



Knowledge and Awareness of Tourette's Syndrome among the General Population in Saudi Arabia

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Authors' contributions

This work was carried out in collaboration among all authors. All authors read and approved the final manuscript.

Article Information

Editor(s):

(1) Dr. Stefka Mantarova, Military Medical Academy, Bulgaria.

Reviewers:

(1) Susanne Buechner, General Hospital of Bolzano, Italy.

(2) Hakan AK, Yozgat Bozok Univeristy, Turkey.

Complete Peer review History: <http://www.sdiarticle4.com/review-history/66549>

Original Research Article

Received 18 February 2021

Accepted 19 March 2021

Published 24 March 2021

ABSTRACT

Background: Tourette's syndrome (TS) is one of the most complicated disorders in case history and its discovery. It is a childhood-onset regulated neurobehavioral disorder characterized by multiple motor tics plus one or more phonic vocalizations tics. The management of TS requires appropriate education and support.

The Aim: The present study built the interest to assess the knowledge and awareness of definition, causes, symptoms, diagnosis, complication, and treatment of Tourette's syndrome (TS) in different regions in Saudi society and try to improve the false thoughts about this disease.

Material: A cross-sectional survey was distributed throughout the regions in *Saudi Arabia*, by the help of 27 data collectors, between October 2020 to January 2021. An online questionnaire was designed. It included informed consent and 11 questions about the sociodemographic data and questions regarding signs, symptoms, complications, and management about TS. It was distributed via various social media apps.

Methods: SPSS for Windows v22.0 IBM Inc..SPSS for windows Rel 15.0 2006 Chicago Inc.

Results: A total of 5526 adult participated in the present study. 70.7% where females and 29.3% males. More than half of them 75.3% in age group 20-29 in about 81.6% have university degree or

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above. 63.5% of the respondents heard about TS and 58% correctly defend the syndrome as disorder involve uncontrolled repetitive movement or unwanted sounds.

Conclusion: The present study found that majority of the respondents were aware of Tourette's Syndrome in KSA, but they had poor knowledge about the Tourette's Syndrome.

Keywords: Tourette's syndrome; Saudi Arabia; neurobehavioral disorder; motor tics; vocalizations tics.

1. INTRODUCTION

One of neuropsychiatric disorders is Tourette's syndrome (TS). It is one of the most complicated disorders as regard history and discovery. So going back where the history of (TS), French neurologist Gilles de la Tourette was the first to discover TS. The first point of discovering (TS) was when Gilles interested in 'jumping Frenchmen of Maine' which's unusual condition ranged of obscure culture-bound startle syndromes. This guided Gilles to search of a similar phenotype in Paris which resulted in clinical series in 1885, describing tics echolalia and obsessional. For about 90 years (TS) was recorded as bizarre footnote in psychiatric textbooks. It was discovered in New York in 1970s [1].

Tourette's syndrome is a childhood-onset regulated neurobehavioral disorder characterized by multiple motor tics plus one or more phonic vocalizations tics. Tics are involuntary, stereotyped, repetitive movements. They are brief twitch-like movements of varying degrees of complexity, purposefulness and amplitude. They can be almost continuous but sometimes are light. In some people, they started milder than usual, then do become more noticeable as the time progressed. Occasionally a single examination cannot confirm a credible history of tics. All published descriptions used the phrase 'wax and wane', and most patients described some weeks or months as being more or less severe for no special reason. They were also generally aware of new tics appearing and old ones disappearing over time, and of having orchestrated sequences of certain tics. Some tics have a compulsive quality and merge into other obsessional symptoms. Tics can come in florid bouts, something the patient community refer to as 'tic attacks' or 'tic fits' [1].

