



Epilepsy-related romantic and sexual relationship problems and concerns: Indications from Internet message boards☆



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ABSTRACT

The objective of this study was to, utilizing a Big Data set and innovative methods, explore romantic and sexual relationship-related concerns among people with epilepsy and their partners. We applied Word Adjacency Graph modeling to more than 2000 message board posts, and five distinct categories of romantic and sexual relationship-related concerns emerged. We conclude that persons with epilepsy are at particular risk for the experience of decrements in their romantic and sexual relationships, which can negatively impact their self-management and overall health.

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1. Introduction

The Internet has become a major source of information and sharing among people of all demographics. In the United States, nearly 87% of adults use the Internet [1], and 72% of Internet users report searching for health information online or discussing health-related problems on social media platforms [2,3]. Advances in mobile phone accessibility and technology have further facilitated the public's use of the Internet, social media, and mobile apps to gather and discuss health-related information, with smartphones increasingly accessible to people across socioeconomic statuses, levels of education, and ethnic groups, and with 62% of smart phone users reporting that they use phones to seek health information [4]. Use of the Internet for health information has become a prevalent practice, both for patients and among family and friends seeking to better understand health issues [5,6].

The pervasiveness of Internet use, including social media and mobile apps, for health-related searches and discussions has resulted in large repositories of information about people's health interests, concerns, and experiences. This, in turn, has led to the creation of large and complex datasets, termed Big Data, which reflect the public's organic

questions and concerns about health [7]. Big Data sets are highly reflective of a wide range of populations and demographics, providing a national or international snapshot of issues that often are not openly discussed nor captured with traditional research methods. For this reason, Big Data sets tend to provide pools of data that are more generalizable than that generated by standard research methods, which utilize a limited sample. Thus, Big Data is increasingly used to study a wide variety of health-related issues, including uncovering various aspects of health phenomena. In this paper, we use a Big Data set to explore the understudied topic of romantic and sexual relationships in people with epilepsy (PWE). In particular, we explore romantic and sexual relationship-related problems and concerns among PWE and their partners.

1.1. Epilepsy and romantic relationships

Epilepsy is the fourth most common neurological disorder in the United States, with as many as 3 million people affected. It is a chronic neurological condition consisting of recurrent and unprovoked seizures that can be associated with a wide range of seizure types and vary in severity from person to person. Epilepsy is also associated with multiple comorbid conditions affecting mental and physical health. For example, PWE are more likely to suffer from depression and anxiety, and are also more likely to be socially isolated, less likely to maintain long-term relationships or be employed, less likely to be married, and generally have a lower quality of life when compared with those without epilepsy [8,9]. Seizure control is the best defense against additional health problems

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for PWE, but even those whose seizures are well-controlled are more likely to be depressed and anxious than those without epilepsy [9,10]. Prior quantitative research has documented the physical and emotional problems PWE face, and qualitative studies have explored their worries and concerns [8,9,11,12]. Existing Big Data sets that include epilepsy-related discussions and inquiries of PWE, as well as their partners, family members, friends, and caregivers, provide a unique mechanism to better understand the most salient epilepsy-related concerns. This information can be helpful not only to patients and health information seekers, but also to clinicians and researchers, as it provides a personalized perspective into the lives of PWE uninfluenced by social biases or by discomfort with face-to-face discussions in which the subject matter is considered taboo.

One critical area of concern for those with chronic disorders as well as healthy populations – and one quite understudied in PWE – regards one's intimate (i.e., romantic and/or sexual) relationships. The need for social connection is an essential component of human psychology [13], and studies have shown that having a supportive and high-quality intimate relationship has significant psychosocial, physiological, and medical implications. Higher quality close relationships predict better psychological well-being, physical health, and quicker recovery from illness [14], while dissatisfaction with one's intimate relationship quality has been linked to depression, drug use, decline in immune functioning, and increased risk of cardiac failure leading to death [15–18], among other negative outcomes. For instance, in studies of patients with chronic heart failure, having a high-quality intimate relationship predicted survival over an 8-year period, and did so beyond the effects of individual risk factors including self-efficacy, psychological distress, and perceived emotional support from others in the social network [19]. Similarly, in a meta-analysis examining the impact of relationships on health outcomes across 148 studies and 308,849 participants, researchers found a 50% increase in survival likelihood as a result of stronger relationships [20]. Sexual experiences are one facet of relationships that can be particularly vulnerable to health issues. This is particularly profound given that, in adult relationships, sexuality and sexual satisfaction are primary facets of relationship function and satisfaction. For instance, low sexual satisfaction is among the strongest predictors of separation and divorce, and sexuality-related problems are among the most frequently cited reasons for divorce [21–23].

