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Understanding Contexts and Challenges of Information Management for Epilepsy Care

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Abstract

Epilepsy is a common chronic neurological disease. People with epilepsy (PWE) and their caregivers face several challenges related to their epilepsy management, including quality of care, care coordination, side effects, and stigma management. The sociotechnical issues of the information management contexts and challenges for epilepsy care may be mitigated through effective information management. We conducted 4 focus groups with 5 PWE and 7 caregivers to explore how they manage epilepsy-related information and the challenges they encountered. Primary issues include challenges of finding the right information, complexities of tracking and monitoring data, and limited information sharing. We provide a framework that encompasses three attributes – individual epilepsy symptoms and health conditions, information complexity, and circumstantial constraints. We suggest future design implications to mitigate these challenges and improve epilepsy information management and care coordination.

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Keywords

Epilepsy; Seizure; Information Management; Self-Management; Information Sharing; Information Monitoring; Design Framework

1 INTRODUCTION

Epilepsy is one of the common chronic neurological diseases along with migraine, stroke, and Alzheimer's disease in the United States. About 3.4 million people (3 million adults and 470,000 children) in the U.S. and around 50 million people worldwide have epilepsy [45, 132, 137]. Epilepsy brings about a seizure, which is an electrical disturbance suddenly occurring in the brain [79]. A person is diagnosed as having epilepsy if they have a recurrence of more than two seizures that influence one's behaviors, movements, emotions, and cognition [79]. People with epilepsy (PWE) and caregivers of people with epilepsy (e.g., their family members and friends) face various challenges in their daily lives. Challenges include low quality of care and coordination, side effects from drugs and treatments, stigma, unstable employment, risks of sudden unexpected death (SUDEP), and others [32, 86].

PWE require daily self-management to achieve desirable outcomes, such as mitigating symptoms, reducing seizure frequency, and improving their well-being and quality of life. Their self-management includes controlling seizures, managing triggers, and medications, and communicating with their healthcare providers. Often, epilepsy self-management involves other people, such as caregivers. For example, when PWE have a seizure, caregivers can help them track seizure triggers and patterns that PWE cannot recall are important in managing epilepsy. The role of caregivers is more critical when PWE are children who are not likely capable of fully understanding and self-managing their conditions [10, 83, 85, 88]. Although personal health information management is also one of the significant self-management work [106], research has shown that PWE and caregivers' performance in information management is relatively poor [9, 80], and there is a need to design and evaluate self-management-enhancing interventions for PWE and caregivers [126]. Despite the development of information management tools such as a seizure tracker and the existing literature on the challenges of epilepsy self-management, human-computer interaction (HCI) research has not much focused on the sociotechnical challenges that hinder PWE and caregivers' technology use for effective information management.

Our research aims to understand the contexts and challenges of information management, including technology usage, and to explore potential design implications for information and communication technologies (ICTs) to improve epilepsy information management and care coordination. Our research questions are: (1) How do PWE and caregivers seek and manage information?; (2) What information management barriers have PWE and caregivers experienced?; (3) What are the design opportunities for ICTs to help PWE and caregivers address these issues?

We conducted focus group interviews with five PWE and seven caregivers to uncover how they manage epilepsy-related information and what challenges they have faced. First, we found that there is information overload due to PWE's different symptoms and health

conditions. caregivers who have a child with epilepsy could face additional difficulties as the child is not always able to convey their seizure experience precisely. Second, there is complexity in monitoring data due to diverse types of epilepsy-related data, decentralized tools, and difficulties in inputting data because of frequent seizures and multiple care recipients. Third, they experience difficulty in information sharing due to limited availability of professionals or a lack of awareness. Based on our findings, we frame the challenges of epilepsy information management with three attributes – individual epilepsy symptoms and health conditions, information complexity, and circumstantial constraints. Finally, we propose a framework and design considerations for epilepsy information management systems where a holistic consideration of the three attributes would help to alleviate the current challenges of and fully support PWE and caregivers' effective information management and care coordination.

This work contributes to the literature of HCI and healthcare for epilepsy. First, our research extends the studies on health information management in HCI fields. While information management is a well-researched topic, this work presents a unique case for information management due to its highly complex nature of epilepsy, which is understudied in HCI literature. Second, our research also contributes to epilepsy literature, which has traditionally more focused on treatment adherence, seizure, and lifestyle management, by focusing on PWE and caregivers' current practices and challenges of using ICTs to manage their epilepsy. Third, we propose a new framework that unpacks and articulates the design considerations for epilepsy information management. Our design framework points to future research directions and sociotechnical design opportunities in information management by providing three attributes that support complex chronic illness management.

The following sections explain epilepsy and seizures as well as the challenges of living with epilepsy. We also introduce information management as an essential part of self-management for healthcare, relevant literature, and currently available consumer healthcare technologies. Then, we explain our methodology and findings. Finally, we suggest and discuss our framework and design considerations for future ICTs that could mitigate PWE and caregivers' challenges and improve their information management.

2 RELATED WORK

2.1 Epilepsy

Epilepsy is one of the most common neurological diseases worldwide. It is a noncommunicable brain disorder causing more than two seizures [79]. About 50 million people have epilepsy [45, 132, 137], and one in 26 people could develop epilepsy during one's lifetime [7, 44]. It is estimated that about 0.6% of children in the U.S. have active epilepsy [21, 110, 137]. Seizure is a sudden, unpredictable, and uncontrolled electrical activity in one's brain that might last for a while [79]. The symptoms of seizures can be drastically different. Some PWE show visible symptoms such as falling or shaking, while others show invisible and undetectable symptoms such as unfocused sight and blanking out. Sometimes, PWE experience difficulty in remembering when the seizure occurred. The International League Against Epilepsy [33, 113] has categorized seizures depending on the location of the brain where seizures begin (e.g., one hemisphere or both), one's

awareness while having a seizure (e.g., full, partial, or no awareness), or other behavioral characteristics (e.g., motor or non-motor). Similar to the symptoms, the triggers of seizures are diverse. Some triggers can easily be recognized by PWE and caregivers, but other triggers might not be so noticeable. Common triggers are specific time, lack of sleep, stress, flashing lights, alcohol, and particular foods [112].

Epilepsy can influence the health and daily lives of PWE and caregivers in different ways. The chances of living without seizures are high if they are properly diagnosed and treated [132]. By having proper medications and treatment options, most PWE can successfully manage their seizures [61]. Other than seizures, ways that epilepsy can affect PWE are other comorbidities [21, 132] with higher risk of premature death [131]. In the case of severe epilepsy, PWE and caregivers are prone to experiencing physical, psychological, social, and financial burdens [27]. Specifically, PWE are more likely to experience physical issues like restricted mobility and exhaustion, which might bring about lowered focus and performance in their workplace and other limitations [126]. There are also risks of medication side effects, cognitive and memory problems, social isolation, and stigma [27, 32, 53, 77, 120]. Psychological and emotional problems (e.g., depression, anxiety, or frustration from stigma, public misconception, and/or uncertainty of having seizures) are likely to influence PWE and caregivers' lives negatively [39]. Often experiencing loneliness, PWE are concerned about how they will be perceived and how people would react when they experience a seizure in public [27]. PWE are also more likely to harbor the perception that their lives have been changed (e.g., ability to sleep well) in a more negative way [84]. These negative changes in their emotions and perceptions have the potential to further trigger seizure occurrences [12]. Additionally, PWE face the issues of low quality of care, unstable employment, complex care coordination, and SUDEP [32, 86]. Long-term care is more likely to cause additional physical, psychological, and socioeconomic issues (e.g., stress, burnout, reduced working hours, quitting working entirely, etc.) and negative impact on their well-being [1, 114, 130].

