



## Mind the gap: Exploring information gaps for the development of an online resource hub for epilepsy and depression



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### ABSTRACT

**Purpose:** Depression is common in epilepsy, and is often under-detected and under-treated. The motivation to create a depression eHub for persons with epilepsy is to connect them to the best available online resources to effectively manage their depression. The study sought to: 1) identify facilitators and barriers to accessing resources related to management of epilepsy and/or depression and 2) discuss gaps in available resources (free and in the public domain) and 3) identify suggestions for future content.

**Methods:** Semi-structured interviews were conducted with ten patients with epilepsy and a history of depression. Using inductive analysis, two team members engaged in a process of textual open-coding utilizing a conventional content analysis approach whereby content was conceptually clustered based on the research questions. A phenomenological framework was applied to describe the phenomenon of online health resource access and utilization from the perspective of people with epilepsy.

**Results:** Facilitators to the use of online resources included information credibility, thoughtful organization, and accessibility of resources. Barriers included difficulties finding and piecing together information from many different sites. Patients reported difficulty having the motivation to seek out resources while depressed, which was compounded by feelings of stigma, social isolation, and lack of control. Gaps in resources included a lack of information about living with epilepsy day-to-day and resources for family and friends. Suggested content included information to raise awareness about epilepsy and depression; questionnaires to screen for symptoms of depression; stories of other patients with epilepsy and depression via video or moderated forums; current research and news; local community resources; and tools and strategies to manage depression in epilepsy.

**Conclusions:** There is a gap in accessible resources for patients with epilepsy and depression as well as barriers that include epilepsy-related restrictions, depression-related impairments, lack of awareness, and stigmatization. These results should be used to guide the development of e-Health resources for patients with epilepsy.

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### 1. Introduction

The prevalence of active depression in patients with epilepsy is estimated at 23% [1]. Depression in persons with epilepsy often goes under-detected and under-treated, with as many as 70% of currently depressed persons with epilepsy not receiving any form of treatment [2]. Depression can decrease quality of life and lead to poor disease self-management [3,4].

As many as 57% of persons with epilepsy seek information online regarding their health, according to a recent study [5]. Online resources present an avenue for persons with epilepsy to address knowledge gaps and improve awareness of mental health issues in epilepsy, identify symptoms, and promote self-management strategies for mental health conditions. However, existing epilepsy resources are scarce, and the quality and accuracy of these online resources and information is questionable [6–8].

Online interventions show promising results for aiding the treatment of depression and increasing quality of life among those with neurological conditions [9,10]. Researchers recently collated existing mental health resources and rated the quality of the evidence to better

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inform users for the general population, but not for epilepsy specifically [11]. This approach, called an eHub, seeks to utilize the growing amount of online resources by collating already-existing resources that are of high quality and publicly available. An eHub could aid in addressing the needs of persons with epilepsy and depression, while complementing traditional and in-person interventions. Further, an eHub can easily be adapted to the local context by inclusion of location-specific resources, such as how to access in-person support and links to community organizations. This project was initiated to identify current gaps and barriers regarding the availability, reliability, content, and utility of current online resources designed for people with epilepsy and depression.

## 2. Materials and methods

Through collaboration between clinical researchers in neurology and psychiatry, the research team sought to address the following questions: (1) What resources (informational or otherwise) about the interplay between mental health and neurological conditions are currently available, and being used, by patients with epilepsy? (2) How do patients assess existing resources related to management of epilepsy and/or depression? (3) From the perspective of patients, what are the gaps and barriers to using available resources? (4) From the perspective of patients, how can an eHub serve their needs in relation to accessing information related to epilepsy and depression?

Data collection occurred over a period of six weeks from November–December 2015 in Calgary, Alberta and consisted of semi-structured open-ended interviews with ten patients. Participants were recruited using convenience sampling via two channels: through the Calgary Epilepsy Program registry in which patients had enrolled and had provided consent to be contacted for future research ( $n = 7$ ), as well as those who consented to be contacted for future research from a previously completed study (NEurological disease and Depression Study – NEEDS) ( $n = 3$ ) [12]. Eligibility criteria included: diagnosis of epilepsy; current or recent history of diagnosed depression (within two years) by a health care provider or Structured Clinical Interview for DSM-IV (SCID-4); ability to participate in a one-on-one interview (no moderate–severe cognitive delay); ability to provide consent; and English speaking. The patients identified using the SCID had major depressive disorder with or without comorbid dysthymia. A diagnosis of depression by a health professional indicates clinically significant symptoms, but did not allow the characterization of the subtype of depression. Ethics approval was attained from the institutional research ethics board at the University of Calgary with all participants providing written informed consent. All interviews were completed in private rooms and lasted between 50 and 70 min.

