



Assessing knowledge of symptoms and first-aid care of epilepsy in Grenada, West Indies



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ABSTRACT

Epilepsy is a chronic neurological disorder that is increasingly prevalent in developing countries. It is critical to provide appropriate support to patients during seizures in order to prevent injuries. False beliefs regarding the etiology or pathogenesis of the epilepsy and inadequate health information may put patients with epilepsy or other seizure disorders at increased risk of injury. Our objective was to assess the level of epilepsy awareness amongst the general population in Grenada and educate the participants regarding proper first-aid measures. A pilot questionnaire containing a total of 25 items surveying the knowledge, attitudes, and first-aid care of epilepsy was presented to 200 adult residents of Grenada as face-to-face interviews. Study participants were recruited over a nine-month period on a voluntary basis at health fairs, in local communities, and on the campus of St. George's University. Our results indicate that 35 out of 198 (17.7%) respondents erroneously believed that medicine should be placed in a person's mouth during a seizure, and 83 out of 200 (41.5%) answered that a person who is convulsing should be held down. Furthermore, 128 out of 195 (65.6%) respondents erroneously believed that seizures occur when there is low brain activity and an additional 35 out of 199 (17.6%) regarded epilepsy as a contagious disorder. Our data suggest that persons with seizures and/or epilepsy may be at increased risk of injury in Grenada due to common misconceptions and false beliefs. It is critical that epilepsy awareness is promoted in developing countries, such as Grenada, where inadequate health information may be common.

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1. Introduction

Epilepsy is a chronic neurological disorder that is characterized by recurrent seizures. It is estimated that 50 million people worldwide suffer from epilepsy with the majority (nearly 80%) residing in developing countries [1]. Taking proper first-aid measures to support a patient with epilepsy during seizures is critical to prevent injuries and complications. To date, only limited data have been published about the level of epilepsy awareness in the Caribbean. One earlier survey collected information from medical professionals and government offices in Grenada, Barbados, St. Lucia, St. Vincent and the Grenadines, and Trinidad and Tobago [2] and one general population survey has been conducted in Jamaica [3]. Some published studies discuss the problems related to the knowledge and care of epilepsy in developing areas in Africa and Asia [4,5]. In addition, a very recent study aimed to explain how the existing beliefs, knowledge, cultural and educational background, and economical status affect the self-reported diagnosis as “epilepsy” or “seizure disorder” in the District of Columbia (DC, USA) [6]. It has been shown that besides the lack of knowledge of diagnosis of epilepsy amongst the general population, there is also a lack of proper epilepsy

care in developing countries, as well as in low-income areas globally. This was also shown in the five English-speaking Southern Caribbean countries in the earlier study by Krauss et al. [2]. For example, there is no specialized neurologist in Grenada, and most patients with epilepsy are referred to see one of the main hospital-affiliated internists or pediatricians. There are also only minimal imaging services and, until very recently, minimal use of the latest antiepileptic drugs in Grenada [2]. Amongst the general population in the Caribbean, there are many misconceptions and false beliefs about epilepsy that may put patients at increased risk of injuries during seizures. The objective of this study was to survey the level of epilepsy awareness in a sample of the general population in Grenada, West Indies, in order to better promote awareness and support the development of guidelines for epilepsy management and care. Education about proper epilepsy care was also provided to participants in the form of discussion about incorrect answers and with a brochure describing epilepsy.

2. Methods

2.1. Content of epilepsy survey

The survey “Assessing Knowledge of Symptoms and First Aid Measures for Epilepsy amongst General Population in Grenada” was

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approved by the St. George's University Institutional Review Board (SGU IRB approval #15009). The survey, which was conducted by eight students of the SGU School of Medicine, was supervised by the faculty principal investigator. The pilot survey consisted of 25 questions or comments containing multiple choices, true/false, and check-all-that-apply options and was divided into four parts. Part A of the survey contained demographic items, such as gender, age, education level, and parish of residence (which is not necessarily the same where the survey was administered). Part B contained items relating to the participant's experience with epilepsy, including family history of epilepsy, past experience in helping a patient with seizures, and sources of information about epilepsy. Additionally, Part B contained a scale to rate each respondent's self-reported knowledge level of epilepsy, ranging from one to ten, with one representing "I know nothing" and ten representing "I know everything". Parts C and D of the questionnaire included items related to facts about epilepsy and first-aid measures that should be performed in the event of seizures.

