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# The Non-Mysterious Mass Illness in Le Roy, New York

In early 2012 the story of fifteen sick children in the same high school in Le Roy, New York, hit the media, which labeled this rash of symptoms as a "mystery illness." Of course, doctors were described as "baffled" (Almasy and Spellman 2012). Over a short period of time the teens started to exhibit involuntary movements and vocalizations described as tics, similar to the symptoms of Tourette syndrome.

In response to the media attention, several groups and individuals came forward to publicly hypothesize about what might be causing this rash of symptoms. Antivaccinationists suspected that it was a vaccine—or environmental toxin, at least—that had caused the illness. Chiropractor Russell Caram speculated that

> The other possibility here are HPV vaccines, Gardasil and Cervarix. The timing becomes more easily explained—as most children "get their shots" (and boosters, such as DTaP and the flu shot) before enrolling in school in the fall. It also satisfies the girls-only attack (even though they're trying to convince boys to get the Gardasil shot also), as well as the age group. (Caram 2012)

Caram's hypothesis suffers from more than the fact that it is pure speculation. Half of the children affected by the illness did not even receive the Gardasil or Cervarix vaccines, nor is there any evidence to suggest that either vaccine can cause such neurological symptoms in the first place. (Similarly, no evidence supports the claim that Tourette syndrome can be caused by vaccines or toxins.) When Caram wrote the article, only girls showed signs of the illness, but later one boy also developed symptoms, which further suggests that the HPV vaccines are not to blame.

Those who have made it their mission to expose the risks of environmental toxins see in this case a possible environmental toxin. Apparently, some of the parents of the affected children called upon famous activist Erin Brockovich, who sent her team to investigate. She has speculated about "... whether students have been exposed to contaminants from the train derailment that occurred within a few miles of the school in December 1970. That derailment spilled cyanide crystals and leaked carbon tetrachloride" (Ciavarri 2012).

Of course, an environmental toxin such as carbon tetrachloride would not explain the timeline of the illness or its predilection for girls. Why would a forty-year-old spill suddenly have an adverse effect on people living in the general area? The results of a search for environmental toxins in the area have already turned up negative, and the students themselves have tested negative for toxic exposure. However, this poses the problem of proving a negative. Brockovich claims that the search has not been thorough enough, but such a claim can be made arbitrarily without limit. You can keep searching for toxins with lower and lower thresholds until you find something. Toxins are ubiquitous in the environment in background concentrations generally too low to worry about, but if you look hard enough you can find something—especially if it's something you want to find.

Rosario Trifiletti, MD, PhD, is an expert in a rare condition known as PANDAS (pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection), and she has come forward to claim that *this* is what these children have (Swedo et al. 2012). I cannot get into a thorough evaluation of this complex condition, but suffice to say that Trifiletti, who claims to be personally treating some of its patients, is a major promoter of this diagnosis. There is a tendency to see what we know, and experts in a narrow illness often see their pet disease everywhere. The National Institute of Mental Health's (NIMH) definition of PANDAS does not seem to fit this case well. Age of onset for PANDAS is supposed to be between three and puberty, but the Le Roy children are between the ages of twelve and eighteen. There is no indication that PANDAS is a selective illness, affecting girls more than boys. Furthermore, PANDAS is a clinical diagnosis without laboratory confirmation; part of that clinical diagnosis is that symptoms are triggered by a streptococcal infection (such as strep throat), which does not appear to be the case here. PANDAS also involves more than tics—it can include mood changes and obsessive compulsive symptoms, too. Altogether, based on publicly available

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information, PANDAS does not seem a great fit for answering the question of this "mystery illness."

The "mystery illness" has become a Rorschach test of sorts: people see in the illness a diagnosis that fits their worldview or pet cause. But now that the dust has settled somewhat on this outbreak, what can we reliably say about it? To review the facts of the case, eventually fifteen children were affected with involuntary tics, which are sudden "jerk-like" motor movements, between October 2011 and January 2012. All fifteen of the children attend the same junior-senior high school and range in age from twelve to eighteen; all but one of them is female. All of the children have been examined by pediatric neurologists—twelve of the fifteen at the Dent Neurological Institute by the same two neurologists, including Laszlo Mechtler, MD.

Mechtler—and, in fact, all of the pediatric neurologists who have examined any of the children—has come to the diagnosis of conversion disorder and mass psychogenic illness. A conversion disorder occurs when psychological stress manifests as physical symptoms. We take this for granted to some degree; when people feel anxious they may get sweaty, nauseated, or short of breath and have palpitations. People who experience panic attacks can have these symptoms along with difficulty swallowing and episodes that may resemble certain types of seizures with feelings of being separate from reality or from themselves. These are physical symptoms resulting from purely emotional stress. But in some cases, psychological stress can also lead to neurological symptoms—pretty much any neurological symptoms, such as weakness, difficulty speaking, loss of vision, and involuntary movements.

It is important to note that this is a known and well-established syndrome (Stone et al. 2011). Neurologists see patients with conversion disorder frequently, and many cases positively demonstrate that the neurological symptoms are not due to any damage or lesion in the nervous system but rather to psychological stress. For example, it can be demonstrated in someone with psychogenic blindness that their visual system actually works. Similarly, many patients with psychogenic seizures display features that are neuro-anatomically incompatible with actual seizures.

It is always challenging to deal with conversion disorder. We medical professionals try very hard to accurately and constructively convey to patients and their families what is happening, but unfortunately our culture attaches an undeserved stigma to psychological ailments, and many patients resist such a diagnosis. We tend to focus on the positive—psychogenic symptoms can completely cure themselves (and usually do with encouragement and reassurance to the patient) because there is no irreversible damage to the nervous system.

The diagnosis of psychogenic illness, however, is also partly a diagnosis of exclusion. It is often the case that a physical ailment underlies the psychogenic symptoms and has, in fact, triggered them. The diagnosis, therefore, is usually made only after a thorough workup to rule out other causes.

In the case of the children in Le Roy, doctors report that they have thoroughly evaluated the children—including screening them for any toxins, infections, or signs of a physical illness—with completely negative results. The school has been examined also, and no environmental toxins or chemicals have been discovered.

Here we are probably dealing with not only a psychogenic illness but also a case of mass psychogenic illness, which is also a known phenomenon that can even be induced experimentally (Broderick et al. 2011). In cases of mass psychogenic illness, the appearance of symptoms in other people, which causes anxiety about a contagious illness or a toxic exposure, can be the stressful trigger. In susceptible individuals this can induce a psychogenic illness that mimics the symptoms of those already affected. Media coverage only enhances this phenomenon; in fact, some speculate that social media increased the spread of the Le Roy children's illness.

The Le Roy case has all the hallmarks of a mass psychogenic illness. Most of the symptomatic individuals are women who are part of the same small, close-knit community and have social contact with each other. The diagnosis is therefore not based entirely on the exclusion of other causes; the case also has a natural history and epidemiological features that fit a mass psychogenic illness. Although the available details of this case point to a mass psychogenic illness as the culprit, there may be one or two index cases of true Tourette syndrome that triggered the outbreak. It is an important lesson, as most people underestimate the ability of our brains to generate physical symptoms.

On the one hand, there are the neurological experts who have presented what seems to be a sound diagnosis. On the other, there is a circling of those who want to promote their causes or ideology. In the middle of all this are the students and their families who have to deal with a delicate neurological ailment before the public eye. We can certainly hope that science and reason win out, but often the most alluring and media-friendly answers come from the cranks who would manipulate the diagnoses of experts to weave a sinister tale. ■

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