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mHealth tools in the management of epilepsy

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SUMMARY

Introduction. Epilepsy is a persistent neurological condition characterized by frequent seizures that are not triggered by an environmental or reversible stimulus. Although not yet widely used, mobile health (mHealth) innovations have enhanced epilepsy care and prevention and are expected to play an increasing role in the ownership of smartphones, wearable devices and innovation in medical technology.

Aim. The present review paper aims to summarize the current state of knowledge regarding the use of mHealth tools in epilepsy management.

Discussion and Conclusions. In this paper, we review available mHealth tools that influence key epilepsy management elements. These components include patient education, self-management directly affecting seizure control, diagnosis and therapy, and managing medical data. mHealth solutions are a promising approach to epilepsy self-management; further work is needed to explore their effectiveness.

Key words: applications • mhealth • wearables • epilepsy • management

INTRODUCTION

Epilepsy is one of the most common disorders of the nervous system, conceptually defined in 2005 as a brain condition with a lifelong predisposition to epileptic seizures (Fisher et al., 2005). The revised functional definition means that epilepsy may also be considered present in individuals with other causes, which have a high probability of a persistently reduced seizure threshold and therefore of a high recurring risk, following an unprovoked seizure (Fisher et al., 2014). It is a health problem as well as a social and economic one. Epilepsy affects over 65 million people worldwide (Ngugi et al., 2010).

Among people with epilepsy (PWE) and their healthcare providers, there are overlapping needs for improvement of patient education, self-management which directly influences, seizures management, diagnosis and therapy and medical data management. According to the several published studies, only 65–70% of PWE respond to current treatments to control their seizures (Brodie et al., 2011; Kwan, Brodie, 2000).

The widespread adoption of mobile phones and smartphones provides a promising opportunity to improve epilepsy care and self-management. Telehealth administered through mobile devices (mHealth) allows health providers to exchange information with patients or offer direct care, education, or remote monitoring (Lustig, 2012) (fig.1).

While there is little scientific proof in many aspects of the efficacy of mHealth applications (Marcolino et al., 2018; Free et al. 2013), one of the definitions that emerge in the Health 2.0 literature is "patient empowerment 2.0" (Bos et al., 2008). This defines a citizen's active en-

Review paper

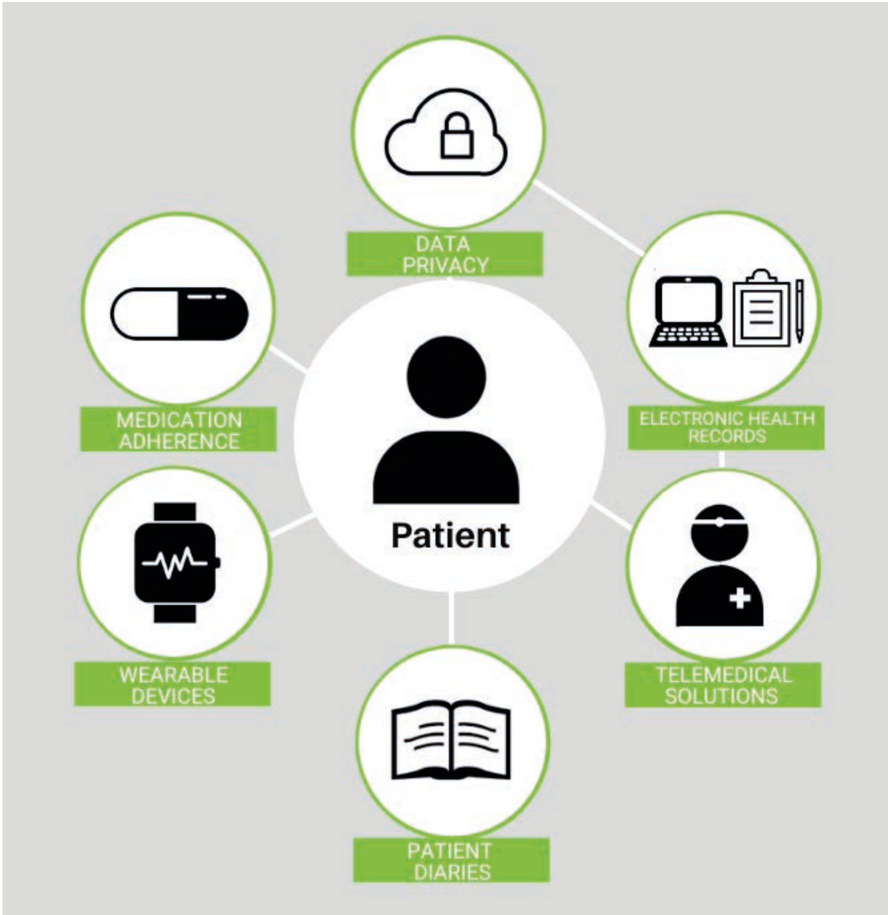

Figure 1. Examples of mHealth tools.

