# SUPPORTING EVERYDAY SELF-MANAGEMENT PRACTICES
# FOR PEDIATRIC PATIENTS WITH EPILEPSY

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Jonathan Bidwell

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# SUPPORTING EVERYDAY SELF-MANAGEMENT PRACTICES FOR PEDIATRIC PATIENTS WITH EPILEPSY

Approved by:

Dr. Elizabeth D. Mynatt
College of Computing
*Georgia Institute of Technology*

Dr. Lauren Wilcox
College of Computing
*Georgia Institute of Technology*

Dr. Rosa Arriaga
College of Computing
*Georgia Institute of Technology*

Dr. Cam Escoffery
School of Public Health
*Emory University*

Dr. Sookyong Koh
Neurology Department
*Children's Healthcare of Atlanta*

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# ACKNOWLEDGEMENTS

# TABLE OF CONTENTS

# LIST OF TABLES

# LIST OF FIGURES

# LIST OF SYMBOLS AND ABBREVIATIONS

| | |
|---|---|
| AED | Anti Epileptic Drug |
| CHOA | Children's Healthcare of Atlanta |
| EMA | Ecological Momentary Assessment |
| PAM | Patient Activation Measure |
| SEM-CD | Self-Efficacy for Managing Chronic Disease 6-item Scale |

# CHAPTER 1. INTRODUCTION

Everyday life presents considerable challenges for people living with epilepsy.

Epilepsy self-management includes a broad range of daily health behaviors that afflicted persons use to help mitigate their seizures and inform clinical decision-making [1]. Many patients and caregivers struggle to adopt these behaviors due to the burden of data collection and reporting. New mobile health or mHealth sensing and data input capabilities could provide opportunities for facilitating aspects of these patient and caregiver data collection needs, which in turn could better inform clinical decision making and patient self-reflection within the context of self-management.

My research is grounded in the fields of Human and Computer Interaction (HCI) and health informatics and investigates the role that mobile and wearable computing devices can play for supporting epilepsy self-management.

The inspiration for this work has stemmed from my first-hand experiences working with patients, caregivers and clinicians at the Children's Healthcare of Atlanta (CHOA) and Emory University Hospital (EUH). I began interviewing caregivers and clinicians to establish technical requirements for wearable seizure detection devices. In the process, I discovered an even stronger need for more supportive, comprehensive, family-based data collection tools. My focus gradually shifted towards investigating methods and strategies for encouraging consistent and prompt daily self-reporting. In this thesis, I will present the design, development, and evaluation of pediatric epilepsy self-management tools and interventions that I developed for supporting patients, caregivers, and clinicians.

My thesis statement is as follows:

**Epilepsy self-management can be improved through the introduction of mobile and wearable interventions that enable adolescent patients and family members to collect the types and characteristics of data that clinicians need during epilepsy diagnosis and treatment, respectively, and also increase patient engagement - an indicator of successful, future self-management in preparation for adult self-care.**

My research findings have since helped to address the following knowledge gaps within HCI and health informatics:

1. **Establishing data collection needs during epilepsy treatment** - There is a need to clarify technical aspects of data collection requirements for developing mobile and wearable data collection tools. My results established clinician, patient and caregiver needs as a first step in determining how to best balance tradeoffs between active and passive data collection between clinical appointments.

2. **Investigating new methods and strategies for improving data collection quality** - There is a need to improve data collection quality for addressing patient, caregiver, and clinician information needs. My results established the performance of wearable seizure detection devices and evaluated the feasibility of using mobile phone surveys and health tracking tools for consistent, prompt and reliable data collection.

3. **Evaluating the impact of these methods and strategies on patient engagement** - There is a need to evaluate the impact of data collection tools on patient health outcomes. My results showed that daily mobile phone surveys can have a positive impact on patient engagement as an important factor for successful long-term patient

self-management outcomes [2], [3].

In this thesis, I will present my findings from five research studies. I describe each set of findings in terms of both clinical applications for supporting patient care and technical implications for informing the design of pediatric mobile and wearable tools for supporting epilepsy self-management practices.

The remainder of this thesis is structured as follows: I present background information on epilepsy, describe motivating related work, discuss my research studies, my findings and contributions, and describe avenues for future work.

# CHAPTER 2.    BACKGROUND

## 2.1 Epilepsy self-management

### 2.1.1 New challenges for everyday computing

Epilepsy is a neurological condition characterized by recurrent, unprovoked seizures [4]. Fifty million people are impacted by epilepsy worldwide [5]. In the United States, "1 in 26" people will be diagnosed with epilepsy [6] at an estimated cost of $12.5 billion [7]. Epilepsy is the fourth most common neurological disorder after migraine, stroke and Alzheimer's disease [8].

Most patients can significantly reduce the risk of seizures by taking daily medications and making lifestyle changes [3]. Medications known as antiepileptic drugs (AED) have been shown to be effective for 60-80% of patients [4], [9]–[12]. In addition, patients can often "self-manage" sleep, mood, exercise and other behaviors to further reduce the risk of seizures and increase quality of life (QoL) [2].

Epilepsy self-management refers to a range of practices for addressing the impact of seizures on daily life. These practices are recommended as a part of treatment and typically include: 1) taking seizure control medications [13], 2) informing health care providers by documenting seizures and their contributing behaviors [14], [15] such as sleep [16], [17], and exercise [18], [19], and 3) learning to self-regulate behaviors for managing symptoms [3]. The current standard of care is for patients and caregivers to maintain a "seizure diary" for logging the date, time and a description of seizure events. In addition, patients and caregivers are often asked to observe and document a wide range

of additional health-related events and behaviors between appointments such as seizure counts, sleep duration, physical activity, stressful events and life changes, alcohol use, food intake, menstruation-cycles and medication adherence [20], [21].

In practice, patients and caregivers struggle with the data collection aspects of these epilepsy self-management practices for a range of reasons. Lifestyle changes such as sleep and stress can be difficult to implement due to pressures of work and school.

Many patients see these tasks as a daily burden [22]. Social stigma [23] can discourage patients from taking medications while at school. Night time seizure reporting can present particular challenges. Most patients are unable to report seizures during sleep (>85%) and 32% of the patients fail to report seizures while awake [24]. Memory and cognitive impairments are also prevalent among patients with epilepsy [25]–[27]. Patients may be unconscious and unable to recall details during or following seizure events [28].

Similarly, many caregivers also struggle with patient data collection. Studies have shown that caregivers often disagree on important seizure characteristics [29]. Logistics and record keeping [30] issues such as collecting seizure reports from school can be difficult for caregivers to keep up with. Caregivers may not be awake to report patient seizures at night [31]. In practice, families at CHOA and Emory tend to discontinue seizure diaries shortly after diagnosis (0.5 - 2 months).

Health tracking devices (or tools/technologies) stand to support data collection but currently provide mixed performance relative to patient-self-reporting. For example, Fitbit exercise and sleep reports have been shown to agree well with patient self-reports of these behaviors [32] while the SmartWatch and similar seizure detection devices tend

to over-report seizure events when compared with patient and clinical observations [33].

These daily self-reporting and self-management barriers present two sets of problems. First, patients with poor self-management skills also tend to have poor seizure control. Living with poorly controlled seizures can be highly stressful for patients and caregivers [34]. High rates of seizures are shown to be associated with greater unemployment [35], depression [35], [36], cognitive decline [37] and increased mortality rates [38]. Second, inaccurate or incomplete self-reporting can negatively impact treatment. Newly diagnosed patients try an average of two AEDs before finding one that is both effective and tolerable [39] (ideally the goal is for patients to be on as few medications as possible to control seizures). This AED search can take 6-12 months [40] during which time patients often experience debilitating medication side-effects. Neurologists at CHOA typically see patients every 6 weeks while adjusting medications, and every 6 months after an effective medication is found. Medication dosages may require further adjustment over the course of treatment to remain effective. In turn, poor self-reporting can prolong the AED search process, resulting in patients being exposed to medication side-effects for longer than necessary, and similarly increase the difficulty of making medication adjustments, resulting in patients continuing to have seizures that may otherwise be addressed with a change in dosage or treatment.

Everyday computing and mobile and wearable technologies stand to help address these self-management challenges but solutions in this area are not well explored. Electroencephalogram (EEG) and video (vEEG) equipment are currently used to provide clinicians with accurate seizure reporting during 2-5 day hospital visits, but these tools

require patients to wear EEG electrodes on the scalp at all times, restrict patient movement and require input from trained technicians to interpret results [41]. EEG electrodes can be connected to patient-worn ambulatory EEG (AEEG) recording computers for extended monitoring outside of the clinic; however, these systems present a host of problems such as noisy or missing EEG readings due to loose electrode connections and often do not include video cameras for observing important clinical seizure symptoms. Non-EEG seizure detection devices have been proposed [33]; however, these devices tend to report high numbers of false alarms and are subsequently less useful for supporting clinical decision making [42]. Health Insurance Portability and Accountability Act (HIPPA) compliant data collection services are expensive and have limited flexibility for research studies. Health tracking technologies for fitness and activity tracking have not yet been adapted to reflect patient behavioral factors that impact seizure likelihood such as sleep and exercise. Meanwhile, prospective technology developers currently lack basic design guidelines for specifying patient data collection and self-management requirements [43]. It is, therefore, important for researchers to investigate new mobile and health tracking approaches for addressing current shortcomings and providing patients and caregivers with more effective and convenient data capture, access, summarization, and interpretation.

My research has responded to these needs by first establishing patient, caregiver and clinical data collection needs and then developing and evaluating new mobile and wearable data collection tools to answer unexplored HCI and health informatics research questions. In contrast to a more traditional, siloed research agenda such as signal analysis for seizure detection [44], my goal was to understand and address broader social and

technical challenges that arise when mobile and wearable data collection tools are introduced into a patient's everyday environments.

*2.1.2 Supporting adolescent patients*

My studies share a common focus on investigating and supporting family self-reporting within the context of pediatric self-management. In contrast to previous researchers, my studies focus on three needs that are critical to consider when designing for pediatric patients but have received less attention when designing for adults:

1. **Self-regulating patient behaviors** - Notable risks associated with poor self-management include poor seizure control that can lead to serious seizure-related injuries [45] and death [46], [47] negative personal and family financial repercussions [7], [48] and embarrassing social consequences such as incontinence in public [49]. In addition, having epilepsy is known to reduce the Quality of Life (QOL) [49] for both patients and caregivers [34], [50]. Many patients and caregivers already maintain seizure diaries that document seizures, sleep [16], exercise [18] and other behavioral factors with the goal of adopting behaviors that reduce the likelihood of seizures. It is important to better understand these needs and investigate the extent that technologies can encourage reviewing behaviors and staying within recommended behavior guidelines on a daily basis.

2. **Self-reporting during treatment** - Neurologists rely almost exclusively on patient self-reporting to adjust medications during treatment [33]; however, patients and caregivers rarely keep detailed records. This issue is especially problematic within epilepsy as roughly half of all newly diagnosed patients with epilepsy (53% of

patients) require trying one or more AEDs before finding one that can control

seizures [39]. The process of finding an effective drug can take months or even years,

during which time patients often experience debilitating side effects. It is, therefore,

important to understand clinical information needs from the perspective of data

quality requirements and to investigate ways that technologies can help collect health

data that is meaningful for informing clinical treatment [51].

3. **Increasing self-reliance for adult care** - Many adolescent patients with epilepsy fail

   to achieve a smooth transition between pediatric and adult self-care with higher than

   usual numbers of seizure events and missed appointments [52]. Help and support

   from caregivers such as reminders to take medication and regulate behaviors such as

   sleep and exercise may become increasingly impractical as adolescents become more

   independent. Moreover, adolescent patients are often faced with additional peer

   pressure to engage in drinking, drugs and other behaviors that can contribute to

   increasing the likelihood of having seizures during this time [29]. It is, therefore,

   important to investigate the extent that technologies can help to engage pediatric

   patients in preparation for leaving home for college, and eventually adult self-care. In

   addition, such tools stand to further ease this transition by including caregivers in this

   process as needed until patients are able to master self-management skills.

I, therefore, argue that there is a strong need for further research aimed at addressing

underexplored gaps within this body of literature. My studies have addressed aspects of

these shortcomings throughout.

**2.2 Collaborators**

The research study team included collaborators from Georgia Tech, Emory University, CHOA and Empatica Inc. Dr. Beth Mynatt and I developed a range of mobile apps and tools at Georgia Tech. Dr. Cam Escoffery played a leadership role throughout and guided the use of survey instruments at Emory's Rollins School of Public Health. Dr. Sookyong Koh and Kristen Hass helped to recruit families and provided epilepsy-related subject matter expertise at CHOA. Dr. Rosalind Picard and Daniel Bender provided E4 wristbands as industry partners at Empatica Inc. Finally, Dr. Sandra was an early champion of our research. She helped us to secure funding and introduced us to staff working at the Emory University Hospital and CHOA epilepsy monitoring units.

# CHAPTER 3.    RELATED WORK

This chapter presents related work within mobile and wearable self-reporting tools and how this work has informed my research and study designs.

## 3.1 Data collection needs

Important health data are often unavailable to clinicians during treatment. In practice, while patient and caregiver collected data is essential for informing epilepsy self-management, specific aspects of these data collection needs remain poorly understood within the literature.

1. It is important to understand patient and caregiver data collection needs with respect to self-management,

2. It is also important to understand clinicians needs for informing treatment and then finally,

3. It is important to communicate these needs to prospective technology developers to aid in the design of self-management health-tracking tools.

*3.1.1 Establishing patient and caregiver data collection needs* - Epilepsy impacts every patient differently. It is common for clinicians to ask a range of questions during appointments. Interviews with families and clinicians at CHOA suggest that caregivers generally collect data by hand and maintain records in an ad-hoc manner (e.g. notepads and calendars). In an ideal case, this information helps families to learn patient symptoms and develop self-management practices; however, in practice patients and caregivers

provide either too much or too little information during clinical visits. There are no current standards for seizure reporting and no guidelines regarding data that patients find useful during the transition from pediatric to adult self-care. It would, therefore, be beneficial to investigate patient and caregiver data collection needs.

*3.1.2 Establishing clinical data collection needs* - Neurologists need patients and caregivers to provide consistent and accurate self-reports for adjusting medications; however, these needs are not well defined in the literature. For example, a patient with poor sleep and a stressful week at school may have seizures regardless of medication. It is important to have accurate data in this case as a clinician must be able to distinguish between the effectiveness of medications for controlling seizures and poorly managed health behaviors. Furthermore, the relationship between clinical data collection needs and current self-reporting capabilities remains poorly understood. It is only recently that researchers have begun to survey clinicians for establishing a consensus regarding these needs[33], [42], [53].

Paper and pencil seizure reporting templates have been published by non-governmental organizations (NGOs) such as American Epilepsy Society (AES) [54]. However, while these resources are reportedly popular among clinicians, the forms do not document sleep [16], exercise [18], stress [55] and other behaviors that are known to impact seizure likelihood from the literature [20]. Haut et al. [20] performed a paper seizure diary study among adult patients and identified behaviors that could predict seizures; however, these behaviors were not verified and no similar paper-based studies have occurred since then.

Mobile and electronic seizure reporting studies have included a more exhaustive set of

reporting fields but tend to focus on patient responses as opposed to the attainment of specific clinical information needs [30], [43]. Le et al. [56] evaluated smartphone-based seizure diaries for documenting seizure events and reporting daily health information apps among both pediatric and adult patients with epilepsy [57], [58]; however, no clinical feedback was solicited, and no clinical implications were discussed. It would, therefore, be beneficial to investigate clinical data collection needs.

*3.1.3. Establishing data collection needs for guiding technology developers* - Technology developers would benefit from guidance regarding how these platforms can address daily epilepsy-specific data collection needs among pediatric patients. Mobile and wearable devices have also been proposed for seizure detection [33], patient sleep, exercise, stress and medication intake data; however, limited research is available regarding the extent to which these technologies address clinical data collection needs (e.g. context-sensitive notifications). For example, Cramer et al. [59] employed a "smart" pill bottle to evaluate medication adherence among adult patients with epilepsy, but the study did not include pediatric patients. Whitney et al. [60] successfully employed pedometers among pediatric patients with epilepsy for investigating the relationship between physical activity and QOL, but the study was limited to one week [61], [62]. Interesting systems have also been proposed but not implemented. Fisher et al. [30] proposed using "biosensors" to reduce the burden of completing seizure diary entries. No studies to date have followed up on these concepts. In other cases, research is based on outdated platforms or interactions such as mobile EMA using PDAs [63]. Moreover, manual seizure diary entries and automated seizure detection systems have traditionally been evaluated separately. There is an increasing need to investigate both approaches together for

supporting data collection. It would, therefore, be helpful to investigate the applicability of existing mobile and wearable device methods to inform technology developers.

In studies, #1, #3 and #5, I surveyed patients, caregivers, and clinicians to establish data collection needs with respect to mobile and wearable self-reporting tools. My technology review in study #1 evaluated a broad range of inertial, video and multimodal seizure detection devices [33] with the aim of specifically addressing clinical data collection needs. In addition, in study #5, I expanded this scope to further investigate patient and caregiver data collection needs for guiding future technology development.

## 3.2 Data collection quality

Even when health data is available, it is often unreliable. Health reporting is an integral part of successful epilepsy self-management but requires consistency and reliability. Incomplete, inaccurate or poorly documented reports are common due to difficulties with collecting, reporting and interpreting this information.

Mobile and wearable technologies serve to help patients and caregivers report more consistent, prompt and reliable data for clinical decision making, yet the daily use of these tools remains underexplored and evidence suggests that maintaining data collection practices over time can be difficult [64]. This presents three challenges with respect to data quality:

1. It is important to understand the consistency, promptness, and reliability of patient and caregiver reported data for identifying how to best support clinical treatment,

2. It is similarly important to understand the current performance of mobile and

wearable devices beforehand as a starting point for making improvements, and finally,

3. It is important to understand clinical data quality requirements for establishing how to best utilize input from patients and technologies.

The following sections discuss each of these challenges in more detail:

*3.2.1 Improving data quality among patients and caregivers* - The state of patient and caregiver data quality is currently not well understood. The consistency, promptness, reliability and social stigma associated with data collection can each impact the quality of data that clinicians receive during treatment, yet these issues have largely been ignored within the literature [30]. Most patients are unable to report seizures at night due to cognitive impairment [24]; similarly, caregivers are often less able to observe patient seizures while sleeping at night. New onset epilepsy patients and caregivers typically report detailed health information during the first few months of treatment, yet they gradually collect less and less detailed information over time. Meanwhile, social stigma may contribute to further issues while at school such as foregoing medications or not documenting medication intake. Mainstream health tracking devices such as Fitbit [65] products are not specifically designed to report consistency, promptness, and reliability of self-regulatory behaviors that can impact seizure likelihood such as insufficient sleep. These issues present a host of challenges as incomplete or inaccurate self-reports can mask important changes such as "breakthrough" seizures [66] or seizure triggers during treatment. It is, therefore, important to establish patient and caregivers self-reporting

capabilities as a first step for improving data quality.

*3.2.2 Improving mobile and wearable data quality* - Mobile and wearable technologies stand to greatly improve data quality during treatment [67]. So far, few studies have quantified these performance requirements. Additionally, there can be considerable performance variation between devices. Health tracking devices such as the Fitbit pedometer have been shown to perform well when compared against clinically validated medical instruments [32], [68]; however, seizure detection devices continue to exhibit considerable performance variation [33]. FDA approval can be expensive and time-consuming. Further, a majority of commercial products are not evaluated in clinical settings. My technology review highlighted considerable variability with respect to data quality [33]. For example, Beniczky et al. [69] and Lockman et al. [70] each evaluated similar inertial sensing wristbands; however, Beniczky reported 0.2 false alarms per 24 hours with the Epi-Care Free [69] while Lockman reported 204 false alarms per 24 hours with the Smartwatch [70]. It is, therefore, important to conduct similar studies for establishing the extent to which mobile and wearable devices can improve data quality.

*3.2.3 Improving clinical data quality* - Even as the quality of data from wearable devices can be improved, the data itself needs to align with clinical requirements during epilepsy treatment and patient self-care.

 Importantly, there are currently no standards with respect to self-reporting; clinical data quality requirements are not well explored within the context of designing mobile and wearable technologies for supporting epilepsy treatment. In the past, considerable research has focused on seizure detection [69], [70] with less emphasis on the required

quality, feasibility, and interpretation of self-reported data [42]. There is evidence to suggest that additional components such as context-sensitive notifications [71], goal setting [2] and incentives [72], [73] could stand to further improve data quality; but few studies have investigated these approaches among adolescent pediatric patients with epilepsy. It is, therefore, important to establish clinical data quality requirements in order to align current patient and caregiver, and technology capabilities for improving data quality during treatment.

In studies, #2, #4 and #5, I investigated data collection quality with respect to patient and clinical data collection needs, and evaluated the performance of a recent commercial seizure detection wristband [74] that may be applicable for long-term patient use outside the clinic, and addressed current gaps in the literature by focusing on pediatric patient populations. In study #5, I further investigated the impact of mobile and wearable technologies, context-sensitive notifications and the impact of motivational strategies on the quality of patient and caregiver collected data (i.e, consistency, promptness, and reliability between patient and caregiver collected responses).

## 3.3 Data collection evaluation

Even when health data is captured well, benefits to self-management outcomes are rarely quantified. Mobile and wearable tools need to be designed for daily use. Daily routines and habits can be difficult to change. Health tracking and fitness devices are frequently abandoned within the first few months of use [75] with estimates as high as one-third of devices being abandoned after the first month [76]. It is, therefore, important to investigate the practical implications of mobile and wearable data collection and self-

management tools within the context of daily routines.

These practical issues present the following three challenges for data evaluation:

1. It is important to evaluate tools in terms of daily patient and caregiver context of use,

2. It is also important to evaluate tools in terms of social acceptability, and finally,

3. It is important to evaluate tools in terms of health metrics that are associated with effective patient self-management.

*3.3.1 Evaluating daily context of use* - Mobile and wearable data collection tools should be practical for patients and caregivers to use on a daily basis yet the relationship between the consistency, promptness, and reliability of self-reporting responses remains poorly understood. Electronic seizure diary studies have reported response rates [30], [63]; however, these studies have yet to examine self-reporting with respect to other types of tools (e.g. counters and seizure detection devices). The context of these interactions has not been explored in detail. Haut et al. [63] collected the time of each self-report but did not include any additional contextual information that may be able to help account for possible social influences (e.g. geographic location or caregiver proximity). In some cases, patients may experience different levels of self-reporting burden depending on time and place during the day. It may be crucial to consider the context of use for frequent and consistent utilization.

*3.3.2. Evaluating social acceptability* - The social acceptability and context of mobile and wearable tools must also be considered and are poorly understood among adolescent patients. Benson et. al. [23] studied the social impact of epilepsy among adolescents and

highlighted a strong desire to conceal epilepsy from others. Borus. et al. [77] found that while adolescent patients aged 15-24 benefited from Continuous Glucose Monitoring (CGM), patients in this age group had poor adherence compared to adults. "30% of adolescent patients used the technology for 6 or more days per week compared with 86% of patients older than 25 years and 50% of patients aged 8-14 years" [77]. It may, therefore, be important to investigate social stigma surrounding pediatric self-reporting tools to encourage adoption.

*3.3.3. Evaluating patient health metrics* - Finally, data collection tools must be evaluated in terms of health outcomes that are important for pediatric patients with epilepsy. To do this, I evaluated a subset of questions from the Self-Efficacy for Managing Chronic Disease 6-item Scale (SEM-CD) [78] and Patient Activation Measure (PAM) [79] as indicators that have been linked with effective pediatric self-management [2]. Increased AESMMI and PAM scores have been linked with improved self-management outcomes [1]. In addition, practices that help in reflecting on and documenting health behaviors are important skills for adult self-care. It is therefore important to evaluate measures that relate to these skills and have been linked with successful patient self-management.

In study #5, I evaluated the following: 1) context of use with respect to mobile phone location and patient and caregiver proximity when using a mobile application for anticipating convenient times and places to issue notifications to complete daily self-management practices, 2) social acceptability of using intake and exit surveys, and finally, 3) changes in  patient engagement between intake and exit.

**3.4 The state of epilepsy-specific self-reporting**

The research community has been slow to investigate the potential benefits of mobile and wearable computing tools within epilepsy self-management for three reasons:

*3.4.1. Health tracking and self-reporting performance requirements are often unspecified.* Health tracking devices are typically not validated against clinical instruments. Likewise, self-reporting requirements are typically not described in terms of specifications for health tracking technologies. In this case, the goal is to find a middle ground. Health tracking devices may be more than sufficient for answering certain types of questions. In addition, galvanic skin response (GSR) and heart rate variability (HRV) sensing is becoming increasingly available among wearable fitness devices such as the Fitbit Charge 2 [65] and may be useful for helping patients to recall behaviors or reflect on stressors over time. It is, therefore, important to establish performance and self-reporting requirements for determining appropriate devices and applications to study.

