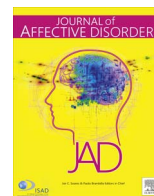




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Research paper

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



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## 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

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<sup>1</sup> CREST.BD is a Canadian government (Canadian Institutes of Health Research) funded multidisciplinary network dedicated to advancing bipolar disorders research and knowledge exchange, particularly embracing Community-Based Participatory Research.

(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.

## 4. Methods

### 4.1. Team

The project was conducted by the Collaborative REsearch Team to study psychosocial issues in BD (CREST.BD), which specializes in CBPR in BD research and knowledge exchange (Michalak et al., 2012b; Michalak et al., 2015; Michalak et al., 2016). The core study team included academic researchers (one of whom lives with BD) and two co-researchers with lived experience of BD ('peer researchers'), complemented by several research assistants and undergraduate volunteers.

### 4.2. Definition of self-management

Following an informal review of existing definitions of self-management by one of the study peer researchers (MWS), developed a working definition of self-management (see Table 1).

### 4.3. Overview

The project was conducted at the University of British Columbia (UBC) between 2012 and 2014 and comprised five phases. Ethics approval was secured from the UBC Behavioural Research Ethics Board.

### 4.4. Phase 1: Qualitative research dataset content analysis

Study peer researcher SL retrospectively re-analyzed the raw interview ( $n=29$ ) and focus group ( $n=3$ ) transcriptions generated in our prior qualitative research (Suto et al., 2010). Where possible, participant statements were extracted verbatim from transcripts.

### 4.5. Phase 2: Academic and grey literature reviews

Systematic academic (lead: SH) and grey (lead: SL) literature searches were performed. Search terms used for both literature reviews included the following: *bipolar disorder, hypomania, mania, manic depression* paired with *self-management, relapse prevention, coping, wellness, stay-well, self-care, self-help, chronic disease management and symptom management*. The academic literature search was conducted between August 2012 to January 2013 using MEDLINE (OvidSP), PsycINFO, EMBASE and PubMed. 'Grey literature' refers to manifold nonconventional document types that are not peer-reviewed or controlled by commercial publishers (Alberani et al., 1990). The grey literature search was conducted from July to September 2012 using Google.com. All combinations of the above search terms were entered, and the top 25 websites identified were reviewed. The search included diverse websites, mostly mental-health and BD-related organization homepages, and diverse content, including government or agency reports, dissertations, podcasts, videos, conference proceedings, blogs and chat forums. A Google search and informal consultation with CREST.BD membership were also performed to generate a list of the most highly regarded BD academic and lay books. Fourteen academic and three lay books (full list available upon request) were read in their entirety (lead: MWS). Regardless of the source, individual statements regarding specific self-management strategies were extracted. For each source, the reviewer recorded whether the specific strategy was described as being useful for maintaining balance in mood, dealing with depression and hypomania/mania. Strategies that were specifically designated for depression, but not hypomania or mania, were not recorded.

### 4.6. Phase 3: Content analysis

To organize the content produced from Phases 1 and 2, the project team met on a weekly/biweekly basis (May 2012 - January 2013). Between January - July 2013 strategies deemed irrelevant (not speaking directly to self-management, or speaking solely to self-management of depressive states), potentially harmful, and/or duplicate/unclear were removed; the remaining set was edited into unambiguous actionable statements/items.

### 4.7. Phase 4: Delphi Consensus Consultation

#### 4.7.1. Participants

Two panels were formed to develop consensus guidelines. The first consisted of people with lived experience of BD, the second of BD healthcare providers. Inclusion criteria for people with lived experience were: (1) 19 years or older, (2) able to communicate in English, and (3) self-report of diagnosis of BD type I, II or NOS. Inclusion criteria for healthcare providers were: (1) 19 years or older, (2) able to communicate in English, and (3) self-report of being a healthcare provider working with patients with BD. Participants specified whether they wanted to be designated as a person with BD or a healthcare provider ( $n=3$  healthcare providers with BD chose to be designated as healthcare providers).

#### 4.7.2. Survey design

For both panels, two online surveys (Round 1 and Round 2) were delivered via Qualtrics. Participants were able to save their work and return to the survey at a later time, and a glossary of problematic terms was provided. The core of each survey was a list of strategies; participants were asked to rate each strategy's helpfulness for (1) maintaining balance in mood and (2) stopping progression into hypomania and mania. Ratings were made on a 5-point Likert scale (1 = 'Very unhelpful' 2 = 'Unhelpful' 3 = 'Neither helpful nor unhelpful' 4 = 'Helpful' 5 = 'Very helpful'). Demographic, clinical and/or healthcare profession data were also collected.

