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Smartphone Access, Use, and Acceptability Among People with Epilepsy:

A Needs Assessment of an mHealth Application

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

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Background: Individuals living with a chronic condition like epilepsy must adopt successful self-management (SM) techniques to adhere to medications, prevent seizures, and maintain a healthy quality of life. A smartphone based SM application has the potential to improve SM behaviors among this population as a handheld device can provide more consistent monitoring through frequent interaction with the individual. Additionally the cost-effectiveness, remote capabilities, and confidentiality of a mobile device can address the economic, transportation, and stigma-related challenges faced by people with epilepsy (PWE).

Purpose: Using the Diffusion of Innovations (DOI), the purpose of this study was to understand the compatibility of mobile phone technology with the lifestyles of PWE, the complexities they encounter in using this technology, and their current SM practices, felt needs, and communication behaviors.

Methods: A total of ten PWE with access to smartphones participated in three over-the-phone focus groups. The focus groups were semi-structured and approximately 2 hours in duration. Data were analyzed using deductive and inductive codes based on the DOI constructs and research questions. The codes were systematically analyzed within and across the three focus groups to identify patterns and themes.

Results: Participants were 29.20 (±9.69) years old, predominantly female (n=7), African American (n=6), and reported having epilepsy for 13 years (±6.5). Participants were the primary owners of their smartphones, used their smartphones daily, and used their smartphones in creative ways to SM their epilepsy. Participant suggested 5 content areas for a smartphone app for PWE: 1) logging of medication adherence and seizure type and frequency, 2) emergency services for and in response to unexpected seizures, 3) credible information resource for new treatments and research, 4) a tool to facilitate communication with physician, and 5) support for PWE.

Conclusion: There is a strong potential for smartphones to address the SM needs of PWE as well as a potential for health providers to use mHealth tools with this population.

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Finally, my heartfelt gratitude to all the participants of this study for your time and for openly sharing your stories and experiences with epilepsy. I hope the results of this research will benefit you and the countless others living with epilepsy.

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CHAPTER I: INTRODUCTION

Epilepsy, a neurological disorder characterized by recurrent seizures, affects approximately 2.3 million Americans and is the fourth most common neurological disorder in the United States after migraines, stroke, and Alzheimer's disease (CDC, 2013). Individuals living with a chronic disease like epilepsy must adopt successful self-management (SM) behaviors in order to adhere to treatment, manage symptoms, make lifestyle changes, and sustain a healthy quality of life (Dilorio, 1997). People with epilepsy (PWE) who are unable to adhere to medication regimens and make lifestyle adjustments face an increased risk of uncontrolled or breakthrough seizures potentially impacting employment, driving risks and licensing, and mortality (Faught, 2008; Hovinga, 2008). Reviews of existing SM programs for adults with epilepsy suggest that SM interventions can improve treatment compliance, increase knowledge about epilepsy, and may improve health outcomes (Bradley, 2009; Dilorio et al., 2010; Shaw, 2009).

Emory University, with support from the Centers for Disease Control and Prevention (CDC), has successfully developed and tested an online SM intervention for adults with epilepsy (Dilorio, Bamps, Walker, & Escoffery, 2011; Dilorio, Escoffery, McCarty, et al., 2009b; Dilorio, Escoffery, Yeager, et al., 2009a). WebEase (Web Epilepsy Awareness, Support, and Education) is a theory-based intervention, incorporating concepts from the social cognitive theory, the transtheoretical model, and motivational interviewing (Emory University, Dilorio, & Helmers, 2012). WebEase aims to assist people with controlling their epilepsy by promoting medication adherence and encouraging the adoption of practices that reduce stress and improve sleep. A randomized control trial (RCT) found the WebEase program to be effective in improving SM, increasing medication adherence, and increasing self-efficacy compared to those who did not complete any modules (Dilorio et al., 2011).

The positive outcomes of the WebEase program have encouraged researchers to propose expanding the program to a mobile phone platform (Dilorio et al., 2011). A mobile phone-based application for people with epilepsy holds real promise for improving SM of seizures. Compared to internet-based interventions, mobile phone interventions have the potential to promote more frequent interactions with the individual and in the context of their daily behaviors (Riley et al., 2011). Advances in mobile technology, such as Bluetooth, location services, and data tracking, also allow tailoring of interventions on mobile devices to individual needs (Riley et al., 2011). Additionally, a mobile phone application can address certain unique challenges faced by PWE; the portability, cost-effectiveness and remote capabilities of mobile phone technologies can help address the financial and transportation barriers faced by this population (Epilepsy Foundation of America, 2007; 2013) as well as potentially improve SM with more consistent monitoring. Furthermore issues of stigma that many PWE face due to their condition (De Boer, 2008) may be mitigated through the confidentiality provided by a personal hand-held device.

Though there is great potential, a SM mobile phone application for PWE poses a number of challenges. Given the complexity of the WebEase online program, a mobile phone application could most likely only be offered on smartphone devices. Due to the cost of smartphone ownership and the financial and employment issues faced by PWE, this technological requirement may be prohibitive to participation. While research has found that PWE have access to computers and the Internet and are receptive to using both for accessing health information (Escoffery et al., 2008), no research has been conducted to assess if they hold the same perspectives for mobile devices. Furthermore there is an overall dearth of evidence-based and theory driven mobile phone applications for the SM of any chronic health conditions (Riley et al., 2011; Tomlinson, Rotheram-Borus, Swartz, & Tsai, 2013) with no published research to date on smartphone applications for PWE in particular. Thus a qualitative assessment of PWE regarding their access, comfort, and use of mobile technology is necessary to ensure the success of a mobile phone intervention.

Purpose of the Study

This research study was the first stage in a comprehensive plan to revise and adapt the WebEase online SM tool for PWE to a mobile phone platform (Dilorio et al., 2011; Dilorio et al., 2009a; Dilorio et al., 2009b). As the first stage of this research agenda, the purpose of this study was to explore the technological and information preferences of PWE in order to develop an informed mobile application that is tailored to their needs. This research was guided by the Diffusion of Innovations (DOI), a theory that explains the process by and rate at which an innovation is adopted in a population (Rogers, 2003). Using the DOI, this thesis research explores the process of adoption of two innovations among PWE: smartphones and a smartphone SM application. This study aimed to answer the following research questions:

1) How compatible is smartphone technology with the lifestyles of PWE?

2) What are the complexities PWE encounter in using and accessing smartphone technology?
3) What are PWE's current epilepsy SM practices, and how do they prefer to receive information on treatment and SM techniques?
4) What are the SM felt needs for PWE, and how can a mobile phone application meet these needs?

To answer these research questions this study conducted qualitative research through three focus groups of adults with epilepsy. The results of this needs assessment will inform the development of the first theory driven and evidence-based mobile phone intervention for PWE, add to the literature on mobile phone applications for health outcomes (mHealth), and potentially create a more sensitive, thoughtful, and possibly more effective intervention by involving PWE's voices in the critical formative process.

CHAPTER II: LITERATURE REVIEW

Epilepsy

Epilepsy is one of the most prevalent neurological disorders with approximately 150,000 new cases diagnosed annually in the United States (England, Liverman, Schultz, & Strawbridge, 2012). Characterized by recurrent seizures, epilepsy is a spectrum disorder that includes 25 syndromes and numerous kinds of seizures that vary in severity from benign to life-threatening (England et al., 2012). There are multiple causes of epilepsy including but not limited to stroke, head injury, and brain tumors (National Institute of Neurological Disorders and Stroke, 2007). PWE also suffer from other comorbidities, particularly mental illnesses like depression and anxiety (Rai, 2012; Schoenberg et al., 2011). Given this diversity in both cause and expression of epilepsy, health outcomes for the disorder also follow a gradient, with PWE experiencing differential burdens on their physical and mental health and quality of life (England et al., 2012).

Disease Burden and Impact on Quality of Life

Epilepsy burdens individuals, relationships, families, and society. On a societal level, epilepsy imposes a significant economic burden resulting in an estimated $9.6 billion in direct medical care costs per year in the United States (Yoon, 2009). The societal cost of epilepsy is also reflected in lost productivity with PWE reporting higher levels of wage-based lost productivity than individuals with the chronic diseases of diabetes and depression (Libby, 2012). An analysis of a national level survey also found that epilepsy, after controlling for comorbidities, was associated with an annualized 89.4 million excess role impairment days (Kessler, 2012).

There are also documented disparities among PWE in the United States. Although epilepsy affects people of all ages, ethnicities, and social backgrounds, children and older adults represent the fastest growing segments of new cases of epilepsy (England et al., 2012). For children, epilepsy increases their dependence on caregivers and can impede their academic achievement and their ability to find employment later in life (Moffat, Dorris, Connor, & Espie, 2009). For older adults, epilepsy can inhibit their ability to live independently and place additional burdens on any existing physical and mental health conditions they may face (Laccheo et al., 2008; Leppik, 2004). Epilepsy presents considerable economic disparities with individuals of lower socioeconomic status reporting higher incidence of epilepsy (Heaney et al., 2002) and PWE reporting living in households with the lowest annual incomes (Kobau et al., 2008).

In turn, epilepsy significantly impacts an individual's quality of life. PWE report markedly worse quality of life than those without a history of epilepsy (Jacoby, Snape, & Baker, 2009; Kobau, Luncheon, Zack, Shegog, & Price, 2012; Kobau et al., 2008; Loring, Meador, & Lee, 2004). Symptoms of depression and seizure worry have been identified as health-related factors contributing to low quality of life among PWE (Leidy, Elixhauser, Vickrey, Means, & Willian, 1999; Loring et al., 2004). Unemployment and inability to work are also major factors contributing to a worsening quality of life among this population. Obtaining and maintaining employment is a particular challenge for PWE with only 42% of PWE over the age of 18 reporting employment versus 70% of individuals who do not have a history epilepsy (Libby, 2012). Affordable health care remains a major concern for PWE due not only to employment issues but also high premiums for pre-existing conditions (Epilepsy Foundation of America, 2007).

