

“I Didn’t Want to Be One of the Contaminated People”: Confronting a Mystery Illness in a Rural American Landscape

2013-04-08 10:37:28

By

A small-town high school in western New York became the focus of news media attention from late 2011 to early 2012. Nearly two dozen teens and one adult, all but one female, exhibited spasmodic movements and vocalizations with no easily detectable cause. The outbreak provoked a cascade of conflicts, leaving them largely unresolved even as the symptoms subsided and life returned to a semblance of normalcy for the afflicted and their neighbors.

This post trains an ethnographic eye on the reporting of this “mystery illness”. It relies heavily on web-archived news, mostly that which directly engaged with and was accessible to the principal actors—the afflicted and their families, local residents, medical practitioners and researchers, government and school officials, and the reporters themselves. The post sketches out the various narratives that these actors crafted to make sense of and grapple with the outbreak. It focuses in particular on two explanatory narratives:

- a) The first, proposed by medical professionals and supported by officials, was that the illness was psychosomatic in nature, arose from a nexus of social and psychic stresses, and was exacerbated by patients and community members (and journalists) questioning the diagnosis; and
- b) The second, proposed by activist counter-experts and accepted by a range of the afflicted and their families and neighbors, was that the illness was environmental in nature, came from a toxic or infectious agent, and was exacerbated by officials’ incompetent or conspiratorial dismissal of alternative explanations and treatments.

I intend to show how these narratives offer insights into the state of expert and lay conceptions of illness in the contemporary United States. First, the case highlights an intensified conflict between experts and non-experts, in

part due to the proliferation of counter-experts and diverse epistemic communities, but also due to the proliferation of credible and complex environmental health threats. Second, the Le Roy outbreak brings to light an underlying agreement on, but persisting ambivalence toward, an implicit dualistic model of human nature among medical experts and laypeople. The agreement and ambivalence are especially apparent where the model connects mental health and illness to environmental factors. Following these two sections, I will briefly discuss the insights provided by an ethnographic approach to this case.

A Brief Chronology in Multiple Voices

A review of archived news articles and broadcasts reveals many attempts to understand the outbreak, not all of them consonant or forming a coherent whole. The dual origins of the outbreak seemed to lie in May 2011. In [Le Roy](#), a town of 4,000 in the Genesee River watershed in western New York, it began with one “index case,” a high school student who had previously been diagnosed with Tourette’s syndrome ([Owens 2012d](#)). In [Corinth](#), an equally small town near the state capital, Albany, two female students (who were also softball teammates) collapsed and became ill within days of each other (Edwards 2012; [Fraser 2012](#); [Roman 2012](#)). Only later would their illnesses be linked, albeit tenuously, to those in Le Roy (Bleck 2012; [Walker 2012](#)).

By the beginning of the 2011-2012 school year in September, a succession of students (and one adult) in Le Roy began falling ill (Tan 2012c; [Owens 2012f](#)). Reports differed on who was first (cf. [Owens 2012b](#); [Stephanopoulos 2012](#)), but all agreed that the afflicted students reported a sudden and dramatic onset, either waking from an otherwise uneventful nap ([Asztalos 2011](#)) or passing out unexpectedly ([Dominus 2012](#)). Then they began to manifest bodily tics (jerking arms, twitching necks) and wordless vocal outbursts, which were only temporarily suppressed and quickly grew tiresome and painful (see Video 1 below). While several of the early afflicted in Le Roy had previously diagnosed health problems (Melville 2012), these new symptoms caused consternation among their families and neighbors.

Vid.1: Jason Carroll interviews Melisa Phillips, Thera Sanchez, and Lydia Parker (AC360, CNN, 2012-01-18)

Once the total reached six students, the [Le Roy Central School District](#) under Superintendent Kim Cox quietly began to take action. They requested environmental testing of the school building from the [Genesee](#)

[Valley Educational Partnership](#) in October ([“Doctor: Mystery Illness Among Le Roy Girls Is Psychological” 2012](#)), and then from [Workfit Medical](#) of Rochester in December. As the case became public, and reported, the GVEP also provided the District with the aid of the Rochester-area law firm of [Harris Beach LLP](#), whose “senior manager of media and community relations,” [William Albert](#), served as the school’s legal advisor and contact person. And they notified the parents of individual afflicted students as soon as they became symptomatic.