#### 4.7.3. Recruitment and survey completion

Recruitment for Round 1 occurred between November 2013 and February 2014. A single recruitment advertisement was developed targeting people with BD (with no stipulations or assessments regarding level of recovery or functioning) and BD healthcare providers and sent electronically to approximately 500 potential participants (around 350 people on the CREST.BD email list and 150 individuals identified within the co-authors' personal networks) and to major mental health and research organizations. Concurrently, two recruitment videos (<http://tinyurl.com/j9m3e99> and <http://tinyurl.com/zo54adb>) were released via the CREST.BD YouTube channel. Participants were eligible for inclusion worldwide, but countries targeted for recruitment were Canada, US, UK and Australia. Only participants who completed the Round 1 were eligible for Round 2. Participants completing both rounds were entered to win one of two prize packages valued at \$500 each (a collection of the BD books, DVDs, etc.). The Round 2 survey was open throughout April 2014.

### 4.8. Phase 5: Statistical analysis

To assist with grouping strategies into useful themes, and to explore possible redundancy between strategies, exploratory factor analyses (EFA) were conducted on Round 2 Likert scale ratings (analyses were conducted separately on maintaining balance and stopping progression). Principal components analysis extraction was used, and oblique rotation was applied to extracted factors. Number of factors to extract was determined by Kaiser's criterion,

the Scree test and parallel analysis. Factor loadings  $> |.4|$  were considered significant. The size of the final sample, particularly in relation to the number of analyzed variables, was small. Findings for both analyses must therefore be interpreted cautiously.

## 5. Results

### 5.1. Phase 1: Qualitative research dataset content analysis

A total of 262 candidate self-management strategies (see Fig. 1) were identified and extracted from the qualitative transcripts (described above).

### 5.2. Phase 2: Academic and grey literature reviews

The academic literature search generated 368 potentially relevant peer-reviewed publications, 39 of which were appropriate for full review; the search produced 108 potential strategies. A total of 950 relevant websites were identified for review, yielding 2816 potential strategies. Within the 17 books reviewed, 1016 potential strategies were identified (767 from academic books and 249 from lay books).

### 5.3. Phase 3: Content analysis

Phases 1 and 2 generated 4202 potential strategies, of which 111 were discarded as unintelligible, leaving a final tally of 4091 to examine for duplicates; 3598 duplicates were identified and removed. The wording of the remaining 493 strategies was then edited (keeping the wording as close to the original source as possible) to produce items which represented clear, actionable self-management strategies (Table 1).

### 5.4. Phase 4: Delphi Consensus Consultation

#### 5.4.1. Round 1

**5.4.1.1. Participants.** In Round 1, 370 people with BD (Panel 1) and 199 healthcare providers (Panel 2) consented to participate. Completed surveys were received from 101 people with BD (27% completion rate) and 52 healthcare providers (26% completion rate). Demographics are presented in Tables 2 and 3, respectively.

**5.4.1.2. Usefulness ratings.** Round 1 ratings tended to be relatively high in both panels. Mean ratings for maintaining balance were 4.11 ( $SD=.39$ ), and 4.03 ( $SD=.44$ ) for healthcare providers and people with BD respectively. For stopping progression, corresponding means were 3.95 ( $SD=.48$ ) and 3.79 ( $.44$ ).

Analysis of Delphi data typically requires a quantitative definition of 'consensus' at this point of the process, although there is considerable variability across studies with regards how consensus may be determined (Jorm, 2015). Analysis of Round 1 data indicated high agreement between the two panels: Spearman's rho comparing the rank ordering across panels was .83 ( $p < .001$ ) and .85 ( $p < .001$ ) for maintaining balance and stopping progression respectively. We therefore combined the ratings of the two panels to give each strategy a single maintaining balance rating and a single stopping progression rating at the end of Round 1.