2.2 Epilepsy Information Management & Technologies

Self-management is essential in dealing with one's chronic disease and relevant health issues and in improving their well-being and quality of life [32]. Being able to easily track their medical records and collect relevant data, notes, and other resources can better facilitate one's self-management [73]. Information management helps PWE and caregivers be knowledgeable, access tailored information for their specific needs, and to be able to implement the tasks of self-management [98]. Despite its benefits, information management requires a substantial amount of effort to transfer and manage information [5]. This may partially explain why PWE perform relatively poorly on managing epilepsy-related information, seizure, safety, and lifestyle than on their medication management behaviors [9, 80]. Moreover, newly diagnosed patients commonly experience information overload from learning how to manage their epilepsy conditions, adding to their psychological burden [64, 70, 122].

Information technologies have been utilized as effective tools for self-management and health care while mitigating physical and time restrictions of the traditional ways, such

as paper-based information management and in-person interactions with professionals and support groups [24, 106, 118, 119]. Prior research has demonstrated that ICTs for healthcare (e.g., smartphone apps, online programs, online health communities) have positively influenced health outcomes of people with chronic diseases, including epilepsy [28, 65]. There are ICTs for epilepsy self-management that are commercially available [4, 36, 66, 115, 116, 121]. Table 1 shows examples of the existing ICTs and a summary of their main features. These are mostly mobile apps designed to record, track, and manage epilepsy-relevant information. While some of them focus on one specific type data (e.g., seizure tracking), others cover multiple types of data. There are a few wearable devices for seizure detection and mobile apps for seizure first aid. The mobile apps for epilepsy can roughly be categorized based on four features: “seizure log”, “medication”, “third-party communication”, and “during seizure” [2]. For example, a smartphone app *Seizure Tracker* aims to record the characteristics of seizures such as time, length, symptoms, types and triggers (See Figure 1) [116]. Similarly, *Nile (My Seizure Diary)*, a web and mobile-based app developed by Epilepsy Foundation, provides multiple functions (e.g., tracking drugs and seizures; logging and sharing diary) for better decision-making and individualized epilepsy management (See Figure 2) [36]. Wearable devices *Smart-Watch Inspyre™* [121] and *Embrace2* [31] aim to detect seizures. Finally, *Seizure First Aide* offers basic information about common seizures and first-aid care, with the function to record the incident [4].

Despite the abundance of ICT tools for epilepsy management, there has not been any systematic investigation on the contexts and challenges of PWE and caregivers’ information management and their ICT usage for epilepsy care. Without regarding the contexts and challenges, PWE and epilepsy-related organizations might achieve little success in incorporating these technologies in their information management practices [46, 119]. Some PWE are prone to feeling emotional stress from self-management and have negative perceptions of ICTs (e.g., privacy, their ability to utilize the tools) [66]. Moreover, these self-management tools are not designed for children with epilepsy, making the children with epilepsy and their caregivers frustrated [37].

HCI studies on epilepsy have focused primarily on developing and evaluating technologies that can sense and alert seizures [16, 48, 49, 104]. Other HCI studies have discussed intelligent decision support systems for better diagnosis [78, 123]; neurofeedback training games for seizure reduction [108]; monitoring systems for SUDEP forecast [127, 136]; systems for optimal medication dose prescription regarding pharmacological responsiveness [43]. Fewer studies have focused on information management of PWE and caregivers, although there are studies on information management of people with other chronic diseases, such as diabetes, dementia, Parkinson’s disease, migraine, HIV, etc. [18, 29, 72, 76, 93, 95, 101].

3 METHODS

3.1 Data Collection

We recruited participants from epilepsy-related support groups on social media (e.g., Facebook, the Epilepsy Foundation forum). Eligibility criteria were: (1) older than 18 years old and (2) must have been diagnosed with epilepsy or is the primary caregiver of a person

with epilepsy. Since children's health is mostly managed by their parents, children were excluded in this research. 12 participants attended one of four focus groups conducted via Zoom, a teleconferencing platform. We conducted four groups because it has been confirmed that 2–3 focus groups are sufficient to uncover four-fifths of all themes, and 3–6 focus groups for nine-tenths [40]. There were five participants at the first session, one at the second, three at the third, and three at the final session.

The focus groups were conducted utilizing a semi-structured discussion guide. The discussion guide was created jointly with healthcare professionals specializing in treating PWE patients, in order to better understand PWE's contexts and to avoid unintentional harm regarding their stigma. We asked how they search for and monitor their epilepsy information, how they share information with other people, what challenges they faced, what technologies they use to manage information, and what kinds of technologies they want to have. Each session lasted approximately an hour. The focus group participants consisted of five PWE (four females & one male) and seven caregivers (all females), all primary caregivers. The PWE range in age from 25 to 43 (Avg. 33.4), and they have had epilepsy for about 8 years on average (one participant chose not to answer this question). The caregivers range in age from 31 to 67 (Avg. 39.8). Each caregiver participant holds the primary responsibility of taking care of one PWE, with the exception of one participant who takes care of three children with epilepsy. The care recipients that caregivers provide care for are aged between 2–30 (Avg. 9.8). The care recipients have had epilepsy for about 7 years. Only one PWE care recipient is an adult, and the rest are underage. Although there was no specific guidance on this, the participants did not attend the focus groups with their caregivers or care recipients. Table 2 shows the basic demographic information of the participants.

3.2 Data Analysis

The focus group sessions were audio-recorded and transcribed later. In order to understand common challenges that our focus group participants experienced, we applied the thematic analysis inductively [25, 60]. Two researchers read and coded the same transcripts separately. Each researcher coded sentences in the transcripts to identify themes depending on its meaning and implication. We iteratively coded and discussed to resolve disagreements. After the discussions, we clustered the codes and created essential themes that are relevant to information management. The examples of the emerging themes are 'Overwhelming information,' 'Many kinds of information to track and remember,' 'No one solution,' 'Lack of support from experts,' and 'Burden to explain the complicate symptoms.'. Finally, we conducted the affinity diagram to make the themes more concise and specific and to categorize them into higher level themes [13, 56].

4 FINDINGS

Our findings indicated that PWE and caregivers faced the following challenges when managing epilepsy information: (1) difficulties in finding the right information; (2) complexities in tracking and monitoring data; (3) limited information sharing. We detail these challenges and participants' desires in the following subsections.

4.1 Difficulties in Finding the Right Information

4.1.1 A wide range of epilepsy-relevant information.—We found that PWE and caregivers felt the information overload because they were exposed to a wide range of epilepsy-relevant information, with no single piece of it catered to their needs. Even though PWE were all diagnosed with “epilepsy,” each PWE experienced different types of seizures, symptoms, triggers, medications, treatments, side effects, and contexts, and there were complex impacts from the combinations of those factors. Thus, there were many kinds of information about epilepsy and no one solution for epilepsy management.

Participants claimed that it was difficult to find suitable and safer medications or treatments to reduce side effects and improve health effectively, since some worked for someone but not for others. This required them to spend more time looking into the wide-ranging information to find better or the best medications or treatments for their successful epilepsy management.

FG2-E1: “It’s challenging because what works for person A is not going to work for person B.”

