ORIGINAL ARTICLE

Poor level of public knowledge toward essential tremor in Saudi Arabia: a crosssectional study

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ABSTRACT

Background: Essential tremor (ET) is considered as one of the most common movement disorders and a frequent reason for a neurological consultation. The study aimed to assess the level of knowledge regarding ET among the population in different regions of Saudi Arabia.

Methods: This cross-sectional study recruited 1,471 Saudi participants. An online, valid questionnaire covering sociodemographic data and tremor-related questions was used. The data were entered into Microsoft Office excel and exported to STATA version 16. Simple and multiple logistic regression analyses were used.

Results: The mean age and standard deviation was 32 (\pm 11) with 59% of the participants less than 33 years. Moreover, 52% were males, 73% have a bachelor's degree, 42% were from the central region, 10% were health practitioners, and 1% had an ET. Only 4% of participants had a good level of knowledge concerning tremors, whereas 96% had a poor level of knowledge. Health practitioners [Adjusted odds ratio (AOR) 2.57, 95% confidence interval (CI): 1.33-4.97], and those who have bachelor degrees or above (AOR 2.59, 95% CI: 1.09-6.10) were associated with a good level of knowledge.

Conclusions: The knowledge about ET within the Saudi Arabia's population is poor. Planning health educational programs in collaboration with policy makers and other stakeholders for public is essential.

Keywords: Knowledge, tremor, essential tremor, Saudi Arabia.

Introduction

Essential tremor (ET) is considered as one of the most common movement disorders and one of the frequent reasons for neurological consultation [1,2], occurring in 1 out of every 25 people older than 40 years of age [3,4]. In the United States, seven million people are estimated to be affected by this disorder [4,5]. The worldwide pooled prevalence of ET was measured to be 0.9% and could be as high as 4%-6% in people older than 60 years of age [6].

Epidemiological studies have identified several risk factors for ET. First of all, age is considered as a clearly risk factor for ET as several studies have shown an age-associated rise in the incidence [7] and prevalence [8,5] of ET. Ethnicity has been linked to ET with higher prevalence in Caucasians than in African-Americans has been reported in two community-based studies [9,10]. Also, a family history of ET is a risk factor for ET, as

several observations showed that the disease is running in some families [11,12].

ET is described as an action tremor, benign, or kinetic, that predominantly affects the upper limbs but can also involve the head, jaw, or voice, with occasional involvement of other body parts [13]. Although the

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disease is a benign condition, it can become very disabling for patients, both functionally and psychologically [14]. The tremor is typically progressive, as up to one-fourth of ET patients retire prematurely, and more than half prefer not to apply for a new job due to their hands' tremulousness [4]. ET may also manifest with non-motor symptoms and has been associated with depression and anxiety [15]. Additionally, it might bring embarrassment to the patient [16]. The treatment of ET primarily involves pharmacotherapy and surgery. In patients in whom dysfunction or embarrassment is not an issue, medications are not indicated. Drugs may be used to lessen functional disability and reduce embarrassment, while surgery has a role in severe, disabling cases refractory to medications [1].

Despite the high prevalence of ET based on the published literature, unfortunately, ET does not possess the same public attention as similar, less-prevalent movement disorders, such as Parkinson's disease (PD). Public awareness, as well as misconceptions, negative attitudes, and ET stigma, may have a considerable impact on patients' quality of life [4,17]. Only a handful of studies worldwide have investigated how knowledgeable the public is toward ET. In some untreated patients, it could become a burden to their daily activities and become very disabling [18]. In the literature, few studies assessing ET patients and/or their families were published. Literature suggests that the overall knowledge of ET among population is low [4,19,20].