Strategies in the upper quartile of mean usefulness ratings for either maintaining balance or stopping progression were progressed to Round 2. Because the Round 1 survey generated a large number of strategies with relatively high ratings, an arbitrary numerical cut-off (e.g., above 4) would have yielded far too many candidates for Round 2; accordingly, we selected the upper quartile to focus the second survey. There was significant overlap

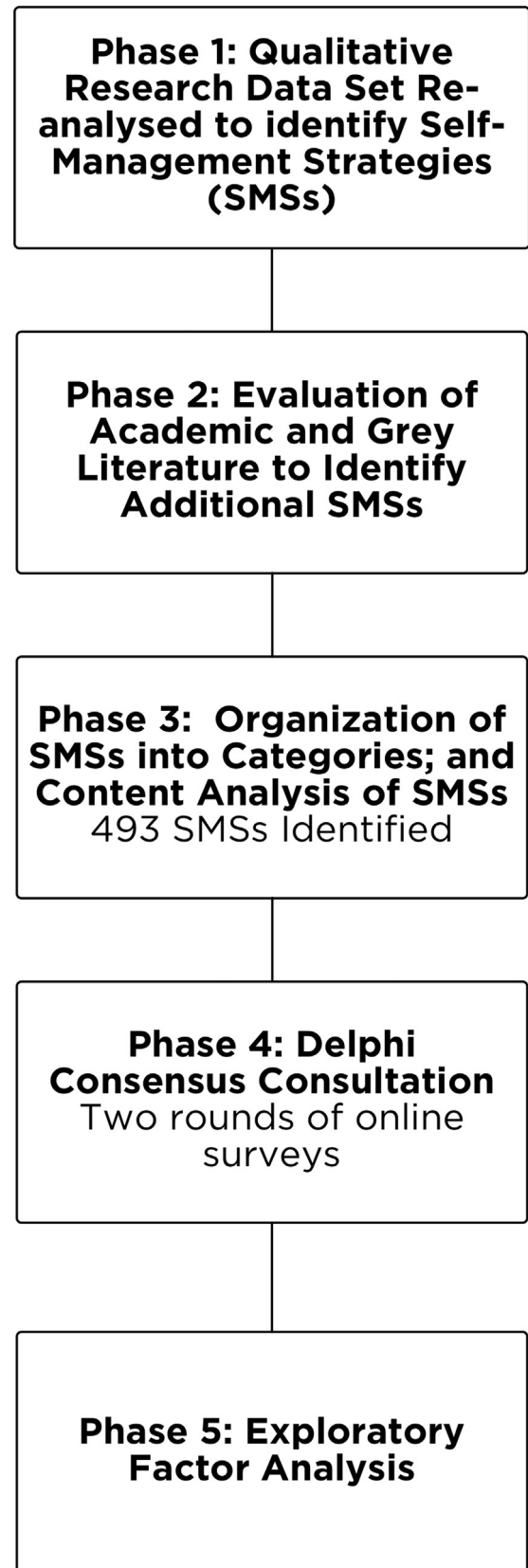


Fig. 1. Self-management strategy identification and reduction, phases 1–5.

between ratings for either maintaining balance or stopping progression, with  $n=75$  strategies appearing in the upper quartile for both. A further  $n=41$  strategies fell into the upper quartile for

**Table 1**  
Definition of self-management adopted.

"Bipolar disorder (BD) self-management refers to the plans and/or routines that a person with BD uses to promote health and QoL. Healthcare professionals can provide information about BD self-management strategies and support for their application. Family, friends and caregivers can also be involved in developing strategies and supporting the person in using them. However, outside of hospital settings, it is typically the person with BD who chooses their approach to self-management and enacts and tailors their own strategies. Most strategies, regardless of whether they originate solely with the person with BD or are developed in collaboration with others, can be considered self-management strategies."

maintaining balance only, and  $n=39$  fell into the upper quartile for stopping progression only. A total of  $n=155$  (i.e.,  $75+41+39$ ) items were taken through to Round 2.

#### 5.4.2. Round 2

**5.4.2.1. Participants.** Panels were reconvened for Round 2 analyses to generate ratings of the  $n=155$  strategies. Recruitment retained 83/101 (82%) of the people with BD and 43/52 (83%) of the healthcare provider panel members. Demographics are presented in Tables 2 and 3, respectively.