In a previous study the prevalence rate of Tourette's syndrome in Canada in 2016" was 0.3-0.7% [2]. The symptoms were simple or complex motor and vocal tics. Eye blinking,

shoulder shrugging and head jerking were examples of simple motor tics. Whereas, repeating observed movements, bending, or twisting and stepping in a certain pattern were complex motor tics. The simple vocal tics were throat clearing, grunting, and barking. Complex vocal tics were repeating one's own words or phrases, using vulgar, obscene or swear words and repeating others' words or phrases [3]. Tourette's syndrome is accompanied frequently by deficit hyperactivity disorder, or anxiety disorders. Also, (TS) patients show obsessive compulsive, which may lead to more distress and disability than tics [4]. The management of TS requires appropriate education and support. The tics can be treated with habit reversal cognitive behavioral therapy, medications (most commonly alpha agonists and antipsychotics), local intramuscular injections of Botulinum toxin and some severe, refractory cases have responded to deep brain stimulation surgery (DBS) [5].

TS is a persistent condition although usually bothers adults less than children, perhaps through a combination of tics improving with age and coping strategies. Thus its peak severity is on average of 13 years, while some people develop tics for the first time later than that. There are relatively few prospective data as there are no lifelong studies. Patients attending adult clinics are numerous but represent biased samples that are less typical. It is hard to deduce distant memories of childhood symptoms, so hearing from family members is precious [6,1].

The present study aimed to measure the extent of community awareness of Tourette's Syndrome and spread awareness in the regions of Saudi Arabia in order to better understand the needs of a patient with this syndrome, diagnosis, treatment and to gain support from the community. Moreover, To increase the knowledge and awareness about Tourette's Syndrome in the population of KSA, whether Saudi or non- Saudi, by letting them search and think more about it. Thus changing what they think of false beliefs about this syndrome.

2. MATERIALS AND METHODS

2.1 Material

A cross-sectional survey were distributed randomly throughout the regions in Saudi Arabia by the help of 27 data collectors, between October 2020 to January 2021. 5526 adult male and female participants of Saudi Arabia population above 20 years old, lived in five regions of KSA were the material of the present study .The five regions were: Eastern, Western, Central, Northern, southern.

The participants were asked to answer a previously designed electronic self-administered questionnaire. It included informed consent and 11 questions about the sociodemographic data and questions regarding signs, symptoms, complications and management regarding TS. It was distributed via various social media apps .Ethical informed consent was taken before from each participant.

2.2 Statistical Analysis

2.2.1 Data analysis

After data were extracted, it was revised, coded and fed to statistical software IBM SPSS version 22 (SPSS, Inc. Chicago, IL) [R]. All statistical analysis was done using two tailed tests. P value less than 0.05 was considered to be statistically significant. For knowledge regarding Tourette's syndrome, each correct answer was scored one point and total summation of the discrete scores of the different items was calculated. A patient with score less than 60% (13 points) of the maximum score was considered to have poor awareness while good awareness was considered if he had score of 60% (14 points or more) of the maximum or more. Descriptive analysis based on frequency and percent distribution was done for all variables including demographic data, and knowledge items. Cross tabulation was used to assess distribution of participants knowledge regarding Tourette's syndrome according to their personal data. Relations were tested using Pearson chi-square test (P value <0.5, considered significant).

3. RESULTS

3.1 Demographic Results

A total of 5502 out of 5526 Participants completed the study questionnaire whose ages

ranged from 20 to 57 years with mean age of 29.6 ± 11.8 years old. Exact of 27.4% were from Western region, 27.3% were from North region, 20% from central region, 13.6% from eastern region, and 11.6% from southern region. Majority of the respondents were females (70.7%) and Saudi (96.8%). As for education, 81.6% of respondents were university graduated. Exact of 53.8% of the study participants were single Table 1.