*3.4.2. Seizure diary apps do not incorporate data from health tracking devices.*

Existing seizure diary systems do not receive data from health tracking devices. Scheherazade et al. [56] studied smartphone seizure diary usage among 1,944 adolescent and adult patients with epilepsy. The app asked users to document seizure events, sleep, mood, side effects, medication intake along with additional information such as uploaded photos and video and reporting menstrual cycles in the case of female users. Many of these health indicators can now be collected automatically using wearable health tracking devices instead of being entered by hand. In addition, the native Android and iOS mobile operating systems have each introduced "health" services for simplifying the storage and

access of health-related data from a range of health tracking devices. These challenges present immediate opportunities for reducing the current data entry burden of mobile seizure diary apps and enabling patients to more easily reflect on data collected from existing health tracking devices.

*3.4.3. Long-term adoption of such devices necessitates that patients and caregivers find data collection devices to be useful.*

The literature highlights a critical need for understanding and shaping patient and caregiver data collection needs. This need is especially true among pediatric patients. Haut et al. [63] evaluated twice daily mobile phone surveys among adult patients with epilepsy. The survey completion rates were excellent with patients completing diaries for a median of 112 days [63]. No such studies have compared responses with automated seizure reporting or been conducted with pediatric patients, and similarly, no such studies have investigated the use of self-reporting tools that utilize input from wearable health tracking devices beyond the clinic. Furthermore, no studies have directly compared the reliability of seizure diary reporting between patients and an external collector such as a caregiver. More work is warranted in order to understand patient and caregiver needs, and establish the extent that these approaches may be applicable among pediatric patients.

If successful, these approaches could reduce self-reporting overhead by enabling passive health tracking devices to answer questions that patients and caregivers would otherwise have to enter by hand (e.g. "Did you get more than 8 hours of sleep last night?") or by helping patients to reflect on past behaviors when answering questions (e.g. seizure diary

apps include questions on emotional state).

## 3.4 Research Traditions & Methods

### 3.4.1 Everyday computing perspective

My research is inspired by perspectives from everyday computing. Everyday computing considers computing challenges that scale across time, space and stakeholders [80]. It can be hard to change people's daily routines. In this case, supporting patient and caregiver self-management requires designing not only for specific moments but also between appointments. This perspective can help us to preemptively consider problems.

My mobile Ecological Momentary Assessment (EMA) studies draw on these perspectives both in terms of being conducted "in the field" and also scaling data collection needs, interactions and outcomes over time, place and between multiple stakeholders.

1. **Scaling across time** - Interruption is a fact of life. More than "walk up and use". Future data collection tools need to support data collection that takes place over time and takes into account frequent interruptions and the patients' social and environmental context when reminding them to complete specific tasks. Impaired cognition can make it difficult for some patients to promptly report seizures. In study #5, I attempted to make maintaining data entry as effortless as possible by sending reminders that attempt to anticipate patient self-reporting delays based on patient input during an intake survey and ensuring that patients and caregivers can resume partially completed surveys for anticipating interruptions.

2. **Scaling across context** - Mobile app

reminder notifications need to be delivered at the right time and place throughout the day. In study #5, I integrated contextual information to infer when patients are busy at school and used geospatial and wireless proximity information to prompt interactions between patients and caregivers. In this work, I further attempted to prioritize app notifications during the most effective times and places for encouraging consistent, prompt and reliable self-reporting along with wearable device adherence.

> **3.** **Scaling between stakeholders** - Mobile apps need to support input from multiple stakeholders. For example, caregiver observations are often required for reporting nighttime seizures, and pediatric patients often require assistance with remembering to take medications until developing these skills on their own. Most self-management tools are designed for a single adult user [64]. Epilepsy self-management extends beyond the patient. In study #5, I designed a mobile app around the need for joint patient and caregiver data collection, data access and self-reflection.

My goal has been to apply these Everyday Computing perspectives to help provide an even greater contribution to the HCI and health communities, offering contemporary mobile and wearable design implications that account for the fluid and "messy" nature of daily computing interactions.

*3.4.2 Ecological Momentary Assessment (EMA)*

My studies are also inspired by Ecological Momentary Assessment (EMA) as a study design method from behavioral science and HCI fields.

"Ecological momentary assessment (EMA) refers to a collection of methods often used in behavioral medicine research by which a research participant repeatedly reports on symptoms, affect, behavior, and cognition close in time to experience and in the 'participants', 'natural environment' [81]. This broad definition describes surveys that are administered within a patient's natural "environment" during specific times [82], [83] as opposed to before or during a clinical appointment. These survey assessments are typically administered on either a schedule of pre-scheduled or randomized events such as with "beeper" and "experience sampling" studies [84] from HCI or triggered based on based on behavioral events such as an increased heart rate [85].

Notable benefits of EMA over traditional surveys include responses that are collected in the "real-life context of the environment" [86] (i.e. ecological validity) and with reduced recall bias. In general, the more responses generalize to everyday settings the better in terms of collecting accurate health data (i.e. ecological validity); meanwhile, the more recent the event the fewer participants were influenced by problems such as imperfect memory [87]. This approach offers convenience to researchers and respondents alike as mobile phone survey websites can be used to create surveys that can be completed from anywhere; native smartphone applications are also available for offering additional convenience and native reminder notifications [67]. In the case of epilepsy treatment, neurologists rely greatly on access to accurate patient and caregiver feedback for adjusting medications.

Notable drawbacks include both validating responses and random sampling at inopportune times. For example, in an ideal situation, researchers and clinicians would be

able to observe a patient in his or her natural environment without influencing his behavior. In practice, researchers may not be able to observe patients in person and therefore be unable to account for the reasons behind notable behaviour changes over time (i.e, stress levels throughout the course of a day). Moreover, the "mode of questionnaire administration can have serious effects on data quality" [88]. For example, "events important to the researcher may be missed". "If someone is socially anxious and has only a few social interactions in a day, all these events may be missed if signals do not co-occur during the times of the social interactions. Important events can be defined to instigate their recording" [89].

Mobile EMA is increasingly recognized as a viable and preferred approach over paper and audio based methods for assessing patient health changes between appointments [86], [87]. Health surveys are often completed in waiting rooms for this type of data, however being in a clinical setting and recalling details from the last visit is known to impact the quality of responses (i.e, recall bias) [87]. Many respondents feel anxious (i.e. white coat hypertension [90] or put on the spot or rushed with a doctor present (i.e. Hawthorne effect or observer effect [91]). Meanwhile, biographical memory limitations can make accurate recall difficult or impossible since the last visit. EMA instruments can provide a more accurate picture of patient behaviors by administering surveys in the patients' natural environment over multiple sessions, rather than a single sitting, and additionally recorded to account for backfilled responses. Lastly, mobile EMA studies have a long history and have been successfully used for collecting data among adult patients with epilepsy [64] and pediatric patients with chronic conditions. Internet-enabled smartphones and the advent of apps such as LifeData [92] and RedCap [93] have

simplified EMA survey deployment in recent years.

My work in study #5 utilized a mobile EMA app. In addition, to administering patient and caregiver surveys my EMA app collected patient and caregiver contextual data such as location and patient-caregiver proximity as additional information for anticipating response validity throughout the day [32] (e.g. enabling survey reminders to be sent when a patient is at home rather than at school).

# CHAPTER 4.    RESEARCH NARRATIVE

## 4.1 Thesis statement, Research Questions, and Contributions

In this thesis, I present the design, development, and evaluation of mobile and wearable pediatric epilepsy self-management tools and interventions for supporting patients, caregivers, and clinicians. My thesis statement is as follows:

**Epilepsy self-management can be improved through the introduction of mobile and wearable interventions that enable adolescent patients and family members to collect the types and characteristics of data that clinicians need during epilepsy diagnosis and treatment, respectively, and also increase patient engagement as an indicator of successful, future self-management in preparation for adult self-care.**

My initial research aided in clarifying clinical data collection needs as well as the feasibility and impact of mobile and wearable data collection interventions on patient self-reporting and self-efficacy. In the process, I identified an urgent need to better support patient and caregiver self-reporting and self-management along with notable strengths and shortcomings of current data collection tools. I then investigated several new mobile and wearable technology interventions aimed at helping patients and caregivers to collect a broader set of health information during treatment. Table 1 describes the relationship between my studies and research questions for reference.

# Table 1 - Research results and study-specific research questions

| Research Results | Study # | Questions |
|---|---|---|
| **1    Establish data collection needs** | | |
| What are patient, caregiver and clinician data collection needs during treatment, and how do these needs translate into mobile and wearable design specifications? | 1 | What data do clinicians need vs. what can technology provide now as a starting point? |
| | 3 | What data do clinicians need vs. what patients can provide now as a starting point? consistency, promptness, and agreement? |
| | 5 | How do patient/caregiver attitudes towards clinical data collection needs compare before and after using mobile/wearable tools? |
| **2    Improve data collection quality** | | |
| How consistently and promptly can current patients/caregivers and mobile/wearable tools collect clinically relevant health data, and to what extent can tools be extended to improve data quality? | 2 | To what extent can a seizure detection wristband improve the quality of "seizure count" data as compared with self-report? |
| | 4 | To what extent can a patient/caregiver video review of wearable detected seizure events further improve the quality of "seizure count" data as compared with self-report? |
| | 5 | How can mobile phone surveys help patients and caregivers to more 1) consistently and 2) promptly collect clinically relevant health data as a part of daily self-management practices? |
| | 5 | To what extent are patients and caregivers able to consistently, promptly and reliably complete daily mobile phone surveys with questions on seizures, sleep, exercise, medication adherence, and stress? |
| | 5 | To what extent can the additional use of health tracking devices and subsequent access to health tracking data improve patient/caregiver promptness and reliability? |
| | 5 | How does data collected from active patient/caregiver surveys compare with the same type of data collected using passive health trackers? |
| | 5 | How can goal setting, point-based rewards and context information from mobile and wearable devices complement mobile phone surveys to help patients and caregivers to document self-management behaviors and complete these behaviors on a daily basis? |
| **3    Evaluate patient self-efficacy scores** | | |
| How can mobile and wearable technologies improve patient self-efficacy as a starting point for designing effective data collection approaches and strategies? | 5 | How effective are mobile surveys for increasing patient health scores as proxies for successful health outcomes: patient self-efficacy and activation? |
| | 5 | To what extent can mobile phone surveys and a clinical audience improve patient self-efficacy? |
| | 5 | To what extent can health tracking hardware and access to data summaries improve patient self-efficacy? |
| | 5 | What are the impacts of an additional mobile survey goal setting and extrinsic rewards condition on patient self-efficacy? |

The remainder of this section will describe the progression of my research and findings in more detail.

### 4.1.1 Establish data collection needs

My first set of research questions reflect the importance of establishing data collection needs and the extent that these needs are being met by current technologies and current patient/caregiver data collection efforts.

To address these research questions, in studies #1 and #3, I performed a literature review and surveyed practicing clinicians to establish a deeper understanding of clinical needs. These studies investigated the current state of clinical data collection needs with respect to the current state of mobile and wearable data collection devices and the current state of patient and caregiver data collection capabilities.

Next, I sought to understand mobile and wearable computing needs from the perspective of patients and caregivers. My final study (#5) sought to clarify these needs by similarly administering intake/exit surveys to establish patient and caregiver attitudes and beliefs towards data collection while using a range of different mobile and wearable devices: smartphones, smartwatches, fitness trackers and proximity tags.

### 4.1.2 Improve data collection quality

My second research question reflects the need to investigate mobile and wearable tools methods and approaches aimed at improving data quality for supporting these needs.

To address this research question, I first performed a technology review in study #1. The results established the performance of current seizure detection technologies as a starting

point for understanding and assessing clinical data quality requirements. Next, I established a research collaboration with a company called Empatica Inc. My research with the company in study #3 evaluated the performance of E4 seizure detection wristbands. The results showed that while the wristbands did provide seizure counts that were more accurate than unassisted patient self-reports from past studies, more work would be needed as devices over reported seizures.

In study #4, I investigated using a video review as a possible approach for addressing this issue of data collection quality. The patients and caregivers were asked to review and annotate video footage of wristband-detected events. To date, we've seen near perfect agreement between patients/caregiver and electroencephalogram technicians. The initial results show that most patients and caregivers can indeed identify and reject video clips that do not contain seizure events and that correctly dismissing these false alarms can improve the overall quality of reported seizure counts.

Then, in study #5, I evaluated the feasibility of patient and caregiver mobile and wearable platforms for increasing the consistency and promptness of traditional paper-based seizure diary entries. In addition, I investigated the extent that patients and caregivers can consistently and promptly collect health data using a range of mobile and wearable devices: smartphones, proximity tags and health tracking devices.

*4.1.3 Evaluate patient self-efficacy and patient activation scores*

Finally, my third research question reflects the need to evaluate relevant clinical patient health outcome impacts of these mobile and wearable data collection tools. In studies #5, I included three self-efficacy questions from the Self-Efficacy for Managing Chronic

Disease 6-item Scale (SEM-CD) [78] and the full, thirteen-item Patient Activation

Measure (PAM) [79] as instruments linked with successful patient self-management.

Intake and exit SEM-CD and PAM questions were administered to evaluate the "degree

of confidence that individuals have in their ability to perform tasks within medication

taking, seizure control, and general epilepsy management" [1].

# CHAPTER 5. RESEARCH CONTRIBUTIONS

My research has made a positive impact on both the lives of patients, caregivers and clinicians, and to the fields of HCI and health informatics by contributing to the design and development of epilepsy self-management tools.

In the past, few studies had investigated self-reporting data collection needs among epilepsy clinicians [23]. Important considerations such as data collection consistency, promptness, and reliability were poorly understood prior to our research [31].

My contributions included 1) developing and evaluating new mobile and wearable data collection approaches, 2) providing design implications to guide the future development of mobile and wearable technologies, and 3) inform in the state of personal data captured outside of the clinic to support patient outreach pediatric transition to adult self-care.

Table 2 highlights the relationship between my research studies and objectives.

**Table 2 - Research studies and objectives**

| Studies | 1. Establish data collection needs | 2. Improve data collection quality | 3. Evaluate patient self-efficacy and activation scores |
|---|:---:|:---:|:---:|
| #1 Epilepsy technology needs review | ✓ | | |
| #2 Neurocognitive self-reporting needs | ✓ | | |
| #3 Seizure detection wristband evaluation | | ✓ | |
| #4 Rejection of non-seizures from retrospective video of wristband events | | ✓ | |
| #5 Mobile/wearable data collection surveys | ✓ | ✓ | ✓ |

# CHAPTER 6.    RESEARCH STUDIES

## 6.1 Study #1 - Epilepsy technology needs review

My first study established clinical data collection needs from a clinician and technology perspective by asking the question "What data do clinicians need vs. what can technology provide now as a starting point?" [33]).

*6.1.2 Summary*

| Published - Seizures, '15 |
| --- |
| Bidwell, Jonathan, et al. "Seizure reporting technologies for epilepsy treatment: A review of clinical information needs and supporting technologies." Seizure-European Journal of Epilepsy 32 (2015): 109-117. |

Epilepsy diagnosis and treatment currently relies on patients and caregivers to collect health data for informing clinical decision making. However, patient and caregiver self-reports are often either inconsistent, incomplete or unavailable. Many patients and caregivers struggle to collect the data that clinicians need. In turn, limited or inaccurate self-reports can result in misdiagnosis, untreated seizures and prolonged exposure to medication side-effects required before finding an effective AED.

Mobile and wearable technologies stand to help address this challenge by helping patients and families to collect more consistent and reliable data, but clinical requirements for developing these tools are all but unknown. The purpose of this study was to establish design recommendations for mobile and wearable technologies as they relate to aiding clinical decision-making. I conducted interviews, a literature review, and a survey to

investigate clinical information needs during diagnosis and treatment. I then focused on these clinical needs during my subsequent research.

The main contribution of this work is identifying a gap between reported sensing capabilities and the performance metrics that are needed for addressing clinical information needs. In the past, literature did not present consistent, standardized metrics for making performance comparisons between seizure detection devices and patients' self-reporting capabilities. My review included a meta-analysis where I derived translated published performance in terms of F-score to compare performance between seizure detection devices and current patient self-report.

My findings highlighted a strong need for helping patients and caregivers to collect more accurate seizure counts and further for helping to collect video to assist clinicians in distinguishing between generalized and focal patient seizure types. I also identified several shortcomings and future opportunities for designing mobile and wearable tools for supporting patients and caregivers data collection during epilepsy treatment.

*6.1.3 Related work*

Literature reviews from Pediaditis et al. [94] and Van de Vel et al. [95] provide a comprehensive overview of seizure detection technologies but do not investigate clinical information needs or comment on additional self-reporting technology opportunities beyond seizure detection. Moreover, the authors did not use a uniform set of statistics when reporting performance results. It was, therefore, difficult to make performance comparisons between systems. Finally, the studies were completed several years prior to 2012 and 2013, and the reviews did not include more recent devices.

*6.1.4 Method*

The study had three main phases: The first phase of the study included interviews and surveys. We interviewed and surveyed 11 practicing neurologists and established a consensus that seizure counts, as opposed to seizure duration or intensity, were the most important clinical data type.

The second phase of the study was a comprehensive technology review. The review included a broad range of existing research and commercial seizure detection devices but intentionally excluded EEG-based devices that are typically considered impractical for use at home.

The third phase was to compare seizure detection performance to current patient self-reporting. We reviewed the literature on patient self-reporting and selected studies that compared patient reports against the same type of video/EEG observations that were used for evaluating the seizure detection devices. We extrapolated F-scores values for each seizure detection device and patient self-reporting study and compared performance across different types of devices and different modalities as shown in Figure 1.
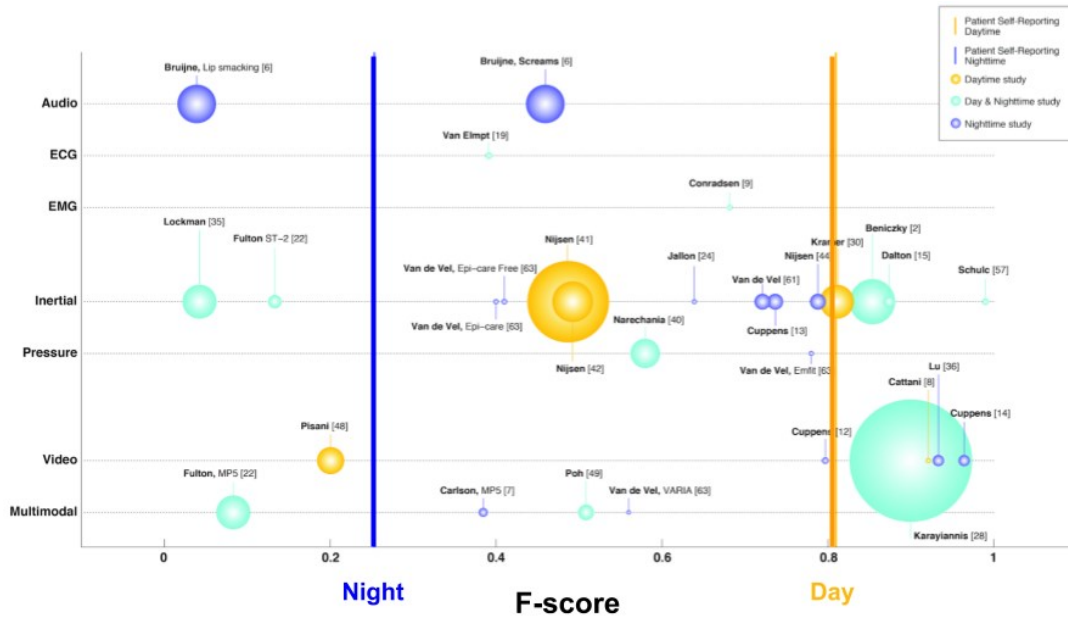
**Figure 1 - Technology review seizure reporting performance comparison - Multiple types of non-EEG seizure detection systems are compared against patient self-reporting on a continuous F-score scale from 0.0 to 1.0, read left to right, where 0.0 is worst and 1.0 is shows the best performance (Please see Appendix A for a full page copy of the figure).**

*6.1.5 Results*

In our questionnaire, 100% of neurologists reported that seizure count was the "most important" information that patients and caregivers could provide them during treatment; similarly, 100% of neurologists indicated they would like to have a video of patients prior to selecting an AED during an initial consultation. This information is particularly important for enabling neurologists to select the correct class of AED for patients during diagnosis and then subsequently for evaluating the efficacy of the AED during treatment.

In our technology review, I further identified that only a subset of available technologies surpassed patient self-reporting performance due to high false positive rates. We observed that inertial seizure detection devices coupled with video capture for recording

36

seizures at night could stand to address collecting seizure counts that are more accurate than current patient self-reporting during day and night time use.

Figure 1 presents an F1-score performance for each type of system alongside patient day and night time reporting for comparison. F1-score is a continuous scale from 0.0 to 1.0 and can be read left to right, where 0.0 is worst and 1.0 is the best performance. Each seizure detection system is represented as a circle for given class technology. The circle color indicates the time of day that the system was evaluated and diameter represents the relative number of patients that had at least one seizure during each study. Self-reporting performance is shown using vertical lines where the leftmost line (blue) indicates nighttime performance and the rightmost line (orange) indicates daytime performance.

*6.1.6 Discussion*

My interview, survey, and technology review results highlighted four important findings:

1. **Neurologists need accurate self-reported seizure counts above all else.** Treatment requires accurate seizure counts. All respondents (11 of 11 neurologists) reported that seizure counts were the most important data type to them during both diagnosis and treatment. This finding makes a strong case for introducing seizure detection devices to provide more accurate seizure counts.

2. **Low-cost video could help clinicians during initial epilepsy diagnosis.** Initial diagnosis calls for accurate seizure descriptions. All neurology respondents reported they would like to have a video of patients prior to selecting an initial AED, however, only 30% of these respondents currently had

access to video from patients. In turn, providing families with video capture tools may be useful for distinguishing between patients with generalized and focal type seizure events.

3.      **Existing devices are best suited for nighttime use when patients are less able to report seizures.** High false positive rates remain problematic for the majority of day and night time seizure detection devices; presently only a subset of devices surpassed patient self-reporting during the day. In addition, most devices perform better at night than during the day as daytime activities such as teeth brushing are more difficult to distinguish from seizure-related movements. This finding suggests that existing devices may be most beneficial for use at night when patients have the most difficulty reporting seizures.

4.      **Existing seizure detection devices work best for Generalized Tonic-Clonic Seizures (GTCs) that involve considerable limb movement.** Existing devices are only capable of detecting GTC type seizures that involve considerable limb movement. This finding is critically important; only 30% of patients have GTC seizures that are characterized by limb movements by definition. By contrast, 70% of patients have focal seizures that do not necessarily exhibit limb movements. For example, focal dyscognitive seizures often present during sleep transitions and may involve lip smacking and vocalizations without limb movements. Furthermore, absence seizures are most common among younger patients and often include no motor movements at all. This finding suggests a need to measure additional signals based on a patient's specific seizures and symptoms. The

good news from an activity recognition perspective. Most patients tend to present with the same symptoms over time. It may, therefore, be possible to build more accurate patient-specific models as proposed by Cuppens et. al [96].

My findings contribute to addressing existing knowledge gaps between current patient self-reporting, clinical information needs and patient and caregiver self-reporting technologies. In the past, researchers compared the performance of seizure detection devices [95] but did not compare performance with patient "self-report" and further did not investigate how clinicians prioritized seizure count to other types of information during "clinical decision making".

*6.1.7 Conclusion*

In this study I conducted interviews, a literature review and a questionnaire to investigate clinical information needs during diagnosis and treatment, respectively. I then performed a detailed review of current seizure detection devices based on these needs and identified several underexplored design opportunities that would later guide my subsequent studies. The study highlighted strengths and shortcomings of current technologies and highlighted several opportunities for supporting epilepsy self-management.

My paper was published in Seizures '15 and Intech Open Science, '17. I also presented at the Neurological Disorders Summit (NDS),'16. The review provided a first-of-its-kind comparison between the performance of these devices and patient self-reporting. These findings greatly informed my work. I have since come to see the data collection as an area that presents the greatest challenge to pediatric patients and is best suited for the capabilities of current technologies.

## 6.2 Study #2 - Neurocognitive self-reporting needs study

My second study investigated clinical data collection needs from a clinician and patient/caregiver perspective with the question "What data do clinicians need vs. what patients can provide now as a starting point?"

My technology review in study #1 highlighted the need to further establish specific types, priorities, and characteristics of patient self-reported data. I began to consider how these self-reporting needs might translate to different schools of medicine that also rely heavily on patient self-reporting. In addition to speaking with neurologists specializing in epilepsy, I also began interviewing healthcare professionals from psychiatry and sleep medicine. I was surprised to learn that these fields also had few self-reporting guidelines. I initiated a study with my colleagues from CHOA and Emory to further clarify clinician information needs and better understand clinician perspectives regarding patient and caregivers self-reporting capabilities. The results built on my findings from study #1 and helped me to prioritize self-reporting needs to collect in study #5 such as mental health.

*6.2.1 Summary*

The treatment of neurocognitive conditions relies heavily on patient self-reporting to inform treatment and stands to benefit from the development of technological tools that support patient data collection activities and shared decision making between patients and

providers. Health tracking technologies stand to help patients and caregivers collect this data but technology developers need guidelines for developing these tools. The specific types and characteristics of the data that clinicians need are not well known.

