study describes learning experiences of service users in self-managing BD that provide a possible explanation for these varying effectiveness.

Design: A phenomenological design.

Setting: Three specialized community care clinics for service users with BD.

Method: Face-to-face, open, in-depth interviews, guided by a topic list, along service users (N=16) with BD I or II. Interviews were digitally recorded and transcribed verbatim prior to analysis in Atlas.ti 7.

Findings: Unlike existing studies, which suggest that individual abilities of service users determine outcomes in self-management of BD, the current study found that self-management of BD is a learning process that takes place in a collaborative network. We identified five categories: acknowledgment of having BD, processing the information load, illness management, reflecting on living with BD, and self-management of BD.

Conclusion: The success of self-management depends on the acknowledgement of individual limitations in learning to cope with BD, and willingness to use a social network as a back-up instead. Especially, the dormant fear of a recurrent episode is a hampering factor in this learning process.

BACKGROUND

Bipolar disorder (BD) is a severe chronic mental illness characterised by fluctuating mood and activity patterns, alternating between euthymic, hypo-manic or manic, major depressive, and mixed-mood episodes. The diagnosis can be classified according to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* as a bipolar I disorder when a service user endures at least one manic episode. When suffering one or more depressive episodes accompanied by at least one episode of hypomania (milder features of mania, not severe enough for a necessary acute hospitalisation), the disorder is classified as bipolar II (APA 2013). The lifetime prevalence of BD is approximately 1%, with a cumulative incidence of 1.5 to 2% in the European Union population between 18 and 65 years (Pini et al. 2005).

The morbidity of BD is substantial due to frequent, recurrent episode rates at 60% within two years and 75% in a five-year span (Judd et al. 2002). Service users are estimated to be symptom free for half a year, and to endure sub-syndromal or syndromal symptoms of depression for 35%, and hypo-manic or manic symptoms for 10% of the remaining time, whether they are diagnosed as bipolar I or II, and whether or not they follow treatment (Kupka et al. 2007). BD is associated with higher functional impairment, self-perceived stigmatisation, and decreased autonomy compared to control groups without BD (Rosa et al. 2010, Vazquez et al. 2011). The severity of symptoms is associated with a lower quality of life during all states of BD (Robb et al. 1997, Gazalle et al. 2007, Goossens et al. 2008).

The recommended treatment of BD consists of three components: pharmaceutical treatment, psycho-education, and self-management support (Nolen et al. 2008, Bauer et al. 2009). Although, pharmaceutics are considered the primary choice of treatment, evidence shows the effectiveness of psychosocial support (Crowe et al 2010, Reinares et al 2014), psycho-education (Colom et al 2003, Colom et al. 2005), and additional psychological therapy (Lam et al 2009), where service users are taught to identify and react on prodromal signs and symptoms to promote self-management (Morriss et al 2007, Goossens et al 2010).

Self-management is the ability to manage the signs, symptoms, and consequences of a chronic condition (Barlow et al. 2002). Although, the evidence of self-management promoting strategies in BD is gradually growing (Janney et al. 2014), studies, such as those by Perry et al (1999), and Scott et al. (2007), show that patient education is not always effective across the full range of service users with BD. The experiences of service users with a severe mental illness are essential to take in account when designing, delivering and evaluating interventions that promote the ongoing learning process of recovery and personal identity (Repper and Brooker, 1998, Repper and Perkins, 2003). In line with this approach we want to address the question what lies behind of the varying success rates of patient education by describing what learning activities service users undertake themselves to give personal meaning to self-management of BD. Therefore, the aim of this study is to describe and categorise the subjective learning experiences of service users in self-managing BD to be used as input for designing future interventions of self-management education in BD.

METHOD

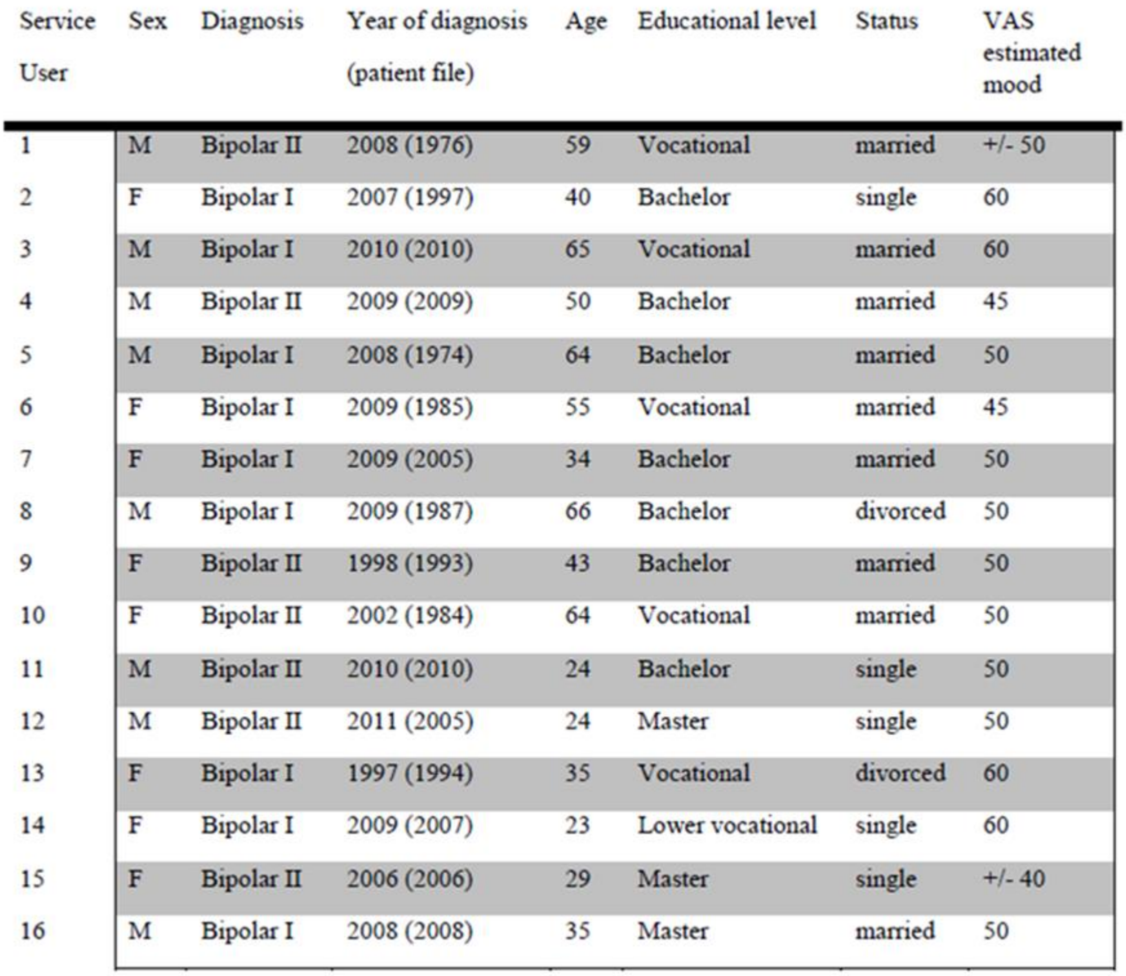
Design

We have chosen descriptive phenomenology for its philosophical claim to 'go back to the things themselves' emphasising on the construction of meaning given to a phenomenon from the different perspectives of lived-through experiences of subjects (Husserl 1973, Husserl 1984). Because descriptive phenomenology is a philosophical approach without a clear-cut qualitative methodology, we have used key elements pragmatically as for reflection to guide qualitative data-collection and data-analysis (Giorgi 2005; Dowling 2007). We took six steps to conduct the phenomenological content analysis, wherein steps 1 and 2 resemble the *epoche*, e.g. ruling out subjective ideas of a phenomenon from a natural attitude. Step 3-5, *bracketing*, e.g. withholding from a definitive conceptualisation about the phenomenon, and 6 considered as the *eidetic reduction*, e.g. different subjective ideas on a phenomenon transferred to a unified concept of a phenomenon.

Ethical considerations

According to the regulations of the *Central Committee on Research Involving Human Subjects* (http://www.ccmo.nl) in the Netherlands, local executive boards of each participating institute separately granted approval for recruitment and data collection. All participants received written information on this study and signed informed consent forms before starting the interview. Data gathered in this study was treated confidentially and anonymously.

Table 1: Demographic characteristics of interviewed



Service User	Sex	Diagnosis	Year of diagnosis (patient file)	Age	Educational level	Status	VAS estimated mood
1	M	Bipolar II	2008 (1976)	59	Vocational	married	+/- 50
2	F	Bipolar I	2007 (1997)	40	Bachelor	single	60
3	M	Bipolar I	2010 (2010)	65	Vocational	married	60
4	M	Bipolar II	2009 (2009)	50	Bachelor	married	45
5	M	Bipolar I	2008 (1974)	64	Bachelor	married	50
6	F	Bipolar I	2009 (1985)	55	Vocational	married	45
7	F	Bipolar I	2009 (2005)	34	Bachelor	married	50
8	M	Bipolar I	2009 (1987)	66	Bachelor	divorced	50
9	F	Bipolar II	1998 (1993)	43	Bachelor	married	50
10	F	Bipolar II	2002 (1984)	64	Vocational	married	50
11	M	Bipolar II	2010 (2010)	24	Bachelor	single	50
12	M	Bipolar II	2011 (2005)	24	Master	single	50
13	F	Bipolar I	1997 (1994)	35	Vocational	divorced	60
14	F	Bipolar I	2009 (2007)	23	Lower vocational	single	60
15	F	Bipolar II	2006 (2006)	29	Master	single	+/- 40
16	M	Bipolar I	2008 (2008)	35	Master	married	50

Setting and recruitment of participants

This study took place from January 2012 until April 2013 in three specialised community care clinics across the Netherlands for service users with a BD. The recruitment of potential participants started with community psychiatric nurses (CPN's) whom we asked to recruit service users who met the inclusion criteria. Service users were included according to the following criteria: diagnosed with bipolar I or II according to their service user file, were able to understand and speak Dutch, and were in a euthymic-mood state at the time of the interview. Mood state was considered euthymic when service users estimated their mood to be between 40 and 60 on a Visual Analogue Scale of 0 to 100, based on the Life Chart Method Self Rating scale (Spearing et al. 1997, Denicoff et al. 2000) at the time of the interview. We recruited participants through purposive sampling with a wide variety in age, gender, educational level, marital status, and diagnosis, as presented in Table 1.

Data Collection

Sixteen service users were interviewed through in-depth face-to-face, open interviews of 45 to 115 minutes. All interviews were digitally recorded and transcribed verbatim. The starting question of every interview was the following: "What does self-management of BD mean according to, or for you?" Subsequently the interviewer probed into service users' experiences by questioning how they had learned to manage signs, symptoms, and consequences of bipolar disorder. To guide the interview, we used a topic list with themes based on the general model of an activity system formulated by Engeström & Sannino (2010) including 'use of instruments', 'meaning of self-management', 'subjective learning experiences, 'division of family-responsibilities', 'influence of social network or community' and 'lifestyle habits and rules'. The interviewer (SvdH) used the themes from this topic list to guide the interviewees when they narrated beyond the scope of this study. Guiding topics were adapted when new insights emerged from the analysis of each interview and from peer debriefing by the research team (SvdH, PG, CT and TvA). This inductive methodology was used rigorously until no topics were added or replaced and data were saturated. We kept a logbook including observational, theoretical, and analytical memos to be used for interpretation during the data analysis.

Data Analysis

We took six steps to conduct the phenomenological content analysis, wherein steps 1 and 2 resemble the *epoche*, (ruling out subjective ideas of the researchers) Step 3-5, *bracketing* (withholding preliminary conceptualisation), and step 6 as the *eidetic reduction*, (different perspectives on self-management of BD). The six steps of data analysis are the following:

1. Three analysts (SvdH, PG and CT) started by separately reading full transcripts thoroughly to 'grasp a first idea of the essence' of the interviews from a respondents perspective that functioned as a discussion point for peer debriefing later on.
2. One analyst (SvdH) summarised the full transcripts and sent them to the respondents as member check. Aside from some textual corrections, we only received confirmation that the essence of the interviews was well understood and interpreted.
3. The interviewer (SvdH) put the emerging concepts during the text analysis into the *ATLAS.ti 7 data analysis software package* as unlinked open codes (Friese 2012), i.e. without connecting the

label to the actual text fragments. The other two analysts (PG and CT) hand-labelled a random selection of transcripts and used them in peer debriefing to increase the interpretations' trustworthiness.

4. These first interpretations of emerging concepts were compared and discussed among three analysts (SvdH, PG, CT) until a consensus was reached. This intermediate step was taken to avoid researcher bias as much as possible by a rigorous procedure wherein unlinked open codes were considered merely to be interpretations of one analyst rather than being closely related to the respondents' view and therefore removed from the dataset.
5. After peer debriefing, one of the analysts (SvdH) labelled text fragments of the full transcripts in *Atlas.ti 7*.
6. These labels were inductively categorised based on similarity in meaning until a thorough description of the learning experiences of service users was reached . One analyst (TvA) reflected on the categorisations of the other three analysts during this process.

FINDINGS

We identified five categories of service users' (N=16) personal learning experiences towards self-management of BD: *acknowledgment of having BD*, *processing the information load, illness management*, *reflecting on living with BD*, and finally *self-management of BD*. To stipulate the data's authenticity, participants' quotes will illustrate key features in the above-mentioned categories. The numbers in brackets behind the quotations correspond with of respondents in Table 1.

Acknowledgment of having BD

Almost all service users were eager to tell their story and immediately started narrating the first time they experienced bipolar symptoms. Service users with bipolar I who experienced a full-blown manic episode did not recognise symptoms when they occurred for the first time. Most service users with bipolar I experienced the period of being hospitalised as a blur; therefore, many of them stated that they wanted to avoid a recurrence. Some of them were preoccupied to create some sense by filling in the gaps in their memory void about their hospitalisation period. These first reflections led to their confrontation with the reality of being mentally ill:

> 'I was opposing the diagnosis . . . and against 'being institutionalised.'. . . You know everyone is outside and I am here inside. . . . I did not realise or acknowledged being ill . . . for the whole two years. . . . I was just angry and rebellious about being hospitalised against my will. . . . That is the reason that I am reading the piles of notes I made during that period of time . . . to realise that I was just ill.' [Service user 7]

Most service users with bipolar II remembered their first hypo-manic episode as a period wherein they felt great and special, and they would love to experience those emotions again. Most of them did not label hypomania as part of a mental illness, although they acknowledged negative consequences. All service users stated that they wanted to avoid a recurrent depressive episode at all costs after they had experienced it once. The unknown terrible impact of the downside of BD was, for many service users, the urgent reason to seek professional help:

> 'You have to experience it. . . . When you experienced it once, you feel the dreadfulness of it. You immediately know it . . . that moment when you slipping away into that depressive feeling. You feel awful; everything is black. When you are lifting up towards a manic episode, you do not seem to notice it at all, but you recognise

the beginning of a depressive episode at once, because everything around you becomes colourless.' [Service user 8]

Processing the information load

The majority of service users mentioned that they felt overwhelmed by fear and hopelessness when they finally received the diagnosis of BD. Sometimes the service user information, as provided by CPN's, often seemed to come too soon, or it was too much at once, because the service users struggled with the emotional impact of being diagnosed with a severe mental illness:

'I experienced a full-blown manic episode and ended up being institutionalised with this label. 'Miss, you have BD.' It was simply something I could not accept for a long time. . . . This label of being mad--it seemed it came out of nowhere.' [Service user 2]

Some service users mentioned that it was strenuous to grasp large amounts of information provided in the aftermath of an acute episode because they experienced an increased intolerance to noises and bright lights, lack of concentration, and memory lacunae:

'I used to pick up a book and start to study. I used to read a lot and memorised [everything I read] at once, but now I am only able... or able again, depending on how you look at it... to grasp small pieces of information. It takes me a considerable amount of time to read things and 'stick it' to my mind.' [Service user 4]

Complex information seemed best understood when a nurse provided it in small amounts and made use of metaphors, examples, and/or visualisations to explain the abstract manic and depressive features of BD:

'I think it is very recognisable for people who suffer from BD that you do not need to have all of the information fired at you at once, because you cannot comprehend it. I used to do several things at the same time, especially in my manic episodes. . . . But nowadays I cannot do that anymore, just one thing at a time.' [Service user 14]

Using simple examples helped service users to grasp difficult concepts and made it easier for them to be aware of personal signs and symptoms that easily could lead to a recurrent episode, such as being aware of controlling their sleep-wake cycle to prevent a recurrent episode:

'I was a volunteer at the Red Cross for about a week, but hardly slept during that period. We were sleeping with four persons in one small room, and we had to get up early every day. So, [name of the nurse] said that it was probably the trigger of my manic episode, whereupon he gave the example that most soldiers during war time collapse due to a lack of sleep. . . . I believe him. I think that it is correct what [the nurse] said about those soldiers. If you do not sleep for a long time, your brain is not capable of functioning anymore.' [Service user 6]

Illness management

Most service users experienced BD as an illness that is difficult to control, and acute phases usually end with devastating consequences for themselves and for their loved ones. One of those consequences was unemployment or early retirement, which led to the issue of how to cope with feelings of purposelessness that could trigger a recurrent depressive episode. Most service users had a common idea that they should structure their days somehow to maintain a stable mood. Some service users, mostly men, started active hobbies such as sports or voluntary physical labour, believing that regulating their activities and controlling hypo-manic and manic features was necessary.