Table 1. Socio-demographic data of study participants, Saudi Arabia

| Socio-demographic data | No | % |
|------------------------|------|-------|
| Region | | |
| Central region | 1103 | 20.0% |
| North region | 1502 | 27.3% |
| Eastern region | 749 | 13.6% |
| Western region | 1508 | 27.4% |
| Southern region | 640 | 11.6% |
| Age in years | | |
| 20-29 | 3150 | 57.3% |
| 30-39 | 940 | 17.1% |
| 40-49 | 1038 | 18.9% |
| 50+ | 374 | 6.8% |
| Gender | | |
| Male | 1613 | 29.3% |
| Female | 3889 | 70.7% |
| Nationality | | |
| Saudi | 5156 | 96.8% |
| Non-Saudi | 171 | 3.2% |
| Educational level | | |
| Below secondary | 38 | .7% |
| Secondary | 976 | 17.7% |
| University / above | 4488 | 81.6% |
| Marital status | | |
| Single | 2959 | 53.8% |
| Married | 2543 | 46.2% |

3.2 Awareness Results

Table 2 illustrated public knowledge regarding Tourette's syndrome. Exact of 36.5% of the respondents heard about Tourette's syndrome and 58% correctly defined the syndrome as disorder that involves uncontrolled repetitive movements or unwanted sounds. The most reported symptoms and motor signs that appear on the person with this syndrome. by participants were head jerking, shoulder shrugging (53.3%) followed by Eye blinking, eye darting (36.3%), and nose twitching, mouth movements (22.3%). Considering signs of movement that appear on Tourette's syndrome, touching objects, repeating observed movements was known among 31% of the participants, followed by bending, obscene

signs (27.8%), and Stepping in a certain pattern, hopping (20%) while 30.7% incorrectly reported for stumbling. As for vocal signs and symptoms for Tourette's syndrome, 36% of the participants selected use obscene words, 29% reported grunting & coughing, and throat cleaning & barking was reported by 22.9% of the respondents. Exact of 22.9% of the study participants knew that the cause of Tourette's syndrome is unknown while family history & gender were reported as its risk factors by 26.8% of the participants. The most known complications of Tourette's syndrome by the participants were hyperactivity disorders (49.1%), obsessive compulsive disorder (49.1%), anxiety (49.1%), and depression (34%). About treatment methods of Tourette's syndrome, anti-seizure medications were reported by 18.6% of the participants, followed by electromagnetic medications (15.4%), and antipsychotic medications (12.7%). Medical history with the clinical examination methods for diagnosis of Tourette's syndrome were reported by 91.6% of the study participants. Psychotherapy as another effective treatment methods for the syndrome was reported by 35% of the participants followed by behavioral therapy (34.6%), and deep brain stimulation (33.7%). Totally, 19% of the study participants had good knowledge level regarding Tourette's syndrome (Fig. 1).

Table 3. showed distribution of participants' knowledge regarding Tourette's syndrome by their demographic data. Good knowledge was detected among 22.3% of participants at southern region followed by those at Eastern region (21.1%), Western region (21%) compared to 14.6% of those at North region with reported statistical significance ($P=0.001$). Exact of 23.7% of participants aged 20-29 years had good knowledge level regarding Tourette's syndrome compared to 14.4% of those aged 50 years or more ($P=0.001$). Also, 20.6% of female participants had good knowledge level in comparison to 15.4% of males ($P=0.001$). About 20% of university graduated participants had good knowledge regarding Tourette's syndrome compared to 15.8% of those with secondary education level ($P=0.041$). Good knowledge was also detected among 24.1% of single participants in comparison to 13.3% of married group ($P=0.001$).

4. DISCUSSION

The present study included a total of 5502 participants from all regions of Saudi Arabia, 20.0 % were from the central region, almost (27.3 %) and (27.4%) were from north and western region respectively, while only 13.6% and 11.6% were from eastern and southern region.