FG3-C3: “My daughter has intractable epilepsy as well. So, for her, it’s a lot of finding out what types of seizures she’s had, what types of seizures she could have, what things could work, what things obviously are not going to work.”

Even though there were epilepsy-specific information sources (e.g., the Epilepsy Foundation website), FG3-C2 described current websites as containing too much information without a convenient tool to search for exactly what they need. Attempting to locate the information for their specific health conditions with the use of inconvenient tools made them more overwhelmed and exhausted. They were more burdened with information overload from manually sifting through much diverse epilepsy-related information to identify the right one for them.

FG3-C2: “[It is] too much for my brain to handle. And so, even now looking at the [epilepsy.com](https://www.epilepsy.com) website it seems overwhelming. There’s a lot of click here, click there. [...] Like, are you a caregiver to toddlers, or elementary kids, or middle school kids, or adult children. Or are you a caregiver to your parents. They all have different aspects to it. [...] It’s getting to more specific information versus general information for everybody in epilepsy.”

The issue of finding the right information was particularly challenging for those who have been recently diagnosed, like FG3-C2. When first diagnosed, PWE and caregivers struggled with finding sources, such as websites, online health communities, and support groups, that serve as a hub for useful information. They said that finding good information sources would be helpful not only for getting ideas for treatments and medications but also narrowing down the questions they should pose to their doctors or other people who can help.

FG3-C2: “I remember that three years ago. I had no idea of where to even start and looking everything up was very overwhelming. [...] Giving some sort of idea or even helping narrow down the questions to ask for the [health care] providers [would be helpful].”

Thus, participants mentioned that they had sought informational support from others with similar health conditions and circumstances. For instance, FG1-E3 wanted to connect with other people who experienced similar symptoms and took similar medications she might take to expect the effects of the medicines. Also, FG1-E3 and FG3-C1 wanted to find others of similar age to be connected. They believed they could get better information from other PWE and caregivers' experiences, such as coping strategies and proper treatments and medications.

FG1-E3: "I'm usually looking for support groups as well and open forums about topics, about epilepsy and how other people are dealing with their medicine and how they're feeling on similar medications that I may be taking. [...] One thing I wish is, I find it hard trying to find other people my age who have epilepsy. So if there could be an app that could connect me to people in their mid-twenties with epilepsy who I could relate to and talk to like, that would be great."

FG3-C1: "I think more specific groups through Facebook, you can get to know people. You know about them and learning, and you can find other people. For example, my son has focal frontal lobe epilepsy so I have specifically [...] tried to figure out who all has kiddos with left frontal lobe issues and what they're dealing with."

4.1.2 Dealing with babies/children's epilepsy—Dealing with babies/children's epilepsy, caregivers, who were parents of babies and young children with epilepsy, said they faced additional difficulties in information management. They were concerned that children might not precisely express or explain what they felt when they experienced seizures and other relevant symptoms. FG3-C2 explained how difficult it was to notice and fully understand their children's epilepsy, and this difficulty hindered them from identifying the symptoms and their needs.

FG3-C2: "We have one child who's failed six drugs, and most of the time he's had a side effect, especially like behavioral side effects. And that can be subtle so like are they just being toddlers or is this really side effect of the medicine and how to know the difference between the two, which is hard to do with toddlers."

Moreover, we found that young PWE could develop different symptoms of epilepsy as they grew. In this case, as FG4-C1 experienced, caregivers needed to keep searching for and adapting to new information, understanding and managing these newly emerged health conditions, and finding new proper treatments.

FG4-C1: "For all the medications we've tried to be proactive with looking into them ahead of time, because we've never reached a state that she's been controlled with seizures at all. We've switched quite a bit over the years. It's still the same as we see new behavioral things. And I think it changes a lot just at that age and having a younger child because they're constantly growing and it's different stages with her too to then look and see, try to research and do some on our own."

In summary, participants experienced difficulties in locating the right information because of the overabundance of information about epilepsy stemming from diverse symptoms,

medications, and treatments. The current information resources were not structured for their convenient navigation. Most vulnerable to this issue were PWE and caregivers who are first diagnosed with epilepsy and parents of babies or young children with epilepsy due to the lack of experience and understanding of symptoms and health conditions.

4.2 Complexity in Tracking & Monitoring Data

4.2.1 Keeping managing multiple data.—Successful tracking and monitoring could help PWE and caregivers keep taking medications on time, find patterns in their symptoms and/or triggers, and prevent seizures (e.g., avoiding flashing lights or smells that trigger seizure). We found that each participant had different needs for data entry due to their diverse health conditions and contexts. They often struggled with tracking and monitoring various types of epilepsy-relevant data. The types of data they collected were the time and frequency of seizure occurrences, symptoms, triggers, medications, side effects, and even consequences of seizures (e.g., injury). Since menstrual cycles and/or diet could affect PWE's epilepsy symptoms, some participants, like FG1-E3, tracked and monitored these types of data as well that is seemingly unrelated to epilepsy.

FG1-E1 “Definitely kept track of the injuries. I could say, ‘okay this happened. I need help here.’ [...] [I manage] different logs and things like that.”

FG1-E3: “The only app I’ve really used is an app to track my periods because during my periods I feel like my epilepsy symptoms change drastically. So, with monitoring my periods, I’ve been able to write notes in that app and jot things down of how this month might have been different than last month during the week of my period and how my symptoms have gone.”

We also found that participants encountered situations where they could not track and monitor symptoms and events. For example, FG4-E1 said she could not log her seizure data when she had severe seizures. They, especially PWE participants, claimed that a seizure could impair their ability to remember and/or log the time and symptoms.

FG4-E1: “If the seizures are really bad, I can’t even be in front of the computer. It’s very difficult. I’m just like lying down in bed.”

Moreover, caregivers could not always stay with their care recipients to monitor their epilepsy-relevant data. For example, if their children went to a school, caregivers could not log and track seizures and any other information on behalf of their care recipients. Therefore, they wanted to enlist the help of secondary caregivers in the school, such as a teacher, a school nurse, or their friends, to record data.

FG4-C2: “I would kind of like it if they could also input, like if there was seizure activity during their time. They could document, even like a video upload if they had that would be awesome too.”

4.2.2 Decentralized & inconvenient tools.—To log the data they wanted, each participant was using different tools in different ways (e.g., paper-based and/or digital tools, a single tracking tool, or a combination of multiple instruments). The functionalities of the tools that the participants were currently using were: tracking PWE's health-relevant

data, taking notes for other types of information (e.g., research articles, news), scheduling doctor's appointments, and reminders for medications and appointments. Depending on their specific needs, they were using several tools to handle different data types.

FG3-C1: "I used the notes app in my iPhone. I have a huge running list of behaviors or seizures even like medical records numbers at the hospital. I also use the stopwatch if I am trying to time a seizure. [...] I had just used [seizure tracker] through the computer. So, I went through and inputted all of them."

We found that the main reason PWE and caregivers were utilizing multiple tools was that there was no integrated tool that combines several functions for epilepsy management. Participants claimed it was inconvenient and complex to use several tools concurrently. When we asked them about what kinds of tools they would like to have for epilepsy management, participants answered that they would like to have one centralized app that can fulfill individuals' information management needs. For example, FG1-C1 wanted an app that helps PWE take medication on time and manage the appointments.

FG1-C1: "It would be awesome if there was some kind of app that you could program in the time of day that they're supposed to take their medicine and it could automatically alert you instead of having to set an alarm or put a reminder in your calendar. So, or even if you could put like upcoming doctor's appointments, just kind of manage all of the stuff in one place."