Throughout the fall the original afflicted girls and the adult female appeared one by one in the offices of neurologists, most of them going at least once to the [Dent Neurologic Institute](#) ([Hopkins 2012](#); [Tan 2012a](#); [McFadden 2012](#)) of suburban Buffalo ([Mrozek 2012b](#)). Some were taken out of school by their parents ([Conte 2011](#); [Trent 2012](#)), while others attempted to attend class despite the tics. Rumors begin to circulate among neighbors and classmates about this growing cohort, attributing their symptoms to smoking synthetic marijuana at the same party ([Gay 2012](#); cf. [Mrozek 2012a](#)), feigning illness to avoid school (or punishment for bullying the index case) ([Moran 2011](#)), and the human papillomavirus vaccine ([Cooper 2012](#)).

Vid. 2: Reporters interview Lori Brownell, Tosha Brownell, Alycia Nicholson, and Randy Nicholson (*News 4 at 10:00*, WIVB, 2012-01-24)

A letter acknowledging the “Tourette’s-like symptoms” ([Klinck 2011](#)) sent in early November 2011 to all parents did little to dispel these rumors. It did, however, lead to the first burst of news reporting, exclusively local and regional, and to the persistent journalistic framing of the outbreak as a “mystery illness” ([“Update: LeRoy Students Exhibit Tourette-Like Symptoms” 2011](#); [Gallivan 2011](#); [“Tourette-Like Symptoms In LeRoy HS Still Not Understood” 2011](#)), due in part to interviews of concerned but poorly informed parents ([Brean 2011](#)) and one pseudonymous afflicted girl ([Conte 2011](#)). Though few additional news stories appeared in the remainder of 2011, students continued to fall ill, and the District called on the Genesee County and New York State Departments of Health for help ([“No ‘Infectious or Environmental Causes’ in Le Roy Tourette Investigation” 2011](#)).

A community meeting in the second week of January 2012 ([Owens 2012a](#))—arranged by the school district and featuring health officials—gave the only indication that the outbreak was becoming worse. At that meeting health officials reported twelve student cases ([Fischer 2012](#)), though they assured attendees that this did not constitute a public health emergency ([McGowan 2012a](#)), as no environmental or infectious had been identified in tests of the school or the students ([King 2012](#)). Furthermore, they said

the students had been diagnosed and were being treated by their doctors, citing federal medical privacy rules ([HIPAA](#)) to explain why they could not share the diagnosis. Parents of some of the afflicted began at this meeting to express their displeasure with the District, health officials, and physicians for their handling of the outbreak. Some denied that doctors had even made a diagnosis ([DeSmit 2012a](#); Brean 2012), while others—led by James DuPont, Jr., and Beth and Don Miller—flouted HIPAA by citing, and disparaging, the diagnosis of [conversion disorder](#).

Vid. 3: Charlie Rose and Erica Hill interview Dr. Jennifer McVige (*This Morning*, CBS, 2012-01-30)

The day after the first community meeting, DuPont, the Millers, and several other parents met at DuPont's TV shop (Brean 2012) in nearby Stafford to form a support group and plan an end-run around the authorities. The plan included taking to the regional and national news to publicize their suffering and thereby solicit assistance from experts not associated with the District, health departments, or the Dent Institute. Thera Sanchez and Katie Krautwurst were filmed at home and then in a studio interview with their mothers, Melisa Phillips and Beth Miller, respectively, for NBC's national *Today Show* ([Robach and Curry 2012](#)). Brooke DuPont and her father followed on the *Today Show* several days later ([Adams 2012a](#)). Lydia Parker ([Cooper 2012](#); [Trent 2012](#)), her mother Heather ([Pinsky 2012c](#)), and her younger brother Zachary ([Gruenauer 2012](#)) were quoted in newspaper and TV stories. Chelsea Dumars and her legal guardian Dave Watson gave interviews to regional and national TV stations (Robach 2012; [Wooten 2012](#)), as did Traci Leubner ([McGowan 2012b](#); [Stephanopoulos 2012](#)), while Lauren Scalzo spoke exclusively to national media ([Pinsky and Spellman 2012b](#); [McFadden 2012](#)). Nearly all of these appeared at least once (some more than once) on the HLN talk show, *Dr. Drew*, whose host, [Drew Pinsky](#), enthusiastically positioned himself as their advocate, featuring the outbreak on a string of broadcasts in January and February (e.g., [Pinsky 2012a](#); [Pinsky 2012b](#); [Pinsky and Spellman 2012c](#); [Pinsky 2012e](#)).