Remarkable was that some service users mentioned that they were alert to keep chats and conversations for going too deep when visiting friends or plan activities when feeling down in order to prevent a recurrent depressive episode. They choose this strategy to avoid topics that might trigger a negative spiral of thoughts due to their friends' good intentions to lend an ear to their problems as they had experienced in the past. In order to make sure they definitely would take action, service users made a mutual agreement with their dedicated CPN's:

'I did not practice sports anymore, but my appointed nurse advised me to do so to get me moving again. Afterward, I gradually started going to the gym, and I eventually felt better. It opened my eyes to the fact that it is important to do things to prevent a further downfall and a way out of the depression. She [the nurse] made our mutual agreements very concrete and verified afterwards.' [Service user 11]

Most service users said that they started managing their illness once they learned how to identify, recognise, and respond adequately to early warning signs and triggers in everyday situations. Service users felt confident about knowing what to do, when they felt reinforced by their appointed CPN's. According to guidelines for BD, service users should use such instruments as life charts and relapse prevention plans for monitoring mood and planning activities in different mood states. However, most service users who had an instrument used or checked it occasionally, when they felt it was necessary, or they said they already knew the content by heart:

'I have a life chart, but I haven't used it for a while. For me it has more value if I feel it is getting worse . . . and a relapse prevention plan. . . . We made it once as part of the psycho-education program, but it was not all that for me. . . . You know, it is different every time. . . . I do not feel that it provides me recognisable signs. . . . I mean, during depressive episodes, it is hard to feel anything at all.' [Service user 12]

Instead of using instruments, some service users used their caregivers to 'mirror' or 'monitor' their mood by picking up verbal or non-verbal signals even if these signs were not explicit, whereupon service users responded with reversed actions as a preventive measure. Some service users and caregivers used a mutual code word to point out a 'red flag' to avoid perpetual discussions that might trigger a service user into a hypo-manic state:

'Well if my sister says it is better not to go to a party when I tend to be in a hypo-manic episode, she cannot say that to me straightforwardly because then I start getting angry and do not listen any more. You, know I am very sensitive when I am in that mood state. However, if she disguises the message, using our code phrase 'a little bit jumpy,' I very well know that it is better to pick up this sign and listen carefully to her advice if I want to prevent a recurrence.' [Service user 15]

Reflecting on living with bipolar disorder

Managing their illness was something most respondents had learned by trial and error, having experienced enough situations to know that, staying actively involved in a social life is a strategy to prevent slipping into a depressive episode, and avoid social activities in case of a looming hypo-manic state. Overall, it seemed that service users found it easier to regulate their activities, such as by guidance of a pocket diary or other means, than to gain insight into their emotional triggers. However, some service users gained insight into underlying mechanisms that might trigger symptoms by reflecting on the emotional outcomes of everyday situations. Reflections on the consequences of their own actions led to rediscovered feelings of regained control and self-confidence:

'At a given moment, you start to reflect on things. You start to think about what is not suitable for me right now, what does and does not help me at this moment.' [Service user 9]

Thinking about ways to integrate BD into daily life enhanced autonomy and personal recovery for most service users. However, these reflections also opened a cynical perspective such that regardless of what preventive measures were taken, a recurrent episode was inevitable:

‘So, the way I see it, it’s [the illness] hopefully something that belongs to the past . . . and never will come back. . . . But despite all efforts, it is a sword of Damocles hanging above my head, or some kind of unpredictable wild animal, a predator, that is watching me closely waiting to strike me at any given time. It feels like it isn’t something you can control.’ [Service user 7]

The service users commonly felt this uncertainty and fear of not being able to respond in a timely way to prevent a recurrent episode. Some service users learned to cope with these uncertainties by a laissez-faire attitude or by using humor. Others learned to keep faith during acute episodes by constantly reminding themselves of the temporality of it, force themselves to keep seeing ‘bright spots’ to prevent being lost in the darkness of a depressive episode. Nevertheless, most service users acknowledged the fact that they somehow had to overcome the fear of a recurrence as a means of integrating BD into their lives:

‘You have to learn to recognise your signs… you have to learn to recognise it and ‘play’ with it. You have to overcome your fear--that fear of a recurrence--by trusting your medication, yourself. My appointed nurse told me that it is all right to let things go for a while just to see how much you can take. You have to experience it for yourself, just to know what your boundaries are and how to cope with it. . . . If you can master it in that way, for me, that is self-management.’ [Service user 16]

Self-management of bipolar disorder

Some service users felt that the constant fear of a relapse was a motive for caregivers to consider the control of bipolar symptoms a full-time job for service users, and therefore let service users do nothing else then taking care of avoiding triggers. Service users stated that caregivers who were highly alert were actually restricting the service users’ learning process towards self-management. When service users experienced more confidence in controlling their illness, they felt more willing to be actively involved in daily life. As a response to this regained autonomy, some caregivers became even more restrictive, fearing that a new (hypo-) manic episode would occur. Service users who adequately managed their symptoms felt that trust and confidence worked reciprocally experiencing that caregivers responded with putting faith in their capabilities. The gradually progressing learning process of service users self-managing BD enhanced mutual trust between service users and their caregivers, creating the awareness that service users were competent enough to pick up responsibilities again, re-joining their partners in raising the children or restarting working, i.e. integrating BD into their lives:

‘It felt like a real gamble when I restarted working, due to the irregular hours and decreasing Lithium at the same time… but my psychiatrist and partner supported me by putting faith in me. Because of this confidence I was given, I was careful not to break our mutual trust.’ [Service user 9]

Overall, it seemed that service users had learned to reclaim their autonomy by setting clear boundaries in what they wanted to do themselves and by knowing when their social network needed to intervene. The majority of service users seemed to understand that self-determination has its limitations when one is in a manic, a hypo-manic, or a depressive episode, and they acknowledged that they were willing to accept that their social network temporarily taking the lead during recurrences. Some service users mentioned that trusting others to make important decisions for them when they were not able to think rationally at that particular moment was a means towards a higher form of autonomy. Service users generally saw this back-up construction as an important precondition for self-managing BD, for it provided them with a safe haven wherein they learned to find new ways to integrate this illness into their lives:

> ‘I now feel like a mother and child united in one person. I refer to myself as a mother to her child. The child wants to take another ride in the carousel, but the mother says it has been enough for today: We have to go home now and take a good night sleep. Tomorrow we can go for that ride again if you like. . . . You know, for me, this is a kind of self-management.’ [Service user 2]

DISCUSSION

Our findings show that when service users acknowledge their capabilities to cope with BD are limited during acute episodes, mutual trust opens the possibility to authorise their social network to take the lead when necessary. This social backup, on condition that it is temporary, provides a ‘peace of mind’ as Daggenvoorde et al (2013) puts it, because service users know that others are there and have the know-how to intervene adequately in case of a looming manic, hypo-manic, or depressive episode. However, service users have to take several learning steps towards self-management of BD to attain this goal. First of all, it is a precondition for therapy adherence to be diagnosed as having BD. Gazalle et al. (2007) shows that the number of years a person goes undiagnosed has negative consequences for the treatment of BD. The results in our study show that service users found it difficult to make sense of the diagnosis BD, and the concept of ‘self-management of BD’ had to be constructed on basis of the learning experiences of service users themselves. These findings are in line with the study of Inder et al (2010) stating that the acceptance of being diagnosed with BD depends whether or not a service user is able to make sense of the concept of BD before the illness can be integrated in their identity and self-perception. However, in contrast with this study, we showed that the acceptance of the diagnosis BD *per se* is not necessary to start a learning process towards self-management of BD, as long as service users at least acknowledge that they have personal, relational or occupational problems due to the features of this condition, and are willing to learn how to cope with the consequences.

In our study, we found that service users preferred small pieces of information, and practical examples, tailored to familiar concepts e.g. oppositional background, during psycho-education, because the impact of BD along with memory lacunae made it strenuous for service users to grasp large amounts of information about the course and the features of the illness. The extreme emotional and fluctuating course of this illness has a great impact on the abilities of service user to identify and control the features of BD (Crowe et al 2012). A key factor for successful self-management of BD, according to service users’ learning experiences, is the early recognition of symptoms. Early recognition of symptoms of BD is well investigated, and proven to be effective for preventing recurrent episodes (Morriss et al 2007). Many service users in our study found it easier to identify activity-related prodromal symptoms, than emotional fluctuations. These findings confirm by the studies of Goossens et al (2010), and Russell & Browne (2005), in which is stated that fluctuations in energy level, sleep, thought, and social functioning, are easier to recognise than emotional triggers.

In our study, we found that instruments such as the retrospective, and prospective life charts, and relapse prevention plans, that are recommended in guidelines for treatment of BD (Nolen et al. 2008, Bauer et al. 2009), were rarely used by service users to identify and control the symptoms of BD. These findings are confirmed by the study of van Bendegem et al. (2014), wherein service users often feel reluctant to consistently make use of life charts. In addition, we found that (social) learning by recognising signals from people in a network, was preferred above the use of instruments. Service users in our study, stated that they learn from reflection on outcomes of reversed actions in social interactions, a strategy which is shown to be promising in a recent study on dialectical behavioural therapy techniques in the treatment of BD (van Dijk et al. 2013). The main purpose of a relapse prevention plan is to identify, and respond timely on prodromal symptoms in order to regain control. We found relapse prevention plans were also used to reflect on outcomes of actions in everyday situations. These reflections promoted self-confidence, and reduced the overwhelming feeling of fluctuating emotions that hamper autonomy (Crowe et al 2012).

The side-effect of reflections on living with BD also opened a cynical perspective that regardless of what actions were taken to integrate BD into their lives, a recurrent episode seems inevitable. These findings, conflict with the results of Pollack (1996), who stated that 'being prepared' (to prevent a recurrent episode) is a successful way of self-managing BD. In contrast, our findings show that preoccupation or 'being too prepared' leads to a paralysing fear for a recurrence, and therefore hampers the development of self-management. In our study, we found that high alertness on recurrent episodes often leads to disagreements between service users and caregivers on how to cope with BD. The studies of Barrowclough et al (2003), and Miklowitz (2007), showed that the level of expressed emotions (criticism, hostility, and/or emotional over-involvement) of caregivers negatively influence the course of the illness, confirm our findings.

In our study, service users mentioned that good intentions of caregivers sometimes felt as over-protective and restricted them in their learning process towards self-management of BD. Good intentions or mistrust of over-protective caregivers were often interpreted as a disqualification, a feeling of incapability to manage the illness themselves, closely to the feeling 'flawed' as described in the study of Crowe et al (2012). Service users, in our study, who adequately managed these feelings of self-doubt experienced that trust and confidence worked reciprocally when caregivers responded with putting faith in their capabilities to cope with BD. This gradual progress of service users self-managing BD enhanced mutual trust between service users and their caregivers and facilitated the integration of BD in daily life, additional to the findings of Inder et al (2011).

Service users who felt being competent enough to pick up social roles and responsibilities again, re-joined their partners in raising the children or restarted working, and regained their autonomy, which can be considered as an important step towards personal recovery of BD (Bonney and Stickeley, 2008). We found that service users had learned to reclaim their autonomy by setting clear boundaries in what they wanted to do themselves and by knowing when their social network needed to intervene. Service users considered self-management as a learning process of integrating the chronic condition into their lives. These findings are confirmed in the studies of Kralik et al (2004), and Inder et al (2008), which showed that boundary-setting, mobilising social resources, and integrating BD in ones' concept of 'self' are key concepts to 'create order in the disorder'.

Implications for practice

A range of self-management promoting programmes for service users with severe mental illnesses is developed in the last decade, e.g. Illness Management and Recovery (Mueser et al. 2002), the Health and Recovery Peer Program (Druss et al. 2010), the Wellness Recovery Action Planning (Cook et al. 2012) and the Chronic Disease Self-Management Program (Lorig et al. 2014), that aim on the reduction of symptoms, increase hope, and empower personal recovery. Our findings described possible factors that hamper or facilitate service users' learning process towards self-management of BD, which provide insights to tailor future interventions in self-management educational programmes. In our opinion CPN's should keep an open discussion with service users and caregivers and re-label problems into learning situations where both play an active role in building mutual trust and thereby enhancing self-management of BD.

Strengths and limitations

Our choice for a purposive selection of service users via CPN's ensured a 'variation of perspectives' (Husserl, 1984), and so ruling out the danger of recruiting a too homogenous sample of service users that might provide us an unilateral view on 'self-management of BD'. However, this method has restrictions in generalising our findings. First of all, our study was conducted in a Dutch context, so caution must be taken when transferring these results to different cultural and healthcare settings. Furthermore, we used a phenomenological method of open interviewing, a guiding topic list, and inductive analysis of data, and therefore limited the replicability of this study. Nevertheless, by linking our findings to previous studies we have provided insights that are transferable to similar situations, settings, and practices.

CONCLUSION

Self-management of BD is a process wherein service users gradually learn how to recognise and to react to consequences that follow from a reflection on their own actions of daily situations. Mutual trust and open communication are key attitudes that promote the exploration and the gradually shifting of boundaries in a network where mistakes are considered to be learning activities to reflect on. We state that, a social network that functions as a safe back-up environment wherein service users can learn to overcome the fear of a recurrence by exploring personal boundaries, and open new ways to integrate this chronic condition into their lives, is an important precondition for self-management of BD.

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Chapter 5

Informal Caregivers' Learning Experiences With Self-Management Support of Individuals Living With Bipolar Disorder: A Phenomenological Study.

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ABSTRACT

Background: The degree of informal caregiver involvement influences patients' self-management of bipolar disorder (BD).

Objective: This paper aims to provide a description of informal caregivers' learning experiences in self-management support of BD in order to guide professionals in tailoring future psychosocial and psychoeducational interventions.

Design: In-depth open interviews with ten informal caregivers of patients with BD who followed treatment in the context of specialised outpatient bipolar care were conducted.

Results: Four learning phases emerged from the phenomenological analysis describing the informal caregivers learning process: (1) understanding bipolar disorder, (2) overcoming dilemmas in informal caregiver support, (3) dividing tasks and responsibilities, and (4) Acquiring a personal definition of self-management support for patients with bipolar disorder.

Conclusion: By grasping the concept of BD, informal caregivers gradually learn how to overcome dilemmas resulting from living with someone with BD, and how to control the expression of emotions. They learn to reflect on the nature of conflicts, and how to share the responsibilities of illness-management with patients and professionals. Mastering these skills eventually allows them to define and delimit their supporting informal caregiver role in the patient's self-management of BD.

Practice implications: Our findings provide information regarding the educational needs of informal caregivers in order to tailor counselling, and psychosocial and psychoeducational interventions in specialised outpatient care for patients with BD.

BACKGROUND

Self-management of a chronic illness is one part of the treatment in the Chronic Care Model and part of the definition of health as stated by the World Health Organization (Huber et al., 2011; Wagner, Austin, & VonKorff, 1996). Self-management improves outcomes and reduces the costs of healthcare because the patients are actively involved in their treatment (Lorig & Holman, 2003; Newman, Steed, & Mulligan, 2004). The primary goal of self-management education is to increase the individual's ability to overcome the negative consequences of living with a chronic condition and maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

Bipolar disorder (BD) is a chronic mental illness characterized by the extreme fluctuation of emotions, energy levels or activity patterns. In the European Union, BD has a prevalence rate of approximately 1% in people between 18–65 years of age (Pini et al., 2005). The morbidity of BD is substantial because of recurrent episodes that alternate between euthymic, (hypo)manic, or major depressive mood states, with frequent relapse rates up to 60% within two years and 75% in a five-year span (Judd et al., 2002). BD can be differentiated into two subcategories: 1) BD I when at least one manic episode, that is, an episode of persistently elevated mood with an abnormally high level of activity for most hours of the day and that exists for at least a week, has occurred in the illness history of an individual; or 2) BD II, when an individual suffers from one or more depressive episodes for at least two weeks, and these episodes are accompanied by at least one episode of hypomania, that is, milder features of mania that are not severe enough for acute hospitalization (American Psychiatric Association, 2013).

According to international multidisciplinary guidelines, the treatment of BD consists of pharmaceutical therapy (Bauer, Biswas, & Kilbourne, 2009; Kupka et al., 2015), psychosocial support (Crowe et al., 2010), psychoeducation (Colom et al., 2003; Colom & Lam, 2005), additional psychological therapy (Lam, Burbeck, Wright, & Pilling, 2009), and self-management education (Perry, Tarrier, Morriss, McCarthy, & Limb, 1999). Professional support in the self-management of BD entails teaching individuals living with BD to monitor mood and activity by utilizing a life chart and to efficiently counteract prodromal signs and symptoms using preset interventions from a relapse prevention plan (Daggenvoorde, Goossens, & Gamel 2013; Goossens, Kupka, Beentjes, & van Achterberg, 2010; van Bendegem, van den Heuvel, Kramer, & Goossens, 2014).

Although the term "self-management" may suggest that individuals living with BD are solely responsible for their outcomes (Janney, Bauer, & Kilbourne, 2014; Jones, Deville, Mayes, & Lobban, 2011; Trappenburg et al., 2013), numerous studies have shown that the active involvement of informal caregivers positively affects the course of BD (Miklowitz, 2007; Perlick et al., 2010; Scott, Colom, Pope, Reinares, & Vieta, 2012). However, caregiver involvement has an excessive cost. Being an informal caregiver of someone with BD is associated with high rates of emotional burden and experienced distress (Beentjes, Goossens, & Poslawsky, 2012; Jönsson, Wijk, Danielson, & Skarsater, 2011; Reinares et al., 2006). Also, providing informal care for someone with BD has a massive impact on relationships (Goossens, van Wijngaarden, der Klein, & van Achterberg, 2008; Granek, Danan, Bersudsky, & Osher, 2016) and can lead to serious mental problems (Perlick et al., 2016; Steele et al., 2010). Providing informal care for someone who has BD means balancing between competing needs and coping with feelings of being pulled on and rejected at the same time (Lewis, 2015; Rusner, Carlsson, Brunt, & Nystrom, 2013). Yet it is widely known that informal caregivers play a significant role in signaling the prodromal symptoms of upcoming episodes (Goossens et al., 2010). Often, the person with BD will find it difficult to recognize these changes, so having an external person who is able to observe any variations in behavior can be vital for successful early interventions (Regeer et al., 2015).

Teaching informal caregivers how to support individuals in coping with the consequences of living with BD is essential for the well-being of both the caregiver and individual with BD (Fiorillo et al., 2015; Miklowitz & Chung, 2016; Reinares et al., 2016). However, the literature on how informal caregivers learn to support individuals with their self-management of BD is scarce. Therefore, the aim of this study was to describe how informal caregivers have learned to overcome the impact of emotional burden and experienced distress, and how they have developed a personal definition of efficient self-management support for individuals living with BD.

METHOD

Research Design

A modified descriptive phenomenological method based on the philosophical ideas of Edmund Husserl (1973, 1984) was chosen as the study design. Because descriptive phenomenology is a philosophical approach without a clear-cut qualitative methodology, it was modified into an inductive method of data collection and analysis to meet the criteria for empirical qualitative research (Dowling, 2007; Giorgi, 2005). In contrast to the original descriptive phenomenology, our approach used the concepts of the expansive learning theory (ELT) as a guiding interview tool to set the framework for the interview topics to prevent interviewees from narrating beyond the scope of the study's aim (Engeström & Sannino, 2010). For data collection and analysis, we used a six-step inductive empirical method similar to a parallel study on learning experiences of individuals living with BD (van den Heuvel, Goossens, Terlouw, van Achterberg, & Schoonhoven, 2015).