The purpose of this study is to establish clinical information needs among clinicians from additional neurological fields: sleep and psychology to examine similarities that may be relevant given comorbidities between epilepsy, narcolepsy, and depression. In this study, my colleagues and I conducted a literature review to establish an initial list of relevant symptoms and triggers among specialized providers in neurology, psychiatry, and sleep medicine. In-person expert panel sessions were then conducted with 14 clinicians (5 epilepsy, 4 psychiatry, and 5 sleep medicine specialists) to assess clinician use of these symptoms and triggers as patient-reported data during diagnosis and treatment. Then a survey was conducted to establish a consensus regarding the availability and quality of patient data being collected.

The resulting findings highlighted several important yet underexplored data collection and design opportunities for supporting the diagnosis, treatment, and self-management of these three fields as well as expose gaps between clinical data needs and patient practices. The main contributions of this work have included:

1. Identification of the type, priority, and characteristics of self-reported data that clinicians need from patients.
2. Identification of common clinical self-reporting needs between traditionally separate medical fields.
3. Identification of design implications for the development of future patient self-

reporting tools.

## 6.2.2 Related work

The treatment of neurocognitive conditions relies heavily on patient self-reporting to inform treatment and stands to benefit from the development of technologies that support patient data collection and shared decision making between patients and providers.

Medical professionals often ask patients to collect and report health-related data for informing clinical decisions; however, patients often struggle with self-reporting responsibilities due to a range of social, technical and organizational barriers [1], [4]. This type of feedback is central to the diagnosis and treatment of neurocognitive conditions as clinical specialists must often rely on patient and caregiver self-reports that are often incomplete, inconsistent or inaccurate in the absence of more easily quantified information. For example, epilepsy, psychiatry and sleep medicine specialists often ask patients to keep track of factors such as mood that may be subjective and difficult for patients to accurately report between appointments. Interpreting quantitative measures such as patient blood glucose levels in the case of diabetes is typically much easier for clinicians by comparison.

Many patients struggle with self-reporting responsibilities due to a range of social, technical and organizational barriers [1], [4]. Health tracking technologies [6] and health reporting tools [7] have the potential to greatly reduce the burden placed on patients and collect more clinically significant health information [9]; however, building effective data collection tools requires understanding clinical data needs. These needs are often unknown or underspecified in the medical literature.

In this study, I sought to establish design guidelines for addressing two gaps within the related work. There is a need to establish both 1) patient health reporting capabilities in order to align data collection efforts with clinician needs and expectations and 2) additional parameters such as the type, priority, and characteristics of the desired health reporting data in order to develop effective mobile and wearable data collection tools.

6.2.2.1 Patient Self-reporting challenges

Health information can also be challenging for patients to collect and therefore be unreliable even when available or collected too infrequently to be informative [82], [97]. These issues present notable challenges for patient care:

1.　**Reporting availability** - Patient self-reporting is often relied upon heavily or exclusively but critical information may not be available due to social stigma [23], nonadherence [98] or inability to observe clinical presentations [24], [99]. Sometimes there may be simply a lack of awareness of what information is relevant for patients to collect and bring to appointments such as in the similar case of patients with chronic migraines [97]. For example, neurologists who treat epilepsy know that most patients (> 85.5%) are unable to observe seizure events at night [24] also resulting in missing data [30], [100].

2.　**Reporting usefulness** - Patient self-reported data may not include the right level of detail for a clinical consultation. For example, consumer health and wellness devices may collect data that is unsuitable for certain applications [101] or patients may not know what information to collect due to a large number of possible symptoms and triggers [102]. Furthermore, to the best of our knowledge, there are no

standard data collection apps, forms or guidelines for informing this process.

3.    **Reporting reliability** - Patient self-reporting may not agree with clinical

measurements. For example, numerous studies have also questioned the validity of

both objective and subjective methods for measuring aspects of sleep monitoring

within the sleep medicine field [103], [104]. Many patients struggle to maintain paper

and pencil diaries documenting changes in mood [105]. Non-compliance and recall

bias [87] also present similar barriers to mental health [30], [87]. In addition,

measurement validity can be difficult to assess given absence of quantitative

measurements or validated study designs [30].

4.    **Reporting difficulty** – Patient self-reporting can be difficult and

burdensome for patients to collect between appointments [106]. Neurologists and

psychiatrists often ask patients to document and report data such as the time, date and

a description of symptoms before, during and after clinical presentations [30], [105],

[107]. For example, neurologists often ask patients to keep a food journal to help

identify possible triggers of migraines.

5.    **Reporting frequency** - Finally, self-reporting may not be frequent enough

to enable clinicians to adjust seizure control medications between appointments. For

example, caregivers of patients with infantile spasms (IS) need to be especially

careful to provide frequent and detailed seizure reports [53] as uncontrolled seizures

can have tragic lifelong consequences such as decreased cognitive function [108]. In

other cases, self-reports may be documented too frequently and result in "information

overload" for clinicians seeking to interpret self-reports within a typical 15-minute

clinical visit [109], [110].

## 6.2.2.2 Health tracking design challenges

Health tracking priorities among clinicians and the patients' role in self-reporting are each often under-specified in the literature. There is considerable interest in behavioral surveillance [111] as input for both assessing, diagnosing chronic conditions [112] and evaluating self-management during treatment. However, little is known regarding what data should be collected, when it should be collected, and how this data monitoring benefits patient care. The Chronic Care Model [2], [113] is instructive for understanding the role of clinical systems and self-management within patient care but does not clarify specific types of clinical information that patients should keep track of for informing treatment and similarly does not recommend specific self-management practices for achieving positive long-term outcomes.

Health tracking technologies can play a major role in reducing the burden of patient data collection [114], but the current literature provides limited guidance regarding the specific types and characteristics of data that clinicians need patients to collect for them. Non-regulated health and wellness devices and regulated medical devices tend to play different roles when it comes to answering clinical questions during diagnosis and treatment [115]. For example, the Fitbit Charge 2 [116] can measure step count and sleep but is not designed to answer specific clinical questions such as "how did the patient's resting heart rate change after prescribing a stimulant?". By contrast, the Natus Ambulatory EEG [117] is designed to answer a narrow set of clinical questions, such as "where is a seizure originating?", but does not provide physical activity or sleep

information as more general parameters that can impact seizure likelihood.

It is therefore important for research to address this mismatch between technology data collection requirements and clinical data collection needs for informing diagnosis and treatment. If researchers can establish these clinical information needs then technology developers may be able to more effectively prioritize development within specific clinical areas [118] and develop new products that better indicate and address patient self-reporting needs. Meanwhile, mental health is receiving increased attention from researchers with efforts to predict patient depression from speech [119], social media usage [120] and facial expressions [121]. While these advancements are promising, a more systematic approach to understanding patient data needs could better inform the development of such technologies as health tracking data collection tools [122].

*6.2.3 Methods*

The first phase of the study was to establish an initial list of self-reporting data collection needs. I conducted a literature review and worked with subject matter experts to establish a list of important symptoms and triggers within epilepsy, psychiatry and sleep medicine, respectively.

I then conducted card-sorting exercises with 4-5 neurologists from each subspecialty. The card-sorting panels included 5 epilepsy providers at Children's Healthcare of Atlanta, GA, 4 psychologists at the Grady Memorial Hospital, GA and 5 sleep specialists at the Emory Sleep Center, GA.

The second phase of the study was to survey neurologists for prioritizing this list of

sorted needs. I administered an online survey to 20 additional clinicians over a 5-week period. The respondents included 4 mid-level nurse practitioners who treated patients with epilepsy, 2 epileptologists, 6 psychiatrists and 8 sleep specialists.

*6.2.4 Results*

6.2.4.1 Self-reporting needs

The first step for our research was establishing the type of patient self-reported data that clinicians need from patients. I began by interviewing 1-2 subjects matter experts from each subspecialty. I then performed a literature review to construct a corresponding list of useful symptoms and triggers to consider when diagnosing and treating each condition. The lists are summarized in Table 3 for reference and each included between 66 and 96 symptoms and triggers. The complete lists can be made available available upon request.

**Table 3 - Symptoms and triggers by neurocognitive condition**

|          | Epilepsy | Major Depression | Narcolepsy | Total |
|----------|----------|------------------|------------|-------|
| Symptoms | 48       | 49               | 53         | 150   |
| Triggers | 11       | 23               | 43         | 77    |
| Total    | 66       | 72               | 96         | 234   |

6.2.4.2 Self-reporting priorities

Next, I investigated the priority of the patient self-reported data and compared the priorities between neurocognitive fields. The "top 20" highest ranked symptoms and triggers are shown in Table 4. The table highlights specific characteristics of the self-reported data that clinicians need from patients.

**Table 4 - List of clinical patient self-reporting needs during diagnosis & treatment**

| Rank | Symptom/trigger | Useful (% reported yes) | Available (% reported yes) | Reliable (% reported yes) | Difficult (% hard to report) | Frequent (% reported monthly) |
|---|---|---|---|---|---|---|
| Epilepsy | | | | | | |
| 1 | Status seizures | 100.00% | 100.00% | 83.33% | 16.67% | 33.33% |
| 2 | > 2 seizures in 24 hours | 100.00% | 100.00% | 83.33% | 0.00% | 33.33% |
| 3 | Patient Age | 66.67% | 83.33% | 100.00% | 0.00% | 33.33% |
| 4 | Daytime seizures events | 100.00% | 100.00% | 50.00% | 16.67% | 50.00% |
| 5 | Nighttime seizure events | 100.00% | 33.33% | 33.33% | 66.67% | 33.33% |
| 6 | Auras (pre-ictal) | 100.00% | 50.00% | 50.00% | 66.67% | 16.67% |
| 7 | Viral infections | 83.33% | 16.67% | 33.33% | 33.33% | 16.67% |
| 8 | New onset of cancer | 83.33% | 50.00% | 83.33% | 0.00% | 16.67% |
| 9 | Seizures at sleep transitions | 83.33% | 33.33% | 66.67% | 16.67% | 16.67% |
| 10 | Impaired sleep and daytime alertness | 83.33% | 50.00% | 50.00% | 33.33% | 16.67% |
| 11 | Seizure onset time at night | 66.67% | 33.33% | 0.00% | 83.33% | 16.67% |
| 12 | Drug & alcohol use | 66.67% | 33.33% | 16.67% | 50.00% | 16.67% |
| 13 | Menstruation cycles | 83.33% | 33.33% | 50.00% | 33.33% | 50.00% |

| Rank | Symptom/trigger | Useful (% reported yes) | Available (% reported yes) | Reliable (% reported yes) | Difficult (% hard to report) | Frequent (% reported monthly) |
|---|---|---|---|---|---|---|
| 14 | New pregnancy | 83.33% | 50.00% | 83.33% | 16.67% | 33.33% |
| 15 | Academic decline | 100.00% | 16.67% | 50.00% | 16.67% | 16.67% |
| 16 | Impaired language abilities | 83.33% | 50.00% | 66.67% | 33.33% | 16.67% |
| 17 | Depression symptoms | 83.33% | 66.67% | 33.33% | 66.67% | 16.67% |
| 18 | Suicide attempts | 83.33% | 16.67% | 33.33% | 83.33% | 16.67% |
| 19 | Impaired memory | 100.00% | 33.33% | 0.00% | 33.33% | 16.67% |
| 20 | Heart disease | 50.00% | 0.00% | 66.67% | 16.67% | 16.67% |
| Major Depression | | | | | | |
| 1 | Suicidal thoughts | 100.00% | 100.00% | 83.33% | 0.00% | 50.00% |
| 2 | Decreased need for sleep | 100.00% | 100.00% | 66.67% | 50.00% | 16.67% |
| 3 | Depressed mood | 100.00% | 100.00% | 66.67% | 33.33% | 33.33% |
| 4 | Fatigue/loss of energy | 100.00% | 100.00% | 66.67% | 16.67% | 33.33% |
| 5 | Hopelessness | 100.00% | 100.00% | 83.33% | 16.67% | 33.33% |
| 6 | Loss of interest in activities | 100.00% | 100.00% | 83.33% | 16.67% | 33.33% |
| 7 | Psychomotor retardation/agitation | 100.00% | 100.00% | 33.33% | 50.00% | 33.33% |
| 8 | Trouble concentrating | 100.00% | 100.00% | 50.00% | 33.33% | 33.33% |
| 9 | Weight loss/gain | 100.00% | 100.00% | 50.00% | 50.00% | 50.00% |
| 10 | Worthlessness/guilt | 100.00% | 100.00% | 100.00% | 0.00% | 33.33% |
| 11 | Drug & alcohol abuse | 100.00% | 100.00% | 16.67% | 83.33% | 33.33% |
| 12 | Insomnia /hypersomnia | 100.00% | 100.00% | 83.33% | 16.67% | 33.33% |
| 13 | History of antidepressant medications | 100.00% | 100.00% | 50.00% | 66.67% | 0.00% |
| 14 | Impaired sleep quality | 100.00% | 100.00% | 66.67% | 33.33% | 16.67% |
| 15 | Increased sleep latency | 50.00% | 50.00% | 50.00% | 50.00% | 33.33% |

| | | Useful (% reported yes) | Available (% reported yes) | Reliable (% reported yes) | Difficult (% hard to report) | Frequent (% reported monthly) |
|---|---|---|---|---|---|---|
| 16 | Insomnia | 100.00% | 100.00% | 50.00% | 50.00% | 16.67% |
| 17 | Lower sleep efficiency | 100.00% | 100.00% | 33.33% | 66.67% | 33.33% |
| 18 | PTSD | 100.00% | 100.00% | 66.67% | 33.33% | 16.67% |
| 19 | Postpartum depression | 83.33% | 66.67% | 33.33% | 66.67% | 0.00% |
| 20 | Pregnancy | 100.00% | 100.00% | 66.67% | 0.00% | 16.67% |
| **Narcolepsy** | | | | | | |
| 1 | History of napping within the same day | 75.00% | 87.50% | 37.50% | 0.00% | 0.00% |
| 2 | Loss of muscle control (cataplexy) | 87.50% | 87.50% | 75.00% | 37.50% | 37.50% |
| 3 | Hallucinations | 87.50% | 87.50% | 50.00% | 37.50% | 37.50% |
| 4 | Excessive sleep movements | 87.50% | 87.50% | 37.50% | 100.00% | 25.00% |
| 5 | Sleep paralysis at sleep transitions | 87.50% | 87.50% | 62.50% | 25.00% | 12.50% |
| 6 | Irregular sleep jerks | 75.00% | 87.50% | 37.50% | 87.50% | 12.50% |
| 7 | Sleep paralysis | 87.50% | 87.50% | 75.00% | 37.50% | 25.00% |
| 8 | Paroxysmal sleepiness | 87.50% | 87.50% | 25.00% | 37.50% | 25.00% |
| 9 | Motor disorders during sleep | 87.50% | 87.50% | 50.00% | 37.50% | 12.50% |
| 10 | Daytime sleep attacks | 100.00% | 87.50% | 25.00% | 12.50% | 25.00% |

| Rank | Symptom/trigger | Useful (% reported yes) | Available (% reported yes) | Reliable (% reported yes) | Difficult (% hard to report) | Frequent (% reported monthly) |
|---|---|---|---|---|---|---|
| 11 | Impaired ability to drive | 100.00% | 87.50% | 12.50% | 37.50% | 37.50% |
| 12 | Efficacy of short naps | 87.50% | 75.00% | 50.00% | 37.50% | 12.50% |
| 13 | Rousing behaviors | 87.50% | 75.00% | 62.50% | 12.50% | 12.50% |
| 14 | Active sleepiness | 100.00% | 87.50% | 25.00% | 25.00% | 37.50% |
| 15 | Consequences of sleepiness | 100.00% | 87.50% | 50.00% | 37.50% | 25.00% |
| 16 | Intake of caffeine | 100.00% | 87.50% | 62.50% | 0.00% | 12.50% |
| 17 | Excessive sleepiness | 87.50% | 87.50% | 50.00% | 25.00% | 12.50% |
| 18 | Subjective sleepiness | 87.50% | 87.50% | 50.00% | 12.50% | 0.00% |
| 19 | Passive sleepiness | 100.00% | 87.50% | 37.50% | 12.50% | 25.00% |
| 20 | Naps during the day | 87.50% | 87.50% | 62.50% | 0.00% | 12.50% |

## 6.2.4.3 Self-reporting consensus

### 6.2.4.3.1 Self-reporting data types and characteristics

Table 5 summarizes our key research findings in terms of design implications for neurocognitive self-reporting tools. The table shows the "top 2" most reported survey responses after filtering for responses in terms of 'symptom/triggers' that were considered either "useful but not available" or "useful but difficult to collect".

In addition, the table is intended to serve as a design reference for developing patient self-reporting technologies and highlights clinician consensus regarding 1) priority and 2) characteristics of select patient health indicators during diagnosis and treatment.

**Table 5 - Neurological condition and self-reporting design implications**

| Neurological Condition | Design implications | | | | |
|---|---|---|---|---|---|
| | Available (Yes/No) | Reliable (Yes/No) | Difficult (Yes/No) | Frequent (Yes/No) | Reporting affordance |
| Epilepsy | | | | | |
| Depression / Suicide attempts | Yes | No | Yes | No | Manual reporting with validated survey |
| Medical history / History of Presenting Illness (HPI) | No | Yes | No | No | Manual reporting with non-validated survey |
| Major Depression | | | | | |
| Trouble concentrating | Yes | No | Yes | Yes | Manual reporting with validated survey |
| Weight gain/loss | Yes | Mixed | Yes | No | Automated data collection and reporting |
| Narcolepsy | | | | | |
| Impaired ability to drive | Yes | Mixed | Yes | Mixed | Manual reporting with automated contextual prompts |
| Excessive movements during REM | Yes | Mixed | Yes | Yes | Automated data collection and reporting |

6.2.4.3.2    Low inter-rater agreement within conditions

Next, I calculated Krippendorff's alpha (α) percent agreement between clinician survey responses within each of our neurocognitive conditions: epilepsy, major depression, and narcolepsy. α controls for agreement by chance and is suitable for comparing categorical variables between two or more respondents. Table 6 shows the extent that each set of survey respondents reported the same answers to multiple choice questions.

**Table 6 - Krippendorff's alpha agreement per condition**

|               | Epilepsy | Major Depression | Narcolepsy |
|---------------|----------|------------------|------------|
| All Questions | 35.54%   | 28.10%           | 21.35%     |

*6.2.5 Discussion*

The respondents highlighted several design opportunities as shown in Table 5. Epilepsy specialists expressed a need for mental health records that were considered "useful" but are often not available to them during patient visits. In addition, respondents from all three fields expressed a need for more reliable and frequently collected data. Our findings included a need for suicide and depression screening within epilepsy treatment, reliably evaluating patient concentration and weight changes for major depression, and driving impairment and excessive REM movements when treating patients with narcolepsy.

The overall consensus among raters within each field was notably lower than expected. Table 6 highlights the Krippendorff's alpha agreement between survey respondents; while the overall agreement was low there was considerably higher agreement on responses for several key symptoms/triggers within each field.

Please see our paper titled "Investigating design opportunities for supporting patient self-reporting within neurocognitive fields" for a more detailed discussion of these findings [53].

*6.2.6 Conclusion*

The study produced a set of prioritized clinical information needs and relevant self-reporting benchmarks during treatment. The results established specific clinical patient self-reporting needs during diagnosis and treatment. Moreover, the findings stand to improve clinical decision making by clarifying important aspects of self-reporting that were not available in the literature (e.g. consistency, promptness, and reliability).

The research was completed in January 2015 and submitted to CHI in 2017. My study was among the first to investigate performance requirements for driving the performance requirements for these devices. In addition, I then drew upon these findings to suggest design implications for mobile and wearable self-management tools.

My next two studies, studies #3 and #4, focused on addressing the need for increasing data collection quality. The study objectives included evaluating the performance of E4 seizure detection wristbands and investigating the utility of patient and caregiver video review for addressing the problem of over-reporting seizures when using the wristbands.

**6.3 Study #3 - Seizure detection wristband evaluation**

Published - Epilepsia, '17

Onorati, Francesco,...Bidwell, et al. "Multicenter clinical assessment of improved wearable multimodal convulsive seizure detectors." Epilepsia 58.11 (2017): 1870-1879.

My third study investigated the extent to which wearable seizure detection wristbands may be able to improve data quality by first asking "To what extent can this seizure detection wristband improve the quality of "seizure count" data as compared with self-report?" and then clarifying "How does the performance of wearable seizure detectors compare to current patient self-report for increasing seizure count accuracy?"

I contacted Empatica's Chief Scientist, Dr. Rosalind Picard and initiated research to evaluate the performance of Empatica's E4 wristbands in 2014. The E4 had recently been released. Dr. Piccard's company was seeking clinical partners in preparation for FDA approval. My colleagues at CHOA and Emory agreed to help evaluate the wristbands in exchange for us being able to use them during upcoming studies.

The relationship was mutually beneficial for two reasons. First Empatica needed ground truth vEEG annotations for both evaluating wristband performance and providing labeled training examples for further improving performance. Second, I was seeking an affordable wearable seizure detection device for my upcoming research; this provided my colleagues and me with access to the company's latest seizure detection devices.

Moreover, my technology review [33] highlighted that some but not all devices performed better than patient self-report. My colleagues and I were interested in improving seizure reporting performance in our future work.

*6.3.1 Summary*

Many patients have seizures at night that often go unnoticed and therefore unreported. Neurologists rely on patients to provide accurate seizure counts during treatment [24]. This presents a problem as inaccurate seizure counts can make self-reflection difficult for patients and make evaluating medication efficacy difficult for clinicians. It would, therefore, be useful to evaluate the performance of new seizure detection devices aimed at providing patients and clinicians with more accurate seizure count information.

In this study, my colleagues and I evaluated the performance of Empatica E4 wristbands among pediatric and adult patients. The study included 69 patients who were diagnosed with epilepsy and a total of 246 days of recorded wristband measurements among six separate epilepsy centers. Hand-annotated video-electroencephalography seizure events were collected from 69 patients at six clinical sites. Wrist electrodermal activity and accelerometer measurements were concomitantly recorded, obtaining 5,928 hours of data (55 recorded events from 22 patients).

My site at CHOA/Emory contributed data from 32 patients of the overall 69 patients. The wristbands successfully detected 52 out of 55 convulsive seizure events and performed better than both the prior state-of-the-art and current patient self-reporting capabilities at night. The wristbands classified a wide range of motor seizures including generalized tonic-clonic (GTC), focal motor (FOCM), secondarily GTC, tonic, myoclonic and clonic seizures [123], [124]. In addition, the wristbands collected non-motor EDA [125], [126] and peri-ictal autonomic dysregulation [127]–[129] measurements aimed at helping clinicians to assess warning signs for Sudden Unexpected Death in Epilepsy (SUDEP) as

future work. The main contribution of this study is a performance evaluation to improve the state of knowledge regarding wearable seizure detection false positive rates.

*6.3.2 Related work*

Mobile and wearable devices have been proposed for helping patients and caregivers to more accurately report seizure events [33]. The key challenge is designing a system that is both acceptable for long-term use and can provide clinically relevant information during treatment. Electroencephalography (EEG) based systems are the current gold standard for detecting, characterizing and diagnosing patient seizures yet these systems are bulky, require wearing uncomfortable electrodes on the scalp and are not practical for long-term use. Most patients are unable to report seizures while sleeping (85.5%) [24] and under report seizures overall (around 50%) [99] (e.g. patients with focal epilepsy that have seizures during sleep/wake transitions). Meanwhile, neurologists must rely on patient and caregivers to accurately report seizure counts and seizure symptoms between appointments yet these reports are known to be inaccurate [30]. For example, more objective data collected at home could also help improve physicians' clinical decisions [33], [42] by providing more accurate insights into seizure timing and autonomic disruption, for example by observing the amplitude of post-ictal electrodermal activity (EDA) surge, a correlate of long-duration PGES following GTC seizures [128]. It is, therefore, critical for developing new seizure detection systems that can provide long-term reporting and alert caregivers in the home.

Many wearable systems have been proposed for detecting convulsive seizures (CS), but most systems report high numbers of false alarms [33], [95], [130] and therefore offer

limited utility during treatment. The SmartWatch [70], [131], Epicare Free watch [69], [132], Epilert [133] and Brain Sentinel [134] are each sold as commercial products that attempt to typically detect seizure events using accelerometry (ACM) [69], [70], [133], [135] and electromyogram (EMG) [134], [136] sensors [137], [138]. The challenge is that motion and muscle activation measurements during daily behaviors such as tooth brushing and exercise often mimic motor manifestations that are associated with CS, and systems tend to inflate seizure counts by falsely reporting non-seizure behaviors as seizure events. For example, the SmartWatch has reported an average of 204 false alarms per day [70] with default settings. This presents a problem as the resulting seizure counts tend to be less accurate than patients and clinicians need during treatment [42].

Many systems attempt to sidestep this over reporting issue by providing users with an adjustable sensitivity setting; however, this is not a principled approach. Increasing the sensitivity results in false alarms, while decreasing sensitivity increases the risk of seizure events. It is, therefore, important to evaluate the performance of these devices and also to assess the extent to which these devices can address clinical data quality needs [139].

