The POEM Study: Testing the Impact of a Digital Health Platform in U.S. Veterans with Epilepsy

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PatientsLikeMe is a free online community where people with life-changing illnesses and their families can share their experiences and outcomes, and learn how to improve their care through peer-to-peer interactions.

Over 250,000 patients across 200+ conditions have joined PatientsLikeMe. Of these, over 8,300 are living with epilepsy and associated seizure disorders.

The PatientsLikeMe Epilepsy community was enhanced in 2010 and 2012 in collaboration with UCB. A user survey of 220 patients revealed many patient-reported benefits of using an online community, such as better management of medication side effects, decreased emergency department utilization, increased medication adherence, and better understanding of types of seizures experienced (Wicks P, et al. 2012). Perceived benefits of sharing health data between people with epilepsy on an online platform, Epilepsy and Behavior, 23:16-23.

The Veterans Health Administration (VHA) established the Epilepsy Centers of Excellence (ECOE) in 2008 to support the needs of Veterans dealing with epilepsy. The ECOE network consists of 4 regional centers and 16 epilepsy sites across the United States, serving thousands of patients annually. The VHA and ECOE were interested in evaluating a novel online platform to support the needs of our VA patients.

The purpose of the POEM Study for Optimal Epilepsy Self-management and Self-efficacy was to assess the impact of the digital health management platform PatientsLikeMe (PLM, www.patientslikeme.com) in a population of U.S. Veterans with epilepsy. The digital intervention included a social media forum, condition-specific tracking tools, and educational resources.

We conducted a pragmatic trial in U.S. Veterans with epilepsy who had not previously used the PLM platform. We utilized mixed recruiting techniques, including direct patient contact, mail campaigns, and social media advertising. Patients registered through an online study website and completed informed consent and validation queries before entering the study. Participants initially completed two validated surveys representing the primary study outcomes: the Epilepsy Self-Management Scale (ESMS)(Likert Scale 1-5, 38 items, range 18-95) and Epilepsy Self-Efficacy Scale (ESES) (Likert Scale 1-10, 24 items, range 24-120) at least six weeks after first use of PatientsLikeMe. Scores improved over six weeks for both the ESMS (140 to 154 points, p=0.02) and ESES (244 to 254 points, p=0.02) total scores (Figure 1). The greatest change was observed on the ESMS information management subscale (20 to 22 points, p<0.001)(Figure 2).

Results

A total of 249 Veterans (Figure 3) with epilepsy consented, was enrolled, and completed the first survey (Figure 4). The mean age was 50.2 years, 80.7% were male, and 75.1% were non-Hispanic white, consistent with U.S. Veteran demographics. 92 participants (36.9%) completed the second survey at the conclusion of the study. Scores improved over six weeks for both the ESMS (140 to 154 points, p=0.02) and ESES (244 to 254 points, p=0.02) total scores (Figure 1). The greatest change was observed on the ESMS information management subscale (20 to 22 points, p<0.001)(Figure 2).

Conclusions

This pragmatic study of an online health management platform demonstrates statistically significant improvements in established epilepsy metrics of patient self-management and self-efficacy. This work demonstrates the potential impact of digital health solutions in epilepsy and serves as a foundation for further research.

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