Moreover, participants argued that preexisting tools (e.g., a seizure tracker, a note) were not much convenient. Each required them to manually input too detailed and burdensome information to the point that the purported usefulness of the app no longer seemed alluring to them. Moreover, some tools did not have features to visualize the data into the forms what they wanted to see it in, such as graphs and patterns, preventing PWE and caregivers from tracking and monitoring useful data effectively. Eventually, these tools became useless and interfered efficient epilepsy management.

FG3-C1: "I would say the last two or three months of the recordings into that seizure tracker app but I haven't done anything with it. I haven't even logged onto the thing because I want to be able to see a graph and maybe see if there are any timing things. So, I've put them into here but I haven't really fully embraced or used it yet at this point."

FG3-C3: "I am not okay with putting that much information. And then the Apple watch came out with the epi-watch app and so I downloaded that in order to try and use it. But it doesn't record like I want it to. I can basically get the information that I need or want from the regular Apple watch. So, I didn't find it to be beneficial."

4.2.3 Frequent seizures & multiple care recipients.—When PWE and caregivers experienced seizures and related events frequently, or when caregivers needed to take care of more than one PWE, their tracking and monitoring tasks brought about more burden and fatigue. For example, FG3-C2 has three children, who all have different types of epilepsy and health conditions. She needed to take copious notes and manage and track multiple epilepsy-related information for each child separately.

FG3-C2: “Since we have three kids, there’s no way I can keep track in my brain. So I keep track in a binder with tabs as well as all their test results and everything else. I like to have the physical copies of everything.”

FG4-C1 reported that her care recipient had seizures several times a day. Her smartphone app for logging seizure data required her to input many details each time, which made the task of logging data for the seizure more burdensome for her. Participants wanted to be able to easily and quickly input information they deem useful instead of trying to meet the requirements mandated by a tracking app.

FG4-C1: “We used the epilepsy diary for just a little period of time, but [her child] has quite a few seizures every day. To be honest, it was kind of a pain to have to go get into your phone, pull your app up. And then it wants a lot more details. You could put so many things but it’s time consuming. And in reality, you have many other things that you’re doing during your day besides just tracking those. [...] I want to log the information real quick. The app is too detailed. I don’t think you have to put all of it in there.”

To summarize, the various types of data PWE and caregivers needed to track and the current decentralized and inconvenient tools for epilepsy were an obstacle for PWE and caregivers in tracking and monitoring epilepsy-related data in an effective way. Frequent seizures and events and multiple care recipients were the factors that made additional difficulties for data tracking and management. They thus desired to have a more centralized and convenient tool to increase efficiency and effectiveness and reduce the burdens of tracking and monitoring multiple data.

4.3 Limited Information Sharing

4.3.1 Limited availability of healthcare professionals.—Participants experienced frustration when they could not successfully communicate with healthcare professionals. Their current communication with their doctors included sharing most up-to-date information like health conditions for better epilepsy management and sending epilepsy-related news articles and/or scientific resources to discuss better options for medications and treatments. Their need with regards to communicating with doctors was getting confirmation from their doctors whether the information they found is helpful for them.

FG1-E1: “There’s research, but I also go to my doctor and asked the basic, okay, what do you think about this? Or can you tell me about something that we haven’t tried yet? Which was how I managed to finally find the treatment that’s been working for the last three years.”

FG3-C3: “I kind of bounce things off of her doctor when we have our visits as to what could help and what may not.”

While proactive in sharing information with doctors, they were feeling discouraged from limited opportunities to share information. The limited availability of healthcare professionals made it difficult to determine whether what they found was helpful or not and consequently manage epilepsy better. For example, participants could not visit their doctors as frequently and even during the visit there would not be enough time to discuss

all the updates. Calling or emailing doctors was an option but this did not always generate prompt responses. FG3-C1 claimed that the professionals were not likely to look at what they shared if it was through e-mail. Thus, participants just resorted to bringing in paper copies to share information when they visited healthcare professionals.

FG3-C1: “With the physicians I tend to bring in paper copy. If it’s like a specific article I want to share with them, I can e-mail them but they’re not going to look at it. So, I have to, with the physicians or the providers, catch them face to face and actually physically talk to them about it. [...] something paper that they can scan in the chart or take with them and hopefully that they look at it later.”

They also argued that the limited time for each appointment made it difficult to share the full updates. FG4-C1 expressed in particular that they would like to have some tools or systems that allow them to share information in advance ahead of the appointment to utilize the limited face-to-face time they have with the healthcare professionals more efficiently.

FG4-C1: “It wouldn’t be me constantly giving some whole big backstory of what’s been happening over the last week or two. It would be nice if they had that already. It’s just time consuming for me to take all these notes down [...] then relay it on where the doctor could just quickly pull it up if it’s something that she would have access to. And be able to say, okay, I can see what’s going on.”

4.3.2 A lack of epilepsy awareness.—Another obstacle to information sharing was a lack of epilepsy awareness among people around participants. They wanted to share information about their current health conditions with other close family members to discuss epilepsy management and get support from them. Some like FG1-C2 even shared information outside of the family, with her closest friends to get opinions.

FG1-C2: “I’ve talked to my family and share with them and my closest friends [...] discuss with them then he’ll tell me what he thinks is best to do.”

However, some participants were frustrated when they shared information and experience with their family and friends because they did not seem to fully understand epilepsy. Like FG1-E3, PWE found it difficult to explain their disease because of their complicated health conditions including the side effects (e.g., memory loss) and the postictal state, which is the recovery period to be normal state after a seizure. While some PWE recover immediately, others might take a few minutes to hours [35]. They claimed that many people do not know epilepsy well and how the seizure can affect one’s function and mental health. This lack of awareness from others created extra burden for PWE when attempting to share information and to get proper support for epilepsy management.

FG1-E3: “One thing I’ve realized when doing that is that it’s kind of hard for them to fully understand what I’m going through. [...] It’s different everyday with medication and so it’s kind of hard to even explain [...] like every day is not the same and these are memory loss as a huge side effects I experienced as well. And so, it’s kind of hard for them to fathom that, and understand it.”

To summarize, participants experienced the challenges of information sharing due to the limited availability of healthcare professionals and the general lack of public awareness for

epilepsy. In response, they wanted to find a more effective and convenient way to share information with healthcare professionals as well as family and friends to get proper support they need without possibility of misunderstanding.

5 DISCUSSION

5.1 Framework for Design Consideration

In this work, we identified contexts and challenges that PWE and caregivers face when they manage epilepsy-related information. The complicated nature of epilepsy is the primary cause behind these challenges. We found that existing ICTs were inadequate for effectively supporting PWE and caregivers. Future technologies would be more beneficial for epilepsy management if it could be designed to reflect the complex challenges and contexts rather than focusing on one single challenge. To this endeavor, more integrated technological solutions should be solicited from a systematic identification and approach to potential design space.

We propose a new framework that articulates the complex attributes regarding the contexts and challenges (See Figure 3). We categorize the factors that might influence PWE and caregivers' information management into three dimensions – individual epilepsy symptom and health condition, information complexity, and circumstantial constraint.

Individual Epilepsy Symptom & Health Condition—Individual Epilepsy Symptom & Health Condition indicates the differences of personal symptoms and health conditions among individuals. Each PWE may experience common or unique types of seizures, seizure triggers, hormonal response, varying health conditions over time, and other personal factors. It is easier to find information and coping strategies for those who experience epilepsy in a way that is more commonly experienced, for there are plenty of information that other PWE have shared. On the other hand, if a PWE's symptoms and health conditions are rare, complex, or more unstable than those of other PWE, PWE and caregivers will need to invest much more effort to seek information that is tailored for them.

