



# Mass psychogenic illness and the social network: is it changing the pattern of outbreaks?

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In October 2011, several adolescent girls at a high school in the town of Leroy, New York (pop. 7641), spontaneously developed facial tics, muscle twitching and garbled speech. By early January 2012, it was revealed that the New York State Health Department had diagnosed the students (by now, 14 women and 1 man) with conversion disorder. News of the 'mass hysteria' diagnosis has been vigorously challenged by parents who have formed their own advocacy group. Several victims have appeared on national television to denounce the diagnosis; celebrities have tweeted support for the students and expressed scepticism over its psychogenic origin, while some physicians have publicly suggested alternative explanations. This case has dominated headlines in the USA and continues to generate anxiety and controversy. A common folk theory attributes the symptoms to exposure from a nearby toxic dump, prompting environmental activist Erin Brockovich to challenge the diagnosis and open an independent investigation to determine the 'real' cause.

There is increasing recognition that mass psychogenic illness (MPI) is underappreciated, under-reported and poses a significant health and social problem.<sup>1,2</sup> The financial impact includes the cost of testing to eliminate environmental and organic causes, and the response by emergency services and public health specialists who expend precious time and resources. Schools and factories may temporarily close, resulting in lost production and income, and educational outcomes may be disrupted. When the diagnosis is challenged, students and workers may refuse to enter the premises and erode public confidence in the health system. Ongoing anxiety over the possible existence of a toxic

agent may contribute to a variety of stress-related illnesses. The financial burden can be enormous. In 1999, an MPI outbreak in the Belgian school system over the suspected contamination of Coca-Cola products prompted a recall costing the company an estimated US\$250 million.<sup>3</sup> In 2007, a fainting episode among a group of anxious Australian schoolgirls who had received inoculations for the human papillomavirus, resulted in AU\$1 billion being wiped from the stock market value of the corporation producing the Gardasil vaccine.<sup>4</sup> Disputed diagnoses surrounding vaccination programmes have resulted in social protests and parents refusing to inoculate their children, placing them at unnecessary risk for preventable diseases.<sup>5</sup> Finally, victims can get trapped in wider social arguments and conflicts, especially when the veracity of their symptoms is challenged, impeding their recovery.

There are two main types of MPI. The most common in Western countries (anxiety hysteria) is triggered by extreme, sudden stress within a close-knit group. It is usually triggered by a foul or unfamiliar odour that is perceived to be harmful. Symptoms are transient, benign and typically include dizziness, headache, fainting and over-breathing. Most victims recover within 24 hours and there is an absence of pre-existing tension within the group. A second type (motor hysteria) arises from long-term anxiety and features motor agitation. Common symptoms include twitching, shaking, trouble walking, uncontrollable laughing and weeping, communication difficulties and trance states. Symptoms appear slowly over weeks or months under exposure to longstanding stress, and typically take weeks or months to subside, after the stress has been reduced or eliminated.<sup>6</sup>

## Is the Leroy outbreak mass psychogenic illness?

Inevitably there have been voices questioning the diagnosis. Fox News medical consultant, internist Marc Seigel confidently asserted that the victims were suffering from chronic streptococcus infections, a view supported by neurologist Rosario Trifiletti.<sup>7,8</sup> On 7 February 2012, Trifiletti announced that eight of the Leroy victims had a 'PANDAS-like illness'. This diagnosis was immediately contested by Susan Swedo, discoverer of PANDAS Syndrome. In noting that it is a clinical diagnosis and not dependent on lab tests, she observes that the presence of high levels of strep antibodies are extremely common in school-age students.<sup>7</sup> Brockovich suggests that the symptoms may stem from a 40-year-old cyanide dump near the school, although the Environmental Protection Agency and state health department found no evidence of contamination after extensive testing of the school grounds. But these do not address key observations: Why is the illness confined almost exclusively to adolescent girls? Why aren't siblings and parents affected, or those who have been working at the school for longer periods? Why would it take decades for symptoms to manifest, and then in such an abrupt fashion? At the time of writing, the most plausible diagnosis remains that made by the local physicians, based on the social patterning of victims combined with negative environmental and organic tests. However, it is certainly possible that the initial index case may have an organic diagnosis, but not those subsequently afflicted. This is a pattern that is frequently reported in other MPI episodes.

## The Leroy outbreak in context

The Leroy incident is of significance as it marks the third recorded school outbreak of conversion disorder with motor disturbances to occur in the USA since 2002. Until now, outbreaks of MPI affecting motor function have rarely been reported in Western countries. During the 20th century there were only four reported cases in the USA, most involving sexual tension and interpersonal conflict among girls. In 1939, an epidemic of leg twitching erupted at a high school in Bellevue, Louisiana. The index case feared her boyfriend

would end their relationship if he saw how poorly she danced. When her twitching enabled her to avoid dance classes and rekindled her boyfriends' affections, the symptoms spread to six other girls.<sup>9</sup> In 1962, blackout spells swept through an African-American school in Louisiana in which a significant proportion of students were sexually active, breaching local mores. Twenty girls and one boy exhibited symptoms which followed the pregnancy of a student and her subsequent transfer to reform school, and coincided with rumours that authorities were going to administer pregnancy tests and send offenders to a school for juvenile delinquents.<sup>10</sup> In 1970, a group of 78 mostly female students aged 15–19 experienced convulsions, tremor and stomach cramps while attending a US summer school programme. The context of the outbreak, which persisted for one week, was not provided.<sup>11</sup> In 1976 at Mount Pleasant, Mississippi, 15 schoolgirls experienced seizures characterized by shaking and loss of consciousness. The trigger was identified as a schoolgirl rivalry over the affections of a boy and a belief in magic spells.<sup>12</sup> In contrast, contagious conversion disorder accompanied by motor dysfunction is common in developing countries where dozens of cases are reported annually in Asia and Africa. They often involve collective spirit possession and are triggered by a belief in witches, demons and ghosts.<sup>13,14</sup>

