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Review

A review of mobile apps for epilepsy self-management

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ABSTRACT

Mobile health app developers increasingly are interested in supporting the daily self-care of people with chronic conditions. The purpose of this study was to review mobile applications (apps) to promote epilepsy self-management. It investigates the following: 1) the available mobile apps for epilepsy, 2) how these apps support patient education and self-management (SM), and 3) their usefulness in supporting management of epilepsy.

We conducted the review in Fall 2017 and assessed apps on the Apple App Store that related to the terms "epilepsy" and "seizure". Inclusion criteria included apps (adult and pediatric) that, as follows, were: 1) developed for patients or the community; 2) made available in English, and 3) less than $5.00. Exclusion criteria included apps that were designed for dissemination of publications, focused on healthcare providers, or were available in other languages. The search resulted in 149 apps, of which 20 met the selection criteria. A team reviewed each app in terms of three sets of criteria: 1) epilepsy-specific descriptions and SM categories employed by the apps and 2) Mobile App Rating Scale (MARS) subdomain scores for reviewing engagement, functionality, esthetics, and information; and 3) behavioral change techniques.

Most apps were for adults and free. Common SM domains for the apps were treatment, seizure tracking, response, and safety. A number of epilepsy apps existed, but many offered similar functionalities and incorporated few SM domains. The findings underline the need for mobile apps to cover broader domains of SM and behavioral change techniques and to be evaluated for outcomes.

1. Introduction

Epilepsy is the fourth most common neurological disorder after migraine, stroke, and Alzheimer's disease and impacts 3 million adults and 470,000 children in the U.S. [1]. Many patients struggle with daily epilepsy self-management practices such as remembering to take medications, maintaining prescribed sleep, exercise, and stress behaviors [2]. Mobile health (mHealth) smartphone applications promise to play an increasingly important role in epilepsy treatment, yet limited research has explored the availability and applicability of existing resources. The Global Observatory for eHealth defines mHealth as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices [3]." Notably, while over 72% of the population have a smartphone in the U.S. [4], these applications are not widely adopted within clinical practice.

There is currently a lack of theory, evidence-based practices, or incorporation of clinical expertise [5,6] for facilitating patient education, symptom management, and provider communication about health issues. This presents a key challenge for patients, caregivers, and clinicians who need support with practices. Moreover, while apps are emerging as mechanisms for behavioral change for many health topics including physical activity [6,7], disease management [8], and coping strategies such as mindfulness [9], there is limited evidence to highlight what approaches are effective.

People with chronic conditions, such as people living with epilepsy, face challenges with managing complex behaviors and tend to have poor psychosocial adjustment and lower quality of life [10]. Epilepsy self-management (SM) is defined as the total of steps taken and processes used by a person to maximize seizure control and quality of life and to minimize the impact of having a seizure disorder [11]. Furthermore, SM education and skills help people with epilepsy (PWE) to increase their self-efficacy and enable them to better cope with their disease to lead better quality lives [11,12]. Interventions designed for adults with epilepsy have been developed and increased SM [10]. For example, a web-based SM program has been shown to increase self-efficacy, medication adherence, self-management, and knowledge and to decrease perceived stress [13].

Children living with epilepsy also face psychosocial, mental health, and SM challenges. They experience school difficulties associated with

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memory limitations or developmental delays, more limited activities, poorer social functioning, and higher levels of depression and anxiety than children who do not have epilepsy [14]. A review of 24 SM interventions for children with epilepsy and/or their caregivers found significant impacts on individual (i.e., reduction in mental health/behavioral problems, self-efficacy, quality of life) or family outcomes (i.e., parental knowledge, family functioning) [15]. None of the interventions focus on a technology-based platform that can impact a population that is difficult to reach for intervention due to potential transportation hassles, access issues, or scheduling difficulties for caregivers.

There is a potential role for technology and mobile apps to assist with patient care and epilepsy treatment. At the diagnosis stage, healthcare providers can encourage patients to monitor their seizure activity and triggers through paper tracking logs or seizure trackers [16]. For PWE, tablet-based interventions can facilitate communications with providers around SM topics and behavioral goal setting [17]. For those with uncontrolled epilepsy, providers could offer online or mobile tools to assist with medication adherence or other unmet patient educational topics [13]. However, the evidence of the effectiveness of mHealth for epilepsy SM is unknown. It is therefore important to understand the availability, functionalities, and applicability of existing resources as a starting point for answering these questions.

Use of mobile apps for epilepsy SM is an understudied area; more research could inform patient-centered care in offering tools and support for patients. In addition, understanding what eHealth tools exist for epilepsy SM is important for education and supporting behavioral health because chronic disease SM is comprised of many behavioral skills domains. For example, the Mobile App Rating Scale (MARS) was designed to systematically assess eHealth and mHealth interventions [15]; it has been applied to commercial and health apps [18].