Approximately 23% of PWE report cost as a barrier to seeking care (Kobau et al., 2008), resulting in inadequate attention to their illness with only 52.8% of adults with active epilepsy reporting that they had seen a neurologist or an epilepsy specialist in the past 12 months (Kobau, Yao-Hua, Zack, Helmers, & Thurman, 2012). Moreover, mobility of PWE is severely limited, as most US states will not issue a driver's license to someone with epilepsy without a physician's approval and meeting a required seizure-free period, which can range upward to a year in some states (Epilepsy Foundation of America, 2013).

PWE also face disproportionate stigma, discrimination, and social exclusion, due to misconceptions about the disorder among the public as well as due to the physical hazards of unexpected seizures and the helplessness of people who witness them (De Boer, 2008; International League Against Epilpesy, 2003). PWE are often denied employment due to misinformed ideas about the risk of seizures in the workplace, sometimes denied custody in divorce hearings, and, if experiencing a mild seizure, can be mistaken as drunk and wrongfully arrested and detained (Epilepsy Foundation of America, 2007). Internalized stigma as a result of epilepsy can lead to lower self-esteem, higher levels of depression, and heightened symptom severity (Boyd, Adler, Otilingam, & Peters, 2013).

Epilepsy Self-Management

Like other chronic illnesses, PWE must adopt successful SM techniques to manage symptoms and sustain a healthy quality of life (Dilorio & Henry, 1995). SM educational interventions for epilepsy aim to teach strategies for the prevention and management of seizures through medication adherence, increased knowledge, and the development of skills to improve PWE's confidence to address their needs (Dilorio, 1997; Dilorio et al., 2006). Adherence to antiepileptic medications is particularly difficult for people with epilepsy. In a cross-sectional study of 1,278 elderly patients with epilepsy, 41% were non-adherent to their antiepileptic medications, which resulted in a calculated $2674 increase in per-patient medical costs due to this non-adherence (Ettinger, Manjunath, Candrilli, & Davis, 2009). An additional study found that 29% of adults with epilepsy reported being non-adherent to medications which was also found to be associated with reduced seizure control, lower quality of life scores, seizure-related job loss, decrease in productivity, and seizure related car accidents (Hovinga, 2008). The consequences of non-adherence can be serious for PWE as a retrospective cohort study reported an over 3-fold increased risk in mortality among non-adherers compared to those who adhered to their antiepileptic medications (Faught, 2008).

A variety of interventions have aimed at improving SM behaviors in PWE. Systematic literature reviews of SM education for adults with epilepsy concluded that SM education can improve treatment compliance and knowledge (Bradley, 2009) and may improve certain behavioral outcomes and reduce seizure frequency (Shaw, 2009). SM behaviors for epilepsy have also been shown to be a strong predictor of self-efficacy (Dilorio et al., 2006; Robinson et al., 2008). Research has also found a direct relationship between unsuccessful SM and stigma with those reporting higher levels of perceived stigma also reporting lower levels of self-efficacy to manage epilepsy (Dilorio et al., 2003). However research has shown that PWE may be better at managing adherence to medications than at managing healthy lifestyle changes (Kobau & Dilorio, 2003; McAuley, McFadden, Elliott, & Shneker, 2008). Additional challenges to successful SM interventions include cost to participants and the program, encouraging participation, access to program services, sustainability of the program, and maintenance of SM techniques post intervention (Dilorio, et al., 2009b; Jerant, Friederichs-Fitzwater, & Moore, 2005; Mittan, 2009).

Selecting an appropriate platform for epilepsy SM programs may address barriers of cost, encourage active participation, and improve the maintenance of SM behavior and positive lifestyle changes. A pilot test of a telephone-based SM program found high user satisfaction and efficacy afforded by using the telephone delivery platform (Dilorio, Reisinger, Yeager, & McCarty, 2009). Computer or Web-based applications, known as eTools, also hold promise for successful epilepsy SM (Shegog et al., 2013). WebEase is a theory-based, interactive, Internet-based SM program for adults with epilepsy that aims to improve medication adherence, sleep quality, and stress reduction (Dilorio, et al., 2009b). Based on the social cognitive theory, transtheoretical model, and motivational interviewing, the online intervention achieves this through three interactive learning modules targeting medication adherence, stress, and sleep management and a data-entry component, known as MyLog, where users record their seizure and health-related information. WebEase has been positively assessed for acceptability and usability among adults with epilepsy who showed improved epilepsy SM behaviors, medication adherence, sleep quality, self-efficacy, and social support post intervention (Dilorio et al., 2011; Dilorio, et al., 2009a). Given the success of this online SM tool, translating the WebEase program onto a mobile phone platform may address barriers to SM behaviors within this population while encouraging similar positive outcomes.

Mobile Phone and Wireless Technologies

Mobile phone and wireless technologies have seen striking rates of adoption within the past decade. As of 2013, 91% of Americans reported owning a mobile phone compared to 65% in 2004 (Smith, 2013). Furthermore as of 2013 a majority of Americans were smartphone owners with 56% of US adults reporting owning a smartphone (Smith, 2013). A smartphone is distinguished from other mobile phones in that it runs an operating system similar to that on a computer. Smartphones, accordingly, have more sophisticated features such as Internet connectivity, web browsing, video streaming, document editing capability, and other general-purpose applications (National Telehealth Technology Assessment Resource Center, 2013). The two most popular smartphone platforms in the United States are iPhone (Apple Inc.) and Android (Google Inc.), which represent 25% and 28% of the mobile phone owner population, respectively (Smith, 2013). However, it should be noted that the iPhone operating system (iOS) is a closed-source software exclusive to Apple products (Kendrick, 2011). The Android operating system, on the other hand, is mostly open-source, and is used by a number of manufacturers (Kendrick, 2011).

Digital Divide

Although a majority of the American population owns a mobile phone with more than half owning a smartphone, there are noticeable disparities in the access, use, and knowledge of information communication technologies (ICT) among different demographic groups. There are pronounced age differences in smartphone ownership. Younger adults, regardless of economic status, are more likely than older adults to own a smartphone with 76% of young adults aged18-24 identifying as smartphone owners compared to 18% of adults 65 years or older (Smith, 2013). Smartphone ownership is also associated with income level and education attainment: 78% for individuals from households reporting incomes of $75,000 or more versus 43% for those from households reporting incomes of less than $30,000 per year, and 70% for individuals with a college education or above compared to 36% for adults with less than a high school education (Smith, 2013).

The type of smartphone platform also varies by different demographic characteristics. Although iPhone and Android users each account for approximately 25% of smartphone owners as a whole, those with greater education attainment and higher household incomes more often report owning an iPhone (Smith, 2013). Furthermore, preference in terms of smartphone platform falls along racial/ethnic lines. Although African Americans and Hispanics report higher levels of smartphone ownership than Whites (64% and 60% respectively compared to 53% for Whites) (Smith, 2013), African Americans are less likely to own an iPhone than Whites or Hispanics, with only 16% reporting iPhone ownership compared to 27% for Whites and 26% for Hispanics. African Americans are more likely to own an Android, with 42% reporting that their smartphone was an Android compared to 26% for Whites and 27% for Hispanics (Smith, 2013). This racial/ethnic difference in smartphone platform preferences are pertinent for this thesis research given that the proposed WebEase mobile phone application may only be available on one smartphone platform, limiting its reach to a diverse population.

Surveys have further shown that some of the greatest digital disparities are among people with disabilities. Of adults who reported living with a physical, mental, or emotional disability that interferes with activities of daily living, only 54% used the

Internet compared to 81% of the general population. For those who do use the Internet, many do not use high-speed broadband connections (Fox, 2011). A federal survey found that 39% of American adults who do not have high-speed broadband Internet access are living with a disability (Horrigan, 2010). While no data are available on disabled persons' access to and use of smartphones, they may experience similar, if not more pronounced, disparities in use, access, and knowledge of smartphone technology, given that adults living with a disability tend to be older, have lower levels of education attainment, and live in households reporting the lowest incomes (Fox, 2011).

Mobile Potential

Although there are pronounced disparities in the use of, access to, and knowledge of ICT, mobile phones have shown promising results in bridging the digital divide. Mobile phones are changing the ways in which Americans access online services and information: 57% of American adults report using their mobile phone to go online, with 1 in 5 mobile users doing most of their Internet browsing on their phone (Duggan & Smith, 2013). More significantly, demographic groups that have previously been marginalized by ICT access like minorities, the less educated, and less affluent are reporting greater use of and dependence on mobile technologies (Zickuhr & Smith, 2012). Minority groups report greater reliance on their mobile devices for web browsing with 60% of Hispanics and 43% of African Americans reporting that their mobile phone was the main device they used to access the Internet compared to 27% of Whites (Duggan & Smith, 2013). Those of lower economic status also report greater reliance on mobile Internet use with 45% of individuals with household incomes of less than $30,000 per year reporting mobile phones as their primary technology to access the Internet compared to 27% for individuals with household incomes of $75,000 and above (Duggan & Smith, 2013). Similarly adults with a high school education or less report greater reliance on mobile Internet use than college graduates (45% and 21% respectively) (Duggan & Smith, 2013). These statistics illustrate the potential for reaching previously hard-to-reach populations through mobile phone applications.

mHealth: Promise, Potential, and Gaps in the Literature

mHealth, the use of mobile and wireless technology for health outcomes, health research, and healthcare services, is a nascent yet growing field (Nilsen et al., 2012; Riley et al., 2011; Tomlinson et al., 2013). The field of mHealth developed, in part, as a response to the rapid adoption of mobile phones in the United States and worldwide. The growing ubiquity of mobile phones and the technological advances of wireless devices have presented an opportunity to "advance research, prevent disease, enhance diagnostics, improve treatment, reduce disparities, increase access to health services and lower health care costs in ways previously unimaginable" (Nilsen et al., 2012, p. 6).