*6.3.3 Methods*

The study included 69 patients with epilepsy. The patients had already been admitted to an Epilepsy Monitoring Unit (EMU) and were recruited by a nurse who obtained informed consent in accordance with Emory and CHOA Internal Review Board (IRB). The patients were instrumented with Empatica E4 wristbands. Hospital staff recorded patient video and EEG, and the wristbands recorded wrist acceleration and electrodermal activity (EDA) for detecting seizure events.

56

The wristband measurements were uploaded to a server and analyzed separately using a modified version of the Poh et al. [140] seizure detection algorithm. Measurements from each wristband were analyzed separately within a 10-second sliding window with a 50% overlap. Next, a set of statistical features was computed to summarize the EDA and accelerometry measurements. These features were sent to a support vector machine (SVM) classifier for estimating the probability that a seizure had occurred within each window. Each seizure was reported as an onset and duration that included the current window and any consecutive adjacent windows with reported seizure activity.

The study evaluated the performance of two separate seizure detection algorithms that each included a set of features and a support vector machine (SVM) as an automated classifier for estimating the probability of seizure events. The first algorithm is from Poh et al. [140] and well documented. The computed features were evaluated using the original SVM classifier from the study. The second algorithm was developed by Empatica Inc. Researchers at the company defined additional statistical features and re-trained the original SVM classifier with additional examples of seizure and non-seizure data. These features are proprietary and therefore regrettably cannot be discussed or re-examined for repeating our results. In each case, the onset timestamp of each event was then compared against our ground truth vEEG reference annotations.

Next, I calculated performance in terms of precision, recall, and F1-score. "Recall or sensitivity is the fraction of all seizures that were detected. High recall values reflect a low chance of under reporting or missing a seizure" [33].

$$\text{Precision} = \frac{\text{true positives}}{(\text{true positives} + \text{false positives})}$$

"Precision is the fraction of all relevant seizures that are detected. High precision values reflect a low chance of over reporting seizures or triggering false alarms" [33].

$$\text{Recall} = \frac{\text{true positives}}{(\text{true positives} + \text{false negatives})}$$

"In both cases, a naive system could achieve perfect recall by reporting 'true' at every opportunity and likewise achieve perfect precision by reporting 'false'" [33]. F1-score balances over and under reporting are as follows:

$$F1 \; \text{score} = 2 * \frac{(\text{precision} * \text{recall})}{(\text{precision} + \text{recall})}$$

Most previous studies only report results for patients with seizures (PWS) and only a few have presented statistics based on all patients. In our study, I chose to calculate precision based on only PWS [33]. It should be noted that including all patients would have been preferable to provide more realistic performance. A typical EMU visit ranges 2-5 days, however, not all patients have seizures during this time period. In our case, I opted to include only PWS in our analysis so that I could compare our results with those from a greater number of studies.

*6.3.4 Results*

My colleagues and I collected wristband recorded ACM and EDA data from 69 patients who were diagnosed with epilepsy. Inclusion criteria included all English speaking pediatric and adult patients with a diagnosis of epilepsy. Informed consent was obtained

from all patients and additionally from patient guardians in the case of adult patients with developmental delays and pediatric patients.

The resulting dataset included over 246 days of recording of wristband recorded ACM and EDA measurements (5,928 hours, median 22.3 hours per session). EEG technicians labeled 55 CS type seizures from 22 patients. The wristbands detected 52 out of 55 CS type seizure events. The majority of patients had less than 1 false alarm every 4 days. The mean latency of detection was less than 40 seconds for both classifiers. The classifiers failed to detect non-CS type seizures; however, no nocturnal seizures were missed among patients with CS type seizures.

The E4 ACM and EDA measurements were analyzed using two separate algorithms for comparison. The original seizure detection algorithm from Poh et al. [44] missed few seizures but presented frequent false alarms with a recall of 93.8%, a precision of 34.88%, and with 2.6 false alarms per day. By contrast, a modified version of the Poh algorithm performed notably better with a recall of 95.8% and a precision of 51.0% with 0.2 events per day.

Table 7 presents a performance comparison of both algorithms alongside prior-art system patient self-reporting. The prior-art systems include the studies by Poh et al. [140], Beniczky et al. [69] and Schulc et al. [135] as three top-performing systems that are most applicable to the proposed Empatica E4 wristband design. Hoppe et al.'s [24] studied patient self-reporting capabilities. I referred to analysis from Bidwell et al.'s technology review [33] for extrapolating patient self-reporting precision, recall, and F1-score.

**Table 7 - System and patient self-reporting performance comparison**

| Systems | F1-score | Precision | Recall | PWS |
|---|---|---|---|---|
| Onorati [141] | 0.66 | 0.51 | 0.95 | 22 |
| Poh [140] | 0.51 | 0.35 | 0.94 | 7 |
| Beniczky [69] | 0.85 | 0.81 | 0.90 | 20 |
| Schulc [135] | 0.99 | 0.98 | 1.0 | 3 |
| Patient self-reporting | | | | |
| Daytime [142] | 0.81 | 1.00 | 0.68 | 91 |
| Nighttime [142] | 0.25 | 1.00 | 0.15 | 91 |

*6.3.5 Discussion*

The study evaluated an improved algorithm that employs ACM and EDA measurements for detecting CS among pediatric and adult patients. The improved algorithm can indeed increase the quality of "seizure counts" over current, unassisted patients self-reporting at night. In Hoppe et al. [24] patients failed to report > 85% of seizures while sleeping and patients were assumed to be "perfect reporters" [24] with zero false alarms. The wristbands were evaluated during the day and night.

The results in Table 7 shows that the latest E4 seizure detection wristbands from Onorati et. al [141] slightly outperformed the state-of-the-art during our study. The wristbands achieved an F1-score of 0.66 while the previous wristband model achieved 0.51 [140].

The performance also suggests that the wristbands may be better suited for use during at night rather than during day. The wristbands performed better than patients at night but worse than patients during the day. The wristbands achieved an F1-score of 0.66 for reporting seizures during the day and night (seizures detection times were not cataloged in our final analysis). This performance is better than patient reporting performance at night (F1-score 0.5) but worse than patient reporting during the day (F1-score 0.81).

The study showed that the E4s performed better than patients for reporting seizures at night. In turn, the E4s and similar performing seizure detection devices are well suited for measuring seizure frequency at night when patients are less able to report seizures [24]. Moreover,  "breakthrough" seizures can occur when a patient's medication gradually loses effectiveness over time. Long-term monitoring of night time seizures could help identify "breakthrough" seizures among patients that sleep by themselves, and also

provide caregivers with greater peace of mind that loved ones remain seizure free.

The study also highlighted two notable limitations of current seizure detection devices. First, high numbers of false alarms remain problematic. The wristbands were trained to provide a near perfect 95.0% recall with a resulting precision of only 51.0%. In the future, more work research is needed to discriminate between teeth brushing, dancing and other non-seizure behaviors that resulted in false alarms. Second, non-CS type seizures were not detected. Most pediatric patients (70%) have focal type seizures [143]; these seizures do not necessarily exhibit limb movements. The wristbands failed to detect seizures among all patients with nonconvulsive focal seizures with symptoms ranging from vocalizations to hand flapping to back arching. More research is needed for investigating non-motor patent biomarkers during seizures. In the future, patient-specific seizure modeling as proposed by Cuppens et al. [144] may provide a viable path for both reducing false alarms and better accounting for differences among seizures with less distinct motor movements.

6.3.5.1 Implications for design

The study highlighted two design implications for future mobile and wearable self-management research.

**1. Enrollment was easier than expected within an inpatient EMU setting** - Issues such as the aesthetics of the devices would likely be much more critical in a patient's typical social setting. The wristbands had minimal decoration. I was informed on several occasions that the color, size, and texture of the wristbands looked like "a medical device". In some cases, younger patients only agreed to wear the wristbands after

decorating them with stickers. My intuition is that patients may have been more amenable towards wearing the wristbands because they were already instrumented with EEG caps and had little else to do during the 2-5 day visit. In all, only 2 out of 31 families (6.45%) declined to participate when approached.

**2. Instrumenting patients was only possible with caregiver assistance** - The caregivers were essential for two reasons: getting patients excited about wearing them and helping to fasten the wristbands without pinching patients. The wristbands were also made of stiff rubber. The stiffness made it difficult to fasten the wristbands without pressing down hard on the underside of the wrist. I asked caregivers for help with sensitive patients and wrapped the wristbands in soft, adhesive medical bandages as an added precaution for reducing skin irritation.

*6.3.6 Conclusion*

My wristband evaluation study investigated the performance and feasibility of using a new type of wearable seizure detection wristband for everyday seizure monitoring. This study evaluated the performance of the Empatica Inc.'s E4 seizure detection wristbands among pediatric and adult patients. The results showed that the E4s has an incremental improvement over the state-of-the-art, and the wristbands performed better than patient self-reporting at night. E4 wristbands may, therefore, be well suited for seizure counts when patients are sleeping and less able to report seizure events. These findings contributed to the state of knowledge regarding wearable seizure detection performance among pediatric and adult patients. Please refer to Chapter 7 for a more detailed discussion of design implications across each of our studies.

To publish our findings, my colleagues and I submitted a manuscript to Epilepsia,'17. My advisor, Dr. Elizabeth Mynatt and I published a book chapter on our findings in Intech Open Science, '17. The study shaped my research in two ways. First, I was disappointed by the high false alarm rate and poor performance among non-CS seizure types. I have since abandoned the prevailing notion that "seizure detection" must be strictly automatic. In study #4, I included patients and caregiver in the process of rejecting wristband-detected false alarms. Second, I was surprised to learn how few resources there were beyond seizure detection. In study #5, I propose using the E4 wristbands only at night and focusing instead on supporting additional sleep, exercise and mood self-reporting.

## 6.4 Study #4 - Rejecting non-seizures from retrospective video of wristband events

| Presented - CHI WISH Workshop, '17 |
| --- |
| Bidwell, et al. "Rejection of Non-seizures from Retrospective Video of Reported Epileptic Seizure Events." Conference for Human-Computer Interaction, WISH Conference, 2017 |

My fourth study investigates a new approach to improving data quality by asking the question "To what extent can a patient/caregiver video review of wearable wristband-detected seizure events further improve the quality of 'seizure count' data as compared with self-report?". Rather than of developing another seizure detection device, I instead investigated the feasibility of utilizing patient and caregiver video annotations to improve data collection quality prior to appointments.

### 6.4.1 Summary

Epilepsy treatment requires accurate patient and caregiver seizure reporting. Neurologists

currently must rely on patients and caregivers to accurately document the number of seizures that occur between appointments [145], [146]. Many patients and caregivers struggle with this task [147], [148], and patient and caregiver seizure reports are known to be highly inaccurate [27], [147], [149], [150]. Electroencephalography (EEG) systems are not practical for long-term monitoring in the home as special training is required for instrumenting patients with scalp electrodes and "reading" or interpreting the EEG measurements. Non-EEG mobile and wearable seizure detection systems are now available but currently fall short of patient, caregiver and clinician performance requirements [33], [42]. The result is that without accurate seizure counts neurologists are often unable to determine the effectiveness of medication adjustments for controlling seizures. It is, therefore, imperative that researchers investigate new approaches for increasing the quality of seizure reporting during treatment.

The purpose of this study is to investigate a new approach for supporting seizure reporting among patients and caregivers. The study included 5 patients. The sample included a subset of patients and caregivers that were enrolled in study #3 (4 pediatric patients and caregivers from the CHOA and 1 adult patient from Emory University Hospital, respectively). In study #3, each patient was instrumented with seizure detection wristbands while being video recorded during 2-5 day EMU visits. The wristbands recorded the onset times of probable seizure events.

This study responded to a long-standing need to address a performance gap between current seizure detection wristband performance and clinical self-reporting requirements during treatment. The participants were asked to annotate video recordings of previously

recorded wristband detected events. I investigated the extent that patients and caregivers could reject false alarms (e.g. non-seizure related behaviors such as head scratching).

The main contribution of this work was a new video approach that stands to improve the quality of self-reported seizure counts that are available to clinicians. The results showed that patients and caregivers were able to correctly reject false alarms and thereby reduce the problem of over-reported seizure counts prior to clinical appointments. The approach has been shown to accomplish the following:

1. Enable patients to report seizures that would otherwise be missed,

2. Require minimal training on the part of patients and caregivers,

3. Measure seizures events without uncomfortable EEG electrodes,

4. Increase seizure reporting accuracy beyond current technology limitations and

5. Highlight an approach that may practical for long-term use in the home.

*6.4.2 Related work*

Neurologists rely on patient and caregiver reported seizure counts for adjusting patient meditations. The standard of care is for families maintain a "seizure diary" for logging the date, time and a description of seizure events. In practice, most patients and caregivers under report seizures while non-EEG seizure detection devices tend to over-report them. This tradeoff presents two sets of challenges for informing treatment:

1. **Most patients under report seizures** - Many patients and caregivers struggle with seizure reporting due to impaired consciousness both during and following seizure events [99]. Moreover, patients tend to have the most trouble reporting seizures at night. In a study from Hoppe et al. [142] more than 85% of adult patients failed to report nighttime seizures and reminding patients to fill in reports did not improve reporting performance [24]. Eyewitness accounts from caregivers often disagree on important seizure reporting details [147], [151] and caregivers are often less able to respond to patient seizures at night [152]. It is, therefore, important to enable patients and caregivers to review seizures.

2. **Most devices over report seizures** - The majority of seizure detection devices over report patient seizures [33]. My literature review showed that most devices had high false alarm rates and that systems tended to exhibit high recall and low precision. For example, Narechania et al. [153] evaluated the MP5 pressure sensing mattress and reported a recall of 89.0% and a precision of 43.0% (i.e, reporting false alarms rather than missing seizures).

It is, therefore, important to investigate new approaches that can achieve these clinical

performance requirements. If successful, the proposed video review approach could increase the accuracy of seizures reporting in the home.

*6.4.3 Methods*

The study was conducted at the Emory University Hospital and Children's Hospital of Atlanta (CHOA) hospitals and included 5 patients (1 adult and 4 pediatric) during 2-5 day epilepsy monitoring unit (EMU) visits. The patients each had prior histories of seizures were being observed as a part of epilepsy diagnosis or treatment. The video review process consisted of the following three steps:

1. **Measuring wristband-detected seizure events -** The patients were instrumented with Empatica E4 wristbands on the left and right wrists for detecting seizure events while being video recorded. The wristbands recorded accelerometry and electrodermal activity. These measurements were analyzed offline using a previously published seizure detection classifier [140]. The onset time and duration of probable seizure events were documented for each patient.

2. **Indexing video of wristband-detected events** - The video recordings were then indexed or clipped into short segments that spanned +/- 10-seconds before and after the onset of each wristband-detected seizure event. Then I randomly indexed up to two video clips per day to simulate additional false alarms.
   The wristbands had reported an average of two false alarms per 24 hours in a previous study [140]. In practice, the wristbands often reported fewer than two seizures per day. Instead of disqualifying patients with low numbers of wristband reported seizures I simulated prior performance by randomly indexing up to two

additional video clips. Simulating these false alarms guaranteed that each participant

would review at least two clips per 24 hours of recording and enabled us to further

investigate how well patients and caregivers could reject false alarms.

3. **Identifying and rejecting false alarms** - The study coordinator scheduled a video

   chat meeting following the patient's visit. The participants jointly reviewed and

   annotated the video clips. This process involved reporting "Yes", "Maybe" or "No"

   depending on whether the patient appeared to be having a seizure. My colleagues and

   I then calculated seizure count performance for both the video reviewers and E4

   wristbands. EEG technicians had previously hand-annotated the onset and interval of

   seizures using vEEG as a part of the patient's normal medical treatment. The

   participants' video review responses were then analyzed to determine the extent that a

   video review might further increase wearable seizure detection performance.

*6.4.4 Data collection*

The hardware selection was intended to provide a similar experience to what they might

expect when using consumer devices in the home. The patient was video recorded 24/7

throughout his or her EMU visit. The video was captured using a ceiling mounted Sony

IPELA EP520 (720 x 480 pixel resolution) installed at the EMU. In addition, an external

infrared illuminator was located next to the cameras for facilitating video capture at night.

The resulting video quality was comparable to that of a consumer home security camera

such as the Foscam FI8918W [154]. The wristbands had a battery life of 36 hours, a data

storage capacity of 48 hours and recorded ACM and EDA measurements. The wristband

measurements were uploaded to a server where a previously published seizure detection

classifier from Poh et al. [44] was run to detect probable seizure events.

The video review process was conducted using a screen sharing application called TeamViewer Live. The application featured cross-platform support and enabled patients and caregivers to speak with the study coordinator and optionally control his mouse and keyboard during the video review.

*6.4.5 Results*

The study included 5 patients. My colleagues and I enrolled 4 pediatric patients at CHOA and 1 adult patient from Emory University Hospital. The families were enrolled on a first-come, first-serve basis during inpatient EMU visits at the respective locations.

Inclusion criteria included all English speaking pediatric patients with a diagnosis of epilepsy along with patient guardians. Informed consent was obtained from all participants. In each case, patient guardians were asked whether they would prefer to review video with the patients or on the patient's behalf during enrollment. In addition, my colleagues and I obtained informed consent from patient guardians in the case of pediatric or adult patients with developmental delays

The patient population was a subset of the patients that we had enrolled for evaluating the E4 seizure detection wristbands in study #3. My original plan had been to include all 32 patients from this cohort; however, the time-consuming nature of scheduling follow-up video calls limited our analysis to 5 of these families.

The setup time for the video review was between 15-20 minutes and lasted 3 minutes on average. The participants correctly rejected 8 out of 8 false alarms.

*6.4.6 Discussion*

My initial results showed near perfect agreement with our ground truth observations and highlights that a patient and caregiver video review can indeed increase the quality of wristband-detected seizure counts for addressing clinical performance requirements. The video review concept may also be achievable in the short-term for three reasons.

1.      **Seizure detection devices tend to over report seizures** - Mobile and wearable seizure detection systems tend to report high numbers of false alarm rates [33]. The participants in the video review were able to identify 100% of false alarms to help address this problem.

2.      **Patients and caregivers tend to under report seizures** - The majority of patients have the opposite problem and tend to under report [24]. The use of video enables patients and caregivers to see events that they may have missed. Many security cameras already have video indexing features [155].

3.      **Hardware and software are affordable and readily available** - Finally, seizure detection devices and video recording hardware are becoming increasingly affordable and therefore may be applicable for extended use for patients at home or college. The SAMi Sleep Activity Monitor [156] can already be purchased online.

In the future clinicians may be able to greatly improve self-reporting seizure reporting quality by sending patients and caregivers home with video review hardware for dismissing misclassified wristband-detected seizures between appointments. Informal interviews conducted following the review suggest that privacy may not be a chief

concern among families; two caregivers remarked that they would like to see patient seizures at night, and when asked, the patients each said that they would be comfortable with having caregivers perform this task on their behalf.

*6.4.7 Conclusion*

This study examined the extent that a patient and caregiver video review can improve the quality of seizure counts that are reported using commercially available seizure detection wristbands.

The study employed Empatica E4 seizure detection wristbands and video recording during patient EMU visits. The wristbands detected seizures that patients would likely have otherwise missed or have been unable to report [24]. The subsequent video review enabled patients and caregivers to review video of wristband detected seizure events and reject false alarms. The resulting annotations addressed clinical performance requirements by rejecting false alarms that would otherwise contribute to over reporting and could thereby improve the quality of seizure counts.

The initial results show that introducing a video review can indeed improve the quality of automated seizure counts from a pair of wearable seizure detection wristbands. The participants successfully identified and rejected 8 out of 8 false alarms. These findings suggest that pairing seizure detection wristbands with additional video capture could help to address high false alarm rates among current non-EEG seizure detection devices by enabling patients and caregivers to improve the quality of seizure count reports prior to clinical appointments.

**6.5 Study #5 - Mobile/wearable self-management interventions**

My fifth and final study reflects all three research aims: establishing data collection needs, improving data collection quality, and evaluating patient engagement.

Moreover, how can existing mobile and wearable technologies enable patients and caregivers to more consistently, promptly and reliably collect patient health data on seizures, sleep, exercise, medication intake, and stress?

My colleagues and I chose to focus on supporting patient and caregiver self-reporting within the context of using mobile and wearable technologies in an effort to address self-management challenges that are unique to pediatric patients with epilepsy as described in chapter 1. The study was designed to help address the following three self-management challenges:

1. **Self-regulating patient behaviors** - New onset patients with epilepsy need to identify and practice effective habits for regulating certain behaviors such as sleep and exercise. Mobile and wearable technologies may be able to help summarize and present data for increasing patient self-efficacy.

2. **Self-reporting during treatment** - Neurologists need access to consistent, prompt, and reliable patient health data that families often fail to provide. Mobile and

wearable technologies may be able to help facilitate active and passive data collection for supporting clinical decision-making.

3. **Increasing self-reliance for adult care** - Many adolescents need additional support from caregivers as they learn to take on epilepsy self-management responsibilities. Mobile and wearable technologies could help to enable greater collaboration during this transitional period.

In this section, I present a mobile EMA study that involves the application of mobile and wearable technologies. The study had the following three objectives:

1. **Evaluate feasibility**- My first objective is to evaluate the feasibility of mobile EMA data collection in terms of consistency, promptness, and reliability between twice daily patient and caregiver surveys.

2. **Evaluate approaches -** My second objective was to evaluate the positive or negative impact of health tracking dashboards, motivational strategies and context-sensitive notifications on patient and caregiver self-reporting and patient engagement.

3. **Evaluate experiences** - My third objective is to investigate overall patient and caregiver user experience. It is important to understand interactions and use cases that are compelling or create barriers. In response, we looked at sustained use in the field between patients family members and healthcare providers.

*6.5.1 Introduction*

The purpose of this study was to investigate the effectiveness of mobile EMA surveys and supporting mobile and wearable technologies within the context of addressing daily

needs for pediatric epilepsy treatment.

Epilepsy treatment relies heavily on patients and caregivers to collect accurate patient health data for informing treatment, and many patients and families struggle with these daily responsibilities. Meanwhile, pediatric patients must learn how to manage and self-regulate behaviors in preparation for adult care and successful self-management. Mobile EMA surveys can be administered on smartphones, and evidence among adult patients suggests that these types of surveys may be helpful for informing epilepsy treatment [20]. Mobile and wearable technologies stand to further enhance mobile EMA effectiveness. However, research into the applicability of these benefits and attempts to adapt current mobile and wearable technologies for daily self-reporting among pediatric patients with epilepsy has been limited [30], [42]. Mobile smartphones are accessible, and most adolescents and caregivers do not require specialized training for tasks such as creating an account with a user profile for storing data.

As a pilot study, my key results centered on identifying when and how families responded to regular survey requests and establishing the feasibility of using this information to inform clinical care.

My findings included establishing existing data collection practices among patients and caregivers, evaluating the feasibility and performance of using mobile EMA and health tracking interventions to report patient health information and further evaluating impact of these interventions on patient engagement. Finally, an additional contribution of this work are design implications in Chapter 7 with the aim of informing the development of future self-reporting and management tools.

Medical literature and clinicians agree that patient reported seizure counts, medication adherence, sleep quality, mood, and sudden changes in exercise are important to consider when making medication adjustments [53]. However, there is limited guidance available regarding what health data families should collect and how often it should be collected. The most consistent requirements can be found in seizure reporting forms such as the Epilepsy Foundation, Seizure Observation Record [157] and include reporting time, number and duration of seizures.

Electronic seizure diaries are thought to reduce the overhead of keeping track of paper reports when patients and family members are attempting to document seizures and seizure triggers [158]. However, many patients struggle to report seizure events [15], [159]. Studies show that family and friends often disagree on important details when observing seizures [160], and diary techniques are known to be susceptible to response bias when information is entered after the fact [158].

Mobile phone EMA studies have become increasingly popular in recent years due to the widespread prevalence of smartphones [161], [162]. However, the clinical impacts of these studies are often limited due to short deployment periods or small numbers of participants [163]–[165]. EMA is a research method in which participants complete short sets of survey questions "in the moment" rather than responding to a longer survey at a later point in time [166]. Haut et al. [63] received high EMA response rates among adult patients with epilepsy, but the study did not include pediatric patients.

Mobile and wearable applications may also stand to improve mobile EMA effectiveness.

The introduction of context-sensitive notifications, health tracking dashboards, and motivational strategies have each been shown to be effective for supporting aspects of self-management among patients with chronic conditions.

1. **Context sensitive notifications** - "Blood glucose, spirometry, adherence (e.g. the number of cigarettes/pills), blood pressure, weight, physical activity, mental state, side effects" can now be documented using mobile phones [167]. Kaushik et al. [168] have shown that context-sensitive medication reminders can be more effective than traditional reminders that are scheduled at predefined times. Moreover, while Arsand et al. [71] have recommended similar types of reminders for pediatric patients with diabetes, context sensitive notifications have yet to be explored within the scope of epilepsy self-reporting and self-management.