According to the available literature, no local epidemiological studies have been conducted about ET in the population, nor are there published studies measuring the level of knowledge toward ET in Kingdom of Saudi Arabia. Poor general knowledge about ET affects the person's perception of the disease and delaying the opportunity for early diagnosis and management. Furthermore, it is fundamental to increase community awareness of ET, as better public understanding of the facts of the disease will engage patients more in the community, release the stress of psychological impact on them and improve the quality of life including jobs functional performance. Therefore, our study's aim is to determine the extent of knowledge regarding ET among the population in different regions of Saudi Arabia. In order to gain additional perspectives and associations, we also assessed the level of knowledge among patients with a related tremor disorder. Finally, we examined whether a range of socio-demographic factors influenced this knowledge.

Subjects and Methods

A quantitative observational cross-sectional study was conducted among the Saudi Arabia population with a non-probability sampling technique. An online survey was distributed through social media apps from July to August 2020. The participants included mentally competent Saudi Arabian adults. Those younger than 18 years or who could not complete the questionnaire for any reason were excluded.

A predesigned, validated questionnaire was used based on a previous study [4]. The survey was constructed using an online platform, google forms (Google LLC, Mountain View, CA). The questionnaire consisted following variables: demographic factors (age, gender, education, address, and occupation), diagnosis of the disease, and 15 items related to tremor knowledge.

The knowledge level was defined as "good" or "poor" based on Bloom' cut off point. Participants with knowledge score 60% or above were considered as having good knowledge, and those with scored below 60% were considered having poor knowledge [21,22]. The scoring system was established as follows: the last 15 questions were the only questions included in the scoring system. For each correct answer, one point was added; if the answer was incorrect, 0 points were given. The scoring system was divided into two categories: poor knowledge (0-8 points) and good knowledge (9-15 points).

The sample size was considered as a type I error of 5%, a statistical power of 80%, and an assumption that the level of good knowledge regarding tremors was 50% in order to get the highest sample size. The anticipated non-response rate was 30%. The required sample was at least 500 participants. Data collection started on July 17, 2020, and lasted until August 9, 2020. We used an onlinebased survey distributed through social media apps. Informed consent was obtained from all participants as they received the questionnaire after clicking on the link, the front page showed the study title, purpose, and asked for the participant's permission. The survey's title was "Public Knowledge Toward ETs in Saudi Arabia". If they agreed to participate, they were asked to click "start the survey" and then proceeded to answer the survey questions.

Data were entered by Micosoft Office excel and exported to STATA version 16. Descriptive statistics were performed in frequencies and percentages for categorical variables, and mean, and standard deviation were used for continuous variables. For analytical statistics, simple logistic regression analysis was used to demonstrate an association between factors with a good level of knowledge. Multiple logistic regression analysis was used to calculate adjusted odds ratio and 95% confidence interval (CI) for sociodemographic factors associated with a good level of knowledge as dependent variable including all factors in simple logistic regression as independent variables. The area under receiver operating characteristic (ROC) curve was used to assess the model fitness. A two tailed p value of 0.05 or less was considered as a strong evidence against null hypothesis.

Results

A total of 1,471 participants were included in the study. Eight hundred and seventy-one (59%) of the participants were less than 33 years, 772 (52%) were males, 1,077 (73%) had a bachelor degree, 614 (42%) were from the central region, 152 (10%) were health practitioners, and 19 (1%) had an ET. Descriptive characteristics are detailed in Table 1.

Only 60 of the participants (4%) had good knowledge of tremors, whereas 96% had poor knowledge. Frequency distribution of the knowledge questions showed that 31% of the participants have read or heard about ETs, 40% knew that the main symptom of ET is shaky hand, 30% stated that arms that shake when someone has ET, and 14% stated that ET is different from PD. Moreover, 25% stated that ET is different from the type of tremor that people can get when they become old or frail, only 4% knew the typical age of onset of ET, 10% stated that children cannot get ET, 34% stated that genes and unknown causes initiate ET as shown in Table 2.