A growing number of Americans are also interested in mHealth tools with 52% of smartphone owners reporting that they use their phone to look up health or medical information online. Women, African Americans, Hispanics, college graduates, individuals aged 30-49, and individuals with household incomes of $50,000 or above all report above average rates of use of their mobile phone for accessing health information (Fox & Duggan, 2012). Furthermore, 1 in 5 smartphone owners report downloading a health application (app), with exercise and fitness apps being the most popular (Fox & Duggan, 2012).

Although there is great potential, the evidence for positive mHealth outcomes is severely lacking. The enthusiasm for mHealth interventions currently outpaces the science, and experts in the field have called for more rigorous research on the health outcomes, long-term effects, and cost effectiveness of existing mHealth interventions as well as the development of more theory-driven and evidence-based mHealth programs (Collins, 2012; de Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car, & Atun, 2012; Nilsen et al., 2012; Sherry & Ratzan, 2012; Tomlinson et al., 2013). mHealth holds promise for the SM of chronic disease through the close monitoring, cost-effectiveness, and convenience afforded by a mobile device. However, a Cochrane systematic review of mobile phone messaging applications for the SM of chronic illnesses found significant gaps in the published literature and very few studies that met the methodological standards for quality evidence (de Jongh et al., 2012). A more focused, systematic review of 47 iPhone apps for smoking cessation yielded few that adhered to the established guidelines for smoking cessation set forth by the US Public Health Service (Abroms et al., 2010). This paucity of both mHealth evidence and evidence-based mHealth programs presents the risk of ineffective and fragile outcomes at best, and harmful consequences at worse (Nilsen et al., 2012).

An additional gap in the mHealth literature is the lack of theory-driven research. While many of the current mHealth interventions target health behavior, few incorporate behavioral science theory into the development of interventions. In a systematic review of mHealth interventions, Riley et al. (2011) discovered that while a small number of interventions reported a theoretical basis, few within this subset tested the theoretical constructs proposed in the intervention. This scarcity of theory driven mHealth interventions presents another recommendation for improving the rigor of the mHealth field (Tomlinson et al., 2013).

A final gap in the mHealth literature is the lack of formative research of user's needs, characteristics, and situation prior to the development of mHealth programs. The US Department of Health and Human Services recommends that in order to achieve greater acceptance and impact, e-health tools will require "greater attention to the intended user's diverse perspectives, circumstances, and experiences regarding health information and digital technologies, as well as their differing capacities for health management" (Office of Disease Prevention and Health Promotion, 2006). This thesis research aims to fill these gaps by evaluating the needs of people with epilepsy through a theoretical framework and informing the development of an evidence-based, theory-driven mHealth intervention.

Diffusion of Innovations

The Diffusion of Innovations (DOI) theory provides an appropriate framework to examine smartphone use, access, and acceptability among PWE. Developed by Everett Rogers in 1962, the DOI aims to explain the process by and rate at which an innovation is adopted in a population (Rogers, 2003). Although initially proposed for the field of agriculture, the DOI has been applied and adapted to multiple disciplines since its introduction (Rogers, 2003).

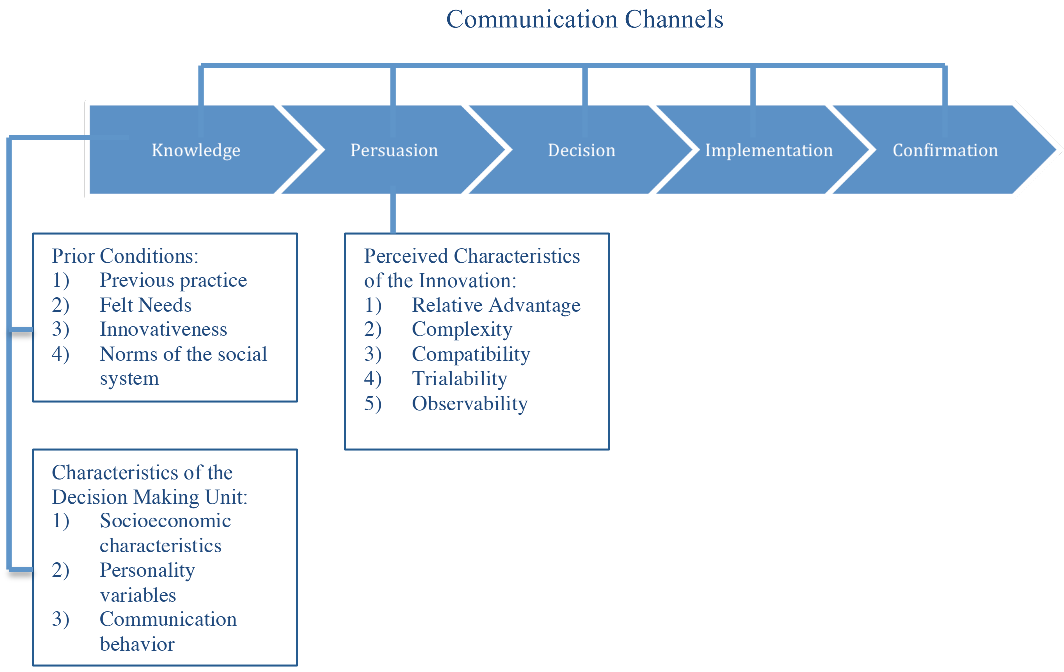
There are four main elements to the DOI: 1) the innovation, 2) communication channels, 3) time, and 4) the social system. Following these four core elements, diffusion is defined as "the process in which an innovation is communicated through certain channels over time among the members of a social system" (Rogers, 2003, p. 5).

An innovation is “an idea, practice, or object that is perceived as new by an individual or other unit of adoption” (Rogers, 2003, p. 12). This thesis examines the adoption process for two innovations: 1) smartphones and 2) a smartphone SM application for PWE.

The process for the adoption of an innovation among members of a social system is termed the innovation-decision process (figure 1). The innovation-decision process consists of 5 stages: 1) knowledge, 2) persuasion, 3) decision, 4) implementation, and 5) confirmation. Since smartphone adoption must precede smartphone SM application adoption, the two innovations explored in this research follow separate but overlaying trajectories along this 5-stage innovation-decision process.

For examining the adoption of a smartphone SM application, this research will focus on the knowledge stage of the innovation-decision process. This stage begins when the decision making unit is “exposed to an innovation’s existence and gains understanding of how it functions” (Rogers, 2003, p. 171). This knowledge stage is influenced by prior conditions and the characteristics of the decision-making unit. The term decision-making unit is particularly applicable to this study given that PWE, depending on their level of disability, may have a caregiver who makes decisions for them. Determining who are the decision-makers and the decision-makers’ role in the use, access, and knowledge of technology will be an important consideration in this qualitative research. Communication channels are another construct that will be explored in this thesis. Understanding the communication channels of PWE, where they hear about SM techniques, and who they hold as reliable sources of information will help determine the best dissemination plan for the WebEase mobile app.

Figure 1: Innovation-Decision Process (Adapted from Rogers (2003))



When examining smartphone adoption among PWE, this research will explore the knowledge, persuasion, and decision process with a focus on two constructs of the perceived characteristics of the innovation: complexity and compatibility. The perceived characteristics of the innovation will also be examined in regards to the smartphone SM application as understanding what aspects of a smartphone app for PWE that may encourage them to adopt an app for their SM needs will help with the development of a successful intervention.

Diffusion of Innovations in mHealth literature

The Diffusion of Innovations theory has been used extensively for examining the rapid adoption of mobile telephony in various populations. Rogers used cell phone technology in two examples in the 5th edition of The Diffusion of Innovations (Rogers, 2003). Several studies in fields outside of medicine and public health have utilized the

DOI to examine smartphone adoption (Lee, 2014; Park & Chen, 2007) and usage patterns of smartphone applications (Verkasalo, López-Nicolás, Molina-Castillo, & Bouwman, 2010). The DOI's application to mHealth specifically, however, has been limited. Most of the published studies focus on mHealth for healthcare systems and its adoption and use by healthcare professionals (Doyle, Garrett, & Currie, 2013; Putzer & Park, 2010, 2012; Ward, 2013) rather than by the general public for disease SM.

Conclusion

Epilepsy is a serious disorder that affects the lives of millions of Americans, severely impacts quality of life, and imparts significant economic burdens to society. PWE must adopt SM techniques to manage symptoms and maintain a healthy quality of life. However, finding a proper platform for SM education programs is crucial to improve health outcomes, encourage behavioral change, and address the unique barriers to access that many PWE face.

An mHealth program presents a promising option for PWE, given the remote capabilities, confidentiality, and cost-saving benefits of mobile technology. However, this literature review shows that the mHealth field lacks theory-driven and evidence-based interventions as well as rigorous formative research prior to intervention development. Using the DOI as a conceptual framework, this thesis fills these gaps in the literature by conducting rigorous qualitative research on the prior conditions, characteristics, and knowledge of PWE in regards to smartphone technology.

CHAPTER III: METHODS

This qualitative study is the first stage of a comprehensive plan aimed at adapting the Webease online SM tool for PWE to a mobile phone platform. The goals of this study were to understand the compatibility of mobile phone technology with the lifestyles of PWE, the complexities they encounter in using this technology, and their current SM practices, felt needs, and communication behaviors. The findings of this study will provide a needs assessment that will help develop a SM mobile phone application that is more sensitive, accessible, and acceptable to PWE.

Participants

Individuals were eligible to participate in the study if they were 18 years of age or older; had a diagnosis of epilepsy for 3 months or more prior to enrollment in the study; resided in the Unites States; were able to read, write, and understand English; and were willing to participate in a 2-hour focus group. This study was approved by the Emory University Institutional Review Board.

