

AWARENESS OF TOURETTE'S SYNDROME AMONG HEALTHCARE WORKERS IN KARACHI.

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Abstract

Background

It is a developmental disorder that develops in childhood and adolescence age to a variety of repeated movements and vocal sounds. These repeated and fast movements are called tics. Almost 90 percent of patients with Tourette's syndrome may suffer from one other mental health issue and they face many disabilities and stress were seen in these patients. The prevalence ratio showed that around 1 percent was found in young people aged from 5 to 18 years old. Mostly boys are more prone to this disorder as compared to girls.

Objective

To determine the awareness of Tourette syndrome among healthcare workers in Karachi.

Methodology

A cross-sectional study was done from June to November 2024, the population of the study was healthcare workers from seven districts of Karachi and the sample size was 384, the non-probability purposive sampling technique was used. The validated questionnaire was used to evaluate the perception of healthcare workers regarding Tourette syndrome. The data was analyzed through SPSS version 23.0.

Result

There were 384 healthcare workers recruited from seven districts of Karachi. The knowledge of Tourette syndrome was found in 65.36%, the exposure of healthcare workers with the diseased person was found in 17.44%, the awareness of the cause of the disease was found in 68.48%, The question related to the role of physical therapy in Tourette syndrome 13.28% of healthcare workers replied yes.

Conclusion

Our study concluded the level of awareness regarding the Tourette syndrome was proved to be higher but the exposure of the disease was minimal among healthcare workers of our study.

Keywords: Situational awareness, Tourette syndrome, Healthcare system, Healthcare workers, Tic disorders.

Introduction

It is a disorder that is related to a neurological condition that causes undesirable changes or unwanted movements performed by the individual repeatedly and rapidly. This condition is known as Tourette’s syndrome(TS). [1] The cause of this syndrome was unknown. It is a developmental disorder that develops in childhood and adolescence age to a variety of repeated movements and vocal sounds. These repeated and fast movements are called tics. [2] Tics can affect children by around 0.52 to 0.77 percent and in adults, it affects around 0.05 percent. Tics may be classified as simple and complex tics.[3] In simple tics, the movement is sudden and repeatedly which involves an insufficient number of muscle groups, and in complex the coordinated movements are involved by different groups of muscles.[4] Almost 90 percent of patients with Tourette’s syndrome may suffer from one other mental health issue and they face many disabilities and stress were seen in these patients.[5] The prevalence ratio showed that around 1 percent was found in young people aged from 5 to 18 years old.[6] Mostly boys are more prone to this disorder as compared to girls. They have less quality of life than healthy individuals. Those patients who suffer from this disorder need medical attention and healthcare services like medications, rehabilitation, behavioral therapy, nursing care, and education. [7]

The first survey was held in the U.S. in 2007 the National Survey of Children’s Health, reported that 0.3 percent of children aged 6-17 years old were found with Tourette’s syndrome. [8] The signs and symptoms of this disorder were mild to moderate and in most cases, the symptoms were mild to severe. [9] Most of the children can suffer from tics movement as well as co-morbid like asthma. It requires the major attention of healthcare professionals that they can manage these types of individuals with their expertise. They need to treat the conditions and their co-morbid which can impact their life on daily activities and enhance their symptoms.[10]

Healthcare professionals can participate in managing this disorder by their skills. In this disorder, pharmacological treatment plays an important role in managing the disorder to control the symptoms, tics, and psychological impairments. Through medicines, patients can reduce or control their symptoms of depression in Tourette's syndrome.[11] The quality of life and physical activity of these patients was disturbed they also required rehabilitation programs or exercises to overcome their faults and issues related to their functions. Rehabilitation programs help the individual to modify, recreational activities, and re-educate the person regarding their needs.[12] Nutritionists can also play an important role in managing the syndrome. Like in children, many supplements and multivitamins can help to enhance their physical health, treat nutritional deficiencies, also treat allergies.[13] On the other hand, nursing care is also helpful in guiding the patients and their family members to educate them regarding their coping mechanisms to decrease the effect of this syndrome.[14] The aim of the study that to find out the awareness of healthcare professionals regarding Tourette’s syndrome because they know about the condition then they will treat and diagnose the patient easily.

