



Online epilepsy counseling in Croatia: What do users want to know?



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ABSTRACT

Purpose: The purpose of this study is to better understand which specific epilepsy-related issues are cause for seeking out professional advice online.

Method: An online epilepsy counseling service introduced by the Croatian Epilepsy Association allows users to anonymously submit questions related to epilepsy via e-mail or online contact form, which are later answered by an epilepsy professional. The questions were classified both by inquirers and by content. Inquirers were classified as patients, patient's parents, family members, partners, and friends of patients with epilepsy. In terms of content, questions were divided into three groups: medical, socially-oriented, and unclassifiable questions.

Results: In sum, 355 e-mails, which included 513 questions, were analyzed. The vast majority of inquirers were patients themselves (48%) and parents of patients (28%). While 76% of questions concerned the medical aspects of epilepsy, there was as well significant interest in administrative and practical issues associated with the diagnosis of epilepsy. Among medical questions, the most popular concerned prognosis (15%) and second opinions (14%); among socially-oriented questions, inquirers were primarily interested in matters associated with their profession (28%). As well, the parents of patients were more likely to question an epilepsy diagnosis than the patients themselves ($p < 0.001$).

Conclusion: According to the results of this study, it is clear that epilepsy professionals should invest more time in discussing with patients the topics which interest them the most, as well as refer them to other professionals that can help them with non-medical epilepsy-related issues, and advise them on reliable Internet sources.

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1. Introduction

On a daily basis, millions worldwide use the Internet as a resource for health-related information. The emergence of the Internet and systematized electronic health records (EHR) have made it possible for patients to assume a more active role in managing their own personal healthcare [1]. In addition, the Internet has already proven its potential in terms of promoting healthier living habits, and making individuals more aware about preventing diseases [2]. Where it regards epilepsy-related issues, patients and their caregivers often use the Internet to find answers to a variety of questions [3]. Research suggests several reasons why patients search for answers online, including dissatisfaction with the care received [4]; low trust in one's doctor [5,6]; unanswered questions following a patient check-up [7]; and poor emotional

support [8]. Online support group members often rely on the Internet to learn more about their health situation [9], particularly as epilepsy is one of many chronic conditions in which patients are frequently under informed [10,11]. Yet despite the overwhelming popularity of the Internet among persons with epilepsy, there is no study that systematically investigates Internet use among these patients and their caregivers. The aim of this study, therefore, is to better understand which specific epilepsy-related issues are cause for seeking out professional advice online.

2. Methods

The Croatian Epilepsy Association (Hrvatska udruga za epilepsiju—HUE) maintains an official Croatian-language website (www.epilepsija.hr), which offers basic information on epilepsy symptoms, diagnosis, seizure first-aid advice and other treatments, epilepsy and HUE-related news, activities, online counseling, and a list of advisory centers. The online counseling feature encourages website visitors to obtain more information via a contact form and/or an e-mail address. According to data provided by Google

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Analytics, the Croatian Epilepsy Association's website received 72,549 unique visits between January 1, 2013 and June 16, 2015. More than half of these visitors (37,037; 51.06%) came from Croatia; the remaining 35,512 (48.94%) hailed from other, mostly neighboring countries, which share the same or have a similar language.

This study examines all of the questions received via the Croatian Epilepsy Association's contact form and e-mail address for the period January 1, 2016 and June 16, 2015. All questions were answered by neurologists, neuropediatricians, social workers, and jurists, respectively, who cooperate regularly with the Croatian Epilepsy Association. Based on a pivotal analysis of 150 questions, two of the authors of this study (M.M. and L.F.), agreed on a singular classification system to be used in this study. These 150 questions were also included into the final study (described below). The e-mails were classified in two ways: by sender (inquirer); and by content (topic).