Vid. 4: Cynthia McFadden interviews residents, afflicted, families, and doctors (*Nightline*, ABC, 2012-02-07)

The parents' activism was countered almost immediately by pediatric neurologist [Jennifer McVige](#) and neurological oncologist [Laszlo Mechtler](#), the Dent Institute doctors treating most of the afflicted. Bolstered occasionally by colleagues in [Buffalo](#), [Rochester](#), and elsewhere, they defended their diagnoses of conversion disorder (e.g., [Robach and Lauer 2012](#); [Rose and Hill 2012](#)), expanding it to mass psychogenic illness (MPI)

once more than a handful of cases were involved. McVige and Mechtler also directed criticism towards sensationalist reporting, citing potential transmission of symptoms through the news media (e.g., [Owens 2012i](#)). For their part, news organizations continued to emphasize the mysteriousness of the illness even after it was officially labeled MPI, and they circulated dramatic videos on TV and the internet of the afflicted exhibiting tics. The lone adult among the afflicted, nurse practitioner Marge Fitzsimmons ([McGowan 2012c](#); [Pinsky 2012d](#); [Putman 2012](#)), made numerous media appearances on her own, against Mechtler's advice, to counterbalance the activists' claims and to call for compassion and understanding for all the afflicted.

The number of reported cases in Le Roy continued to increase through January, with news coverage noting two more in one week ([Tan 2012b](#)), three the next ([DeGeorge-Pike 2012](#)), and so on, up to a total of twenty (Adams 2012d; [Owens 2012f](#)). By late January, the activists' outreach campaign had netted them some media allies and a set of counter-experts. Environmental activist [Erin Brockovich](#) had initially been contacted by the Millers in December ([Pinsky 2012b](#); [Pinsky 2012c](#); [Pinsky and Spellman 2012c](#)). Her colleague, water quality specialist [Robert Bowcock](#), came in from California to follow up on a rising tide of phone calls and e-mails from Le Roy that pointed to environmental concerns ([Arnold 2012](#); [LaDelfa and Kingston 2012](#)). These included a yellow-orange substance on the school athletic fields ([Pinsky 2012b](#); [Owens 2012e](#); [George 2012b](#)), the six natural gas wells on the school property ([Orr 2012a](#); [Mrozek 2012d](#)), and above all the 1970 spill of [trichloroethylene](#) (TCE) on the now-defunct [Lehigh Valley Railroad](#) near Gulf Road four miles east of town ([Jayson and Weise 2012](#); [Drantch 2012](#); [Orr 2012c](#)). Brockovich and Bowcock maintained a tense, primarily mediated, relationship with the Le Roy superintendent, each side accusing the other of acting unprofessionally and jeopardizing the afflicted girls' recoveries by thwarting their efforts (see [Owens 2012g](#); [Cox 2012](#)).

Vid. 5: Drew Pinsky interviews Erin Brockovich (*Dr. Drew*, HLN, 2012-01-27)

At around the same time, New Jersey pediatric neurologist [Rosario Trifiletti](#) contacted the activist families and offered to examine their daughters for free ([Mrozek 2012b](#); [McFadden 2012](#)). Given his support of the idea that some infections could set off an autoimmune reaction that attacked brain tissue and triggered obsessive-compulsive disorder ([PANDAS](#) or PANS), it was perhaps not surprising that he reported tell-tale streptococcus and mycoplasma infections in each of the girls he examined ([Owens 2012h](#); [White 2012b](#)). In interviews, Trifiletti and the Dent Institute doctors clashed over the interpretation of treatment of the girls'

symptoms, as well as whether and how they needed to coordinate care (see [Holmes 2012a](#); [Holmes 2012b](#); [McVige and Mechtler 2012](#)).