2. **Health tracking and dashboards** - Health tracking and dashboards have also been shown to help patients with self-regulation. Guendelman et al. [169] showed that asthma diaries can significantly increase self-management indicators. Electronic seizure diaries have been explored within the context of pediatric epilepsy [30], but specific data collection needs were not studied. Moreover, studies suggest that self-reporting can increase patient self-efficacy [170]; however, more work is needed to assess trade-offs between active and passive data collection approaches among patients and caregivers.

3. **Motivational strategies** - Intrinsic and extrinsic motivational strategies can encourage pediatric patients with chronic conditions to perform similar daily self-management tasks such as patient-specific goal setting within the context of diabetes management [71] and external incentives, "pay for performance" incentives in the case

of childhood asthma management with outcome measures such as reduced "missed school days, missed workdays, and parent or patient confidence" [171]. Motivational strategies have been shown to be effective in other fields but have not been well explored in pediatric epilepsy treatment.

It would, therefore, be beneficial to investigate mobile and wearable interventions for supporting pediatric epilepsy self-reporting and self-management. In this study, I investigated the use of manual (active) data collection via mobile surveys and automated (passive) data collection approaches using health tracking devices.

*6.5.3 Methods*

The study included 30 families. The families were asked to complete EMA surveys using a mobile app for 30 days, and they were then randomly assigned to one of three conditions during enrollment. The survey questions reported on five topics that are important for epilepsy treatment: patient seizure counts, medication adherence, mood, sleep quality and exercise data. The participants each received daily reminders and notifications to complete surveys. To increase self-reporting accountability, I instructed the families that a clinician would review the data once per week. In practice, the clinician only reviewed a subset of families. Each family received a $20 gift card upon completing the study.

The study included three conditions: a baseline control and two experimental conditions. Each study condition included 10 families and shared a number of common sets of study components and outcomes measures. The experimental conditions each included the same mobile EMA surveys, clinical audience, and outcome measures as the baseline

condition but provided families with additional resources as shown in Table 8.

**Table 8 - Main study experimental conditions**



The research was informed by a 15 family pilot for the baseline and experimental

conditions. The remainder of this chapter elaborates on each study condition in more

detail. The following are key lessons that I learned from our pilot study:

- Importance of a single app - For the pilot, we used bookmarks for online surveys but
  we learned the importance of having an app-type environment for ease of usage.

- Higher response rates among patients than caregivers - The patients were more likely
  than caregivers to continue self-reporting. No caregivers reported for the entire 30
  day study period; while three patients reported for all 30 days.

- High drop-out rates were common during the initial phases of the study. Most
  participants did not complete self-reports after the first week of the study.

- Early adopters and champions - Identifying and working with a core group of beta-

testers were useful for addressing initial problems with the app such as daily reminders that were issued too frequently by accident.

### 6.5.3.1 Baseline Study Condition

Mobile and wearable devices are becoming increasingly capable of measuring many of the same behaviors that patients and caregivers are already asked to document as a part of "seizure diaries" [30].

The baseline study condition included 10 families and evaluated the feasibility of patients and caregivers using mobile EMA surveys to collect patient health information over 30 days. The surveys were administered daily, weekly, and following patient seizures events. The surveys documented five aspects of patient health: seizures, medication adherence, sleep, mood, and exercise. We selected these categories to reflect behaviors that patients and caregivers are already asked to *actively* report as a part of "seizure diaries" [30] and also could be *passively* reported using mobile and health tracking devices. I analyzed the responses to evaluate data collection practices, self-reporting performance, and changes in patient self-efficacy and PAM scores between intake and exit.

6.5.3.1.1 Mobile EMA component

My colleagues and I developed a mobile app called EpiSense for administering mobile
EMA surveys, sending reminders and reviewing patient data as shown in Table 9.

**Table 9 - EpiSense mobile EMA app/hardware components**



The app was designed to investigate the feasibility of patients and caregiver self-reporting
and provide a platform for evaluating subsequent experimental interventions.

*6.5.3.1.1.1. Surveys*

The participants were asked to complete four types of surveys with separate sets of
questions for patients and caregivers, respectively. The app administered intake and exit
surveys at the start and end of the study, daily and weekly surveys and event-contingent
seizure reporting surveys following patient seizure events.

The daily and weekly surveys collected information on patient seizures, medication adherence, sleep, exercise, mood, and location. The intake and exit surveys collected demographic information and patient engagement information. I reviewed and edited each set of questions with clinicians for feedback on response burden and question coverage. Each survey took 1-5 minutes for participants to complete. The total time commitment was estimated at 7-15 minutes per week.

The surveys included questions from 13 short-form instruments as shown in Table 10 and Table 11. I selected surveys that were both age and reading-level appropriate and also had been validated in extant research.

For example, the following three questions were selected from the Self-Efficacy for Managing Chronic Disease 6-item Scale (SEM-CD) [78] (questions 4-6):

1. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do? (4)
2. How confident do you feel that you can the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? (5)
3. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life? (6)

**Table 10 - Intake and Exit mobile EMA survey categories and instruments**

| Instruments | Intake Survey | | Exit Survey | |
|---|---|---|---|---|
| | Patient | Caregiver | Patient | Caregiver |
| **General** | | | | |
| Demographics | | 3 | | 3 |
| Data collection practices | 3 | | 3 | |
| **Self-efficacy** | | | | |
| Self-Efficacy for Managing Chronic Disease 6-item Scale (SEM-CD) [78] | 3 | | 3 | |
| **Activation** | | | | |
| Patient Activation Measure (PAM) [79] | 13 | | 13 | |
| **Seizures** | | | | |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | 2 | 2 | 2 | 2 |
| Epilepsy Foundation [157], [173] | 2 | 2 | 2 | 2 |
| **Medication** | | | | |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | 1 | | 1 | |
| **Sleep** | | | | |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | 1 | | 1 | |
| Medical Center Sleep Center [174] | 1 | 1 | 1 | |
| **Mood** | | | | |
| Patient-Reported Outcomes Measurement Information System (PROMIS) [175] | | 1 | | 1 |

| Spence Children's Anxiety Scale (SCAS) [176], [177] | 1 | | 1 | |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | 2 | | 2 | |
| Exercise | | | | |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | 1 | 1 | 1 | 1 |

**Table 11 - Morning and weekly mobile EMA survey categories and instruments**

| Instruments | Daily Survey | | Weekly Survey | |
| --- | --- | --- | --- | --- |
| | Patient | Caregiver | Patient | Caregiver |
| Seizures | | | | |
| Epilepsy Foundation [157], [173] | 2 | | | 2 |
| Medication | | | | |
| Morisky Medication Adherence Scales 8 (MMAS-8) [178] | 1 | 1 | 1 | 1 |
| Sleep | | | | |
| Pittsburgh Sleep Diary (PghSD) [179] | 2 | 2 | | |
| Children's Sleep Habits Questionnaire (CSHQ) [180] | | 1 | | 1 |
| Adult Epilepsy Self-Management Measurement Instrument (AESMMI) [172] | | | 1 | |
| Mood | | | | |
| Patient-Reported Outcomes Measurement Information System (PROMIS) [175] | 2 | 4 | 2 | 4 |
| How I Feel Chart TKG Inc [181] | 1 | | | |
| Exercise | | | | |

| CDC Middle School Youth Risk Behavior Survey [182] | 4 | 4 | 3 | 3 |
|---|---|---|---|---|

The majority of questions could be adopted verbatim with no changes in wording from the original survey instruments. I adapted several questions to clarify either the response interval (e.g. adding "in the last week" to questions) or the relationship between the participants (e.g. adding "your child" to questions to caregiver directed questions).

### 6.5.3.1.1.2. Reminders

The participants received reminders to complete daily survey instruments. The reminders were displayed as native in-app notifications on the participants' phone. The mechanics of reminders differed between study conditions. "Baseline" condition reminders followed a predefined schedule. The EpiSense app checked for survey completion every 5 minutes and triggered up to two notifications per day. By contrast, "health tracking dashboard" and "motivational strategies" condition reminders also checked for survey completion but triggered when the patient and caregiver were in close proximity as shown in Table 12.

**Table 12 - EpiSense daily survey reminders and patient-caregiver proximity tag**
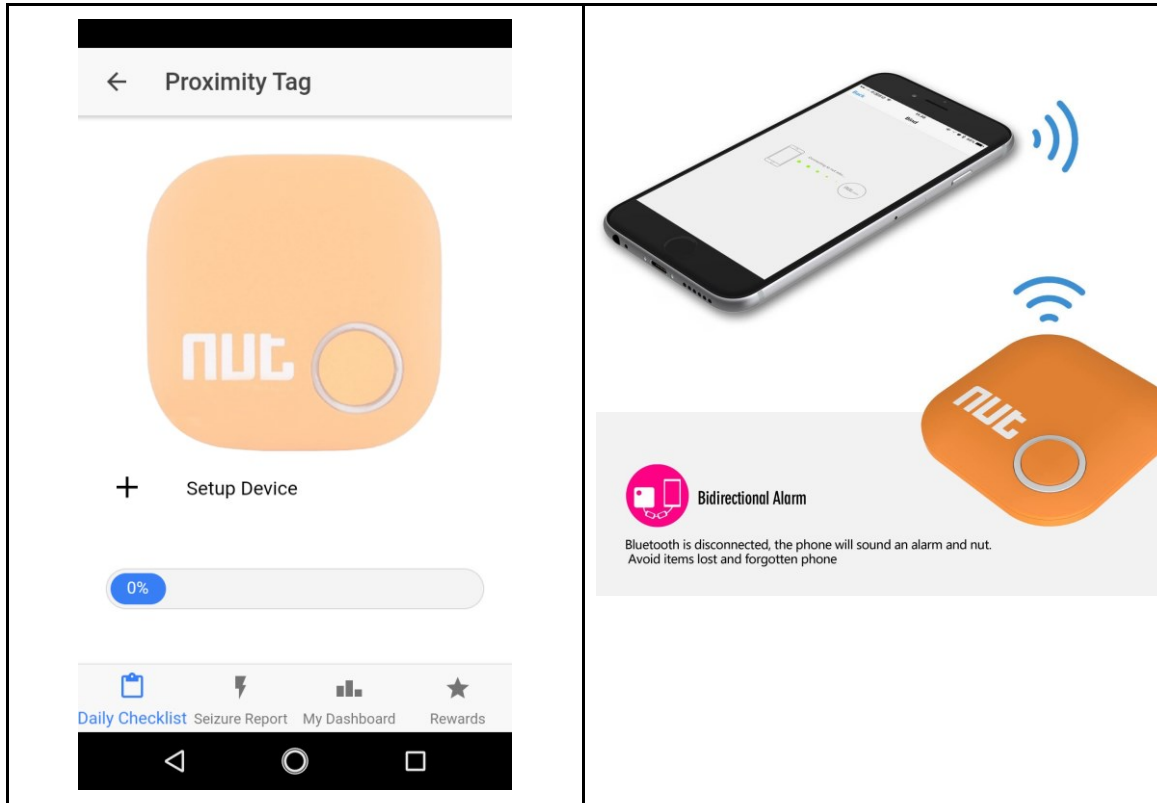
The reminders were sent according to the following schedule to accommodate typical school routines:

1. Intake and exit survey reminders were sent once per night at 8 pm

2. Morning and evening reminders were sent at 7 am and 8 pm, respectively

3. Weekly reminders were similarly be sent at 8 pm.

*6.5.3.1.1.3. Clinical Audience*

My informal interviews suggested that many caregivers perceived self-reporting as the patient's responsibility. The study included a nurse practitioner who reviewed patient and caregiver data once per week.

The nurse practitioner served as a "clinical audience" with the goal of further increasing

accountability and motivating caregivers to participate (i.e.collecting data could benefit

your child's treatment). The EpiSense app included a clinical dashboard for reviewing

patient and caregiver collected data during the study. The dashboard featured a timeline

summary of seizure counts, medication adherence, mood, sleep quality and exercise data

along with descriptive statistics as shown in Table 13.

**Table 13 - EpiSense clinical dashboard showing patient and caregiver collected data (Top-left) list of patients, (Top-right) clinical settings for maximum and minimum ranges and (Bottom) patient data displayed within specified ranges**
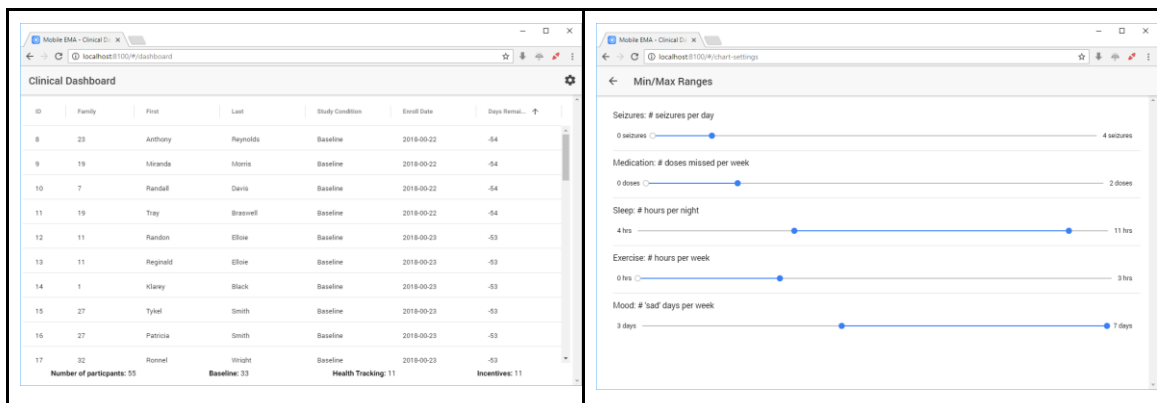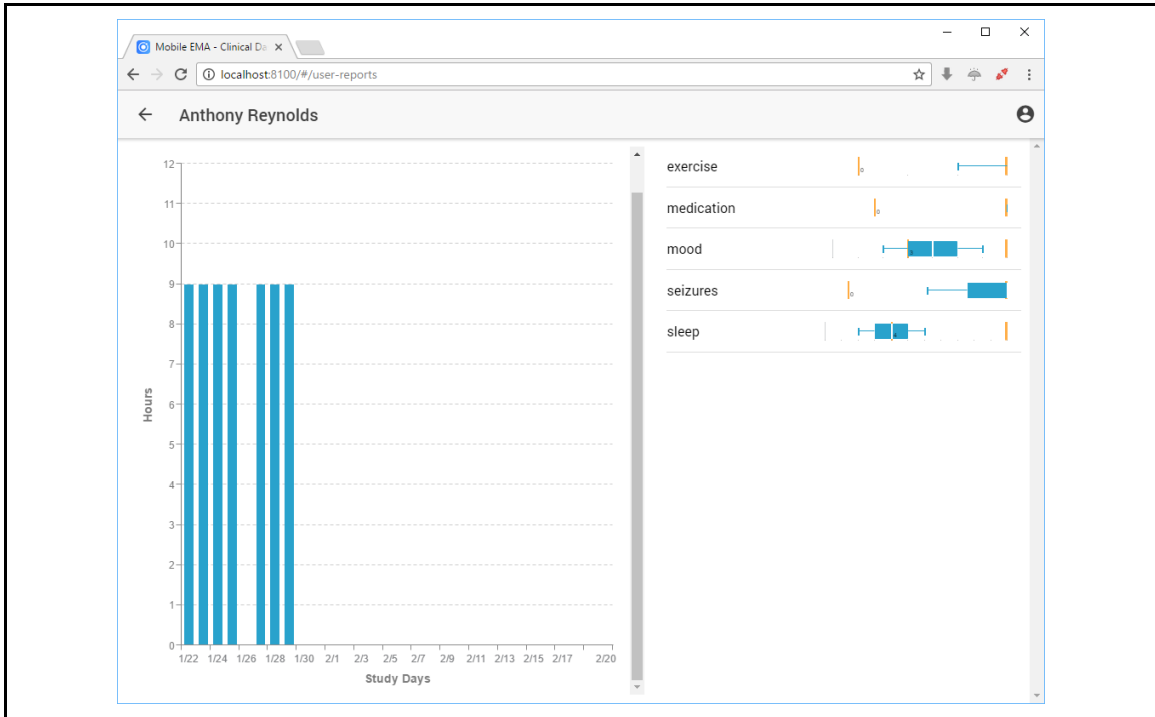
## 6.5.3.1.1.4. Software Architecture

The EpisSense app used the HIPPA compliant CHOA Redcap service to ensure that collected mobile phone survey responses and collected data remained confidential during the study. The Auth0 authentication platform was used for managing user login and passwords. Native SQLite was used for local data storage. The Redcap API was used as a remote storage platform. The participants' data was formatted as JSON files, encrypted and uploaded to Redcap as a file attachment each day as shown in Table 14.

**Table 14 - EpiSense and Redcap software architecture diagram**



6.5.3.2 Experimental Conditions

The study included the following two experimental conditions: 1) a health tracking dashboard and 2) motivational strategies. In each case, the participants were asked to complete the same mobile EMA surveys using the app but received additional resources. The relative impact of each condition was evaluated by comparing self-reporting and patient engagement outcomes against those from the baseline condition.

6.5.3.2.1 Health tracking dashboard

Health tracking devices were issued to patients and caregivers with the goal of encouraging patients' self-reflection and self-regulation. The devices measured patient medication adherence, sleep, exercise and helped to coordinate daily survey reminders. The EpiSense app presented this information on a health tracking dashboard that could be accessed "on-demand" during the study.

6.5.3.2.2 Motivational Strategies

Health trackers and an additional financial incentive were issued to participants for encouraging patients to complete a daily personal health goal. The patients set a health goal at the start of the study and received $5 a day in credit each time they completed the goal. The health tracking devices were used to assess whether or not patients achieved the goal (e.g. Fitbit sleep duration was used to assess the goal "get at least 8 hours of sleep each night").

In addition, the health tracking data were collected and compared against the patient and caregiver mobile EMA survey responses for an additional perspective on the reliability of patient self-reports (e.g. device reported sleep duration vs. self-reported sleep duration)."

6.5.3.3 Enrollment

The study included 30 families of patients with epilepsy at CHOA. The families were enrolled on a first-come, first-serve basis at the CHOA North Druid Hills outpatient clinic. Inclusion criteria included all families that have a child being treated for epilepsy at CHOA between the ages of 10-18 years old with access to an Android or iOS smartphone. The patient and caregiver had to own a smartphone. Exclusion criteria included non-English speaking participants and patients with severe intellectual disability and whose caregiver deemed that they would not be capable of completing daily surveys.

The families were enrolled following outpatient appointments. The nurse practitioner introduced them to an onsite study coordinator from Georgia Tech. The study coordinator then enrolled families and walked participants through installing the app and using any

applicable health tracking devices as summarized in Table 9.

My colleagues and I elected to enroll at least 30 families to provide a representative
patient population. The clinic admitted an average of 40-85 patients per week, and
epilepsy specialists see 10-50 families per week. The patients reflected a range of
socioeconomic backgrounds, levels of education, and types of epilepsy. I enrolled a total
of 48 families at a rate of 1-4 patients per week over a period of 18 months. 15 families
were recruited as beta-testers for the EpiSense app and were not included in the analysis.
33 families were recruited for the study. 3 of these 33 families either did not follow
through with installing the app or had other technical difficulties such as out of date
Android devices that prevented them from completing daily surveys.

6.5.3.4 Outcome Measures

My colleagues and I evaluated data collection practices, self-reporting performance and
patient engagement for each study condition.

6.5.3.4.1 Data collection practices

Intake and exit surveys were administered during study enrollment and completion. The surveys included questions on participant demographics and data collection practices.

6.5.3.4.2 Self-reporting performance

Self-reporting performance was assessed in terms of the consistency, promptness, and reliability of completing daily and weekly surveys. The surveys included questions on seizures, medication, sleep, exercise, mood, and location.

Self-reporting reliability was evaluated in terms of the percent agreement between patients and caregivers. Table 15 shows the agreement criteria that we used for between patients, caregivers, and devices.

**Table 15 - Reliability - Agreement criteria for measuring consensus between patients, caregivers, and health tracking devices**

| Data Type | Agreement Criteria |
| --- | --- |
| Seizures | Both respondents report the same number of patient seizure on a given date |
| Medication | Both respondents agree that a patient did or did not take his or her medications |
| Sleep | Respondents report sleep duration reports within +/- 1 hour of one another |
| Exercise | Both respondents agree that a patient exercised for at least 60 minutes |
| Mood | Both respondents report that a patient's mood is either above or below 75 on a continuous mood scale between 0-100 |

6.5.3.4.3 Patient engagement

The intake and exit surveys also measured patient engagement. The patients were asked to complete three questions from the Self-Efficacy for Managing Chronic Disease 6-item Scale (SEM-CD) [78] and the entire thirteen question PAM [79]. I calculated the relative change between these scores at intake and exit to assess the extent that each study condition may be able to improve patient self-efficacy and activation.

6.5.3.5 Data collection

The study collected intake and exit surveys, mobile contextual information, mobile EMA surveys, caregiver proximity information, and passive health tracking measurements. The following list describes each of these data collection instruments in more detail:

1.  **Intake surveys** - The participants each completed intake survey responses for establishing demographics, data collection practices. In addition, all patients were asked to complete the SEM-CD and PAM for assessing self-efficacy, and activation; "motivational strategies" patients were asked to select a personal health goal.

2.  **Exit surveys** - The participants were also asked to complete an exit survey. The exit survey included the same set of intake survey questions on data collection practices, patient self-efficacy, and activation along with additional user experience questions.

3.  **Mobile app usage** - The EpiSense app also collected patient and caregiver proximity and app usage information. This contextual information was sampled every hour and additionally each time the participants submitted a survey response. Finally, the app enabled participants in the "motivational strategies" condition to track whether or not

patients completed daily health goals.

4. **Daily survey responses** - The participants completed once daily, once weekly and event contingent mobile EMA surveys as previously described. The EpiSense app collected these responses to support treatment in the areas of seizure management, medication adherence, mood, sleep, and exercise.

5. **Health tracking device data** - The patients in the "health tracking dashboard" and "motivational strategies" conditions received additional health tracking devices that included a Fitbit Charge 2 and morning and evening Tricella pillboxes. Information from these devices was displayed on a patient health dashboard.

6. **Health activity/fitness tracker -** The patient were instructed to wear the Fitbit Charge 2 during the study for tracking daily exercise, sleep, and mood. A sedentary lifestyle can increase the risk of seizures. The Fitbit tracked step count and duration of moderate to intense exercise each day.

7. **Caregiver proximity tag -** The caregivers in the "health tracking dashboard" and "motivational strategies" conditions received an additional Bluetooth tag and a credit card sized insert that adhered to the back of his or her phone to carry the device. The patient's app paired with the tag to facilitate survey reminders when the Bluetooth tag came within range. The Received Signal Strength Indicator (RSSI) was measured every 2 minutes with the aim of triggering notifications when patients and caregivers were both nearby for encouraging discussion and peer support between participants.

8. **Medication adherence pillboxes** - Each family also received two Tricella pill boxes for measuring morning and evening medication intake. Most patients take morning

and evening medications at home. Medication is typically administered by a nurse at school. The pillboxes recorded the time that drawers were opened and closed to remove medication and sent this information to the patient's phone via Bluetooth.

<u>6.5.3.6 Analysis</u>

My analysis had the following three objectives:

1. **Evaluate feasibility and efficacy** - The first objective was to identify positive aspects of user experiences based on daily data collection practices and technology usage within each condition. I began by computing descriptive statistics on data collection practices and technology usage to better understand existing participant self-reporting practices. I then analyzed self-reporting performance to highlight opportunities for improving data quality. Finally, I compared patient self-efficacy and PAM scores between each study condition as an indicator of patient engagement.

2. **Evaluate experimental conditions** - The second objective was to identify study conditions that increased self-reporting performance metrics and improved patient engagement. In each study condition, I evaluated and compared 1) data collection practices, 2) self-reporting performance metrics, and 3) patient engagement scores.

3. **Evaluate the context of use** - The third objective was to identify conditions that increase patient self-efficacy and PAM scores as compared with study outcomes from patients in the "baseline" condition.

*6.5.4 Results and Discussion*

The study was conducted in two phases: a testing phase and a production phase. Please

see Appendix C for more detailed family-by-family self-reporting comparisons.

1.  **Testing Phase -** The testing phase included field testing mobile surveys during a 4 month evaluation period. I enrolled 15 families as beta-testers. Low response rates prompted me to make a number of changes such as reducing the frequency of surveys from twice daily to once daily and reducing the number of questions overall. The low response rate also motivated the experimental condition with motivational incentives.

2.  **Production Phase -** The production phase occurred during the next 20 months. I recruited 33 families and made considerable refinements to the app including adding support for context sensitive notifications, integration with health tracking devices, summarizing health information on a mobile dashboard, and enabling patients to monitor the completion of daily health goals.

The remainder of this chapter will only refer to results from the production phase due to notable changes between EpiSense app following the testing phase.

## 6.5.4.1. Demographics

In the final study, the patients were age 10-15 (Mean, 11.2, SD 4.31), primarily female 60.0% (male 40.0% and prefer not to disclose 0.0%), and split equally between races white and black (white 50.0%, black 50.0% and Asian/Pacific Islander 0.0%). Neary all patients were enrolled in elementary school at the time of the study, 80.0% (80% elementary school and 20.0% high school). Most patients had well controlled epilepsy. The average time since diagnosis varied between 0-5 years (Mean 2.0, SD 1.9 years). The majority of caregivers reported that patients had been seizure free for at least 5 months prior to enrollment (Mean 5.94 months, SD 8.88 months).

