Research paper

# Effective self-management strategies for bipolar disorder: A community-engaged Delphi Consensus Consultation study

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### ARTICLE INFO

### ABSTRACT

*Background:* Self-management represents an important complement to psychosocial treatments for bipolar disorder (BD), but research is limited. Specifically, little is known about self-management approaches for elevated mood states; this study investigated self-management strategies for: (1) maintaining balance in mood, and (2) stopping progression into hypomania/mania.
*Methods:* To identify the common components of BD self-management, Delphi Consensus Consultation methods were combined with a Community-Based Participatory Research (CBPR) approach across five study phases: (1) Qualitative dataset content analysis; (2) Academic/grey literature reviews; (3) Content analysis; (4) Two Delphi rounds (rating strategies on a 5-point Likert scale, Very Unhelpful-Very Helpful), and; (5) Quantitative analysis and interpretation. Participants were people with BD and healthcare providers.
*Results:* Phases 1 and 2 identified 262 and 3940 candidate strategies, respectively; 3709 were discarded as duplicates/unintelligible. The remaining 493 were assessed via Delphi methods in Phase 4: 101 people with BD and 52 healthcare providers participated in Round 1; 83 of the BD panel (82%) and 43 of the healthcare provider panel (83%) participated in Round 2—exploratory factor analysis (EFA) was conducted on Round 2 results.
*Limitations:* EFA was underpowered and sample was not ethnically diverse, limiting generalizability.
*Discussion:* High concordance was observed in ratings of strategy effectiveness between the two panels. Future research could usefully investigate the provisional discovery here of underlying factors which link individual strategies. For example, 'maintaining hope' underpinned strategies for maintaining balance, and 'decreasing use of stimulants' underpinned strategies to interrupt hypo/manic ascent. There is merit in combining CBPR and Delphi methods.

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## 1. Introduction

Many bipolar disorder (BD) publications begin with so-called 'bipolar misery statistics' (Lobban et al., 2012), speaking to the considerable disability and dysfunction associated with the condition. Indeed, most data in the field paint a bleak picture. Even optimal medication management fails to ward off mood episodes in many living with BD (Gitlin et al., 1995), a mood disorder frequently characterized by high rates of relapse and hospitalization

(Gitlin et al., 1995), and poor functioning and quality of life (QoL) (Chengappa et al., 2005; Robb et al., 1997). Given that 6–10% of people with BD are at high risk of suicide (Nordentoft et al., 2011) and that, on average, they lose 9 years of life (Crump et al., 2013), the condition represents a serious personal and public health concern that should not be downplayed.

Yet, there is also evidence that people with BD can flourish (Lobban et al., 2012; Michalak et al., 2012a; Michalak et al., 2006; Murray et al., 2011; Russell and Browne, 2005; Suto et al., 2010). Living well with BD typically requires more than pharmacological approaches alone; psychosocial interventions are also key (Miklowitz, 2008a), but frequently underutilized, in part because of inaccessibility of formal services (Hickie et al., 2006; Hickie and McGorry, 2007), skepticism about particular interventions (Joukamaa et al., 1995; Jorm, 2000), lack of perceived need for treatment (Meadows and Burgess, 2009; Meadows et al., 2002), self-stigma (Bayer and Peay, 1997), lack of insight (Kessing et al., 2006), and a preference for self-management (Andrews et al., 2001). In fact, self-management approaches offer an important alternative; as well as decreasing people's reliance on healthcare providers, they can serve to empower and give a sense of greater agency.

Most trials assessing the impact of supported self-management for unipolar depression have demonstrated superiority over care as usual (Houle et al., 2013). Yet, whilst there exists a rich literature on self-management of chronic conditions more broadly (Jonkman et al., 2016), research on self-management in BD is comparatively sparse and mostly qualitative. For example, Pollack (1996) investigated self-management amongst inpatients using semi-structured interviews (Pollack, 1996), identifying a range of successful strategies including self-monitoring of medication use, becoming knowledgeable about BD, and stress management. Several studies have sought to identify effective self-management strategies used by people who manage their BD successfully. For example, in an Australian sample, Russell and Browne (2005) found that people with BD self-reporting a lack of relapse for at least two years described themselves as being actively engaged in self-management practices (Russell and Browne, 2005), including: identification of triggers and warning signs, management of sleep and stress, use of support systems, lifestyle changes, engagement with treatment and stay well plans. Mansell et al. (2010) investigated a UK-based sample of people with BD who had not relapsed in two years, observing that the early detection of warning signs, while helpful, may also lead to unproductive hyper-vigilance (Mansell et al., 2010).

