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Experiences of remote mood and activity monitoring in bipolar disorder: A qualitative study

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ABSTRACT

Background: Mobile technology enables high frequency mood monitoring and automated passive collection of data (e.g. actigraphy) from patients more efficiently and less intrusively than has previously been possible. Such techniques are increasingly being deployed in research and clinical settings however little is known about how such approaches are experienced by patients. Here, we explored the experiences of individuals with bipolar disorder engaging in a study involving mood and activity monitoring with a range of portable and wearable technologies.
Method: Patients were recruited from a wider sample of 50 individuals with Bipolar Disorder taking part in the Automated Monitoring of Symptom Severity (AMoSS) study in Oxford. A sub-set of 21 patients participated in a qualitative interview that followed a semi-structured approach.
Results: Monitoring was associated with benefits including increased illness insight, behavioural change. Concerns were raised about the potential preoccupation with, and paranoia about, monitoring. Patients emphasized the need for personalization, flexibility, and the importance of context, when monitoring mood.
Conclusions: Mobile and electronic health approaches have potential to lend new insights into mental health and transform healthcare. Capitalizing on the perceived utility of these approaches from the patients' perspective, while addressing their concerns, will be essential for the promise of new technologies to be realised.

1. Introduction

Symptom assessment in bipolar disorder (BD), like many other mental health disorders, is based upon self-report measures. Self-reported symptoms are highly dependent upon an individual's ability to accurately recall information and communicate complex mood states, aspects of assessment that many patients find difficult [1]. In addition, subjective self-report of manic and depressive symptoms is influenced by decreased illness insight, especially during manic or hypomanic episodes [2]. In recent years, the use of remote mood monitoring for BD has grown dramatically [3]. Reporting symptoms via text and e-mail in response to scheduled prompts overcomes the challenge of patient recall and is an easy and inexpensive way to collect mood data prospectively and longitudinally [4].

Objective monitoring, particularly activity monitoring, also has the potential to indicate clinically important changes in symptoms [5,6]. Many symptoms of BD manifest in changes of physical [7–9] and social activity [10]. Research exploring objectively monitored activity as an indicator of diagnostic classification and mood changes has benefited from advances in the sophistication and widespread accessibility of portable and wearable technologies. The increasing ubiquity of smart phones with in-built actigraphy, light and other sensors provide a platform for collecting such data remotely, whilst wearable activity monitors are increasingly popular and provide a practical solution to long-term activity monitoring. However, if such approaches are to be successful in the management of BD, they need to be acceptable to patients.

A number of studies are currently exploring multi-sensor monitoring in BD to explore whether objective measures can provide clinically meaningful information [11–14]. Although preliminary findings have demonstrated correlations with clinician-rated depressive symptoms [15] and accurate mood state recognition in small samples of BD patients [16], we know very

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little about the perceived clinical usefulness of monitoring from patients. Few studies have explored patient experiences of using these technologies [17,18], and those that have tend to focus on the usefulness and usability of device systems to collect and visualise data. In addition, some studies interpret device compliance as the sole indicator of tolerability [4,19]. We wanted to explore how patients interpret and use such data in ways that might be clinically useful. We conducted a qualitative study with the aim to explore the experiences of patients with BD who have engaged in remote mood and activity monitoring as part of the Automated Monitoring of Symptom Severity study (AMoSS), in order to understand the personal and clinical benefits to patients using these technologies, and to identify any potential barriers to use. A qualitative approach was employed because it is flexible, grounded in individual experiences, and because we know so little about how tolerable or acceptable automated symptom monitoring is to patients.

2. Material and methods

Ethical approval for the study was obtained from East of England NHS Research Ethics Committee (13/EE/0288) and practice was informed by the principles manifest in the Declaration of Helsinki.

