

Is Twitter reinforcing negative perceptions of epilepsy?

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A revealing study published in *Epilepsy & Behavior* provides evidence that the perception of epilepsy is not faring well in social media. Kate McNeil and colleagues from Dalhousie University in Canada analyzed data collected from Twitter to provide a snapshot of how epilepsy is portrayed within the twitter community.

Twitter, a social networking platform launched in 2006, allows its users to communicate through posting of "tweets" limited to 140 characters. Twitter has gained worldwide popularity since its inception, with approximately 110 million tweets per day from 200 million users worldwide counted in January 2011. Twitter's role in a number of revolutions, including the 2011 Egyptian revolution and the 2010-2011 Tunisian protest, has confirmed its ability to influence culture and perceptions on a global scale.

In their study McNeil and colleagues analyzed 10,662 tweets collected during one week in April 2011 mentioning the word "seizure" or "seizures". They found that 41% of these seizure-related tweets were considered to be derogatory in nature.

Fortunately there were a few tweets that spoke out against mocking those with seizures. For instance, "Why do people joke about [epilepsy](#) and seizures? Do they joke about cancer? Attach your brain 2 a car battery & see how funny it is!" articulates this point emphatically. The researchers do argue, however, that the online voices of those speaking out against such negative stereotypes and disparaging remarks need to be

stronger. They emphasize the need for improved epilepsy education to advance public knowledge and behavior on the topic.

The study concludes that although Twitter could hold the power to positively affect how epilepsy and seizures are perceived, currently an epilepsy stigma is being perpetuated instead.

"While we are well aware of the stigma faced by people with epilepsy, we were shocked to see just how pervasive the problem is in social media. It certainly emphasizes a need for public campaigns to combat these negative attitudes," said Dr. Brna, corresponding author of the study, based at Dalhousie University in Canada.

Dr. Joseph Sirven, Professor of Neurology and Chair of the Department of Neurology at Mayo Clinic in Arizona, in an accompanying editorial wrote, "It is now time for the epilepsy community to rise up, have our own [Twitter](#) revolution, and alter the way the condition is perceived. There is too much suffering and too great a burden for this to go unchecked...By taking charge, we can potentially change the equation and allow the silent voices of individuals with epilepsy to rise up, revolt, and finally correct the misperceptions and eliminate the stigma associated with the condition once and for all."

More information: The article is "[Epilepsy in the Twitter era: A need to re-tweet the way we think about seizures](#)" by K. McNeil, P.M. Brna, and K.E. Gordon. The editorial is "[It's time for an epilepsy Twitter revolution](#)" by Dr Joseph Sirven. Both article and editorial appear in *Epilepsy & Behavior*, Volume 23, Issue 2 (March, 2012), published by Elsevier.

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