While epilepsy SM apps have been reviewed, the review was limited to descriptive assessments. Panhker et al. reviewed smartphone apps for epilepsy and found 28 apps focused on SM. The review evaluated apps in terms of the following descriptive features: seizure diaries, medication tracking, and/or video recording [19]. However, systematically assessing epilepsy SM apps with MARS, as well as evaluating SM domains, would provide a more comprehensive assessment of the quality and focus of epilepsy SM apps available. Without a systematic assessment, it is difficult to compare between other domains. Further research could contribute to the understanding of how apps can assist with patient self-care and well-being.

The purpose of this study to conduct a systematic review of mobile apps related to epilepsy. It will describe their features and evaluate the use of SM domains and behavior strategies in their content. The research questions answered were: 1) what are the available mobile apps for epilepsy?; 2) how do they rate on scales of engagement, functionality, esthetics, and information on the MARS?; and 3) how do they support patient education and SM? These findings will highlight notable gaps in supporting pediatric and adult SM practices as future research and inform the development of future mHealth interventions.

2. Methods

A systematic search of epilepsy apps was conducted in September 2016 in the U.S. We searched the iTunes app store. The search terms included “epilepsy” and “seizure.” We excluded apps that were strictly intended for healthcare professionals, epilepsy conferences/meetings, or journals/newsletters; however, this distinction was not always clear until downloading the app. We conducted reviews and extracted data until Fall 2017.

2.1. Eligibility requirements

The inclusion criteria consisted of the following apps: 1) focused on epilepsy, 2) developed for PWE or the general public, and 3) written in English. Exclusion criteria included apps, as follows, that were: 1) not written in English, 2) for professionals, 3) for a conference or meeting, 4) not focused on epilepsy, 5) exceeded $5 in cost, and 6) for other reasons (i.e., did not work). The first list of eligible apps was reviewed and duplicates resulting from the search terms were removed. Then, we conducted preliminary screening for relevance and excluded those that did not meet the inclusion criteria.

The apps and their descriptions were reviewed for relevant information related to the research questions. The research team downloaded each app and conducted the review that was documented systematically through two online extraction forms. The first extraction form was developed in Google forms to abstract key descriptors about each app including its name, platform, year posted, cost, target audience, the number of downloads, behavioral techniques, and general description. The second abstraction forms was developed in Excel to document the MARS ratings for each app. The research team was trained on the abstraction process and practiced rating 5 apps together to ensure understanding of each data field and consistency in rating. The raters entered data on the apps description and rating scores on the online data abstraction forms. Two reviewers reviewed apps independently. After independent review, the reviewers met to discuss ratings and reached consensus on the final ratings and elements. Each app was evaluated with respect to the following three sets of criteria: 1) MARS rating, 2) SM topics, and 3) behavioral change techniques. These criteria are described below.

2.2. MARS

The MARS was designed for rating eHealth and mHealth interventions [19]. It has 1 descriptive classification section and 3 areas of assessment as follows: MARS mean, subjective quality, and perceived impacts. It has four objective subscales of engagement, functionality, esthetics, and information quality. Each item is rated on a 5-point scale (1-Inadequate, 2-Poor, 3-Acceptable, 4-Good, 5-Excellent). The MARS has demonstrated excellent internal consistency ($\alpha = 0.90$) and interrater reliability (ICC = 0.79) [20]. For this study, we modified the Classification section for the app review and used 4 MARS subscales. In addition, we included an assessment of satisfaction, which measured the overall star rating of the app from 1 = one of the worst apps to 5 = one of the best apps I have used.

2.3. Self-management domains

Eleven domains of epilepsy SM have been identified as descriptive assessments with a newly developed Adult Self-Management Measurement Instrument (AESMMI) [21,22]. We reviewed apps and indicated if the app covered any of the 11 domains. The domains are healthcare communications, treatment management, social support, medication adherence, seizure response, wellness, stress management, safety, coping, seizure tracking, and proactivity. We added one domain related to the transition of care from children and adolescents to adult.

2.4. Behavior change techniques

In addition, we also employed a behavior change taxonomy by Abraham and Michie as an additional descriptive assessment to determine the use of behavior change techniques in the apps [23]. They classified 26 main techniques to change behaviors that are common across behavioral change theories. Some of these techniques include prompting self-monitoring of behavior, providing feedback on performance, planning social support or social change, prompting goal setting, and providing contingent rewards.

2.5. Data analyses and summary

Descriptive elements from the abstraction forms were summarized into an app description table, including audience, purpose, target age, and costs. The three sets of indicators were then analyzed as follows.