The caregivers tended to be college educated (30.0% high school, some college 20.0%, 50% college and 20.0% college or above), female 90.0% (male 10.0%) and of white race 50.0% (black 50.0% and Asian/Pacific islander 0.0%).

The nurse practitioner had 5 years of experience prescribing medications and worked full-time at CHOA. Her schedule included an estimated 160 average of hours of direct patient care per month at the time of the study.

## 6.5.4.2. Data collection practices

Intake surveys were used to establish baseline measures on self-reporting behaviors. Table 16 shows the percentage of all participants that reported they were already collecting patient data prior to the study along with the method used for data collection.

**Table 16 - Historic self-report of data collection practices**

Intake survey responses: patients (n=14), caregivers (n=10)

Prompt: I keep track of how often I have seizures
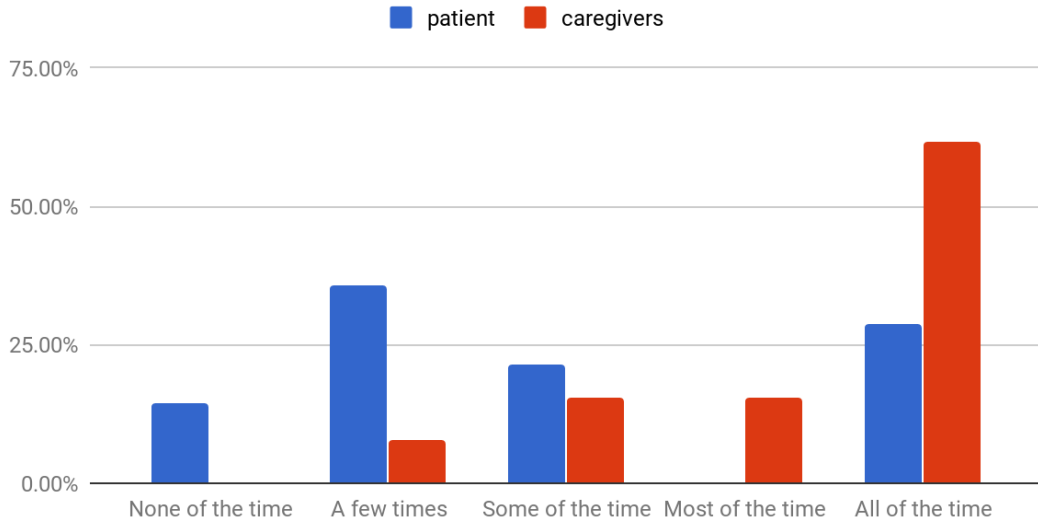


Patient Intake Survey Responses (n=12)

Prompt: I record my seizures with
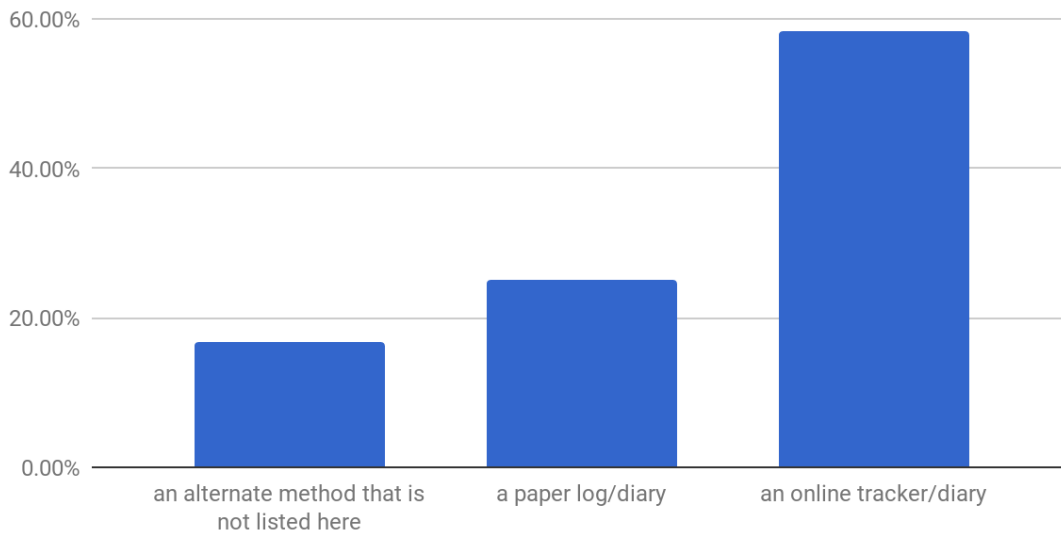


6.5.4.3. Self-reporting performance metrics

This section will present the consistency, promptness, and reliability of self-reporting

98

among patients and caregivers. My colleagues and I encountered two sets of challenges that impacted our evaluation approach.

1. **Many participants did not engage beyond completing the initial intake survey.** In response, results will be presented twice: once in terms of all participants and once in terms of only those participants who reported data past study day 5 of 30.

2. **Many families did not collect data past the first week of the study.** In response, results will similarly be presented twice: once in terms of all participants and once in terms of only those participants that continued reporting past the first week of the study (i.e. past day 5 of 30).

3. **Most patients did not report exit surveys.** In turn, patient engagement will be discussed in terms of patient case studies rather than descriptive statistics due to the low number of intake and exit survey responses. 13 patients completed the intake survey; only 2 patients completed the exit survey.

6.5.5.1. Data collection practices

This section investigates current patient and caregiver data collection practices. Intake surveys responses in Table 16 show that all caregivers (10 out of 10 caregivers) and most patients (12 out of 14 patients) responded that they reported seizure frequency (i.e. how often seizures occurred). In addition, while most patients did not regularly keep track of seizures, patients preferred electronic tools. This suggests that patients may be good candidates for using mobile apps for self-management purposes.

Internet connectivity and the popularity of electronic seizure diaries among patients

suggest that a mobile platform may be well suited for patients and caregivers. The patients tended to use electronic data collection tools (5 out of 14 patients) over paper diaries and alternative methods (4 out of 14 patients and 4 out of 14 patients). Nearly all participants had access to the internet. In one case, a patient had an older Android tablet that was unable to connect to the internet via wifi. The caregivers had a mix of Android and iOS smartphones with monthly data plans. The patients had similar smartphones but less consistent internet access. Most patients relied on wifi for for downloading the app during enrollment while others had data plans. The EpiSense app supported offline access. Internet connectivity did not appear to be an issue for us during the study.

### 6.5.5.2. Self-reporting performance metrics

This section investigates how can mobile interventions help patients and caregivers to more consistently and reliability collect clinically relevant health data during treatment.

### 6.5.5.2.1 Consistency

The consistency of patient and caregiver self-reports is important for attributing cause and effect between patient health behaviors and seizure frequency. Most of the families in our study struggled to consistently collect data; however, families in the experimental conditions were able to collect data much more regularly.

The participants tended to fall into one of two groups: those that reported for the entirety of the study and those that stopped reporting following enrollment or after the first week. Non-starters were most frequent among families in the baseline condition with 7 of 16 families not completing any surveys and all families from the experimental conditions

completing at least one survey. In Appendix C, we can see that roughly one third of participants (11 families, 36.66%) stopped collecting data after 1 week (5 of 30 days).

In addition, self-reporting tended to be the most consistent among families of patients that had frequent seizures. In Appendix C, we can see that patients from families 4 and 24 reported seizures. These families reported more consistently than families 12 and 32 that were in the same study condition but were patients did not report having seizures.

Interestingly, we did not observe a causal relationship between the date of patient seizure events and the subsequent consistency of self-reporting. For example, there was no noticeable uptick in overall self-reporting frequency in the days following seizure events.

6.5.5.2.2 Promptness

The promptness of self-reporting is important to consider for anticipating recall bias. In the past, studies have studied the consistency of patient reporting but not the promptness of reporting [56]. In our case, participants received up to two daily reminders to complete daily and weekly surveys at 7 am. The average time delay or latency between the 7 am target time and participant responses was 9.38 minutes after the first reminder (SD 6.27 minutes) among all study conditions.

Introducing patient-caregiver proximity reminders appears to have had an impact on promptness in the experimental conditions. The promptness of participant reporting is shown in Appendix C. The average latency was highest among participants in the "baseline" study condition at 12.67 minutes followed by "health tracking" at 7.46 minutes and "motivational strategies" at 3.77 minutes.

6.5.5.2.3 Reliability

The reliability of self-reporting is another important consideration given the absence of traditional ground truth measurements for certain daily survey questions. In this case, we measured pairwise inter-rater reliability between patients, caregivers and devices reports on patient seizures, medication intake, sleep, mood and exercise as shown in Appendix C.

In some cases, the generalizability of our results are limited by the number of families that reported data on the same dates. My colleagues and I rarely received self-reports from both sets of participants on the same dates. Instead, a single engaged patient or a single caregiver tended to provide most of the self-reports. For example, in Appendix C we can see that patients but not caregivers regularly reported submitted daily surveys in families 1, 6 and 26. By contrast, caregivers but not patients regularly reported in families 8, 23 and 31. In response, I will present individual case studies to investigate the question "when patients and caregivers reported data, what did they agree and when did they disagree?".

Table 17, shows percent agreement between patients and caregivers given study dates when both the patient and caregiver submitted daily surveys on the same study dates. The highest agreement was on seizures at 89.89% followed by sleep at 49.07%. Medication intake and and exercise appear to be more difficult for both participants to observe at 32.89% and 14.29%, respectively. In addition, Table 18 presents percent agreement between study conditions in terms of five levels of agreement: "None" for no agreement (0%), "slightly" (1-25%), "moderate" (26-50%), "agree" (51-75%) and "strongly agree" (76-100%). It should be noted that no seizures occurred during the baseline condition. No

agreement was present among respective medication and sleep reports. This disagreement

could be due to "false" being the default response when respondents skipped questions.

**Table 17 - Reliability - Percent agreement between patient and caregiver. (Top) Daily self-reporting among all families. (Bottom) Daily self-reporting among only those families that continued reporting past past day 5 of 30 of the study.**

% Agreement (0-30 days)



% Agreement (0-30 days)
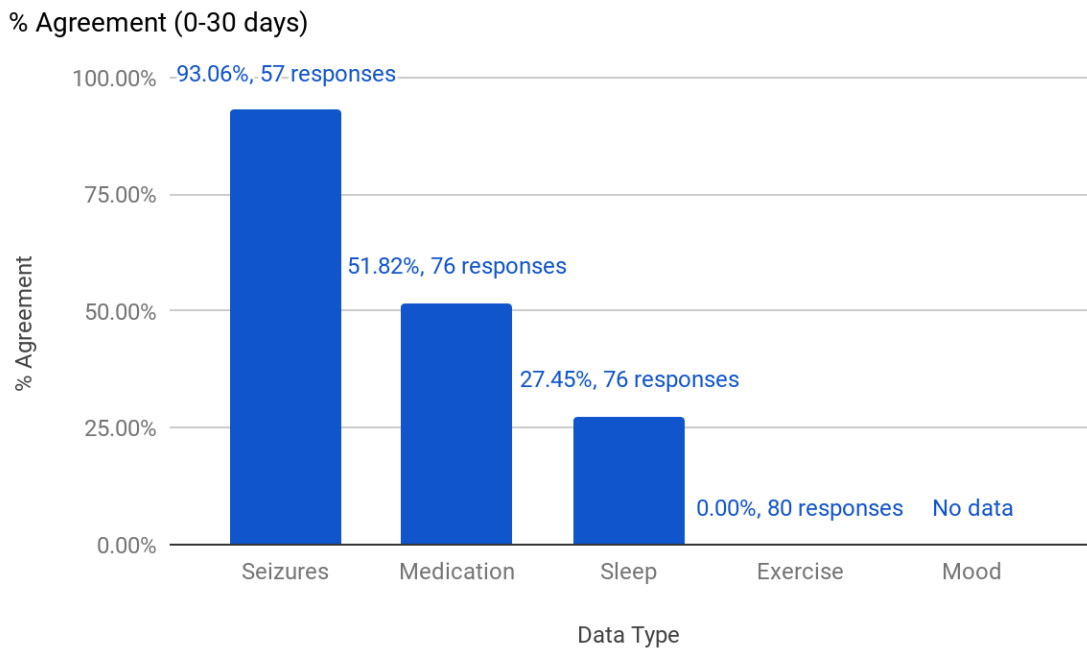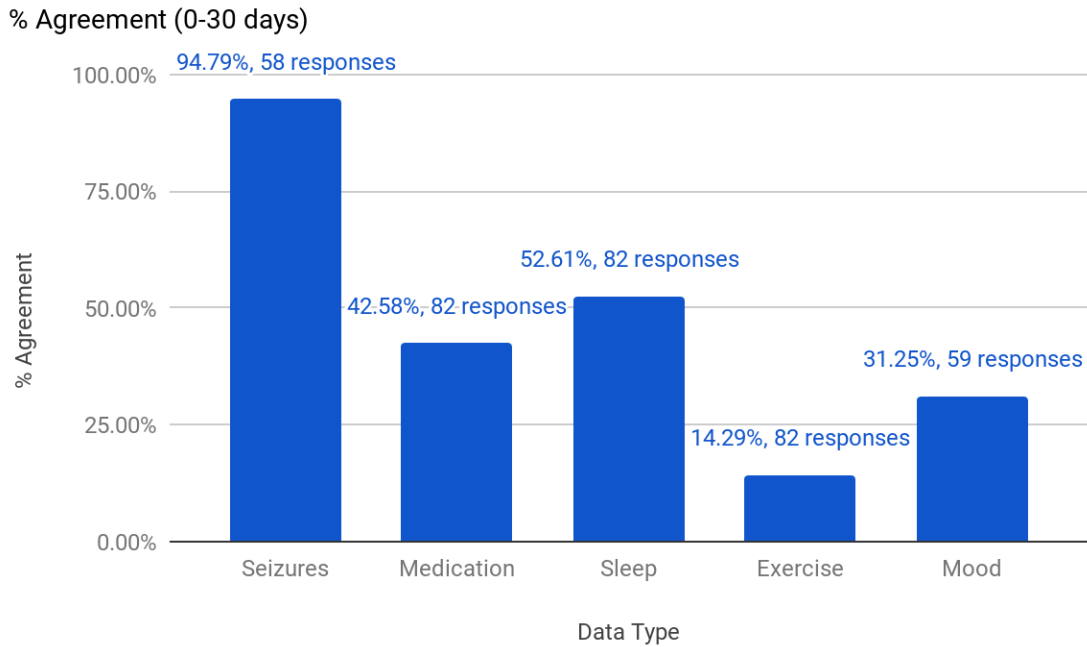
**Table 18 - Reliability levels by study condition**

| # | Study Condition | Data Type | | | | |
|---|---|---|---|---|---|---|
| | | Seizures | Medication | Sleep | Exercise | Mood |
| 1 | Baseline | None | Strongly | Moderate | Moderate | Moderate |
| 2 | Health Tracking | Strongly | None | Moderate | None | Moderate |
| 3 | Motivational Strategies | Strongly | None | Moderate | None | Moderate |

6.5.5.3. Patient Engagement

This section investigates the effectiveness of mobile interventions for increasing patient engagement. Intake and exit patient SEM-CD and PAM scores showed a slight improvement for patient 65 in the "motivational strategies" condition with a change of 48.00 and 29.90, respectively. By contrast, patient 27 from the "baseline" condition had a slide degrease with a change of -119 and -7.41, respectively.

This initial decrease in PAM could be due to patients discovering the need to better manage symptoms. In a study from Disabato et al. [183]; patients experienced a similar decrease in PAM following an intervention. It follows that a a short-term decrease in PAM could be a natural part of is a natural part of developing self-management skills.

The intake and exit surveys included the SEM-CD and PAM instruments for measuring changes in patient engagement. In practice, we only received 2 out of 30 patient exit surveys thereby limiting our ability to make direct comparisons on patient engagement measures. In response, we will only present patient case studies where both intake and exit surveys are available.

Table X and Table 20 shows the mean SEM-CD and PAM scores during the intake surveys. The charts show 5 sets of SEM-CD and PAM survey responses from patients in the "baseline" condition, 5 from patients in the "health tracking dashboard" condition and 2 sets of responses from patients in the "motivational strategies" condition.

Table 21 shows survey results for two specific patients where we had both intake and exit surveys. The results suggest that patient engagement may decrease for patients in the "baseline" condition and increase for the "motivational strategies" condition.

The SEM-CD and PAM scores both decreased for patient 27 in the "baseline condition". It could be that self-reporting causes some patients to recalibrate their previously held health beliefs. In the short term, patient engagement may decrease as patients realize the need to develop certain aspects of self-management. By contrast, SEM-CD and PAM scores both increased in the case of patient 65 in the "motivational strategies" condition. It could be that goal setting and financial incentives motivate certain patients to address long-standing self-management issues.

**Table 19 - Patient engagement - Intake SEM-CD scores by study condition**

## Intake SEM-CD Scores
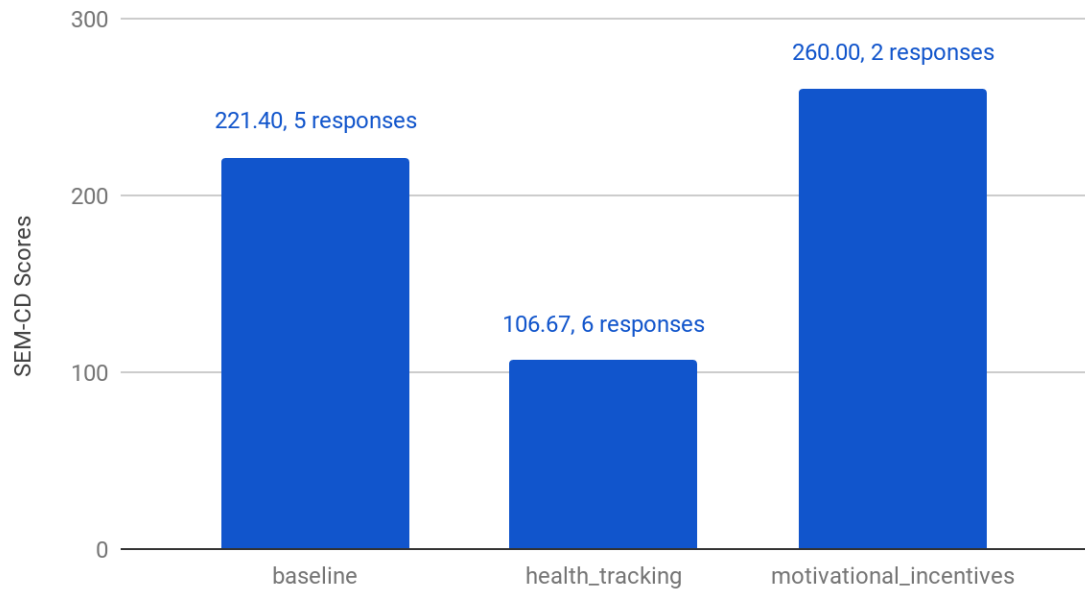


## Table 20 - Patient engagement - Intake PAM scores by study condition

## Intake PAM Scores
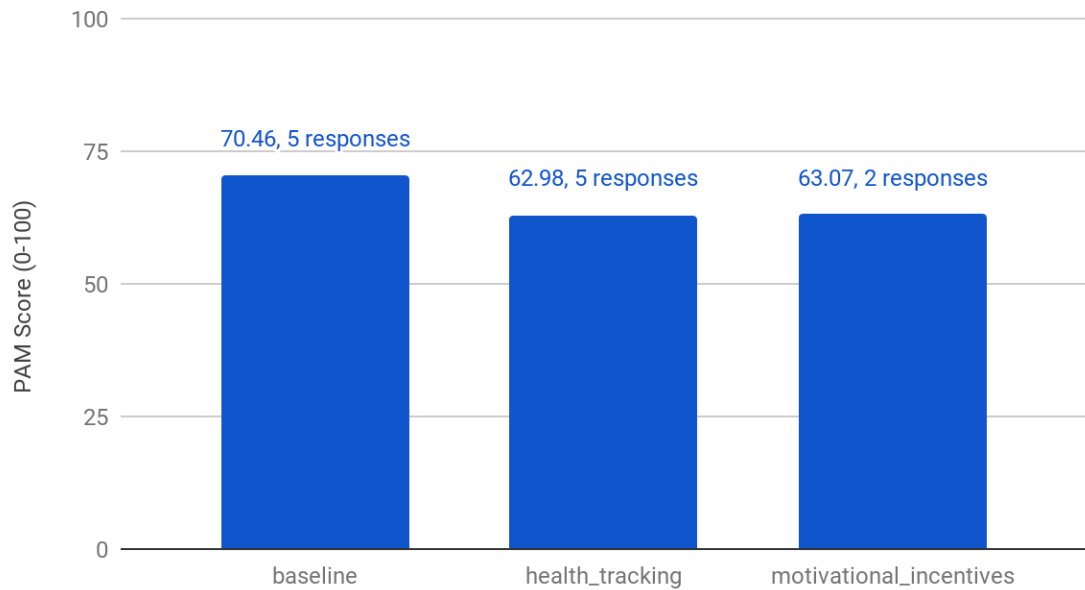
**Table 21 - Patient engagement - Case studies (patients 26 and 56)**
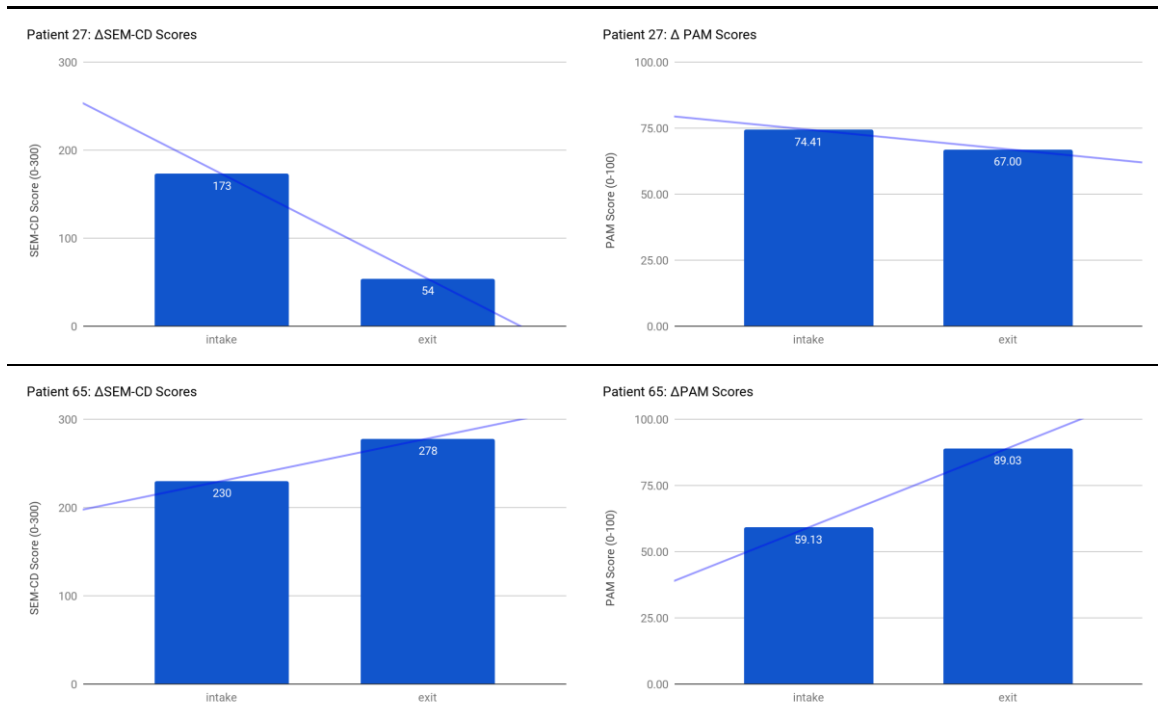


*6.5.6 Conclusions*

This study investigated the feasibility and effectiveness of mobile EMA surveys and mobile and wearable technologies within the context of addressing daily needs for pediatric epilepsy treatment.

My colleagues and I administered mobile EMA surveys among pediatric patients and caregivers to collect daily information for informing epilepsy treatment and improving patient self-efficacy and activation. In addition, I investigated the role that introducing additional health tracking, a health tracking dashboard and motivational strategies could play in further improving the consistency, promptness and reliability of EMA surveys. For example, patients and devices are likely best for collecting mood and exercise data

while caregivers are likely best at collecting seizures, medication intake and sleep.

The results among families that continued reporting past the first week of the study highlighted three important findings.

1. Mobile EMA may be well suited for patients. Most patients that report seizures keep track of them using an electronic method (e.g. tablet, website).

2. Mobile EMA is feasible for collecting daily patient and caregiver self-reports. The EpiSense app enabled participants to successfully complete health daily surveys.

3. Motivational strategies are important for engagement. Initial case studies suggest that enabling patients to select a health goal and receive daily financial incentives can increase patient SEM-CD and PAM scores.