The Le Roy school district decided to arrange a second community meeting in early February 2012 to address persistent fears and uncertainty among residents ([Owens 2012e](#); [Clarke 2012](#)). The context for the meeting was inflamed by news reporting, which reached its peak in the first half of the month. Journalists' accounts increasingly featured counter-narratives on the outbreak, some emanating from the environmental activists, some already in circulation in the community—that the new junior-senior high school building rested on contaminated fill from the TCE spill site ([Pinsky and Spellman 2012a](#); Miller in [Blue 2012](#)), or that the gas wells were drawing the “plume” of TCE into town ([Pinsky 2012b](#); [Owens 2012c](#)). Reporters also emphasized community factionalism spurred by the outbreak ([Conte 2012](#); [Redick 2012a](#); [Spellman 2012](#)) and the general tensions caused to Le Royans by being the focus of so much attention ([Callahan 2012](#); [Rivers 2012](#)).

At the February meeting, Superintendent Cox introduced staff from [Leader Professional Services](#) of suburban Rochester, whom the district had hired to perform more extensive environmental tests and, if necessary, to remediate any hazards. Though this could have been interpreted as a victory for their campaign, the activist families objected to Leader's testing plan (not least its projected expense) and argued for allowing the Brockovich-Bowcock team to continue their independent, *pro bono* investigations ([Redick 2012a](#); [White 2012b](#)). They framed the plan as one more instance of the District downplaying or dismissing residents' concerns about the environmental quality of the new school building. One earlier instance they cited to support this framing involved unexplained “vapors” that supposedly sickened several teachers in their classrooms ([Pinsky and Spellman 2012c](#)). Despite the activists' objections, both Superintendent Cox and Leader's staff expressed confidence that the study's results would bring closure to the community's environmental concerns ([Coniglio 2012](#); [Orr 2012c](#)).

Vid. 6: Chris Conte reports on the second community meeting (13 *WHAM News at 6:00*, WHAM, 2012-02-04)

By late February, new cases of the “mystery illness” had stopped appearing, the activist afflicted were retreating from the media, and reporting was winding down. For Dent patients: counseling, medication for preexisting conditions, and no contact with any kind of media. For Trifiletti's charges: antibiotics and no media restrictions. Despite these differences—and the continuing hard feelings between the physicians—both groups claimed to improve over the spring and summer ([Mrozek 2012c](#);

[Owens 2012j](#); [Holmes 2012b](#); [Pinsky 2012e](#); [Dominus 2012](#)). By contrast, Lori Brownell and Alycia Nicholson in Corinth continued to suffer symptoms and haphazard treatment ([Crowley 2012](#)), even though they too had sought the media spotlight for the same reasons the Le Roy activist families had.

There were occasional small spikes in news interest from March 2012 on, though nearly exclusively from regional and local organizations. The federal Environmental Protection Agency ([EPA](#)) arranged for the removal of barrels of contaminated soil from the [Gulf Road spill site](#) in late February ([Scott and Buckley 2012](#)), later confirming that no TCE had moved toward the school ([“EPA Releases Groundwater Results from LeRoy Train Site” 2012](#)). Leader shared the (negative) results of their school tests in a massive document and a brief press release in June ([Noce 2012](#); [Redick 2012b](#); [Crichton 2012](#)), and Bob Bowcock—this time with a New York City lawyer in tow—returned to Le Roy for a late-August town meeting ([Adams 2012e](#); [Gruba 2012](#); [Hong 2012](#); [DeSmit 2012c](#)). The last significant flurry of news came when the State Department of Health informed reporters of two new afflicted students in September ([Hassett 2012](#); [“Tic-like Symptoms Return To LeRoy” 2012](#)), which the Dent neurologists linked to general tensions over the beginning of the school year and the specific stressor provided by coverage of Bowcock’s meeting ([Orr 2012f](#)). Finally, an independently produced documentary involving many of the key actors was [aired on Channel 4](#) in the United Kingdom in late October. While it provided some new insights into the outbreak—including the continued suffering of the first afflicted, Lori Brownell ([Blue 2012](#))—it inspired no follow-up reportage in the US.