Sampling and recruitment

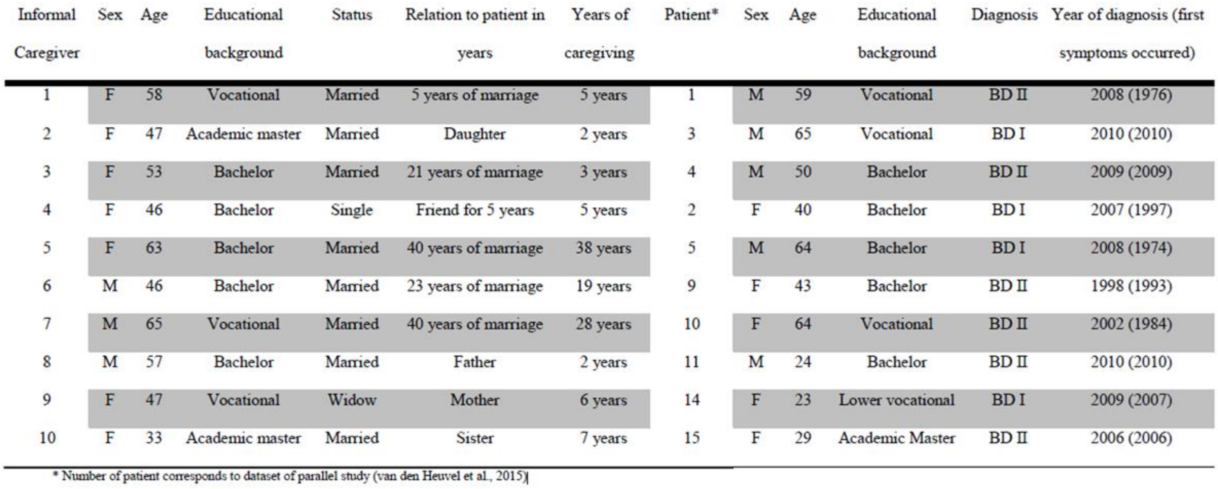
From January 2012 until April 2013, we recruited Dutch participants involved in informal caregiving for persons diagnosed with BD I or II. Participants could be spouses, family members, or friends of the people with BD. The recruitment of the participants started by asking individuals living with BD who were part of a parallel study (van den Heuvel et al., 2015) to identify significant persons (the informal caregivers in this study) who were there for them during acute phases and supported them in self-management activities. No other inclusion criteria were set. Although our sample was collected based on convenience, we purposively searched for heterogeneity to meet the phenomenological principle of multiple perspectives (Husserl, 1973, 1984).

Ten informal caregivers, five being marital partners, two parents, one sister, one a close friend, and one a daughter, agreed to be interviewed. The mean age was 51.5 (SD=9.6) years, and seven respondents were female; the highest educational level was on academic level, the lowest vocational, with the mean year of experience in informal caregiving being 11.5 (SD=12.5). We defined the length of being an informal caregiver as starting from the year the first symptoms occurred or when the relationship started. In some cases, this period of time extended to the year in which the correct diagnosis was set. Socio-demographic data are presented in Table 1.

Ethical considerations

According to the principles of the Declaration of Helsinki (http://www.ccmo.nl), the Dutch *Central Committee on Research Involving Human Subjects* found no objections to this study. Nevertheless, ethical guidelines for research governance were followed, meaning that all the participants signed an informed consent form after they received written and spoken information before the interview started. The data gathered in this study were treated as confidential and processed anonymously.

Table 1: Demographic characteristics of interviewed informal caregivers



Informal Caregiver	Sex	Age	Educational background	Status	Relation to patient in years	Years of caregiving	Patient*	Sex	Age	Educational background	Diagnosis	Year of diagnosis (first symptoms occurred)
1	F	58	Vocational	Married	5 years of marriage	5 years	1	M	59	Vocational	BD II	2008 (1976)
2	F	47	Academic master	Married	Daughter	2 years	3	M	65	Vocational	BD I	2010 (2010)
3	F	53	Bachelor	Married	21 years of marriage	3 years	4	M	50	Bachelor	BD II	2009 (2009)
4	F	46	Bachelor	Single	Friend for 5 years	5 years	2	F	40	Bachelor	BD I	2007 (1997)
5	F	63	Bachelor	Married	40 years of marriage	38 years	5	M	64	Bachelor	BD I	2008 (1974)
6	M	46	Bachelor	Married	23 years of marriage	19 years	9	F	43	Bachelor	BD II	1998 (1993)
7	M	65	Vocational	Married	40 years of marriage	28 years	10	F	64	Vocational	BD II	2002 (1984)
8	M	57	Bachelor	Married	Father	2 years	11	M	24	Bachelor	BD II	2010 (2010)
9	F	47	Vocational	Widow	Mother	6 years	14	F	23	Lower vocational	BD I	2009 (2007)
10	F	33	Academic master	Married	Sister	7 years	15	F	29	Academic Master	BD II	2006 (2006)

* Number of patient corresponds to dataset of parallel study (van den Heuvel et al., 2015)

Data collection

The interviewer (SvdH) collected data through in-depth and open face-to-face interviews (35–110 min.) with the informal caregivers separately from their loved ones at a place of the caregivers' convenience (at home or at the university). All interviews were digitally recorded and transcribed verbatim. The starting question was the following: What does self-management of BD mean to you? Subsequently, the interviewer prompted the interviewees' answers concerning support to individuals living with BD and asked additional questions based on the central concepts of the ELT (Engeström & Sannino, 2010), which holds the premise that learning situations are activated in a collaborative network. The central topics of the ELT were used for additional questions whenever the interviewees were narrating beyond the scope of the current study, and these topics included themes about the division of family responsibilities, the supporting role of the informal caregiver during different stadia of the illness, and the way the caregivers coped while living with someone who has BD. The guiding topics of the aide memoire were adapted when new insights emerged from the analysis of each interview and from peer debriefing by the research team (SvdH, PG, CT, LS, and TvA). This inductive methodology was used rigorously until no topics were added or replaced, in which case the data were considered saturated.

Data analysis

The analysis started with three analysts (SvdH, PG, and CT) separately reading the transcripts thoroughly to grasp the essence of the interviews. Summaries of the transcripts were sent to the respondents as a member check to verify that what they had said was well-interpreted. Aside from textual corrections, all respondents agreed with our interpretations. The first interpretations were entered in the *Atlas.ti 7* data analysis software package codebook (Friese, 2012), that is, without connecting the codes to the transcripts. Two analysts (PG and CT) hand-labeled a random selection of transcripts.

The interpretations of all analysts were compared and discussed in peer debriefing to increase the trustworthiness and reduce researcher bias; this was carried out until a consensus was reached about the meaning of the concepts. Concepts on which we agreed were also entered in the database codebook. After this step, the text fragments of the full transcripts in *Atlas.ti 7* were labeled. Codes that could not be labeled to a text fragment were considered to be a preliminary interpretation of the researcher and were therefore removed from the dataset.

This intermediate step was made to ensure that inopportune ideas from the researchers' natural attitude were disentangled conform the phenomenological methodology (Husserl, 1973, 1984). In the final step, the labels were inductively categorized based on similarity in meaning until a thorough "thick description" of learning experiences was reached. Two analysts (LS and TvA) supervised and reflected on the final themes that were composed during the analysis.

RESULTS

The phenomenological analysis provided a "thick description" of the learning experiences of informal caregivers (N = 10) when supporting individuals who were self-managing BD. Based on these experiences, we logically reconstructed the informal caregivers' learning process into four phases: *understanding bipolar disorder, overcoming the dilemmas in self-management support for individuals living with BD, dividing tasks and responsibilities,* and *acquiring a personal definition of self-management support for individuals living with BD.*

Understanding bipolar disorder

The first time informal caregivers were confronted with the symptoms of BD, they did not know how to interpret the odd behavior, which was utterly deviant from the normal characteristics of their beloved ones:

> His behavior was abnormal, completely different from the modest person we knew before. He turned into being supercilious and overconfident, and later on, he became very timid and hesitant… until he was not able to do anything, anymore… (Informal caregiver 8)

After the acute phase was over and a diagnosis had been given, most informal caregivers were eager to gather lots of information, primarily from the Internet, to grasp the abstract concept of "bipolar disorder." This basic understanding of the course and nature of the illness allowed them to relabel what they had previously called "odd behavior" into the signs and symptoms of BD. Through their eagerness to learn about the nature of BD, informal caregivers felt confident about what was anticipated to be their supporting role by the time they joined the individual living with BD when visiting his or her appointed healthcare professional. However, informal caregivers reported that to their surprise, individuals living with BD were not as willing to learn as much about the illness as they were. This difference in need for knowledge led to the caregivers' assumption that the individual living with BD was non-compliant, not interested in his or her well-being, or did not comprehend the importance of knowing what to do to prevent a recurrent episode:

> When the diagnosis of [name individual living with BD] was set, I immediately started reading lots of information about the illness. He avoided all conversations about the manic-depressive illness. He was convinced that he had recovered. So he was acting as if nothing had happened… But I, on the other hand, never stopped reading new information about the illness. I even joined the Dutch Bipolar Patient and Informal Caregiver Association. (Informal caregiver 5)

Although informal caregivers had learned to recognize and efficiently respond to early signs and symptoms of BD, they also mentioned the difficulty of differentiating between the normal and abnormal behavior and activities of individuals living with BD:

> When we read the information leaflet that summed up the features of BD, we recognized some things. However, when the first symptoms reoccurred, we did not recognize it as such at once. He [her father] just gradually started to behave differently. The symptoms appeared insidiously […] that is the elusiveness of this disease; you never know when an episode will recur. So, that is why… for instance if there is a sale at a store and he buys a thing or two… or more… I have to be alert. Just in case. You never know for sure. (Informal caregiver 2)

Overcoming the dilemmas in self-management support for individuals living with BD

Most informal caregivers said that they found support and understanding from peers in sessions organized by the Dutch Bipolar Patient and Informal Caregiver Association when trying to comprehend the difficulties they faced. However, the dreadful stories of some peers also sketched a fearsome image of BD: an unpredictable mental illness. Along with their own insecurities, this induced a fear for future episodes:

> I keep her in sight and see that she takes her medication on time, but I try to let it go sometimes… to let her decide on her own what to do on some occasions. It is hard to let go of her, just because I am afraid of a recurrent episode… that dormant fear is always there. (Informal caregiver 9)

The dormant fear of a possible exacerbation and the assumptions that the individual living with BD lacked acknowledgement of having a chronic mental illness was the leitmotiv for informal caregivers to take the lead in delaying, or better, preventing a recurrent (hypo)manic or depressive episode for the sake of all stakeholders:

> My mother was… or we all, were constantly on top of him… It must have felt quite oppressive for my father… that he might have thought that we should back off and leave him alone for a while… but my mother, she was all over him, telling… no, summoning him, to take the medication that he needed for his own sake… (Informal caregiver 2)

Despite these good intentions, overprotectiveness and taking full control counteracted the situation and led to conflicts. Another problem informal caregivers had to overcome was the moral dilemma of what to do when they received early signals of a recurrent episode. Was it wise to confront the individual living with BD or inform professionals without permission of the individual when he or she was reluctant to take advice? Sometimes, informal caregivers' protective behavior even fed the stubbornness of individuals living with BD, which resulted in the individuals refusing any form of treatment, with recurrent episodes and rehospitalization as the outcome.

At the other end of the spectrum, there were informal caregivers with laissez-faire attitudes toward self-management. These caregivers hardly ever interfered in the individuals' attempts to regain control over BD. They were often drawn into a mediating role that sometimes led to situations where they became caught in the crossfire of escalating conflicts between individuals living with BD and others:

> If you want to be an informal caregiver, I think you have to be sure about what you are up to because it comes with great responsibilities and demands a lot of the time. I do not always like it. I mean, we have a good understanding and a natural sister bond, but sometimes… it is emotionally very demanding. There are days on which I am the one who is caught in the crossfire between family quarrels. (Informal caregiver 10)

Dividing tasks and responsibilities

Gradually, informal caregivers learned that self-management of BD does not entail them taking responsibility for the individual's situation because decisively taking control sooner or later led to tension. Fortunately, for informal caregivers who were on the borderline of a burnout, the individual living with BD responded emphatically to the signals of his or her exhausted partner by taking care of family matters:

> My father died a few months ago and before that I took care of him…That was a very burdensome time. I felt exhausted and emotionally overwhelmed… I said to him I could not bear it anymore… and he understood that very well; he picked up the responsibilities I used to do and took care for our family… A year ago, I thought this was never going to happen anymore… (Informal caregiver 3)

By this time, informal caregivers also embraced the idea that the individual with BD should be intrinsically motivated to self-manage his or her BD, and this should not be initiated by the caregiver. Instead, putting trust in the abilities of an individual living with BD to maintain his or her health induced the informal caregivers' confidence and capabilities to cope with a person who lives with BD:

> Even if things tend to go wrong with her, I am not scared because I have the confidence that I know what I have to do to regain control. That builds your confidence, knowing what to do… That is why I do not call the professionals each time she has a minor mood swing. (Informal caregiver 7)

This increased sufficiency of self-management support to individuals living with BD started with the wish of both the caregiver and individual to restore the reciprocity in their relationship. When communication was restored, it became clear to the informal caregiver what sort of support the individual living with BD actually needed. Open communication about the source of conflicts yielded the insight that mutual agreement had to be reached regarding the extent to which they both allowed this mental illness to disturb family living. Keeping balance in mood and activity was often a trade-off:

> It was a good move to let her work at the kindergarten. It helped her a lot to get around people again. At first, she found it quite exhausting, but she learned to take breaks and balance her activity level. We often discuss whether or not she should do something. It is all about finding a balance in activities and responsibilities; if you do one thing, you have to keep in mind that another thing has to go. (Informal caregiver 6)

Acquiring a personal definition of self-management support for individuals living with BD

Over time, informal caregivers acquired a keen eye for recognizing the signs and signals of a prodromal phase of an episode, even before the individual living with BD noticed it. However, informal caregivers acknowledged that these insights were the source of many conflicts. Reflections on previous phases made them aware that it was better to bring up the urgency of the message without being emotionally drawn into a discussion. A creative way to avoid conflicts was to communicate with "code words" or "red flags" without expressing emotions:

> Usually, I can tell by the sound of her voice what her current mood is. If I, for example, ask her what she is up to and she tells me that she has lots of things going on or planned, I tell her that I have the *feeling* that you are a little too "jumpy"… we use that expression instead of the term "hypomania" because it does not have that pathological connotation about which she is so sensitive. We have chosen to use this kind of expression as a code word. My sister immediately recognizes the red flag without confronting her with her illness, and therefore she is willing to let, or do, things to counteract a mood swing. (Informal caregiver 10)

Overall, informal caregivers gradually learned how to support self-management by moderating their intrusiveness. They learned to provide positive feedback and step back when things went well. Informal caregivers grasped that individuals living with BD were empowered by putting trust in their good intentions and capabilities to self-manage BD. This trust in knowing what to do could restore the long-lost self-esteem of both the individual with BD and caregiver:

> What you should preserve is confidence, self-esteem… nothing is more disastrous for someone's confidence than not being able to trust your own mind anymore… that must be horrifying… I consider it of utmost importance that an individual's confidence is restored… by picking up small activities and responsibilities… just to let her know, that she is able to do things again, step by step… looking for strongholds, that is self-management support. (Informal caregiver 7)

DISCUSSION

According to our findings, the learning process of informal caregivers started with an endeavor to comprehend the concept of BD. This learning strategy provided the basic knowledge with which to fulfil a supporting role, which seems a successful effort that indeed reduces the number of early relapses of (hypo)manic and/or depressive episodes (Perlick et al., 2010). However, we found that gaining basic knowledge with which to comprehend BD also had its downsides. Collecting information about the features of BD did not immediately yield insight into the differences between pathological and normal behavior of individuals living with BD. It also unintentionally created a gap in knowledge, acceptance, and motivation between informal caregivers and individuals living with BD that led to distress, mutual incomprehension, and conflicts in the first phase of this learning process. Seeking help from peers led to more recognition and support from other informal caregivers, but also had the adverse effect of hearing about negative experiences that created a horrible image of an unpredictable disease with a high rate of recurrent episodes that were impossible to control (Jönsson, Skarsater, Wijk, & Danielson, 2011; Jönsson, Wijk, et al., 2011).

It is well-known that close informal caregiver involvement increases the complexity of the caring process for all stakeholders (Chatzidamianos, Lobban, & Jones, 2015; Peters, Pontin, Lobban, & Morriss, 2011). We believe that this complexity of care delivery can be explained by the asynchrony of differentiated learning phases between informal caregivers and individuals living with BD (van den Heuvel et al., 2015). In the present study, we found that the more the informal caregivers were involved in the treatment of the individual living with BD, the more it seemed to them that the individuals living with BD became reluctant to accept help. These findings are in line with literature that reports disenfranchised feelings about caregivers' contributions to care for individuals living with BD and high rates of perceived burden of informal caregivers because of the consequences of recurrent episodes, frequent hospitalizations, and lack of commitment or non-adherence to treatment by the individuals living with BD (Beentjes et al., 2012; Reinares et al., 2006; Lewis, 2015). Some informal caregivers who were a parent or child were closely involved and highly alert to prodromal symptoms because of their dormant fear of a recurrent episode. In contrast, the informal caregivers who were somewhat more distantly related, such as siblings or friends, were the ones who found an efficient definition of self-management support by balancing between being there for an individual living with BD and meeting their own needs.

The learning phase wherein daily tasks were divided was the tipping point where informal caregiver involvement was tempered and individuals living with BD started taking on more family responsibilities. Our findings are in line with the literature that shows that informal caregivers look for a balance between self-effacement (putting the needs of others first) and self-fulfillment (putting the needs of themselves first) to prevent being brought down by the burden caused by living with someone with BD (van der Voort, Goossens, & van der Bijl, 2009). Informal caregivers are always a step ahead in recognizing prodromal symptoms, almost like a seismograph, before the individual who lives with BD notices the signs (Rusner et al., 2013). So when the informal caregivers opt for self-effacement, the individual living with BD interprets this help as meddling and becomes reluctant to accept it. Our results show that this often culminates in an absolute need for informal caregiver to control. However, informal caregivers often feel one step behind the needs of the individual living with BD, so when the informal caregivers aim for self-fulfillment, individuals living with BD tend to feel abandoned, especially when a prodromal phase of a recurrent episode has occurred (van den Heuvel et al., 2015). Therefore, informal caregivers end up in a paradoxical situation on account of an attract–repel attitude of the individual living with BD (Rusner et al., 2013; van der Voort et al., 2009).

Despite good intentions, overprotectiveness and taking control worked against the situation and led to conflicts. Studies have confirmed that the high expression of emotions and a criticizing or uninterested attitude on the part of informal caregivers are detrimental to effective outcomes in the treatment of BD (Granek et al., 2016; Miklowitz, 2007; Scott et al., 2012). The consequences of emotional over-involvement and high expression of emotions in the (non)verbal communication of informal caregivers are recognized as a negative moderator of outcomes in the treatment of BD (Fredman, Baucom, Boeding, & Miklowitz, 2015; Kim & Miklowitz, 2004; Leff & Vaughn, 1985). Informal caregivers in our study learned that escalating conflicts fed the stubbornness of individuals living with BD, who then boycotted all forms of treatment as a means of protest, thus leading to more recurrent episodes over time (Miklowitz et al., 2009; Miklowitz & Chung; 2016; Reinares et al., 2016).

Later on in the learning process, informal caregivers became aware that efficient support of individuals in self-managing BD meant confining their emotional overreactions and learning to communicate in a non-confrontational style to avoid disagreement and a high expression of emotions. For instance, by using a code word to warn the individual living with BD about an upcoming prodromal sign without becoming too emotionally involved. Open communication, mutual trust, and reciprocity restored the relationship between informal caregiver and the individual living with BD. Informal caregivers eventually understood that efficient support in the self-management of BD meant resisting what the French philosopher Emmanuel Levinas (2012) called “the endless responsibility that goes out from the compelling call expressed in the face of a needing person.” Instead of primarily responding to upcoming episodes with emotional over-involvement, informal caregivers learned to reframe the “call for help” of an individual living with BD as the need to help them overcome their perceived helplessness.