gagement in the use of information and communication technology in his or her health and care process.

mHealth is also an affordable option for improving health promotion, disease prevention, care, and monitoring in Low-income Countries where pilot projects are developed. Initial findings from interventions conducted in Low and Middle-Income Countries show that mHealth provides a wide variety of advantages, including better clinical outcomes, medication adherence, health engagement, and the opportunity to seek expert advice (Hurt et al., 2016).

Therefore, mHealth is crucial to the concept of comprehensive healthcare, in which information and resource services can reach anyone, anywhere, anytime, overcoming various obstacles.

AIM

The present review paper aims to summarize the current state of knowledge regarding the use of mHealth tools in epilepsy management.

MATERIALS AND METHODS

This review includes recent papers identified using the PubMed database. The search was conducted in July 2020 with terms: mobile apps, mhealth, wearables, epilepsy, and management. It includes papers written in English during 2010–2020. Additionally, the different references highlighted in the original papers were also included as necessary.

DISCUSSION AND CONCLUSIONS

Overview of types of m-health epilepsy tools in the literature

Patient education

There are several mobile apps aimed at educating patients about epilepsy and how to manage it. Escoffery et al. (2018) conducted a thorough review of available apps tailored for people with epilepsy. The study reported on 20 apps, and most of them focused on teaching patients about their epilepsy or how to treat it. Howev-

Table 1. Types of information included in the electronic diary

Medical history	birth history, growth and development, past illnesses and hospitalizations, injuries, surgeries, allergies, vaccinations, substance abuse, diet, obstetric/gynecologic history
Seizures	causes, duration, dates
Therapy	drugs taken, side effects, missed/additional pills
Additional files	videos, documents, exam results
Additional events	sleep deprivation, stress, menstruation, alcohol/drugs use

er, the apps had additional features which varied from app to app.

An example of an interventional study was performed using EpApp mobile application (Le et al., 2016; Marne et al., 2018). In the experiment, self and general knowledge of epilepsy among participants increased after the intervention. Additionally, significantly fewer medication reminders were needed by the patients compared to baseline. App architecture, quality, accessibility, and utility measures were rated very well.

Self-management apps

Diaries

Diaries are a form of so-called patient-reported outcomes. Electronic diaries provide an alternative to the traditional paper-based seizure diaries (table 1). These may be implemented on dedicated handheld devices or as software loaded on a standard smartphone or another commercially available device (Fisher et al., 2012). Such devices potentially allow programming to improve data validity, real-time transmission of data, reminders to subjects, and other features. Contrary to conventional paper-based seizure diaries, e-diaries can be more effective when analyzing information quickly and directly using digital devices (Brigo et al., 2020).

Another useful advantage of electronic diaries compared to the paper ones is that information submitted by individual users can be collected anonymously for the entire population of the users to assess demography, seizure count, side effects, and therapeutic response. The most famous examples are My Epilepsy Diary at (https://www.epilepsy.com/living-epilepsy/epilepsy-foundation-my-seizure-diary) and Seizure Tracker (https://seizuretracker.com) (Le et al., 2011).

Over 6 months, using a smartphone app improved self-management scores for epilepsy in people in a randomized controlled trial conducted in western China (Si et al., 2020).

Apps to encourage adherence

According to the World Health Organization, adherence to long-term treatment for chronic diseases in developed countries is 50 percent on average. The rates are much lower in developed countries (World Health Organization, 2003).

It is undoubtedly difficult for many patients to follow treatment guidelines. Non-compliance with medication is a significant obstacle to seizure freedom in epilepsy patients (Elsayed et al., 2019), and lack of compliance tends to be associated with increased healthcare costs in adult epilepsy patients (Davis et al., 2008).

In a review, three categories of adherence strategies used in smartphone apps were identified – a reminder (alarm/push notification/SMS), behavioral strategy (gamification/personal tracking/external monitoring), and educational strategy (Ahmed et al., 2018).

