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# Ecological momentary assessment of mood and movement with bipolar disorder over time: Participant recruitment and efficacy of study methods

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## Abstract

**Objectives:** Mobile technology and ambulatory research tools enable the study of human experience in vivo, when and where it occurs. This includes cognitive processes that cannot be directly measured or observed (e.g., emotion) but can be reported in the moment when prompted.

**Methods:** For the Bipolar Affective Disorder and older Adults (BADAS) Study, 50 participants were randomly prompted twice daily to complete brief smartphone questionnaires. This included the Bipolar Disorder Symptom Scale which was developed to briefly measure symptoms of both depression (cognitive and somatic) and hypo/mania (affrontive symptoms and elation/loss of insight). Participants could also submit voluntary or unsolicited app responses anytime; all were time- and GPS-stamped. Herein, we describe BADAS study methods that enabled effective recruitment, adherence and retention.

**Results:** We collected 9600 app responses over 2 year, for an average response rate of 1.4×/day. Over an average of 145 consecutive days (range 2–435 days), BADAS participants reported depression and hypo/mania symptom levels (a.m. and p.m.), sleep quality (a.m.), medication adherence (a.m.) and any significant events of the day (p.m.). They received $1/day for the first 90 days after submitting both a.m. and p.m. questionnaires.

**Conclusion:** BADAS study methods demonstrates the utility of ecological momentary assessment in longitudinal psychiatric research.

**KEYWORDS**
ambulatory assessment, bipolar disorder, ecological momentary assessment, self-care

# 1 | INTRODUCTION

Large numbers of persons with severe mental illness are living to later life for the first time in human history. This includes bipolar disorder (BD), a severe and disabling psychiatric condition that affects up to 5 million older Americans; this number is expected to double within 15 years (Thomas, 2010).

BD causes shifts in mood and energy levels more severe than the normal ups and downs (Sajatovic et al., 2015; Shobassy, 2021). Instead, BD is characterized by extremes in mood and behavior, affecting one's ability to carry out day-to-day tasks and maintain relationships (Goodwin & Jamison, 2007; King & O'Rourke, 2015). Change in BD symptoms can occur over days, hours, even minutes (i.e., rapid cycling). Symptom insight is also variable, often most compromised when most symptomatic (da Silva et al., 2015).

This paper describes study methods and data collection for the Bipolar Affective Disorder and older Adults (BADAS) study. Following the recommendations of Trull and Ebner-Priemer (2020), we discuss how BADAS study methods correspond to contemporary best practices in ambulatory mental health research. This has enabled effective participant recruitment, adherence and attention.

# 2 | BIPOLAR AFFECTIVE DISORDER AND OLDER ADULTS STUDY

For the BADAS study, we recruited an international sample of young and older adults with BD. Participants were required to have a BD diagnosis, a smartphone and (register for) a PayPal account for remuneration. Given low BD prevalence (Goodwin & Jamison, 2007), international data collection was warranted to recruit a sample sufficient for contemporary data analyses for ambulatory research (e.g., multilevel modeling, Trull & Ebner-Priemer, 2020).

Prospective participants first took part in screening interviews by phone or skype to ensure that they met study inclusion criteria (e.g., date of BD diagnosis, subtype if known). We also collected emergency contact information (preferably their psychiatrist) in case they reported thoughts of self-harm during data collection. Diagnoses were corroborated by partners (Yerushalmi et al., 2021) and confirmed with the subset of participants who took part in qualitative interviews (e.g., Canham et al., 2018; Stalman et al., 2018).

Participants were asked if they currently lived with a partner (e.g., spouse), if their partner also had a smartphone, and their partners' email address in order to request their participation in the BADAS Connect couples study (Yerushalmi et al., 2021). Both BADAS and BADAS Connect participants completed online questionnaires each month.

Participants (and partners) were instructed how to download the BADAS app (or BADAS Connect app) onto their respective smartphones. Apps were activated once email addresses were registered in the backend system by the study coordinator after screening. This ensured that only registered participants could access the app and submit study responses (King et al., 2016).

During screening interviews, participants were asked to specify *windows of general availability* in which they were most likely to be available to complete brief ecological momentary assessment (EMA) questionnaires on their phone when prompted. As noted by Trull and Ebner-Priemer (2020), random data collection is ideal when measuring dynamic phenomena like BD symptomology that can fluctuate over short intervals.

As importantly, these windows of availability precluded prompting when participants were consistently unavailable (e.g., sleeping, collecting children from school). One factor integral to participant retention over months of daily data collection is minimizing irritants to ongoing data collection (e.g., no 3:00 a.m. prompts). Persistent hassles, even if comparatively minor, can lead to attrition from longitudinal research. Thorough field testing of apps and other tools is necessary to minimize such irritants (King et al., 2016).

