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Research paper

Self-management in young adults with bipolar disorder: Strategies and challenges

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ABSTRACT

Background: Early adoption of effective self-management strategies for bipolar disorder (BD) results in better clinical outcomes and increased quality of life. Therefore, facilitation of these strategies in young adults who are early in their illness course is vital. However, an understanding of self-management practices and needs of young adults with BD is lacking. This study explores young adult's perspectives of disorder self-management practices and challenges.

Methods: Young adults with BD completed an online survey about disorder management strategies and challenges. Self-management was investigated through self-report and ratings of literature-derived strategies. Results were analysed using descriptive statistics and qualitative thematic analysis.

Results: Eighty-nine participants aged 18–30 (M=24.4; SD=3.9) completed the survey. Adherence to treatment, disorder psychoeducation, and sleep-management were the strategies rated most helpful. Six participant-reported self-management strategies were identified (1) Maintaining a healthy lifestyle; (2) Treatment attendance and adherence; (3) Participation in meaningful activities; (4) Engagement with social support; (5) Meditation and relaxation practices; and (6) Symptom monitoring. The most common self-management challenges experienced by young adults concerned the nature of the disorder, interpersonal relationships, and stigma.

Limitations: Participants likely represent a sub-set of young adults engaged with healthcare and therefore may not be representative of the population.

Conclusions: Strategies reported vital by those successfully managing their disorder are not adequately utilised by young adults with BD. Both differences in strategy use and perceived self-management challenges represent important areas of clinical support and intervention. This increased understanding will help facilitate self-management skill development in this population.

Bipolar disorder (BD) is a chronic, episodic mental health condition, which, like other chronic conditions, requires long-term active management. The majority of chronic condition management is performed outside of healthcare professional contact. Indeed, clinical guidelines for BD are beginning to include recommendations for the development of self-management strategies in individuals with the disorder (National Collaborating Centre for Mental Health, 2014).

Adjunctive psychological therapy, which results in significant improvements over-and-above those from medication alone (Reinares et al., 2014), can facilitate the development of disorder management strategies (National Collaborating Centre for Mental Health, 2014). The early adoption of effective management strategies is associated with better symptom and functional outcomes, and increased quality of life (QoL; Colom et al., 2010). Furthermore, longitudinal findings indicate that early intervention with "systematic and thorough treatment can potentially stay the course of this condition" (Pg 197; Michalak et al., 2013) and lead to QoL improvements in young adults in the early stages of the disorder (Michalak et al., 2013; Oldis et al., 2016). Unfortunately, few individuals with BD have access to psychological services (Lam et al., 2010). Consequently, the development of self-management skills in young adults, who are in the early stages of BD, is an important alternative and adjunct to clinical care (Jones et al., 2011; Leitan et al., 2015).

Self-management refers to the individual taking central responsibility for the management of their health, through the development of skills to effectively manage symptoms and maintain QoL (Janney et al.,

Abbreviations: ASRM, Altman Self-rating Mania Scale; BD, Bipolar Disorder; PHQ-9, Public Health Questionnaire-9; QoL, Quality of Life

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2014; Jones et al., 2011; Lorig and Holman, 2003; Sterling et al., 2010). Quality of life considerations are of particular importance due to the consumer driven rise of the personal recovery perspective in mental healthcare, which has extended the meaning of recovery beyond that of the medical model (Leitan et al., 2015; Sterling et al., 2010). The traditional medical perspective is illness- rather than health-orientated, emphasising symptom absence and measures of clinical and functional outcomes (Slade, 2010). Instead, personal recovery emphasises the individual's adaptation to their health condition, living life with meaning alongside the illness (Anthony et al., 2003). Investigations of staying well (Russell and Browne, 2005) and recovery (Todd et al., 2012; Veseth et al., 2012) in BD have endorsed this perspective, with individuals reporting that self-management must extend beyond the medical model.

This understanding is reflected in the increasing body of research regarding the role of self-management in BD. Mainly qualitative in nature, studies examining self-management conducted with individuals effectively managing their disorder report the use of self-management strategies across the biopsychosocial spectrum (Murray et al., 2011; Russell and Browne, 2005; Veseth et al., 2012). Consumer reported strategies used to stay well include treatment adherence, sleep-management, and maintaining a healthy diet and exercise, as well as psychoeducation, identifying triggers, social support, relaxation, and having a stay-well plan (Murray et al., 2011; Russell and Browne, 2005). Importantly, these strategies mirror advice provided by health professionals based on the common core elements of evidence-based psychosocial interventions (Murray et al., 2011).