Mobile App Rating Scale (MARS) developed by researchers aims to establish standards in assessing the quality of mobile health apps (Stoyanov et al., 2015).

Several reviews with the use of MARS were performed identifying top-rated advanced mobile applications (Medisafe, Dosecast, MyMeds, CareZone, My Pillbox, MedicineList+b) as well as basic ones (My heart, my life; MediWarec; MyMedManager; Pill Reminder) (Santo et al., 2016).

In another example, women with epilepsy (WWE) included in the study with WEPOD App tracked seizures and antiepileptic drugs. The WEPOD App is a customized diary where WWE can track their menstrual cycle, sexual activity along with seizure and drug diaries. 75 percent of women were compliant with the electronic diary, tracking drug use for >80 per cent of days; these women were included in the adherence analysis. Application users reported high adherence to AEDs (97.1%) (Ernst et al., 2016).

Control of seizures

Seizure detection methods can be based on a range of techniques, including EEG signal analysis and non-EEG-based techniques (Ryvlin et al., 2018) such as automated analysis of recordings of digital videos (Karayiannis et al., 2006), detection of rhythmic, repetitive movements by accelerometers (Lockman et al., 2011) or data obtained from surface electromyography (Beniczky et al., 2018; Szabó et al., 2015).

Wearable seizure monitors will enhance current strategies by offering continuous ambulatory monitoring, more precise seizure counts and early intervention warnings (Jory et al., 2016). The proposed multimodal wrist-worn seizure detectors offer more accurate seizure counts than previous automatic detectors and traditional patient self-reports while maintaining tolerable false alarm levels for mobile surveillance. The multimodal system also provides an objective description of motor behavior and autonomic dysfunction with potential SUDEP warning benefits, aimed at enriching seizure characterization (Onorati et al., 2017).

Johns Hopkins EpiWatch is an Apple Watch app developed for research purposes. App users should manage epilepsy by monitoring drugs, seizures, and potential causes or side-effects. Provided information can be accessed at any time, and a dashboard allows the caregiver to view a data summary. EpiWatch enables family members or caregivers to be alerted during seizures. (Krauss et al., 2017).

In a study conducted by Szabó et al. (2015) each subject had surface eletromyographic (sEMG) electrodes mounted on the arm suspected to be primarily or mainly involved in clinical semiology in the middle of the biceps and triceps muscles. Out of two hundred seizures or incidents involving EMG and video-EEG reported simultaneously, Brain Sentinel's algorithm detected 20 out of 21 GTCS. Reviewed seizure-detection algorithm has demonstrated excellent sensitivity and precision in the GTCS classification.

The continuation of the research of wearable monitoring device (sEMG) developed by Brain Sentinel for the detection of generalized tonic-clonic seizures (GTCS) was undertaken in a prospective multicenter Phase III trial (Halford et al., 2017).

One other research introduces a novel wrist-worn tonic-clonic seizure warning device. The system senses the sudden, uncontrolled, repeated movement of the limbs. When detected, the watch sends a signal to a monitor, warning system, or smartphone through a Bluetooth connection that records the date and time of the incident, the duration of the movement, and the full motion data are displayed graphically. The watch includes a miniaturized three-dimensional motion/accelerometer sensor that senses the subtle and gross body part movements (wrist, ankle) on which the watch is worn. The mathematical detection algorithm installed in the SmartWatch uses pattern recognition and feature analysis to determine whether the observed patterns of motion indicate those induced by a GTC seizure (Lockman et al., 2011; Kramer et al., 2011).

Epilepsy Diagnosis and Therapy

The increasing availability of smartphones with cameras makes it easy to produce a video clip of seizures that can be easily transmitted to an epileptologist using electronic communication devices. Examining these home-made video recordings can enhance diagnostic accuracy, help identify differentials with certain paroxysmal conditions, or recognize epileptic seizures (Tatum et al., 2020).

The Clinical Decision Support System (CDSS) is an application that analyzes data to help health care providers make choices and suggest next steps in patient care. A CDSS uses knowledge management to obtain clinical advice based on multiple patient-related data factors.

One of the algorithms used in the diagnosis of epilepsy is based on a study from Nepal that examined 50 regularly asked questions in a consecutive cohort of 67 patients, some with epilepsy and some without epilepsy.