Round 2 ratings, not unexpectedly, tended to be high. Total mean rating for Round 2 strategies was 4.4/5 (range 3–5) in the people with BD panel and 4.5/5 (range 3–5) in the healthcare provider panel. The three highest rated strategies in Round 2 for people with BD for maintaining balance were: Never run out of medication; Learn to manage stress; and Prioritize sleep and rest (all rated 4.8/5). For healthcare providers, the three highest rated strategies for maintaining balance were: Commit to getting to sleep (4.8/5); Learn to manage stress (4.8/5); and Exercise regularly (4.7/5). The three highest rated strategies for stopping progression in people with BD were: Never run out of medication; Prioritize sleep and rest; and Be aware of early-warning signs (all rated 4.8/5). The three highest rated strategies for stopping progression in the healthcare provider panel were: Be aware of early-warning signs (4.9/5), Do not ignore BD symptoms (4.9/5) and Prioritize sleep and rest (4.8/5).

Generally, strategies pertaining to healthcare (e.g., "Find a healthcare provider who has experience working with people with BD") and medication (e.g., "Never run out of medication") were highly endorsed by both panels for both maintaining balance and stopping progression. Strategies relating to early-warning signs were highly endorsed for stopping progression, while relationship-focused strategies (e.g., "Cultivate loving, healthy

relationships") were highly endorsed (especially by people with BD) for maintaining balance.

As with Round 1, the two panels generated comparable patterns of rating: Spearman's rho comparing ranks was .48, ( $p < .001$ ); and .72, ( $p < .001$ ), for maintaining balance and stopping progression respectively), so we again combined the ratings of the two panels to give each strategy two final Round 2 ratings, one for maintaining balance and one for stopping progression.

#### 5.5. Phase 5: Quantitative analyses

##### 5.5.1. Strategies for maintaining balance

A total of 117 strategies were subjected to EFA investigating maintaining balance (75 of which also participated in the EFA of stopping progression, below). As with the previous analysis, Bartlett's Test of Sphericity was significant,  $\chi^2(6786)=12007.22$ ,  $p < .001$ , but the Kaiser-Meyer-Olkin measure of sampling adequacy was .35, below the recommended value of .60 (Tabachnick and Fidell, 2007). The correlation matrix contained numerous correlations  $> .5$ , the diagonals of the anti-image correlation matrix ranged from .16 to .66, and communalities were all above .70.

Again, Kaiser's criterion seemed to overestimate the number of factors, with 33 components meeting the criterion of eigenvalue  $> 1$  and accounted for 77.6% of the variance. The Scree test and parallel analysis, in contrast, both suggested the extraction of four meaningful components (explaining 35.1% of the variance). These four factors were extracted from a second PCA with direct oblimin rotation, and the resulting four-factor structure is presented in Table 4.

Simple structure was achieved, with the exception of one item (*Appreciate periods of not being in a BD episode*) that had almost identical loadings on Factors 1 and 3. Interpretation of item content suggested that Factor 1 (22 items) could be described as "Calming" strategies, Factor 2 (24 items) as "Medical management" strategies, Factor 3 (12 items) refers to strategies related to "Maintaining hope", while strategies related to "Physical activity" seem to be the core of Factor 4 (9 items).

##### 5.5.2. Strategies for stopping progression

A total of 113 strategies were subjected to EFA investigating self-management of stopping progression (75 of which also participated in the EFA of maintaining balance, above). Preliminary investigations of factorability suggested with some qualification that the data were suitable for factor analysis. Bartlett's Test of Sphericity was significant,  $\chi^2(6328)=10970.01$ ,  $p < .001$ , although the Kaiser-Meyer-Olkin measure of sampling adequacy was .43,

**Table 2**  
People with BD demographics and clinical characteristics.

Survey round	n	Gender	Self-reported diagnosis	Mean (SD) self-reported duration of time living with BD	Self-reported taking medication?	Ethnic background	Country of Residence	Employment (full- or part-time)
Round 1	101	78% female	49% Bipolar I 48% Bipolar II 4% Other	24.4 (13.5)	87% "yes"	2% Asian 93% Caucasian 4% Mixed 2% Unspecified	57% Canada 37% United States 3% UK 1% Italy 1% France 1% Australia	48%
Round 2	83	78% female	43% Bipolar I 49% Bipolar II 7% Other	22.5 (12.1)	78% "yes"	2% Asian 92% Caucasian 1% Hispanic 2% Mixed 2% Unspecified	57% Canada 35% United States 4% UK 1% Italy 1% France 1% Australia 1% Guatemala	42%

**Table 3**  
Healthcare provider demographics and characteristics.

Survey round	n	Gender	Mean (SD) age	Mean (range) years in practice	Mean (range) number of BD patients treated	Professional affiliations
Round 1	52	69% female	47.3 (13.5)	16.0 (2–45)	180 (4–5000)	10% occupational therapists 6% nurses 23% psychiatrists 25% psychologists 4% psychotherapists 10% social workers 22% other helping professions
Round 2	43	67% female	46.8 (13.1)	16.4 (1–45)	85.4 (1–150)	5% occupational therapists 5% nurses 26% psychiatrists 26% psychologists 2% psychotherapists 10% social workers 26% other helping professions

below the recommended value of .60 (Tabachnick and Fidell, 2007). The correlation matrix contained numerous correlations  $> .5$ , the diagonals of the anti-image correlation matrix ranged from .33 to .75, and communalities were all above .72.