METHODOLOGY

A cross-sectional survey was conducted among the healthcare workers from seven districts (Malir, south, west, east, central, north, and Korangi) of Karachi from May to November 2024. Data was collected from a sample size of 384. The sample size was calculated through Raosoft.com software according to the healthcare workers of Karachi. The non-probability purposive sampling was used to select the research participants. The inclusion criteria were both male and female genders, healthcare workers like physicians, physical therapists, Nurses, and Dieticians who are working in hospitals of Karachi, age group between 20 to 55 years, working experience of 1 year to 30 years. Healthcare workers who were working in an academic environment and were not willing to participate were excluded from the research. The validated questionnaire was used which was previously used in the research done in 2013 in which demographic

data of research participants and questions related to the perception of among the research participants regarding the Tourette syndrome are present. [15] The analysis of data was done through SPSS version 23.0 software.

RESULT

A total 384 number of healthcare workers were recruited from seven districts of Karachi. The demographic information of the research participants including age, gender, professions, working area, and working experience is shown in Table No.1:

Table: 1 Demographic Characteristics of Healthcare Professionals

Variables	Frequency (%)
<u>AGE</u>	
20-30	123 (32.03%)
31-40	116 (30.20%)
41-50	104 (27.08%)
>50	41 (10.67%)
<u>GENDER</u>	
Female	183 (47.65%)
Male	201 (52.34%)
<u>HEALTHCARE PROFESSIONALS</u>	
Physicians	106 (27.60%)
Physical Therapists	121 (31.51%)
Nurses	91 (23.69%)
Dietician	66 (17.18%)
<u>CURRENT WORKING EXPERIENCE</u>	
	123 (32.03%)
1-2 years	127 (33.07%)
3-4 years	134 (34.89%)
>5 years	
<u>WORKING AREA</u>	
IPD	112 (29.16%)
OPD	97 (25.26%)
Rehabilitation center’s	123 (32.03%)
Old age home	52 (13.54%)

When we asked questions regarding the knowledge about the Tourette’s syndrome about 65.36% said yes and 34.63% said no about the disease.

When we asked the healthcare workers about what they faced with this condition, they replied 17.44% yes and 82.55% no.

In response to the question regarding knowing the signs and symptoms of this condition, 13.80% replied yes, and around 86.09% said no.

When we asked a question related to Tourette’s syndrome whether these patients should married or not they answered 27.34% yes and 72.65% no.

Regarding questions related to the employment of the person who suffered from this type of disease, around 33.59% of the healthcare workers replied yes, and 66.40% replied no.

When we asked the questions to healthcare workers whether these patients were a form of insanity or not, the healthcare professionals replied 24.21% yes, and 75.78% replied no.

The question asked the workers of healthcare related to know the causes of Tourette’s syndrome replied around 68.48% yes and 31.51% replied no.

In response to the question related to the role of physical therapy in the treatment of Tourette syndrome 51(13.28%) responded yes and 333(86.71%) as shown in Table. No:2

Table: 2. Questions related to the knowledge of Tourette’s syndrome.

S. No:	Questions	Yes	No
1.	Have you ever heard or known about the disease?	251 (65.36%)	133 (34.63%)
2.	Have you faced any patients regarding this problem?	67 (17.44%)	317 (82.55%)
3.	Do you know about the person who shows the signs and symptoms of the disease?	53 (13.80%)	331 (86.09%)
4.	Do you think the patients with Tourette syndrome should marry or not?	105 (27.34%)	279 (72.65%)
5.	Do you think patients with Tourette syndrome should be employed like other normal people?	129 (33.59%)	255 (66.40%)
6.	Do you think Tourette syndrome is a form of insanity or not?	93 (24.21%)	291 (75.78%)
7.	Do you know the cause of Tourette syndrome?	263 (68.48%)	121 (31.51%)
8.	Do you think is there any role of physical therapy in the treatment of Tourette syndrome?	51(13.28%)	333(86.71%)

The representation of data related to healthcare workers recruited from seven districts of Karachi is shown in the categorical figure below:

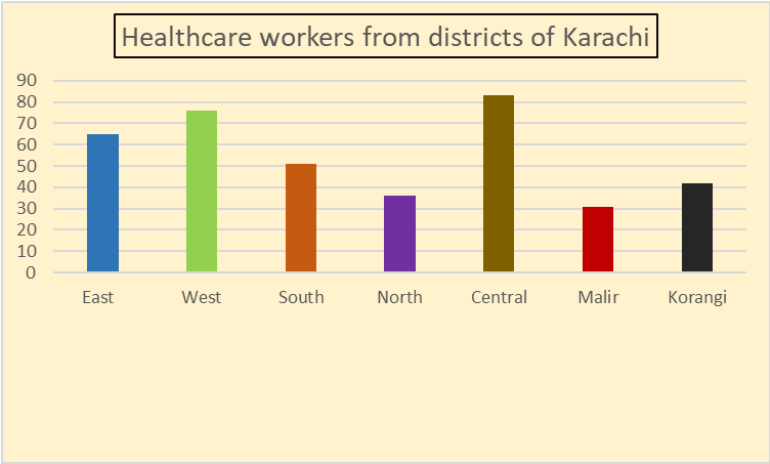


Figure No.1: Categorical presentation of responses of Healthcare workers from seven districts of Karachi

