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Suspended at the Brink of Death: Encephalitis Lethargica and Allaying Public Fears, 1916-1926

Simone M. Caron
Department of History, Wake Forest University
1834 Wake Forest Road, Winston Salem, NC 27109

ABSTRACT

This article examines the outbreak of encephalitis lethargica during the era of World War I. It analyzes the scientific discussions concerning encephalitis lethargica at the national level and provides a microanalysis of how newspapers and public health bulletins in Forsyth County, North Carolina, covered the topic. These sources of information kept the public informed about the latest scientific theories, outbreaks, and means to avoid the disease, and downplayed the severity of the disease to assure the alarmed public that there was no reason to panic despite the unknown etiology of encephalitis lethargica.

Keywords: encephalitis lethargica, public health, World War I.

Encephalitis Lethargica, often referred to as "sleeping sickness," has puzzled scientists since its widespread occurrence as a public health threat from 1916 to 1926. First described by neurologist Constantin von Economo, it targeted the midbrain and basal ganglia and presented with symptoms of profound lethargy, movement disorders, psychiatric disturbances, and often coma and death. Although no resurgence of the same scale has occurred since then, sporadic cases still exist in the twenty-first century. Researchers then and now have yet to determine a proven cause, leading to unanswered scientific questions. Given its uncertain nature in the era of modern medicine, one can imagine the panic that ensued during the epidemic in the era of World War I. At that time, many scientists attributed its cause to the Kansas Influenza epidemic of 1918 to 1919. Scientists now doubt that connection. What role did local newspapers play in allaying societal fears of this frightening disease? This article examines the scientific discussions concerning encephalitis lethargica at the national level and provides a microanalysis of how newspapers and public health bulletins in Forsyth County, North Carolina, covered the topic. These periodicals downplayed the severity of the disease and touted preventative health measures to assure the alarmed public that there was no reason to panic despite the unknown etiology of encephalitis lethargica.

Most scholarly publications on encephalitis lethargica have been done by medical professionals and biomedical researchers. Oliver Sacks, the noted neurologist, published the classic work on this topic in 1973. His book *Awakenings* and the movie based on it starring Robin Williams and Robert Dinero are the best-known sources on encephalitis lethargica. Sacks documented the use of L-DOPQ in the 1960s to awaken postencephalitic patients in Beth Abraham Hospital in the Bronx, but unfortunately the treatment led to numerous adverse effects in the recovered

patients.[*] The latest book by Molly Caldwell Crosby examines this illness through case studies of patients and the doctors who cared for them.[†] Work by Kenton Kroker examines how neurologists in New York City used this disease as a means to integrate the relatively new field of neurology into the biomedical community and the field of public health. By the early 1920s, according to Kroker, New York City had become the international center for Encephalitis Lethargica research.[‡] Emily Erekson Cowan and Joel A. Vilensky examine the disease outbreak in Ohio, where twelve deaths occurred by summer 1919, leading doctors and public health officials to work together to expand medical research to develop a proper diagnosis.[§] Two recent events have briefly increased attention to this disease. First, a number of articles came out in the late 2010s to celebrate the centennial of this "strange" and "mysterious" disease.[**] Second, the Covid-19 pandemic led some scholars to compare post encephalitis lethargica symptoms to Covid "long-haulers."[††] This article adds to the historical understanding of the strange phenomenon by analyzing how newspapers and public health bulletins tried both to allay panic and to prevent further outbreaks of this disease through preventative measures.

Encephalitis Lethargica emerged in Europe in 1916 during World War I and spread around the world with peaks in 1920 and 1924, infecting over one million people until the late 1920s when it declined. At a time when Neurology and Psychiatry were expanding rapidly in the medical profession, doctors and researchers scrambled to discern the cause of or treatment for it, authoring more than nine thousand scholarly articles on the topic in the 1920s. The disease caused much social anxiety for a number of reasons. First, patients experienced a range of symptoms from lethargy, high fever, and, in severe cases, coma and death. Second, the onset of symptoms was so rapid that people could fall into a coma-like state while eating at a table and remain in this condition for weeks or months. Third, it had a very high mortality rate: thirty-three percent of those infected died. Fourth, fifty percent overall but seventy percent of children who survived encephalitis lethargica experienced severe personality alterations or other disabilities. Some developed neurological disorders similar to Parkinson's Disease. Encephalitis Lethargica did not seem to be contagious as members within the same household did not succumb to it, although some recent scholars claim asymptomatic carriers could account for this seeming lack of transmission. Most of those afflicted had earlier experienced flu-like symptoms but shared little else in common. As quickly as it arrived on the scene, it disappeared from public view by the mid-1920s as cases plummeted, although they still occurred sporadically over the next century.[‡‡]

[*] Oliver Sacks, *Awakenings* (New York: Vintage Books, 1973).

