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Societal problems that patients with epilepsy are facing in Sharjah, UAE

Abduelmula R. Abduelkarem *

Pharmacy Practice and Pharmacotherapeutics Department, College of Pharmacy, University of Sharjah, P.O. Box 27272, Sharjah, United Arab Emirates

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ABSTRACT

The aim of this cross-sectional study was to assess the knowledge and gauge the level of understanding and attitudes of the public towards patients with epilepsy in Sharjah, UAE. A questionnaire-based survey was used, and a total of 400 surveys were distributed in several parts of the city. Among 388 (97%) returned surveys, 94.3% reported that they had heard about epilepsy, and 62.9% believed that epilepsy is a curable disease. More than half of the respondents believed that epilepsy is not a mental illness, and 61.1% respondents that epilepsy is a nervous system disorder. Interestingly, almost 4% of the sample believed that epilepsy is either a supernatural power or an evil spirit. Despite the fact that more than 80% of the respondents accepted that people with epilepsy can become useful members of society and can receive academic education, almost half of the sample reported that society discriminates against people with epilepsy, and 14% of respondents still think that people with epilepsy should be isolated from the healthy population. Furthermore, when respondents were asked if they will allow their son or daughter to marry a girl or boy with epilepsy, 213 (82.5%) and 217 (81.4%) of the respondents reported either "No" or "Don't know", respectively. Negative attitudes and inadequate knowledge among the public in Sharjah, UAE likely contribute to the stigma and discrimination faced by those with epilepsy in this region. Educational programs are urgently needed to increase awareness and to improve knowledge and attitudes among the public.

1. Introduction

Epilepsy is a chronic neurological disorder affecting almost 50 million people of all ages around the world [1], and 94% of patients with epilepsy, unfortunately, do not receive appropriate treatment in developing countries according to a WHO report [2]. In the Arabic language, the term used for epilepsy is As-Saraa. The majority (85%) of the 50 million people with epilepsy live in developing countries, which represents an important public health problem [3].

Besides managing their chronic medical illness, patients with epilepsy have to deal with the social label inflicted on them by the society [4]. One important source of the negative impact on most aspects of health-related quality of life of patients with epilepsy is the social stigma and discrimination [5,6]. Stigma is precisely described by Boer [7] as follows: children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe. This explains how people with epilepsy are marginalized in society as a result of negative public attitudes towards epilepsy both in developed and in developing countries [5,8]. Almost half of patients with epilepsy reported feeling stigmatized by their disease in one particular study [9]. Some patients, in other similar studies, even find that the social attitude, the stigma, and discrimination against epilepsy are more devastating than the disease itself [10,11]. In developing countries, where the incidence and prevalence of the disease are expected to be higher than those in developed countries, the stigma and discrimination add more problems to the patients who may already be suffering from inappropriate care and ignorance [12].

Several studies were conducted for the same purpose and had highlighted the high prevalence of negative attitudes and misunderstanding towards epilepsy [12–16]. However, there is still inadequate research on the public understanding and attitudes in Sharjah, UAE. The aim of this cross-sectional study was to assess the knowledge and gauge the level of understanding and attitudes of the public towards patients with epilepsy (PWE) in Sharjah, UAE.

2. Method

2.1. Study design and population

The present research was a cross-sectional survey-based study conducted on people living in selected areas of the Emirate of Sharjah, UAE from January 1, 2015 to April 30, 2015. Sample size was calculated based on the total population of the Emirate of Sharjah which was estimated to be 1 million in 2012–2013 [17]. The minimum effective sample size for this particular study was estimated to be 384, using the online sample size calculator [18] with a confidence interval of 95%, 5% margin of error, and 50% for the expected response distribution. A sampling frame and an up-to-date electronic population database were not

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* Tel.: +971 503655610.
E-mail address: aabdelkarim@sharjah.ac.ae.

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available for the researchers during the study period, and accordingly, a convenience sampling technique was used.

A total of 400 questionnaires were distributed randomly by the researchers in several parts of the study sites in Sharjah such as universities, malls, and cafes. Participants were initially approached, and complete details about the study were given to those who gave their verbal consent for participation. They were also asked to sign on the cover page of the survey as consent to take part in the study after being told their participation was anonymous and that responses would be used for research purposes only. A total of 10 to 15 min was given to each participant to complete the survey, available both in Arabic and English versions, which are the most spoken languages in the country. Around 20 people declined to participate in the study because of time constraints, complete lack of knowledge about the disease, or lack of interest. Interestingly, a couple of people refrained from participation because of an irrational fear of getting the disease, claiming that it is "bad luck". However, the fact that some participants took the forms and did not complete them or did not answer all the questions is an indication that autonomy was maintained for the purpose of this study. There is no requirement to obtain ethical approval for such a study in the UAE. Participants were asked about their personal history of epilepsy before they were recruited into the study, which included participants above 15 years of age with no personal history of epilepsy and the ability to understand the questionnaire either in Arabic or English.