Recruitment

Participants for this study were recruited from the Emory Comprehensive Epilepsy Center in Atlanta, Georgia. Flyers were posted at the clinic site to advertise the project (Appendix A). Clinic staff also identified potential participants from among the epilepsy patients they served and referred them to the principal investigator, who was available at the clinic site to talk with interested individuals and provide more information about the study. If a member of the research team was not available or present at the time, the clinic staff provided the patient with the contact information for the principal investigator. Eligible participants were also recruited through web advertisements and twitter posts on the Epilepsy Foundation of Georgia and Managing Epilepsy Well (MEW) Network websites and associated social media channels.

Individuals who were interested in participating in the study contacted the principal investigator directly through the phone number or email address provided on recruitment materials. After contacting the principal investigator to express their interest in being involved in the study, potential participants were asked to fill out demographics and contact information forms to ensure they met the eligibility requirements for enrollment into the study. These forms were distributed and collected at the clinic sites by the principal investigator, through a confidential on-line survey link, or over the phone, depending on the participant's preference, location, and access. The principal investigator then reviewed these documents and assessed if participants met the eligibility requirements. Eligible participants were then sent an invitation through email to participate in the study.

Measures

Demographic information analyzed included gender, age, ethnicity, household income, education level, employment status, technology access and ownership, and epilepsy related information including seizure type and current epilepsy treatment. This information was obtained at screening through a demographic survey form (Appendix B).

Table 1
Sample Focus Group Questions

Topic of Discussion	Sample Questions
Smartphone Compatibility	• *What do you primarily use your smartphone for?* • *How much do you rely on your smartphone on a daily basis?*
Smartphone Complexity	• *What are some disadvantages to using a smartphone?* • *what are some challenges to using or accessing new technology?*
Current SM Practices	• *What things do you currently do to prevent or reduce seizures?*
Source of epilepsy and SM information	• *Where did you learn about these treatment options/ what made you decide to follow this course of treatment?* • *How do you stay informed about treatment options, epilepsy self-management techniques, and epilepsy in general?*
Felt SM Needs	• *Is there something that you wish you had to help you with your epilepsy?* • *What are some of the challenges you face when managing your epilepsy?*
Smartphone App for epilepsy SM	• *If you could create a mobile app for people with epilepsy, what would it look like?*

The focus groups were semi-structured, following questions, activities, and prompts from the focus group guide (Appendix C). The focus group guide was developed based on the DOI constructs and the study's overall research questions to obtain opinions from PWE on the complexity of smartphones and the compatibility of the technology with their daily lives, where they obtain information on SM techniques, their felt needs in regards to SM of epilepsy, and suggestions for a smartphone app to address these needs (Table 1).

Focus Group Procedures

To better accommodate the limited mobility and issues concerning transportation facing many people with epilepsy, all the focus groups were conducted by phone, using a secure conference call line operated by Emory University. Upon recruitment into the study, a copy of the informed consent document (Appendix D) was sent to participants through email for their review and records. A week prior to the focus group session, the principal investigator called each participant, to remind him or her about the study, ensure the participant received and looked over the informed consent document, and to determine if the participant had any questions prior to the conference call. At the start of the focus group, the co-facilitator read the informed consent script verbatim and obtained verbal consent from all members on the call to participate in the study.

Three focus groups, each consisting of 3-4 adults with epilepsy, were conducted for this study. Each focus group was approximately 2 hours in duration and participants received a $20 gift card in appreciation of their time and contribution. It was initially proposed that two of the three focus groups were to be homogeneous: one consisting of individuals who had access to smartphones and a second for individuals who did not have access to smartphones. The third focus group was to be mixed, including individuals who had access to smartphone technology and those who did not. However, due to difficulties in recruiting PWE without smartphones, these methods were revised to three homogenous focus groups of individuals with access to smartphones to reflect the population reached through the study’s recruitment methods.

The principal investigator of this study moderated the focus groups, with assistance from a focus group co-facilitator who, herself, was a person with epilepsy.

The principal investigator was trained in qualitative methods through the Rollins School of Public Health qualitative methods course. As moderator, the principal investigator led the focus group through the questions from the focus group guide. The co-facilitator assisted the moderator by helping to maintain the flow of conversation, ensuring that all participants had a chance to speak, and taking detailed notes during the focus group session. Additionally, due to the co-facilitator's experience with epilepsy, the co-facilitator was also able to assess participant comfort and, if they occurred, identify and address adverse events, such as seizures, during the focus group sessions.

Post-Hoc Procedures

As a result of the difficulties in recruiting PWE without smartphones, one-on-one interviews with PWE without smartphones were also included in the study protocol post-hoc, in an attempt to better accommodate the schedules of this hard-to-reach subgroup. In addition, a key-informant interview was added to the methodology for the purpose of gaining more information on the difficulties in recruiting PWE without smartphones. The key informant was selected based on her involvement with recruitment for this study as well as her knowledge of PWE through her role in the clinic.

Data Collection, Management and Analysis

Focus group sessions were audio recorded for accuracy with a digital recording device. The moderator and co-facilitator also took detailed notes during the focus group sessions for additional accuracy and to provide information to supplement the recordings. All recorded focus group sessions were transcribed verbatim by the principal investigator and de-identified during the transcription process. The original digital, audio-recorded files were stored on the principal investigator's password locked computer and deleted following the completion of the thesis research.

The principal investigator first drafted an a priori codebook based on the focus group guide and DOI framework. The principal investigator then coded the transcripts using MAXQDA version 10, and revised the codebook as needed. An independent reviewer trained in qualitative methods simultaneously coded the transcripts from the three focus groups and met with the principal investigator to assess inter-coder agreement and discuss revisions needed for the codebook. Once all transcripts were coded and the codebook finalized, the codes were systematically analyzed within and across the three focus groups to identify patterns and themes. The data from participant's demographic forms collected at screening were also included in this study to supplement the qualitative data. The data collected from the demographic forms were compiled and descriptively analyzed using IBM SPSS version 21.

CHAPTER IV: RESULTS

Study Participants

A total of 12 individuals were recruited and screened for this study. However two were unable to participate, one due to scheduling conflicts and the other could not be reached following screening. Ten PWE participated in three focus groups, two with a total of three participants each and one with four participants. The mean age of participants was 29.20 (±9.69) years (Table 2). A majority of the participants were female (n=7) and African American (n=6). In terms of employment status, four of the participants reported that they were unable to work due to disability while three reported that they were currently students. Only one participant reported full time employment. Participants reported high levels of education attainment with four reporting a graduate level education while three reported some college education. There was a range in regards to reported socioeconomic status and while one participant reported a household income of $75,000 or above, the remaining participants (n=9) reported household incomes at or below $50,000.

Participants had been diagnosed with epilepsy for a mean of 13 years (± 6.5) (Table 3). Half of the participants reported experiencing a seizure in the past 30 days prior to screening for the study. Of these participants, the mean number of seizures experienced in the past month was 5.80 (± 9.76). A majority of the participants (n=6) reported tonic-clonic (grand mal) as the main seizure type experienced. When asked to describe their current epilepsy treatment, a majority of the participants reported treating their epilepsy with medications. Additional treatment methods mentioned by participants were vagus nerve stimulation (VNS) (n=2) and brain surgery (n=1).

Table 2

Demographics of Focus Group Participants

	Total (n=10)	Focus Group 1 (n=4)	Focus Group 2 (n=3)	Focus Group 3 (n=3)
Age (years), mean (sd)	29.20 (9.69)	30 (14.31)	31.67 (2.52)	25.67 (9.69)
Gender, n				
Male	3	2	0	1
Female	7	2	3	2
Race, n				
White	3	0	1	2
African American	6	3	2	1
Other	1	1	0	0
Employment Status, n				
Full-time	1	0	1	0
Currently not working	1	0	0	1
Student	3	2	0	1
Unable to work due to disability	4	2	2	0
Do not wish to say	1	0	0	1
Household Income, n				
$10,000 or less	1	0	1	0
$10,001 - $15,000	2	0	1	1
$20,001 - $25,000	1	1	0	0
$35,001 - $50,000	2	1	1	0
$75,001 or above	1	0	0	1
Do not know	3	2	0	1
Education, n				
Grades 9-11 (some high school)	1	1	0	0
Grade 12 or GED (high school graduate)	1	0	0	1
College 1 to 3 years (Some college)	3	2	1	0
College graduate	1	1	0	0
Graduate School	4	0	2	2

Table 3

Epilepsy Characteristics

	Total (n=10)
How long ago have you been diagnosed with epilepsy? (in years, mean (sd))	13 (6.56)
Have you had a seizure in the past 30 days? (Yes, n)	5
If yes, how many seizures have you had in the past 30 days? (mean, sd)	5.80 (9.76)
Type of seizure usually experienced (n)	
Complex Partial	1
Absence (petit mal)	1
Tonic-clonic (grand mal)	6
Multiple types reported	2
Current Epilepsy Treatment (n)	
Medication	6
Vagus Nerve Stimulation (VNS)	1
Multiple treatments	2
Medication and VNS	1
Medication and brain surgery	1
Not reported	1

Technology Access of Focus Group Participants

All 10 participants in this study had access to a smartphone that they used on a daily basis. When asked about the model and make of their smartphones, half of the participants reported owning an iPhone, three with access to the iPhone 4 and two with access to the iPhone 5S, the latest model of iPhone at the time of this study (Table 4). Four participants reported owning phones that ran on an Android platform while one participant reported using a phone that runs on the Windows platform (Model: ATIV Odyssey). All 10 participants reported having access to the Internet or WiFi in their home. Out of the 10 participants, 8 reported owning or having access to a laptop computer at their home while 4 reported access to a desktop computer. In addition to owning smartphones, half of the participants reported owning or having access to a tablet, and three reported having access to a dedicated electronic reader. Only four participants reported owning a digital music player, possibly due to participant's use of smartphones as a multipurpose device. Furthermore, seven of the ten participants reported not maintaining a landline phone in their household, possibly reflecting a national trend towards mobile-phone-only households (Blumber & Luke, 2013).

