

Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder

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Abstract. Mental disorders affect individuals and societies around the world negatively, with the health-related burden of 32,4% out of the overall disease burden. This large part of the overall burden underlines a growing need for innovation to support the treatment of mental disorders like schizophrenia and bipolar disorder. This empirical study features two groups of patients; a group of nine patients diagnosed with bipolar disorder and a group of twelve patients diagnosed with schizophrenia. The patients in the study carry a smartwatch for six weeks, continuously collecting data into a digital health platform. Additionally, they answer five daily wellbeing questions in a mobile app. To supplement that data, they also answer a questionnaire three times over the interval and at the end of the period they attend a semi-structured interview. We offer four main aspects to consider for PGHD in mental health: i) sharing data easily with healthcare professionals, ii) being able to engage with your own PGHD, iii) the watch use can help the patients regulate routine in their daily life, iv) tonality and phrasing.

Keywords. Schizophrenia, Bipolar Disorder, Digital Platform, mHealth, eHealth, Smartwatch, Mobile Application, Mental Health

1. Introduction

Mental disorders cause individuals and societies around the world effects that cannot be measured easily. The estimated mental health-related burden accounts for 32.4% of years lived with disability (YLD) of all YLDs' in the world [1], not to mention the often overlooked effects mental illness can have on close family and friends. One of the more severe, chronic mental disorders is bipolar disorder (BD), which has a reported prevalence of 0.6% [2]. Patients diagnosed with BD experience extreme mood swings and activity fluctuations from being hyperactive to total inactivity. Patients with BD generally suffer from sleeping difficulties and may struggle with day-to-day tasks [3]. Schizophrenia is another serious chronic mental disorder with a reported prevalence of 0.3% [2]. The disorder causes extensive paranoia and delusions that affect the quality of life negatively. Schizophrenia patients also face various life challenges, such as a low employment rate (below 20%) and high homelessness (up to 20%) [4]. Research suggests that increased

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physical activity can improve wellbeing for patients with schizophrenia as well as BD [5]. In fact, these two disorders are often researched together due to similarities in symptoms [6].

Digital platform (hereafter "platform") is essentially software that facilitates a connection between user's needs and what a service provider has to offer. The supply and use of platforms is becoming increasingly established, for example in healthcare [7]. In a healthcare setting, a platform can potentially create a bridge between a patient and healthcare professionals through monitoring of patient-generated health data (PGHD). PGHD in a platform setting encompasses data produced and collected by patients, which is brought into a healthcare platform to enhance the quality of care. PGHD is any clinically relevant data collected and used by patients and either shared or not shared with healthcare professionals, and PGHD can in some sense contribute to increased wellbeing or health outcome. A study on PGHD from wearables for self-monitoring reports that patients believed that using wearables to regulate their symptoms has the potential of improving the overview of their condition [8]. In this project we collect PGHD with smart devices; both automatically (with a smartwatch) and manually via a mobile app. All data is collected and visualized in a platform.

This paper is based on an empirical study that features two groups of care recipients (hereinafter patients) who are under medical care; one group diagnosed with BD and the other group with schizophrenia. The interventions with the patients include increased physical activity, which has proven effective for treatment of the two disorders. Patients also attend structured consultations with a healthcare professional where they are asked, among other things, to assess their quality of sleep. Our project entails the design of a platform that enables health data to be visualized and accessed, to involve the patients to a larger extent in their own care. Through the empirical, multidisciplinary research project reported on herein, our goal is to provide insights into both the clinical value as well as the increasingly important value of PGHD in mental healthcare. From that, we seek to answer the research questions: i) How should a smartwatch and a mobile app be used to support treatment of schizophrenia and BD? and, ii) how can a digital a platform function as a bridge between patients and healthcare professionals?

2. Methods

We have designed and developed a digital health platform to be used in psychiatric care, called DataWell; which reflects the use of data for wellbeing. The platform is under further development through a co-design approach in this project. Our platform combines the following PGHD types. From the a Withings Steel HR smartwatch we gather heart rate monitoring (beats per minute), sleep monitoring (sleep duration, sleep depth, interruptions), activity monitoring (estimation of ten activity types), and step count (based on distance). The sensors in question are: heart rate infrared sensor, day and night motion sensor and high precision MEMS 3-axis accelerometer². A reason for choosing this particular smartwatch is their unusually low power consumption. The battery charge lasts up to 25 days, which we consider an important factor when it comes to patients with severe mental illnesses. Additionally, Withings provide accessible, structured data through an API, which is convenient when building a new platform. Although outside the scope

²<https://www.withings.com/eu/en/steel-hr>

of this paper, it is important to mention that we have data from the electronic patients records (EPR/EHR) for two years.

The process of the data gathering is as follows. The patients who accept to partake in this six weeks study answer a questionnaire three times (week one, three and six). The questionnaire includes a collection of validated constructs to measure level of anxiety, depression severity, view towards technology, self-efficacy, empowerment, and impact of self-monitoring. The idea behind that data collection is to create a link between the outcome of the questionnaire and the way patients choose to use the platform, watch and mobile app. They carry a smartwatch for these six weeks, collecting data into our platform. They also answer five daily questions on general wellbeing in our mobile app, which we designed as a part of this project and the mobile app feeds data into the platform. During the research period, the healthcare professionals are able to monitor their patients, through the platform. Both patients and healthcare professionals attend semi-structured interviews separately at the end of the six-week period, where the focus is on user experience and usability of the platform and their view on data-driven mental health and on continuously collecting PGHD. The analytical approach for the interviews is content analysis and the results will be used to further guide the design and development of the platform. In this paper, we focus on findings from the patients. We have included 21 patients in total. Three of those dropped out during data collection due to sickness or issues related to comfort. From that, nine patients are diagnosed and treated for BD (two dropped out) and twelve patients are diagnosed and treated for schizophrenia (one dropped out). Thus, seven patients with BD and eleven with schizophrenia have completed all data collections steps.