But, since 2002, there have been three further reports in the USA at schools in North Carolina, Virginia and now New York. In 2002, 10 girls at a high school in North Carolina were stricken with headaches, dizziness, muscle twitching and numbness. The malady rarely occurred in class, but struck students in the hallway between classes, in the cafeteria or in the schoolyard during recess. The first stricken was a cheerleader, and the fear of 'catching' her seizure may have made her fellow cheerleaders and other classmates nervous, triggering their blackout spells. This case marks an oddity in the literature as the victims were spread among students in the ninth, 10th and 11th grades; just three were in the same class.<sup>15</sup> Previously, MPI outbreaks in schools typically occurred in close-knit groups of students sharing classrooms. In 2007, an epidemic of twitching limbs, headaches and dizziness was reported at William Byrd High School in Virginia. Media reports indicate that those affected (9 girls and a

female teacher) were scattered about the school.<sup>16,17</sup> The outbreak occurred amid a spate of public health concerns for the Roanoke County Public Schools including an asbestos scare, and warnings about a drug-resistant *Staphylococcus* (Golden Staph) infection that was blamed for the death of an area resident. The Leroy case not only marks the third incident of its type within a decade, it is the first vigorously disputed case of this rare form of conversion disorder to occur in the USA during the Social Networking Era.

During the initial stages of the Leroy outbreak, actions by the New York State Health Department exacerbated the situation by contributing to public fear. In early January 2012, the Department announced that it was withholding public release of the diagnosis due to state privacy laws. This position triggered widespread criticism and suspicion, undue alarm and national media speculation as to the existence of a 'mystery illness'. The resultant anxiety transformed the case into a public health issue where the rights of the public to know, outweighed the privacy rights of a small group. The social hysteria surrounding the diagnosis prompted an independent neurologist treating some of the victims, David Lichter, to publicly disclose the diagnosis.

One consequence of this is also unique in the annals of such episodes – where people can stay up-to-date with the latest events, view the girls on Youtube, receive Twitter updates, follow Facebook links and Internet blogs. We are aware for example that these videos have been circulating among networks of specialists in psychiatry and movement disorders, prompting much speculation. Lichter observes: 'It's remarkable to see how one individual posts something, and then the next person who posts something not only are the movements bizarre and not consistent with known movement disorders, but it's the same kind of movements. This mimicry goes on with Facebook'.<sup>18</sup>

MPI is typically spread through sight and sound. Telecommunications are an extension of our eyes and ears. Are telecommunications and social media replacing the necessity of being in direct visual or verbal contact with other victims? If so, could this account for the recent appearance of outbreaks in the USA and mark a historic shift in the spread of conversion disorder? It is

unclear if MPI could spread solely via social media among people with no other pre-existing connection. Although a high proportion of the movement disorder videos uploaded by users to YouTube appear to show disorders that are psychogenic in origin,<sup>19</sup> previous, dramatic cases of medically unexplained illness attributed to novel health risks in individuals have failed to spread among those who have viewed them on YouTube and if anything, the intense scepticism that some reports are met with online may actually hinder their spread.<sup>20</sup> Outbreaks of contagious conversion disorder may exhibit a different pattern among students in close physical proximity to victims and the existence of a perceived harmful agent that is viewed as a direct threat. This may explain why in Leroy, symptoms are not confined to a class or group but are scattered throughout the school. We may be witnessing a milestone in the history of MPI where the primary agent of spread will be the Internet and social media networks. Communication with the neurologists treating 12 of the victims supports this view. 'As soon as the media coverage stopped, they all began to rapidly improve and are doing very well,' they report. At the time of writing, all but one of their patients 'are free of tics and vocalizations'.<sup>21</sup>

## Conclusion

The Leroy case may mark a new transformation in the dialectics of MPI. This is the first case in which, to our knowledge, those affected have been able to 'put their case' directly to the wider public. It may be that they will come to regret this with the passage of time, since by doing so they become public property, and their right to confidentiality has been severely compromised. It is likely, as indeed is already happening, that their illnesses will now become symbolic of wider issues, such as the continuing controversy over waste dumps or a wider scepticism about medical authority and diagnosis. As individuals they become caught up in the battle of diagnosis, both on and offline. And, as Hadler memorably said when discussing a non-contagious but contested diagnosis, fibromyalgia, 'if you have to prove you are ill you can't get well'.<sup>22</sup>

New pressures are also visible now in the response of public health authorities. In general, most cases of MPI probably never get reported,

at least not beyond the local press. One of us (RB) has a vast file of newspaper reports that go no further than the local media, and never become the subject of controversy, debate, let alone ever make it to the academic and professional press. Public health officials and those in authority, such as head teachers and school superintendents, often manage successfully to strike the right balance between investigation, reassurance and confidentiality, creating an atmosphere in which anxiety can dissipate, fear subside and those affected can return to health with their dignity and self-respect unaffected. The rise of social media means that all of these goals are far more difficult if not impossible to achieve, as seen clearly in the Leroy case.

The advice in handling episodes has until now not changed since that given during the latter Middle Ages to quell outbreaks of conversion disorder in European nunneries and repeated over the centuries since: offer reassurance, separate the victims and keep them out of the school environment until the symptoms disappear. Given the proliferation of the Internet and social media networks, this latter recommendation may prove problematic. Local priests, who were inevitably summoned to exorcize the 'demons', faced a daunting task given the widespread belief in witchcraft, but they were fortunate in one regard: they did not have to contend with mobile phones, Twitter and Facebook.

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