The unadjusted and adjusted association between sociodemographic characteristics and outcome variable were shown in Table 3. The unadjusted analysis shows that the odds ratio of having good knowledge was significantly higher among males (OR: 1.72, 95% CI: 1.00-2.95), those with bachelor degree or above (OR: 2.37, 95% CI: 1.01-5.56), and who were health practitioner (OR: 2.53, 95% CI: 1.34-4.79). The adjusted odds ratio of having good knowledge was 2.6 times higher among those with bachelor degree and above than

those with high school or below (p = 0.030). Moreover, who were health practitioners had 2.5 times more likely to have good knowledge than who did not (p = 0.005).

Discussion

ET is considered as one of the most common movement disorders and a prevailing reason for frequent neurological consultation [1,2]. The prevalence of ETs in the literature, to date, has shown variable results; thus, it is not precisely known [3]. Moreover, ET knowledge among the population reported in the literature was low [4,5]. To the authors' knowledge, public awareness of ET has not been previously studied in Saudi Arabia. Hence, this is the first study focused on assessing the knowledge toward ET in different regions of Saudi Arabia. Our study's demonstrated that 96% of the population had poor knowledge about ET. Moreover, nearly 69% of the population had never even heard of ET. In comparison to another highly prevalent neurological condition, surveys about epilepsy indicate that more than 90% of respondents are aware of such a condition [23].

In the literature, few studies assessing ET patients and/or their families have been published. At Yale New Haven Hospital, a questionnaire was disseminated to more than 200 patients at different outpatient clinics found that knowledge towards ET was low contributing to 10%-15%

	Frequency	%	
Age			
≤32	871	59	
>32	600	41	
Gender			
Male	772	52	
Female	699	48	
Education level			
≤ High school	300	20	
Bachelor	1,077	73	
Postgraduate	94	7	
Are you a health practitioner?			
Yes	152	10	
No	1,319	90	
Do you have ETs?			
Yes	19	1	
No	1,452	99	
Regions			
Center	614	42	
East	227	15	
West	369	25	
North	176	12	
South	85	6	

Table 1. Characteristics of the study participants (number = 1,471).

 Table 2. Frequency distribution of knowledge regarding tremors among studied participants.

Items	Frequency	%
Have you ever heard or read about "essential tremor" (known as "benign tremor," "kinetic tremor," or "familial tremor")?		
Yes	461	31
Incorrect/don't know	1,010	69
What is the main symptom of ET?		
Shaky hands	592	40
Incorrect/don't know	447	60
What parts of the body can shake when someone has ET?		
Arms (with or without other)	441	30
Incorrect/don't know	1,030	70
Is ET the same as or different than PD?		
Different	211	14
Incorrect/don't know	1,260	86
Is ET the same as or different than the type of tremor that people can get when they become old and frail?		
Different	368	25
Incorrect/don't know	1,103	75
What is the typical age of onset of ET?		
21-30	55	4
Incorrect/don't know	1,416	96
Can children get ET?		
No	143	10
Incorrect/don't know	1,328	90
What do you think causes ET?		
Genes/unknown cause	515	35
Incorrect/don't know	956	65
What types of doctors generally take care of a patient with ET?		
Neurologist	557	38
Incorrect/don't know	914	62
Could diet and exercise prevent or help control ET?		
No	110	7
Incorrect/don't know	1,361	93
Do you think the symptoms of ET can be medically controlled?		
Yes, but not well	180	12
Incorrect/don't know	1,291	88
Is there some type of brain surgery to treat ET?		
Yes	133	9
Incorrect/don't know	1,338	91
Do you think ET is a curable disease?		
No	174	12
Incorrect/don't know	1,297	88
What do you think is the average memory/thinking deficit of a patient with ET?		
Mild problem	137	9
Incorrect/don't know	1,334	91
Do you think people with ET die at a younger age than those who do not?		
No	408	28
Incorrect/don't know	1,063	7