[†] Molly Caldwell Crosby, *Asleep: The Forgotten Epidemic That Remains One of Medicine's Greatest Mysteries* (NY: Penguin, 2010).

[‡] Kenton Kroker, "Epidemic Encephalitis and American Neurology, 1919-1940," *Bulletin of the History of Medicine* 78.1 (Spring 2004): 108-47.

[§] Emily Erekson Cowan and Joel A. Vilensky, "Awakenings in Ohio," *Timeline* 26.2 (2009): 42-53.

[**] Bart Lutters, Paul Foley, and Peter J. Koehler, "The Centennial Lesson of Encephalitis Lethargica," *Neurology* 90.12 (2018): 563-67.

[††] Kenton Kroker, "Encephalitis Lethargica: Last Century's Long Haulers?" *Canadian Medical Association Journal* 193.37 (2021): E1468-70; Michael Brainin, Yvonne Teuschl and Ellen Gelpi, "'Spanish Flu,' Encephalitis Lethargica, and COVID-19: Progress Made, Lessons Learned, and Directions for Future Research," *European Journal of Neurology* 31.1 (2024): 16312.

[‡‡] Dennis Rosen, M.D., "Asleep," *Journal of Clinical Sleep Medicine* 6.3 (2010): 299.

Although scientists in the twenty-first century have examined brain samples from the afflicted a century ago, no clear causation has been found. Three main theories have been advanced in an attempt to explain the disease: one, environmental factors such as toxicity; two, infectious diseases, either viral or bacterial; and three, most recently, post-infectious basal ganglia autoimmune disorder.[§§] With no definitive knowledge of this disease in the high tech biomedical world of 2025, its emergence in a nation wracked by unprecedented deaths from the global influenza pandemic elicited profound societal responses. Local public health messaging published in both newspapers and state health bulletins had two goals: one, to educate the populace on the latest scientific theories and developments, and two, to reduce panic by explaining tactics to pursue in order to lessen the chances of further outbreaks.

The first Forsyth County, NC, newspaper coverage of encephalitis lethargica occurred in the summer of 1918, two years after cases had been reported in Europe. Seeking to elucidate possible causes for it, the *Winston-Salem Journal* covered the work of British researchers who realized it was connected to the brain but were unsure of its cause, postulating that it could be related to gas poisoning from the war, bodily injury, or even alcoholism; this uncertainty led them to reason that further research "may reveal some microbe as the cause of the disease." The newspaper article ended with an alarm bell: "very frequently it is fatal."[***] Yet the article also eased fears by associating cases with war time events such as battle wounds and chemical warfare, or with personal behaviors such as substance abuse that did not apply to most people in the local community. This messaging allowed locals to distance themselves from the threat of the disease. Other local articles covered theories advanced by Dr. John Harvey Kellogg of Battle Creek, Michigan, who asserted that "many, if not all" of the cases "may have been Botulinus poisoning" in canned food: lab results linked three deaths in Grand Rapids to botulism in canned spinach. Eighteen other deaths in New York, Michigan, and Ohio were linked to canned olives.[†††] Again, the article eased public anxieties by attributing death to food products from which local citizens could abstain. Avoiding canned food in a county replete with fresh produce from copious farmlands surrounding the urban center would be easy for most locals.

Other newspaper articles did not cover the debates over causation and instead concentrated on assuring the public that encephalitis lethargica was not transmissible from person to person. Several pieces discussed attempts by Dr. Royal S. Copeland, New York City Health Commissioner, to calm fears by asserting that most researchers believed it was "not contagious in the ordinary sense." He pointed to New York City data for 1920 that showed only two instances of one household with more than one case; in both cases, only two family members were affected.[‡‡‡] Simon Flexner, Director of the Rockefeller Institute for Medical Research and member of the New York State Public Health Council, countered this theory with a scientific paper he published tracing the disease's origin to Austria in 1916, its spread to England and France in 1918, and then to the US in early 1919. He concluded it was indeed of a

[§§] Leslie A. Hoffman and Joel A. Vilensky, "Encephalitis Lethargica: 100 Years after the Epidemic," *Brain* 140.8 (August 2017): 2246-51.

[***] "War Reveals New Disease Known as Mesencephalitis," *Winston-Salem Journal*, 26 June 1918, 5.

