Review article

Digital tools for epilepsy: Opportunities and barriers

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ABSTRACT

This review and commentary presents and discusses the major categories of digital tools that are currently available to epilepsy patients. This review synthesizes the breadth of resources that may be used to create a comprehensive self-management platform. The manuscript organizes the discussion into the following topics: self-management education programs, electronic diaries for self-monitoring, and automated wearables for seizure detection. Despite being available for many years, these tools are utilized by only a small fraction of epilepsy patients. To directly address this, the discussion section will opine on some of the possible barriers, including a lack of historical precedent or prescribing infrastructure, a lack of financial incentives, concerns about data privacy or liability, and uncertainty about the supporting evidence for these solutions.

1. Introduction

Epilepsy is one of the most common chronic neurologic conditions in the United States, with approximately 3 million individuals diagnosed (Tian et al., 2018). This makes an epilepsy diagnosis the fourth most common neurologic condition, ranking behind headache, stroke, and dementia. In addition to the unpredictable seizures that define epilepsy, there are a host of social, lifestyle, and workplace challenges that detract from the quality of life of patients with epilepsy. Fortunately, there are many FDA-approved medications, and these therapies are effective at preventing seizures for the majority of patients. However, there are a substantial number of patients who are not successfully treated with medications; these patients may require more advanced medication combination approaches, therapeutic devices, or even surgical interventions to better manage their seizures. For all epilepsy patients, regardless of treatment requirements, a robust platform of care management tools, education, and social support is necessary to optimize the odds of success.

Historically, epilepsy patients sought out and received education and disease management support through a mix of interactions, including face-to-face discussions with nurses and physicians, paper-based instructional materials, and patient-facing lectures or support groups. Unfortunately, these resources are not ubiquitously available to patients, due to a lack of widespread dissemination, the burden on healthcare team time, and the resources necessary to create and update content. The digital era has promised to dramatically increase the accessibility of these types of resources, both by lowering the cost and intensity of creating content and by facilitating immediate on-demand access for all types of patients. A so-called 'techno-therapeutic' approach would arm epilepsy patients with an optimized suite of educational and disease management tools to adjunctively support a traditional pharmaceutical or device-based treatment plan (Page et al., 2018).

This review aims to present and discuss the major categories of digital tools that are currently available to epilepsy patients. Although prior review articles have focused on specific elements of digital solutions, this review synthesizes the breadth of resources that may be used to create a comprehensive and individualized self-management platform. The review organizes the discussion into the following topics: self-management education programs, electronic diaries for self-monitoring, and automated wearables for seizure detection (Table 1). Within these categories, individual interventions have been studied and available to patients for years, but the evolution of a digital 'ecosystem' promises the potential to integrate these tools in a manner that can meaningfully benefit patients' health.

The manuscript will also present a commentary on the possible concerns that are preventing more widespread adoption of these digital health resources. Despite being available for many years, these tools are broadly utilized by only a small fraction of epilepsy patients, depending on the type of intervention (Page et al., 2018). Many of the discussed programs and devices have been implemented in a research environment; however, the majority of comprehensive epilepsy centers do not have a mechanism for disseminating or supporting these patient aids. To directly address this, the discussion section will focus on some of the

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Table 1
Digital tools for epilepsy.