Information Complexity—Information Complexity means the characteristics (e.g., types, amount) of epilepsy-relevant information and tools that PWE and caregivers need to understand and handle. Depending on their needs, the information can be simple to find, track, and share, or it can be complex. Some PWE and caregivers may need to collect and look into a larger amount of information and more diverse types of health-related data (e.g., eating food, sleep time, mood swings, behavioral issues) using different kinds of tools. The collected data can be used to see the effects of medications and treatments, and other epilepsy-relevant patterns, but if the data is complex to manage, it would be challenging for PWE and caregivers to utilize and integrate the information in an effective way.

Circumstantial Constraint—Circumstantial Constraint indicates physical, psychological, social, environmental, and other situational factors that PWE or caregivers cannot control (e.g., availability of useful resources and healthcare professionals; one's epilepsy awareness and attitude toward PWE) that might block PWE and caregivers' effective information management. If the circumstantial constraint is strong (e.g., no available informational

resources, convenient tools, or caregivers), managing information would be challenging. On the contrary, a weak constraint would facilitate PWE and caregivers' information management for epilepsy care.

Therefore, if one's epilepsy symptom and health condition are unique; the information they need to manage is complex; and the circumstance around them constrain their actions or behaviors strongly; information management would be more difficult for them (See the red cube (upper right) in Figure 3). On the other hand, if their symptom and health condition are more common among other PWE; information they manage is simple; and their circumstance does not restrict them, their information management would be easier (See the green cube (lower left) in Figure 3). Optimal technologies for epilepsy information management should be designed with where the technologies are positioned in these dimensions and what other factors they need to regard carefully in mind. The following sections show our discussions on potential sociotechnical solutions that aim to overcome the barriers and facilitate effective epilepsy information management regarding the above attributes.

5.2 Personalized knowledge repository for epilepsy information recommendation

One key design suggestion is a personalized knowledge repository that provides epilepsy information recommendations, which could reduce the burdens of seeking the right information. "Health information seeking behavior" has been studied and defined as one's activities looking for information to cope with their illness and to promote their health [62]. Similar to our findings, prior studies found that the current online information seeking tools do not fully satisfy information seekers despite the potential benefits of these technologies. They argue that insufficient mechanism and health technologies hinder people from finding and accessing useful information for their health and ultimately block effective self-management [52, 99]. Moreover, the information PWE and caregivers need to seek and manage can differ depending on one's symptoms and health condition. This finding aligns with the research that shows the differences in information needs and management behaviors between people with the same disease that is manifested in multiple different ways (e.g., breast cancer and colorectal cancer) [92]. While online health communities can be a helpful place to receive informational support, it has been shown that discovering timely and valuable information could be challenging due to the high volume of content [50]. This challenge can bring about information overload, which has been identified as a negative factor for psychological health conditions and disease management of people with chronic diseases and their caregivers [19, 57, 68, 70, 122].

Seeking information can be more challenging for PWE and caregiver, who have to deal with unique and complex symptoms, side effects, and/or relevant health conditions and data. They may need to spend much more time and effort to collect and find the right and meaningful information from a substantial amount of epilepsy-related data. For example, PWE could respond differently to drugs and treatments, including adverse drug interactions. Most seizure medications show drug interactions, and many herbs and dietary supplements could also negatively impact the effects on seizures [17, 26, 34, 103]. This complicated issue can also be seen in the case of people with chronic comorbidities, who also often experience

interactions among drugs and treatments and difficulties in prioritization and care [97]. The research on drug interactions is still ongoing, and as participants claimed, they have to keep trying to access and find information about the complex effects of drugs and treatments. Moreover, due to the limited availability of their doctors, they often need to research and understand a lot of information that is scattered across online websites, communities, and academic and scientific repositories on their own. Finding the optimal medication dose for individual PWE requires trial and error on the part of PWE and caregivers for a long time [43].

Prior research developed diverse types of personalized health information systems. It has been identified that these systems can help users feel less overwhelmed and facilitate and improve their health management. Some things that these systems could do are, for instance, recommending more helpful information for their health, communicating with other care stakeholders, and helping users immediately respond to new symptoms or side effects [23, 38, 51, 54, 67, 91, 107]. Customization, simplicity, and health-care connection are considered as important features for epilepsy self-management applications, which are aligned with our design suggestions [2]. We suggest that future personalized knowledge repositories for epilepsy should be designed to consider PWE and caregivers who have to deal with unique symptoms and health conditions and/or complex information (See Figure 4). It could be able to collect and integrate diverse types of data, such as existing healthcare resources, personal health data, contextual data, and user preferences, to provide optimal information by using machine learning [58, 134]. The data may include: what they experience (e.g., seizures, symptoms, triggers, side effects); where and when they experience seizures or relevant symptoms; what they take (e.g., medications, treatments, food); what they want to see (e.g., patterns, appropriate medical resources); and other personal information (e.g., age, gender, and living conditions). The system also needs to be designed to analyze existing evidence of drug interactions and conditions of adverse reactions. Then, it can match the specific health conditions of PWE to the information on potentially effective treatments or warn them against certain treatments based on personal health conditions. Similar web services that are integrated with electronic health record systems already exist, which utilize risk-prediction algorithms to leverage patient data and estimate the benefits of other alternative drugs and treatments [96]. This personalized information management system can be applied to other chronic diseases management (e.g., comorbidity, bone marrow transplant, coronary artery disease [19, 68, 97]), where patients and their caregivers are also challenged by diverse health conditions and complex information.

5.3 Automated & integrated management

Another design consideration is a more automated and centralized system that integrates diverse information management functions and tools (e.g., seizure tracker, medication management, appointment reminder). As we found from participants, having to manually input data was burdensome when managing a large amount of various types of data necessitated by frequent seizures, the postictal state, multiple care recipients with epilepsy, or the struggle with understanding their care recipients' symptoms. The centralized and automated system would prove to be convenient to PWE and caregivers by alleviating the

burdens of utilizing multiple tools to manage data. The need for a centralized tool has also been identified in prior literature on people with various chronic diseases, who need to handle several types of information for individual diseases [5]. Previous research on epilepsy has also emphasized the need to integrate digital tools and ecosystems that meaningfully benefit PWE's health [119].

In order to reduce PWEs and caregivers' burden of data input, the system may also adopt biomedical technologies (e.g., wearable devices for measuring biomarkers), smart home sensing technologies, or complex networks analysis on several types of resources (e.g., PWE's posts on social media) [26, 30, 94, 105, 129]. As tracking seizures is one of the key elements in epilepsy self-management [2], the system that incorporates biomedical technologies can be one way to monitor and analyze the actual effects and patterns of seizures, drugs, drug interactions, and side effects [26, 102]. The system can also be integrated with other context-aware technologies that automatically detect seizure triggers and environmental limitations around PWE (e.g., the absence of primary and secondary caregivers). The automatically and synthetically analyzed data could provide feedback (e.g., a possibility of having a seizure, overall health condition) to avoid any potential risks and improve their self-management [11, 128].

The system should also put privacy and security at the forefront, although our participants did not mention this much, as prior literature on personal health information has pointed out threats to privacy and security within the system [8, 106, 117, 124, 138]. Therefore, the system should balance the benefits and the potential risks of automatically accessing private data.