2.1. Participants

Participants were 21 individuals who were members of the wider AMoSS sample of 50 BD participants. The AMoSS study is a prospective longitudinal study where participants monitor their mood daily using a study-specific smartphone app, complete weekly mood measures using the True Colours system (https://www.oxfordhealth.truecolours.nhs.uk/www/en/) and wear movement sensing devices. In addition, participants have one week of intensive monitoring where they complete ten times daily mood ratings and monitor a number of physiological variables. Full study details can be found in the supplementary materials online (see also http://www.conbrio.psych.ox.ac.uk/the-amoss-study). Recruitment into AMoSS was via outpatient secondary mental health services and advertising in the community. Exclusion criteria were minimal but included lack of capacity to consent and those who had been a psychiatric inpatient in the last month. Informed consent was obtained from all participants. Participants underwent screening by an experienced psychiatrist (KEAS) using the Structured Clinical Interview for DSM-IV (SCID) and met criteria for DSM IV BD. Individuals were invited to interview when they had completed 12 weeks of mood and activity monitoring, or had withdrawn before this time ($n = 1$). Purposive sampling was used to ensure that those who had left the study and those who had submitted incomplete data were also included. No individuals refused to participate in an interview. Once data saturation occurred, no further participants were invited to interview.

2.2. Data gathering

In the majority of cases interviews were conducted in person ($n = 13$, 62%) and the remainder were conducted by phone. Interviews were conducted by one of three members of the research team (KEAS, PP, LA). Participant interviews were conducted using a semi-structured topic schedule and were audio-recorded (for full topic schedule and more information about qualitative interviews see Supplementary Material). Interviews varied in length from 20 to 100 minutes.

Demographic data were gathered from all participants, including age, gender and current medication (Table 1). Quantitative feedback regarding frequency of questionnaire prompting and tolerability of actigraphy devices was collected on feedback forms between weeks 8 and 12 of the study. Participants were asked to indicate, using 7-point Likert scales, the convenience of mood prompting and the convenience and comfort of monitoring devices (1 being not at all uncomfortable/not at all inconvenient and 7 being very uncomfortable/very inconvenient). Feedback forms also provided an opportunity for participants to give more detailed written feedback regarding how devices were used and worn

Table 1
Demographic and clinical characteristics of participants. Values are numbers of cases (percentages in brackets) unless otherwise specified.

	Total ($n = 21$)		
	Diagnosis		Overall
	BDI ($n = 14$)	BDII ($n = 7$)	
Mean age at study start (SEM, range), years	43.43 (3.2, 26–63)	46.29 (4.08, 33–63)	44.38 (2.49, 26–63)
Female gender, *n* (%)	9 (64.3)	5 (71.4)	14 (66.7)
Current medications			
Lithium, *n* (%)	6 (42.9)	2 (28.6)	8 (38.1)
Anticonvulsant, *n* (%)	6 (42.9)	2 (28.6)	8 (38.1)
Antipsychotic, *n* (%)	6 (42.9)	5 (71.4)	11 (52.4)
Antidepressant, *n* (%)	5 (35.7)	3 (42.9)	8 (38.1)
Anxiolytic, *n* (%)	1 (7.1)	0 (0.0)	1 (4.8)
Hypnotic, *n* (%)	1 (7.1)	0 (0.0)	1 (4.8)
None (drug free), *n* (%)	3 (21.4)	0 (0.0)	3 (14.3)
Mean weeks depressed[a] at 3 months (SEM, range), percentage	15.83 (7.55, 0–100)	22.86 (14.59, 0–100)	18.17 (6.82, 0–100)
Mean weeks mood elevated[b] at 3 months (SEM, range), percentage	15.23 (6.7, 0–70)	8.44 (7.04, 0–50)	12.97 (4.99, 0–70)
Employment status			
Employed full-time, *n* (%)	5 (35.7)	5 (71.4)	10 (47.6)
Employed part-time, *n* (%)	5 (35.7)	2 (28.6)	7 (33.3)
Student, *n* (%)	1 (7.1)	0 (0.0)	1 (4.8)
Unemployed, *n* (%)	3 (21.4)	0 (0.0)	3 (14.3)
Education level			
O-level/GCSE, *n* (%)	1 (7.1)	0 (0.0)	1 (4.8)
AS/A-level/HND/BTEC, *n* (%)	2 (14.3)	1 (14.3)	3 (14.3)
Degree (includes NVQ level 5), *n* (%)	7 (50.0)	3 (42.9)	10 (47.6)
Post-graduate degree, *n* (%)	3 (21.4)	3 (42.9)	6 (28.6)
Missing data, *n* (%)	1 (7.1)	0 (0.0)	1 (4.8)

SEM: Standard Error of the Mean.
[a] Defined as QIDS > 10.
[b] Defined as ARSM > 5.