3. Results

The majority of patients felt encouraged by monitoring their data continuously and expressed interest in continuing the data collection. Meeting the patients three times over the data gathering interval, and especially the in-depth interview at the end has enabled a unique opportunity to understand the patients and how this approach affects them. One patient summarized her view with the words: “This really matters.” which is encouraging for the continuation of the study.

Overall, we identify four main findings. *Firstly*, sharing data with healthcare professionals seems to come quite easily to them. Most of the patients are used to sharing all sorts of things with healthcare professionals and feel that the data sharing in this experiment is no invasion, but rather supportive. On that note, another patient shared: “It’s good that healthcare professionals have access to the data, because they’re just trying to help you.”

Secondly, an important finding has to do with the empowerment of the patient, a feeling that many of them describe. One patient said: “Seeing your own health data is a good feeling.”, while another shared: “It encourages you to see an overview of the steps.” What can be learned from that is that observing and monitoring one’s own data helps in the empowerment process.

Thirdly, is that the usage of the watches is different between individuals. One patient described his opinion on how the experience with the watch has been like: “I’m not quite sure, but it was really new to me because I have not worn anything like this before that

measures heart rate, steps and sleep.” Continuing, now on his view on if there have been some changes since the start of data gathering: “Yeah, a little bit at least, I’m going to bed at the right time now.” In general, some patients like to monitor their data closely, see the steps “coming in” over the course of the day and reflect on them in terms of how they feel and how they’re doing that day. Others want to let it rest for a few days and then see a chunk of data in the platform. This gives them context and understanding on they’re feelings and the development of the disease for the days in question.

Lastly, regarding the mobile app and the way that the questions in there are formulated, we found that inclusiveness in all communication with patients and putting ourselves in the patients’ shoes is truly important. One patient said: “Maybe what I got out of this was that you just reflect a little bit about how, you know you get these questions, then you wonder how was the stress today. You tune a little bit into yourself with this too.” Another patient expressed gratitude and satisfaction in the phrasing of the questions in the mobile app stating that the questions were inclusive and that they addressed them as a “thinking human being” and not a “7 year old” or “someone stupid.”

4. Discussion

When discussing health platforms and PGHD, it is vital to reflect on the data collected, the way the data is presented and used. To begin with, data can consist of either a few values of data points or multiple ones and the granularity of data is thereby important to consider [9]. Also, when showing trends, they can be relational, hierarchical, or a combination of the two, which is an important aspect to consider when choosing types of graphs that can help the patient understand their data. Each data entry is not an autonomous entity; rather, it is a part of an array in which data over time builds up a larger data set that can then be visualized, for the dual purpose of i) functioning as decision-support for the healthcare professionals and ii) triggering self-care and self-monitoring for patients [10]. We consider self-monitoring to be the tracking of health-related information for patients and using that information to monitor wellbeing or health systematically. Prior research has shown that using wearables for self-monitoring can introduce an increase in the activity of the consumer [11], and in this paper, we corroborate those findings by showing that wearables are by most in our patient group, considered empowering. With that in mind, when designing a health platform that takes in extensive amounts of data, we recommend that it is done in a participatory work with all stakeholders involved and especially highlight the importance of giving the patients a voice in that process. Cognitive impairment is a common observation for individuals with schizophrenia [6] and BD [12], it can result in difficulties with written information. Because of that, the way PGHD enters the conversation, and the way the data is collected, discussed and used are key aspects of this research project. Consequently, we focused on helping the patients collect the PGHD, to understand their data and to reflect on their data. From our findings we conclude that in mental healthcare, PGHD can improve the wellbeing of patients. PGHD points towards a patient perspective through patient centricity and PGHD can improve partnership with the healthcare professionals, in line with [13].

In conclusion we have derived knowledge about the kind of data that is useful in mental health services and when it proves to be an effective addition to existing clinical treatment. Our findings can be summarized and forwarded through four major aspects: i)

sharing data easily with healthcare professionals is an important factor for a platform to be implemented in clinical practice, ii) being able to engage with own PGHD, empowers patients that are diagnosed with BD or schizophrenia, iii) the watch use can help the patients regulate routine in their daily life, iv) tonality and the way patients that are diagnosed with BD or schizophrenia are addressed in conversations, is vital. From our findings, we conclude that collecting PGHD into a platform outlines a key feature of future support in treatment of schizophrenia and BD.

4.1. Limitations

In this project the patients observe their own physiological health data, combined with their daily mental status, to observe trends in how their psychological health fluctuates in context with the physiological data signs. However, some patients forgot to fill out the daily survey in the mobile app, which might have caused them overlook those trends. Future work will include notifications in the mobile app, to compensate for that. Another direction in future work is to analyze if some patients show signs of dis-empowerment through an approach like this, possibly with a higher level of anxiety, stress, dropout rate, etc. Another aspect worth mentioning, is the inclusion of patients which was a considerable challenge due to their preexisting diagnosis, which renders them unable to predict what kind of day it will be; if they will be able to show up or not. There was about a 50% dropout rate during the appointments, but with perseverance of the first author when re-booking sessions multiple times, we managed to get all patients to meet with us.

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