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Movement Disorders on YouTube — Caveat Spectator

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TO THE EDITOR

For many patients and their families, the Internet has become the primary resource for medical information, in addition to providing a forum for patients to share their personal experiences. Movement disorders, which include Parkinson's disease, dystonia, and tremor, are common neurologic conditions that readily lend themselves to demonstration by video. We were recently alerted by our patients to content regarding movement disorders that is available on YouTube (www.youtube.com), the third most visited Web site.¹ However, a brief search revealed that many of the videos seemed to us to be atypical for the specific form of movement disorder the person in the video was purported to have. In fact, some of the videos showed movements characteristic of psychogenic movement disorders, the movement-disorder counterpart of conversion disorder (i.e., symptoms that are not attributable to a medical disorder or to feigning and are judged to be associated with psychological factors).² We therefore asked seven neurologists who were experts in movement disorders to independently evaluate the most frequently viewed YouTube videos

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of patients purported to have a movement disorder and to judge whether the movement disorder depicted appeared to be psychogenic or organic.

Using the keywords dystonia, Parkinson's, chorea, myoclonus, tics, and tremor, we searched YouTube in January 2011 and selected videos from the top 3% of the most often viewed videos in each category that were uploaded by patients and were of sufficient quality. Although a proper diagnosis of organic or psychogenic movement disorder relies on the results obtained from the patient's history and standardized examinations (which were not available to the raters), movement disorders by their nature can be seen and evaluated without special examination techniques. We asked the raters to base their judgments on published diagnostic criteria for psychogenic movement disorders² that are related to aspects of the movement disorder apparent on simple observation.

Of 29 videos showing people with movement disorders, 66% were rated as psychogenic and 34% as organic, with excellent interrater agreement (Table 1). The accompanying comments on the site recommended specific treatments in 53% of the videos considered to show a psychogenic movement disorder but in only 20% of those considered to show an organic movement disorder.

For patients with a movement disorder, the information available on YouTube may be misleading and may provide an inaccurate impression of the disorder and its treatment. One video described as showing facial dystonia showed different patterns of facial spasm that appeared to be triggered by an electrical stimulator, and it suggested that dystonia could be alleviated if the patient wore cotton clothes and avoided radiation. Other recommendations were potentially more serious, proposing the use of immunosuppressive agents or invasive or expensive diagnostic tests, and some videos claimed that profound benefit could be had from interventions such as craniosacral massage and herbal remedies prescribed by health care providers.

The fact that such a large number of videos showing psychogenic movement disorders are available on the Internet highlights an underlying problem that affects virtually every medical specialty, and the information these videos provide can interfere with the effective recognition and care of patients with a movement disorder. Physicians should caution their patients to be wary of relying on information from potentially unreliable Web sources and should also help to make reliable medical information freely available to those with either organic or psychogenic disorders.

References

1. Alexa. YouTube.com Alexa Traffic Rank. 2011. <http://www.alexacom/siteinfo/youtube.com>
2. Fahn S, Williams DT. Psychogenic dystonia. *Adv Neurol*. 1988; 50:431–55. [PubMed: 3400501]

Table 1
Assessment of Videos Showing Movement Disorders on YouTube.*

Variable	Keyword					Total
	Dystonia	Parkinsonism	Chorea	Myoclonus	Tics	
Videos found — no.	2620	10,200	5125	410	5450	6290
Selected	8	2 [†]	5	3	4	8
Assessed	8	1	5	3	4	8
Rated as psychogenic/organic — no./no. (IRC)	5/3 (0.90)	1/0	3/2 (0.89)	3/0 (1.00)	0/4 (1.00)	7/1 (0.87)
Level of certainty [‡]	4.43±0.59	5.00±0.00	4.17±0.50	4.47±0.33	4.14±0.48	4.27±0.74

* Plus-minus values are means ±SD. Interrater agreement was determined with the use of the interrater reliability coefficient (IRC) and the intraclass correlation coefficient. The strength of agreement was designated as fair (IRC = 0.21 to 0.40), moderate (IRC = 0.41 to 0.60), substantial (IRC = 0.61 to 0.80), or excellent (IRC = 0.81 to 1.00). Statistical analyses were performed with Predictive Analytics Software Statistics, version 19.

[†] One of the two videos was not assessed, since it had been removed from YouTube by the time the raters carried out their assessments.

[‡] Levels of certainty range from 1 to 5, as follows: 1 = 0 to 20%, 2 = 21 to 40%, 3 = 41 to 60%, 4 = 61 to 80%, and 5 = 81 to 100%.