DISCUSSION

The neurological and developmental disorder is characterized by multiple tics which may occur at the age of 21 years and above for one or more than one year known as Tourette syndrome. [16] In the present study, we observe the perception of healthcare workers regarding Tourette syndrome. From our study, it has been observed that research participants are mostly related to the rehabilitation centers about: 32.03% which showed the relevance of the field of physical therapy with the disease as compared to other professions. A study done in Riyadh reported there is a lack of awareness regarding Tourette syndrome among medical students and physicians while family physicians have better knowledge related to Tourette syndrome. [17]

From our study, 65.36% of research participants were ever listen about the disease and its consequences to the affected person while a study conducted in the USA concluded that there is a small amount of knowledge among their research participants regarding TS. [18]

The participants of our research had the exposure of the patients affected with Tourette syndrome about 17.44% while an experimental study conducted in Sweden revealed, that therapist support and prevention of responses of children have positive clinical effects and also found improvement in the severity of tics movement. [19]

From our study, 13.80% of healthcare workers were aware of the signs and symptoms of the patients who have Tourette syndrome Only 27.34% of our research participants thought that the patients having Tourette syndrome should marry and the rest of the participants said that they should never do marriage because it can further affect the life of spouse and also affect the quality of life of the affected person in comparison to this a study conducted in Taiwan reported the patients of TS showed negative attitude due to their tics they can interact positively with the spouse and can give harm to them.[20]

The results of our study showed only 33.59% of research participants thought that TS patients should be employed somewhere at a job while the research conducted in the UK reported, that people affected by TS have societal unacceptability and have stereotypes and disturbed behavior which causes the self-determination in the behavior of the affected person. [21]

The results of our study concluded, that 24.21% of healthcare workers in our study thought that TS is a type of insanity while a study reported, that the main drawback of TS patients was they have more aggressive behavior and anger issues that can cause harm to the peoples who are in the surrounding of them. [22]

A study done in Malaysia reported that awareness of Tourette syndrome was not sufficient among the common citizens, parents, and teachers even though some children affected with TS were not going to school. [23] while in our study 68.48% of healthcare workers were aware of the cause of the Tourette syndrome.

Physical therapy is a vast profession and it can manage patients having problems related to neurodevelopmental issues but the results of our study showed, that only 13.28% of research participants know about the role of physical therapy in the management of Tourette syndrome as compared to this a study reported, physical therapy in combination with gut microbial composition was effective to diminish the tics movement. [24]

CONCLUSION

From the present study, it is concluded that the awareness of Tourette syndrome was higher in healthcare workers but their exposure to disease-related patients was minimal. This disease is not well-recognized by the general public therefore, there is a need to improve knowledge among citizens through seminars, training programs, webinars workshops that will help the parents in future guide them on how they control their child's symptoms and lead them to live the better quality of life.