Name of Program or Tool	Type of Intervention	Outcomes Measured (or Intended Population)	Setting of Intervention	Web Resource
WebEase Program (Web Epilepsy Awareness, Support and Education)	Self-management program: Six-week modular education program conducted online	Validated questionnaires on self-management and self-efficacy; adherence, stress, sleep quality, quality of life	Online (with in-person option)	www.webease.org
PACES (Program of Active Consumer Engagement in Self-Management)	Self-management program: Eight-weeks of weekly in-person, small group educational sessions	Validated questionnaires on self-management, self-efficacy, quality of life, and anxiety	In-person only (with possible telephone and internet-based options)	https://managingepilepsywell.org/paces
HOBSCOTCH (Home-Based Self-Management and Cognitive Training Changes Lives)	Self-management program: Eight sessions conducted in-person or virtually	Memory and attention in adults with epilepsy	In-person or virtually over phone or tablet	https://managingepilepsywell.org/hobscotch
PEARLS (Program to Encourage Active Rewarding Lives)	Self-management program: Eight sessions of psychiatric counseling	Depression or dysthymia in adults with epilepsy	In-person with phone availability	https://managingepilepsywell.org/pearls
Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts)	Self-management program: Eight group session conducted over telephone	Quality of life and depression in adults with epilepsy	Group sessions over telephone	https://managingepilepsywell.org/uplift
TIME (Targeted Self-Management for Epilepsy and Mental Illness)	Self-management program: In-person group sessions, with follow up telephone support	Mental health metrics in adults with epilepsy	In-person and telephone	https://managingepilepsywell.org/time
SMART (Self-Management for epilepsy patients with history of negative health events)	Self-management program: Eight group teleconference sessions, with telephone follow up	(Poorly controlled epilepsy patients and disadvantaged patient groups)	Teleconferencing via internet and telephone	https://managingepilepsywell.org/smart
My Seizure Diary	Mobile electronic diary	(Patients with epilepsy and caregivers/family)	Mobile or internet-based diary	diary.epilepsy.com/login
Seizuretracker	Mobile electronic diary	(Patients with epilepsy and caregivers/family)	Mobile or internet-based diary	Seizuretracker.com
EpiDiary	Mobile electronic diary	(Patients with epilepsy and caregivers/family)	Mobile diary	Epidiary.com
SmartWatch	Seizure detection wearable	Detection of convulsive seizures	Wrist-worn watch style device	www.smart-monitor.com/about-smartwatch-inspyre-by-smart-monitor/
Apple Watch	Seizure detection wearable	Ongoing validation studies	Wrist-worn watch style device	www.apple.com/watch
Brain Sentinel	Seizure detection wearable	Detection of convulsive seizures	Device affixed to biceps	www.speacsystem.com/
Embrace	Seizure detection wearable	Detection of convulsive seizures	Wrist-worn watch style device	www.empatica.com/en-eu/embrace/

barriers to adoption, including a lack of historical precedent and prescribing infrastructure, a lack of financial incentives, concerns about data privacy or liability, and a lack of consensus about the strength of the supporting evidence for these solutions.

2. Patient education programs (self-management)

Patient education is an intuitive and important element of optimizing self-care; the majority of healthcare providers impart some education to patients and caregivers during visits. However, these discussions are usually informal, lack a structured 'curriculum', and may not be reinforced with patients. Perhaps as a result of this, a number of structured epilepsy self-management programs have been created and rigorously tested to better facilitate patient education and empowerment (Table 1). Epilepsy self-management has been 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 (DiIorio et al., 1996; Escoffery et al., 2018). A related concept called self-efficacy has been defined as the 'beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments' (DiIorio et al., 2009). Patients who successfully improve their self-efficacy through self-management practices have been demonstrated to successfully complete self-care tasks, such as taking medications and engaging in other healthy behaviors (DiIorio et al., 2006). The importance of epilepsy self-management was highlighted in an Institute of Medicine (IOM) 2012 report (Epilepsy Across the Spectrum), commenting on behavioral interventions to improve health outcomes and the quality of life for epilepsy patients (Hesdorffer et al., 2013).

Self-management practices are potentially valuable for all patients with epilepsy but may be most beneficial for cohorts of patients who require specific action plans. With improved recognition of urgent epilepsy-related scenarios, such as seizure clustering, status epilepticus, and SUDEP (sudden unexpected death in epilepsy), there is an opportunity to empower patients and families to view a 'seizure rescue plan' as a formal element of a treatment paradigm (Smith et al., 2018; Fleeman and Bradley, 2018; Cole and Gaspar, 2015). Although seizure planning is but a single element of a comprehensive self-management curriculum, this feature may serve as a 'gateway' to additional patient engagement.