# 3 | ECOLOGICAL MOMENTARY ASSESSMENT

Participants were prompted by their smartphones to complete EMA questionnaires twice daily; symptoms of depression and hypo/mania were measured both a.m. and p.m.. In the morning, we also measured sleep quality and medication adherence. In the p.m., we asked about any important events of the day (e.g., conflict with partner), impact on mood, perceived control over the event, and its importance. BADAS Connect participants completed a single p.m. questionnaire, prompted within 30 min of their partner (i.e., yoked app; see Yerushalmi et al., 2021).

Participants were randomly prompted up to three times within 30-min data collection windows. If they did not respond within the first 20 min, a second prompt was sent; and a third and final was sent 5 min thereafter (if they do not respond to the first or second prompt). Participants could select a distinct or dedicated tone to distinguish from other smartphone prompts (e.g., boing vs. pizzicato).

Participants could also submit voluntary or unprompted EMA questionnaires at anytime if they missed a questionnaire. This enabled event-based data collection following especially salient experiences in the moment (Trull & Ebner-Priemer, 2020). Both voluntary and prompted EMA questionnaires were time- and GPS-stamped; GPS information was collected throughout the day with participants' knowledge and consent. See Figure 1.

GPS measurement allows us to map symptoms of both depression and hypo/mania over time for each participant. We assumed that symptoms of hypo/mania would be reflected in more frenetic patterns of movement, suggestive of more energy and distractibility; by contrast when depressed, participants were assumed to move more deliberately (A → B → A) or hibernate in the home, suggestive of low energy and social withdrawal. Such patterns of movement could function as proxy indicators of BD symptomology, and used to detect

**FIGURE 1** Ecological momentary assessment of bipolar disorder (BD) symptoms

the onset of BD mood episodes (see https://vimeo.com/72778974) and problematic behaviors (e.g., reckless spending).

Ecological momentary assessment questionnaire responses were conveyed immediately when the phone was connected to the Internet or a cellular network. If out of range, questionnaires were stored in the device then relayed automatically when reconnected. The BADAS app stores the timing of prompts for 14 days ensuring that participants were prompted as scheduled even if outside of Internet or cellular range. The BADAS Study was conducted with ethical approval from Simon Fraser University, Burnaby (BC), Canada.

## 4 | METHODS

### 4.1 | Participants

We recruited 50 adults with BD; roughly half 45+ years of age, using social media advertising micro-targeted to those with BD (Canada, United States, UK, South Africa, Australia). Participants were drawn from a global population of 6.2 million English-speaking, Facebook users with *bipolar disorder interests*. Such euphemisms are used by Facebook in place of diagnostic labels.

Social media machine-generated algorithms are unique not so much for their *sensitivity* but *specificity* (i.e., exclusion of those who do not have BD). Persons recruited via Facebook do not be representative of the population but we can be confident these are persons with BD because only persons with BD received Facebook advertisements (King et al., 2014). As discussed elsewhere (O'Rourke et al., 2018), this methodology enables recruitment of a subset of persons with BD who describe themselves victims or survivors of mental healthcare, who avoid all clinical

content and self-medicate with marijuana (Canham et al., 2018; Stalman et al., 2018). Standard outpatient recruitment via psychiatric and mood disorders clinics does not capture this subset of those with BD.

### 4.2 | Design

Over 4+ months, participants were randomly prompted twice daily to complete EMA questionnaires on their smartphones. If their schedule changed (e.g., shift work), participants could email the study coordinator to adjust accordingly. Future prompts would be recalculated next time the app was connected to the server. Partner app prompts would also be rescheduled accordingly.

### 4.3 | BD symptom measurement

We first developed the Bipolar Disorder Symptom Scale ($BDS_x$) to briefly measure symptoms of depression and hypo/mania (O'Rourke et al., 2016, 2018). Respondents indicate the degree to which each of 20 mood adjective corresponds to how they feel at that moment. Elevated responses to both depression and hypo/mania subscales correspond to blind psychiatric diagnoses of depression and hypo/mania mood episodes (Osher et al., 2020). See Figure 2.

Exploratory and confirmatory factor analyses indicate a robust four-factor model of $BDS_x$ responses (O'Rourke et al., 2016, 2018), consisting of two depression factors (cognitive and somatic symptoms) and two hypo/mania factors (affrontive symptoms and elation/loss of insight). Affrontive symptoms of hypo/mania are correlated with both cognitive and somatic symptoms of depression (O'Rourke et al., 2021). This allows us to measure mixed depression and hypo/mania symptoms, common to most BD mood episodes (Shim et al., 2018). Developing measures specifically for EMA is ideal; most researchers instead cherry-pick items from existing measures with limited pilot testing (i.e., psychometric properties untested; Trull & Ebner-Priemer, 2020).