Kaiser's criterion suggested 34 components (accounting for 78.6% of the variance). However, review of the scree plot and parallel analysis both suggested only three meaningful components. Consequently, three components were extracted from a second PCA with direct oblimin rotation applied. The three factors explained 29.9% of the variance.

The resulting three-factor structure is presented in Table 5. All items had primary loadings over  $> |.4|$  with only one cross-loading item (*Contact healthcare provider if sleep pattern is disrupted*, primary loading on Factor 3, secondary loading on Factor 2). Inspection of item content on Factor 1 (31 items with significant loadings), suggested that this factor could be interpreted as "Forward planning". Factor 2 (29 items) could be interpreted as "Early intervention" strategies. Finally, Factor 3 (9 items), the latent variable of Factor 3 could be described as "Decrease stimulants."

## 6. Discussion

This study was conducted to advance the literature on self-management strategies for BD, with the specific objective of building evidence on strategies deemed most effective (by people with BD and BD healthcare providers) for maintaining balance in mood, and stopping progression into hypomania and mania. Methodologically, the study used a novel approach in that it applied Delphi Consensus Consultation methods within a CBPR framework and then culminated with quantitative analyses which allowed us to develop provisional hypotheses about underlying factors that may link preferred approaches for self-management in BD. For maintaining balance in mood states, EFA suggested that factors of 'calming oneself', 'medical management', 'maintaining hope', and 'physical activity' may be important. For stopping progression into hypomania or mania, EFA suggested that strategies were linked by factors of 'planning ahead', 'intervening early' and 'decreased use of stimulants'.

The findings have implications for conceptual understanding of self-management in BD. On theoretical grounds, we have previously argued (Murray and Michalak, 2012) that self-management approaches complement medical management in BD. The present findings suggest that both healthcare providers and people with lived experience of BD concur: High concordance was observed between panel ratings. This finding aligns with recent conclusions by Jorm (2015), who observed that several Delphi studies in the mental health arena have likewise found

reassuringly high agreement between the two types of experts (Jorm, 2015). Here, for example, both panels elevated strategies pertaining to healthcare interventions and medication treatments. This finding contrasts with earlier results related to sub-threshold depression, where lifestyle-related psychosocial factors were preferred by patients (Morgan and Jorm, 2009). In BD, the present data suggest, there is broad consensus on a net positive cost-benefit analysis of medications and medical management for addressing particularly the manic pole. Our data therefore tend to discourage the polarisation of medical and self-management approaches, and highlight broad recognition of a holistic approach to this biopsychosocial disorder. It should be noted that the high endorsement of the importance of pharmacotherapy in our study may, however, have been influenced by our sampling approach. By recruiting through the CREST.BD network we may have been accessing potential participants with specific interest in BD research and treatments. Alternatively, the length of the survey may have biased towards people with BD who were more stable.

### 6.1. Clinical considerations

An important outcome here was the strong concordance between ratings in the two panels. An earlier qualitative study noted that coping behaviours employed by people who manage their BD well overlap substantially with the explicit content of evidence-based psychological treatments (Murray et al., 2011). The present study gives further evidence of a shared valuing of strategies particularly related to hypo/mania, providing an empirical foundation for strongly collaborative working relationships between patients and healthcare providers. Indeed, a recent review of self-management strategies thought to be effective in BD (Janney et al., 2014) map well onto the strategies highlighted here, and onto the common ingredients found in evidence-based psychosocial treatment interventions for BD (Miklowitz et al., 2008b).

