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Socialization characteristics in persons with epilepsy

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ABSTRACT

Objective: The purpose of this report was to describe social behaviors and preferences in adults with epilepsy, including self-reported use of various socialization media (face-to-face and indirect communication) as well as perceived social barriers.

Methods: 1320 consecutive persons with epilepsy (PWEs) confirmed through inpatient video-EEG monitoring were administered a questionnaire on the day of their first appointment. The questionnaire was designed to assess preferences in socialization practices, frequency of interpersonal contact, use of social media, and perceived barriers to socialization. The survey was developed to gain a better understanding of the socialization behaviors and preferences of our patients for the future development of customized activities in our wellness program.

Results: Our sample revealed higher rates of unemployment and single status as compared to the US Census of 2012. With regard socialization however, many were quite social (86% reported daily/weekly communication with friends and family via telephone, 71% saw relatives in person weekly, 68% saw friends weekly, and 65% reported using the computer daily/weekly to socialize). Facebook® was the preferred on-line social media. Indoor/solitary activities were most common with 63% stating they watch TV/read/use the computer followed by physical exercise and spending time outdoors (36%). The frequency of socialization with friends, relatives, and coworkers decreased with the respondents' age and the longer the respondent had carried the diagnosis of epilepsy. Respondents who were taking a greater number of AEDs or were considered refractory were less likely to consider participating in socialization-enhancing activities. The primary barriers to socialization that respondents endorsed were driving prohibition and medication side-effects. Respondents expressed the greatest interest in online support groups or educational programs (31%), office-based support groups (25%), and volunteering (19%).

Conclusion: Although the respondents indicate that they do face barriers to socialization, a majority report frequent communication with relatives and friends via phone, in-person and social media. When designing wellness interventions with this group of patients in the future, online, as well as face to face options for support appear to be desired by a number of PWEs.

1. Introduction

Epilepsy is the fourth leading neurologic disorder with a lifetime prevalence of 3.8% in the United States [1]. Persons with epilepsy (PWEs) report impoverished quality of life and convey a significant negative impact on their social functioning as a result of a variety of factors, including issues directly related to epilepsy (e.g., seizure frequency, seizure worry, severity of epilepsy, and adverse effects resulting from antiepileptic drugs (AEDs). In addition, epilepsy poses a further unique burden on PWEs due to the physical hazards that can result from epileptic seizures that can occur quite unpredictably [2]. Other recognized contributors to poor quality of life in epilepsy include discrimination in the work setting and potential difficulties regarding certain occupations, prohibitions to driving, and restrictions to participate in physical exercise [3–5].

Developmental theory and studies in epilepsy indicate that concealment of epilepsy from others could lead to social withdrawal [6,7]. Perceived loneliness and/or perceived social isolation is considered problematic as there is evidence that suggests that loneliness impacts emotional wellbeing and is augmented by functional limitations over time. Loneliness has been found to be a risk factor for a host of mental and physical health problems including depressive symptomology, impaired

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cognitive performance, and cognitive decline [8]. As an ill person becomes more aware of the constricting social network and his/her declining participation he/she may feel sadness, anger, despair, and reduced self-esteem [9]. Social isolation can also represent an important barrier to treatment compliance [10]. Perceptions of social support are considered an important factor that might contribute to illness severity [11].

The most frequent comorbid psychiatric disorder in epilepsy is depression with an estimated lifetime prevalence of 6% to 30% in population-based studies and with an estimated risk of suicide 10 times higher than that in the general population [12]. Hospital-based and community studies have indicated that there is an estimated prevalence of anxiety disorders of around 10–25% of PWEs [13,14]). The severity of these associated psychosocial comorbidities along with stigma, another key psychosocial comorbidity, can affect PWEs' quality of life and limit healthy social behaviors [2].

Stigma was reported by 51% of respondents in a large-scale study of 5000 PWEs [15] and by 53.4% in a more recent study of 1500 PWEs [16]. Surveys of general US population over the last decade still reveal that negative stereotypes about PWEs (including dangerousness or contagiousness), concerns about risk and safety in PWEs, and lower expectations regarding work and other social roles in PWEs are still held by a substantial number of respondents [17–20]. Negative stereotypes and ignorance in the general population can impact PWEs' proper insertion into society. While feelings of stigma, psychological distress, and difficulties including social isolation and low social competence [15] are commonly reported in PWEs, strong social support is associated with a more positive quality of life, improved psychosocial functions and a lower sense of stigma [21–23].