Mobile EMA interventions can therefore play a role in supporting patients and caregiver data collection and patient self-management between clinical appointments. In addition, more research is needed for engaging families, incentivizing daily patient and caregiver data collection and increasing patient SEM-CD and PAM.

# CHAPTER 7.    IMPLICATIONS FOR DESIGN

The following is a summary of our findings to serve as guidelines for developing future pediatric self-management tools. This section consolidates our findings from studies 1-5 and highlights additional design insights from our conversations during enrollment.

These design insights include approaches for addressing data collection needs, improving data collection quality in terms of consistent, prompt and reliable patient and caregiver data collection, and increasing patient self-efficacy and PAM scores.

## 7.1 Establishing Data Collection Needs

The first set of design implications were derived from patient, caregiver and clinician self-reporting and self-management needs. These design implications include prioritizing self-reporting to reflect patient priorities such as reporting mood while at school as well as recommending technology interventions that address social stigma considerations.

It would be beneficial to prioritize additional information on standard seizure reporting forms. Mental health and sleep related responses could be highly beneficial for clinicians. In addition, not all information has to be entered by the patient as discussed in study #2.

The PedsQL [184] is an excellent example of a short form survey that captures relevant psychological information during treatment. In our local area, researchers at CHOA are considering the use of several mental health screeners during outpatient research studies.

**7.2 Improving Data Collection Quality**

The second set of design implications focused on the extent to which mobile and wearable devices and incentives can improve data quality. The following are six recommendations that draw from our research for improving data quality:

1. **Navigating data collection roles -** Minimizing the response burden is a must for long-term data collection. It is therefore important to choose the best person or device for collecting specific types of information. Health tracking devices agreed well with self-reported exercise, medication intake and sleep. It may therefore be helpful to focus or limit "active" patient data collection to mood, focus caregiver efforts on documenting seizures and focus "passive" health tracking data collection devices on the remaining areas of exercise, medication intake and sleep, respectively.

2. **Reviewing nighttime seizure reports -** In study #4, I showed that patients and caregivers can greatly reduce false positives given video of wristband detected seizure events. It may, therefore, be helpful to incorporate an additional video review for reducing false alarms when using seizure detection wristbands.

3. **Implementing motivational strategies for consistent and prompt data collection -** It is also important that data collection be both consistent and prompt for informing treatment and identifying successful self-management strategies. In study #5, we found that the "motivational strategies" condition increased engagement. It may therefore be helpful to apply similar incentives at the onset of an intervention for establishing a baseline of patient and caregiver self-reports and passive sensing reported measures. For example, patient reported sleep duration may have a systematic bias and tend to be reported one our earlier than Fitbit reported sleep

duration. Then passive health tracking measures could supplement or replace patient and caregiver self-reporting after this initial motivational incentives stage.

4. **Encouraging reliable data collection among families** - It is important for clinicians to be able to rely on self-reported data collection. In study #5, my colleagues and I experimented with traditional reminders and patient-caregiver proximity reminders. Informal conversations with families suggested that reminders in general were useful. It may therefore be useful to experiment with multiple approaches for reminding patients and then use the approach that elicits the most consistent response for individual families.

5. **Reflecting on patient health as a part of daily/weekly routines** - The health tracking dashboard was frequently used by caregivers, less so by patients. It appears from the EpiSense app usage logs that caregivers used the app at particular times of the day or on particular days of the week such as the weekend. It may, therefore, be helpful to ask participants to input a prefered schedule in advance or predict this schedule automatically based on weekly routines.

6. **Respecting patient and caregiver privacy -** It is also important to respect patient and caregiver privacy. A central goal of self-management is for patients to become self-sufficient at managing epilepsy. Interventions should be evaluated to ensure that patients feel more empowered and independent, not less. In study #3, patients expressed that they would be comfortable with having a caregiver review video of them, but were often expressed discomfort with reviewing seizure videos. It may be safest to design support services for use in the home as opposed to a public setting.

## 7.3 Evaluating Patient Engagement

The third set of design implications focused on the extent that mobile and wearable devices and incentives can improve patient engagement. Overall patients and caregivers from our studies were generally eager to try new technologies and consider new technology applications, seeing such services as opportunities to improve their quality of life. In addition, initial result from study #5, show that the motivational strategies that we explored increased patient engagement. I would, therefore, recommend patient goal setting and financial incentives for future studies.

# CHAPTER 8.    CONCLUSIONS

Epilepsy self-management practices are essential for effective epilepsy treatment yet patients and caregivers often cannot complete these tasks due to a range of logistical, social and epilepsy-specific challenges.

My colleagues and I investigated the feasibility and effectiveness of mobile and wearable technologies for supporting daily epilepsy self-reporting and self-management among a diverse group of adult and pediatric patients with epilepsy.

My subsequent research results have identified a range of clinical information needs during epilepsy treatment and highlighted several approaches for addressing them.

- Seizure detection wristbands and a follow-up video review process can provide more accurate patient seizure reporting during treatment by reducing false alarms.
- Daily patient and caregiver surveys can provide clinicians with additional types of health data that are important to have during treatment such as medication intake, sleep, mood and exercise.
- Goal setting and daily financial incentives can increase patient and caregiver engagement for some, at least during an initial phase of data collection.

The remainder of this section summarizes key findings related to the following three research needs:

## 8.1 Establishing Data Collection Needs

The most pressing clinical data collection need among clinicians was accurate seizure

counts. It's critical that patients and caregivers maintain accurate records of seizures between appointments yet studies have shown that patients often struggle with this task and are typically unable to report seizures at night. In addition, behaviors such as daily medication intake, sleep, exercise and mood are also important seizure precipitates yet typically not available.

My colleagues and I also gained valuable insights regarding data collection practices and privacy preferences. In study #4 patients reported that they would be comfortable having a caregiver review video of possible seizure events in bed. In study #5 patients similarly reported that they would not mind having a caregiver and clinician review the data that they collected. In each case, I observed patient safety and independence may outweigh certain privacy concerns.

It is therefore essential to consider these factors when evaluating how computing may be able to support patient and caregiver data collection.

## 8.2 Improving Data Quality

EMA is a feasible approach for collecting data from patients and caregivers but must be designed around routine interactions to be useful and adopted.

Health tracking can be a collaborative activity between patients and caregivers. Mobile Everyday Computing [80] has served as a useful research and design during out studies. Interviews with families in studies #3, #4 and #5 highlighted a myriad of different family scheduling constraints. In study #5, I intentionally designed for interruptions and flexible scheduling. Introducing "contingent" reminders within the "health tracking" and

"motivational incentives" conditions better accommodated caregivers with "late" shifts and patients with phone use restrictions or events such as after-school basketball practice.

## 8.3 Evaluating Patient Engagement

The "baseline" condition appears to have had a neutral to negative impact on patient engagement patient 27's responses showing a decrease in SEM-CD and PAM scores.

No exit surveys for evaluating SEM-CD and PAM among patients in the "health track dashboard" condition.

"Motivational strategies" had a positive impact on patient engagement. Many patients checked on daily goal attainment multiple times per day. Initial results based on patient 65's responses showed an increase in SEM-CD and PAM scores between intake and exit.

# CHAPTER 9. CONTRIBUTIONS

My research has contributed to the fields of HCI and health informatics by addressing long-standing gaps within the literature and laying the groundwork to develop future tools for supporting pediatric and adult epilepsy treatment and patient self-management.

In study #5, I designed and evaluated a mobile data collection application based on clinical self-reporting needs that I identified from studies #1 and #2, and family self-management needs that I identified from studies #3 and #5. For example, daily surveys prioritized information that clinicians reported needing most during studies #1 and #2 (e.g. seizure counts, medication adherence, sleep, mood, and exercise).

My key contributions include:

1. **Establishing data collection needs during epilepsy treatment** and investigating the extent that current technologies may be suitable for addressing these needs,

2. **Investigating new methods and strategies for improving data collection quality** as well as identifying the need to improve specific aspects of data collection quality,

3. **Evaluating data collection utility from the perspective of improving patient engagement** with respect to patient self-efficacy and activation scores.

Table 22 describes the main results of each of my studies as a first step for addressing each of the three respective epilepsy self-management needs that I identified.

**Table 22 - Research results and research contributions**

| Research Contributions | |
|---|---|
| **#1 Establishing data collection needs** | • Improved the state of knowledge regarding self-management data collection needs by:<br>  ○ Establishing clinical self-reporting data collection needs<br><br>• Established design insights for mobile/wearable self-management tools by:<br>  ○ Reported the extent that current devices address these needs<br>  ○ Reported the extent that patients/caregivers can use these devices<br>  ○ Reported patient/caregiver preferences with respect to mobile EMA and active/passive data collection |
| **#2 Improving data collection quality** | • Improved the state of knowledge regarding data collection quality by indicating when and where mobile/wearable interventions might further improve upon mobile EMA outcomes.<br>  ○ Showed that Empatica E4 seizure detection wristbands can improve "seizure count" data quality relative to patient self-reporting at night<br>  ○ Showed that a patient and caregiver video review of E4 wristband detected seizure events can improve "seizure count" data quality<br><br>• My studies also:<br>  ○ Evaluated patient and caregiver consistency, promptness, and reliability when collecting data using mobile EMA surveys<br>  ○ Showed that a clinical audience may increase mobile EMA adherence and reliability<br>  ○ Showed that a health tracker may increase mobile EMA adherence and reliability<br>  ○ Showed that goal setting and rewards further may increase adherence and reliability<br>  ○ Identified differences between active and passive data collection reliability |
| **#3 Evaluating patient engagement** | • Evaluated the impact of these data collection on patient health scores.<br>  ○ Reported the impact of these tools on patient self-efficacy [185].<br><br>• My studies have shown that, for some families, motivational strategies such as goal setting & financial incentives may increase patient engagement |

More broadly, my findings serve to guide the development of future, family focused,

mobile and wearable epilepsy self-reporting and management tools.

In Chapter 7, I presented a set of design implications for supporting both clinical treatment and daily self-management among patients, caregivers and clinicians as an important step for ensuring that patients make a successful transition between pediatric to adult self care.

# CHAPTER 10.    FUTURE DIRECTIONS

I recently accepted a postdoc position at the Boston Children's Hospital (BCH).

I am excited to continue our research in the area of pediatric epilepsy treatment. I will be working with a team to develop seizure detection devices and self-management tools.

## 10.1 Establishing data collection needs

### 10.1.1 Sustained passive sensing

It is important to be able to reflect back on patient health information prior to a seizure event. The challenge is that people tend to be less motivated to collect patient information in the absence seizures or when health information doesn't appear to change over time.

Most families are asked to report patient seizures during routine appointments. Newly diagnosed patients and patient caregivers tend to collect detailed patient health information for the first few months following diagnosis but then gradually collect less detailed information over time. For example, one mother showed us a spreadsheet that diligently tracked of her daughter's daily medication intake, sleep, diet, mood and menstrual periods for two months following diagnosis but tapered off by the third month. Similarly, a father showed us his entries from a SeizureTracker app that he used for documenting his daughter's seizures. He initially documented his daughter's medication, postictal symptoms and seizure type but later only reported seizure onset time and duration as the other information did not change.

"Motivational strategies" and passive health tracking devices from study #5 may be helpful for enabling families to monitor for sudden changes in patient health without having to manually collect as much information. For example, an intervention could include financial incentives that encourage patients and caregivers to gradually scale up daily self-reporting to include additional types of patient health information beyond seizure counts such as medication intake, sleep, exercise and mood. This more detailed information could then serve as an initial baseline of typical patient behaviors. Health tracking devices could then be used to identify significant changes from this baseline without additional patient or caregiver reporting.

*10.1.2 Informing Treatment*

Healthcare costs are increasing. New forms of patient outreach could help to address aspects of these challenges. I recently worked with a team of undergraduates at Georgia Tech and a nurse practitioner at CHOA to develop a clinician dashboard as described in Chapter 6. More work is needed. For example, existing electronic health records (EHR) are poorly suited for showing temporal relationships between medication intake and behavioral factors that can impact seizure control as shown in Figure 2.

It may therefore be beneficial to investigate these types of workflows and relationships further for supporting clinical practice.
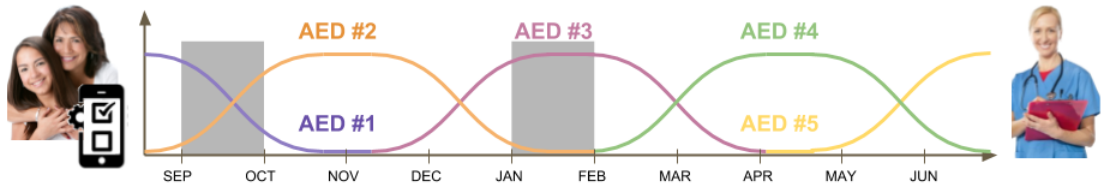
**Figure 2 - Examining temporal relations between medication and seizure control**

## 10.2 Improving data collection quality

Existing seizure detection devices do not detect non-convulsive seizures. It would be helpful to support a broader range of seizure types. In my research, I looked into the feasibility of additional types of sensing. Environmental sensors tends to be less intrusive but provide a poorer signal while patient worn devices tend to be more intrusive with the benefit of a better signal as shown in Figure 3. EEG headbands with soft conductive thread and higher resolution pressure sensing mattress pads can likely detect more subtle seizures and limb movements that likely would not have been detected during previous studies. In both cases, my proposed video review approach from study #2 could help to collect patient specific seizure examples for patient specific machine learning.
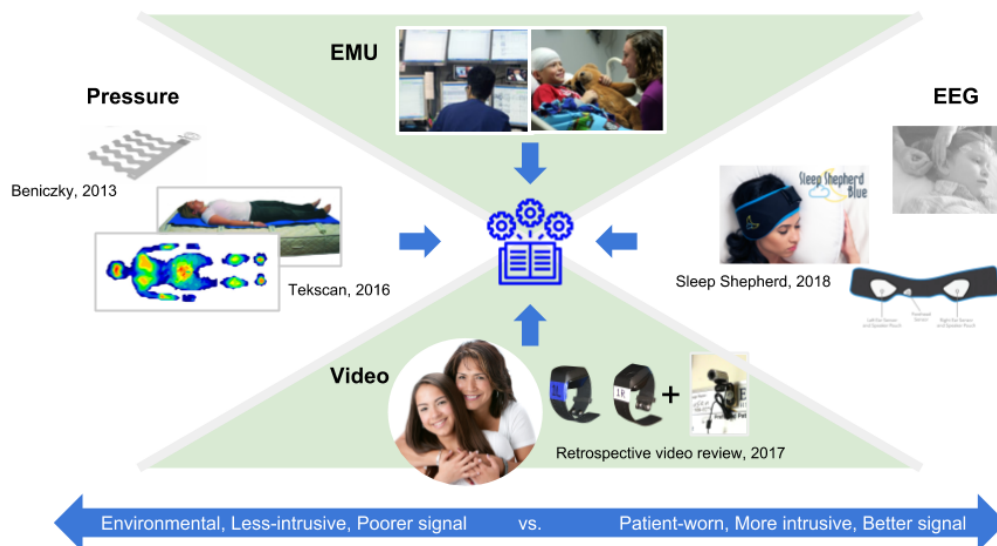
**Figure 3 - Non-convulsive seizure detection and sensing considerations**

## 10.3 Evaluating patient engagement

### 10.3.1 Transition Readiness

Improved metrics for predicting transition readiness. "Transition of care" is an important component of pediatric epilepsy treatment. The Transitional Readiness Assessment Questionnaire (TRAQ) and PAM are each useful instruments for assessing a patient's knowledge and skills prior to adult care but require patients to complete lengthy surveys.

Health tracking and other forms of passive data collection could play a role in developing new types of transition metrics that make similar predictions but with much less data collection burden on the parts of patients and caregivers. For example, in the future, we could investigate whether reduced variability among patient and caregiver self-reports correlates with increased readiness for transition as shown in Figure 4.
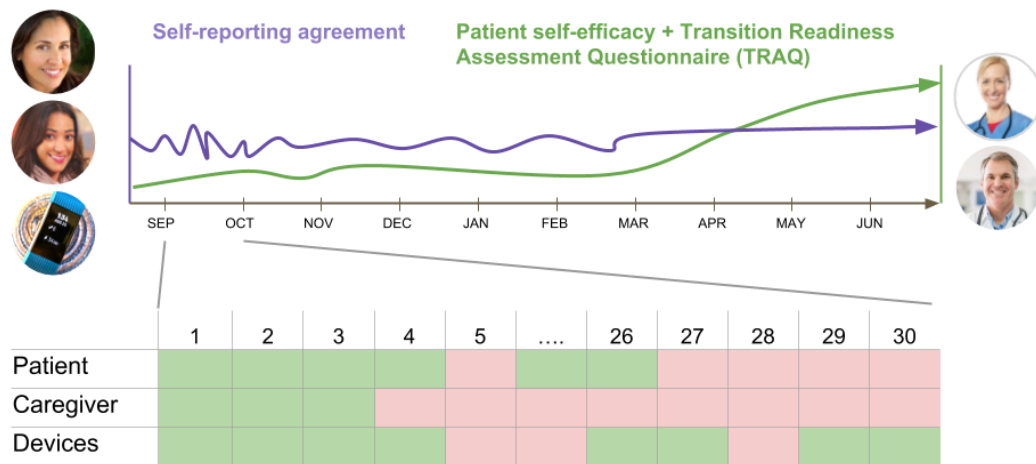


**Figure 4 - Health tracking metrics for transition readiness**

# 11. APPENDIX A.    SEIZURE DETECTION PERFORMANCE
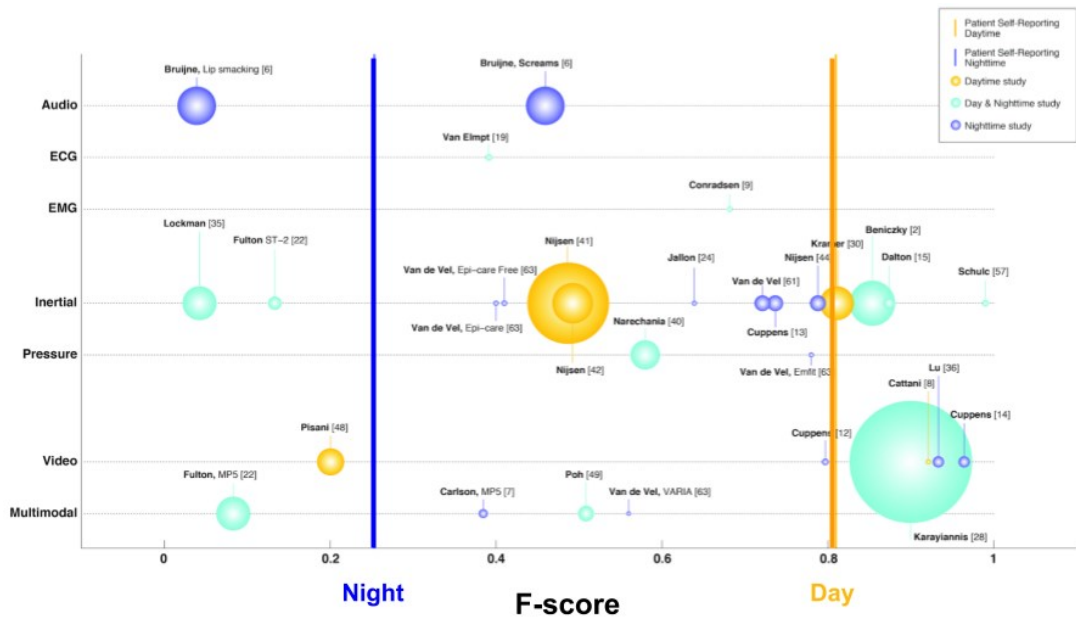
# 12. APPENDIX B.        SURVEY INSTRUMENTS

## 12.1 EpiSense Surveys

### 12.1.1 Patient

#### 12.1.1.1 Morning

1. What time did you go bed?

   _____

2. What time did you wake up?

   _____

3. Did you take all of your medicine yesterday?

   Yes No

4. How are you feeling this morning?

   _____

   Sad            Neutral            Happy

   (Place a mark on the scale above)

5. Did you have any seizures yesterday?

   Yes No

6. Were you physically active for a total of at least 60 minutes yesterday? (Add up all the time you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time)

   Yes No

7. Are you at home? school? or somewhere else? (we're wondering whether people tend to answer questions at home or school each day)

Home School Somewhere else

12.1.12 Weekly

1. Did you have any seizures this week?

   Yes No

2. Did any of the seizures last longer than 5 minutes?

   Yes No

3. Did you take all your medicine this week?

   Yes No

4. In the past 7 days I felt nervous

   Never Almost Never Sometimes Often Almost Always

5. In the past 7 days I felt scared

   Never Almost Never Sometimes Often Almost Always

6. In the past 7 days I felt worried

   Never Almost Never Sometimes Often Almost Always

7. In the past 7 days... I go to bed and wake up at about the same time every day

   _____

   Never                                    Always

   (Place a mark on the scale above)

8. On an average school day this week... How many hours did you play video or computer games or use a computer for something that was not school work per day this week? ((Count time spent on things such as Xbox, PlayStation, an iPod, an iPad or other tablet, a smartphone, YouTube, Facebook or other social networking tools, and the Internet.))

126

I do not play video or computer games or use a computer for something that is not school work Less than 1 hour per day 1 hour per day 2 hours per day 3 hours per day 4 hours per day 5 or more hours per day

9. On an average school day this week... How many hours did you watch TV?

   I do not watch TV on an average school day Less than 1 hour per day 1 hour per day 2 hours per day 3 hours per day 4 hours per day 5 or more hours per day

10. During the past 7 days, on how many days were you physically active for a total of at least 60 minutes per day?

    _____ (Add up all the time you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time.)

### 12.1.1.3 Intake

1. I keep track of how often I have seizures.

   None of the time A few times Some of the time Most of the time All of the time

2. I keep track of when my seizures occur.

   None of the time A few times Some of the time Most of the time All of the time

3. I keep a record of the types of seizures I have.

   None of the time A few times Some of the time Most of the time All of the time

4. I record my seizures with…

   an online tracker/diary a paper log/diary an alternate method that is not listed here

5. Please describe any alternate seizure tracking methods that you use

   _____

6. Have any seizures occurred in the last 30 days?

   Yes No

7. How SEVERE (INTENSE) were your seizures overall?

_____

Very           Mild Moderate        Very Severe

(Place a mark on the scale above)

8. I take my seizure medicine at about the same time each day.

   None of the time A few times Some of the time Most of the time All of the time

9. I do things that I enjoy to help manage stress.

   None of the time A few times Some of the time Most of the time All of the time

10. I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to

    manage stress.

    None of the time A few times Some of the time Most of the time All of the time

11. In the past 30 days I worry that something bad will happen to me

    Never Sometimes Often Always

12. I go to bed and wake up at about the same time every day

    None of the time A few times Some of the time Most of the time All of the time

13. In the past 30 days I exercise at least half an hour most days of the week

    None of the time A few times Some of the time Most of the time All of the time

14. Would you say that in general your health is -?

    Excellent Very Good Good Fair Poor

15. Do you have any difficulties with memory?

    Yes No

16. How confident do you feel that you can keep any other symptoms or health

    problems you have from not at all interfering with the things you want to do?

_____

not at all confident                    totally confident

(Place a mark on the scale above)

17. How confident do you feel that you can the different tasks and activities needed to
manage your health not at all condition so as to reduce your need to see a doctor?

_____

not at all confident                    totally confident

18. How confident do you feel that you can do things other than just taking
medication to reduce how much not at all your illness affects your everyday life?