The present study goes beyond previous research, however, in conducting a preliminary EFA to explore underlying factors that might link the individual strategies. We see this novel approach as paralleling recent research into psychotherapies for BD, where attention is shifting from comparison of *surface strategies* towards identification of underlying *change mechanisms* (e.g. Perich et al., 2014). To our knowledge, this is the first empirical study to identify 'maintaining hope' as a theme across strategies for maintaining balance. Often mentioned in the psychosocial literature (particularly in the recovery literature, e.g., Wang, 2009), the potential for *hope-reinforcing behaviours* to maintain stable mood is a specific hypothesis warranting further investigation. Likewise, generic lifestyle strategies for maintaining wellness in BD often canvas the potential utility of *physical activity*, but the present analysis raises

**Table 4**  
Factor loadings and communalities based on a principal component analysis with oblimin rotation for 117 maintaining balance items (n = 126).

Item statements	Calming	Medical management	Maintaining hope	Physical activity
Allow time for relaxing activities (e.g., hot bath, reading, massage)	.738			
Spend time in a relaxed, quiet place	.644			
Avoid scheduling too many social events, especially on week nights	.633			
Do not take on too many projects	.611			
Get organized	.587			
Be patient and persistent in seeking help and finding solutions for problems	.582			
Attend talk therapy (e.g., with counsellor, social worker, psychologist)	.558			
Aim for eight hours of sleep per / night	.527			
Do not overwork	.527			
Do not expect perfection	.496			
Set realistic expectations	.495			
Be organized financially	.474			
End unhealthy relationships	.468			
Unwind before going to bed	.459			
Break large tasks down into small, manageable steps	.447			
Do not take on other peoples' problems	.444			
Practice moderation	.443			
Prioritize sleep and rest	.437			
Take care of basic needs first (e.g., food, shelter, clothing, hygiene)	.435			
Focus on living life in the present	.433			
Reframe thinking when feeling overwhelmed; take a step back and try to be objective	.424			
Limit disruptions to social routines and body rhythms	.412			
Get an accurate, comprehensive diagnosis		-.697		
Keep prescriptions and blood tests up-to-date		-.692		
Have healthcare professionals work together to provide the best care		-.674		
Find the right medication regime (e.g., least side effects, best symptom control)		-.672		
Do not ignore BD symptoms or think that they will disappear on their own		-.654		
Make a plan for how to remember to take medication every day		-.627		
Attend regular appointments with healthcare professionals		-.613		
Accept that BD is a chronic condition that requires long-term management		-.610		
Take medications as prescribed; do not adjust without consulting with doctor		-.604		
Never run out of medication (e.g., have refills and extras)		-.586		
Use past experience to identify early-warning signs		-.584		
Plan treatment when mood is stable		-.583		
Realize sleep problems are a part of BD rather than a personal flaw		-.538		
Find a healthcare provider who has experience working with people with BD		-.528		
Identify supporters who can best cope with periods of acute illness		-.522		
Increase vigilance if early-warning signs detected		-.510		
Be aware of early-warning signs		-.477		
Identify and resolve issues that might contribute to relapse		-.461		
Be aware of changes in routine and sleep patterns when travelling		-.452		
Do not ignore underlying vulnerability to BD		-.442		
Appreciate periods of not being in a BD episode		-.423	-.421	
Accept the diagnosis of BD		-.422		
Get extra help and support during difficult periods		-.420		
Learn recovery skills from those who live well with BD		-.414		
Believe in oneself (e.g., ability to cope; personal strengths)			-.573	
Accept that it is okay to cry, act happy and be emotionally expressive			-.565	
Never give up hope			-.550	
Accept that bad BD days will happen			-.539	
Have courage and believe in the potential to live successfully			-.534	
Understand that BD is a medical condition like any other (e.g., diabetes)			-.497	
Fill life with positive things			-.492	
Be kind to others (e.g., sensitive, tolerant, gentle)			-.474	
Be determined to improve quality of life			-.466	
Understand that it is part of being human to have tough days			-.462	
Cherish relationships			-.412	
Avoid self-stigma			-.407	
Exercise regularly				.868
Remain active				.745
Find enjoyable physical activities (e.g., bicycling, swimming)				.745
Develop healthy and balanced diet plan				.589
Go for walks				.552
Commit to getting to sleep				.489
Spend time in nature (e.g., go to park, lake or ocean)				.445
Have good communication at work (e.g., seeking job accommodations, maintaining good work relationships)				.439
Seek balance socially (e.g., between work and play; solitude and time with others)				.418

Note. Factor loadings < ± .4 are suppressed.

**Table 5**

Factor loadings and communalities based on a principal component analysis with oblimin rotation for 113 stopping progression items (n = 126).