Strengths and limitations of the study

Qualitative research has its limitations when it comes to the validity and reliability of a study’s results; therefore, different criteria are formulated that are more applicable to this approach to ensure its scientific rigor (Lincoln & Guba, 1985). By using a phenomenological method of open interview techniques guided by a topic list and an inductive data analysis, the replicability of this study became limited. However, to increase the trustworthiness of our results, we audited our process by using a logbook of field notes, performed peer debriefing and researcher triangulation, and used a computer-assisted qualitative data analysis software package.

Our recruitment strategy led to a convenience sample of informal caregivers that does not ensure the preferable “variation of perspectives” of a phenomenological approach, so our description of the views on self-management support for individuals living with BD might not be as “dense” as it could have been if the sample were purposively set (Husserl, 1973, 1984). However, we increased the rigor of our phenomenological content analysis by using a constant stepwise approach until data saturation has been reached. We considered the data to be saturated when no new topics were heard during the interviews.

Although our results are limited to the context of the Dutch healthcare system, the insights into learning how to support self-management as an informal caregiver might be transferable to similar situations, settings, and practices. To guarantee the authenticity of our study’s results, informal caregivers’ learning processes were affirmed by the original citations of respondents. Confirmability was achieved by sending respondents written summaries of the transcripts as a member check.

Conclusions and relevance for clinical practice

We have logically reconstructed that informal caregivers learn in phases, first by comprehending the concept of BD, then overcoming the dilemmas stemming from living with someone with BD, next to gradually understanding the devastating results of emotional over-involvement and high expression of emotions and solving this by a division of responsibilities, and finally, later knowing how to define and delimit their supporting role in the self-management of BD. We want to emphasize that there is no “final phase” in this learning process because learning requires lifelong maintenance. The different phases in this learning process are not chronological, but instead are intertwined and sometimes co-existing. The learning phase of an informal caregiver depends on what outcomes his or her supporting actions sort and, on the episodic fluctuations of the individual living with BD. Our findings indicate that self-management support for individuals living with BD is a cyclic process that evolves over time and comes with a changing attitude toward a measure of informal caregiver involvement that is appropriate for the learning phase of the self-management of the individual living with BD.

In our opinion, professionals should recognize the differences in the educational needs of both individuals living with BD and informal caregivers. The asynchrony of learning processes of both can easily grow into a source of conflict that ultimately leads to a vicious circle of triggering recurrent episodes. Further research is needed to specify the didactical professional role required for each phase in the learning process of individuals living with BD and their informal caregivers. Nevertheless, based on our findings, we advise professionals to aim their actions toward guiding the flow of information and correcting misunderstandings when informal caregivers are learning to comprehend BD. In the next learning phase, professionals should focus on the relationship between the informal caregiver and the individual living with BD to support them in overcoming the dilemmas of caregiving. When responsibilities are shifting, professionals could teach informal caregivers how to cope with insecurities and support individuals living with BD through positive reinforcement.

The increased attention toward the self-management of chronic illnesses also entails that informal caregivers must be properly equipped to address the demands of efficient self-management support for individuals living with BD. Psycho-educational programs wherein both individuals living with BD and informal caregivers can partly deliver the knowledge that is necessary to cope with the negative consequences of BD. However, to develop and refine the supporting skills informal caregivers require, more attention should be given to self-management support for individuals living with BD by inserting it as a routine part in the conversation during consultations.

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Chapter 6

Self-management Education for Bipolar Disorders: a Hermeneutic-Phenomenological Study on the Tacit Knowledge of Mental Health Nurses

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ABSTRACT

Background: Self-management of bipolar disorder (BD) education is a complex nursing intervention in which patients and informal caregivers are taught to be actively involved in self-monitoring and self-regulating activities. Some studies question if nurses are sufficiently equipped to deliver these educational tasks. Other studies suggest that nurses have gathered their knowledge implicitly by experience, but to date this tacit knowledge is not described from the experiences of mental health nurses (MHNs) in ambulant BD care.

Objective: To detect the tacit knowledge used by MHNs by interpreting their experiences in delivering self-management education to people with BD and their informal caregivers.

Methods: A phenomenological-hermeneutical study amongst MHNs (N=9) from three ambulant BD care clinics in the Netherlands. Face-to-face, open, in-depth interviews guided by a topic list, were conducted and transcribed verbatim prior to the hermeneutical analysis.

Findings: We found five categories resembling the complex character of self-management interventions provided by MHNs; Building a trustful collaboration, Starting a dialogue about needs and responsibilities, Explaining bipolar disorder, Utilizing mood monitoring instruments, and Conceptualizing self-management of BD.

Conclusion: Eventually MHNs use tacit knowledge to cope with situations that demand an outside-the-box approach. Self-management education is partially trained, and partially mastered through experience.

Practice Implications: In order to facilitate long-term self-management of BD, the collaboration of a supporting network is essential.

INTRODUCTION

Bipolar disorder (BD) is a severe chronic mental illness, characterized by fluctuating activity patterns and mood swings that alternate between euthymic, (hypo) manic, major depressive, or mixed episodes, affecting 1% of the (European) population between 18-65 years (American Psychiatric Association, 2013; De Graaf, ten Have, van Gool, & van Dorsselaer, 2012). Acute treatment of BD consists predominately out of symptom reduction and relapse prevention by pharmaceutical interventions and clinical admission. When the symptoms are in remission, the treatment continues in an ambulant setting with focus on medication adherence, psychological and psychosocial support, and self-management education (Bauer, Biswas, & Kilbourne, 2009; Crowe et al., 2010; Kupka et al., 2015).

Self-management of BD is a continuous learning process of self-regulation, active involvement, and reflection that demands proper educational guidance and support to flourish (Michalak,et al., 2016; Morton, Michalak, Hole, Buzwell, & Murray, 2018; van den Heuvel, Goossens, Terlouw, Van Achterberg, & Schoonhoven, 2015). It entails pharmaceutical treatment maintenance, learning to monitor mood and register activities via life charting, and timely recognition of and responding to prodromal symptoms to counteract recurrent episodes, preferably in conjunction with informal caregiver support (Goossens, Kupka, Beentjes, & van Achterberg, 2010; Janney, Bauer, & Kilbourne, 2014; van Bendegem, van den Heuvel, Kramer, & Goossens, 2014).

Self-management of BD education is a complex intervention aiming to improve health outcomes, and is mostly delivered by nursing staff (Clark, 2008; Coster & Norman, 2009; Jones, Deville, Mayes, & Lobban, 2011). However, in some studies it is questioned if nurses are sufficiently trained to comprehend the complexity of self-management education (Been-Dahmen, Dwarswaard, Hazes, Ista, & van Staa, 2014; Lawn et al., 2009, Pols et al., 2009). Instead of being skilled in self-management education during formal training it is more likely that nurses have enriched their knowledge implicitly by professional experience (McDonald, Rogers, & Macdonald, 2008; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2014).

Implicit learning in nursing practice is often described as tacit knowledge. However, the concept of tacit knowledge refers to a synthesis between implicit knowledge, gradually accumulated (without reflection) over the years by clinical experience, and formal explicit knowledge, systematically mastered by, and reflected upon, in professional training (Welsh & Lyons, 2001). Tacit knowledge evolves over time from a tacit understanding of people and clinical situations into recognized events that become routinized actions with rapid decision making. However, most implicit clinical decision making is not critically used, and often recalled by nurses as ‘a hunch’, with reflection afterwards. This implicit situational character makes it difficult to study how tacit rules underpin intuitive decision making processes (Eraut, 2000; Meerabeau, 1992; Welsh & Lyons, 2001).

Tacit knowledge is hard to detect because individuals might not recognize what they have acquainted over years. Nevertheless, tacit knowledge plays an important part in mastering skills, developing expertise, and reflective practice in healthcare professions (Evans & Kersh, 2004; Kinsella, 2009; Patel, Kaufman, & Arocha, 1998). This premise holds especially for mental healthcare wherein both persons and situations are often difficult to ‘read’, explaining why mental health nurses (MHNs) rely heavily on their experiential knowledge in clinical decisions (Campbell, Massey, Broadbent, & Clarke, 2018; MacNeela, Scott, Treacy, & Hyde, 2010).

Aim of the study

The general aim of this study is to detect the tacit knowledge used by MHNs by interpreting their experiences in delivering self-management education to people with BD and their informal caregivers.

METHOD

Design

We have used a hermeneutic-phenomenological approach in the tradition of Heidegger (1957) and Gadamer (1986). Hermeneutical phenomenology is an iterative-narrative method of data gathering and data-interpretation (Dowling, 2007; Giorgi, 2005; Thirsk & Clark, 2017). This method was favored over descriptive phenomenology (Husserl, 1973) for two methodological reasons: 1) the experiences of two researchers as a nurse with people of BD would interfere descriptive analysis because 'bracketing' of prejudgments would be impossible. Instead, we deliberately made use of the knowledge and experiences of all researchers during the iterative process of data collection and -analyses as a 'preunderstanding' according the hermeneutical-phenomenological philosophy (Heidegger, 1957; Gadamer, 1986; Thirsk & Clark, 2017); 2) We considered tacit- and explicit knowledge to be intertwined. To differentiate the former from the latter, we asked questions to capture the explicit knowledge acquainted in basic training, from textbooks and multidisciplinary guidelines, and invited the respondents to reflect on the tacit understandings, rules, and actions that guided their decisions in peculiar experienced cases. By doing so, we made the implicit, explicit (Kothari, Bickford, Edwards, Dobbins, & Meyer, 2011; Kothari et al., 2012).

Ethical considerations

There were no objections to conducting this study according to the Dutch regulations for medical-ethical review following the declaration of Helsinki (http://www.ccmo.nl). The local executive boards of participating institutes granted approval for recruitment and data-collection. All participants received written information, and signed an informed consent before an interview was started. All data gathered was treated confidentially and anonymously.

Setting and recruitment of participants

The interviewer (SvdH) informed the multidisciplinary teams of three community care clinics for specialized treatment of BD across the Netherlands through a short presentation and delivered additional information written in brochures to recruit MHNs. Participants were included when being registered nurses with experience in delivering self-management education to people with BD and their informal caregivers. Out of the available candidates we recruited a purposive sample of MHNs that varied in age, gender, educational level, and working experience, as presented in table 1.

Table 1: Demographic characteristics of interviewed MHNs

CPN	Job classification	Sex	Age	Years of experience (with BD-patients)
1	Master Advanced Nurse Practitioner	M	54	35 (7)
2	Master Advanced Nurse Practitioner	M	43	19 (5)
3	Community Psychiatric Nurse	F	32	10 (4)
4	Master Advanced Nurse Practitioner	F	48	25 (2,5)
5	Community Psychiatric Nurse	M	43	17 (4)
6	Community Psychiatric Nurse	F	32	13 (1)
7	Community Psychiatric Nurse	F	50	20 (13)
8	Community Psychiatric Nurse	M	37	12 (4)
9	Community Psychiatric Nurse	M	52	35 (7)

Data collection

The interviewer (SvdH) collected data through in-depth topic list guided face-to-face interviews of 35-90 minutes with nine MHNs on which we reached saturation. All interviews were digitally recorded and transcribed verbatim. Each interview started with the question: ‘What does self-management in BD entail to you?”. Subsequently, the interviewer probed on the interviewees’ answers about what challenges, successes, frustrations, and dilemmas they encountered, and how they had coped with these experiences.

We started with a topic list based on modified themes of the general activity model from the Expansive Learning Theory of Engeström & Sannino (2010) assuming that learning activities are situated in a collaborative network, to guide the interviewees when they narrated beyond the scope of our research. The topic list entailed themes such as; the ‘(division of) responsibilities’, ‘(shared) decision making processes’, ‘mutual expectations of treatment’, and utilizing ‘(instruments) of mood monitoring’. After each analysis of a previous interview, new themes were added to the aide memoire and used for probing answers in the next interview.

Data analysis

Three analysts (SvdH, PG and CT) separately read the full transcripts thoroughly and interpreted the data from their professional perspective, in line with the hermeneutical principle that the background of the analysts is part of the interpretation. SvdH is an experienced psychiatric nurse, and nurse educator, PG is an experienced advanced nurse practitioner in ambulant bipolar care and a senior researcher, CT is an experienced educationalist and a senior researcher. LS and TvA are both experienced senior supervisors and nurses, who guided the discussions of SH, CT and PG.

We used a six-step hermeneutic-phenomenological approach based on the work of Heidegger (1957) and Gadamer (1986) in which the steps 1-3 of or analysis iteratively were repeated., These steps are in accordance with the hermeneutical premise that each preunderstanding (*Vorstehen*) leads to an affirmed understanding (*Verstehen*), when this procedure iteratively is repeated until data saturation is obtained (*Hermeutische Zirkel*). The six steps we took in our hermeneutical data analysis were:

1. Three analysts (SvdH, PG and CT) separately read the full transcripts thoroughly. Next they discussed their first ideas about each interview as preunderstandings from their professional perspectives in a peer debriefing in order to increase trustworthiness (Lincoln & Guba, 1985). The interviewer (SvdH) inserted then his concepts in the ATLAS.ti 7 data analysis software package as open codes (Friese, 2012).

2. The three analysts (SvdH, PG, CT) intermediately compared and discussed the preunderstandings (open codes) after two or three interviews until they reached consensus about the conceptual meaning (label) of a phrase. Based on the new insights that emerged from the peer debriefing, the open codes of the interviewer were either kept, altered or refined in the data set.

3. The transcripts analyzed were summarized and all respondents received their summary as a member check. Besides some textual remarks, we only received confirmations implying that our interpretations were correct.

4. We categorized the labels on similarity in meaning until no topics were added or replaced, considering the data to be well understood and therefore saturated. Two analysts (LS and TvA) supervised the process and reflected on the other three analysts in this final phase of the analysis.

5. The summaries of the member checks and responses were part of an audit trail that also included a logbook with observational, theoretical, and analytical memos. The logbook was used during data collection in order to guide interpretations when writing the final narrative (*Horizont*).

6. All categorized codes were written out in a narrative. The summaries and audit trial was read again and compared with the narrative. The final narrative was revised until we considered the central question was answered well and the essence was grasped (*völlig Verstehen*).

RESULTS

MHN's' experiences in providing self-management support

Five overarching themes reconstruct how self-management of BD is provided by MHNs and what tacit and explicit knowledge underpin their decision making processes: *Building a trustful collaboration*, *Starting a dialogue on needs and responsibilities*, *Explaining bipolar disorder, Utilizing mood monitoring instruments*, and *Conceptualizing self-management of BD.* The first four themes resemble the educational process towards self-management of BD. The fifth theme categorizes an overall view on what self-management of BD education entails. To differentiate tacit knowledge from explicit knowledge, the latter is written in italic text. Tacit knowledge is indicated by phrases starting with 'MHNs' followed by a verb.

Building a trustful collaboration

The Dutch multidisciplinary guideline for treatment of BD prescribes that individuals start with receiving information and using mood monitoring instruments. However, after the remission of an acute episode, persons with BD and their informal caregivers often struggle to regain a new equilibrium in the unbalanced mood, and they puzzle on how they get familiar with the features of the illness. Therefore, the MHNs in our study considered that starting with ambulant treatment is the beginning of a learning curve, and spent the first few appointments on acquaintance instead.

> "The first thing I do is to get acquainted in the beginning. I choose this approach on purpose, I find it very important to invest in our collaboration. Sometimes so much, that I forget that I have to introduce some others things as well, such as mood monitoring instruments, according the [multidisciplinary] guideline [for treatment of BD]." (MHN 1)

MHNs learned that the time spent on acquaintance is a good investment to build a trustful collaboration that would pay off in case of a recurrent episode. It also gave people with BD and their informal caregivers the opportunity to recover from the acute episode, to tell their story and reflect on the impact of the diagnosis. *However, not all persons with BD are convinced of the correctness of their diagnosis, or accept having BD*. MHNs interpreted this phenomenon as a temporary phase of grief.

> "Just as the phases of grief that were described by Kübler-Ross, accepting one has bipolar disorder is not linear, it goes back- and forward. I do not believe that anyone fully accepts having a chronic illness, there is always opposition, angriness, despair… those kind of feelings stay lingering… full acceptance seems not attainable, and one might even question if it is required." (MHN 2)

MHNs found it particularly difficult when a person with BD did not speak about his current condition, *just because he enjoyed the elevated mood too much, or out of fear of hospitalization and increasing medication.*

> "Why do I have to explain to them why I'm feeling great? Maybe they start all over again with their life style advices and restrictions…I am not into it right now, I feel awesome" That is the reason why persons with BD experience recurrent (hypo)manic episodes, they want to keep that elevated mood. But, sooner or later it tips over. That is exactly the learning part of the experience, and sometimes it takes years for someone to figure that out… okay it is better not to masquerade my problems or else history might repeat itself. That is what I call 'managing your illness'. (MHN 8)

Masquerading dwelling symptomatic features might lead to a full episode. That is why MHN' altered their aim into building a trustful collaboration wherein persons with BD have the opportunity to talk frankly about their affliction *instead of starting with the prescribed introduction of instruments for mood monitoring.*

Starting a dialogue about needs and responsibilities

The primary aim of self-management education is to keep the person with BD in control, with additional support of informal caregivers and professionals. Therefore, MHNs facilitated 24/7 professional support by telephone, on the condition of only to use it in a case of emergency, because they had experienced that 'being present at a distance' evoked confidence in self-managing BD.

“Why should we think patients aren’t capable of managing their own health? Why should they not make their own calculations of whether they can comprehend a situation or not, and ask for help if they do not know what to do anymore? And if it happens that a patient feels he was not capable in doing so... then it is a great opportunity to start a dialogue...”(MHN 2)

A challenge is the measure of informal caregiver involvement, especially when the informal caregiver is not willing to let go of the caring role, or is not convinced of the possibility of self-managing BD. On the other hand, MHNs also mentioned that the autonomy-model of self-management sometimes did not appeal to the cultural expectations of informal caregivers.

“Well, I was thinking about a woman who is 6o years old, from Pakistan and doesn’t speak Dutch… she lives at her sons’ home and receives full care from her daughter-in-law. She is diagnosed with BD II, and suffers from long depressive episodes with a few hypomanic episodes. When I visited them for the first time I worried a lot, and I wanted to intervene to diminish the burden of the informal caregivers… At this point a year has past and I hardly have to do anything… they are managing it all by themselves and they all feel fine with it… maybe we should call it informal caregiver-management instead.”(MHN 6)

Psycho-education is a key intervention to increase the knowledge of BD, essential to learn to recognize symptoms and how to cope with this illness. However, MHNs encountered a difference between the receptiveness of the person with BD and the informal caregiver. The former is often doubting the diagnosis and reluctant to even name the illness, whilst the latter is often well informed. MHNs struggled to navigate between the contrasting information needs and were sometimes drawn into family quarrels.

“Well, the mother wants to know if BD is a chronic illness? How long does it take to get better?… and he is very young… so it is hard to give a prognosis…you just hope there will be no recurrent episode… but if it happens there is no doubt he has it, and maybe he has to take down his medicine for the rest of his life… It is hard to tell such things in front of the client, because… you know, I do not want to scare him off for what might come… on the other hand you do not want to misinform the informal caregiver… I do not know what other colleagues have told you about these kind of things… but… I find this very difficult… to manage these kind of problems …” (MHN 9)

To prevent quarrels with high expressed emotions out of fear to trigger a new episode, MHNs purposively reframed discussions about roles and responsibilities into self-management actions.