2.2. Questionnaire development

A 33-item questionnaire (4 sections: personal information, knowledge, understanding, and attitudes) had been developed with questions used in previous similar studies to gather the required information and to facilitate comparison with other studies [15,19,20]. Amendments were made whenever any questions were deemed culturally inappropriate or outdated conceptually. The questionnaire was split into 4 parts. The first section of the survey concerned 'the personal information' (10 items) and aimed to identify the participants' demographic data such as age, gender, educational level, occupation, and their familiarity with the disease. The second section, regarding "Knowledge among the public on the etiology, symptoms, and the effective methods in treating epilepsy" (3 items), aimed to capture the participants' knowledge about the main causes of the disease, symptoms, and the methods of treatment. The third and fourth sections were designed to gauge the understanding and the attitudes of the public towards PWE (10 questions each). For sections 3 and 4 of the survey, answer options of "Yes", "No", and "Don't know" were given. (A copy of the survey can be obtained from the researchers upon request).

The questionnaire was also translated into Arabic and was sent to an Arabic language expert for inspection and remarks. The questionnaire designed in Arabic was also validated by the forward–backward translation method, to ensure conceptual equivalence.

2.3. Validity and reliability testing

The validity of an instrument is the extent to which it actually measures what it is designed to measure. In survey work, this refers to the extent to which the questions collect accurate data relevant to the study's objectives. Evidence of validity may be gained through observation, expert and lay judgment, and empirical inquiry. Despite the fact that the tool used for this particular study was a validated survey and had been extensively used in previous studies [15,19,20], to ensure the face validity of the instrument after being slightly modified to suit our target sample and translated into Arabic, the questionnaire was sent to two faculty members and one physician with extensive experience in survey design study. Furthermore, the researchers were also asked to read the survey and to give their feedback, if any. All of their views and comments were considered and then incorporated into the final version of the questionnaire.

To assess test–retest reliability, the questionnaire was distributed to 10 participants (not included in the final sample) randomly chosen from the study areas. The second response was elicited two weeks after the initial test. No problems were highlighted, and test–retest reliability was calculated using Spearman's correlation coefficient (r). The rho value was 0.73, which implies an acceptable level of test–retest reliability. The alpha coefficient was 0.7, indicating that most of the items included make a valid contribution to the overall score.

2.4. Data analysis

The participants' responses were encoded, and the data were analyzed using Statistical Package for the Social Sciences (SPSS, version 20.0, Chicago, IL, US).

Descriptive analysis was used to calculate the proportion of each group of respondents with each statement in the questionnaire. Chi-Square test was used to ascertain the association between the dependent variables (responses for questions addressing understanding and attitudes towards epilepsy). The level $p < 0.05$ was considered as the cutoff value for significance.

3. Results

A total of 400 surveys were distributed, of which 388 were returned, giving a response rate of 97%. More than half of the sample was female (223; 57.5%) and belonged to the age group of 20–29 years old (217; 55.9%). Three hundred thirteen (80.7%) of the respondents reported that they had a university degree, and 266 (68.6%) reported that they work in nonhealth-related jobs. Table 1 summarizes the characteristics of 388 participants included in the study.

3.1. Personal information

When participants were asked whether they had heard about epilepsy or not, the majority of respondents (366; 94.3%) reported "Yes". However, more than half (224; 57.7%) reported that they had never seen anyone who was having an epileptic seizure. Only 52 (13.4%) and 133 (34.3%) participants reported that they had a close relative with epilepsy and knew someone with epilepsy other than relatives, respectively. Two hundred forty-four (62.9%) of the respondents thought that epilepsy is a curable disease, and the majority (364; 93.8%) reported that epilepsy is not a contagious disease. Table 2 summarizes the personal information of the 388 participants included in the study.

Table 1
Characteristics of the 388 participants.

Characteristic	Frequency (%)
Gender	
Male	165 (42.5)
Female	223 (57.5)
Age (years)	
<19	47 (12.1)
20–29	217 (55.9)
30–39	65 (16.8)
40–49	42 (10.8)
>50	17 (4.4)
Educational levels	
Primary level	4 (1.0)
Elementary level	12 (3.1)
Secondary level	59 (15.2)
University level	313 (80.7)
Occupation	
Health-related	122 (31.4%)
Nonhealth-related	266 (68.6%)