

Research paper

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.

1. 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

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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, 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 and Aranda, 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 and 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 et al., 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., 2015).

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.

2. 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

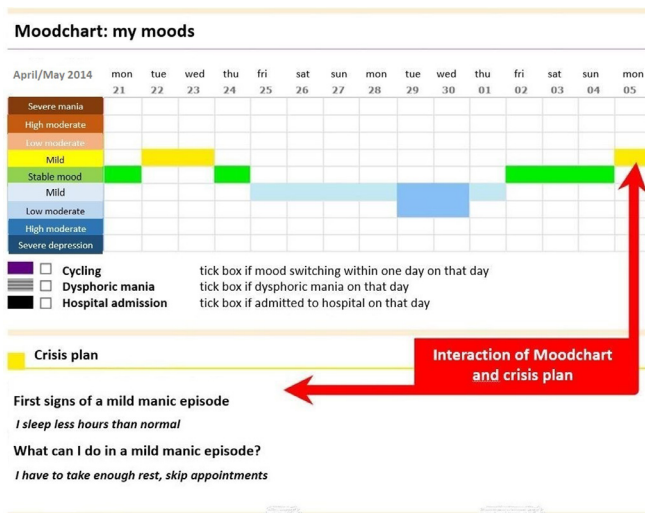


Fig. 1. Mood chart and crisis plan interaction.

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 Fig. 1. The mood graph interface is illustrated in Fig. 2.

2.1. 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.

2.2. 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

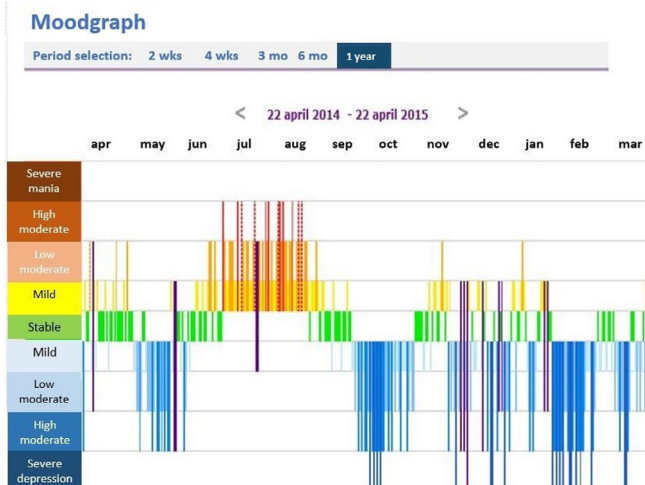


Fig. 2. Mood graph interface.

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