“You have to explain to informal caregivers that some actions are quite understandable, and that it is part of the illness, nothing personal. I often try to ‘de-accuse’, or reframe the action, to something as being a part of self-care, or self-management… For instance, ‘canceling a visit on a short notice’ becomes ‘withdrawing from social engagements to counteract an uplifting mood’. It creates mutual understanding.” (MHN 1)

Explaining bipolar disorder

MHNs found that the concept of ‘bipolar disorder’ seemed too complex for some individuals to grasp, making it hard to view the possibilities of self-managing this illness.

“I aim on the context of someone’s personal experiences, not over weeks, but over years.. in hindsight… what problems have occurred? This retrospective reflection helps people to get some first insights into their pattern of mood swing and (lack of) activities. The down side of this approach is that it confronts them with the fact that it might well be bipolar disorder… even when they recognize some of it, they have a hard time acknowledging it. Clients experience this illness as a very vague concept, it is hard for them to grasp.”(MHN 5)

Therefore, MHNs gradually altered their psychoeducational goals from *explaining bipolar disorder* to correcting misunderstood or incorrect information found on the internet, and by connecting existing knowledge to previous coping behavior or the social-occupational background of an individual with BD. They used metaphors to explain medical jargon and tangling the abstract features of BD into the narrative of the person with BD.

"Sometimes I call it the 'conjuncture of mood' when I ask him *person with BD* about his current mood state, you know he has a rapid cycling BD … and he is an economy student, so I tried to tie in, in his language… asking him if he is in a high conjuncture, or… most of the time you are trying to connect to one's own narrative."(MHN 3)

MHNs drew simple pictures to visualize the complex course of (hypo)manic and depressive mood episodes collected from *the reconstructed patterns of former mood swings of the retrospective life chart* to induce awareness and hindsight. MHNs found that illness-reconstruction evoked valuable insights into the triggering events that had led to a (hypo) manic or depressive episode by individuals with BD.

"Often when people see this booklet for the first time, they mention that they are not that severely ill. So, I developed a method during psycho-education where we use a retrospective life chart to let patients and caregivers draw the pattern of activities and mood based on their own experiences. And all of a sudden people start noticing things afterwards… start reflecting on the first symptoms that occurred … It produces a great insight." (MHN 5)

Utilizing mood monitoring instruments

The use of mood monitoring instruments is strongly recommended in the Dutch multidisciplinary guideline for BD, but additionally MHNs developed a systematic sequence to augment the utility of mood monitoring instruments. Starting with the retrospective life chart to map the course of the illness to detect 'red flag events' as input for a relapse prevention plan. Followed by the prospective life chart to teach how to monitor current mood, and pinpoint prodromal symptoms of episodic mood swings. MHNs found that sequentially utilizing these instrument empowered persons with BD and gave them a sense of mastery and self-confidence in managing BD.

"Self-management in this field is about teaching people with BD and their informal caregivers how to utilize the prospective life chart... monitoring their mood and activity pattern. This instrument is very helpful for recognizing prodromal symptoms… to manage some control over it… to regain autonomy. Knowing what to do, and knowing when someone has to take over." (MHN 3)

Although the life chart is the most utilized instrument to monitor mood, MHNs found that additionally using the perspective of the informal caregiver is vital to enhance reflection.

"You try to involve the informal caregiver into the process of mood monitoring. They are the ones who often recognize prodromal symptoms much earlier than the person with BD. I'll always discuss this with a client, to let them know that is part of getting to know oneself… that others can help you how to learn to reflect upon your own behavior… because everyone has got some blind spots…." (MHN 4)

Introducing the relapse prevention plan to persons with BD according multidisciplinary guidelines is a delicate process. MHNs noticed that individuals who were struggling with acceptance of their illness, *described their prodromal symptoms and actions* from a third-person perspective to avoid the implication of being personally responsible for the consequences. Therefore, MHNs developed a more subtle non-confronting approach to personalize mood monitoring instruments.

"... And in the next phase I'll ask them to write 'I...' in front of their prodromal symptoms to test its validity... 'I become anxious when standing in the queue for groceries'… 'I get irritated at the cashier'. Although it is confronting, it also implies it is YOUR red flag, a personalized relapse prevention plan that is tailored to your situation."(MHN 7)

MHNs found a positive additional effect of the personalized relapse prevention plan, it also functioned as a self-binding contract in which is agreed on forehand what interventions are allowed by whom during a crisis, with a view to being on speaking terms afterwards. MHNs saw it as a ratification of a trustful collaboration.

"The most useful instrument to create collaboration is the relapse prevention plan. However, the description of symptoms have to be very clear, as detailed as possible. You can use it very well on sudden occasions [where] it is important to hold on to what is agreed upon and written down… I have never experienced a problem with my own clients afterwards, even when I had to force them… because we agreed upon it on forehand. If I had a problem with someone, it was with a person that I had not spoken to before." (MHN 9)

Conceptualizing self-management of BD

MHNs knew the term 'self-management' from the Dutch multidisciplinary guideline for BD. However, opinions differed on the conceptualization.

"Sometimes the concept of self-management of BD is completely misunderstood by the patient… it is interpreted as 'I am going to do this on my own'… 'without medication, without help of others'… if you take it that literally, it might be a problem. It illustrates the gravity of this concept in our practice…" (MHN 6)

MHNs stated that self-management of BD is an explication of what was always the case, but nowadays, the roles, responsibilities and actions are more overt. A coalition of stakeholders know what to do and can decide when and whether or not to intervene to prevent full episodes.

"That is why you have to build a trustful collaboration… If you come with this life-chart booklet and emphasize the importance of it… they will respond to you that they expect you to help them to diminish their maladies… And they are right. But, self-management opens opportunities to get back in control of your life. People don't want to be solely dependent on the doctor's advice and medication, and that is where I come in to sell the product [self-management], by saying here is your chance to do something about it!" (MHN 5)

Self-management implies being in control, and control entails autonomy and clear judgement. However, the margin to do so is related to a euthymic mood episode. MHNs learned that beyond this range of rationality, the autonomy slips away and others have to take over.

"[When] they navigate between 45 and 55 points on a mood scale… in between these [euthymic] margins we are able to book progress in terms of self-management of BD. […] When it is a crisis situation I am quite straightforward to take over, but sometimes I decide to let the client figure it out by himself and learn from it… of course I am watching him like a hawk and intervene before anything bad happens." (MHN 7)

MHNs found that the success of self-managing BD depends on the capability of an individual to reflect upon his actions, and the interaction with significant others. But, self-management education hampers when an individual lacks the ability or refuses to see his part in the process, which often happens when mood episodes alternate, or in cases of comorbidity, such as personality disorders or substance use.

I had a client who is quite impossible so to say… He had made a mess of his life, debts, lost his driver's license, relational problems…the usual story… [but] the problem is that he also has some personality problems and drug use… every time you think, now he has suffered the consequences… he should know by now… he just does it over and over again, without learning from it."(MHN 9)

MHNs considered self-management of BD education as a learning process that needs a scaffolding network of stakeholders delivering support to an individual, but, if necessary also temporarily take over control until he is back on his feet.

> “It is as teaching a child cycling. You have to build the bicycle, assemble the side-wheels, and adjust the stability to the personal needs. If he falls, in spite of all efforts, we are there to pick him up afterwards and fix the damage that is done. We help him to get back on the saddle, give a little push and let them go… hoping they do not fall again, or when he does the story repeats until they manage to cycle on their own.”(MHN 8)

DISCUSSION

The aim of this study was to detect the tacit knowledge used by MHNs when delivering self-management of BD education by interpreting their experiences. Instead of starting with information and psychoeducation as recommended in the multidisciplinary guidelines (Colom & Lam, 2005; Kupka et al., 2015), we found that MHNs prioritized acquaintance and a dialogue on the impact of BD. MHNs also added the use of metaphors in psychoeducation to explain difficult concepts, and developed a language that accumulated information to existing (occupational) knowledge, which is in line with literature that shows that self-management correlates with health literacy (Eckman et al., 2012).

We found that MHNs used the retrospective life chart to reconstruct previous episodes which is basic care, but additionally used this reconstruction to visualize mood patterns to evoke insight (Born, Amann, Grunze, Post, & Scharer, 2014; Honig et al. 2001; Post et al., 2003). The visualized mood patterns helped persons with BD and informal caregivers to pinpoint and describe early warning signs prior to an episode in a relapse prevention plan (Daggenvoorde, Goossens, & Gamel, 2013, Goossens, et al., 2010). The relapse prevention plan in turn was used to personalize the recognition of prodromal signs and symptoms in the prospective life chart to detect upcoming mood swings (Denicoff et al., 2002; Van Bendegem et al., 2014).

MHNs showed that the personalization of mood monitoring instruments creates a feeling of ownership, it confirms a collaboration, and helps informal caregivers to differentiate pathological- from and normal mood fluctuations. A salient finding was the careful approach of MHNs in personalizing a relapse prevention plan to prevent unnecessary feelings of being confronted with one’s inabilities, in line with studies that indicate the detrimental consequences of a confronting attitude (Fredman, Baucom, Boeding, & Miklowitz, 2015).

Our findings might suggest that MHNs primarily aimed their interventions at the wellbeing of persons with BD rather than the informal caregivers. This is closely related to a definition of self-management as ‘an individual’s capacity to manage the signs, symptoms, and consequences of a chronic condition’ (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2003). However, it is well known that BD has a devastating impact on the lives of informal caregivers too (Granek, Danan, Bersudsky, & Osher, 2016; Rusner, Carlsson, Brunt, & Nystrom, 2013). Studies indicate high caregiver burden due to the consequences of recurrent episodes, frequent hospitalizations, and a lack of the person with BD’s commitment or non-adherence to treatment (Beentjes, Goossens, & Poslawsky, 2012; Reinares et. al., 2016; van der Voort, Goossens, & van der Bijl, 2009). Although, informal caregiver involvement has a positive effect on the success of the treatment of BD, we found that MHNs do not aim self-management education directly at them (Miklowitz, 2007; Perlick et al., 2010; Scott, Colom, Pope, Reinares, & Vieta, 2012).

Our study shows that MHNs had to mediate between contrasting perspectives of the person with BD and the informal caregivers on what signs had to be interpreted as symptoms of BD, thereby avoiding emotional escalations that might trigger an episode. MHNs tacitly added a diplomatic strategy to their repertoire, which is fruitful because it is well known that high expressed emotions alter the course of the illness for the worse (Barrowclough & Hooley, 2003; Kim & Miklowitz, 2004; Miklowitz et al., 2009), especially when an individual is shifting to (hypo)mania (Beentjes, Goossens, & Jongerden, 2016). Moreover, by involving informal caregivers in the process of self-management of BD education, the awareness of different perspectives increased, and a dialogue towards a better mutual understanding was opened (van den Heuvel, et.al., 2018).

Additional to basic care, MHNs aimed at building a trustful triadic collaboration with the person with BD and the informal caregiver to function as a safety net and to take over control when necessary. Although it is complex to navigate between the different perspectives, ideas and motivations of persons with BD and their informal caregivers, several studies emphasize the necessity of facilitating a collaborative network to cope with BD (Chatzidamianos, Lobban, & Jones, 2015; Peters, Pontin, Lobban, & Morriss, 2011). Taking over control and deciding what is best for a person with BD, both from a professional- or informal caregiver point of view, might seem the opposite of self-management. However, if agreed upon on forehand, written down in a relapse prevention plan, and all acting accordingly, it enhances trust because all stakeholders can rely on this covenant.

Strengths and limitations

This is a small exploratory study, but we have reached data-saturation and used a solid rigor in our hermeneutic analysis that provided an in-depth description of the tacit knowledge of MHN's when providing self-management education. Although, tacit knowledge is difficult to detect for its covert implicit nature and is cultivated over years (Eraut, 2000; Meerabeau, 1992; Welsh & Lyons, 2001), our interview techniques provoked reflection on clinical experiences in self-management education to manifest tacit decision-making processes. This approach is compatible with our hermeneutic design in which the professional background of the researchers (SvdH, PG LS, TvA, as nurses and CT as educationalist) was functionally deployed in peer-debriefing adding inter-views to the interviews. Nevertheless, we solely focused our attention on MHNs assuming that they are the over-represented discipline in delivering self-management support (Coster & Norman, 2009). Yet, the treatment of BD is interdisciplinary (Bauer et al., 2009; Jones et al., 2011; Kupka et al., 2015). Therefore, we recommend that future studies use multidisciplinary, and thus more representative samples to strengthen the transferability of study results (Lincoln & Guba, 1985).

Conclusions

This study shows that MHNs have a good explicit knowledge of multidisciplinary guidelines, handbooks and scientific literature, but eventually tacit knowledge is used to cope with situations that demand an outside-the-box approach. Self-management education is partially trained, and partially mastered through experience.

Implications for practice

The results of our study show that working within a supporting network is a key component in self-management of BD education. This supporting network promotes an individual's autonomy but also provides possibilities to restrain this autonomy when a person with BD is temporarily not capable to decide for himself. A relapse prevention plan might not have a juridical ground, but it provides both informal caregivers and MHNs with a tool for an open dialogue in which actions during an acute episode can be explained to an individual afterwards. Keeping on speaking terms is essential to maintain a trustful triadic collaboration (Schulman-Green et al., 2012). Furthermore, we recommend the use of vignettes in nursing education to promote reflection (Bertilsson et al., 2018; Herbig, Büssing, & Ewert, 2001).

Declarations

None of the authors have competing interests.

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Contributions

Silvio van den Heuvel (SvdH): designed the study, collected, analysed and interpreted data, and drafted the manuscript. Peter Goossens (PG): co-designed the study, peer-debriefing of analysed and interpreted data, and drafted the manuscript. Cees Terlouw (CT): co-designed the study, peer-debriefing of analysed and interpreted data, and drafted the manuscript. Lisette Schoonhoven (LS): co-designed the study and supervised peer debriefing. Theo van Achterberg (TvA): co-designed the study, and revised the article critically for important intellectual content.

Ethical approval

Ethical review of the full study was conducted by the Radboud University Central Ethical Committee. The Regional Ethical committees of Dimence, Mediant, and Rivierduinen granted access and approval for data collection.

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Chapter 7

Discussion and conclusions

GENERAL DISCUSSION

In this chapter, we discuss the main results of the previously presented studies against the current knowledge on mood monitoring in part I (subsection 7.1), and self-management education for bipolar disorders in part II (subsection 7.2). Second, we present our methodological considerations. Followed by the recommendations for mental health practice, nursing education, and future research. This chapter closes with the main conclusions of this thesis.

7.1. Part I Mood monitoring as a pivot in self-managing bipolar disorder

The central aim of the studies presented in part I addresses the attitudes, use, and perceived utility of mood monitoring instruments of persons with bipolar disorder. In this paragraph we have synthesized the most salient findings of our studies about the attitudes toward the Life Chart Method (LCM), and the Personal Health Record for bipolar disorders (PHR-BD) in two overall points of discussion: the reasons for use (subsection 7.1.1.), and -in contrast- the reasons for non-use (subsection 7.1.2.).

7.1.1. Reasons for use

The first and most notable finding was that person with bipolar disorder frequently use the LCM and additional instruments such as the relapse prevention plan as part of their strategies to stay well and enhance self-management of their illness. Using mood-monitoring instruments induces ownership, enhances collaboration, and helps both the persons with bipolar disorder and their informal caregivers to distinguish between pathological and normal mood fluctuations. Mood monitoring helps persons with bipolar disorder to pinpoint prodromal symptoms of alternating moods, fluctuating activity and energy levels, and detects disturbances in sleep patterns. These findings are in line with studies that mark the importance of using instruments to evoke insights in triggering events to counteract recurrent episodes (Frank, Swartz, & Kupfer, 2000; Goossens et al., 2010; Janney, Bauer, & Kilbourne, 2014).

Second, we found that persons with bipolar disorder benefit from an integrated use of different mood-monitoring instruments such as the relapse prevention plan and the LCM. Our findings showed that synchronizing the mood chart and the personal warning signs from the crisis plan induce quick responses to counteract illness progression. Literature confirms that problem solving is a key element in self-managing a mental illness (Morriss et al., 2007; Perry et al., 1999; Morton et al., 2018).

In line with the previous findings, our studies showed that the monitoring of the episodic course increases illness reconstruction. The visualizing of previous (hypo) manic, euthymic and depressive episodes reconstructs a personal illness narrative that evokes reflection on ones' role in self-managing bipolar disorder. Hence, the integrated use of mood-monitoring instruments increased insight and perceived control by visualizing the illness course in different time graphs. For instance, by altering the displayed interface in time sequences ranging from current mood charting to longitudinal illness course graphs. Mood monitoring is a helpful tool to enhance personal identity and -recovery by restoring a part of one's 'narrative self' (Damasio, 2010; Inder et al., 2010; van der Werf-Eldering et al., 2011).

7.1.2. Reasons for non-use

In contrast to the positive features attributed above, we found that persons with bipolar disorder had several reasons to refuse or stop using mood-monitoring instruments, despite the acknowledged potential supportive value of mood monitoring to enhance self-management of bipolar disorder. Our first finding shows that deliberately opting not to use mood-monitoring instruments is mainly because persons with bipolar disorder doubt the assets in managing their illness or doubt the correctness of their diagnosis. Professionals labeled this reluctant attitude toward mood monitoring as non-acceptance of illness, poor insight in what bipolar disorder entails or how to manage it. Our findings are in line with literature that shows the difficulties that persons with bipolar have with accepting that one has a mental illness, but acknowledging that one has bipolar disorder is a precondition to gain advantage from using mood-monitoring instruments (Inder et al., 2010).

Our studies show that introducing the mood monitoring instruments too early impedes the therapeutic alliance, especially when one is still in doubt about the correctness of the designated diagnosis. Our findings showed that persons with bipolar disorder found it difficult to recognize and comprehend the illness, which consequently hampered the use of mood monitoring instruments. Persons with bipolar disorder experienced mood monitoring as too complex, too much work, and too confronting, not in the least due to the abstract features of their illness itself. For some persons with bipolar disorder mood monitoring means to acknowledge the unrecognizable. Literature shows that dismissing the impact of a psychiatric diagnosis is detrimental to a premature therapeutic alliance (Crowe et al., 2012; Fredman et al., 2015).

An important reason for non-use was the stringent professional adherence to multidisciplinary guidelines with regard to the early introduction of mood monitoring instruments in ambulant treatment without considering the impact of the loss of one’s healthy self. Daily mood monitoring evokes strong emotions, attributed to the impact of having a life-long severe mental illness, and associated with feelings of losing ones’ ‘healthy self’. This is the downside of achieved insight in the course of the illness. Besides its positive features, reflection also opens an unpleasant peak into one’s already wavering identity and troublesome future, and touches the well-known problem of (self)-stigma associated with living with a severe mental illness (Inder et al., 2008; Repper and Perkins, 2003; Vazquez et al., 2011). Literature confirms our findings that urging persons with bipolar disorder to work with mood-monitoring instruments, despite good professional intentions, is counterproductive or even hampering for one’s personal recovery when ‘the agendas are not in close sync’ (Goossens et al., 2008; Lysaker, James, & Leonhardt, 2014).