Table 4

Technology Access of Focus Group Participants

	Total (n=10)
Do you own or have access to a smartphone on a regular basis? (Yes, n)	10
Smartphone model (n)	
iPhone 4	3
iPhone 5S	2
Galaxy S3	2
Galaxy S4	1
Metro 4G (unspecified)	1
ATIV Odyssey	1
Smartphone software platform (n)	
iOS (Apple Inc.)	5
Android (Google Inc.)	4
Windows (Microsoft)	1
Do you have access to WiFi or the Internet in your home? (Yes, n)	10
Do you or your household own or have access to a: (Yes, n)	
Desktop computer	4
Laptop computer	8
DVD player	7
Tablet (e.g. iPad or Samsung Galaxy)	5
Electronic Reader (e.g. Kindle or Nook)	3
Digital music player (e.g. iPod)	4
Gaming console (e.g. Wii or Xbox)	5
Portable gaming device (e.g. Nintendo DS)	2
Telephone (landline)	3
Media streaming device (e.g. Roku or Apple TV)	1

PWE Without Access to Smartphones

No participants without access to smartphones were successfully recruited for this study. Although recruitment posters and flyers were revised to target this population and one-on-one interviews were included in the study protocol post-hoc to better accommodate these participants, none of these individuals were successfully recruited to participate in the research. However the inability to recruit these individuals for this study was a finding itself. One possible reason is that the study's inability to recruit participants without smartphones could reflect greater smartphone ownership among PWE. This said there were a number of limitations in study design and recruitment strategy that may bias such a conclusion.

The key informant was interviewed by the principal investigator for 30 minutes to better understand the possible reasons behind the difficulties in recruiting PWE without smartphones. The key informant explained that many of the individuals without smartphones tended to be older than 60 years of age. These older patients seemed to have low technological literacy, did not know what an app was, and thus were not interested in participating in the study. There were additional barriers to participation in this study among PWE who were younger than 60 but did not have access to a smartphone. The key informant explained that a larger portion of these younger individuals without smartphones did not meet the study requirements of speaking and understanding English. Of those who did meet the English requirements, the key informant explained that these patients generally had lower IQ levels, co-morbidities (schizophrenia and other psychiatric problems), developmental delays, and cognitive difficulties that may have inhibited their active participation in a 2-hour focus group.

Additionally, lower economic status and limited resources were significant issues among PWE without smartphones. Due to these economic barriers, many of these patients relied on government phones or pre-paid phones. The key informant reported that some of these patients were concerned that participating in the study would cost them minutes. Furthermore, the key informant explained that from her experience pre-paid phone users and government phone users were difficult to follow up with since "towards the end of the month they turn them off, or they run out of money, so they can't receive and they can't call back." This instability in regard to phone use, as well as the restrictions of these mobile phone plans may explain why these participants did not contact the lead researcher to take part in the study.

Research Question 1: How compatible is smartphone technology with the lifestyles of PWE?

Smartphone Ownership

The results of the three focus groups indicate that participants were comfortable with smartphone technology and found the technology compatible with their life. All the focus group participants not only had access to a smartphone but were also the primary owners of their phone. This indicates greater use, investment, and familiarity with their smartphones in comparison to individuals who are not the primary users of the mobile phone. Moreover participants were protective of their phones and its contents, indicating the value they placed in these devices. As one participant explained, "I don't like to let them (other people) use it because it's kind of like a violation of my privacy even if they want to call someone." Similarly others expressed that they would feel comfortable sharing their phone but only for emergency situations. As one participant explained, "I let, um, I let some people use my phone, but it's usually if it's an emergency or they didn't have access to another phone."

Several of the participants in this study expressed a keen interest in obtaining new technology and were often the first among their friends and family to purchase their smartphones. One of these participants stated, "I would buy the newest version because of how it works and like the features on it." Some of these participants were also opinion leaders among their friends and family and helped others to decide on adopting certain technology.

Other participants were influenced by people around them, particularly friends, family, and significant others, when purchasing a new device. Although it took them longer to obtain a smartphone, these individuals were not skeptical of the technology and were pleased with the functions of the phone. The sources of information mentioned by these participants included siblings who were computer programmers, significant others involved in IT, and friends in the tech business.

Advantages of Smartphones

Participants described their smartphones' features positively and described several advantages of owning a smartphone over a non-smartphone. Many participants highlighted the multipurpose functions of the smartphone as a strong advantage of the device. For example one female participant highlighted several helpful applications of the smartphone: "It helps you out in so many ways, that if you in any kind of emergency, that you can, the flashlight, the GPS, and, um, the weather updates. You can have all those features." By highlighting the multipurpose function of the smartphone, participants saw their smartphone as an indispensable, multiuse tool that went beyond a device to make and receive telephone calls. As one participant explained:

> So it's basically like having a laptop with you so you're connected with the world. So if you need information, of course, of any sort, whether it be connecting with people or looking up information for research for, like I said, the weather or a map. It's not just a telephone, you know, a lot of us would be lost without it because if we just had our phone we wouldn't know what our email is, we wouldn't know where we were or we wouldn't – we wouldn't have a lot of tools.

These findings illustrate that participants value their smartphones as multipurpose tools and view this versatility as a positive asset of the technology.

Daily Use

Although participants owned smartphones and were positive about the advantages of smartphones, how they used them on a daily basis varied. Some of the older participants tended to be unfamiliar with certain apps, such as social media apps, and other functions of the phone such as blocked calls. Although they agreed that an advantage of smartphones was their mulit-purpose abilities as explained in the section above, these older participants reported mainly using their phone's basic functions like texting and calling on a daily basis. Younger participants reported greater comfort with the multiple functions of their smartphones and used them for a variety of activities such as social media, various downloaded apps such as games, work-related apps, news, and electronic reading apps (Bible and Kindle), and interacted more with their phone on a daily basis. A young female participant (age 19) explained "I use it for school. I use it for everything" and preferred using her phone over other technology like a laptop or tablet.

While some participants found smartphones to be very compatible with their lives, others expressed that they preferred other devices for their needs. One female participant used her laptop more than her smartphone on a daily basis, in part due to the severity of her seizures and level of control of her epilepsy:

> I guess I'm connected to it (laptop) because I tend to stay in my house a lot, and I guess you could say it's my window to the world. I use it to connect to everybody, to talk to people. I watch TV with it on my, I watch with my friends, with my family, uh, through Skype. Everything. Play games. You name it.

Her story illustrates that the compatibility of an mHealth intervention may vary in regards to differing levels of disability and seizure severity experienced by the individual.

Research Question 2: What are the complexities PWE encounter in using or accessing smartphone technology?

Socioeconomic characteristics

The DOI identifies socioeconomic characteristics of the decision-making unit as a variable that contributes to their knowledge of an innovation (Rogers, 2003). Although all participants owned smartphones, participants mentioned cost as a consideration when planning to purchase new technology. Despite reservations about cost, a majority of the participants were willing to pay for a smartphone due to the advantages of the device. For example, one female participant described this cost-benefit decision: "You pretty much, most instances if you shop around, you can get that smartphone for what the, more, what we call our dinosaur phones was getting. The cost is good for what you're getting as well." That being said, cost was often mentioned as more of a consideration when accessing new technology among older participants who were working or out of school than with younger participants who were currently in school. These younger participants were more eager to purchase the latest version of a technology and listed other qualities such as the data capacity, durability, and functions of the device over cost as considerations when purchasing their smartphone.

While participants justified the high cost of a smartphone, they expressed resistance to the relatively low cost of smartphone apps. When discussing downloadable apps for the smartphone, one male participant argued, “If I gotta pay for it, I’m not gonna get it.” This statement reflected a cost bias when it came to content versus hardware. Therefore cost for smartphone content should not consider price alone but also consumer motivations and biases.

Socioeconomic considerations were greater for some participants due to their particular burden of epilepsy. For one participant, her condition directly impacted her employment and income. She explained, “because in my situation I have to watch a lot of finances, because I’m on disability due to seizures.” Returning to the demographic characteristics of the 10 participants, four were unable to work due to disability and thus may also face similar economic barriers that can inhibit their access to new technology and affect their adoption of smartphone apps and content.

Disadvantages of smartphones

In regards to the complexities to using smartphone technology, several participants mentioned some technological disadvantages of smartphones that made them difficult to use. Some of the disadvantages brought up in the focus groups included the smartphone’s small keyboard, the small screen size, short battery life exacerbated by the energy use of applications, and inability to run certain programs, such as creative software, document editing, and word processing. Due to these disadvantages, some participants preferred using other technology, such as laptops, for certain activities. For example, when discussing the small keyboard and screen size of smartphones one participant remarked, "I don't like typing up – it's like it's a lot easier for me to surf the Internet on a laptop and then typing up documents and even emails are always easier on a laptop." These findings illustrate that although the smartphone was a multi-purpose tool with similar technological power and ability of a computer, a mobile platform may not be as convenient, ideal, or appropriate for certain applications.

The focus group participants also illustrated some barriers to using smartphones that were related to their epilepsy experience. A woman with epilepsy who favored using her laptop over her smartphone described the tremors related to her epilepsy as one reason for this preference:

> Um, certain tablets and things that require you to always be grasping it, um, sometimes I get tremors in my hands from grasping things too long. So, anything that can be propped up on its own and is independent of having to be held, I tend to go towards those a lot more than something that doesn't, that requires you to hold it but doesn't have a stand.

A male participant described a different issue in regards to challenges with using technology that were related to his epilepsy: "technology has triggered mine (seizures) before. Like, as I said before, flashing lights or staring at a TV for too long." While individual accounts, these statements reflect the broad range of experiences to be expected with a spectrum disorder like epilepsy and should be important considerations when developing a mobile app for PWE.