While intimate relationships clearly have far-reaching consequences for health and well-being, many studies on the impact of relationships on health have been conducted on samples with relatively healthy individuals. Moreover, a host of studies have indicated that relationship- and sexuality-related issues are not commonly discussed between patients and healthcare professionals. In a nationally representative poll, Marwick [24] found great concern among American adults over talking with their physician about a sexual problem. In this sample, 68% reported that their doctor would be uncomfortable talking about the problem because it was sexual, 71% reported that their doctor would dismiss their concerns, and 76% reported that they would not receive medical treatment for the issue even if they did bring the issue to their doctor's attention. These concerns are not unfounded. In a large study of health professionals from diverse disciplines, researchers found that while 90% agreed that sexual issues are important and should be assessed, 94% were unlikely to initiate discussion of these issues with their patients, and 86% were poorly trained to respond to patient-initiated reports of sexual issues [25]. Other studies have found that medical students [26] and residents [27] do not routinely screen for sexuality-related issues, although sexual dysfunction could signal major medical conditions, such as diabetes, pituitary tumors, and depression [28]. Even in fields of medicine that one might predict pay greater attention to people's sexual lives, there remain significant barriers to discussing issues of sexuality and intimacy. In one US population-based sample of 1154 practicing obstetrician/gynecologists (ob/gyns), only 63% reported routinely addressing sexual activities, with 40% specifically inquiring about sexual problems; other sexuality-related issues were

assessed even less commonly, with only 29% addressing sexual satisfaction, and 14% addressing sexual pleasure experiences [29]. Given that PWE are already at high risk for a lower quality of life and high frequency of depressive symptoms, and their disease outcomes are highly associated with their ability to effectively self-manage, it is vital that the effect of epilepsy and its treatments on various aspects of relationship- and sexuality-related outcomes are examined to determine if this is a viable area for outcome-enhancing interventions.

In terms of epilepsy, Big Data sets generated by Internet health information seekers provide important knowledge about people's lives and experiences, as these tend to be generated organically by PWE and their family, friends, or partners, without the prompting of an interview, survey, or clinical intake form. Moreover, these datasets tend to be generated within PWE's natural home or work environments where they access the Internet, reducing data that are influenced by PWE's concerns for social desirability with researchers or clinicians. Accordingly, data from Internet searches and message boards can reveal PWE's patient-centered voice in relation to their most salient disease-related concerns, as well as that of their partners. Questions about romantic and sexual experiences may be particularly susceptible to social desirability responses and may be overlooked because of either patient or practitioner discomfort. Thus, Internet searches and message boards can be a good way to assess the experiences and concerns of PWE regarding the impact of epilepsy on people's romantic and sexual lives.

1.2. Current study

Through a collaboration with the anonymous US question-answer service ChaCha®, our research team recently applied Word Adjacency Graph (WAG) modeling to a ChaCha® database containing 1.9 billion queries to uncover epilepsy-related questions and concerns among users [30]. This analysis yielded 11 distinct categories of concern for PWE, including a substantial number of epilepsy-related sexual and romantic relationship questions. In reviewing the epilepsy literature, however, we could find only two published studies [31,32] related to sexual and romantic relationship concerns in PWE, indicating a significant need for further research.

The current study employs data from Internet health information seekers, focused on epilepsy-related issues. Here, we focus on patient- and caretaker-generated issues related to sexual behavior and experiences, as well as intimate relationships, as people's romantic and sexual lives are often overlooked in health research. People's sexual experiences have direct impacts on their romantic relationships [21], and close romantic relationships have direct impacts on health [20], which may include patient's disease management, long-term quality of life, and survivorship outcomes. In order to accurately and effectively provide patients with realistic and optimal care, investigations into the role of love, intimacy, and sexuality in clinical populations, including among PWE and their partners, is critically needed. Here, we report on the presence of romantic and sexual concerns among PWE and their partners, as depicted in the user-based EFA dataset, to conduct a needed exploration into these issues.

2. Materials and methods

The source of data for the current study was a large dataset of message board posts from the Epilepsy Foundation of America (EFA) website epilepsy.com, which, as of December 2016, comprised more than 45,000 individual user posts. The purpose of these message boards is to allow PWE and their caretakers, friends, partners, and family to ask and answer questions about living with epilepsy. Thus, unlike other social media sets such as ChaCha®, the EFA dataset is incredibly epilepsy-specific. Initially, the entire dataset was reduced into an intimacy-related subset by searching the following key words (and word roots), which were chosen based on initial findings from our previous ChaCha® and EFA WAG modeling studies [30]: sex, sexual, relationship, divorce,

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