In line with previous findings, our studies showed that persons with bipolar disorder sometimes utilize mood monitoring to please their informal- and professional caregivers out of a sense of responsibility, or as a gesture to avoid the judgement of non-commitment to get well and take all efforts to prevent a recurrent episode. Ultimately, this behavior leads to unauthentic adherence to mood monitoring such as the ‘parking lot effect’, i.e. the completion of ‘homework’ in retrospect just before the meeting with the therapist (Urquhart, 1991). Our findings amplify the need for professionals to involve informal caregivers, and not solely rely on input from the person with bipolar disorder. Collaboration with, and between informal caregivers and persons with bipolar disorder is vital to prevent non-adherence and non-commitment to treatment (Chatzidamianos et al., 2015; Fiorillo et al., 2016; Granek et al., 2016). Particularly when the person with bipolar disorder is in a current (hypo-) manic or depressive episode wherein the ability to self-reflect is limited, consequently limiting the utility of mood-monitoring instruments as a self-assessment tool (Lysaker et al., 2010; van der Werf-Eldering et al., 2011).

7.2. Part II A tree-folded perspective on self-management education for bipolar disorders

The central aim of the studies presented in part II was to unravel the underlying mechanisms of self-management education for bipolar disorders by describing experiences of current practice. Our inductive analyses concluded with the statement that self-management of bipolar disorders entails an asynchrony of learning phases from the perspectives of informal caregivers, professionals, and individuals with bipolar disorder. The Expansive Learning Theory (ELT) that guided the analysis of our studies functions as a conceptual framework to structure this discussion (Engeström, 1987). The ELT entails the central assumption that learning is a collective transformation. Collective learning starts with a critical investigation of established practices that sparks an expansive cycling sequence of learning phases (Engeström & Sannino, 2010).

The first phase of the ELT is characterized by questioning, criticizing or rejecting the established knowledge and practice, followed by the second phase, which entails a search for causes or explanatory mechanisms. The third phase is that of modeling, which means that learners construct a new explanatory model of concepts to overcome a problem encountered. In phase four the learners start experimenting with the new model to test its potentials and limitations before adopting it. When the concept is in line with the expectations, the new way of thinking and acting is adopted and implemented in phase five. The learning cycle ends with the phases six and seven wherein the learner reflects on the outcomes of the implemented concept before the new ideas are consolidated and established into new practice.

Our findings were based on inductive analyses composing three clusters that differ in sequence, length and place from the exact phases allocated in the cycle of learning phases (Engeström & Sannino, 2010). The contrasts between our findings and the ELT-model provides the structure of this section, and we describe the asynchrony between learning phases, starting with the first phase of questioning, analyzing, and modeling the situation to make sense of the abstract features of bipolar disorder (subsection 7.2.1.). In phase two, we discuss the modelling of bipolar disorder management to determine how to cope with this illness in the complexity of a network (subsection 7.2.2.). Phase three describes the examination and implementation of new ideas. In this phase the stakeholders are experimenting with instruments and strategies to manage the illness and prevent recurrent episodic events (subsection 7.2.3.). This section ends with the last learning phase of consolidating self-management of bipolar disorder in daily life, enhanced by reflection and dialogue (subsection 7.2.4.).

7.2.1. Phase 1: Questioning, and analyzing to comprehend 'bipolar disorder'

Our studies show that persons with bipolar disorder find it difficult to grasp their current situation when they start maintenance treatment in ambulant bipolar healthcare after an acute episode. They oppose their designated diagnosis, and question if they have 'bipolar disorder' at all. Literature shows that being diagnosed correctly is a precondition for successful treatment (Gazalle et al., 2007), and the acceptance of a diagnosis is important to restore ones' self-perception and integrating the illness in ones' identity (Inder et al., 2010). Doubting the diagnosis especially occurs after clinical recovery of a (hypo-)manic episode. Afterwards, the persons with bipolar disorder did not recognize the feelings of grandiosity and increased activity as symptoms of a severe mental illness. This reluctance to accept the diagnosis is reinforced by the lack of ability to recognize problems as symptoms of a mental illness (van der Werf-Eldering et al., 2011).

As a response to the reluctant behavior of persons with bipolar disorder, we found that mental health nurses use a non-confronting attitude, prioritize acquaintance, and start with a dialogue on the impact of bipolar disorder in order to engage in the personal story of the person with bipolar disorder. Mental health nurses avoid discussions about the designated diagnosis and establish a solid therapeutic alliance on which they can to rely in case of an emergency, instead of starting with information and psychoeducation as recommended in the multidisciplinary guidelines (Colom & Lam, 2005; Kupka et al., 2015). Evidence shows that improved communication and an enhanced therapeutic alliance between people with bipolar disorder and clinicians contributes to better outcomes (Fisher et al., 2016). With this strategy, mental health nurses anticipate the high probability of recurrent episodes (Ferrari et al., 2016; Judd et al., 2002; Kupka et al., 2007). However, we found that they pay less attention to the role of the informal caregivers in self-management of bipolar disorder, despite the promise of improving outcomes through collaborating with them (Fredman et al., 2015; Reinares et al., 2016).

In contrast to the persons with bipolar disorder, the informal caregivers are not skeptical about the correctness of the designated diagnosis. They are eager to learn all about 'bipolar disorder' in order to manage the illness. Literature shows that the underlying motives of this eagerness to learn fast is, not surprisingly, the detrimental impact of recurrent episodes on relations (Goossens et al., 2008; Granek et al., 2016), and family life (Beentjes et al., 2012; Jönsson et al., 2011; Reinares et al., 2006). The quick learning pace of informal caregivers provides them with the ability to be a step ahead in recognizing prodromal symptoms before the person with bipolar disorder does. This on the positive side is known to reduce the number of recurrent (hypo)manic and/or depressive episodes (Miklowitz et al., 2009; Perlick et al., 2010; Reinares et al., 2016), but it has a downside as well. Literature shows that contrasting perspectives on what to do and when to do it, feeds escalations between informal caregivers and persons with bipolar disorder which can increase recurrent episodes over time, and deepens the reluctant attitude of the latter toward accepting the diagnosis (Miklowitz & Chung, 2016; Reinares et al., 2016).

7.2.2. *Phase 2: Modelling the management of bipolar disorder*

We found that providing informal care for someone who has bipolar disorder means balancing between competing needs and coping with feelings of being pulled on and rejected at the same time. This paradoxical trap is exemplified in the literature. When the informal caregiver opts for self-effacement, the person with bipolar disorder interprets this help as meddling and becomes reluctant to accept it. However, when the informal caregiver aims for self-fulfillment, the person with bipolar disorder tends to feel abandoned, especially after a recurrent episode (Lewis, 2015; Rusner et al., 2013; van der Voort, Goossens, & van der Bijl, 2009). Our findings indicate that mental health nurses feel a moral obligation to support informal caregivers, but, this ethical imperative can also put them in the middle of inter-relational quarrels concerning dual loyalty when a person with bipolar disorder is in crisis (Beentjes et al., 2016; Reinares et al., 2006). Literature shows that informal caregiver involvement is of added value in treatment, but at the same time it increases the complexity of the caring process for all stakeholders (Chatzidamianos et al., 2015; Peters et al., 2011).

The choice of mental health nurses to paramount care for persons with bipolar disorder seems closely related to a widely spread viewpoint on the concept of self-management: as 'an individual's capacity to manage the signs, symptoms, and consequences of his chronic condition' (Barlow et al., 2002). In our view, this well-known definition of self-management is too narrow to capture the complexity of ambulant bipolar care and opt for a network approach. For instance, one of the strategies that informal caregivers use to comprehend bipolar disorder is seeking help from peer group support that leads to better recognition, and support from other informal caregivers. This confirms the need for a collective to learn. However, this approach has the adverse effect of hearing about negative experiences that unintentionally create a horrible image of an unpredictable illness with a high rate of recurrent episodes that is impossible to control (Jönsson et al., 2011a; Jönsson et al., 2011b).

Our findings revealed that persons with bipolar disorder endeavor to make sense of the diagnosis, and struggle to cope with the amount of new and abstract, information. They prefer small bits of information, and practical examples tailored to familiar concepts such as ones' occupational background to enhance recognition. Persons with bipolar disorder find it easier to identify activity-related prodromal symptoms, than emotional fluctuations. The extreme emotional and fluctuating course of this illness has a great impact on the abilities of persons with bipolar disorder to identify and control the features of the illness (Crowe et al., 2012). Literature shows that fluctuations in energy level, sleep, thought, and social functioning, are easier to recognize than emotional triggers (Goossens et al., 2010; Russell & Browne, 2005). We found that mental health nurses used metaphors to explain difficult concepts, and developed a language that accumulates new information to existing knowledge or personal background to enhance the accessibility of abstract concepts.

7.2.3. Phase 3: Examining, and implementing illness management

Despite the positive impact of informal caregivers on outcomes (Chatzidamianos et al., 2015; Fiorillo et al., 2016; Granek et al., 2016), persons with bipolar disorder tend to exclude their involvement in treatment because of fear of over-involvement. Persons with bipolar disorder experience good intentions of informal caregivers as meddling and hampering their learning process towards self-management. Persons with bipolar disorder interpret the interference of over-protective informal caregivers as disqualifying, which left them with a feeling of being 'flawed' and incapable to self-manage the illness (Crowe et al., 2012). Therefore, they are reluctant to share information, either out of protectiveness as to burden their significant others, or in order to not feel as a patient all the time. Our findings are in line with studies reporting that informal caregivers are always one-step ahead in knowledge but also one-step behind on the needs of the person with bipolar disorder, which marks the interpersonal ambivalence of treatment involvement of both (Granek et al., 2016; Rusner et al., 2013; van der Voort, Goossens, & van der Bijl, 2009).

Open communication, mutual trust, and reciprocity restores the relationship between informal caregivers and the person with bipolar disorder when the latter at least acknowledges his limited capacity to cope with the illness. Mutual trust between both opens the possibility to authorize the social network to take necessary actions, especially during acute episodes. Our findings show that when others are willing to take care and have the know-how to intervene in case of a looming manic, hypo-manic, or depressive episode, persons with bipolar disorder experience this as a security break. It functions as a safety net when learning how to keep a balance between the two poles of this illness. Literature shows that the closeness of a social backup provides a 'peace of mind' to persons with bipolar disorder (Daggenvoorde, Goossens, & Gamel, 2013), but on condition that this is a temporary heteronomy, otherwise the informal caregiver support leads to over-protectiveness, and thus hampers the learning process. Taking over control both from a professional- or informal caregiver point of view, might seem the opposite of self-management. However, if agreed upon on forehand that it is temporarily, written down in a relapse prevention plan, and all acting accordingly, it enhances trust because all stakeholders can rely on this covenant.

A prerequisite for this supporting (scaffolding) network is that mental health nurses mediate between the contrasting perspectives of the person with bipolar disorder and the informal caregivers on what signs can be interpreted as symptoms of bipolar disorder, and what not. Mental health nurses use a careful approach in personalizing the crisis plan to avoid emotional escalations that might trigger an episode. This approach is in line with literature indicating the detrimental consequences of a confronting attitude and high expressed emotions in (non)verbal communication (Barrowclough & Hooley, 2003; Fredman et al., 2015; Kim & Miklowitz, 2004; Miklowitz et al., 2009), especially when an individual is shifting to (hypo)mania (Beentjes, Goossens, & Jongerden, 2016). We found that informal caregivers approached this in similar ways by using a code word to warn the person with bipolar disorder about an upcoming prodromal sign, thereby carefully avoiding to bring the message too emotionally or too confronting.

7.2.4. Reflection, and consolidating self-management

Our findings show that informal caregivers learn that efficient self-management support of persons with bipolar disorder entails to confine emotional overreactions and resist what the French philosopher Emmanuel Levinas (2012) called “the endless responsibility stemming from the compelling call expressed in the face of a needing person.” Instead of inclining to restrain upcoming episodes with emotional over-involvement, informal caregivers learn to reframe the “call for help” of an individual with bipolar disorder as the need to help them overcome their perceived helplessness. A conversation about the division of daily tasks and responsibilities is a tipping point wherein informal caregivers learn to temper their involvement, and persons with bipolar disorder learn to reclaim their autonomy by setting clear boundaries in what they want to do themselves and by letting others to know when they need to intervene. Persons with bipolar disorder who pick up their social role and responsibilities again, re-join their partners in raising the children or restart working life, and regain their autonomy. This reclaimed autonomy is known to be an important step towards personal recovery (Bonney and Stickeley, 2008).

We found that mood monitoring instruments are helpful in reconstructing previous episodes and, evoke reflections on outcomes of everyday actions. These reflective acts promote self-confidence, and reduce the overwhelming feeling of a hampering autonomy due to the fluctuating emotion. However, reflection might also gain the adverse effect of having to live with the inevitability of a recurrent episode regardless of what precautionary measures one takes. When informal caregivers and persons with bipolar disorder start to reflect on the impact of managing this illness in daily life, and come to an agreement on how to divide their daily tasks and family responsibilities, they gradually move towards a better way of self-managing bipolar disorder. Self-management is a learning process that ingrates bipolar disorder into daily life, becoming a part of ones’ new narrative self. In contrast to literature (Pollack, 1996), we believe that a preoccupation on health or ‘being too prepared’ leads to a paralyzing fear for that inevitable recurrent episode that hampers the successful development of self-management of bipolar disorder. Our findings are in line with studies pointing out the importance of boundary-setting, mobilizing social resources, and integrating bipolar disorder in ones’ concept of ‘self’ as key concepts in ‘creating order in the disorder’(Kralik et al., 2004; Inder et., al 2008).

METHODOLOGICAL CONSIDERATIONS

This paragraph is divided into two sections, first we discuss the general methodological considerations for our studies. Second, we aim at more philosophically specific methodological discussion points on the qualitative methods used.

7.3. General methodological considerations

The strength of this dissertation is its explorative in-depth qualitative character. Consequently, this explorative nature entails considerable limitations for generalizing the findings of our studies. First of all, the sample sizes of the included studies are small. Our recruitment procedures were established based on convenience, and partly purposeful sampling. Purposive sampling procedures were used to include a variety of participants (Husserl, 1973; Husserl, 1984). This approach is in accordance with qualitative merits providing participants with an equally weighted voice, meaning that the data at the tails of the normally distributed curve and data in the middle are equally important, something that is drawn out by the mean in quantitative studies (Morse, 2015). However, despite our recruiting efforts, female respondents diagnosed with a BD type I were over-presented in all studies.

In the quantitative study included in this thesis we used a small, non-randomized convenience sample without a comparison group. This design was developed for its explorative purpose and therefore not robust enough to detect clinical effects. Both the small convenience sample pre-test and high attrition rate of 41% at post-test makes this study vulnerable to selection-, attrition-, and detection bias (Higgins et al., 2019). Therefore, we have run a post-hoc analysis to investigate the reasons for drop-out. Notwithstanding its limitations, the study was successful in reaching its explorative aims. The results of this study, combined with the insights of the qualitative LCM study guide clinical practice and guide future studies to appropriate designs, feasible for the rapidly changing developments in online interventions and tools for the bipolar population.

The three-folded perspectives of people who live with bipolar disorder, their significant supporting others, and professional caregivers on self-management education for bipolar disorders, deserves credit for shedding light on the underlying mechanisms of self-management education. The use of different phenomenological methods with open topic guided interview techniques unfolded self-induced lived-through learning experiences in coping with bipolar disorder.

Nevertheless, qualitative research has its shortcoming when it comes to the validity and reliability of study results. The replicability of the study is limited by its open inductive character, and the small sample sizes restrict the generalization of the findings. However, when using appropriate constructive scientific criteria to the chosen phenomenological approaches (Lincoln & Guba, 1985), the constant stepwise approach of such analyses ensures analytic replicability by methodological rigor. The constant audit of our analytical process reported in a logbook of field notes, the performed peer debriefing, and the researcher triangulation increased the trustworthiness of our results. The use of a computer-assisted qualitative data analysis software package (Friese, 2012) enhanced the authenticity of our results, and enabled the affirmation of learning experiences by using citations. Confirmability was achieved through member checking by sending respondents written summaries of the transcripts. Moreover, our findings provide insights that are easily recognizable and transferable to similar situations, settings, and ambulant bipolar practices.

7.4. Specific methodological discussion points

When reflecting more philosophically on the qualitative methods used, some choices are noteworthy to complete the methodological picture. First we want to discuss the function of data-saturation, and second, the practice of 'bracketing' in our three phenomenological studies in part II.

7.4.1. Data saturation

Data-saturation is a well-known criterion for methodological quality that found its origins in the grounded theory approach (Lincoln & Guba, 1985). When designing a phenomenological study it is the question to which extend data-saturation should be a mandatory endpoint, and, if so, what criteria should be governed to guarantee methodological soundness? Moreover, it is not always described in qualitative studies how the criterion of data-saturation is met. Data-saturation can be set on different thematic spheres in qualitative studies, for instance on the organizational (Chatzidamianos, Lobban, & Jones, 2015) or the instrumental level (Peters et al., 2011). When asking respondents about their experiences with a particular research theme, the experiences should mark the endpoint of data collection and thereby data-saturation (Kerr, Nixon, & Wild, 2010).

In our studies we used a pragmatic way to encounter this methodological problem. The topic list, based on the research aims, was iteratively updated after each analysis and provided a naturalistic endpoint to determine the saturation of the data. We considered the data to be saturated when respondents did not mention new topics (according to our topic list) during the interviews. This approach is in line with literature that classifies this approach as code-saturation. Therefore we cannot state that our results 'showed it all'. Our data was considered to be saturated, because we 'heard nothing new', as code-saturation does not necessarily mean that all experiences and their meaning are fully understood . Nevertheless, the three studies can be seen as a trilogy on self-management education for bipolar disorders making the combined sample size and final analysis in our discussion suitable for meaning saturation too (Hennink, Kaiser, & Marconi, 2017).

7.4.2. The practice of 'bracketing'

Our second point of discussion is the term 'bracketing'. The literature mostly describes bracketing as the reflection on the researchers' pre-understandings in order to take them into account, or preferably get rid of them during analysis (Dowling, 2007; Giorgi, 2005). In our studies we used the concept originally coined by Husserl (1973; 1984) of the 'phenomenological epoche', i.e. to postpone ones' early judgment on the meaning of a concept, stating that only a real lived-through experience captures the full meaning of that concept.