Research Question 3: What are PWE's current epilepsy SM practices and how do they prefer to receive information on treatment and SM techniques?

Current SM Practices

A majority of participants mentioned medications as their main treatment for their epilepsy. Several participants also brought up regular sleep and stress reduction as additional SM techniques they currently practice. One female participant described her SM practices as follows: "So medication is a huge part of it. But also getting regular sleep is a big part of it and trying not to stress out my body too much." Similarly an older female participant succinctly explained her SM practices of medication adherence and stress reduction: "My best way to manage epilepsy is to go by what the doctors say, take your medicine, and live a calm, stress free life." In regards to the participants' attitudes towards their current SM practices, responses ranged from satisfied with one participant stating that "they're helping pretty well", to acceptable with another participant explaining, "right now we're both at a point where if it's broke don't fix it. I'm going on, this is the longest I've gone where it's been controlled, so don't really, don't want to mess with it at the moment."

Communication Channels: Epilepsy and SM techniques

The Internet was mentioned as a major resource for information on participant's condition and SM techniques. One participant elaborated, "I know my computer has helped me a lot with, um, research on epilepsy, um, it's helped me a lot with finding communities of epilepsy especially nearby or online, Facebook." Some participants mentioned visiting dedicated epilepsy websites, such as the National Epilepsy Foundation, for information on epilepsy research and treatment. Others looked to general websites, like Google and YouTube, to search for information. For example, when asked about his decision to pursue certain treatment options for his epilepsy, a male participant explained, "I looked that up on Youtube when I was checking out the VNS surgery, because I wanted to get some information on it, because I had never spoke to anybody who ever had it." Participants also used social media to stay updated on the latest research and SM techniques. A young female participant stated, "Every once in a while I kinda go on Twitter and I look up the hashtag 'epilepsy', and people have interesting stories, or they'll post kind of new research developments or just kind of their thoughts and it's helpful. "

Doctors and physicians were also a main source of information for epilepsy treatment and SM techniques. A female participant identified her doctor as a major source of information on SM techniques:

> He (neurologist) gave me some really good – he kind of understood more, because he had a daughter that was my same age, and so he kind of knew, as a student how hard it is and whatnot, so he gave me really good advice on how to manage it for my personal life. So I mean I also did a lot of kind of Googling on the Internet and going on Epilepsy Foundation website, but I got most of my information from my doctor.

The above quote also illustrates that while participants identified their doctors as sources of information, they often coupled their physician's advice with their own Internet research. Similarly another female participant described, “You find out information through people, through people that have it, people who are neurologists and there’s the Internet about ways to avoid it.” In short, participants were proactive about gaining information about epilepsy, treatment options, and SM techniques through a variety of communication channels.

Research Question 4: What are the SM felt needs of PWE and how can a mobile phone application meet them?

Previous Practice

Several participants in the focus groups reported currently using their smartphone to help manage their epilepsy. Medication reminders and appointment reminders were popular applications of the smartphone with participants in the study. While some participants used the built in features of the phone like alarms and calendar to set up these reminders, one participant explained that he used a specific app for medication adherence: “Yeah, I have an app that tells me when to take my medicine, and make sure I take it on time, or close to the time.” A few participant in the study explained that they used their smartphones as tools to address their memory problems. One participant highlighted the contacts and memo features of her phone as particularly helpful for her memory problems:

> I use my smartphone for the memory because when the deep brain stimulator was implanted some of my memory is gone. It’s hard for me to memorize anything short term, but I can remember stuff that happened 30 years ago, but its, when I

> put the names and numbers in the phone all I have to do is click on the phone, it gives me the information. Uh, I can even keep notes in my phone.

Another participant described a creative use of her smartphone's camera to help with her memory: "I use my photos, sometimes I – let's say I like something that I drank or something, I'll photograph the bottle because I don't – I won't remember that."

Felt Needs and Suggestions for a Smartphone App for PWE

Participants' suggestions for a smartphone app for PWE fell along 5 content areas: 1) logging, 2) emergency services, 3) communication channel with doctor, 4) information resource, and 5) support for PWE. Participants discussed that logging medications and seizure type and frequency was a particular challenge for them and one that a smartphone application could address. One participant explained both her need for a tool to assist with logging as well as several suggestions for such an application:

> I need to make a log and I used to be better at that, but I would write it down on paper. I guess if there was an app where you could write it and it could make all kinds of charts and show how frequent they were, so it could show you patterns, and that you could also put in medications, levels, and you could see – and you could also write notes like maybe let's say your new cycle, so you could see things spike.

Emergency services were another common suggestion for a smartphone application for PWE. When discussing the challenges of living with epilepsy, several participants expressed fear of having a seizure among strangers and lacking the ability to reach help. For example, a female participant who mainly stays at home due to the severity of her seizures explained "right now I can't really go out because I'm scared of the seizures, because I like have no way of knowing and the uncertainty." Other focus group participant shared stories about a time when they used emergency services. A female participant shared a story of a time when she had a seizure while driving and how her cell phone assisted her in this emergency situation:

> "Because of that phone, because of the phone, a cellphone rather, I'm out of it. (Unintelligible) They were able to find who I was and call someone, a recent number that was on my phone, which was my sister, and let her know what was going on, cause of that phone. "

Given this felt need for security combined with knowledge from previous emergency experiences, participants suggested an app that would streamline access to care in case of emergencies. As a male participant proposed:

> Also I can see that if that was all in an app like that for medical purposes if you were caught out, like you know, (intelligible) medics or somebody, for when people find phones on people they do tend to look up, maybe there will be some sort of, I don't know, feature, it'd be easier for the paramedics to just be able to pull up everything right there.

Another frequent suggestion from participants in the focus group was developing a smartphone app that created a communication channel between patients and doctors. This communication channel took several forms and participants suggested both an app that would provide them with easier access to their physician as well as a way to send detailed logs of medication adherence, seizure type, frequency, and duration, to their doctor to encourage better monitoring and management of their epilepsy. In addition to greater connection with their doctor, some participants suggested a component of an app for accessing credible information about new epilepsy research and treatment. However other participants were not interested in this feature as they felt it would be extraneous information on top of the research they currently do on epilepsy treatments. A female participant explained why she was not interested in an information resource component of an app for PWE:

> Because I've been through a lot of it already, that'd be something maybe I'm not interested in that. You know, it's kind of like to me maybe that's junk mail, you know- go away. I don't need to read that today. So that'd be something totally maybe I'm not interested in.

The final content area for a future smartphone app for PWE was support. One focus group extensively discussed a felt need for a support group for PWE. For 3 out of 4 participants in this focus group, the conference call was the first time they had spoken with other people who had epilepsy. These participants gave positive feedback on the focus group. One participant explained, "Like I was, I was really looking for a program like this, to like, for people who have epilepsy. Like you know, can come together, and just talk and just, you know, help each other out with different things, like." Similarly another participant exclaimed, "This is the closest I've come to a support group. (…) And this is the closest, this has been such a joy or encouragement to me to hear each person giving a sharing of their, their seizure, about epilepsy." Accordingly this group strongly suggested a mobile phone application to connect PWE and provide a forum for support.

Considerations: Perceived Characteristics of the Innovation

While participants provided numerous suggestions for a smartphone app for PWE, they also highlighted a number of considerations for developing a successful mHealth intervention. These considerations can be explained using the DOI construct of perceived characteristics of the innovation, particularly the factors of complexity, relative advantage, compatibility, and observability. In regards to complexity, participants expressed disinterest in a smartphone app with too many functions. While they generally agreed with the 5 content areas discussed above, some suggested having multiple apps for the different content areas to reduce this complexity or a multifaceted app that simplified the content areas with an easy-to-use interface.

Another preference was relative advantage with several participants explaining that a smartphone app should not repeat resources that are already available. One female participant who actively used online support groups expressed some hesitance in having a support function as part of the app due to the existence of support resources online:

> I don't know, depending on how intricate the app would get, you know, just maybe a little RSS feed or scroll, so. But it wouldn't be, I wouldn't make it (support) like a main, main feature. I would think the app would be more for tracking and keeping more personal things. Cause I mean if you wanted to, you know, support, there's twitter and all those online groups and everything.

Tied to the factors of complexity and relative advantage was the issue of compatibility. A participant voiced that the app's compatibility with her current life would be a major consideration for her to use the app:

> Mainly, um, I guess it would be how convenient it was, cause, um, that's the main thing for me, if it's easy to use, and I'm always looking for an easier way to sort of like, you know, fit it into my life. I want to be able to use the app, but not in a way where I'd have to take a huge chunk out of, you know like, take a huge

> chunk out of your time. It would be like, oh, I'm just going to use this app as well, not, okay, I've got to stop, stop everything, I've got to use this app and do this, this, and this and that, and everything. But if it was really convenient, easy to use, quick, bam, I'd be really more likely to use it.

A final consideration was observability. When asked what would persuade them to use the smartphone app for the SM of epilepsy, a male participant succinctly stated, "I'd say that I'd have to see that will help you." Therefore a successful app that is adopted by PWE must first illustrate and communicate its positive qualities to the target audience.

CHAPTER V: DISCUSSION

This thesis research represents one of the first studies exploring smartphone use and access among PWE. The results of the three focus groups indicated that participants with epilepsy who already owned smartphones were comfortable with smartphone technology, were often the primary owners of their devices, were positive about their phones and their technological capabilities, and used their smartphones daily for a variety of purposes. In regards to comfort with smartphones and barriers to accessing smartphone technology, there was some variation in responses between older and younger participants. Older participants tended to report using their phone only for the basic features like calling and texting and reported cost as a major consideration when purchasing new technology. Younger participants, on the other hand, tended to interact with the phone more frequently and in a more involved manner, using it for a variety of functions, and reported specific features of the device such as data storage and battery life as considerations when purchasing a smartphone. These age distinctions are reflective of current trends in the US in smartphone ownership and use (Rainie, 2012).