2.2. Informed consent

Informed consent was obtained verbally from volunteering participants at the beginning of each interview by disclosing the objectives of the study and informing the participants that completing the survey is considered as giving his/her consent. Participants were also informed that he/she had the right to refrain from answering or refuse to participate in the survey at any time, even after having completed the survey. Furthermore, participants were informed that the results of the survey, including demographic information, would be published by the investigators as a scientific article. As the names of the participants were not collected at any point, the information provided by the survey is totally anonymous. Only adult residents (ages 18 and older) of Grenada were included in the study. No identifying information, other than sex, age, level of education, and parish of residence, was collected. All interviewing researchers had completed the National Institutes of Health (NIH) Office of Extramural Research online training course "Protecting Human Research Participants".

2.3. Epilepsy survey methodology

Researchers conducted face-to-face interviews with adult residents of Grenada, West Indies. Survey data was collected from March 2015 through December 2015. Study participants were randomly recruited on a volunteer basis at health fairs held in five of the six parishes of Grenada; St. George, St. David, St. Andrew, St. John, and St. Patrick (not including St. Mark). Interviews were also conducted outside of the health fairs in areas of Grand Mal, downtown St. George's, Grand Anse, and St. George's University campus; all of which are located within the parish of St. George. Furthermore, interviews were conducted in the neighboring dependency island of Carriacou. Inclusion criteria were that subjects were 18 years of age or older, English-speaking, and residents of Grenada. Included female and male participants varied in age and education level. Any recall bias was minimized by focusing the study questions on the participant's knowledge of epilepsy rather than having the participant rely on his/her memory to answer the questions. Only four questions in the survey inquired about the participants' past experiences with epilepsy. No incentives were given to participate in this study.

All interviews were conducted verbally while researchers documented participants' responses on the questionnaire forms. Participants were informed of their right to refrain from answering any of the questions. As the residents of Grenada commonly use the term "fits" as a reference to epilepsy, this terminology was used in conjunction with the terms "epilepsy" and "seizures" while conducting interviews. Following the interview, researchers reviewed all questionnaire items with the participants and properly educated the participants about any misconceptions or false beliefs regarding epilepsy. Additionally,

proper first-aid measures to perform during seizures were discussed with all participants. Educational brochures on epilepsy were distributed to participants at the end of each interview to promote epilepsy awareness.

2.4. Data analysis

Data from each interview were transferred from paper surveys to an online SurveyMonkey® database. The online database is password-protected and accessed only by the participating listed researchers. The principal investigator of the study continues to retain all completed paper surveys in locked storage. Data analysis was conducted using IBM® SPSS® Statistics Version 23. The SPSS® database contained 137 variables. Study results are reported in aggregate without identifying personal information.

3. Results

3.1. Demographics

The survey pilot study used a convenience sample of 200 adult volunteering residents of Grenada, of which 48.5% were male and 51.5% were female. The majority of respondents (107) were between ages 21 and 40 years. Primary school was reported as the highest level of education by 40% of respondents, 33.5% reported secondary school education, and 26.5% reported post-secondary school or above educational level (Table 1). The majority of the participants (69%) were residents of the parish of Saint George. Fig. 1 shows the distribution of participants residing in the various parishes in the mainland of Grenada and on the island of Carriacou.

3.2. Participants' experiences with epilepsy

The majority of the participants (93.5%) reported that they had heard of epilepsy and 43 respondents (21.5%) reported having helped a person with epilepsy in the past. Additionally, 57 respondents (28.9%) reported having a family member with epilepsy or a related disorder. The most common selected family member (20.8%) was "other", denoting a cousin or more distant relative. A first-degree relative having epilepsy

Table 1
Demographics of respondents.

	N	Percent (%)
Gender of respondent		
Male	97	48.5%
Female	103	51.5%
Age of respondent (years)		
18–20	7	3.5%
21–30	53	26.5%
31–40	54	27.0%
41–50	41	20.5%
51–60	27	13.5%
61–65	11	5.5%
65+	7	3.5%
Highest level of education of respondent		
Primary school	80	40.0%
Secondary school	67	33.5%
Post-secondary school	10	5.0%
Vocational school	4	2.0%
Tertiary school (university or college)	39	19.5%
Respondent has heard of epilepsy/fits		
Yes	187	93.5%
No	13	6.5%
Respondent has ever helped someone who had an epileptic episode/fit		
Yes	43	21.5%
No	155	77.5%
No response	2	1.0%

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