In line with this conceptual statement we used 'bracketing' in three ways. First, we purposively chose our peers for researcher triangulation on professional background. Each researcher had familiarity with a subject closely related to our research objectives, for instance ambulant bipolar care, educational science and nursing. They provided a multi-perspective on the collected data which postponed judgement on the meaning of each topic during the analysis. Second, we used member checking as form of bracketing in our study. We sent the summaries of the verbatim transcription to the interviewees. The analysis was postponed until the interviewees had confirmed that the essence of what was written down was well interpreted. Third, the variety of perspectives from different respondents both in study and between studies, functioned as a third form of 'bracketing'. Metaphorically speaking, this kind of 'bracketing' is the same as making several snapshots of a single subject with a digital camera. While zooming in and out, different focus points provide a clear fore- or background. All these snapshots merged together provide a clear image of a single subject. Similar, the different perspectives (learning experiences) of respondents altogether create a clarified picture of what self-management education for bipolar disorders entails.

The sequence of the different phenomenological studies in this thesis is not without purpose. The critique of philosophers as Heidegger (1957) and Gadamer (1986) on the impossibility of bracketing is put into practice in our study on the tacit knowledge of mental health nurses. The reason for this hermeneutical-phenomenological approach was that a study on how mental health nurses teach self-management strategies was too 'close by'. Almost all members of our research team were familiar with, had experience in, or had a proficient knowledge of what educational issues mental health nurses encounter. Therefore, we used a hermeneutic design and arranged this study to be the last to unfold the meaning of self-management education for bipolar disorders against the horizon of the previous two studies (Heidegger, 1957; Gadamer, 1986; Thirsk & Clark, 2017).

RECOMMENDATIONS FOR MENTAL HEALTH PRACTICE

With changing views on 'health and illness', raising healthcare costs up to 3.5-6% of GPD's in the EU, and increased proactive involvement of patients and significant others concerning matters of their own health, self-management of an illness is no longer an ignorable phenomenon (Holman & Lorig, 2000; Huber et al., 2011; OECD, 2018). However, our studies indicate that self-management of a mental illness has a different dynamic compared to most somatic chronic diseases. Having a mental illness seems indissolubly intertwined with financial-, occupational-, emotional-, relational-, and existential problems, being subject to stigmatization, and sometimes living in an altered reality which affects not only the person himself but also his entire social network.

We know that adequate self-management of a chronic (mental) illness is associated with improved outcomes including improved quality of life, symptom reduction, fewer hospitalizations, and reduced costs of healthcare (Newman, Steed, & Mulligan, 2004). But, how to promote self-management? Do we use a generic or illness-specific approach in self-management education? As Newman and colleagues (2004) state, it is quite obvious that chronic conditions do vary in the extent to which they intrude on psychological and social worlds. As a consequence, different illnesses also might have distinct educational demands for effective self-management. This statement seems all too real in ambulant bipolar practice, wherein the illness itself follows an alternating course in emotions and activities. *From the results of our studies we can derive nine advices to enhance self-management education in ambulant bipolar practice*.

First of all, we advise that professionals, informal caregivers and persons with bipolar disorder focus on re-ordering their networks to enhance self-management instead of solely aiming on controlling the dis-order. We detected that a large part of self-managing bipolar disorder is instrumentally driven according the recommendations in multidisciplinary guidelines. However, we consider it as part of the job of professional caregivers to personalize care in line with guidelines in three steps, as suggested in the literature (Gray, 2004): First, to inform the patient about the evidence concerning their condition; Second, allowing the patient to reflect on the options presented and relate those options to the values he or she places on benefit and harm; and Third to individualize the style of consultation to the preferences of the patient.

As a second advice, we recommend to follow a non-confronting strategy to get acquainted as most mental health nurses in our studies do. Avoid debates on the rightness of the diagnosis, and aim for conversations on the personal problems of both persons with bipolar disorder and their informal caregivers. The first step to take, informing the patient about the evidence concerning their condition is a very difficult one in bipolar practice. How would you respond when someone negatively assess your mental sanity? Nevertheless, our findings show that the acceptance of diagnosis is not a necessary precondition per se to adhere to treatment, on the condition that experienced problems are 'recognized' in the full meaning of the word. In our opinion, professionals should keep an open dialogue with service users and caregivers and re-label problems into learning situations where both play an active role, as to build mutual trust and enhance self-management of bipolar disorder. From a didactical perspective it is more reasonable when a professional labels a symptom as a personal issue then to characterize it into an abstract concept with no connection to the inner live-world of an individual whatsoever.

Our third advice is to customize mood monitoring tools to the individual needs and desires of the person with bipolar disorder. Mood monitoring instruments can enhance reflection by visualizing alternating mood patterns during past episodic events. However they are not panaceas, just means to an end, and should they be treated accordingly. This was for instance demonstrated with the altering interfaces in our online PHR-BD study, where the visual personalization enhanced insights and increased motivation to keep utilizing the mood chart. In practice we see that persons with bipolar disorder struggle to comprehend the magnitude of their illness. However, not all persons with bipolar disorder agree, or are emotionally unable to accept these insights when being in a state of mourning or in a current episode.

Fourth, professionals should recognize the overall differences in the educational needs of both individuals living with bipolar disorder and informal caregivers, because the learning processes of both follow a different pace. Therefore, we believe it is best to temper the flow and the amount of information, correct misunderstood or false information, and mediate between both when misunderstandings tend to occur. Professionals should focus on the relationship between the informal caregiver and the individual living with bipolar disorder to support them in overcoming the dilemmas of caregiving. For instance, teaching informal caregivers how to cope with the insecurities, shifting responsibilities and tasks, and positively reinforcing persons with bipolar disorder to act on their own. This approach will synchronize the temporal pace of learning phases, and restoring the self-confidence in self-managing the illness in its path.

Fifth, we recommend that professionals teach informal caregivers to reflect on their share in the dilemmas raising from emotional over-involvement and high expression of emotions. Our results showed the importance of reflection in the learning process of both persons with bipolar disorder and informal caregivers. On the part of the person with bipolar disorder, reflection is required to leap from instrumentally driven relapse preventing illness management to mastering self-management of the illness by integrating it in daily life. This advice is in line with the second task that Gray (2004) administers to professionals, that is allowing the patient to reflect on the options presented and relating those options to the values he or she places on benefit and harm. To this extent, we want to emphasize that there is no "final phase" in learning processes because learning requires lifelong maintenance. The outcomes of supporting actions of an informal caregiver is highly dependable on the episodic fluctuations of the individual with bipolar disorder. Self-management is a cyclic process that evolves over time, it requires reflection to determine which measure of caregiver involvement is appropriate and in accordance with the learning phase of the person with bipolar disorder.

Sixth, we advise that in order to have a significant impact on learning to self-manage bipolar disorder, self-management educational activities should be inserted in routine conversation during consultations. Adequate self-management of bipolar disorder demands that both persons with bipolar disorder and informal caregivers are properly equipped to make decisions based on rapidly changing insights. This means that self-management education has to be partially provided in the context of a consultation, thereby exceeding the propositional knowledge to cope with the negative consequences of bipolar disorder as delivered in psycho-educational programs. As Gray (2004) stated, “decision aids will inevitably, and quite correctly, become as much a part of clinical practice as the stethoscope and the prescription pad.” (Gray, 2004, p. 1468).

Seventh, we advise that professional care providers listen to the stories of their patients more often, as to gain insight into the significance of the (learning) experiences of persons with bipolar disorder and informal caregivers. Professionals ought to reconsider whether or not strict adherence to guidelines and recommendations is appropriate in individual cases. Linking self-management strategies to experiences leads to a supporting network. This supporting network promotes an individual’s autonomy but also provides possibilities to restrain this autonomy when a person with bipolar disorder is temporarily not capable to decide for himself.

Eight, we suggest that, although a relapse prevention plan might not have a juridical ground for mandatory necessary precautions, it provides both informal caregivers and mental health nurses with a tool for an open dialogue in which actions during an acute episode can be explained to an individual with bipolar disorder in an acute episode afterwards. This scaffolding-autonomy principle, provide the means to keep all stakeholders on speaking terms, and is therefore vital to build and maintain a trustful triadic collaboration (Belland, 2014; Belland, 2017; Schulman-Green et al., 2012).

Finally, our ninth advice is that mental health caregivers use metaphors that are closely related to individuals’ background (occupation, study) and vocabulary for conceptual clearance in what is meant by self-management of bipolar disorder. This concerns both the person with bipolar disorder and the informal caregiver. Therefore, we want to draw some attention to the Expansive Learning Theory of Engeström & Sannino (2010) as a communication-model for self-management education of bipolar disorder. This largely unknown learning theory in the field of nursing education, is highly applicable to ambulant bipolar nursing. Operating in the proximal zone of development is one of the key features of scaffolding (Bruner, 1978), and this technique is what nurses actually do in ambulant bipolar care. “It is as teaching a child cycling. You have to build the bicycle, assemble the side-wheels, and adjust the stability to the personal needs, and if he falls, we help him to get back on the saddle, again and again until they manage to cycle on their own.”, as a mental health nurse metaphorically put it in one of our studies. This example shows that the use of (understandable) language, is as an essential element of scaffolding learning (Belland 2014; Belland, 2017; Vygotsky, 1962), which also happens to be the primary vehicle of mental health nursing.

RECOMMENDATIONS FOR NURSING EDUCATION

Educating self-management strategies to cope with chronic mental conditions is predominantly a complex nursing intervention that aims on sustainable behavioral change (Clark, 2013; Coster & Norman, 2009). However, it is debated whether or not nurses are sufficiently equipped for this task due to lack of educational training during basic schooling ((Lawn et al., 2009; Pols et al., 2009; Been-Dahmen et al., 2015). A study of Lake & Staiger (2010) showed that the 65% of the study participants had received no formal training in self-management techniques, resulting in utterly differed views on how to deliver self-management education. Therefore we recommend that self-management plays a central role in the curricula of nursing studies from bachelor to master, and part of refresher courses.

However, we found that self-management as a nursing activity is mostly tacitly accumulated, and cultivated over years. Therefore, tacit knowledge of self-management education is hard to detect because its covert implicit nature (Eraut, 2000; Welsh & Lyons, 2001). In our studies we successfully provoked reflection on clinical experiences in self-management education with our interview techniques to manifest tacit decision-making processes. Based on our results, we recommend the use of problem based case-descriptions such as vignettes to evoke reflection and overt the communication issues and network dynamics in self-management education, in line with literature that marks the importance of enhancing reflection in practice (Bertilsson et al., 2018; Herbig, Bussing, & Ewert, 2001).

Our findings revealed an asynchrony in learning phases between different stakeholders in self-management education that can be used as a blueprint for nursing education to enhance self-management support. We believe that future nurses should be trained to detect and recognize this asynchrony as the start of a necessary learning cycle that enhances self-management. Novice nurses are often inclined to help people by solving problems for them. Notwithstanding their good intentions, these actions implicitly disqualify the learner and hamper the learning process toward self-management of a chronic illness.

RECOMMENDATIONS FOR FUTURE RESEARCH

Our small explorative studies have paved a path for a range of future study programs on self-management for bipolar disorders to be developed, as is confirmed by the research agenda set by persons with bipolar disorder themselves (Maassen et al.,2018).

Firstly, our studies in mood monitoring show that future research is best aimed towards mobile digital instruments that are interconnected with an easy accessible and navigable interface, to enhance utility of mood charting. Interacting modules, as the ones in the PHR-BD, provide coherence in functions and therefore meet the needs of users. These needs have to be taken in account when designing a self-management enhancing eHealth technology (Gliddon et al., 2017; Murnane et al., 2016). Accordingly, the PHR-BD study was the spin-off for an online mood monitoring program for bipolar disorders https://ivido.nl/e-health-programmas/ and the WELLBE-BD study designed to develop an application for mobile phones. However, based on the time spent on implementing the first version of the online PHR-BD, we recognize that it is not feasible to conduct a randomized controlled trial. The rapid development of e-health applications would probably outdate the results of longitudinal prospective studies before they are reported. We recommend that the use of e-health applications becomes part of routine nursing practice, which would speed up future implementations and innovations.

Secondly, we think that longitudinal studies are necessary to determine to what extent bipolar disorder is self-manageable. It is known that external stress factors can trigger genetic bipolar vulnerability suggesting that early recognition and rapid response to stressful events might avoid full episodes. However, in the long run, the illness features tend to operate on their own, i.e. without a clear indication that points towards an external cause (Goodwin & Jamison, 2007). This explains the experience of feeling 'the Damoclesian sword that keep swinging above one's head' despite all measures taken to prevent an episode, that persons with bipolar disorder mentioned in our studies.

Thirdly, we recommend that future studies aim at multidisciplinary samples (i.e. physicians, psychiatrists, and psychologists) of healthcare professionals, as to enhance the representativeness our study results. In our quest to describe possible factors that hamper or facilitate the learning process towards self-management of bipolar disorder, we focused our attention primarily on mental health nurses assuming that they are the over-represented discipline in delivering self-management support (Coster & Norman, 2009).

Fourth, we believe that future research should take health literacy into account as an outcome of self-management education, in line with literature and keeping in mind that language is an essential element in scaffolding learning (Eckman et al., 2012; Vygotsky, 1962). Our studies show that the meaning predicated to the concept of self-management is related to the (learning) activities of persons with bipolar disorder and their informal caregivers and therefore influences clinical outcomes of bipolar treatment.

Fifth, future studies should aim at identifying the most effective components of self-management programs, in line with recommendations in the literature (Clark, 2013). Although, we described the underlying mechanisms of self-management education for persons with bipolar disorder and their informal caregivers, our studies were explorative and underpowered. Studies with larger sample sizes are needed to reproduce our findings and to develop a sound theory for self-management education of bipolar disorders. More specifically, these studies should test the hypothesis of an asynchrony in learning phases as a starting point in developing a nursing curriculum towards self-management education for bipolar disorder (van den Akker, 2003).

CONCLUSIONS

The overall aim of this thesis was to overt the underlying mechanisms of self-management education for bipolar disorders, which we divided into two objectives: 1) to explore the attitudes toward the life chart method and the user-experiences with an online patient health record, and 2) to describe learning experiences in self-management education from a threefold perspective; being the perspectives of persons with bipolar disorder, informal caregivers, and mental health nurses.

The results of our studies that aimed at our first objective provided an insight in the most common reasons for (not) using mood monitoring instruments. The ambivalent nature of persons with bipolar disorder toward mood monitoring instruments emerges from contradictory views. These instruments are the most valued and most used, helping to pin-point prodromal symptoms of alternating moods, fluctuating activity and energy levels, and detect disturbances in sleep patterns. However also, these instruments evoke strong emotions, attributed to the impact of having a life-long severe mental illness. Using mood monitoring instruments induces ownership, enhance collaboration, and helps distinct pathological- from and normal mood fluctuations. However, the concept of bipolar disorder itself is difficult to comprehend, and consequently using mood monitoring instruments is a challenge too.

The online synchronization of the mood chart with the personal warning signs from the crisis plan exceeded the clinical value of using the paper versions in self-management of bipolar disorder. Altering the interface visualizes the illness course in different time graphs, which enhance illness reconstruction and evokes insight and reflection on ones’ role in self-managing bipolar disorder. Nevertheless, the achieved insight has the dormant downside of an unpleasant peak into one’s already wavering identity and troublesome future. Therefore, a delicate first time introduction of mood monitoring instruments in clinical practice is necessary, for it is counterproductive when ‘the agendas are not in close sync’. The latter approach provokes unauthentic adherence to mood monitoring instruments to please caregivers out of a sense of responsibility, consequently limiting the utility of mood monitoring instruments as a self-assessment tool.

The tree folded qualitative approach for reaching our second objective resulted in the description of a learning process wherein all stakeholders gradually learn how to react to consequences of reflecting on one’s own actions in daily situations. The asynchrony in and between learning phases of participants in the bipolar triad, mutual trust, open communication, and a scaffolding network are key components that promote the exploration of boundaries where mistakes can be considered as reflective learning acts, thereby opening new ways to integrate this chronic condition into daily life. An important precondition for self-managing bipolar disorder is a trustful network functioning as a safety guard wherein professionals, informal caregivers, and persons with bipolar disorder can learn to overcome the fear of episodic recurrences. Self-management education does not entail acceptance and engagement alone; it rather encompasses problem solving, and the will to adapt to the consequences of living with bipolar disorder.

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Chapter 8

Summary

SUMMARY OF THE MAIN FINDINGS

The purpose of this dissertation is to overt the underlying mechanisms of a network learning model for professional self-management support to persons with bipolar disorder and informal caregivers, and to provide the stepping stones for further development and testing of this model. We have divided this thesis in two parts as outlined in **chapter 1**. Our research objectives were: 1) to explore the experiences of persons with bipolar disorder in utilizing the life chart method, and test the feasibility and utility of digital mood motoring instruments in an online patient health record, to promote self-management of bipolar disorders; and 2) to describe contrasting learning experiences in self-management education from a threefold perspective; persons with bipolar disorder, informal caregivers, and mental health nurses.

Part I presents two studies concerning mood monitoring. **Chapter 2** describes the results of a phenomenological study about the attitudes and motivations of persons with bipolar disorder towards use or non-use of the Life Chart Method (LCM) for mood monitoring. As a result of in-depth interviews we unfolded fourteen narratives of persons with bipolar disorder. Generally there was a positive attitude towards the LCM and an overall recognition of its added value in monitoring mood and activity as part of treatment. However, respondents mentioned that daily mood charting was experienced as a substantial burden, particularly during the early stages of diagnosis. Hampering factors for utilizing the LCM were prompting the use of the LCM before being able to cope with the impact of being diagnosed with bipolar disorder, the lack of a possibility to personalize the instrument, and the ‘parking lot effect’, i.e. mediocre retrospective reporting right before meeting the professional. We concluded that at least the impact of the diagnosis needs to be taken into account when introducing the instrument for the first time to a person with bipolar disorder.

Chapter 3 shows the results of a pre-posttest study of a tailored online personal health record for persons with bipolar disorder (PHR-BD), used from baseline to 12-months follow-up. The aim of the ‘Self-management and Dialogue in Bipolar Disorder’ project was to evaluate the feasibility and utility of the PHR-BD, as well as to evaluate user-experiences of participants with bipolar disorder, their informal caregivers, and healthcare professionals. Sixty-six participants with bipolar disorder started at baseline. At study endpoint, thirty-nine participants with bipolar disorder, eleven professionals and one family caregiver filled out the evaluation forms. There were no statistically significant differences found in the clinical outcomes between baseline and study endpoint. However, the qualitative evaluations showed that participants frequently utilized the mood chart modules. Using the PHR-BD improved communication between clinicians and participants with bipolar disorder. The customized interface of the mood chart combined with, and linked to the crisis plan increased insight in influencing factors of mood fluctuations. This functional option to alternate the interface from a prospective to a retrospective mood chart, and integration with the personal crisis plan was experienced as having an added value to enhancing self-managing bipolar disorders.

Part II outlines a triadic perspective on self-management education for bipolar disorders, beginning with **chapter 4** wherein a phenomenological design was chosen to describe the learning experiences of persons with bipolar disorder in self-managing their illness. Face-to-face, in-depth interviews were conducted amongst sixteen persons with bipolar disorder I or II. Analyses showed that the learning process towards self-management of bipolar disorder eventuates in a collaborative network. Five themes were found to describe this learning process. At first, acknowledgment of having bipolar disorder is conditional. The moment, the sequence, and the amount of information is vital in comprehending bipolar disorder. Managing the illness by mood monitoring enhances perceived control. However, reflecting on to what extent bipolar disorder should interfere and control (family) life is pivotal in mastering self-management of bipolar disorder. We concluded that successful self-management depends from acknowledging personal limits in coping with the illness, and the willingness to use a network as back-up. A hampering factor in this learning process, that has be to taken in account when educating self-management of bipolar disorder, is the lingering dormant fear of recurrent episodes.