Although cost was listed as a consideration when purchasing new technology, it was not necessarily a barrier to smartphone access as all participants had invested in a smartphone and many participants remarked that they were willing to pay the cost for the features and convenience provide by the device. However, participants were less willing to pay for additional downloadable apps for their smartphone, indicating different cost considerations when it came to smartphone content.

Though a smartphone can have technological power and ability comparable to a personal computer, several participants preferred using their laptop or tablet for certain activities. Some of these activities were ones that involved extensive typing where the smartphone's smaller keyboard proved prohibitively difficult. Likewise, participants found the smartphone's generally smaller screen size difficult for many applications and functions more readily accessible on larger screens. Additionally the level of epilepsy disability played a role in this preference with a participant who stayed mostly in her house due to her epilepsy preferring her laptop over her smartphone. Thus these findings indicate that a mobile platform may not always be convenient, ideal, or appropriate for certain mHealth applications as well as for certain subpopulations of PWE.

The majority of participants in this study self managed their epilepsy through medications, regular sleep, and stress management techniques. Doctors and medical professionals were reported as the main source of information on epilepsy and SM treatment. However participants coupled their doctor's advice with Internet research and some regularly checked social media sites and dedicated epilepsy websites for the latest updates on epilepsy research and treatment.

Even without a specific SM app for PWE, participants in this study reported creative uses of their smartphone to help manage their epilepsy. This included using the phone's built in alarms and calendar for medication and appointment reminders and the memo and camera function for memory problems. Suggestions for a future app for PWE fell along five content areas: logging, emergency services, communication channel with doctor, information resource, and support for PWE. These findings provide positive support for translating WebEase to a mobile platform as two of these content areas, logging and information resource, are currently key components of the WebEase online program (Dilorio et al., 2009b).

However, although the findings support the content of the WebEase online program, translating the program into a mobile platform requires additional considerations. Following the DOI, participants identified four out of the 5 factors of the perceived characteristics of the innovation construct that they felt were important to their use of a smartphone app for PWE. These included complexity, relative advantage, compatibility, and observability. Accordingly a smartphone app for PWE should consider these factors to create a more accessible and acceptable app for this population.

Limitations

There are a number of limitations to this thesis research. The small number of participants (n=10) for this study and the smaller number of participants (n= 3-4) divided into the three focus groups was also a major limitation of this thesis research. Typical suggested size for a focus group is 6 to 8 participants in order to capture diverse opinions while also being a feasible size for the moderator to manage (Hennink, 2014). While this research's over-the-phone approach to focus groups necessitated a smaller size than the recommended 6-8 participants to better manage a virtual group, the small focus group size limited the diversity of opinions, decreased interactive dynamics among group members, and may have increased dominant participants' influence on the opinions of other members in the group (Hennink, 2014). Additionally most of the participants were recruited from the same university-based clinic, which may have biased the results to a specific geographic, cultural, and socioeconomic group. The phone-based focus group methods presented several limitations. The over-the-phone focus group setting made it more difficult to encourage interaction between participants and limited the richness of the data collected, as non-verbal cues could not be observed. A final but important limitation of this study was the lack of opinions from PWE without smartphones. Although the inability to successfully recruit this subgroup was an interesting finding, future research should make greater attempts to reach out this population.

Strengths

Despite these limitations there are also numerous strengths in this thesis research. As theory-driven research, the use of the DOI strengthens the research by providing a conceptual framework for understanding the results. Furthermore, this thesis also fills in a gap in theory-driven mHealth literature. Although the findings are not generalizable, focus groups provide an ideal method for exploratory research by providing rich data on a topic of interest and generating group discussion. While there were limitations to conducing over-the-phone focus groups, this approach addressed the unique transportation issues faced by PWE and encouraged greater participation by being sensitive to the challenges they face. By holding over-the-phone focus groups, this study was able to reach a diverse group of participants who represented different ages, ethnicities, and socioeconomic statuses. Although a key component of focus group composition is homogeneity, sharing a similar, intense experience like epilepsy “creates a strong shared identity among participants that overrides the need to create homogeneity through demographic characteristics” (Hennink, 2014, p. 39). This was clearly evidenced through the positive feedback received from participants. Since many of the focus group participants had never met or talked with other PWE prior to the focus group, they reflected positively on their participation in this study as an opportunity to share their experience, thoughts, and opinions with others whom they felt truly understood the challenges of living with epilepsy. Thus a final strength of this research was providing a source of support for PWE and having positive value not only for research but also for the participants of this study.

Implications and Recommendations

This study suggests that there is great potential for smartphones to address the SM needs of PWE. Not only do many PWE have access to smartphones, they are the primary owners of their phones and use them on a daily basis. Moreover, many are already using their phone in creative ways to self manage their epilepsy. An app for logging medications, seizures, sleep, and stress is promising due to PWE comfort with smartphone technology. Similarly, other components such as emergency services, communication with treatment teams, and support networks, should be considered as either a component of an app or as separate apps to meet the felt needs expressed by participants in this research. Following the finding on cost as a barrier to accessing smartphone content, a successful app for PWE will need to be offered free of charge with no additional fees for content to encourage the highest rate of adoption in this population.

Since physicians were identified as a primary source of epilepsy information among participants, coupled with the suggestion for using the smartphone as a tool to communicate with their doctor, there is potential for health providers to use mHealth tools to connect with patients, improve care through improved monitoring and management of their patient’s condition, and encourage better self-management techniques.

Future research in this area should make more concerted attempts to recruit PWE without smartphones. The results of this thesis suggest that there is a digital divide within the epilepsy population in regards to level of disability, seizure control, socioeconomic status, educational attainment, and experience with comorbidities reflected in current smartphone ownership among PWE. Additional research into this subpopulation and the barriers they face in regards to technology use and access will help prevent this digital divide from reflecting an exacerbated disparity in health.

This thesis research offers several implications for mHealth research. Firstly this research provides nuanced information on participants' mobile phone behaviors that can contribute to the development of an mHealth application that is tailored to their needs and preferences. These findings highlight the importance of formative research for the development of mHealth interventions. Finally, this thesis illustrates the necessity of mHealth research to better understand the larger landscape of digital ownership and use. The results revealed that mobile phones are not simply promising tools for health promotion but are part of a larger cultural landscape of technology access, acceptance, and use. In short, understanding how, where, when, and why individuals use technology in general can illuminate innovative approaches towards using this technology for health-related outcomes.

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APPENDICES

APPENDIX A: RECRUITMENT FLYER

Volunteers Needed for Research Study on Smartphone Use and Access Among People with Epilepsy

Emory researchers are looking for people to take part in a research study to find out if people with epilepsy have access to smartphones, and if so, how they use them in their daily lives and to help self-manage their health.

These focus groups will help researchers to create epilepsy self-management apps (applications) for mobile phones that better suit the needs of people with epilepsy.

If you are: 18 years old or older and have been told by a doctor that you have epilepsy, you may be able to take part in a 2-hour telephone-based focus group session. **Even if you do not have access to or own a smartphone, you may still be able to take part in this study**.

People who take part will be given a $20 gift card to thank them for their time.

To learn more, contact the lead researcher by email at ____________@emory.edu or by phone at (XXX)XXX-XXXX

This research is based at Emory University, Rollins School of Public Health, Department of Behavioral Science and Health Education and sponsored by the CDC epilepsy program.

APPENDIX B: DEMOGRAPHIC SURVEY FORM

Smartphone Access and Use Focus Group
DEMOGRAPHIC FORM

General Information:

Gender: ☐ Male ☐ Female

Date of Birth__________/__________/________

Age: ____________________

What is the highest grade or level of school you have completed?

☐ Never attended school
☐ Grades 1 through 8 (Elementary)
☐ Grades 9 through 11 (Some High School)
☐ Grade 12 or GED (High School graduate)
☐ College 1 year to 3 year (some College)
☐ College 4 years or more (College graduate)
☐ Graduate School
☐ Do not wish to say

Which of the following best describes your current work status?

☐ Full-time employee
☐ Part-time employee
☐ Currently not working
☐ A homemaker
☐ A student
☐ Retired
☐ Unable to work due to disability
☐ Do not wish to say

What is your race/ethnicity?

☐ White
☐ African-American
☐ Hispanic
☐ Other
Please specify:
____
☐ Do not wish to say

Which of the following includes the total income of all persons in your household last year?

☐ $ 10,000 or less.
☐ $ 10,001 to $ 15,000
☐ $ 15,001 to $ 20,000
☐ $ 20,001 to $ 25,000
☐ $ 25,001 to $ 30,000
☐ $ 30,001 to $ 35,000
☐ $ 35,000 to $ 50,000
☐ $ 50,001 to $ 75,000
☐ $ 75,001 and above
☐ I don't know
☐ Do not wish to say

Technology Information:

Do you own or have access to a smartphone that you use on a regular basis?

☐ Yes →
☐ No

If YES, what is the make and version of the smartphone?

____

Do you have access to Wi-Fi or the internet in your home?

☐ Yes ☐ No

Which of the following devices do you or your household own? [Check all that apply]

- ☐ Cell phone (non-smartphone)
- ☐ Smartphone (iPhone, Android phones)
- ☐ Desktop computer
- ☐ Laptop computer
- ☐ DVD player
- ☐ Tablet (such as an iPad or a Samsung Galaxy)
- ☐ Electronic reader (such as Kindle or Nook)
- ☐ Digital music player (such as an iPod)
- ☐ Gaming console (such as Wii or xBox)
- ☐ Portable gaming device (such as Nintendo DS)
- ☐ A telephone (landline)
- ☐ A media streaming device (such as Roku, Apple TV)

Epilepsy Information:

How long ago (in months) were you first diagnosed with epilepsy?