Formal self-management programs for epilepsy have been studied and implemented for decades. The initial programs primarily utilized in-person, curriculum-based sessions (either individual or group) to provide patient education about epilepsy management (Helgeson et al., 1990; May and Pfäfflin, 2002; Aliasgharpour and Dehghan Nayeri, 2013). The reported results from these studies demonstrated successful improvements in disease knowledge, self-management, and elements of epilepsy-specific tracking. However, these initial programs were labor-intensive, requiring staff moderation and in-person attendance by patients. More recent self-management programs have incorporated formal peer support elements (Laybourne et al., 2015; Fraser et al., 2015). And, a growing number of epilepsy self-management programs include a digital platform. This approach serves to increase access, convenience, and usability for many patients who may be unable to travel long distances or commit the in-person time necessary to participate in intensive educational sessions.

2.1. WebEase

One of the first programs to implement this digital strategy was the WebEase platform (www.webease.org) (DiIorio et al., 2011). The WebEase tool includes three educational modules (medication adherence, sleep, and stress) that can be completed online. The original clinical trial successfully demonstrated improvements in epilepsy self-efficacy, self-reported adherence, self-management, and stress levels in an intervention patient group compared with a wait-list control group (DiIorio et al., 2011). This effort represented one of the first well-validated and critically assessed online platforms for delivering epilepsy self-management content.

2.2. Managing epilepsy well (MEW)

In concert with the WebEase program, an online hub resource, hosted through the Managing Epilepsy Well (MEW) network (managingepilepsywell.org) currently provides comprehensive digital resources for epilepsy patients. In addition to WebEase, a variety of other digital self-management programs have been made available, each with a slightly different clinical focus for patients. For instance, the PEARLS and UPLIFT (managingepilepsywell.org/uplift) programs are focused on improving depression and quality of life in epilepsy, while the HOBSCOTCH program aims to assist with memory difficulties (Chen et al., 2018). The MINDSET program (managingepilepsywell.org/mindset) is a digital clinical-decision support system that aims to identify a patient's specific self-management challenges and subsequently craft an individualized educational program (Shegog and Begley, 2017). Currently, each of these programs is generally only available at dedicated epilepsy centers; however, the MEW Network model is intended to develop greater awareness to fuel better dissemination.

2.3. Peer support networks

In addition to formal self-management programs, peer support has increasingly become recognized as a valuable resource for many patients. The WebEase platform has incorporated a social networking peer component to its suite of tools, and there are now multiple online peer support networks available to patients (www.patientslikeme.com, www.myepilepsyteam.com, www.epilepsy.com/forum-topics). Integrated, online peer support was a fundamental part of a self-management study published in 2015, which examined the use of an online and mobile platform in US Veterans with epilepsy (Hixson et al., 2015). This platform included self-tracking tools and formal educational videos, but also included a dedicated epilepsy-specific online peer forum (www.patientslikeme.com/conditions/epilepsy). The study used the same outcomes measures as in prior self-management studies, demonstrating a statistically significant improvement in epilepsy self-management and self-efficacy after six weeks of unmoderated use of the platform (Hixson et al., 2015). Unlike most of the formal self-management programs, this study employed a pragmatic trial design, highlighting the value of these resources in a real-world setting.

3. Data capture (self-monitoring)

Although often discussed separately from self-management topics, the use of trackable data metrics is an increasingly critical element of optimizing epilepsy care. It is well known that patients have difficulty with accurate seizure recall, either due to the nature of an individual's seizure types or simple recall bias (Fisher et al., 2012; Fisher, 2017). Additionally, medication adherence remains a challenge for many patients, with even a single missed or improperly timed dose potentially leading to a seizure (Paschal et al., 2014). Digital tools for improved data capture can potentially aid a patient to better manage their treatment and can create a more accurate data set for helping both healthcare providers and patients make more informed decisions.