Chapter 5 provides a description of informal caregivers' learning experiences when supporting persons with bipolar disorder in self-managing their illness. The phenomenological analysis of ten in-depth open interviews yielded four learning phases that reconstruct the learning process of informal caregivers. The learning process starts with comprehending the abstract features of bipolar disorder, followed by subduing the dilemmas in informal caregiving. The third and fourth phase relate to learning to divide tasks and responsibilities, and ending with a personal account of self-management support for persons with bipolar disorder. We found that informal caregivers gradually learn how to deal with everyday problems when living with someone with bipolar disorder. For instance by controlling the expression of emotions, and reflecting on the origins of conflicts. But also through learning how to share the responsibilities of illness-management with patients and professionals, and thereby delimiting their overprotectiveness.

The closing article on the three-folded perspective on self-management education for bipolar disorder is presented in **chapter 6**, which entails an enquiry on the tacit knowledge of mental health nurses in delivering self-management education for bipolar disorders. In this phenomenological-hermeneutical study we interpreted the experiences of nine mental health nurses. Verbatim transcripts collected via face-to-face, topic list guided in-depth interviews were hermeneutically analyzed. Our analysis provided a thorough description that disentangled the complex character of self-management education to persons with bipolar disorder and their significant others. We found five components of self-management education for bipolar disorders, which were built partly on tacit knowledge and partly on formal knowledge. These components encompass assembling a trustful collaboration, opening a dialogue about needs and responsibilities, comprehending the concept of bipolar disorder, utilizing mood monitoring instruments, and finally tailoring self-management of bipolar disorder. Sound self-management education entails the collaboration of a supporting learning network to facilitate self-management of bipolar disorder on the long run.

Chapter 9

Samenvatting

SAMENVATTING VAN DE BELANGRIJKSTE RESULTATEN

Het hoofddoel van dit proefschrift is de onderliggende mechanismen van een netwerkleermodel voor professionele zelfmanagementondersteuning voor personen met een bipolaire stoornis en mantelzorgers te beschrijven, om deze in de toekomst verder te kunnen ontwikkeling en te testen. Deze thesis is in twee delen verdeeld, zoals beschreven in **hoofdstuk 1**, waarmee twee onderzoeksdoelstellingen zijn behaald: 1) het onderzoeken van de ervaringen van personen met een bipolaire stoornis bij het gebruik van de Life Chart Method (LCM) , en het testen van de haalbaarheid en nut van digitale stemmingsmonitoring in een online patiëntendossier, ter bevordering van zelfmanagement bij een bipolaire stoornis; en 2) vanuit een drievoudig perspectief, te weten die van personen met een bipolaire stoornis, mantelzorgers en psychiatrisch verpleegkundigen, de contrasterende leerervaringen in zelfmanagementeducatie te beschrijven.

In **Deel I** worden twee studies over stemmingsmonitoring gepresenteerd, beginnend met **hoofdstuk 2** waarin het resultaat van een fenomenologische studie over de attitudes en motivaties van personen met een bipolaire stoornis ten aanzien van het wel of niet gebruiken van de LCM wordt beschreven. Via veertien ongestructureerde diepte-interviews is het narratief van personen met een bipolaire stoornis via audiotapes, getranscribeerd en vervolgens geanalyseerd. Over het algemeen was er een positieve houding ten opzichte van het LCM en een algemene erkenning van de toegevoegde waarde bij het monitoren van stemming en activiteit als onderdeel van de behandeling. De respondenten gaven echter aan dat het in kaart brengen van de dagelijkse stemming als een aanzienlijke last werd ervaren, met name tijdens het vroege stadium van diagnostisering. Als belemmerende factoren voor het gebruik van de LCM werden aangemerkt; het introduceren van de LCM voordat de impact van de diagnose bipolaire stoornis is weggeëbd, de onmogelijkheid om het instrument te personaliseren, en het ‘parkeerplaatseffect’, vlak voor de afspraak met een professional de rapportage nog even retrospectieve werd ingevuld. We concludeerden dat er rekening moet worden gehouden met de impact van de diagnose wanneer het instrument voor het eerst wordt geïntroduceerd bij een persoon met een bipolaire stoornis.

Hoofdstuk 3 beschrijft de resultaten van een pre-posttest studie van een op maat gemaakt online persoonlijk gezondheidsdossier voor personen met een bipolaire stoornis (PHR-BD) vanaf de nulmeting tot 12 maanden follow-up. Het doel van het project ‘Zelfmanagement en dialoog bij een bipolaire stoornis’; evalueerde de haalbaarheid, het nut en de gebruikerservaringen van de PHR-BD bij respondenten met een bipolaire stoornis, hun mantelzorgers, en participerende zorgverleners. Zesenzestig deelnemers met een bipolaire stoornis begonnen bij aanvang. Op het eindpunt van de studie vulden negenendertig deelnemers met een bipolaire stoornis, elf professionals en een mantelzorger de evaluatieformulieren in. Er werden geen statistisch significante verschillen gevonden in de klinische uitkomstmaten tussen aanvang en studie-eindpunt. Uit de kwalitatieve evaluaties bleek echter dat deelnemers vaak gebruik maakten van de stemmingsgrafiekmodules. Het gebruik van de PHR-BD verbeterde de communicatie tussen de clinici en deelnemers met een bipolaire stoornis. Bovendien verhoogde, met name de mogelijkheid tot aanpassen van de interface van de stemmingsgrafiek en de digitale koppeling aan het crisisplan, het inzicht in vroege symptomen van mogelijke stemmingsschommelingen. Deze functionele optie om de interface te wisselen tussen een prospectieve en een retrospectieve stemmingsgrafiek, geïntegreerd met het persoonlijke crisisplan werd zeer gewaardeerd en als aanvullend beschouwd om zelfmanagement van een bipolaire stoornis te bevorderen.

Deel II schetst een drievoudig perspectief op zelfmanagementeducatie voor bipolaire stoornissen, beginnend met **hoofdstuk 4** waarin een fenomenologisch design werd gekozen om de leerervaringen in het zelf managen van een bipolaire stoornis. Face-to-face, diepte-interviews werden afgenomen onder zestien personen met bipolaire stoornis I of II. Analyses toonden aan dat het leerproces naar zelfmanagement van een bipolaire stoornis voornamelijk plaatsvindt in een netwerk. Er werden vijf thema's gevonden die dit leerproces beschrijven. In eerste instantie is de erkenning van een bipolaire stoornis voorwaardelijk. Het moment, de volgorde en de hoeveelheid informatie is van belang om een bipolaire stoornis te begrijpen. Het monitoren van gemoedstoestand verbetert de controle van de ziekte. Het reflecteren op de mate waarin de bipolaire stoornis het leven van een individu en zijn familie controleert, is cruciaal voor het daadwerkelijk zelf kunnen managen van een bipolaire stoornis. We concludeerden dat het succes van zelfmanagement wordt bepaald door de erkenning van persoonlijke grenzen in het kunnen omgaan met de ziekte en de mate waarin iemand bereid is zijn netwerk als back-up te laten functioneren. Een belemmerende factor in dit leerproces waarmee rekening moet worden gehouden bij het aanleren van zelfmanagement van een bipolaire stoornis, is de aanhoudend sluimerende angst voor terugkerende episodes.

Hoofdstuk 5 geeft een beschrijving van de leerervaringen van mantelzorgers bij het ondersteunen van personen met een bipolaire stoornis in het zelf managen van hun ziekte. Uit een fenomenologische analyse van tien diepte-interviews hebben we vier leerfasen afgeleid die het leerproces van mantelzorgers reconstrueren. Beginnend met het begrijpen van de abstracte kenmerken van een bipolaire stoornis. Gevolgd door de dilemma's in informele zorgverlening te leren onderkennen waarbij het verdelen van taken en verantwoordelijkheden een grote rol speelt. Het definiëren van wat wordt bedoeld met zelfmanagementondersteuning voor personen met een bipolaire stoornis en in welke verhouding hun betrokkenheid passend is, is het sluitstuk van deze analyse. We hebben geconstateerd dat mantelzorgers geleidelijk aan leren omgaan met dagelijkse problemen als iemand met een bipolaire stoornis ondersteunen. Bijvoorbeeld, het beheersen van de emotionele expressie en het reflecteren op de oorsprong van conflicten, maar ook het leren begrenzen van hun overbezorgdheid door verantwoordelijkheden te delen met patiënten en professionals.

Het slotartikel in het drievoudige perspectief op zelfmanagementeducatie voor bipolaire stoornis wordt gepresenteerd in **hoofdstuk 6**, dat een onderzoek naar de impliciete kennis die psychiatrische verpleegkundigen gebruiken bij het geven van zelfmanagementeducatie voor bipolaire stoornissen rapporteert. In een fenomenologisch-hermeneutische studie interpreteerden we de ervaringen van negen verpleegkundigen in de geestelijke gezondheidszorg. De getranscribeerde face-to-face, afgenomen diepte-interviews werden hermeneutisch geanalyseerd. Onze analyse ontrafelde het complexe karakter van zelfmanagementeducatie voor personen met een bipolaire stoornis en hun naasten door een grondige beschrijving van de ervaringen van psychiatrisch verpleegkundigen. We vonden vijf pijlers waarop zelfmanagementeducatie voor bipolaire stoornissen is gebaseerd, deels op impliciete en deels op formele kennis van psychiatrisch verpleegkundigen. Deze componenten behelzen, het opbouwen van een betrouwbare samenwerking, het openen van een dialoog over de behoeften en de verantwoordelijkheden van alle stakeholders, vat krijgen op het concept 'bipolaire stoornis', het gebruik van instrumenten voor het monitoren van de stemming, en ten slotte het personaliseren van zelfmanagementstrategieën bij een bipolaire stoornis. Verpleegkundigen in de geestelijke gezondheidszorg berusten het geven van zelfmanagementeducatie bij een bipolaire stoornis, deels op hun kennis verkregen door hun formele professional opleiding, en deels op basis van hun ervaring. De laatstgenoemde is veelal impliciet aanwezig. Samenwerking zoeken in een ondersteunend, lerend netwerk van patiënten, hulpverleners en naasten, is essentieel voor succesvol zelfmanagement van een bipolaire stoornis op de lange termijn.

PhD Portfolio

Name PhD candidate: S.C.G.H. van den Heuvel **Department: IQ Healthcare** **Graduate School: Radboud Institute for Health Sciences**	**PhD period 01-01-2011 –** **Promotores: Prof dr. Theo van Achterberg, Prof. dr. Hester Vermeulen** **C0-promotores: Prof. dr. Peter Goossens, Dr. Cees Terlouw**	
	Year	**ECTS**
TRAINING ACTIVITIES		
Courses & Workshops (a)		
- NCEBP Introduction Course for PhD students	2011	1.75
- CaRe S08 Qualitative Research Methods in Health Care (introduction)	2011	1
- EpidM Kwalitatief onderzoek in de praktijk van de Gezondheidszorg (K78)	2012	2
- PAO Heyendael Basiscursus Regelgeving- en Organisatie voor Klinisch onderzoekers	2012	1.5
- European Academy of Nursing Science three-year programme of the Summer School for Doctoral Studies	2013	12
- Radboud University Academic Writing	2013	3
- PAO Heyendael SPSS	2013	1
- Radboud UMC Scientific Integrity	2013	1
- EpidM Epidemiologisch onderzoek: opzet en interpretatie (V01)	2013	4
- EpidM Principes van epidemiologische data-analyse (V20)	2014	3
- Radboud University Refresher course statistics for PhD	2015	2.5
- Radboud University Effectieve schrijfstrategieën	2016	3
Seminars & lectures (b)		
- Masterclass Bipolaire stoornissen at Driebergen, the Netherlands	2017	
- Masterclass Bipolaire stoornissen at Driebergen, the Netherlands	2018	
Symposia & congresses (c)		
- 15th Biennial Conference of the International Society for Bipolar Disorders. Istanbul, Turkey (poster presentation).	2012	
- European Congress of Mental Health Nursing. Helsinki, Turkey (poster presentation).	2012	
- Congres vitale region. Enschede, the Netherlands (oral presentation 20 minutes).	2013	
- Refeermiddag, SCBS Dimence. Holten, the Netherlands (oral presentation 15 minutes).	2013	
- Onderzoeksmiddag Dimence. Zwolle, the Netherlands (poster presentation).	2013	
- APNA Conference. San Antonio, Unites States of America (poster presentation).	2013	
- Summer conference of the European Association of Nursing Science. Nijmegen, the Netherlands (poster presentation).	2014	
- RPNC World Congress. Winnipeg, Canada (oral presentation 20 minutes)	2014	
- Summer conference of the European Association of Nursing Science. Rennes, France (oral presentation 30 minutes).	2014	
- 2nd Steigercongres. Papendal, the Netherlands (workshop 60 minutes).	2014	
- 2nd Steigercongres. Papendal, the Netherlands (keynote presentation).	2014	
- 16th Biennial Conference of the International Society for Bipolar Disorders. Seoul, South Korea (oral presentation 30 minutes).	2014	
- Symposium SCBS Dimence. Deventer, the Netherlands (oral presentation 30 minutes).	2014	
- Symposium SCBS Dimence. Deventer, the Netherlands (keynote presentation).	2014	
- 17the Biennial ISBD/ISAD Amsterdam, the Netherlands (oral presentation 20 minutes).	2016	
- Sympopna Nationaal congres GGZ-Verpleegkunde. Ede, the Netherlands (oral presentation 30 minutes).	2016	
- 5th European conference on mental health. Prague Czech Republic (oral presentation 20 minutes).	2016	
- Referaat Mediant. Enschede, the Netherlands (oral presentation 30 minutes).	2016	
- Refeermiddag, kenniscentrum voor Bipolaire Stoornissen. Wolfheze, the Netherlands (oral presentation 30 minutes).	2016	
- NVvP Voorjaarscongres. Maastricht, the Netherlands (two oral presentations of 15 minutes).	2016	
- Symposium SCBS Dimence. Deventer, the Netherlands (45 min. workshop).	2017	
- Symposium SCBS Dimence. Deventer, the Netherlands (keynote presentation).	2017	
- Weekend van de wetenschap. Nijmegen, the Netherlands (three workshops of 45 minutes).	2017	
- European Congress of Qualitative Inquiry. Leuven, Belgium (oral presentation 30 minutes).	2017	
- Saxion Research Congres. Enschede, the Netherlands (poster presentation).	2018	
Other (d)		
- Teaching activities at Saxion University of Applied Sciences at Deventer and Enschede, GGZ-VS at Utrecht, and Radboud University at Nijmegen, lectures in nursing, research, and ethics.	2010-2020	
TOTAL ECTS (of a):		**35.75**

Curriculum Vitae

Na het behalen van zijn diploma LBO-D in Arnhem kwam Silvio van den Heuvel na een jaar zijn dienstplicht te vervullen als soldaat/gewondenchauffeur tot de beslissing zijn carrière voort te zetten in de verpleegkunde. Startende met de MDGO-VP in Ede waar hij de eerste stappen in de psychiatrie zette op het terrein van GGZ Wolfheze – thans Pro Persona. Na deze opleiding volgde de HBO-V in Deventer waar aan het eind de bachelor scriptie werd afgerond door een onderzoek naar ambulante psychiatrische zorgverlening in Chennai, India. Na enkele jaren te hebben gewerkt in de acute klinische psychiatrische opname binnen de Zwolse Poort, de transculturele psychiatrie van Pro Persona als verpleegkundige en sociotherapeut in de behandeling voor persoonlijkheidsstoornissen bij GGNet rondde hij de studie Wijsbegeerte af aan de Radboud Universiteit. Hierop startte een nieuwe carrière in het hoger beroepsonderwijs aan de opleiding Verpleegkunde van Saxion.

Als docent verpleegkunde bij de Academie Gezondheidszorg van Saxion verzorgde Silvio binnen de opleidingen Verpleegkunde, Praktijk Ondersteuning Huisarts GGZ, Minor Intercultureel Werken, Honoursprogramma Liberal Arts & Science, Master Musculoskeletaal, gedetacheerd aan GGZ-VS te Utrecht, en de Master Advanced Nursing Practice onderwijs in vakken als o.a. ethiek, onderzoekmethodiek, stagebegeleiding, gedragsleer, psychologie, verpleegkunde in de geestelijke gezondheidszorg, wetenschapsfilosofie, studieloopbaanbegeleiding, evidence based practice en afstudeerbegeleiding. Via prof dr. Peter Goossens destijds lector GGZ, en Dr. Cees Terlouw destijds lector Onderwijsinnovatie en doorstroom, werd een promotievoorstel ingediend bij de raad van bestuur van Saxion. Na het binnenhalen van een promotievoucher van het ministerie OC&W voor docenten in het hoger onderwijs begon ook een academische carrière in het onderzoek. Als thema werd het aanleren van zelfmanagementstrategieën voor personen met een bipolaire stoornis gekozen aan het medische faculteit, NCEBP, IQ Healthcare van het Radboud UMC onder begeleiding van prof. dr. Theo van Achterberg, prof. dr. Lisette Schoonhoven en Prof. dr. Hester Vermeulen.

Gedurende zijn promotietraject heeft hij veel verschillende cursussen en deel-opleidingen gevolgd, waaronder de driejarige summer school van de European Academy of Nursing Science. Naast werkzaamheden bij Saxion, is Silvio betrokken als onderzoeker bij het SCBS Dimence waar hij regelmatig onderzoeksintervisie en verdere begeleiding ontving ter ondersteuning van het lopende promotietraject. Eveneens was Silvio betrokken bij het project ‘Zelfmanagement en Dialoog’ in een consortium van het Trimbos Instituut, KenBis, PlusMinus en Patient1.

In de toekomst zal Silvio actief blijven in onderzoek door betrokkenheid bij onderzoeksprojecten als wetenschappelijk medewerker van het SCBS van Dimence, het overdragen van zijn opgedane kennis in onderwijs aan verpleegkundigen en verpleegkundig specialisten in opleiding en zelf als verpleegkundig specialist in opleiding, waarmee een blijvende invloed wordt uitgeoefend op de praktijk, beleid en verdere professionalisering van het verpleegkundige beroep.

Dankwoord

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Prof. dr. Theo van Achterberg. Ik heb je als begeleidend hoogleraar leren kennen als een bijzonder aimabel persoon. Je hebt net zo'n scherp oog voor mijn manuscripten als voor de persoonlijke kant van het promovendus-zijn, getuige de vliegensvlugge respons op mijn zaterdagavond mails met een 'tongue-in-cheeck' opmerking dat er kennelijk iets schort aan ons beider werk-privé balans. Daarmee vervulde je niet alleen je mentorschap op een zeer prettige en motiverende manier maar ben je tevens een van mijn voorbeelden geworden hoe docentschap en academisch onderzoek succesvol te combineren zijn.

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Notes