If epilepsy was probable, predetermined questions were asked about the nature of the episodes. These questions were related to several categories: demography, pre-episode events, eyewitness description of the episode when available, post-episode events, and predisposing factors. Initial testing revealed that this is possible to help identify episodes as epileptic or not by health professionals (Patterson et al., 2014).

Based on a similar algorithm, Epilepsy Diagnosis Aid app was developed and validated by non-professional healthcare workers and inexperienced doctors in 132 patients. The results were compared to the gold standard of a face-to-face consultation by an epilepsy specialist. The sensitivity of the app was 88%, and specificity – 100%. This presentation had considerable advantages over other presentation methods such as papers, electronic calculators, or web platforms (Patterson et al., 2019).

Medical data management

The concept of patient health records (PHRs) originated in the 1970s (Hinman et al., 1977).

It is a fast-growing field of information technology in health area with the goal of increasing patient participation and control, leading to quality of care, reduction of mistakes, choice of treatment, and relationship building between patient-provider. With the rise of mobile computing and the progression of patients' technological aptitude, the mobile PHR (mPHR) use has increased. mPHRs have been developed as an extension of the EHRs to enable patients to access their health information. These documents contain clinical information, such as laboratory reports, and documents of screening tests and immunization (Joshi et al., 2017). Some of the apps also offer extra functionalities such as arranging appointments, integrating information from different healthcare providers, and ensuring that patient information is still available (e.g., in case of a medical emergency).

CONCERNS

Data privacy and cyber-legal concerns arise concerning privacy and security steps to be taken to collect, process, and distribute medical data. Little has been found in terms of legal considerations, guidelines, and regulations related to the use and implementation of mHealth for healthcare services. For example, privacy concerns exist when a patient is the only owner of a mobile phone. Given the data on mobile phone possession, this may be a specific problem for patients of lower socioeconomic status. The confidential data collection by corporations or governments could lead to a variety of problems which could pose a risk of the data to be used for marketing purposes or being hacked (Gurol-Urganci et al., 2017).

Limited studies and data on m-Health – While mHealth is growing in popularity, there is still little proof of its efficacy. Besides, the analysis of mHealth interventions usually does not include feedback from patients and doctors, risk assessment, and the tolerability of intervention (Marcolino et al., 2018).

Technological illiteracy and lack of training – Technological literacy is being defined as the ability to use, manage, understand, and assess technology. Technological illiteracy (Ameen, Gorman, 2009; Alvarado et al., 2017) is a potential barrier that could exclude elderly and non-English speakers from using m-Health technologies. The clinical implications of m-Health in care delivery should require health science curricula to determine the best ways of presenting the topic to both undergraduate students and physicians.

Cost – the cost is a potential barrier to the massive adoption of every medical technology. Also, the use of apps requires owning a smartphone or other expensive devices. Besides, Internet connectivity and bandwidth for high-speed communication can be another big issue in some rural or low-income areas (Combi et al., 2016).

Lack of compatibility – considering the trend in mobile healthcare, compatibility with existing healthcare technologies could have an impact on the intention to use it.

More broadly, integrating data extracted from specific devices and applications into central or government-based electronic health records requires infrastructural development, focusing on compatibility and interoperability between mHealth apps, devices, and hospital management systems (Varshney, 2014; Becker et al., 2014; Sezgin et al., 2017)

Patients' and healthcare providers' perceptions and practices – one of the obstacles identified on the way to scientific inquiry into m-Health for the treatment of epilepsy is the perception among many patients and healthcare providers that sufficient evidence of their safety and efficacy already exists. This finding suggests that the more influential the belief that the application or device will be beneficial and the higher the sacrifice involved to obtain it, the greater the reported response (Leenen et al., 2016).

CONCLUSION

The current evidence shows some benefits of mHealth epilepsy tools use in the management of epilepsy. Mobile and smartphone (mHealth) technologies are likely to have a significant but still undetermined role in epilepsy management. Further work is required to assess the effectiveness of such approaches across a variety of potential clinical and patient-centered endpoints. The quality of research on the efficacy of mHealth interventions in epilepsy is poor. Successful mHealth interventions are likely to involve active patient engagement and a role for healthcare providers. As soon as the long-term efficacy of mHealth technologies has been proven in real-world communities, the use of mHealth technologies should be recommended in the appropriate patient management guidelines.

CONFLICT OF INTEREST

All authors have no affiliations or involvement with any organization or entity having any financial or non-financial interest in the subject matter or materials discussed in this manuscript.

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