The construct validity of $BDS_x$ factors is supported in relation to quality of life with BD (O'Rourke et al., 2021) across BD subtypes (O'Rourke et al., 2021) and by responses from cohabiting partners. For instance, affrontive symptoms of hypo/mania appear to have the greatest negative impact on partners, especially when couples are physically together (i.e., same GPS coordinates; Yerushalmi et al., 2021).

## 5 | RESULTS

Over 2 years, we collected 9600 individual app responses including self-reported depression and hypo/mania scores, time, GPS coordinates (latitude, longitude) and other info. For each participant, we calculated and updated average depression and hypo/mania symptoms levels over time. This allowed us to determine when $BDS_x$ responses were ±1SD and ±2SD their respective symptom averages. In
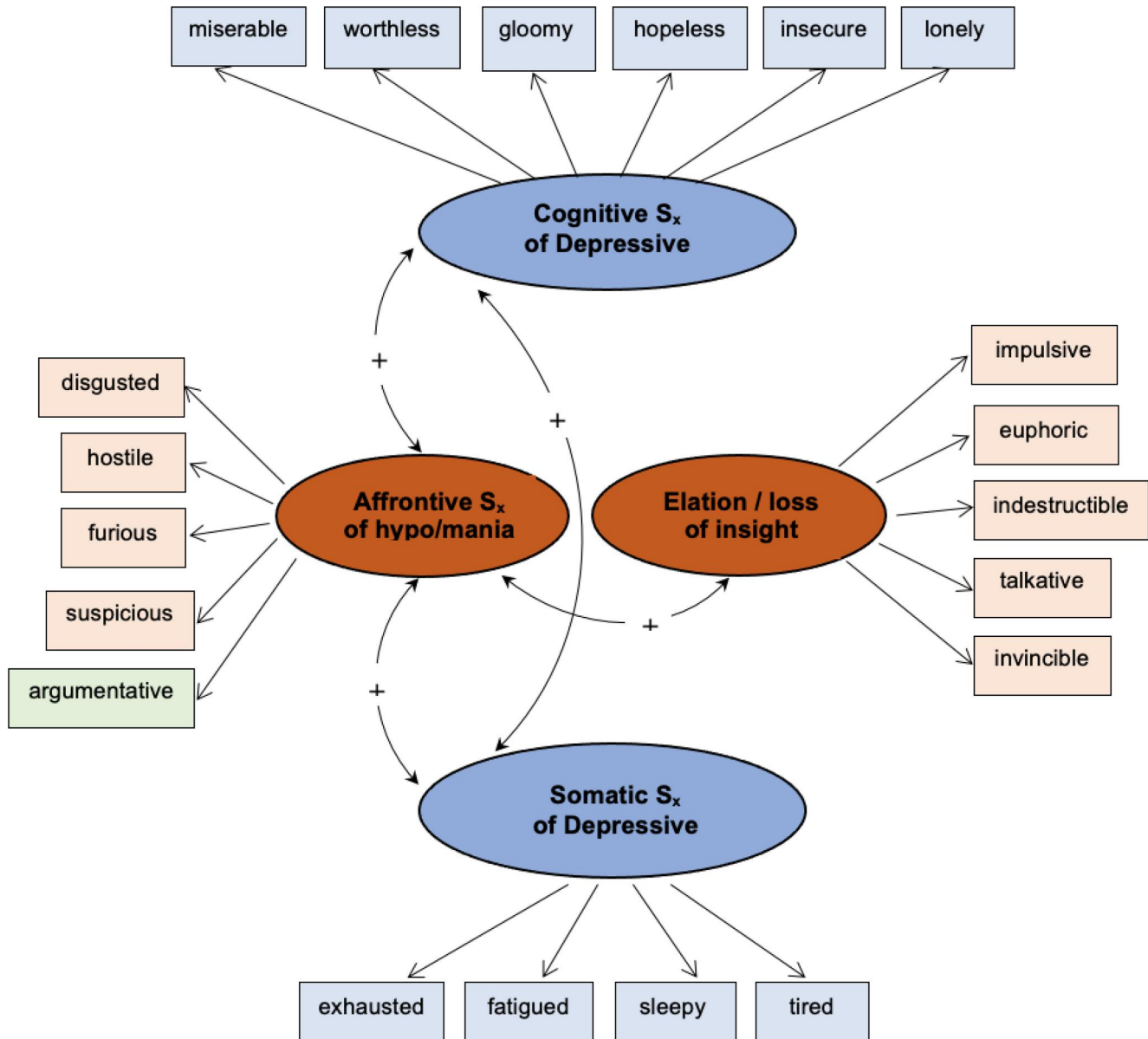
**FIGURE 2** Four-factor model of bipolar disorder symptoms

each instance, these response levels are above BDS$_x$ cut-off levels, suggestive of clinical symptomology (Osher et al., 2020).

