Adoption and Use of a Digital Health Tool (Health Storylines) for Self Management by People with Schizophrenia

self care catalysts
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Schizophrenia & Psychosis Action Alliance

BACKGROUND

There is often an assumption that remote monitoring is challenging to implement among individuals with schizophrenia, due to symptoms such as paranoia and suspicion of technology, however the promise of digital approaches for passive and real-time data collection has recently been emphasized as a result of the COVID-19 pandemic and increased need for digitally-enabled approaches to care and research[1].

This research describes the use of a mHealth app by a self-selected population of users with Schizophrenia to assess the feasibility of using mobile apps for remote monitoring and research, and to characterize the nature of insights that can be gained from patient-reported data among users with Schizophrenia.

OBJECTIVES

The objectives of this research were to:

- Evaluate whether people with Schizophrenia are willing and able to engage with mobile health technology for the purpose of self-monitoring, engagement and research
- Explore qualitative free text data to assess whether people with Schizophrenia trust mobile health technology and willingly share their patient experience
- Assess which tools that users find most appealing to inform future program or research design

METHODOLOGY

Data from Health Storylines users between 2016-2021 who self-identified as being diagnosed with Schizophrenia was analyzed retrospectively. The data includes quantitative tracking and free text journal entries from tools designed to support the self-management of a variety of health conditions, including Schizophrenia.

Number of users, frequency of tool use, and patient-reported data within tools was described, and all free text entries were qualitatively analyzed using the Patient Decision Making Framework (PDMF) as a coding structure. The PDMF is a framework designed to conduct content analysis of patient reported data.

RESULTS

Table 1: Qualitative Themes from Daily Moods (entries may relate to more than one theme)

Theme (PDMF Coding Structure)	N entries	Representative Example Free-Text Entry
Psychosocial: Personality, attitudes and beliefs, emotions, goals and motivations, values, behavior change issues	1760	*"Relieved to find acceptance within this diagnosis. Shock anger disappointment denial grief have all wrapped their ugly heads around the situation and have come to acceptance. I achieved a lot over the past few months"*
Experience: Disease type/stage/ onset/ progression/ severity, Treatment and approach, Coping	1377	*"I can feel my voices starting to subside or turn away, but the process is slow... the first thing that I'm going to do once I'm alone is smoke a cigarette"*
Quality of Life: Physical, Psychosocial, Treatment impact, Coping and adaptation, Lifestyle impact (work, relationships, family)	780	*"I took a nice walk around a couple blocks and found a new circuit for my walking route that feels doable and goes by my friend's apartment! I also talked to someone about some difficult stuff and it went well, and he was able to relieve of my fears. I also started my routines almost on time!*
Influencers and Supporters: HCPs, Community and peers, Family, Caregiver, Scientific Community, Social network	628	*"I am finally back on medication, the Therapist and Psychiatrist were very kind and helpful. I am finally able to contact family again without feeling so low, it was great talking to them, I've missed them and has been months since I have last seen them."*
Other	304	
Decision Conflicts: Diagnosis, Coping and adaptation considerations, Treatment adoption/ Adherence/ Persistence, Other treatment considerations, Decision tradeoffs	185	*"I had made progress at program with my attendance but I am slacking this week. I am very nervous about starting the new job"*
Knowledge: Self literacy, Learning from HCP, community and peers, Online information, Expectations, Experience of others	96	*"I feel determined to get well I read a book by Amy Gamble bipolar my biggest competitor and it helped me out a lot because she went through a lot of psychosis"*

5,012 app users reported Schizophrenia as a diagnosis, all of whom reported having additional comorbidities with 70% reporting two comorbid conditions.

The **most frequently reported comorbidities**: Anxiety disorder, Depression, Bipolar Disorder, ADD/ADHD.

The most used tools :
- Medication Tracker
- Symptom Tracker
- Daily Moods

The most reported symptoms (% of reported symptoms):
- Hallucinations (23%)
- Anxiety (19%)
- Paranoid Behavior (18%)
- Depressed mood (14%)
- Hearing voices (14%)
- Delusions (13%)

The most reported moods (% of reported moods):
- Neutral (44%)
  (many described how they felt, experiencing emotional complexity beyond a specific mood)
- Happy (20%)
- Sad (14%)
- Anxious (12%)
- Upset (10%)

CONCLUSIONS

This descriptive analysis of patient engagement with the Health Storylines app reveals that many people with Schizophrenia are willing and able to engage in mobile health technology for the purpose of self-monitoring, engagement, and research.

The qualitative analysis of the Daily Moods tool revealed wide variation in the number of entries per patient (mean 11.14, SD 25.67, range 1 – 285). The 542 patients who provided free text data offer a glimpse into the experience of Schizophrenia in real-time that can show longitudinal changes as the patient engages with education, behavior interventions, pharmaceutical treatment and day-to-day interactions with their community. This data can enhance more common forms of patient reported data such as ePRO or other structured survey data and solicit the unique challenges of people with Schizophrenia and identify opportunities to address unmet needs.

Future analysis will include a more detailed qualitative analysis of the free text data, incorporating data reported in additional tools such as My Journal, and identifying themes specifically related to the positive and negative symptoms associated with schizophrenia.

Additional research is required to understand the representation of the full spectrum of patients' experience with Schizophrenia that can be assessed using mobile health apps, and the role of patient engagement in the completeness, validity and quality of data collected using mobile health apps.

REFERENCES

1. Herpertz J, Richter MF, Barkhau C, et al. Symptom monitoring based on digital data collection during inpatient treatment of schizophrenia spectrum disorders – a feasibility study. 2021. doi:10.1101/2021.10.01.21264398

AUTHORS & FOLLOW UP

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