Vid. 7: Berkeley Brean reports on Erin Brockovich’s planned town meeting
(*News 10 at 6:00*, WHEC, 2012-08-14)

One lone TV news report ([Brown 2013](#)) aired on the roughly one-year anniversary of the heaviest mediation of the outbreak. It largely took the Dent Institute doctors’ perspective, interviewing only McVige and Mechtler and condemning the alternative explanations and “media circus” that exacerbated the suffering of the afflicted. While the report could be taken as one indication that the mainstream biomedical interpretation of the Le Roy outbreak won out, there is no independent evidence to suggest that either the alternative explanations—or the community tensions that animated them—have disappeared.

Psyche: Nonphysical Source of Physical Ills

The first question to address with the Le Roy outbreak is why doctors,

officials, and scholars converged so quickly—and largely uniformly—on determining the outbreak to be psychological in nature when there appeared to be viable alternative explanations and strong objections to such a determination.

The conventional biomedical model, on which medical professionals based their understanding of the outbreak, differentiates between physical and mental illnesses. This distinction is reflected in and further inscribed by an institutional division between “medical” and “psychological” specialties. However, the model allows for restricted circumstances when a disorder of one type manifests in the other realm. “Somatization” is the term of art for when nonorganic “psychological” suffering manifests in organic “physical” symptoms. Conversion disorder is the transfer of psychosocial stresses into bodily suffering in an individual (Kirmayer and Young 1998, 420), and mass psychogenic illness (also mass sociogenic illness) is contagious conversion within a social group (Boss 1997, 233). Even when news reports cited the research literature on conversion disorder/MPI, they generally ignored the key distinction made by Wessely (1987, 112) between the relatively widespread but transient “mass anxiety hysteria” and the more restricted but longer-lasting “mass motor hysteria” that sufferers in Le Roy exhibited.

Doctors treating the Le Roy afflicted (as well as some of their colleagues) pointed out the positive diagnostic features of conversion disorder, in which the physical-psychological distinction is emphasized. These features included:

1. “symptoms with *no plausible organic basis*;
2. symptoms that are transient and benign;
3. symptoms with rapid onset and recovery;
4. occurrence in a segregated group;
5. the presence of extraordinary anxiety;
6. symptoms spread via sight or sound;
7. a spread occurring down the age-scale, beginning in older or higher status persons; and
8. a preponderance of female victims” (Bartholomew and Wessely 2007, 667, emphasis added).

To drive home the distinctiveness and legitimacy of conversion disorder, one psychiatrist entitled his commentary supporting the diagnosis “A horse doesn’t look like a pencil” ([Merrill 2012](#)).

Medical experts’ statements of defense were usually made in response to charges, some from dissenting physicians (e.g., [Pies 2012](#)), that conversion disorder constituted a “diagnosis of exclusion” (or even of convenience) when no other likely diagnosis presented itself ([Orr 2012b](#);

Melville 2012). Some doctors further emphasized the expertise of neurologists like McVige and Mechtler in sorting out physical and mental ills. Others noted parallel outbreaks in the contemporary US and, more controversially, at some geographical or temporal remove. The intent of drawing such parallels was not only to emphasize their expert awareness and comprehension of the outbreak, but also to counter the “mystery illness” framing found in journalistic and community narratives. Far from being mysterious, in this view MPI constituted a common human reaction to certain types of stressful psychosocial conditions (Kirmayer and Young 1998, 420).