____

Have you had any seizures in the past 30 days?

- ☐ Yes →
- ☐ No
- ☐ Do not wish to say

If YES, how many seizures have you had in the past 30 days?

____

What main type of seizures do you have? [Choose one]

- ☐ Simple partial
- ☐ Complex partial
- ☐ Partial with progression to secondarily generalized
- ☐ Absence (petit mal)
- ☐ Tonic-clonic (grand mal, convulsive)
- ☐ Atonic (drop attacks)
- ☐ Other primary generalized type (myoclonic, clonic, tonic)
- ☐ I don't know
- ☐ Do not wish to say

In your own words, please describe your current epilepsy treatment:

____

____

____

____

____.

APPENDIX C: FOCUS GROUP GUIDE

Welcome

Thank you for agreeing to participate in this focus group.
My name is Margeaux and I am a graduate student at Emory University and the lead researcher on this project. I will be facilitating the focus group.

This is _______. She will be taking notes and assisting me with moderating this focus group.

OK, let's get started.

1. At this point, we will read the consent form. Everyone should have received a copy of the consent form for your records. Is this true for everyone?
2. (Read consent form, go around for verbal agreement)
3. We will be tape recording the discussion today so that we can go back to it and carefully attend to your feedback later. Since we are recording, we need to have a few ground rules to encourage good conversation.
    i. To protect everyone's confidentiality, only use first names. You are free to use a first name that is not your own if you would prefer not to use your name at all.
    ii. Also, we need to agree to protect each other's privacy, so what is said in this room stays here, and is not repeated outside of this room. Do we all agree?
    iii. Only a few people who are part of the study team will have access to these tapes. Once the tapes have been typed up so we can analyze the discussion, they will be destroyed. The typed up version will be kept in a locked file cabinet until we finish analyzing it. After that, it will be shredded.
    iv. Also, please try to speak one at a time so that everyone can be clearly heard. When you speak, please state your name so we know who is talking. For example, say, "This is _______. I think…"
    v. We want to try to keep the discussion to under 2 hours to be respectful of other people's time. Please don't be offended when we need to move on.
    vi. Please try to limit any background noises that may be distracting to you and the other participants. Please turn off your cell phones or put them on silent.
    vii. Would anyone like to add anything to the group rules to make it easier for you all to participate freely?
    viii. What questions do you have? Ok, we will start recording. (TURN ON THE TAPE RECORDER)

Introductions and Icebreaker
We are going to start by going around the room and finding out a little bit about everyone here. When we get to you, please tell us your first name or the name you would like to be called, where you are from, and what type of smartphone you have access to and what feature you like best.

I'll go first. My first name is _________________, I am from ______________, and ___________.

[Go around one at a time and have everyone answer. Try to gently cut off really long answers and ask prompts from more people who don't say very much.]

Let me give you a brief overview of project. The goal of this project is to develop a mobile phone application to help people self manage their epilepsy. It's very important that you all participate and share your thoughts on the materials. There are no wrong answers to any of the questions. You don't have to answer every question, but the more you share, the more we can learn about how to make a successful and effective cell phone app that can really help people with epilepsy.

Does anyone have any questions about the project or their involvement before we begin?

1. To get started, when you hear the word "smartphone", what do you think of?
    a. Why do you think that?
    b. So I have (list words and phrases discussed), can you explain more about _____ (Choose term from the list)? Why does this word come to mind when you hear the word "smartphone"?

2. What do you primarily use your smartphone for?
    a. What are some of the top apps you use?
    b. What are the advantages of having a smartphone?
    c. What are some disadvantages to using a smartphone?
    d. What does a smartphone do that a normal phone can't do?

3. Are you the primary user of your cell phone or do you share your phone with another person?
    a. What made you decide to get a smartphone?
    b. When did you get a smartphone?
    c. What made you decide to get your particular model of smartphone?
    d. Now that you have a smartphone, how much do you rely on it on a daily basis?

4. Besides smartphones, what other technology like the Internet, computers, or tablets, do you use on a daily basis?

5. If you want new technology, what are some things you have to consider before buying or using it?

6. Where do you hear about new technology?
    a. Are you the first person among your friends and family to buy a new device or do you wait for your friends or family to try it first?
    b. Why or why not?

7. Now let's talk about health and epilepsy for a moment. What things do you currently do to prevent or reduce seizures?
    a. Where did you learn about these treatment options/ what made you decide to follow this course of treatment?
    b. Who helps you make decisions about your health?
    c. How do you stay informed about treatment options, epilepsy self-management techniques, and epilepsy in general?
    d. What are some of the challenges you face when managing your epilepsy?
    e. Is there something that you wish you had to help you with your epilepsy?

8. What are some of the challenges of living with epilepsy?

9. How has technology, such as cell phones, the computer, tablet devices, or the Internet, helped you with your epilepsy?
    a. Can you give an example of a time when it was helpful?
    b. Now let's focus just on smartphones- how have they helped you with your epilepsy?

10. On the other hand, what are some challenges to using or accessing new technology?
    a. Do you feel that any of these challenges are more difficult due to your epilepsy?
    b. What are some things that the smartphone does not do that you wish it did that would help you with your epilepsy or be more sensitive to the experiences and challenges you face?

11. In your opinion, what are some reasons a person with epilepsy might want a smartphone app to help manage their epilepsy?
    a. What is it about a smart phone that makes it a good tool for addressing the

    needs of people with epilepsy?
  b. In what ways could a cell phone help you manage your epilepsy?
  c. What would encourage you to get a smartphone app to help with your epilepsy?

12. Now let's do a thought exercise: if you could create a mobile app for people with epilepsy, what would it look like?
    a. Could you explain more why these functions would be helpful?
    b. What would be the most important elements of the app?
    c. If you had to market it, how would you let other people with epilepsy know about the app?

Summary/Debrief:
So what I've heard so far about cell phone applications for epilepsy management is *(give short summary).*
Does that sound right?
Is there anything that I missed?
Do you have any last thoughts?

Well that's the end of the focus group discussion. Thank you very much for your participation.

APPENDIX D: FOCUS GROUP PARTICIPATION INFORMED CONSENT FORM

Emory University
Oral Consent and HIPAA Authorization Script Participation in Research Study Focus Groups

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Title: Qualitative research to understand issues surrounding use of and access to mobile phones for people with epilepsy
Principal Investigator: Margeaux Akazawa, MPH candidate, Department of Behavioral Sciences and Health Education
Supervisor: Dr. Nancy Thompson, PhD, MPH
Co-investigators: Dr. Sandra Helmers, MD, MPH; Dr. Yvan Bamps, PhD

Funding Source: Centers for Disease Control and Prevention

Introduction and Study Overview:

Thank you for your interest in our research study. We would like to tell you everything you need to think about before you decide whether or not to take part in this study. **It is entirely your choice. Even if you decide to take part, you can change your mind later on and withdraw from the research study.**

- The purpose of this study is to learn about the use and access to smart phone technology of people with epilepsy. What you have to say and your discussion in the focus groups will help us create self-management applications for mobile devices that are better suited to the needs of people living with epilepsy.
- This study is based at Emory University, Rollins School of Public Health, Department of Behavioral Sciences and Health Education and funded by the Centers for Disease Control and Prevention.
- The focus group session will take about 2 hours.
- If you join this study, you will be asked to give your honest thoughts and opinions to several questions and talk about these questions with up to 4 other people with epilepsy in the focus group session. The sessions will be audio-recorded for the accuracy of our data collection.
- There are very few risks involved in taking part in this study. One risk is a breach in confidentiality. To protect your confidentiality during the focus group sessions, we ask participants to address each other by their first name only or a made up name of their choice.
- While there are no direct benefits to taking part in this study, we hope that you will have a pleasant time sharing your opinions and experiences with others during this focus group session. Also, your participation may benefit others in the future. To thank you for your time and for taking part in the study, a $20 gift card will be delivered to you after the focus group session is over.
- Your privacy is very important to us. We are committed to protecting your

personal information.

- Your health information that identifies you is your “protected health information” (PHI).
- By consenting to this study, you are giving us permission to use the personal health information. We will not access any of your medical records for this study however we may use the health information and personal information you provided us in the screening interview. PHI that may be used for this study include name and/or initials, date of birth, and how long you have been diagnosed with epilepsy.
- To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA).
- This health information will not be shared with anyone outside the study team, which includes the Principal Investigator and research staff. Any information that is collected from this study that can be identified with you will remain confidential. Any identifying information will be de-identified with a code by the primary investigator and all data collected for this study will be stored on password-protected computer that can be accessed only by the primary investigator. Also, any paper documents with identifying information will be stored in a locked file cabinet and destroyed at the end of the study.
- We will disclose your PHI when required to do so by law in the case of reporting child abuse or elder abuse, in addition to subpoenas or court orders.
- You may revoke your authorization at any time by calling the Principal Investigator, Margeaux Akazawa, or by writing to the address listed on the information sheet that we will send to you. Again, your participation is completely voluntary. Your decision whether or not to take part will not affect your relationship with your doctor or Emory University.

Contact Information:

If, at any time, you have questions about the study, your part in it, your rights as a research participant, or if you have questions, concerns, or complaints about the research you may contact the Principal Investigator, Ms. Margeaux Akazawa, at ________@emory.edu or by phone at (404) XXX-XXXX. If you have any concerns about your rights as a research subject, please contact the Emory Institutional Review Board:

- Emory Institutional Review Board at (404) 712-0720 or toll-free at (877) 503-9797 or by email at irb@emory.edu
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent:

Do you understand or have any questions about anything I just said?
Do you agree to all of the above to take part in the study?

Participant agrees to participate (circle one): Yes No
Name of Participant: ____
Signature of Person Conducting Informed Consent Discussion:_____________________
Date: Time: