Understanding Health Information Management of People with Epilepsy and Their Caregivers

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ABSTRACT

Over two million people in the U.S. are living with epilepsy, which is one of most common chronic neurological condition. They have experienced challenges such as quality of health care, care coordination, and risks of sudden unexpected death. People with epilepsy and their caregivers (PWEC) desire for more resources and improvement in self-management. Our goal is to develop a patient-centered web service for them. Before we develop it, we conducted a focus group study to understand their needs, concerns, contexts of health information management, and experiences. Our preliminary findings include: (1) information seeking for treatment and side effect, (2) information sharing challenges with families and caregivers, and (3) preference for personalization and tailored information.

CCS CONCEPTS

• **Applied computing** → **Health care information systems**; *Health informatics*; • **Human-centered computing** → Human computer interaction (HCI).

KEYWORDS

Epilepsy, Patient, Caregiver, Self-management, Health Information Management

INTRODUCTION

Epilepsy is a chronic medical condition, which is one of the most common neurological diseases such as migraine, stroke, and Alzheimer's disease [3]. Over two million people in the U.S. are living with epilepsy [2]. Challenges of people with epilepsy include quality of care, care coordination, side effects, stigma, uncertainties of social situations, risks of sudden unexpected death, etc [1, 5]. PWEC desire to find more resources and services and improve their self-management [7].

Our research goal is to develop a patient-centered web service for PWEC which will improve PWEC's activation–the degree to which a person has the knowledge, skills, and confidence to manage epilepsy. Our research team will develop a personalized Automated User Resource Atheneum (myAURA) by integrating big data resources into a large-scale epilepsy knowledge graph that will fuel novel network inference methods to recommend and visualize relevant information in a personalized manner. However, before we develop the system, we conducted the first stage of our user study to understand PWEC's needs, concerns, contexts, and experiences in terms of health information management. We present preliminary results of this user study here.

RELATED WORKS

Self-management is a crucial way to manage chronic conditions, promote well-being and quality of life, and prevent illness, misconceptions, and concerns about stigma [1]. As part of self-management, people who have chronic conditions track their medical records, collect data, notes, and articles, all of which are related to their chronic health condition [4]. To manage personal health information, the importance of technologies and patient's central role has been emphasized in previous literature [6]. While there are many studies on people with epilepsy and the effectiveness of self-management, little HCI research has focused on self-management and information management technologies for PWEC.

METHODS

We distributed an online survey on social media and through the Epilepsy Foundation website to screen eligible participants. From respondent we recruited 13 participants who are living with epilepsy or caregivers of people with epilepsy. We distributed a second online survey to understand their epilepsy-related information seeking contexts such as the use of social media, scientific resources and online forum, and basic demographics. Using an online video meeting program, we conducted four focus group interviews with a semi-structured interview guide. Participants consisted of five people with epilepsy (four females & one male) and eight caregivers (all females). The interviews were recorded and transcribed for analysis.

PRELIMINARY FINDINGS

Information seeking for treatment, side effect, and social support

In addition to asking to their doctor, most participants mentioned they mainly look for information about treatment, medications, and side effects from the Internet and see other's experiences from support groups on social media. Specifically, they look for how treatments and medications work, what they need to do, who they can talk to, and how to manage side effects. However, most of them have not used Reddit because they just do not know what it is, and Wikipedia due to reliability.

Information sharing challenges with families and caregivers

In our focus group, participants described diverse ways to share epilepsy-related information, such as sharing links to articles, copying and pasting contents, or capturing and sending screenshots of the information. Some participants expressed that it was difficult to share information with their family members or other caregivers due to complicated medical lingo about their symptoms or other medical terms, often provided by their doctors, or present in scientific articles.

Preference for personalization and tailored information

While there are numerous epilepsy-related resources on the Internet, participants implied complexities in managing scattered and overwhelmed information, while also pointing to the need for more tailored information. To be specific, participants expressed that they desire easy to get information that is more relevant to their specific conditions, and to be able to find support groups near their living area.

FUTURE RESEARCH

These preliminary findings are from our first glimpse in the collected data. We will run additional focus groups, after which we will conduct a content analysis to find out common themes of issues and needs of PWEC. This focus group study is the first stage of our user study and the goal of this stage is to understand their needs and contexts before we develop the platform. After we finish analysis, our team will develop myAURA incorporating our findings. Then, we will proceed our user study into the second stage which will be a pilot test to measure short-term and long-term effects of myAURA on PWEC's activation, readability, memorability, and utility of the platform.

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