Mobile diaries are one category of self-monitoring solution that has been available for many years. Some of the original electronic diaries were effectively digital recreations of paper-based tools (Fisher et al., 2012). However, more recent versions of electronic diaries have been upgraded to include better usability with more efficient mechanisms for seizure reporting, medication entry, and personalized reminders (Table 1). A number of mobile applications on different operating platforms are available, although most are commercial products that

have not been critically studied (Page et al., 2018; Escoffery et al., 2018; Fisher et al., 2012; Pandher and Bhullar, 2016). Recent reviews have identified a large and growing number of epilepsy-specific mobile applications, with most being free and easily accessible (Escoffery et al., 2018; Pandher and Bhullar, 2016). However, a smaller number of these applications were designed specifically for patient management, with the most common features being seizure and medication tracking (Escoffery et al., 2018).

Overall, despite a large number of mobile diaries, there is a need for more comprehensive inclusion of self-management and patient education in these applications (Escoffery et al., 2018). Most are only focused on tracking tools, and do not incorporate proven self-management programs into a single cost-effective and efficient resource. This represents an incredible opportunity for new and existing programs to either build self-management and seizure action planning programs into their platforms or establish easy-to-navigate links to existing hubs, such as the Managing Epilepsy Well network (Shegog et al., 2013; Sajatovic et al., 2017; Begley et al., 2018).

One of the better-known mobile diaries is the product supported by the Epilepsy Foundation, My Seizure Diary (diary.epilepsy.com) (Fisher et al., 2015). The latest version of the My Seizure Diary includes a more efficient, notification-based method for reporting seizures and includes customizable reminders for seizure monitoring, medication dosing, and refills (dairy.epilepsy.com). Earlier versions of the My Seizure Diary have been successfully used in several clinical trials for capturing self-reported data (de Ernst et al., 2016; Meador et al., 2018), and the diary is currently being used in a prospective research program for tracking seizures. Seizuretracker is another popular mobile and online diary option with self-tracking capabilities, including advanced graphing features that display potential correlations between seizure frequency, side effects, and medication changes (www.seizuretracker.com) (Fisher et al., 2012). Yet another epilepsy-specific diary is the EpiDiary (www.epidiary.com) which also offers seizure tracking, medication adherence data, and advanced graphing and report features. EpiDiary is also available in multiple languages, making it potentially attractive for international users. Ultimately, individual patients and caregivers should explore each diary offering, and choose the ones that works best for their needs.

4. Wearable devices

While mobile diaries have improved in usability in recent years, many patients still have difficulties with self-reporting mechanisms (Pandher and Bhullar, 2016; Fisher et al., 2015; Blachut et al., 2015, 2017). The advent of wearable technologies has raised the possibility of 'automated' seizure detection and even medication adherence, independent of patient self-report. While the majority of consumer devices have not been validated for epilepsy patients, a small cohort of products have been specifically designed and tested for this purpose (Table 1). As a group, these wearables provide potential benefit for seizure monitoring (particularly convulsions) for patients at risk of serious consequences such as SUDEP (Gutierrez et al., 2018; Ryvlin et al., 2018; Picard et al., 2017). These wearables utilize a variety of peripheral biometric signals that are often associated with certain types of seizures, including accelerometry, gyroscopy, electromyography, heart rate variability, and electrodermal skin responses (Ramgopal et al., 2014; Reeder and David, 2016; van Andel et al., 2016, 2017; Dumanis et al., 2017; Ryvlin and Beniczky, 2018; Arends, 2018).