Both doctors and officials took pains to emphasize the ontological reality—thus the legitimacy—of the patients’ suffering. They also pointed out that, as a diagnosis, conversion disorder was preferable to biological illness, in that it promised to be treatable without causing lasting damage (see Fitzsimmons in [Moran 2012](#)). But they acknowledged anticipating resistance by the afflicted and their significant others to the diagnosis ([Bauerle 2012](#); [Brown 2012](#); [Orr 2012d](#)). Despite that foreknowledge, doctors especially lamented how this resistance undermined the very treatment and recovery that resisters claimed to seek (Waitzkin and Magaña 1997, 822; Kirmayer and Sartorius 2007, 836; Bartholomew and Muniratnam 2011, 236). In some cases, medical experts blamed a generic “human nature” ([Owens 2012f](#); [Zach and Rose 2012](#)) as the root cause of the resistance; in others they cited culturally and historically specific factors, like post-9/11 conspiracy theorizing in the US (Tan 2012a; [McVige and Mechtler 2012](#)). To believe the former assertion, the afflicted were arguably expressing concern over social identities they feared spoiled (Goffman 1986) by a diagnosis of mental illness. To take seriously the latter assertion, the afflicted and their families must be tactically aligning themselves with an oppositional, counter-expert knowledge to take some control back from medical and governmental authorities.

Whatever the doctors’ claims, cultural systems of meaning have been shown to affect humans’ interpretation and experience of suffering. This is apparent in the diagnosis of, and reactions to, conversion disorder/MPI by the afflicted and their families, who protested that the illness could not be “all in their heads” when it was so obviously “in their bodies” ([Hass 2012](#)). More subtly, they and the counter-experts searched for the ultimate (physical) cause of the (mental) conversion reaction since it made little sense to them that the arrow of causation could point in the other direction ([Moisse and Davis 2012](#); [White 2012b](#); Andriatch 2012).

Manifest in the reporting on Le Roy was how MPI’s features, and its general psychic origin, made some doctors (and most laypeople) uncomfortable (Waitzkin and Magaña 1997, 813). This stems partly from an evolving but still incomplete knowledge of the presumed biological

foundations for the psyche. For example, in interviews ([Dominus 2012](#); [Orr 2012d](#)) several medical experts cited so-called mirror neurons as potentially playing a role in the contagious spread of somatized symptoms (cf. Lee and Tsai 2010). While promising to remove MPI from the uncanny realm of the psyche, such a biomedical move would seem to lead to the unpleasant conclusion that humans' naturally selected sociality itself can make us ill.

A significant portion of the discomfort toward conversion disorder and MPI also grew out of the stigma attached by many Americans to illnesses located in the mind (Bartholomew and Wessely 2007, 666). The afflicted and their kin exhibited concern that they would be treated as "crazy" (Moran 2012) or "fakes" (Zach and Rose 2012) rather than simply "sick" ([Owens 2012f](#); [Callahan 2012](#)). They were also concerned with how the diagnosis of "mass hysteria" brought stigma on the community. In Marge Fitzsimmons' words "it makes it sound like the whole town is crazy" (Adams 2012b). In an opinion piece, reporter Scott DeSmit objected that it lumped Le Roy in with "[t]hird-world countries. Rural. Poor. Weird" ([DeSmit 2012b](#)). Research in medical anthropology suggests that this stigma stems in part from a dualistic model of human nature long prevalent in the West, in which the mind is the seat of volition, ratiocination, judgment, and morality, while the body is the source of nonrational or antisocial emotions, appetites, and drives (Kirmayer and Young 1998; Watson, Ottati, and Corrigan 2003; Hinshaw and Stier 2008). Such a model can be read as placing responsibility for their behavior—and perhaps culpability for their illness—on the afflicted themselves.

Given the broad discomfort with "psychological" illnesses manifested by the various actors, including journalists, there remained a persistent opening for challenges to the official diagnosis of conversion disorder/MPI. And yet most of these challenges—substance abuse, poisoning by chemicals, infection by microorganism—were nevertheless grounded in the dualistic biomedical model.