Interviews were audio-recorded and transcribed verbatim by the research team with each participant assigned a code to maintain confidentiality. Applying conventional qualitative methods of inductive analysis, whereby themes were developed de novo from the transcripts instead of using a pre-existing theme structure, two research assistants with qualitative research expertise applied a content analysis approach using textual coding of transcripts to conceptually cluster interview content based on the study objective and research questions [13]. As there is little research about the experiences or preferences of patients with epilepsy in accessing and using online resources to manage depression, the study team applied a phenomenological theoretical framework to the coding process, which seeks to understand the lived experience of accessing online resources for persons with epilepsy and depression. The team sought to describe, from the perspective of participants, the interplay between epilepsy and depression including potential risks and protective factors; access to and utility of existing resources; and opportunities for the development of an e-Hub for people with co-occurring epilepsy and depression [14].

A staged approach was used to code and analyze data. First, the two qualitative research assistants read through the transcripts to acquire a

preliminary sense of the data and begin to conceptualize primary and secondary themes. Second, each research assistant coded two interviews independently using an open coding approach in the software NVivo. Upon completion of coding the first two interviews, the research assistants each presented their naming convention, including conceptual definitions, and discussed until agreement was reached on code name and definition. The research assistants then devised a coding framework and dictionary that informed the coding process of all subsequent transcripts and was built upon as new themes emerged. When new themes emerged, the research assistants met to discuss whether the creation of a new code or broadening of an existing code definition was required; this process was applied until all ten transcripts were independently coded by two research assistants. When a new code was created, transcripts previously coded were revisited to ascertain whether adjustments to codes were necessary. Once all transcripts were coded, the codes were collapsed and integrated to establish and define themes and sub-themes based on the research questions. Themes were presented back to the principal investigators of the study to assess degree of saturation and pertinent gaps, at which time agreement was sought on primary and secondary themes that emerged from the data and that no further data collection was required.

## 3. Results

### 3.1. Sample

A total of ten persons with depression and epilepsy were interviewed. There were seven female and three male participants between the ages of 27 and 53. Participants were diagnosed with major depressive disorder ( $n = 6$ ), dysthymia ( $n = 1$ ), and unspecified depression ( $n = 3$ ) by a healthcare professional (psychiatrist, psychologist or epileptologist) except in one instance where the patient was diagnosed by a trained upper-year clinical psychology graduate student using a SCID interview. Nine patients had received treatment for their depression in the form of psychotherapy and/or psychotropic medication, while one participant received no form of treatment except for being on a mood stabilizing anti-epileptic drug (AED, e.g. carbamazepine). Five patients had current depression, two patients had remitted depression, and the depression status in three participants was unknown. Half of the participants had less than a high school education, one had a high school education, and three had college or university education. The education status of one participant was unknown. Saturation of themes occurred after the tenth interview. Thematic summaries with illustrative quotes are presented in the subsequent sections. A quantitative summary of theme references is also shown in Table 1.

### 3.2. Fear and anxiety

Fear was related to experiences surrounding epilepsy, including both physical and social components. The physical fear of epilepsy included not understanding what was happening inside their brain that was producing seizures, experiencing symptoms such as auras, and acquiring injuries during seizures. Among those who had experienced a period of being seizure-free as a result of surgery or AEDs, there was a feeling of uncertainty and unease about whether their seizures would return.

Fear also extended into social situations, in which participants described anxiety that they would have a seizure in public. Perceptions of the public were one source of fear, as participants felt that the public lacked an understanding of epilepsy or that their seizures would be judged and stigmatized by others: “[you] get shut in because the outside world doesn’t want to see you anymore. That hurts.” (P3). One participant felt that when he/she had seizures in public, people assumed it was drug withdrawal, commenting that “a lot of people are going to have bad thoughts” (P4).

For some participants, this led to experiences of isolation, preferring to stay home rather than risk having a seizure in public. The sense of

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