This volume of app data averages 196 responses per participant (range: 3–543) over an average of 145 consecutive days (2–435) for an average response rate of 1.4×/day over months, and in a few instances, over a year. This high rate of participant adherence is explained, in part, by receipt of payment for submission of EMAs ($1/day) and online questionnaires ($20/month). More precisely, participants were paid if they completed both the a.m. and p.m. questionnaires on their smartphone when prompted; if they missed either a.m. or p.m. prompt (but not both), they could submit a voluntary questionnaire later that day. Their running total of money earned to date appeared in the top corner each time the app was opened to subtly foster data collection and maintain study engagement. These tactics appear effective in helping to sustain daily data collection over months.

## 6 | DISCUSSION

By design, completion of EMA questionnaires required only 3–5 min. Brevity of measurement was integral to high participant retention and adherence (Trull & Ebner-Priemer, 2020). It is important to note, however, that this totaled 6.5 h on average over the course of this study (i.e., a day of work spread over months). This level of participant commitment is not immediately apparent in EMA research, warranting participant remuneration we contend, especially research with economically disadvantaged populations such as older adults and those with severe mental illness who subsist on disability pensions (e.g., BD; Biasi et al., 2020).

Yet notably, about 20% of BADAS participants opted to give accumulated monies to a BD charity versus receiving themselves. (Income tax deductible for Canadian participants.) This suggests both

intrinsic and extrinsic motivation to take part in this research (personal benefit vs. help others). Most participated in this study to supplement their income whereas others may have been motivated to contribute to BD research and knowledge.

BADAS participants were paid $1/day for the first 3 months of data collection yet as noted above, participants provided daily EMA data for 7 weeks longer on average. Some participants indicated that taking a moment to reflect on their current symptom levels was, in itself, therapeutic (i.e., fostered self-awareness); they described looking forward to these self-assessments to gauge their mood in the moment (e.g., mindfulness; Lovas & Schuman-Olivier, 2018).

Another explanation is that after 3 months, we provided participants with the URL for personalized self-care websites that compiled their self-report and ambient smartphone information (e.g., time/date, GPS coordinates). These websites enabled participants to track their symptom variability over time and identify factors that appear to precede and sustain symptomatology and periods of well-being. In other words, access to self-care websites functioned as

another form of remuneration that enabled sustained data collection over an extended period. See Figure 3.

At recruitment and during the first 90 days of data collection, participants were unaware we later intended to share responses with them. Initially withholding this knowledge was intended to foster unfiltered responding and to encourage continued participation with no further payment. Nor were participants aware at recruitment that they could donate monies to charity. This option was added during data collection.

## 7 | LIMITATIONS AND FUTURE RESEARCH

As implied above, we did not expect a significant percentage of BADAS participants to donate accumulated funds to charity. This suggests varied motivation to participate in mental health research. Future research is required to address motivation to participate in longitudinal research. We noted that BADAS participants were



FIGURE 3  Bipolar disorder (BD) self-care website (example), compiling daily app responses

generally opposed to including partners in couples research; this reticence was unexpected and not directly measured. As recommended by Yerushalmi et al. (2021), future research should first recruit partners then persons with BD to determine if this sequence proves more effective (i.e., partners less likely to act as gatekeepers).

Social media advertising allowed us to recruit an international sample of persons with BD. Yet as described elsewhere (O'Rourke et al., 2021), such participants appear more symptomatic than outpatients with BD recruited via mood disorders clinics. Replication of findings is necessary with participants recruited by more traditional research methods.

Though a subset of those with BD II are affluent entrepreneurs, many are underemployed (Hooshmand et al., 2014), unable to work and subsist on disability pensions. Data collection via smartphones may be ideal for those able to afford digital devices. Yet research methods that exclude those unable to purchase such devices may overstate study findings and limit generalizability to those already functioning more effectively.

## 8 | SUMMARY

In contrast to other EMA research with BD outpatients (e.g., Faurholt-Jepsen et al., 2019), BADAS participants randomly reported subjective experience in real-time and in addition to ambient smartphone data. This amalgamation of subjective and objective data (e.g., GPS coordinates) is consistent with contemporary best practices in mental health research (Trull & Ebner-Priemer, 2020) and especially well-suited to machine learning and computation of personalized wellness algorithms.

In their recent synthesis of BD app research, Patoz et al. (2021) noted that treatment and study adherence varies greatly (i.e., 58%–92%) when reported at all. The methods devised for the BADAS study enabled us to achieve a 1.4/day adherence rate over 4 + months of twice-daily data collection. This included both young and older adults with BD. Tactics such as sharing data with participants (e.g., self-care websites) should be considered when devising future mental health research.

### CONFLICT OF INTEREST
None to report.

### DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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