Item statement	Forward planning	Early intervention	Decrease stimulants
Learn to value and focus on wellness and self-care	.678		
Prioritize and progressively reduce number of tasks	.618		
Reframe thinking when feeling overwhelmed; take a step back and try to be objective	.617		
Learn to say 'no' and set boundaries socially	.609		
Find the right balance of stability in work hours, stress, stimulation and satisfaction	.607		
Set realistic expectations	.601		
Understand how thoughts, feelings and behaviours interact	.595		
Work to slow down racing thoughts	.580		
Let go of things that "push your buttons"	.577		
Do not overwork	.562		
Spend time in nature (e.g., go to park, lake or ocean)	.560		
Break large tasks down into small, manageable steps	.548		
Choose friends and supporters wisely	.548		
Keep thoughts focused, not rambling or obsessive	.548		
End unhealthy relationships	.526		
Reduce expectations regarding workload and social activity	.517		
Do one chore or project at a time	.517		
Unwind before going to bed	.515		
Allow time for relaxing activities (e.g., hot bath, reading, massage)	.510		
Do not take on other peoples' problem	.491		
Cultivate loving, healthy relationships	.469		
Think before spending	.468		
Be organized financially	.464		
Do not take on too many projects	.460		
When working toward deadlines, do not leave a large amount of work until the last minute	.457		
Talk to someone when experiencing major life event	.441		
Practice moderation	.423		
Stop expecting "mountain top"	.415		
Find the right employment fit (e.g., tolerable/likable work, low stress environment, flexibility, good management and accommodations)	.414		
Take breaks (e.g., relaxation, deep-breathing) when working on a task	.409		
Limit disruptions to social routines and body rhythms	.405		
Seek prompt medical attention when early- warning sign detected		.658	
Be aware of early-warning signs		.643	
Have healthcare professionals work together to provide the best care		.641	
Attend regular appointments with healthcare professionals		.627	
Do not ignore BD symptoms or think that they will disappear on their own		.599	
With a doctor, schedule medication intake (e.g., at mealtimes or before bed)		.592	
Identify all problems with a healthcare provider		.575	
Make a plan for how to remember to take medication every day		.566	
Increase vigilance if early-warning signs detected		.560	
Never run out of medication (e.g., have refills and extras)		.557	
Use daily reminders for medication (e.g., phone alarm, emails, sticky notes)		.548	
Find a healthcare provider who has experience working with people with BD		.544	
Identify supporters who can best cope with periods of acute illness		.542	
Find the right medication regime (e.g., least side effects, best symptom control)		.540	
Keep prescriptions and blood tests up-to-date		.540	
Take medications as prescribed; do not adjust without consulting with doctor		.536	
Get an accurate, comprehensive diagnosis		.535	
Enlist friends and family to help identify warning sign		.507	
Accept the diagnosis of BD		.500	
Keep back-up medication in a reserve location (e.g., in desk, purse)		.490	
Accept that BD is a chronic condition that requires long-term management		.487	
Use past experience to identify early warning signs		.482	
Seek hospitalization when needed (e.g., to stabilize)		.453	
Establish a varied and diverse support system (e.g., family, friends, clergy, healthcare practitioners, crisis line)		.450	
Be open to the advice and opinions of support system		.431	
Do not be afraid or ashamed to ask for help		.416	
Take emergency medication if early-warning symptoms are identified		.410	
Plan treatment when mood is stable		.406	
Recognize random content and increased thinking speed as a possible early-warning sign		.403	
Avoid energy drinks			.587
Take a "time-out" if conflict or stress is developing in social relationships			.527
Reduce alcohol intake			.521
Contact healthcare provider if sleep pattern is disrupted		.404	.495
Avoid alcohol before bed			.481
Restrict or monitor internet use for online shopping, gambling or sex-related activities			.457
Prepare bedroom for sleeping and eliminate potential problems for sleep (e.g., no TV in bedroom, use a sleep mask, ensure it is dark and cool, use a fan for white / noise, keep stress out of bedroom)			.454
Avoid excessive stimulation and excitement and maintain a calm environment			.412
Avoid caffeine before bed			.408

Note. Factor loadings &lt; ± .4 are suppressed.



the novel hypothesis that physical activity may be a specific linking theme in mood stability. Future research could investigate the extent to which improvements in this putative change mechanism moderate therapeutic improvements in BD.