Although there are reports regarding quality of life, psychosocial comorbidities, and stigma in epilepsy, to our knowledge, studies focusing on the social behaviors and preferences in PWEs do not exist. With the advent of the internet and new varieties of social media, social behaviors are expanding beyond face-to-face social contact. The purpose of this report was to describe social behaviors and preferences in those with epilepsy, including self-reported use of various socialization media (face to face and indirect communication) as well as perceived social barriers among adults diagnosed with epilepsy. Recognizing current social behaviors could help in elucidating potential patient resources and needs and designing clinical and educational interventions.

2. Methods

This analysis includes 1320 consecutive patients with a diagnosis of epilepsy confirmed through inpatient video-EEG monitoring. In 2010, our epilepsy program constructed a questionnaire that was administered to all patients on the day of their first appointment at one of our 17 outpatient offices in New York or New Jersey. Patients were subsequently evaluated in one of our 6 epilepsy monitoring units (EMUs) in New York or 13 EMUs in New Jersey. The questionnaire was administered in paper-and-pencil form as part of an intake packet that all new patients were given. The questionnaire was designed to assess preferences in socialization practices, frequency of interpersonal contact, use of social media, and perceived barriers to socialization. The motive for developing the survey was to gain a better understanding of the socialization behaviors and preferences of our patients for the future development of customized activities for our wellness program. The complete questionnaire is shown in Appendix A. The questionnaire usage of this study was approved as per the following: Copernicus Group IRB tracking# NRE1-11-155 and protocol number NEREG-003.

Initially, descriptive statistics were used to analyze the data. A second step in the analysis involved examining the potential bivariate relationships between 7 explanatory variables (age, sex, age at epilepsy onset, duration of epilepsy, number of anti-epileptic drugs being taken, seizure frequency, and refractoriness) and 33 lifestyle factors. Refractoriness was defined as any epilepsy patient who failed two or more AEDs. To mitigate the aspect of multiple testing we split the lifestyle factors into several groups and represented each group with 1–2 factors. To determine the factors we employed a factor analysis method. Since most lifestyle factors have distributions very different from a normal distribution, we choose a non-parametric approach, namely, "principal component analysis". For each group, the number of factors to extract was determined using the scree plot. After the factors were determined we examined the relationships between the factors and explanatory variables using non-linear association measures and Mann–Whitney tests.

We standardized the lifestyle factors and split them into 6 groups: Social Characteristics, Socialization Modalities, Socialization Preferences, Use of Free Time, Social activity prevention and Benefit Social Activities. We ran principal component analysis separately on each group. The only exception is Socialization Preferences, composed of only 2 variables. Hence, the variables were kept as they were.

The 3 Social Characteristics (Relationship status, Living arrangements and Work status) factors are represented with 2 principal components, cumulatively explaining 39.173% of variation in the original factors. The 11 Socialization Modalities factors (Communication through telephone, Computer use, Hours of computer use, Socialization through computer, Use of Facebook, Twitter, Computer forums, Chat rooms, In-person time spent with friends, In-person time spent with relatives, In-person time spent with co-workers) are represented with 2 principal components, cumulatively explaining 47.365% of variation in the original factors. The 5 Use of Free Time factors (Going to the movies, Watching TV/reading, Physical exercise, Time with friends and Sleeping) are represented with 1 principal component, explaining 36.731% of variation in the original factors. The 5 factors that might prevent socialization (Stigma, Drinking prohibition, Not able to Drive, Medication side effects, No limitations) are represented with 2 principal components, cumulatively explaining 35.822% of variation in the original factors. Finally, the 5 factors that could benefit social activities (On-line support group, Telephone support group, In-person support group, Participating in an outing, and Volunteering) are represented with 1 principal component, explaining 25.986% of variation in the original factors. In this manner, we represented the lifestyle factors with 2 Socialization Preferences and 7 factors. To adjust for multiple testing, we applied the Bonferroni correction and used a significance level of $0.05/63 = 0.0000793$.

The relationships between age, sex, age of epilepsy onset, duration of epilepsy, number of anti-epileptic drugs being taken, seizure frequency, and refractory nature of epilepsy and 9 lifestyle agents were studied using non-linear association measures (Kendall's tau and Spearman's rho). The relationships between Sex and the 7 lifestyle factors were studied using Mann–Whitney tests.

3. Results

Of the 1320 questionnaire respondents, 606 (46%) were male and 714 (54%) were female. All patients were adults (18 years or greater). Mean age of the sample was 45.07 ± 17.8 years old, mean age of epilepsy onset was 21.42 ± 15.2 years old, and mean duration of epilepsy was 16.33 ± 17.1 years. Two hundred and twenty respondents (16.7%) have generalized epilepsy, 884 (67%) have partial epilepsy and 216 (16.3%) were undetermined. One thousand and seventeen patients (81.1%) were refractory to medical treatment.