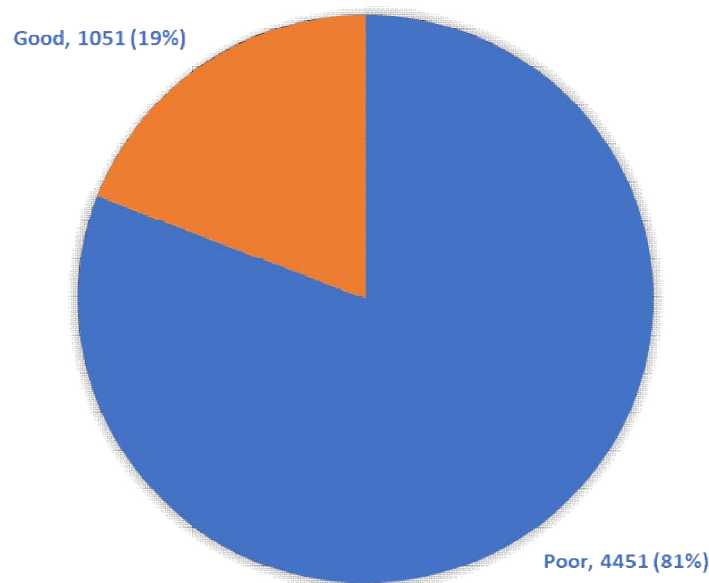


Fig. 1. Overall public knowledge level regarding Tourette's syndrome, Saudi Arabia

Table 2. Public knowledge regarding Tourette's syndrome, Saudi Arabia

| Knowledge items | | No | % |
|---|--|-----------|----------|
| Heard about Tourette's syndrome or saw a person infected with | Yes | 2010 | 36.5% |
| | No | 3492 | 63.5% |
| You think that Tourette's syndrome is | Disorder that involves uncontrolled repetitive movements or unwanted sounds | 3189 | 58.0% |
| | Increased electrical charges in the body due to the frequent use of electronic devices | 538 | 9.8% |
| | Cultural beliefs | 34 | .6% |
| | Don't know | 1741 | 31.6% |
| Symptoms / motor signs that appear on the person with this syndrome | Head jerking, shoulder shrugging | 3040 | 55.3% |
| | Eye blinking, eye darting | 1997 | 36.3% |
| | Nose twitching, mouth movements | 1229 | 22.3% |
| | Don't know | 1921 | 34.9% |
| Signs of movement that appear on Tourette's syndrome | Touching objects, repeating observed movements | 1707 | 31.0% |
| | Stepping in a certain pattern, hopping | 1099 | 20.0% |
| | Bending, obscene signs | 1530 | 27.8% |
| | Stumbling | 1691 | 30.7% |
| | Don't know | 2529 | 46.0% |
| Vocal signs and symptoms for Tourette's syndrome | Grunting & coughing | 1594 | 29.0% |
| | Throat cleaning & barking | 1258 | 22.9% |
| | Use obscene words | 1982 | 36.0% |
| | Vocal cord atrophy | 809 | 14.7% |
| | Don't know | 2544 | 46.2% |
| Cause of Tourette's syndrome | Autoimmune causes | 284 | 5.2% |
| | Unknown causes | 1262 | 22.9% |
| | Inherited (Genetic) causes | 1621 | 29.5% |
| | Don't know | 2335 | 42.4% |
| Risk factors that increase the chance of Tourette's syndrome | Social issues | 525 | 9.5% |
| | Frequent use of devices | 948 | 17.2% |
| | Family history & gender | 1474 | 26.8% |
| | Don't know | 2555 | 46.4% |
| Complications of Tourette's syndrome | Immune disturbance | 826 | 15.0% |
| | Hyperactivity Disorders | 2699 | 49.1% |
| | Obsessive compulsive disorder | 2699 | 49.1% |

| Knowledge items | | No | % |
|--|---|------|-------|
| Treatment methods of Tourette's syndrome | Anxiety | 2699 | 49.1% |
| | Depression | 1870 | 34.0% |
| | Loss of social relationships | 1838 | 33.4% |
| | Don't know | 2014 | 36.6% |
| | Anti-seizure medications | 1025 | 18.6% |
| Methods for diagnosis of Tourette's syndrome | Antipsychotic medications | 698 | 12.7% |
| | Electromagnetic medications | 846 | 15.4% |
| | Heart medications | 46 | .8% |
| | Don't know | 2887 | 52.5% |
| | Medical history with the clinical examination | 1303 | 91.6% |
| | Magnetic resonance imaging | 1229 | 86.4% |
| | Ophthalmoscope | 243 | 17.1% |
| Other effective treatment of Tourette's syndrome | Otoscope | 152 | 10.7% |
| | Don't know | 40 | 2.8% |
| | Behavioral therapy | 1904 | 34.6% |
| | Psychotherapy | 1928 | 35.0% |
| | Deep brain stimulation | 1854 | 33.7% |
| | Exercise | 1160 | 21.1% |
| | Don't know | 2150 | 39.1% |