Environment: Inhuman Threats to Human Health

The official medical narrative of a "purely psychological" illness seemed to have several points in its favor, not least the evidence that no known toxins would cause the exact symptoms (or disappear with the evident lack of damage) exhibited by the afflicted. This makes it crucial to understand why the diagnosis of conversion disorder/MPI was so strongly opposed by so many in the Le Roy case. The ambivalence toward somatization as diagnosis and as illness behavior is one factor, but the insistence with which environmental causes were debated should alert us to a second

important factor.

Academic and medical studies of “mass hysteria” indicate that the frequent presence of credible threats is key to focusing and sustaining outbreaks (Bartholomew and Wessely 2002, 302; Balaratnasingam and Janca 2006, 171). In small-scale and/or strongly religious societies—e.g., Melanesia (Stephen 1999) and the colonial US ([Moyer 2012](#))—one threat deemed credible is witchcraft. In societies racked by intergroup conflict—for example, Palestine (Small and Borus 1987), Kosovo ([Papraniku 2005](#)), Afghanistan ([Casey 2012](#)), and Uganda ([Asedri 2012](#))—poisoning emerges as a credible charge to level against enemies known or suspected.

For contemporary developed societies, medical and social-scientific studies indicate a particularly close connection between environmental concerns and hysteria (Boss 1997, 233; Bartholomew and Wessely 2002, 301; Bartholomew and Muniratnam 2011, 236). Along with disasters and terrorism, pollution poses a culturally credible threat to life and society (Bartholomew and Wessely 2002, 301; Bartholomew and Muniratnam 2011, 236), and not just because of the media-highlighted proliferation of each threat, though that is not a minor issue. Their credibility is also due to the meanings those phenomena have within cultural systems of risk perception and management (Douglas and Wildavsky 1983). For example, consider how US airline passengers manifested great concern about exposure of their private parts by airport screening technology but no comparable concern about exposure to radiation incurred during flights ([Sohn 2010](#); [Simpson 2013](#)). In the case of disasters, terrorism, and pollution, the threat is often conceptualized as something lying outside the bounds of civilized society and beyond the horizon of knowability, something which attacks in an unbidden and unforeseeable manner.

Le Roy residents’ focus on environmental causes for the outbreak has a distinct local basis for credibility. The lifetimes of adult Le Royans included several prominent environmental events in the region. [Love Canal](#), a residential development in Niagara Falls built over a chemical company’s leaking dump, was invoked by a number of those quoted by reporters. For some it served as the prototypical case in which laypersons’ complaints of environmentally linked health concerns were validated by experts and authorities who had initially discounted them ([Kingston 2012](#)). For others, it illustrated how different Le Roy was from other stigmatized communities, in that it was “not [another] Love Canal” (Moran 2012). Le Roy’s own history of industrial pollution was infrequently woven into the narratives; for instance, as some residents told an out-of-town reporter, the Jell-O manufacturing plant routinely turned the creek various unnatural colors ([Dominus 2012](#)). A number of residents emerged to assert the importance of the frequently neglected Gulf Road TCE spill site ([George 2012a](#); [Orr 2012e](#)), an assertion temporarily bolstered by the intervention of

counter-experts like Brockovitch and Bowcock. And the ongoing concern over hydraulic fracturing for natural gas in western New York ([Groeger 2012](#); [Israel 2013](#)) shaped the reevaluation of the (heretofore uncontroversial) wells on the school property ([Mrozek 2012d](#)).

It is also worth noting that the memories of environmental incidents and threats that residents wove into their narratives to explain the outbreak were variable and unevenly distributed. One key example of this was the discrepant claims by residents about how much they and the community knew of the forty-year-old Gulf Road spill. Even within the same family, the adults contradicted each other on how memorable the spill had been ([Jayson and Weise 2012](#); [Blue 2012](#)). Claims of nonknowledge were only partly strategic, though they definitely figured in an ongoing struggle with the authorities over responsibility for remediating the spill and its consequences. The claimed ignorance also fits in with contemporary US conceptions of the environment as a repository of threats that lie hidden from human knowledge and control, emerging in unforeseen or obscure ways to wreak havoc (see Coates 1998; Beamish 2001).