Sociodemographic characteristics	Knowledge level					
	Good <i>N</i> (%) 60 (4)	Poor <i>N</i> (%) 1,411 (96)	OR (95% CI)	<i>p</i> value	AOR (95% CI)	p value
Age group (years)						
>32	24 (4)	576 (96)	0.97 (0.57-1.64)	0.899	1.11 (0.64-1.91)	0.717
≤32	36 (4)	835 (96)				
Gender						
Male	39 (5)	733 (95)	1.72 (1-2.95)	0.05	1.68 (0.97-2.91)	0.063
Female	21 (3)	678 (97)				
Education level						
Bachelor≤	54 (5)	1,117 (95)	2.37 (1.01-5.56)	0.048	2.59 (1.09-6.10)	0.030
≤ High school	6 (2)	294 (98)				
Are you a health practitioner?						
Yes	13 (9)	139 (91)	2.53 (1.34-4.79)	0.004	2.57 (1.33-4.97)	0.005
No	47 (4)	1,272 (96)				

Table 3. Unadjusted and adjusted association between sociodemographic characteristics of the participants and good level of knowledge regarding tremors.

of the study sample [4]. Another study done by Cristal et al. [19] in New Haven, USA, found that overall, ET patients lacked knowledge about their disease as around one third of the patients with ET and their families knew only basic ET information and its features. Nevertheless, when the questionnaire progressed to more profound questions assessing the knowledge of, for example, nonmotor symptoms and prognosis, the participants were poorly knowledgeable, which was surprising given the fact that this was a family study of ET. In our survey, we found that even among the population who had heard of ET, more than half (60%) could not identify its main symptom, 86% could not distinguish ET from PD, 75% thought that ET was different from the type of tremor that people can get when they become old or frail.

Our results indicate that the population lacks knowledge of ET's clinical features and differentiation from PD. As people did not consider ET to be the same tremor that ordinary people could acquire when they become old, to some extent, they could differentiate ET from an age-related tremor. Comparing our results to the findings of Shalaby et al. [4] and Cristal et al. [19] to the question "Is ET the same as or different than Parkinson's disease?", nearly two-thirds (~70%) of Shalaby's et al. [4] participants and nearly four-fifths (~82%) of Cristal et al.'s [19] stated that ET and PD were different. In contrast, in our study, only about one-fifth (14%) of the surveyed population answered that ET was different from PD. Furthermore, when the question "What parts of the body can shake when someone has ET?" was asked, 38 participants of the study conducted in New Haven [19] identified the arms as the body part affected in ET, and 66 participants in the Yale's study [4] research identified the arms. On the other hand, our study showed that nearly one-third (30%) of the population identified the arms (with or without other structural involvement) as the body part affected by ET. Concerning the comparison of previous studies to ours, it is essential to note that the present study's participants were from the general population, which was a different target group i.e., Shalaby's et al. [4] questionnaire was filled by patients visiting different outpatient clinics while Cristal et al.'s [19] was from a family study. Additionally, the questionnaire we used in our study was not the same as those used by the two aforementioned studies. These factors, different target groups, and questionnaires may explain the variability of results among the three studies.

Risk factors and management, when comparing this latter result to an older study, it should be pointed out that in Cristal et al. [19], nearly one in three participants could not distinguish the disease from an age-related tremor. Approximately 1/3 (35%) stated that genes and unknown causes initiate ET and nearly 1 in 9 (10%) stated that children could not get ET. Nearly one in five only knew that ET could be controlled medically but not well and only 9% knew of therapeutic brain surgery. Hence, both the lack of knowledge and presence of misconceptions were quite common.