Table 3. Distribution of participants' knowledge regarding Tourette's syndrome by their demographic data

| Factors | Knowledge level | | | | P-value |
|--------------------|-----------------|-------|------|-------|---------|
| | Poor | | Good | | |
| | No | % | No | % | |
| Region | | | | | .001* |
| Central region | 888 | 80.5% | 215 | 19.5% | |
| North region | 1283 | 85.4% | 219 | 14.6% | |
| Eastern region | 591 | 78.9% | 158 | 21.1% | |
| Western region | 1192 | 79.0% | 316 | 21.0% | |
| Southern region | 497 | 77.7% | 143 | 22.3% | |
| Age in years | | | | | .001* |
| 20-29 | 2405 | 76.3% | 745 | 23.7% | |
| 30-39 | 825 | 87.8% | 115 | 12.2% | |
| 40-49 | 901 | 86.8% | 137 | 13.2% | |
| 50+ | 320 | 85.6% | 54 | 14.4% | |
| Gender | | | | | .001* |
| Male | 1365 | 84.6% | 248 | 15.4% | |
| Female | 3086 | 79.4% | 803 | 20.6% | |
| Educational level | | | | | .014* |
| Below secondary | 31 | 81.6% | 7 | 18.4% | |
| Secondary | 822 | 84.2% | 154 | 15.8% | |
| University / above | 3598 | 80.2% | 890 | 19.8% | |
| Marital status | | | | | .001* |
| Single | 2246 | 75.9% | 713 | 24.1% | |
| Married | 2205 | 86.7% | 338 | 13.3% | |

*P: Pearson X2 test, * P < 0.05 (significant)*

The present work, showed distribution of participants' knowledge regarding Tourette's syndrome by their demographic data. Good knowledge was detected among 22.3% of participants at southern region followed by those at Eastern region (21.1%), Western region (21%) compared to only 14.6% of those at North region with reported statistical significance ($P=.001$) (Table 3). This might be due to higher level of education. They are more urban areas than other regions. More population are there since the climate is better. Moreover; there might be more activities of health awareness campaigns about TS in Eastern and Western regions. In the present study, the majority of participants' age groups were (57.3%) between 20-29 years of age, while, (17.1%) were between 30-39 years of age, and (18.9%) were between 40-49 and only 6.8% were above 50. Female responders were higher (70.7%) than males (29.3%). Most of the participants (81.6%) had a University or above education, (17.7%) had secondary education, and (0.7%) had less than secondary education. Socially (46.2%) were married, and (53.8%) were single, (96.8 %) of them were Saudi.

In the present study the public showed a poor level of knowledge regarding Tourette's syndrome with more than 80%. The north region showed the lowest level of knowledge (85.4 %), females participants had more knowledge (23.7%) than man. the age group from 20-29 also had a highest level of knowledge 23.7%, which reflected the higher informative awareness in younger people. This might be due to their higher use and efficiency of get benefits of social media.

Surprisingly, the participants who had high university education or above had the poorest level of knowledge despite it was lower than who had secondary education (84.2 %) or less (81.6%). This result clarified the importance of engaging more topic, studies and material about Tourette's syndrome in the curriculums.

The majority of the participants (63.5%) didn't hear about Tourette's syndrome which reflected low knowledge about the syndrome. however, 58.0% thought that "Tourette's syndrome is disorder that involves uncontrolled repetitive movements or unwanted sounds" and (9.8%) defined it as "Increased electrical charges in the body due to the frequent use of electronic devices" and only (0.6%) believed it's a Cultural belief and (31.6%) didn't know. Stern, 2018 mentioned the definition of TS.[1]

Furthermore, regarding the knowledge about the signs of movement that appear on Tourette's syndrome (46.0%) didn't know which gave more about the low knowledge about Tourette's syndrome with (31.0%) chose touching objects, repeating observed movements (30.7%) thought it's stumbling and (27.8%) selected bending, obscure signs.

