

## YouTube videos can inaccurately depict Parkinson's disease and other movement disorders

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Looking online for medical information? Viewers beware, doctors caution. After reviewing the most frequently watched YouTube videos about movement disorders, a group of neurologists found that the people in the videos often do not have a movement disorder. As described in a Letter to the Editor in this week's New England Journal of Medicine, such medical misinformation may confuse patients suffering from devastating neurological disorders and seeking health information and advice online.

Many people use the Internet as a primary resource for <u>medical</u> <u>information</u>, and YouTube, the third most visited website on the Internet, is a popular platform for patients to share personal medical stories and experiences on video.

Dozens of YouTube videos show people who believe they have movement disorders such as Parkinson's disease demonstrating and talking about their symptoms. In January 2011, neurologists at University College London began a study when patients alerted them that online videos often proposed a diagnosis and suggested therapies.

Seven neurologists from different countries and medical institutions searched YouTube using six keywords: "dystonia," "Parkinsonism," "chorea," "myoclonus," "tics" and "tremor", and found videos allegedly depicting various movement disorders. They then independently



reviewed the top three percent most-watched videos that were of sufficient quality to review patient symptoms. Out of 29 videos, the majority (66 percent) were identified as showing "psychogenic" movement disorders, meaning that the abnormal movement originates from a psychological condition or mental state rather than a disease with a physical cause, such as Parkinson's. Of these videos, more than half contained advice about specific therapies to treat the movement disorder. Furthermore, the doctors reviewing the videos did so independently, yet their diagnoses agreed in 87 to 100 percent of all cases.

"Patients and doctors have to be very thoughtful and careful when looking for information on YouTube, as well as the Internet in general," commented Mark Hallett, M.D., senior investigator at the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health. "There is a great deal of good information on the Internet, but one has to be careful."

**More information:** "Movement Disorders on YouTube — Caveat Spectator." *New England Journal of Medicine*, published online September 22, 2011, Volume 365, No. 12, pages 1160-1161

Accurate information on movement disorders can be found at <a href="https://www.ninds.nih.gov/disorders/pa">www.ninds.nih.gov/disorders/pa</a> ... rkinsons disease.htm

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