[†††] "Sleeping Sickness May Be Form of Poison," *The Western Sentinel*, 22 February 1921, p. 2.

[‡‡‡] "Sleeping Sickness is More Prevalent," *Winston-Salem Journal*, 20 March 1921, p. 7.

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"communicable nature."[§§§] His prominence in the field of bacteriology lent additional weight to his conclusion in the scientific community, but local papers did not cover his theory of contagion. Whether this omission was intentional to avoid increased alarm in the local community or a result of ignorance of debates in biomedical journals is unclear. Another hypothesis that garnered attention in the local press was a possible connection to viral diseases. Some scientists postulated that the disease was connected to the polio epidemic that struck the United States in 1916, maintaining that encephalitis lethargica was the "first cousin of infantile paralysis."[****] Polio, however, had not been prominent in Forsyth County. Most cases occurred in New York, Massachusetts, New Jersey, and Connecticut; Forsyth County had only one case with no death or paralysis resulting.[††††] Thus this connection would not have raised the same fears as it would have done in the Northeast. Nationally, the most common causal discussion centered around encephalitis lethargica's connection to the influenza pandemic of 1918. Many experts believed half of the cases were "sequels of Spanish influenza."[‡‡‡‡] Yet only one local newspaper covered this possible explanation for the disease. Unlike polio, influenza had ravaged Forsyth County: of 40,000 residents, nearly 20,000 cases had been reported with 200 deaths.[§§§§] Downplaying the connection between influenza and encephalitis lethargica could have helped reduce panic in the local community. In the scientific publications, Flexner dismissed this connection, stating "its relation to other diseases, namely influenza. . .is merely conjectural."[*****]

With little known about the cause and therefore how it spread, coverage of this "strange" disease brought anxiety to a populace already dazed by polio, typhoid, diphtheria, war, and a global influenza pandemic. Although no cases of encephalitis lethargica had yet occurred in North Carolina, the local newspapers' front-page coverage of deaths in New York City and Chicago increased fears among local populations. As of March 14, 1919, the US Public Health Service reported the US had 183 cases with fourteen deaths but cautioned that this number did not reflect reality because physicians were not generally reporting this disease to federal authorities. Moreover, the diagnosis of it was difficult as the main condition physicians looked for was the "presence of stupor, a condition found in many other diseases."[†††††] Many of these early deaths were in New York City, the first of which was Erskine W. Martin, a thirty-five-year old man who fell ill in March of 1919, remained in a coma for five days, and then died on March 13. By March 15 there were forty cases in New York City alone, leading City Health Commissioner Copeland to calm fears by stating there was "no cause for alarm."[‡‡‡‡‡] Despite Copeland's assurances, coverage of five cases in Chicago, all people "suspended at the brink of death," ratcheted up panic. A large picture on the front page of the *Winston-Salem Journal* showed a nurse feeding liquid nourishment to an "aroused" patient who had been in a coma at

[§§§] Simon Flexner, "Lethargic Encephalitis," *JAMA* 74.13 (27 March 1920): 865-69.
[****] Editorial, "Sleeping Sickness," *The Union Republic*, 20 March 1919, p. 1.
[††††] "The Notifiable Diseases: Prevalence during 1916 in Cities of 10,000 to 100,000," *Public Health Reports* 32.34 (August 24, 1917): 1359-62.
[‡‡‡‡] "Sleeping Sickness Follows Influenza," *The Western Sentinel*, 21 March 1919, p. 3.
[§§§§] "Influenza Situation: Some Improvement," *The Union Republican*, 31 October 1018, 6.
[*****] Flexner, "Lethargic Encephalitis," 865-69.
[†††††] "Sleeping Sickness Still Baffles Experts," *Winston-Salem Journal*, 6 April 1919, p. 1.
[‡‡‡‡‡] "Sleeping Sickness Claims First Victim," *Winston-Salem Journal*, 14 March 1919, p. 1.