With a more automated and integrated information management system that considers complex information structure and circumstances (See Figure 5), PWE and caregivers would be able to fulfill their information needs and manage epilepsy information more effectively and efficiently, the specific acts of which encompass information seeking, tracking, monitoring, and sharing. Ultimately, it would positively impact PWE and caregivers' well-being through mitigating the information management overload. People with other chronic diseases that require multiple types of data to collect comprehensive information under limited circumstances (e.g., multiple chronic conditions [5, 97]) would also gain benefits if their self-management systems could adopt these automation and integration functions.

5.4 Social support & care coordination enhancement

Future technologies for epilepsy management would need to enhance social support and care coordination regarding social constraints around PWE and caregivers (See Figure 6) as well as their desire for sharing information and getting better support from other people. Our participants expressed their willingness to share information and get better help from other people, such as healthcare professionals, other PWE and caregivers, family, friends, or their children's teachers. Prior research has shown that effective communication can enhance self-management and healthcare [2, 42, 69]. Sharing more information and even responsibility of care with other care stakeholders is important in discussing needs and problems, helping them collaborate care work, and eventually reinforcing self-management [20, 23, 87]. Group or community-based information sharing sessions with other people could improve one's

self-management [59, 111]. The benefits of social support include: gaining more detailed and relevant information for care, such as treatments, medications, and healthcare providers; preventing mistakes; getting tips on managing their time; exchanging emotional support with others [41]. Social support from social media or online health communities has also been demonstrated to influence one's health positively [47, 71, 90]. Getting support from others would help PWE and caregivers to obtain more useful information and knowledge for better self-management.

Social matching can be utilized to find people who are more knowledgeable and available to provide help. Most of time, doctors would be the best information sources as they better know and understand information like medications and seizure details. However, they often do not have enough time to look over all the information about each patient [2, 97]. The system with social matching features could help PWE and caregivers with mitigating the difficulties in communicating with doctors. Since participants wanted to find other PWE with similar conditions, the system can be designed to match and connect them based on their personal information and circumstances, such as the type of epilepsy and the geographical location [125, 133]. Interacting with others with similar backgrounds and health conditions through social matching would provide more effective social support [63, 72, 82].

There may be cases where PWE may not have run-of-the-mill symptoms and health conditions, which may increase the difficulty in finding the best people to connect to. Prior research has also argued that people who have rare diseases face similar challenges in finding information about their illnesses and support groups with the same condition. As a solution to this, networked peer support has been suggested to promote support among people who have different types of rare diseases [72]. They propose social matching based on characteristics such as abilities, skills, and expertise as opposed to a specific illness, demographic factor, or location. Likewise, the social matching function for PWE and caregivers can be designed to connect PWE and caregivers based on more diverse characteristics to mitigate the difficulties in finding others with exactly the same conditions.

Regarding PWE and caregivers' concerns about the public awareness, the system should be designed with the consideration of sociocultural contexts and the medical information literacy of the general public, which may affect their information management behaviors and communication with other care stakeholders [14, 55]. PWE may inevitably have to involve other people when they have a seizure at their school or workplace [87]. A lack of understanding about epilepsy may entail the underestimation of its severity or negative perception of epilepsy, resulting in insufficient social support for PWE [74, 75, 100, 101, 125, 135]. The system can be designed to provide PWE and caregivers the function that represents medical information and knowledge about epilepsy in a plain language so that they could share information about their illness and experiences with other people more effectively [15]. Prior work on technologies for people with other chronic diseases (e.g., migraine, HIV, Polycystic Ovary Syndrome) has also emphasized the importance of mitigating misunderstanding and stigma and increasing awareness [23, 53, 76, 101]. The system could also provide features that help patients inform people around them indirectly (e.g., anonymous smartphone notifications) just in case PWE might need help [87]. Future

research would be needed on information management technologies that address the issues of epilepsy stigma and awareness.

In summary, we suggest future information management technologies regarding personalized knowledge repositories, automated and integrated management, and social support and care coordination enhancement for more effective and efficient epilepsy information management. Our suggestions are based on multiple attributes of contexts and challenges that PWE and caregivers face when they manage epilepsy-relevant information.

6 CONCLUSION

Our research identified PWE and caregivers' information management practices and challenges from the focus group interviews. We propose a new framework with three attributes of information management challenges that PWE and caregivers face – (1) individual epilepsy symptoms and health conditions, (2) information complexity, and (3) circumstantial constraints. From this, we suggest three major design considerations for a specialized epilepsy information and support management system – (1) a personalized knowledge repository of epilepsy information recommendation; (2) automated and integrated information management; (3) social support and care coordination enhancement.

Our study has the following limitations. First, we focused on identifying PWE and caregivers' current epilepsy information and support management using focus group interviews with 12 participants in four focus groups. While this number is considered sufficient for uncovering underlying themes [40], future research with quantitative methods can be conducted to understand PWE and caregivers' current usage and challenges of technologies for epilepsy management and to generalize the findings reported in this work. Second, our study participants were mostly females whose experiences may not accurately represent those of male PWE and caregivers. However, it is well-documented that women have predominantly been involved in caregiving [22], and the demographics of the PWE and caregivers are typical of those reported in previous epilepsy focus group studies (e.g., [81]). Third, we did not limit our study to a specific type of PWE because we wanted to explore the sociotechnical issues of information management from PWE and caregivers with diverse experiences, situations, challenges, and perspectives. In order to provide more tailored solutions, future studies could focus on specific types of epilepsy populations (e.g., similar age or gender, caregivers with more than two children with epilepsy, generalized vs. focal epilepsy, or urban vs. rural living conditions). Finally, we did not evaluate our design suggestions from the perspectives of PWE and caregivers. Future research could get PWE and caregivers' feedback by using scenarios, sketches, or prototype to see if the technologies we suggest could be helpful and useful in managing epilepsy-related information.

Despite these limitations, our study extends the HCI literature on health information management. While diverse populations and technologies have been studied for this topic, managing complex attributes of epilepsy is less studied in the HCI field. Our research focused on the population of PWE and caregivers to understand their specific issues and provide tailored sociotechnical solutions for them. Second, our paper contributes to the literature on epilepsy that has primarily focused on drug interactions, treatments, seizures,

and lifestyle management by studying how PWE and caregivers seek, monitor, and share epilepsy-related information and what barriers and challenges they have faced. Third, our framework and design implications encompass complicated contexts and challenges. We identifies potential design space and directions for future research on information management technologies for epilepsy as well as other complex chronic illness. For example, future research can utilize this framework to start positioning and designing technologies for epilepsy management (e.g., an information management system focusing on the contexts where the complexity of information is high and the individual conditions are common). Also, our framework can be applied to other populations with chronic diseases, who may also be affected by the complex nature of diseases and environmental factors, such as public stigma. Ultimately, the implementation of our work would help to decrease PWE and caregivers' burdens and limitations and enhance their information management performance and well-being as well.

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CCS CONCEPTS

- **Applied computing** → Consumer health; Health care information systems; Health informatics;
- **Human-centered computing** → *Human computer interaction (HCI)*; Collaborative and social computing systems and tools; Collaborative content creation.