In all these instances, the environment is viewed as a source of threats to personal and communal health. Even when created (or unleashed) by humans, these threats were portrayed as separate from humans (Adams 2012c; [White 2012a](#); [Orr 2012c](#)). This conception is arguably linked to a view of the environment itself as something outside of—and in various ways impinging on—the body and the community (Wakefield and McMullan 2005, 300; Bartholomew and Wessely 2007, 663; Ward Thompson 2011, 187). Here, too, most of those consulted by reporters put emphasis on the causal arrow pointing from environment (hazards) to humans (illness), even when they acknowledged humans' role in creating many of those environmental hazards.

Insights from the Outbreak

The Le Roy outbreak offers us an opportunity to reflect on some of the contours of health and illness conceptions in the contemporary US. The fact that there was any pushback at all to the official medical diagnosis shows a degree of epistemic diversity and motivational heterogeneity among those involved. That this pushback played up the “mysterious” aspects of the illness indicates not only an ongoing concern with suffering that does not clearly and immediately fit into the biomedical model, but also that even relatively well-defined and integrated types of suffering have such stigma that the afflicted, their families, and their community prefer the scariness of the unknown. That the pushback challenged the official diagnosis from within the biomedical realm—and was, if anything,

even more rigidly biomedical in demanding a nonpsychological explanation—highlights an ambivalence toward parts of the otherwise largely accepted model, especially where its “physical” and “psychological” halves meet. That those pushing back sought the ultimate cause of the suffering in human-made hazards also indicates no small amount of ambivalence among Le Royans and others toward their relationship with the humanly-altered landscape around them.

More broadly, the Le Roy case reinforces how humans exist and act within culturally constituted behavioral environments (Hallowell 1955). This is not to say that we create the world around us out of nothing, but rather that we take the elements of the world we experience and imbue them with specific meanings, then behave with reference to those meanings. For Le Royans (as for their fellow Americans), one of the key cultural factors in constituting their behavioral environment was the news media. Reporters working for highly connected media entities engaged with the various actors, linking some of them, setting still more against each other, and were themselves enrolled in the projects of some of these actors. In those interactions and their mediated results, otherwise tacit conceptions of health, illness, human nature, and the environment emerged and were more or less clearly connected to a number of affects and motivations. Mass-mediated controversies like that surrounding the Le Roy “mystery illness” are particularly useful for bringing such constellations of meaning, affect, and motivation to light. And, as I hope this article has suggested, an ethnographic perspective on such controversies can be useful for pinpointing and analyzing those constellations.

Ryan J. Cook earned a PhD in cultural anthropology from the University of Chicago. Pursuing interests in knowledge, expertise, boundary-work, and disasters, he has carried out field research projects in the United States and Mexico. He currently serves as Citizen Science Learning Researcher at the Adler Planetarium in Chicago.

The author extends his gratitude to Eugene Raikhel and the staff of Somatosphere for making the process, from initial idea to finishing touches, a true pleasure. He also wishes to thank Rebecca S. Graff for her extensive and insightful comments on multiple drafts of this article.

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AMA citation

. “I Didn’t Want to Be One of the Contaminated People”: Confronting a

Mystery Illness in a Rural American Landscape. *Somatosphere*. . Available at: . Accessed April 8, 2013.

APA citation

. (). *"I Didn't Want to Be One of the Contaminated People": Confronting a Mystery Illness in a Rural American Landscape*. Retrieved April 8, 2013, from Somatosphere Web site:

Chicago citation

. . "I Didn't Want to Be One of the Contaminated People": Confronting a Mystery Illness in a Rural American Landscape. *Somatosphere*. (accessed April 8, 2013).

Harvard citation

, *"I Didn't Want to Be One of the Contaminated People": Confronting a Mystery Illness in a Rural American Landscape*, *Somatosphere*. Retrieved April 8, 2013, from <>

MLA citation

. "I Didn't Want to Be One of the Contaminated People": Confronting a Mystery Illness in a Rural American Landscape." . Somatosphere. Accessed 8 Apr. 2013.<>