REFERENCES

1. Szejko N, Robinson S, Hartmann A, Ganos C, Debes NM, Skov L, Haas M, Rizzo R, Stern J, Münchau A, Czarnecki V. European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part I: assessment. *European child & adolescent psychiatry*. 2022 Mar;31(3):383-402.
2. Paul’s DL, Raymond CL, Stevenson JM, Leckman JF. A family study of Gilles de la Tourette syndrome. In *Obsessive-Compulsive Disorder and Tourette's Syndrome* 2022 Apr 18 (pp. 64-73). Routledge.
3. Set KK, Warner JN. Tourette syndrome in children: An update. *Current problems in pediatric and adolescent health care*. 2021 Jul 1;51(7):101032.
4. Ueda K, Black KJ. A comprehensive review of tic disorders in children. *Journal of clinical medicine*. 2021 Jun 3;10(11):2479.
5. Soós MJ, Coulson NS, Davies EB. Exploring social support in an online support community for Tourette syndrome and tic disorders: analysis of postings. *Journal of medical Internet research*. 2022 Oct 4;24(10):e34403.
6. Jafari F, Abbasi P, Rahmati M, Hod Hodi T, Kazeminia M. Systematic review and meta-analysis of Tourette syndrome prevalence; 1986 to 2022. *Pediatric neurology*. 2022 Dec 1;137:6-16.
7. Larsh TR, Wu SW, Huddleston DA, Lipps TD, Gilbert DL. Differences in tic severity among adolescent girls and boys with Tourette syndrome during the pandemic. *Neuropediatric*. 2024 Feb;55(01):067-70.
8. Charania SN, Danielson ML, Claussen AH, Lebrun-Harris LA, Kaminski JW, Bitsko RH. Bullying victimization and perpetration among US children with and without Tourette syndrome. *Journal of Developmental & Behavioral Pediatrics*. 2022 Jan 1;43(1):23-31.
9. Green B, Waters A, Jimenez-Shahed J. Pain in Tourette syndrome: A comprehensive review. *Journal of Child and Adolescent Psychopharmacology*. 2024 Nov 19.
10. Tooley AC. *The Public Stigma of Tourette Syndrome*. Illinois Institute of Technology; 2021.
11. Quast LF. *Healthcare Responsibility and Transition Readiness in Adolescents with Tourette Syndrome* (Doctoral dissertation, University of Georgia).
12. Watson KH, Eckland M, Schwartzman JM, Molnar A, Boon W, Hiller M, Scholer S, Mace R, Rothman A, Claassen DO, Riordan HR. The Association of Quality of Life with Psychosocial Factors in Adolescents with Tourette Syndrome. *Child Psychiatry & Human Development*. 2024 Feb 4:1-2.
13. Sørensen CB, Skov L, Aaslet L, Nielsen H, Mortensen M, Lange T, Debes NM, Miranda MJ. Modified Atkins Diet for Tics Requiring Treatment in Tourette Syndrome: A Randomized Controlled Trial of Early Versus Late Initiation. *Journal of Pediatric Neurology and Neuroscience*. 2021 Mar;5(1):86-94.
14. Travis E, Juárez-Paz AV. Experiences of Tourette syndrome caregivers with supportive communication. *Qualitative health research*. 2020 Aug;30(10):1480-90.
15. Katona C. Familiarity with and attitudes to Tourette's syndrome in healthcare students: a pilot comparison with epilepsy. *The European Journal of Psychiatry*. 2013 Jun;27(2):129-36.

16. Katato H, Muniz J, Lopez-Arvizu C, McGuire JF. Evidence-Based Behavior Therapy for Tourette Syndrome. *Psychiatric Clinics*. 2024 Oct 9.
17. Alal wan AA, Alkhamis MA, Samman AM, Alsharif EH, Tarabzoni OE, Khatri IA. The Assessment of Knowledge about Tourette's Syndrome among Medical Students and Primary Physicians in Riyadh, Saudi Arabia: A Cross-Sectional Study. *Neurology Research International*. 2022;2022(1):3018305.
18. Bhikram T, Elmaghraby R, Abi-Jaoude E, Sandor P. An international survey of health care services available to patients with tourette syndrome. *Frontiers in Psychiatry*. 2021 Feb 26;12:621874.
19. Andrén P, Holmsved M, Ringberg H, Wachtmeister V, Isomura K, Aspvall K, Lenhard F, Hall CL, Davies EB, Murphy T, Hollis C. Therapist-supported internet-delivered exposure and response prevention for children and adolescents with Tourette syndrome: a randomized clinical trial. *JAMA Network Open*. 2022 Aug 1;5(8):e2225614-.
20. Lee MY, Wang HS, Chen CJ. Psychosocial experiences in youth with Tourette syndrome: a systematic review and meta-synthesis. *European Child & Adolescent Psychiatry*. 2023 Dec 21:1-6.
21. Malli MA, Forrester-Jones R. Stigma and adults with Tourette's syndrome: "Never laugh at other people's disabilities, unless they have Tourette's—Because how can you not?". *Journal of Developmental and Physical Disabilities*. 2022 Oct;34(5):871-97.
22. Coleman J, Melia Y. Me, My Tics and I: An Exploration of Self-Identity and its Implications for Psychological Wellbeing in Young Women with Tourette's Syndrome. *Journal of Developmental and Physical Disabilities*. 2024 Apr;36(2):367-89.
23. Karuppan nan G, Fong AC, Muhamad F, Moksan DM. Awareness of Tourette Syndrome in Malaysia. *European Journal of Humanities and Social Sciences*. 2021 Jul 27;1(4):29-32.
24. Bao C, Wei M, Pan H, Wen M, Liu Z, Xu Y, Jiang H. A preliminary study for the clinical effect of one combinational physiotherapy and its potential influence on gut microbial composition in children with Tourette syndrome. *Frontiers in Nutrition*. 2023 Sep 15;10:1184311.