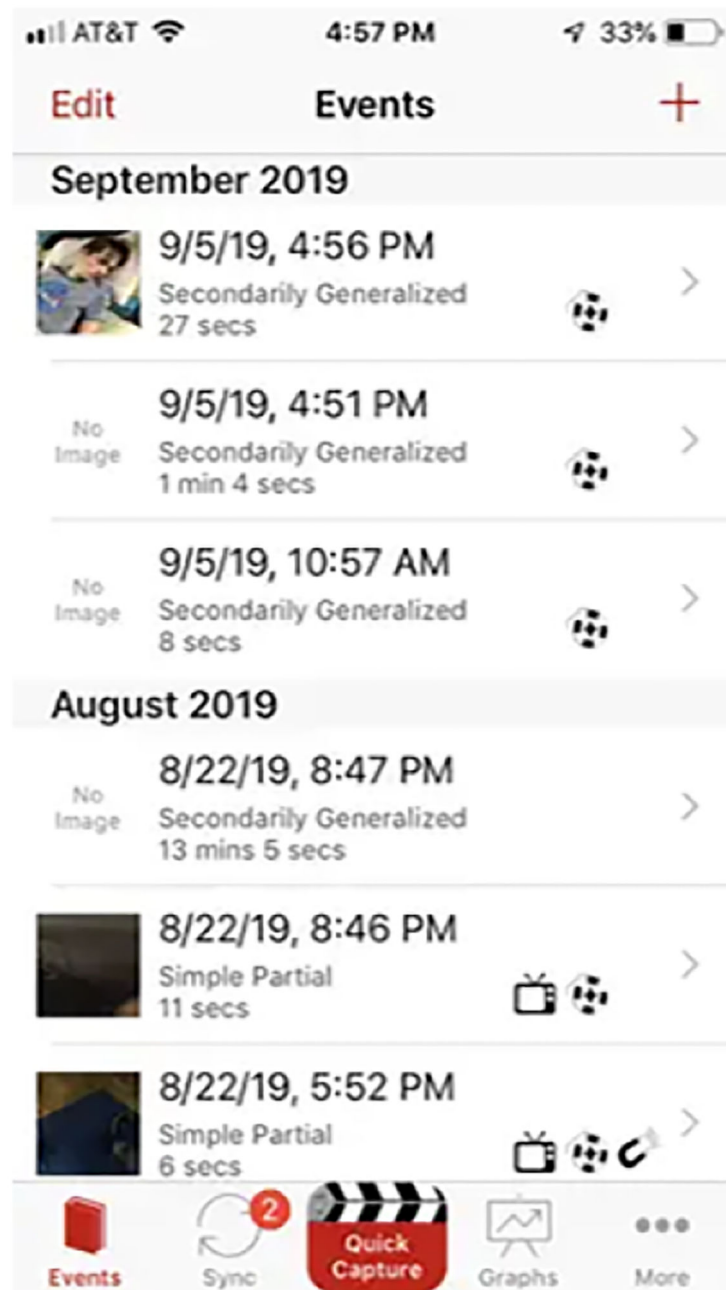


Figure 1: Seizure Tracker. A user can record information about seizures, including time and length of events, seizure types, and even videos.

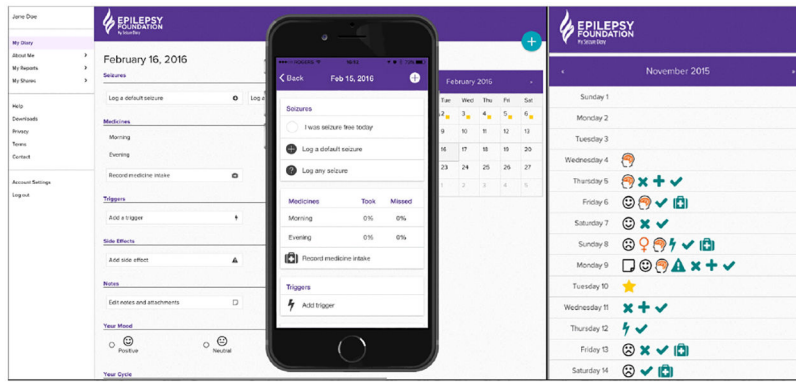


Figure 2: Nile (My Seizure Diary). A user can log and manage multiple types of epilepsy-relevant information, including auras, seizures, side effects, medication, and reminders.

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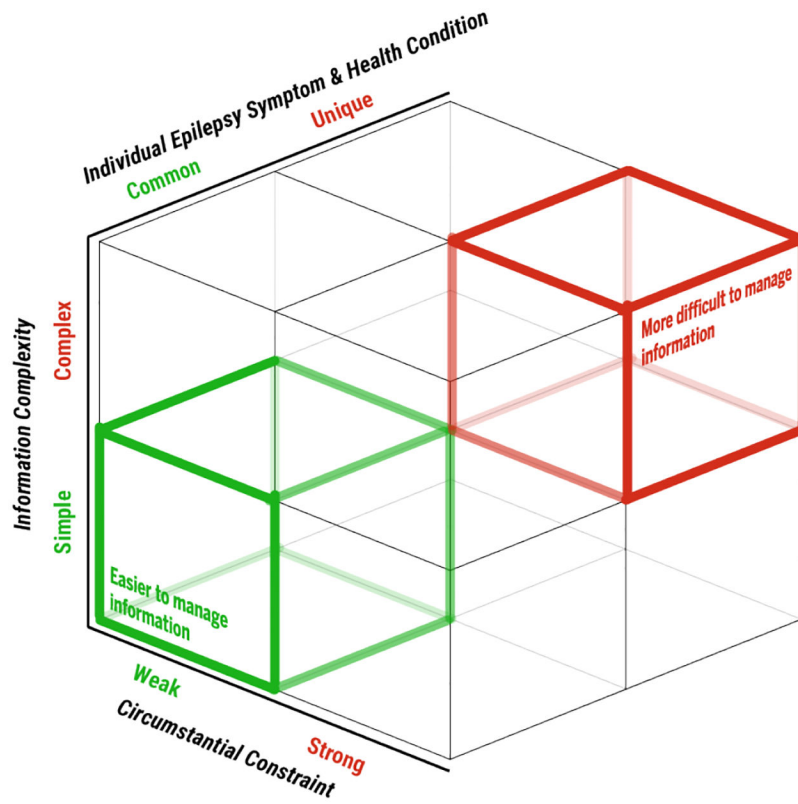


Figure 3:
A Framework for Epilepsy Information Management System Design

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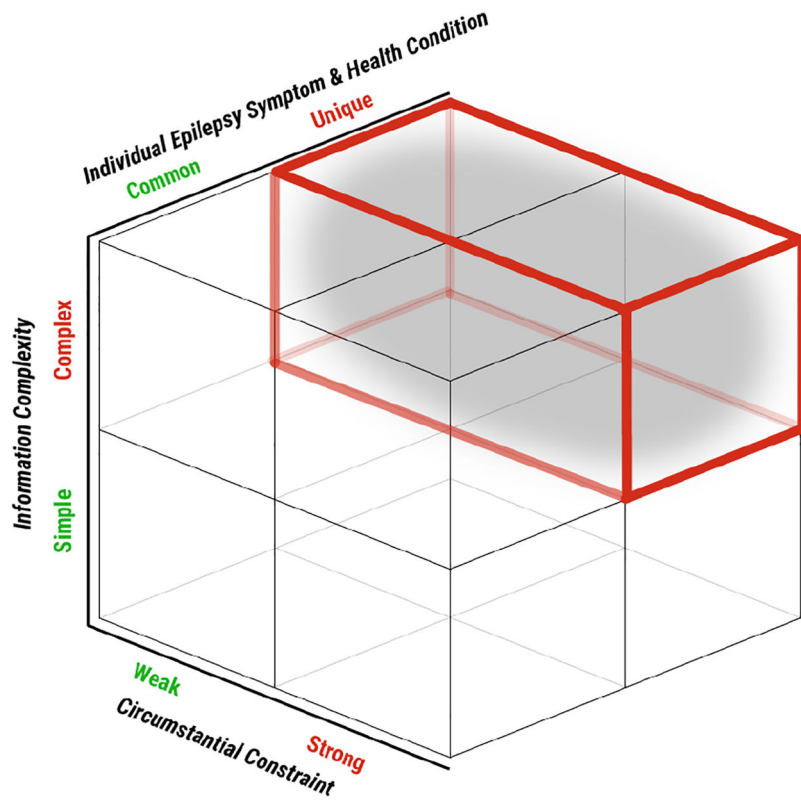