Such insights regarding effective self-management help identify strategies and skills that could assist others. Research demonstrates that some recently diagnosed individuals are unfamiliar with the concept of self-management (Todd et al., 2012). Indeed, studies have alluded to differences in self-management knowledge and needs as a function of illness stage (Murray et al., 2011; Todd et al., 2012). Despite this, literature regarding the self-management practices of younger, more recently diagnosed individuals with the disorder is scarce.

Clearly, there is a need to know more about the self-management practices and needs of young adults who are in the early stages of BD. Such consumer perspectives are critical for guiding efforts to facilitate the development and implementation of effective self-management among young adults with the disorder. Therefore, the aim of the current paper is to: (a) describe the self-management strategies young adults with BD use when euthymic, (b) examine the specific strategies used to manage disorder episodes, and (c) identify perceived challenges in the management of BD for the young adult population.

1. Methods

1.1. Design

The study employed a cross-sectional survey design. Participant recruitment occurred through the Black Dog Institute clinics and volunteer research register, as well as through promotion on the institute website and social media (Facebook and Twitter). Also contacted to promote the survey were approximately 40 external organisations and services that focus on BD or the mental health of young people, including Headspace, Moodswings, LIVIN, and the Depression and Bipolar Support Alliance. The survey was delivered online via the Black Dog Institute Research Engine to allow for anonymous administration. The online administration also ensured participants answered all survey questions.

The study received ethical approval from the UNSW Australia Human Research Ethics Committee (Protocol number: HC15198). Participants who indicated distress by scoring > 15 (moderately severe or severe depression) on the Public Health Questionnaire -9 (PHQ-9; Kroenke et al., 2001), over six (indicating mania) on the Altman Self-rating Mania Scale (ASRM; Altman et al., 1997), or indicated suicidal ideation on question nine of the PHQ-9, were presented a support message that included contact details of support services.

1.2. Participants

Detailed participant information was presented online and participants provided consent by clicking an acknowledgement indicating they had read and understood the information. Screening for eligibility occurred online with a series of initial questions to determine if participants met the following inclusion criteria; diagnosis of BD; aged between 18 and 30 years; had access to the internet; and an ability to read and write English. No exclusion criteria were applied to ensure the sample reflected the widest representation possible using the research design employed.

1.3. Survey measures

A survey investigating young adults perspectives on BD self-management strategies and challenges was created and piloted by three young adults with BD recruited through the Black Dog Institute volunteer network to evaluate its usability. Survey content is further detailed below.

1.3.1. Demographic information

Data on sex, age, country of residence, and current employment status was collected.

1.3.2. Symptoms

Age of diagnosis, date of last episode, and current treatment(s) were collected. To access mood state at the time of survey completion, the PHQ-9 and the ASRM were included. The PHQ-9 is a 9-item self-report measure of depression symptoms experienced within the past 2 weeks. Validity and reliability have been widely established (Kroenke et al., 2001), and standardised PHQ-9 scale cut-offs categorise the current level of depression; 1–4 minimal depression, 5–9 mild depression, 10–14 moderate depression, 15–19 moderately severe depression, and 20–28 severe depression. The ASRM is a 5-item scale of self-reported mania symptoms occurring over the last week. ASRM scores of six or higher are indicative of mania, and higher scores indicate greater symptom severity.

1.3.3. Self-management skills development and support

Participants were asked where they learnt or how they developed their reported self-management strategies, with options of; *1 Psychiatrist, 2 Psychologist, 3 General practitioner, 4 Online information, 5 Information in books/journals/magazines, 6 Self-developed from experience, 7 Family, 8 Friends, 9 Other people with BD, and 10 Other*. Sources of help or advice for self-management were explored via an open-ended question. Finally, who participants involved in the management of their BD was also investigated; *1 Psychiatrist, 2 Psychologist, 3 General practitioner, 4 Family, 5 Friends, 6 Boyfriend/girlfriend/partner,* and *7 Other*.

1.3.3.1. (a) Self-management strategies used when euthymic

1.3.3.1.1. (i) Endorsed literature strategies. To identify self-management strategies relevant to the disorder, JN performed an informal review of the literature regarding consumer perspectives on BD self-management using PsycINFO. JN then reviewed published psychosocial intervention manuals for the disorder (Psychoeducation (Colom and Vieta, 2006), Cognitive Behaviour Therapy (Lam et al., 2010), Interpersonal and Social Rhythms therapy (Frank et al., 2000)) alongside identified studies (Depp et al., 2009; Murray et al., 2011; Russell and Browne, 2005; Suto et al., 2010) to identify relevant strategies. Negative strategies were included in line with previous research (Depp et al., 2009), to ensure all strategies used by the