In relation to preventing hypo/manic relapse, provisional linking themes around planning and intervening early are entirely consistent with existing guidelines (e.g., Malhi et al., 2015) and prior research (e.g., Parikh et al., 2013). The theme of 'decreasing use of stimulants' is noteworthy; while decreasing stimulant use is an implicit or explicit goal of clinical management approaches, the present finding is one of the first pieces of evidence showing that lived experience experts share this insight about interrupting manic ascent. Again, we consider this EFA-derived theme as providing a hypothesis for future research to directions. More research is required into the reliability and validity of the self-management themes identified here in more diverse samples (e.g., youth, ethnically diverse populations, people with BD at different stages of recovery).

## 6.2. Methodological considerations

We combined two primary research approaches: CBPR and Delphi. The use of the CBPR approach gave us credibility as a research team and probably contributed to the good retention rate for Round 2. It also allowed us to be nimble in response to issues with the study as they emerged (e.g., the use of social media for recruitment and the stepping up of that usage when recruitment was slower than expected). Moreover, the inclusion of people with BD as co-researchers was essential for the success of the many phases of the study – especially for the gathering and interpretation of the various strategies in Phases 1–3. The Delphi method was important too, as it gave further credibility to the strategies that were gathered from the scientific and grey literatures, and the Delphi Consensus Consultation phase of the study allowed us to consult with a diverse range of experts on the relative utility of the strategies that were gathered. Taken together, these two approaches – CBPR and Delphi – were complementary and collectively yielded a more credible outcome than if we had used either in isolation.

The project had several limitations. Generalisation must be qualified by low completion rates in Round 1, presumably due to the length of the survey (493 items with two ratings each). No subjective or objective assessment of functioning or recovery occurred in the lived experience sample, and the recruited sample had little geographic or ethnic diversity. Moreover, the literatures accessed were English-language only. Others have reported that people of Chinese descent with BD are more likely to use psychosocial management strategies that emphasized the importance of harmony with others and interpersonal connectedness (Wang et al., 2009). More recent research in Chinese participants with BD delineated problem-focused, emotion-focused, and cultural coping methods (Tse et al., 2014). These studies contrast in part to the management strategies reported here which tended to emphasize self-oriented interventions. Indeed, the top three ranked strategies were not at all interpersonal in nature: "Never run out of medication", "Be aware of early-warning signs" and "Prioritize sleep and rest". Finally, results of EFA analyses must be treated with caution due to the small ratio of sample size to items.

## 7. Implementation of findings

Jorm (2015) noted that putting findings from Delphi studies into practice represents a final, critical, stage. As the literature on self-management strategies for BD expands, so too must our attention to the investigation of the factors that optimize access to, and engagement with, evidence-based strategies. The Internet is

one of the most popular sources of information amongst people with mental health problems (Powell and Clarke, 2006), and represents a prime candidate conduit for self-management knowledge sharing. People with BD are attracted to web-based delivery of self-management information (Todd et al., 2013). Yet, while high-quality online information on BD treatment does (broadly) exist (Barnes et al., 2009), there are prevailing concerns (Monteith et al., 2013). Further, there are few self-management websites specifically designed for people with BD – as noted by others, BD-specific websites should be appealing in their design and include stories of success and recovery, whilst also being designed with common symptoms of BD in mind (e.g., concentration problems) (Todd et al., 2013). A recent review (Leitan et al., 2014) has also highlighted that successful online delivery of self-management strategies requires attention to (preferably tailored) engagement.

With these considerations in mind, we incorporated the results from this project in a new 'Bipolar Wellness Centre' ([www.bdwellness.com](http://www.bdwellness.com)) where people with BD can access cutting-edge evidence and tools to optimize self-management. A range of engagement strategies are embedded within the website (e.g., webinars, videos, a 'Living Library', where users can 'check out' an expert with lived experience of BD via secure telehealth). Serving as a 'gateway' to the website is an online QoL Tool, which empowers users to access tailored self-management evidence and resources based on their personal QoL profile. Results from this Delphi study were integrated into the Bipolar Wellness Centre in diverse ways (for example, top-rated strategies provided via an embedded online poll, which in tandem disseminates our project results and facilitates wider, and more diverse, community input into their effectiveness). The highly rated self-management strategies identified in the current project were also used to guide content selection for videos and webinars, and shared via the peer experts in the Living Library intervention. Attention to ongoing knowledge exchange in this manner will build further knowledge on what self-management strategies people with BD are finding effective, in the real world.

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