The level of the vocal signs and symptoms for Tourette's syndrome Knowledge was also low with vice majority (46.2%) didn't know."Use obscene words "was chosen by (36.0%), while (29.0%) thought it's "Grunting & coughing "then, "throat cleaning & barking" (22.9%) and "vocal cord atrophy (14.7%). Clinical features of TS were reported by Ganos, 2015 [3].

As regards the causes of TS in the present work, only (5.2%) believed the cause of Tourette's syndrome is autoimmune, (22.9%) chose unknown causes, (29.5%) selected inherited (Genetic) causes, while, (42.4%) didn't know.

Furthermore, (46.4%) didn't know the risk factors that increase the chance of Tourette's syndrome.(26.8%) thought it's Family history & gender , (17.2%) believed that frequent use of devices increased the risk and (9.5%) thought it's social issues. The risk factors were reported by Hirschtritt, et al. [4] and Stem [1].

In the present research (49.1%) of the participants thought that one of Complications of Tourette's syndrome is OCD or anxiety or hyperactivity disorders 33.4% chose Loss of social relationships (36.6%) didn't know. A previous study done on school children in USA, reported that Tourette was related to having difficulty in education. Children with severe Tourette symptoms were also more likely to experience these problems compared to children with milder symptoms. This is important information for healthcare providers, teachers and parents. Being aware of the potential challenges related to both Tourette syndrome and other conditions can help them to best support the child's education [7].

As for methods of diagnosis of TS in the present work, (91.6%) of participants considered medical history with the clinical examination was a valid methods for diagnosis of Tourette's syndrome, (86.4%) chose MRI and (17.1%) chose Ophthalmoscope, (10.7%) thought it's Otoscope and only (2.8%) didn't know. TS symptoms are not always well recognized, so some people with TS do not get diagnosed early enough to receive

the right kind of treatment. It was found that only half of children with TS have a diagnosis [7].

As regards knowledge of treatment of TS in the present study, 18.6% of the participant thought that Tourette's syndrome can be treated by anti-seizure medications and (12.7%) chose electromagnetic medications, while only (0.8%) selected heart medications and (52.5%) didn't know.

However, (35.0%) and (34.6%) thought that Psychotherapy and behavioral therapy was one of the other effective treatment of Tourette's syndrome, Deep brain stimulation was the choice of (33.7%) and (21.1%) was exercise, while, 39.1% didn't know. Lines of treatment were stated by Kurlan [5], Mason et al. [8], CDC [9] and Polyanska et al. [10]. Psychotherapy was applied on uninsured children from some households, and assessed their parents' awareness to follow after-school experiences [11,12]. A public health approach for TS and tic disorders seeks answers to these questions and helps develop and evaluate strategies to improve the health and well-being of people with TS [7,11].

5. CONCLUSION

Tourette's syndrome was one of the most underrated topics in Saudi population despite it increasing in the incidence rate in the last few years. Tourette was related to having difficulty in school and needing educational services. The population attitudes and beliefs towards these patients can highly influence the patient thoughts and how they deal with it. The present study found that majority of the respondents were aware of Tourette's Syndrome in KSA, but they had poor knowledge about the Tourette's Syndrome. They showed highly negative attitudes towards the nature of the disease and its progress, diagnosis and management Health education for public, online seminars and more research are needed to raise the public awareness and spotlight to patients suffering from this syndrome.

CONSENT

Ethical informed consent was taken before from each participant.

ETHICAL APPROVAL

An ethical approval for this study was obtained from ethical committee of the University of Hail.

All measures included in the current study comply with ethical standards of the 1964 Helsinki declaration, as well as its related subsequent modifications. Ethical approval number: 20455\5\42 dated 16\4\1442 H.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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Peer-review history:
The peer review history for this paper can be accessed here:
<http://www.sdiarticle4.com/review-history/66549>