4.1. Smartwatch

One of the first medical-grade wearables for automated seizure detection was the Smartwatch wearable by Smartmonitor, with the first generation available in 2010 (Lockman et al., 2011). The wrist worn device performs automated seizure detection based exclusively on accelerometry and gyroscopic data, and in early testing, it demonstrated

favorable sensitivity for detecting convulsive seizure types (Lockman et al., 2011). Later studies demonstrated more modest detection performance (Patterson et al., 2015), but the device still appears to have utility for detecting convulsive events (Velez et al., 2016). Subsequent versions of the device have improved the performance, and have incorporated other ancillary features, including a mobile app with event tracking, alerting for caregivers, and GPS localization (www.smartmonitor.com). Other wearables devices have also leveraged the detection abilities of accelerometry. This includes an EpiCare device (danishcare.co.uk/epicare-free), which has been tested and validated in video-EEG monitoring settings (Beniczky et al., 2013; Meritam et al., 2018), similar to the Smartwatch.

4.2. Apple watch

In terms of more consumer-grade wearables, the Apple Watch is the most prominent entrant into the medical space. Using accelerometry and gyroscopic data, the movement detection features of the Apple Watch are compelling for a consumer device, and the Watch is currently being used in a patient-driven research study on automated seizure detection (paired with a mobile application) (www.hopkinsmedicine.org/epiwatch). However, this effort does not represent the same level of critical validation that has been performed on some of the other wearables for seizure detection. Thus, it remains unclear how the Apple Watch would be integrated into a self-management platform for epilepsy patients.

4.3. Brain sentinel

Another epilepsy-specific wearable is the Brain Sentinel device (brainsentinel.com) (Ryvlin and Beniczky, 2018; Szabó et al., 2015; Halford et al., 2017). This device is usually worn on the upper arm over the biceps muscle and uses electromyography (EMG) signals to automate convulsive seizure detection. This wearable has also been tested and validated in video-EEG monitoring environments, demonstrating good sensitivity for detecting generalized tonic-clonic convulsions (Szabó et al., 2015; Halford et al., 2017). As with the other wearables, the evidence for the accurate detection of other seizure types is more limited (Szabó et al., 2015; Halford et al., 2017). However, for convulsive seizure quantification and alerting, the Brain Sentinel product may be a useful option for some patients.

4.4. EDA devices

The electrodermal skin response (EDA) is the final, notable biometric that has garnered much attention for seizure detection; this approach is essentially a skin-generated electrical signal that indicates the relative activity of the autonomic nervous system (Poh et al., 2010). Research in this area has demonstrated that the EDA response can be dramatic during a convulsive seizure event (Poh et al., 2010; Sarkis et al., 2015). The Embrace wrist worn device, developed by Empatica (www.empatica.com), has leveraged the use of EDA signaling in combination with traditional accelerometry information to bring a more multi-modal approach to automated seizure detection. Validation studies have successfully demonstrated a high degree of sensitivity for convulsive seizures (Poh et al., 2010, 2012; Onorati et al., 2017). The device has also performed reasonably well for the detection of other seizure types, but may not be optimized for event detection outside of convulsions. In addition to the Embrace device, Empatica also produces a 'research-grade' device (the E4), which adds heart rate variability and skin temperature to the list of possible peripheral biometrics that could be added to a composite detection methodology. Finally, it is also noteworthy that the Empatica wearables are paired with a mobile application (the Mate app) that is capable of capturing data for self-tracking.

4.5. Multimodal devices

Recent reviews of the wearable space for automated seizure detection have confirmed the trend towards a multimodal approach to biometric monitoring (van Andel et al., 2017; Leijten, 2018; Elger and Hoppe, 2018). This is perhaps due to the inherent sensitivity limitations of devices with detections based on single biometric signals (Elger and Hoppe, 2018), or due to the individual variability in seizure semiologies. Understandably, a composite detection algorithm utilizing multiple biometrics likely promises a higher sensitivity and specificity (Elger and Hoppe, 2018). Further, for individual patients, a personalized detection algorithm may promise the highest accuracy of all. This could potentially be tailored during a baseline video-EEG monitoring session to capture representative seizures, while multiple wearable biometrics are assessed. This approach has not yet been fully studied, but may represent a potential workflow for the future.