This could be due to inadequate education to the public about ET and its treatment options. ET patients themselves are not exempt either; in previous studies, for instance, a survey of nearly 1,400 ET patients showed that about 1/3 of participants thought the deficiency in their knowledge was mostly because their doctors were not moderately well-educated about ET [5]. At Columbia Presbyterian Medical center, they handed out a brief questionnaire to assess the knowledge of ET genetics to 50 patients. The results showed that most of these patients were also not well informed, as it showed only 24% thought ET is a hereditary disease, 26% answered it's due to anxiety, 14% thought it's due to nerve damage, and 18% answered "don't know." Among the 27 patients who had family history, only 25.9% of them answered it was hereditary. When asked "is it genetics?" 52% answered "yes." From the 50 patients, 46% didn't know the age that their relatives would be safe from developing the disease. The majority of the patients (70%) knew about propranolol and primidone being as medications for ET [20]. A similar conclusion was also reached by another study done at a tertiary care center in Singapore where 6.3% and 12.9% reported that the cause of ET is hereditary while most of them (70%) didn't know the cause. When asked if they thought it was genetics, only 18.9% answered yes, while 55% didn't know. Their results showed that ET patients and their families had poor knowledge of ET genetics [24]. The authors attributed the findings of their research, to some extent, to the possibility that doctors might not have given proper education to their ET patients because they might have viewed ET as a benign condition of less urgency [24].

Physicians and other healthcare providers and foundations should put in the extra effort to improve the publics' knowledge through educational programs and awareness campaigns. Possession of such awareness of ET would be invaluable, especially to ET patients.

Even though researchers work diligently to ascertain and publish such large contributions concerning ET, the information does not necessarily get passed down to patients and/or their families. However, none of these studies has administered a questionnaire to assess ET knowledge in the general population.

Our study demonstrate that educational level and being a health practitioner are associated with greater awareness and knowledge of ET. Contrary to Shalaby et al. [4], where they found that the gender (females) were associated with greater awareness. Among participants with a bachelor's degree or higher, 1,117/1,171 (95%) had poor knowledge of ET. Given the lack of public knowledge regarding ET, potential strategies to adequately educate the public and improve ET understanding should be considered. Nevertheless, even among participants in health-related occupations, 139/152 (91%) had poor ET knowledge. We considered that some of the factors that might have led to the lack of knowledge concerning ET are that the disease may not be very disabling and, thus, people are less likely to know of this disease that plays no part in their lives. Additionally, ET has received minimal attention via social media and other public awareness programs, unlike similar diseases, namely, epilepsy and PD.

Our study should be interpreted within the context of several limitations. In our questionnaire, some of the questions contained complicated terms and topics for the general public, which may have impaired the participants' ability to illustrate their existing knowledge. Furthermore, more focused questions should have been asked to participants who had a "good knowledge level," relating

their source of information about ET, which might guide a future increase in the awareness and knowledge of ET in the population. Although the sample size was adequate for the evaluation (n = 1.471), variations between the region's population number was not respected, accordingly the sample is not representative, and therefore, the findings may not be generalized to the population of Saudi Arabia. Furthermore, online survey might provide less accurate responses out of the selection criteria or double answers from the same participant. Additionally, cross-sectional studies provide a limited amount of strong evidence. Although, selection bias could be a threat for this study, however this is the first study, to the authors' knowledge, where the sample population included different regions of Saudi Arabia. Consequently, this study contributes to the current understanding of the literature by measuring the knowledge in terms of ET's among the Saudi Arabian population.

Conclusion

The study revealed that knowledge about ET within the Saudi Arabia population is poor, which indicates the need for educational programs to improve the awareness of such disorder. Thus, condensed health education programs/campaigns regarding ET for the public via various channels are essential for disseminating transparent information for the early detection and proper management of this disease. Further studies are recommended to clarify the barriers beyond suboptimal knowledge.

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List of Abbreviations

- ET Essential tremor
- PD Parkinson's disease

Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

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Consent to particpate

Written informed consent was obtained from all the participants.

Ethical approval

The study protocol was approved by the Regional Ethical Committee in Qassim on June 23, 2020 (Reference No. 1444-1945130), and conducted in accordance with the ethical principles for medical research involving human subjects as described in the Declaration of Helsinki. Informed consent was obtained from all participants in this study.

Authors' contribution

N.A., and R.A. contribution to conception, design, involvement in drafting the manuscript, and revising the

manuscript critically. Y.A, T.A., A.M., A.D., acquisition of the data, and formal analysis. The authors approved the final manuscript.

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