_____

not at all confident                    totally confident

19. What other CHOA projects are you involved in?

_____

20. When all is said and done, I am the person who is responsible for managing my
health condition (PAM Q1)

Disagree Strongly Disagree Agree Agree Strongly N/A

21. Taking an active role in my own health care is the most important factor in
determining my health and ability to function (PAM Q2)

Disagree Strongly Disagree Agree Agree Strongly N/A

22. I am confident that I can take actions that will help prevent or minimize some
symptoms or problems associated with my health condition (PAM Q3)

Disagree Strongly Disagree Agree Agree Strongly N/A

23. I know what each of my prescribed medications do (PAM Q4)

Disagree Strongly Disagree Agree Agree Strongly N/A

24. I am confident that I can tell when I need to go get medical care and when I can
    handle a health problem myself (PAM Q5)

    Disagree Strongly Disagree Agree Agree Strongly N/A

25. I am confident I can tell my health care provider concerns I have even when he or
    she does not ask (PAM Q6)

    Disagree Strongly Disagree Agree Agree Strongly N/A

26. I am confident that I can follow through on medical treatments I need to do at
    home (PAM Q7)

    Disagree Strongly Disagree Agree Agree Strongly N/A

27. I understand the nature and causes of my health condition(s) (PAM Q8)

    Disagree Strongly Disagree Agree Agree Strongly N/A

28. I know the different medical treatment options available for my health condition
    (PAM Q9)

    Disagree Strongly Disagree Agree Agree Strongly N/A

29. I have been able to maintain the lifestyle changes for my health that I have made
    (PAM Q10)

    Disagree Strongly Disagree Agree Agree Strongly N/A

30. I know how to prevent further problems with my health condition (PAM Q11)

    Disagree Strongly Disagree Agree Agree Strongly N/A

31. I am confident I can figure out solutions when new situations or problems arise
    with my health condition (PAM Q12)

    Disagree Strongly Disagree Agree Agree Strongly N/A

32. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress (PAM Q13)

   Disagree Strongly Disagree Agree Agree Strongly N/A

12.1.1.4 Exit

1. I keep track of how often I have seizures.

   None of the time A few times Some of the time Most of the time All of the time

2. I keep track of when my seizures occur.

   None of the time A few times Some of the time Most of the time All of the time

3. I keep a record of the types of seizures I have.

   None of the time A few times Some of the time Most of the time All of the time

4. I record my seizures with…

   an online tracker/diary a paper log/diary an alternate method that is not listed here

5. Please describe any alternate seizure tracking methods that you use

   _____

6. Have any seizures occurred in the last 30 days?

   Yes No

7. How SEVERE (INTENSE) were your seizures overall?

   _____

   Very            Mild Moderate            Very Severe

   (Place a mark on the scale above)

8. I take my seizure medicine at about the same time each day.

   None of the time A few times Some of the time Most of the time All of the time

9. I do things that I enjoy to help manage stress.

None of the time A few times Some of the time Most of the time All of the time

10. I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress.

    None of the time A few times Some of the time Most of the time All of the time

11. In the past 30 days I worry that something bad will happen to me

    Never Sometimes Often Always

12. I go to bed and wake up at about the same time every day

    None of the time A few times Some of the time Most of the time All of the time

13. In the past 30 days I exercise at least half an hour most days of the week

    None of the time A few times Some of the time Most of the time All of the time

14. Would you say that in general your health is -?

    Excellent Very Good Good Fair Poor

15. How confident do you feel that you can keep any other symptoms or health problems you have from not at all interfering with the things you want to do?

    _____

    not at all confident                    totally confident

    (Place a mark on the scale above)

16. How confident do you feel that you can the different tasks and activities needed to manage your health not at all condition so as to reduce your need to see a doctor?

    _____

    not at all confident                    totally confident

17. How confident do you feel that you can do things other than just taking medication to reduce how much not at all your illness affects your everyday life?

_____

not at all confident                    totally confident

18. What other CHOA projects are you involved in?

_____

19. When all is said and done, I am the person who is responsible for managing my

    health condition (PAM Q1)

    Disagree Strongly Disagree Agree Agree Strongly N/A

20. Taking an active role in my own health care is the most important factor in

    determining my health and ability to function (PAM Q2)

    Disagree Strongly Disagree Agree Agree Strongly N/A

21. I am confident that I can take actions that will help prevent or minimize some

    symptoms or problems associated with my health condition (PAM Q3)

    Disagree Strongly Disagree Agree Agree Strongly N/A

22. I know what each of my prescribed medications do (PAM Q4)

    Disagree Strongly Disagree Agree Agree Strongly N/A

23. I am confident that I can tell when I need to go get medical care and when I can

    handle a health problem myself (PAM Q5)

    Disagree Strongly Disagree Agree Agree Strongly N/A

24. I am confident I can tell my health care provider concerns I have even when he or

    she does not ask (PAM Q6)

    Disagree Strongly Disagree Agree Agree Strongly N/A

25. I am confident that I can follow through on medical treatments I need to do at

    home (PAM Q7)

Disagree Strongly Disagree Agree Agree Strongly N/A

26. I understand the nature and causes of my health condition(s) (PAM Q8)

    Disagree Strongly Disagree Agree Agree Strongly N/A

27. I know the different medical treatment options available for my health condition (PAM Q9)

    Disagree Strongly Disagree Agree Agree Strongly N/A

28. I have been able to maintain the lifestyle changes for my health that I have made (PAM Q10)

    Disagree Strongly Disagree Agree Agree Strongly N/A

29. I know how to prevent further problems with my health condition (PAM Q11)

    Disagree Strongly Disagree Agree Agree Strongly N/A

30. I am confident I can figure out solutions when new situations or problems arise with my health condition (PAM Q12)

    Disagree Strongly Disagree Agree Agree Strongly N/A

31. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress (PAM Q13)

    Disagree Strongly Disagree Agree Agree Strongly N/A

Please rate the level that you agree with the following statements from 1-strongly disagree to strongly agree.

32. The online daily logs/diaries helped me to better understand the behaviors related to epilepsy for me.

    1. strongly disagree 2. disagree 3. somewhat disagree 4. neither agree or 5. disagree 6. somewhat agree 7. agree 8. strongly agree

33. I am glad that I participated in this study.

   1. strongly disagree 2. disagree 3. somewhat disagree 4. neither agree or 5. disagree 6. somewhat agree 7. agree 8. strongly agree

34. I would recommend online daily logs/diaries on behaviors related to epilepsy to other families.

   1. strongly disagree 2. disagree 3. somewhat disagree 4. neither agree or 5. disagree 6. somewhat agree 7. agree 8. strongly agree

## 12.1.1.5 Seizure

1. What time did the seizure start?

   _____

2. How long did the seizure last? (minutes)

   < 1 1 2 3 4 5 >5

## 12.1.2 Caregiver

## 12.1.2.1 Morning

1. What time did your child go bed?

   _____

2. What time did your child wake up?

   _____

3. Did your child take all of his or her medicine yesterday?

   Yes No

4. Did your child go to school yesterday?

Yes No

5. 5 Did your child have any seizures yesterday?

Yes No

6. Was your child physically active for a total of at least 60 minutes yesterday? (Add up all the time that he or she spent in any kind of physical activity that increased his or her heart rate and made it hard for him or her breathe hard some of the time)

Yes No

7. Are you at home? work? or somewhere else? (we're Home wondering whether people tend to answer questions at Work home or school each day)

Home, Work, Somewhere else

12.1.2.2 Weekly

1. Did your child have any seizures this week?

Yes No

2. Did any of the seizures last longer than 5 minutes?

Yes No

3. Did your child take all of his or her medicine this week?

Yes No

4. In the past 7 days, my child felt nervous

Never Almost Never Sometimes Often Almost Always

5. In the past 7 days, my child felt scared

Never Almost Never Sometimes Often Almost Always

6. In the past 7 days, my child felt worried

Never Almost Never Sometimes Often Almost Always

7. In the past 7 days, my child goes to bed at the same time at night

   Never Almost Never Sometimes Often Almost Always

8. On an average school day this week... How many hours did your child play video or computer games or use a computer for something that was not school work per day? ((Count time spent on things such as Xbox, PlayStation, an iPod, an iPad or other tablet, a smartphone, YouTube, Facebook or other social networking tools, and the Internet.))

   I do not play video or computer games or use a computer for something that is not school work Less than 1 hour per day 1 hour per day 2 hours per day 3 hours per day 4 hours per day 5 or more hours per day

9. On an average school day this week... How many hours did your child watch TV?

   I do not watch TV on an average school day Less than 1 hour per day 1 hour per day 2 hours per day 3 hours per day 4 hours per day 5 or more hours per day

10. During the past 7 days, on how many days was your child physically active for a total of at least 60 minutes per day?

    _____

    (Add up all the time you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time.)

12.1.2.3 Intake

1. How many months since your child's diagnosis?

   _____

2. How many seizures occurred since his or her diagnosis?

_____

3. How many days has it been since your child's most recent seizure?

_____ (It's ok to give an approximate answer)

4. Has your child had any seizures in the last 30 days?

   Yes No

5. What types of seizure (s) does your child have?

6. I keep track of how often my child has seizures.

   None of the time A few times Some of the time Most of the time All of the time

7. I keep track of when my child's seizures occur.

   None of the time A few times Some of the time Most of the time All of the time

8. I keep a record of the types of seizures that my child has.

   None of the time A few times Some of the time Most of the time All of the time

9. I record my child's seizures with…

   an online tracker/diary a paper log/diary an alternate method that is not listed here

10. Please describe any alternate seizure tracking methods that you use

11. Please describe any pre-seizure symptoms.

12. Please describe any post-seizure symptoms.

13. How SEVERE (INTENSE) were your child's seizures overall in the past 4 weeks?

    _____

    Very          Mild Moderate        Very Severe

    (Place a mark on the scale above)

14. In the past 30 days my child felt like something awful might happen.

    Never Sometimes Often Always

15. How often would you say that your child's sleep quality varies from week to week?

   seldom some often

16. In the past 30 days my child exercises at least half an hour most days of the week.

   None of the time A few times Some of the time Most of the time All of the time

17. Which health care provider(s) do you see for treatment of your child's seizures/epilepsy? Please select all that apply.

   Primary care provider General neurologist Epileptologist (neurologist who specializes in epilepsy) Other epilepsy specialists (advanced practice nurse, neurosurgeon, psychiatrist) Mental health professional None

18. How old is your child? (years)

   _____

19. What's your child's gender?

   male female other

20. What's your child's race?

   White Black Asian/Pacific Islander American Indian Other

21. Would you say that in general your child's health is -?

   Excellent Very Good Good Fair Poor

22. Does your child have any difficulties with memory?

   Yes No

23. What's your child's highest level of education?

   None elementary high-school/GED some college college college degree or higher

The following questions are about you:

24. What's your gender?

   male female other

25. What's your race?

   White Black Asian/Pacific Islander American Indian Other

26. What's your annual household income? (select range)

   Less than $25,000 $25,000 to $49,999 $50,000 to $74,999 $75,000 to $99,999

   $100,000 to $124,999 $125,000 to $149,999 $150,000 or more

27. How would you describe your neighborhood?

   rural urban suburban none of the above or not sure

28. What's your highest level of education?

   None elementary high-school/GED some college college college degree or higher

29. Has your child ever been held back a grade in school?

   Yes No

30. What is your employment status?

   full time part time unemployed

31. Do you have any work limitations? (e.g. quit job)

32. Do you stay at home full-time as a caregiver?

   Yes No

33. If so how many years have you lived at home?

   _____

34. What other CHOA projects are you involved in?

   _____

1. I keep track of how often my child has seizures.

   None of the time A few times Some of the time Most of the time All of the time

2. I keep track of when my child's seizures occur.

   None of the time A few times Some of the time Most of the time All of the time

3. I keep a record of the types of seizures my child has.

   None of the time A few times Some of the time Most of the time All of the time

4. Have any seizures occurred in the last 30 days?

   Yes No

5. Please describe any pre seizure symptoms.

6. Please describe any post seizure symptoms.

7. How SEVERE (INTENSE) were your child's seizures overall in the past 4 weeks?

   _____

   Very          Mild Moderate       Very Severe

   (Place a mark on the scale above)

8. Please rate the level that you agree with the following statements regarding your

   child's epilepsy treatment.

   None of the time A few times Some of the time Most of the time All of the time

9. My child takes his or her seizure medicine at about the same time each day.

10. My child does things that he or she enjoys to help manage stress.

    My child uses techniques (such as relaxation, guided imagery, and self-hypnosis)

    to manage stress.

11. In the past 30 days my child worries that something bad will happen to him or her

12. My child goes to bed and wakes up at about the same time every day

13. In the past 30 days my child exercises at least half an hour most days of the week

Please rate the level that you agree with the following statements regarding the usability of the mobile app.

14. Did you have difficulty reading the words on your phone screen? Could you conveniently answer the survey questions on the phone?

    no/not at all somewhat very extremely

15. Were the instructions clear to you?

    no/not at all somewhat very extremely

16. Was your participation in this study burdensome?

    no/not at all somewhat very extremely

17. How often did you fill in the surveys directly after the first prompt?

    in less than 50% of the time in approximately 50% of the time in approximately 75% of the time in almost all the times

18. How can we improve the data collection? For example - How could we make the surveys easier? Are there additional aspects of your daily life that you think would helpful to keep track in the future?

Please rate the level that you agree with the following statements regarding your experience with data collection.

19. The online daily logs/diaries helped me to better understand behaviors related to my child's epilepsy.

    strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

20. I am glad that I participated in this study.

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

21. I would recommend online daily logs/diaries on behaviors related to epilepsy to

other families.

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

22. The questions in the dairies/logs helped me to better understand self care related

to my child's epilepsy.

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

23. I will keep notes or monitor seizure using a paper or online diary

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

24. I will keep notes or monitor other aspects of your daily life such as sleep,

exercise, screen time, etc.

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

25. Please comment on how the study help you to "better understand behaviors

related to your child's epilepsy".

strongly disagree, disagree, somewhat disagree, neither agree or disagree,

somewhat agree, agree, strongly agree

26. Please describe any other ways that you may have benefited from participating in the study in other ways beyond better understanding behaviors related to your child's epilepsy?

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

Please rate the level that you agree with the following statements regarding your overall experience as a caregiver.

27. I believe I am more knowledgeable as a caregiver after this study.

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

28. I learned useful caregiving strategies from the study.

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

29. I feel more confident as a caregiver after participating in the data collection.

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

30. I feel I have more caregiving skills after participating in the study.

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

31. The study was relevant to caregiving.

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

32. How did you feel when you had to note your child's seizures and activity such as

sleep and exercise every day twice a day?

strongly disagree, disagree, somewhat disagree, neither agree or disagree, somewhat agree, agree, strongly agree

Please give any comments about the act of noting different aspects of your child's daily living with seizures (e.g., seizures, medication taking, sleep, etc.) that you want to share.

33. Would you like additional information on taking care of your children with epilepsy?

Yes No

34. What types of information would be useful? Please select all that apply.

Medication adherence Self-reporting seizures and lifestyle factors that can impact the likelihood of seizures (e.g. sleep, diet) Tips for managing epilepsy and communicating epilepsy related needs to others during everyday life Other - I'd like additional information about something else

Please describe any additional information that you think may be helpful for taking care of your child with epilepsy.

35. What methods would you prefer for education about these topics? Please select all that apply.

workshop series of workshops web-based course mobile/tablet course mix of these methods other

36. Please describe any other methods that you would prefer for education about these topics.

37. Have you talked to your child about their ability to take care of their health when they turn 18?

Yes No

38. What topics have you discussed? Please check all that applies.

Making appointments How to prepare for appointments Talking to their doctor
My child's medicines How to refill medicines Epilepsy triggers and symptoms
Disclosing to my epilepsy/seizure disorder to others Seizure safety How to get
support from others General wellness (e.g. exercise and eating healthy) Coping
with illness and stress Other

39. Please describe any other topics that you have discussed.

12.1.2.5 Seizure

1. What time did the seizure start?

   _____

2. How long did the seizure last? (minutes)

   < 1 1 2 3 4 5 >5

**12.3 Reference Surveys**

*12.3.1 Self-Efficacy for Managing Chronic Disease 6-item Scale (SEM-CD)*

1. How confident do you feel that you can keep the fatigue caused by your disease
   from interfering with the things you want to do?

   _____

   Not at all confident          Totally confident

2. How confident do you feel that you can keep the physical discomfort or pain of
   your disease from interfering with the things you want to do?

_____

Not at all confident          Totally confident

3. How confident do you feel that you can keep the emotional distress caused by

   your disease from interfering with the things you want to do?

_____

Not at all confident          Totally confident

4. How confident do you feel that you can keep any other symptoms or health

   problems you have from interfering with the things you want to do?

_____

Not at all confident          Totally confident

5. How confident do you feel that you can the different tasks and activities needed to

   manage your health condition so as to reduce your need to see a doctor?

_____

Not at all confident          Totally confident

6. How confident do you feel that you can do things other than just taking

   medication to reduce how much your illness affects your everyday life?

_____

Not at all confident          Totally confident

## 12.3.2 Patient Activation Measure (PAM)

1. When all is said and done, I am the person who is responsible for managing my

   health condition

2. Taking an active role in my own health care is the most important factor in

   determining my health and ability to function

3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition

4. I know what each of my prescribed medications do

5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself

6. I am confident I can tell my health-care provider concerns I have even when he or she does not ask

7. I am confident that I can follow through on medical treatments I need to do at home

8. I understand the nature and causes of my health condition(s)

9. I know the different medical treatment options available for my health condition

10. I have been able to maintain the lifestyle changes for my health that I have made

11. I know how to prevent further problems with my health condition

12. I am confident I can figure out solutions when new situations or problems arise with my health condition

13. I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress

# 13. APPENDIX C.    SELF-REPORTING METRICS

## 13.1 Self-reporting consistency

(Top) All participants (Bottom) participants who reported on eight or more study dates.

Each row represents a family: (Green) patient self-report, (Brown) caregiver self-report.

**Consistency** (1–30)

| | % Completion |
|---|---|
| **Baseline** | |
| 1 | 96.67% |
| 19 | 13.33% |
| 7 | 0.00% |
| 11 | 3.33% |
| 27 | 0.00% |
| 32 | 0.00% |
| 20 | 0.00% |
| 13 | 10.00% |
| 9 | 100.00% |
| 16 | 0.00% |
| 3 | 0.00% |
| 21 | 100.00% |
| 28 | 26.67% |
| 23 | 30.00% |
| 22 | 0.00% |
| 25 | 6.67% |
| **Health Tracking** | |
| 33 | 6.67% |
| 17 | 26.67% |
| 31 | 23.33% |
| 29 | 13.33% |
| 24 | 100.00% |
| 26 | 93.33% |
| 18 | 3.33% |
| **Motivational Strategies** | |
| 35 | 3.33% |
| 8 | 96.67% |
| 14 | 3.33% |
| 5 | 3.33% |
| 4 | 93.33% |
| 12 | 3.33% |
| 6 | 60.00% |
| Average | 30.56% |

**Consistency** (1–30)

| | % Completion |
|---|---|
| **Baseline** | |
| 1 | 96.67% |
| 9 | 100.00% |
| 21 | 100.00% |
| 28 | 26.67% |
| 23 | 30.00% |
| | 70.67% |
| **Health Tracking** | |
| 24 | 100.00% |
| 26 | 93.33% |
| | 96.67% |
| **Motivational Strategies** | |
| 8 | 96.67% |
| 4 | 93.33% |
| 6 | 60.00% |
| | 83.33% |
| Average | 83.56% |

## 13.2 Self-reporting promptness

The promptness of self-reporting, computed as the average latency and standard deviation in minutes from the daily 7 A.M. time to completing the surveys.

| Promptness - Patient (Minutes) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | Mean | SD |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 | 83 | 82 | 81 | 80 | 79 | 78 | 77 | 76 | 75 | 74 | 73 | 72 | 71 | 70 | 69 | 68 | 67 | 66 | 65 | 64 | 63 | 62 | 61 | 60 | 59 | 58 | 57 | 56 | 55 | 54 | 68.54949078 | 8.803407831 |
| 1 | | 84 | 83 | 82 | 81 | 80 | 79 | 78 | 77 | 76 | 75 | 74 | 73 | 72 | 71 | 70 | 69 | 68 | 67 | 66 | 65 | 64 | 63 | 62 | 61 | 60 | 59 | 58 | 57 | 56 | 67.71450343 | 15.28281134 |
| 7 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 11 | 85 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 2.834982804 | 15.52784032 |
| 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 32 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 13 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 19 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 16 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 21 | 78 | 77 | 76 | 75 | 74 | 73 | 72 | 71 | 70 | 69 | 68 | 67 | 66 | 65 | 64 | 63 | 62 | 61 | 60 | 59 | 58 | 57 | 56 | 55 | 54 | | | | | | 55.04124498 | 25.91579951 |
| 28 | 78 | 77 | | | | | | 69 | | | | | | | | | | | | | | | | | | | | | | | 7.471616562 | 22.83481255 |
| 23 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 22 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 25 | 22 | | | | | | | 13 | | | | | | | | | | | | | | | | | | | | | | | 1.172746239 | 4.616836395 |
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 33 | 58 | | | 55 | | | | | | | | | | | | | | | | | | | | | | | | | | | 3.769966713 | 14.35247496 |
| 17 | 50 | 49 | 48 | 47 | 46 | 45 | 44 | 43 | | | | | | | | | | | | | | | | | | | | | | | 12.4132003 | 20.97142735 |
| 31 | 44 | | 42 | | | | | | | | | | | | | | | | | | | | | | | | | | | | 2.86996681 | 10.92516549 |
| 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 24 | 34 | 33 | 32 | 31 | 30 | 29 | 28 | 27 | 26 | 25 | 24 | 23 | 22 | 21 | 20 | 19 | 18 | 17 | 16 | 15 | 14 | 13 | 12 | 11 | 10 | 9 | 8 | 7 | 6 | 5 | 19.59117442 | 8.803407616 |
| 26 | 28 | 27 | 26 | 25 | 24 | 23 | 22 | 21 | 20 | 19 | 18 | 17 | 16 | 15 | 14 | 13 | 12 | 11 | 10 | 9 | 8 | 7 | 6 | 5 | 4 | 3 | 2 | 1 | | | 13.618441 | 8.758086182 |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 5 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 4 | 30 | 29 | 28 | 27 | 26 | 25 | 24 | 23 | 22 | 21 | 20 | 19 | 18 | 17 | 16 | 15 | 14 | 13 | 12 | 11 | 10 | 9 | | | | | | | | | 14.36686756 | 10.40094663 |
| 14 | 30 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 1.003039204 | 5.493871979 |
| 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0 | 0 |
| 6 | | 25 | 24 | 23 | 22 | 21 | 20 | 19 | 18 | 17 | 16 | 15 | 14 | 13 | 12 | 11 | 10 | | | | 8 | 7 | | | | | | | | | 9.888046867 | 9.23588765 |
| 8 | 33 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 1.103039191 | 6.041594469 |
| 35 | 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.0363731261( | 0.1992238168 |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 9.38149 | 6.272119802 |

150

# 13.3 Self-reporting reliability

## 13.3.1 Percent agreement between patient and caregiver seizure counts

**Reliability - Seizures**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 13 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 16 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 19 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 22 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 23 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 25 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 28 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 32 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 17 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 24 | | | | ✔ | ✔ | ✔ | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 26 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 33 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | 100.00% |
| 5 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 | | | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✗ | ✗ | ✗ | ✗ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✗ | | | 79.17% |
| 8 | ✔ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 14 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 93.06% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | 94.79% |

**Reliability - Seizures**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 24 | | | | ✔ | ✔ | ✔ | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | 100.00% |
| 6 | | | | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✗ | ✗ | ✗ | ✗ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✔ | ✗ | | | 79.17% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 89.58% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | 93.06% |

151

## 13.3.2 Percent agreement between patient and caregiver medication intake

**Reliability - Medication Intake**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 13 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 16 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 19 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | ✓ | ✓ | ✓ | ✓ | | X | ✓ | ✓ | ✓ | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | 95.45% |
| 22 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 23 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 25 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 28 | ✓ | ✓ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 32 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 97.73% |
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 17 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 24 | | | | | X | X | X | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| 26 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 33 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 26.67% |
| 5 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 | | | X | X | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | 33.33% |
| 8 | X | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 14 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 20.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | 42.58% |

**Reliability - Medication Intake**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | ✓ | ✓ | ✓ | ✓ | | X | ✓ | ✓ | ✓ | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | 95.45% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 95.45% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | 26.67% |
| 6 | | | X | X | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | | 33.33% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 30.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | 51.82% |

## 13.3.3 Percent agreement between patient and caregiver sleep reports

**Reliability - Sleep**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 13 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 16 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 19 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | X | X | ✓ | X | | X | X | X | ✓ | ✓ | X | | X | X | X | X | X | ✓ | | X | X | X | X | X | X | X | | | | | 18.18% |
| 22 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 23 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 25 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 28 | ✓ | ✓ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 32 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 59.09% |
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 17 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 24 | | | | | X | X | ✓ | | | | | | | | | | | | | | | | | | | | | | | | 33.33% |
| 26 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 33 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 33.33% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | ✓ | X | X | X | ✓ | ✓ | ✓ | X | X | ✓ | X | ✓ | X | X | X | ✓ | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | 26.67% |
| 5 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 | | | | X | X | ✓ | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | 37.50% |
| 8 | ✓ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 14 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 54.72% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | | 52.61% |

**Reliability - Sleep**

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | X | X | ✓ | X | | X | X | X | ✓ | ✓ | X | | X | X | X | X | X | ✓ | | X | X | X | X | X | X | X | | | | | 18.18% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 18.18% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | ✓ | X | X | X | ✓ | ✓ | ✓ | X | X | ✓ | X | ✓ | X | X | X | ✓ | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | 26.67% |
| 6 | | | | X | X | ✓ | X | X | X | X | X | X | X | X | X | X | X | X | ✓ | X | X | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | 37.50% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 32.08% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | | | 27.45% |

*13.3.4 Percent agreement between patient and caregiver exercise reports*

| Reliability - Exercise | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 13 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 16 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 19 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 20 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | | | 0.00% |
| 22 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 23 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 25 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 28 | ✔ | ✔ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 100.00% |
| 32 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 50.00% |
| **Health Tracking** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 17 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 24 | | | | | X | X | X | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| 26 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | X | | X | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| 33 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | | 0.00% |
| 5 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 | | | | | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | | | | 0.00% |
| 8 | X | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 14 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | 14.29% |

| Reliability - Exercise | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | % Agreement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Baseline** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 21 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | | | 0.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| **Motivational Strategies** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | 0.00% |
| 6 | | | | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | | | | 0.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | 0.00% |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | Average | | | 0.00% |

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