5. Digital therapeutics

Other epilepsy therapeutic devices include the vagal nerve stimulator (VNS), responsive neurostimulator system (RNS), and the deep brain stimulator (DBS). Of these, the RNS captures real-time and ongoing seizure quantification data for physician and healthcare team planning, but also features an associated web app (myseizurediary.com) that provides tools for individual seizure tracking. This data can be exported and shared with others. The VNS and DBS devices are not associated with independent patient-facing electronic diaries; however, the settings data for these systems can be entered and tracked on other diaries such as the My Seizure Diary and Seizuretracker. All of these therapeutic devices are capable of capturing important epilepsy-related metrics but are not yet fully compatible with or automatically integrated into the most popular mobile diaries. This highlights the potential opportunity to improve the relationship between more traditional treatment interventions and emerging comprehensive self-management platforms.

6. Discussion

As presented here, a proliferation of patient-facing adjunctive tools have been developed and studied for the management of epilepsy. This includes categories of intensive self-management programs (both non-digital and digital), mobile electronic diaries, and wearable technologies. Individually, these tools may add value to traditional treatment approaches, depending on the needs, interest, and engagement of the patient. While many commercial-facing applications (mostly in the mobile diary category) have not been critically evaluated, more high profile and intensive programs and devices have been validated scientifically, and demonstrated to provide some clinical benefit. Many of these resources have evolved or been iterated to reflect changing technological capabilities or the needs and desires of patients and healthcare teams; thus, the value of these tools is likely to improve.

However, the widespread adoption of these resources as a whole remains limited in the field of epilepsy, particularly in relationship to the utilization of similar programs for diseases such as diabetes and asthma (Helmers et al., 2017). Thus, a commentary would not be complete without a discussion of the potential reasons behind this slowed adoption and identifiable barriers to implementation (Page et al., 2018; Helmers et al., 2017; Crooks et al., 2017; Ozanne et al., 2018; Johansson et al., 2018). These concerns and barriers span the entirety of the healthcare ecosystem, including patient perceptions and experiences, physician and healthcare team behaviors and incentives, and broader infrastructure and policy issues, particularly in the United States. This discussion is not meant to represent an exhaustive list of concerns, but rather reflects the authors' observations of common barriers that were observed during the review of the literature.

From a patient perspective, a simple lack of awareness (Escoffery et al., 2018; Atkinson-Clark et al., 2018) and introduction to these tools is often the greatest barrier. While some patients do naturally seek out educational resources and assistive tools, many do not; additionally, it can be challenging to identify credible and appropriate sources for content. Thus, many patients and caregivers are left with a feeling of isolation and questioning after a medical appointment.

Digital tools also face problems of usability and nonadherence, just as with medications and other traditional therapeutics. Patients may not complete or understand the concept self-management programs. (Perzynski et al., 2017). The current wearables require a significant degree of patient or caregiver maintenance, and face some of the same challenges as daily medication regimens (Meritam et al., 2018). Many epilepsy patients may have psychiatric or medical comorbidities that limit their ability to use more intensive programs (including self-management modules, diary interfaces, and wearables) (Perzynski et al., 2017), even though they would benefit from these services.

Patients and caregivers may justifiably by concerned about data quality and accuracy, since this information will be used for ongoing management decisions (Leenen et al., 2016). Patients report needing to establish a certain level of trust with their healthcare team in order to feel comfortable with the safety of these tools and the use of this data to inform treatment plans (Perzynski et al., 2017);Schachter, 2017). Additionally, patients with epilepsy may continue to feel a certain degree of stigma through the use of these tools. For instance, many of the wearables described earlier are larger, require more maintenance, or appear more unique than traditional consumer products, and patients may feel uneasy about the public display of these devices (Baker et al., 2018).