The inquirers were classified as: (a) patients with epilepsy; (b) parents of patients; (c) family members of patients; (d) partners of patients; (e) friends of patients; and (f) people with no evident relation to a patient with epilepsy. In terms of content, questions were divided into three groups: (a) medical; (b) socially-oriented; and (c) unclassifiable questions. There were thirteen types of medical questions, four types of socially-oriented questions, and a range of unclassifiable questions, which eluded classification within this particular system. If the same e-mail contained several different inquiries, the questions were classified into several categories accordingly. An inter-rater reliability analysis was performed to determine consistency among the reviewers. Questions that were not categorized similarly were discussed among the reviewers, and subsequently classified into the same group.

a) Medical questions (topics and explanation):

1. Prognosis—prognosis of current condition, cure possibility, and possible complications in future
2. Medical test result explanation inquiry—explanation of test results of diagnostic procedures, e.g., EEG, MSCT, MRI, blood tests, etc.
3. Epilepsy diagnosis questioning—adequacy of diagnosis, possibilities that other conditions were overlooked
4. Therapy questioning—adequacy of therapy for current condition
5. Is it a seizure?—inquiries and descriptions of seizure-related episodes
6. Causes of seizures—predisposing factors and causes of seizures
7. Epilepsy diagnosis explanation—explanation of epilepsy diagnosis definitions and questions pertaining to the severity of the condition (e.g., “What is a primary generalized seizure?”)
8. Other symptoms—concomitant symptoms that do not include seizures (e.g., “My hands shook yesterday, does it have anything to do with epilepsy?”)
9. Medication side-effects and interactions—antiepileptic therapy side-effects and their interaction with other drugs, food, and drink
10. Second opinion—second opinions, and recommendations for other physicians and/or institutions
11. Alternative treatment—alternative treatment options not approved as epilepsy therapy, including consumption of vitamins, cannabis, and different herbal preparations
12. Neurosurgical options—criteria for an operation and outcome of neurosurgical treatment
13. Epilepsy and pregnancy—antiepileptic therapy effect on pregnancy outcomes, fertility, medical management during pregnancy, and the risk of epilepsy inheritance.

b) Socially oriented questions (topics and explanation):

1. Professional orientation—possibilities in professional life, job orientation, and potential limitations
2. Legal rights—legal rights and administration issues
3. Driving license conditions—effects of epilepsy on obtaining and maintaining a driving license
4. Association for epilepsy—related to the activities of the Croatian Epilepsy Association, and possibilities of joining the association.

c) Unclassifiable questions

Explanation

As noted above, many questions related to epilepsy fell outside the above-listed topic categories, e.g., “Is it possible to eat red meat if I have epilepsy?” and “Is a massage safe for people with epilepsy?” As well, inquiries which did not contain a specific question but rather related to a patient's life/condition were included here.

Where appropriate, questions were also compared between those asked by patients themselves and those asked by parents of patients, using a χ^2 test. The software used was IBM SPSS Statistics, Version 20.0. The value $p < 0.05$ was used as a criterion for significance of the statistical findings.

3. Results

Between January 1, 2013 and June 16, 2015, the Croatian Epilepsy Association's website received 381 e-mails. As 26 e-mails were not related to epilepsy, 355 e-mails were analyzed in this study. As some of the e-mails consisted of more than one question, the two reviewers classified 513 questions according to the established criteria following the sample analysis of 150 questions, as described in Section 2. Initially, 436 questions (85%) were classified equally. The remaining 77 questions (15%) were only classified equally after agreement was reached that the same type of classification system is to be used for these questions too. Table 1 illustrates questions classified by inquirer, while Table 2 depicts those by content. Likewise, Tables 3 and 4 show classifications among medical and socially-oriented questions, respectively.

The number of questions that question epilepsy diagnosis was significantly higher among parents of patients than among the patients themselves (20/101 among parents vs. 10/171 among patients, $p < 0.001$). Among all of the other medical categories appropriate for comparison, no significant difference was found.

Table 1
Classification of the e-mails, according to the inquirer.

N (number of e-mails)	355
Inquirer	
Patient	171 (48%)
Parent	101 (28%)
Family member	28 (8%)
Partner	14 (4%)
Friend	9 (3%)
Unknown	32 (9%)

Table 2
Classification of the questions, according to the content.

N (number of questions)	513
Questions (content)	
Medical	394 (77%)
Socially oriented	88 (17%)
Unclassifiable	31 (6%)

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