Figure 4:
Design Space for Personalized Knowledge Repository

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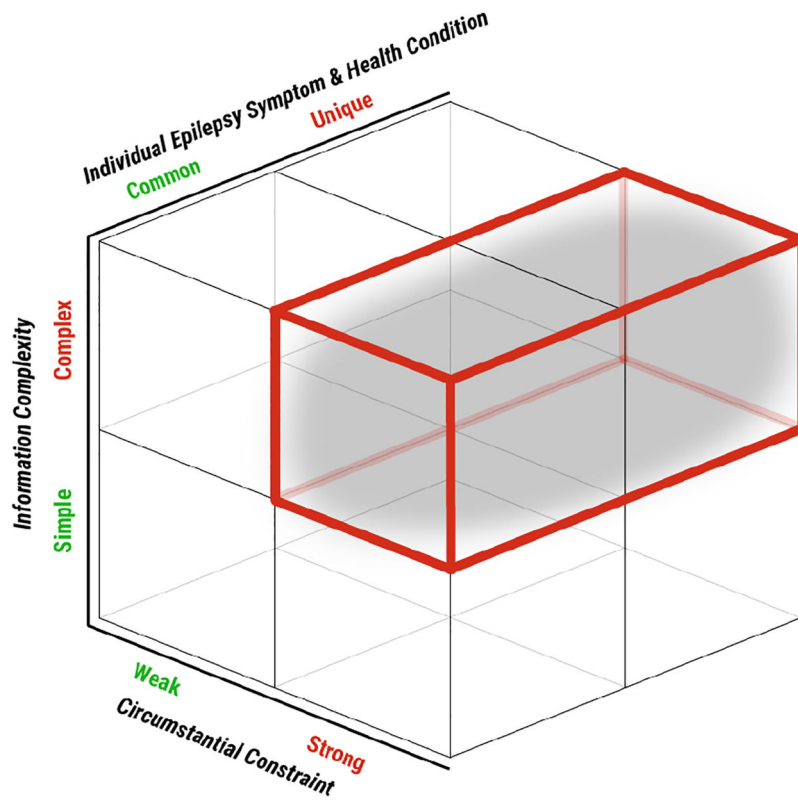


Figure 5:
Design Space for Automated & Integrated Management

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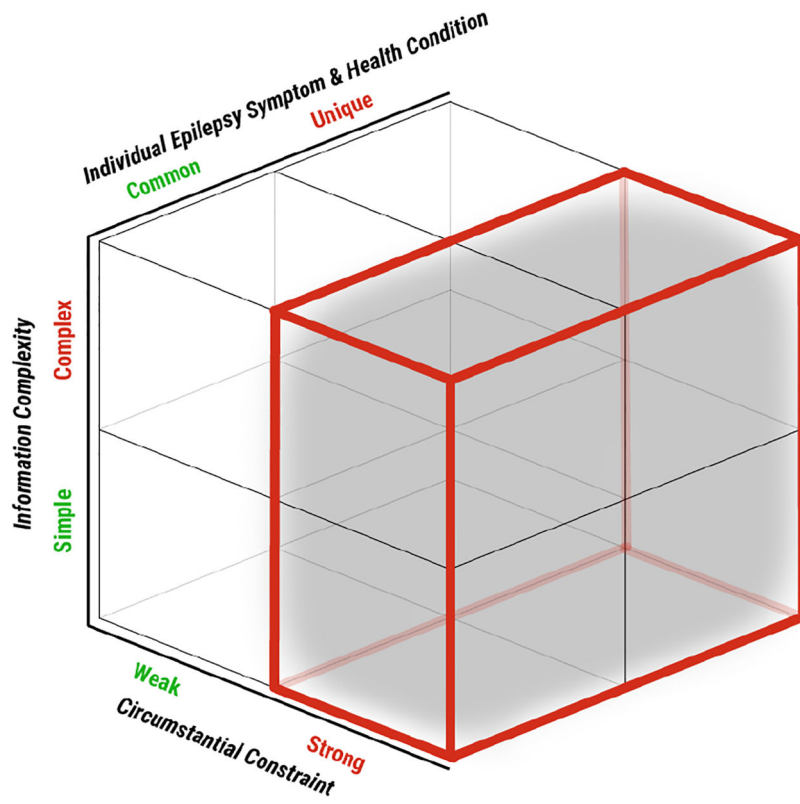


Figure 6:
Design Space for Social Support & Coordination Enhancement

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Table 1:

Existing ICTs for epilepsy self-management

| App/Device | Main Features | Key Pros & Cons |
|---|---|---|
| Epilepsy Journal Epsy Helpepilepsy Nile (My Seizure Diary) Seizure Tracker | Recording, tracking, managing epilepsy information (e.g., seizure, symptoms, triggers, medications, appointments) | <ul style="list-style-type: none"> • Pros: Decision making & medication adherence support • Cons: A lack of comprehensive information provision [37, 89] |
| Embrace2/EmbracePlus Inspyre™ NightWatch SeizAlarm SAMi | Seizure detection, alert, recording | <ul style="list-style-type: none"> • Pros: Timely detection, management & assistance • Cons: Low reliability, sensitivity, & performance of detection [109] |
| Aura: Seizure First Aid Seizure First Aide | Alert, seizure first-aid guidance, recording | <ul style="list-style-type: none"> • Pros: Informing others • Cons: Manual control & poor UX [3, 6] |

Table 2:

Demographic Information of Focus Group Participants. (P = Participant Code, CR = Care Recipient, FG# = Focus Group Session, E# = PWE participant, C# = Caregiver participant, F = Female, M = Male, X = Prefer not to say)

| P | Gender | Age | Age of CR | Since diagnosed |
|---------|-----------|------|-----------|-----------------|
| FG1-E1 | F | 25 | N/A | 5 years |
| FG1-E2 | F | 35 | N/A | X |
| FG1-C1 | F | 40 | 9 | 4 years |
| FG1-C2 | F | 67 | 30 | 21 years |
| FG1-E3 | F | 43 | N/A | 2 years |
| FG2-E1 | M | 29 | N/A | 11 years |
| FG3-C1 | F | 43 | 15 | 13 years |
| FG3-C2 | F | 31 | 5 | 3 years |
| FG3-C3 | F | 39 | 9 | 7 years |
| FG4-C1 | F | 31 | 3 | 1 year 2 months |
| FG4-E1 | F | 35 | N/A | 15 years |
| FG4-C2 | F | 36 | 17 | 5 years |
| Average | PWE | 33.4 | N/A | 8 years |
| | Caregiver | 39.8 | 9.8 | 7 years |

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