Qualitative methods were used to explore successful self-management strategies in 32 Canadian individuals (subjectively and objectively) living well with BD (Murray et al., 2011; Suto et al., 2010). Self-management themes included: sleep, diet, rest and exercise, ongoing monitoring, reflective and meditative practices, understanding BD and educating others, connecting with others, and enacting a plan. Significant overlap between self-management strategies reported by people who manage their BD well and the content of evidence-based psychological treatments for BD was noted (Murray et al., 2011). Somewhat different themes were identified in a study conducted in a New Zealand Chinese BD population (Wang et al., 2009), where BD was viewed through a more positive framework (e.g., maintenance of harmony). A small UK qualitative study spoke to the significance of diverse forms of support for engagement in self-management practices (Todd et al., 2013). Finally, a recent phenomenological study found that people with BD describe self-management of the condition as a learning process that takes place in a collaborative network (Van den Heuvel et al., 2015).

In summary, there now exists body of – mostly qualitative – evidence suggesting that self-management strategies are feasible and effective in BD. Significant questions remain, however.

Existing research only highlights the self-management strategies that people are currently finding effective; it remains possible that additional or alternative strategies could be identified and disseminated. For example, current evidence-based psychotherapies include a range of cognitive and behavioural strategies for responding productively to hypo/mania specifically, and yet these coping responses do not appear in the existing qualitative literature. Further, our knowledge of self-management strategies is more complete in some areas than others. For example, existing evidence for cognitive and behavioural strategies in BD, and qualitative studies amongst people in recovery, provide a solid body of self-management strategies for relapse prevention and mood management. In contrast, little is known about the optimal self-management of problems associated with common comorbidities (e.g., substance misuse). Likewise, management of relationship difficulties linked to BD requires greater attention before sound self-management strategies can be promulgated. Finally, the field would benefit from greater diversity in methodological approaches at this juncture.

The aim of this study was to advance the literature on self-management strategies for BD by identifying the common components of BD self-management for maintaining balance in mood and stopping progression into hypo/mania, by combining two methodological approaches: Delphi Consensus Consultation and Community-Based Participatory Research (CBPR).

## 2. The Delphi method

Modern Delphi methods solicit input from multiple experts, contributing independent views and ratings in an iterative process aimed at achieving substantial consensus (Amos and Pearse, 2008; Powell, 2003), often online (Donohoe et al., 2012). Delphi studies are highly structured and systematic. The initial survey is commonly based on a literature review, but may include information gathered from other sources (Amos and Pearse, 2008; Vernon, 2009). Criteria for consensus, re-rating, and deletion of survey statements or items are applied a priori.

The Delphi method has demonstrated satisfactory reliability and construct validity (Hutchings et al., 2006; Minas and Jorm, 2010). It is frequently used for complex real-world problems when little scientific evidence exists, or when evidence needs clarification, improvement or translation (Davidson, 2013; Hutchings et al., 2006; Minas and Jorm, 2010; Vazquez-Ramos et al., 2007). Delphi methods have been used to explore effective self-management of sub-threshold unipolar depression symptoms (Morgan and Jorm, 2009), antidepressant use (Pacchiarotti et al., 2013) and the development of guidelines for caregivers of people with BD (Berk et al., 2011).

## 3. Community-Based Participatory Research (CBPR)

CBPR is characterized by end-user engagement in all stages of research, from formulating study goals and hypotheses, to planning sampling, design, measures and analyses, to disseminating results (Israel et al., 2010). The goal of CBPR is to shape the research process to fit the perspectives of community members, and thus generate knowledge contributing directly to social change (Cargo and Mercer, 2008; Michalak et al., 2012b). Here, CBPR provided the framework for the use of the Delphi method.