The healthcare team also plays a pivotal role in the education, implementation, and adoption of these ancillary tools. A perceived lack of communication with providers and healthcare team members is frequently reported as a barrier to understanding health conditions and utilizing available tools for epilepsy self-management (Perzynski et al., 2017; Schachter, 2017). Incorporating systematic patient education programs can be challenging, and can often require years of efforts, even with the use of certain incentives. Nonetheless, physician and healthcare team 'championing' of these resources is often critical for success (Helmers et al., 2017).

Additionally, many of the mobile applications for epilepsy have never been critically assessed and are largely the domain of the consumer-facing environment (Escoffery et al., 2018). As such, physicians may feel unprepared to judge the quality of the program, leading them to defer on making recommendations. Even for tools that have been critically evaluated, physicians may be unimpressed with or skeptical of the magnitude of the effectiveness (Leenen et al., 2014). Even with epilepsy wearables, which have demonstrated consistently strong sensitivity for detecting convulsions, physicians may still not appreciate the beneficial effects of these tools or which patients would be most appropriate for their use.

From a logistical perspective, the lack of an existing prescription model and financial reimbursement system also impedes progress in the digital health space. This situation also plagued the greater telemedicine market for years, slowing adoption (although this has begun to change) (Dorsey et al., 2018). For many of the programs described in this review, particularly self-management courses and mobile diaries, the costs to the individual and healthcare system are extremely low. Therefore, the primary barrier to a prescription model is the lack of an efficient prescribing infrastructure in the daily workflow of physicians (Helmers et al., 2017; Perzynski et al., 2017), not necessarily a pure financial disincentive.

There are a number of possible solutions to address these concerns, many of which are already being discussed within the epilepsy community. Newer versions of mobile applications and self-management programs have been refined to be more user-friendly, with recognition of the time requirements of routine data reporting. Marketing campaigns have been launched to increase patient awareness of self-

management programs, and Internet 'hubs' now exist where patients can access multiple resources. However, awareness is still lacking, and more resources should be devoted to increasing patient and caregiver engagement. Patients should feel compelled to inquire with their physicians and healthcare teams about these resources, just as they would inquire about new medications or surgical techniques.

In terms of an evidence-base, for those interventions with supportive academic research, both patient- and provider-facing educational resources should be created to better inform the broader epilepsy community. Where lacking or limited, more efforts should be led to fund and conduct large-scale randomized, controlled trials that could generate more traditional evidence, potentially even supporting a regulatory approval pathway. Admittedly, some of these interventions are likely not suitable for this approach, but in those cases, pragmatic, real-world study designs could still be helpful in generating evidence of benefit.

On the healthcare team side, 'at risk' patients should be identified for self-management and mobile tools; this could include patients who are medically-refractory, those with a high seizure burden or risk of SUDEP, or those with psychological comorbidities such as depression or anxiety. Clinical decision support systems could be created to assist physicians in determining which tools might be most appropriate for certain patients, and these tools could be integrated into existing EMRs. A physician would ideally be able to create a formal prescription at the end of a clinical encounter, linked to the EMR or at a minimum, with a transmission feature to the patient. A non-physician member of the healthcare team could also meet with these patients after the formal clinic visit to review recommendations and aid the patients with set-up and registration. The primary aim of this proposal would be to fundamentally lower the barrier for physician-recommended distribution of educational and supportive materials, creating a more formal system of approval for patients (Schachter, 2017).

Given the review presented here and the preceding discussion on barriers to implementation, it is apparent that a call to action is needed within the epilepsy community. These emerging digital technologies of all forms are rapidly improving in quality and effectiveness, and yet they rarely fit within the traditional ecosystem of medical practice. Therefore, all members of this clinical community are challenged to innovatively develop and practice new solutions that will speed adoption of these tools and ultimately improve the longitudinal self-care of epilepsy patients.

Disclosures

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