Cook County Hospital. Dr. John Dill Robertson, Health Commission of Chicago, assuaged public angst, vowing that the disease was "not contagious" and was "not always fatal."§§§§§

Within a week of the outbreaks in New York City and Chicago, an outbreak transpired in North Carolina. Two cases occurred in Rocky Mount, NC, in March 1919, one white boy who was transported to a hospital in Richmond, VA, and one African American boy who existed in a "dazed condition" for two weeks. Both died.****** A week later a 45-year-old man was diagnosed in Wilmington: he had recovered from influenza but had then been sickened by Encephalitis Lethargica. After a three-week coma, he died.†††††† An unidentified patient in New Bern suffered for five weeks in a "state of coma" before dying.‡‡‡‡‡‡ Augustus Merrimon Kenney, a former UNC Chapel Hill student from Salisbury, recovered from influenza only to developed "an inflammation of the brains (sic) which was diagnosed as a form of sleeping sickness" with death resulting one month shy of his twenty-second birthday.§§§§§§ Four more cases were reported across the state line in South Carolina, prompting the US Public Health Service to send Dr. V.P. Akin to the region to investigate. Akin worked with both the North Carolina Board of Health and the South Carolina Board of Health to discern any possible patterns in the victims; he found none.*******

Local journalists seemed to employ several tactics to reduce public panic in the community over the spread of this disease. Some stories simply lied about the prevalence of the illness. The Twin City *Sentinel* claimed that the 1921 death of Fred Look, a 16 year-old boy in Charlotte, was "one of the few that have been reported in the United States" and that Johns Hopkins had only received "scattering reports."††††††† This ignored national news coverage of the 218 cases reported in New York City alone in the first seven weeks of 1921.‡‡‡‡‡‡‡ The editors of one local paper assured the public that despite "considerable alarm…over the spread of what is called sleeping sickness," New York City public health officials were "coping successfully" with it and were confident that the number of cases would "decrease rather than increase" as spring emerged.§§§§§§§ Other stories made the disease seem nonthreatening. Irene Smith, an 18-year-old teacher in Reidsville, NC, fell into a three-week sleep that "baffled" her doctors. They were able to provide nourishment, allowing her a full recovery. She returned to teaching "apparently none the worse for her long sleep."******** The story gave the impression that Irene benefited from the opportunity to rest for several weeks before resuming the arduous duties of teaching young children. The one case that occurred in Winston Salem brought similar reassuring coverage. G.C. Saunders worked for the City Water Department. He experienced overwhelming

§§§§§ "Sleep Death Newest Disease," *Winston-Salem Journal*, 6 April 1919, p. 12.
****** Editorial, "Sleeping Sickness," *The Union Republic*, 20 March 1919, p. 1
†††††† "A Case of 'Sleeping Sickness' Reported," *The Twin-City Daily Sentinel*, 21 March 1919, p. 2; "The Old North State," *The Union Republican*, 27 March 1919, p. 3.
‡‡‡‡‡‡ "The Old North State," *The Union Republican*, 3 April 1919, p. 1.
§§§§§§ "Augustus Merrimon Kenney," *Winston-Salem Journal*, 4 November 1920, p. 7.
******* "Four Cases Sleeping Sickness in S. Car," *Winston-Salem Journal*, 20 March 1919, p. 1.
††††††† "Charlotte Boy Dies of 'Sleeping Sickness'," *The Twin-City Daily Sentinel*, 3 February 1921, p. 2.
‡‡‡‡‡‡‡ "Sleep Sickness Kills One: Ten New Cases Are Reported, Including Those of Sunday," *New York Times*, 22 February 1921, p. 8.
§§§§§§§ Editorial, "Sleeping Sickness Spreads," *Winston-Salem Journal*, 6 March 1921, p. 4.
******** "Rockingham Girl Sleeps Three Weeks," *The Twin-City Sentinel*, 23 March 1922, p. 12; "The Old North State," *The Union Republican*, 23 March 1922, p. 3.

sleepiness, spent two weeks in a "continual stupor" but was recovering at his home on Poplar Street. His condition was "not considered serious" and was explained by a recent spate of cold weather that "numb[ed] the nerves that control the body." †††††††† Other stories quoted international health experts who assured the public that there was "no cause for alarm as to the possible spread of the disease."‡‡‡‡‡‡‡‡ One article's title is telling, summarizing the work of Professor Guiseppe Sanarelli, a "distinguished" Italian bacteriologists and professor at the University of Bologna: "Italian Scientist on Sleeping Sickness: Thinks Keeping Body Strong is Best Way to Keep Immune to Disease." Sanarelli concluded that encephalitis lethargica attacked only the weak and "run down." People should not be "unduly alarmed," he stated, because many presumably carried the germ but were immune from its impact until a "sudden let down in their physical condition. . .overcomes their power of resistance."§§§§§§§§ This conclusion shifted the blame for the disease to individual behavior: if people followed a righteous lifestyle, they would be protected from this ailment. Newspapers also cited local officials to assure the community that they were safe. Dr. R.L. Carlton, head of the Winston-Salem Public Health Department, stated there was "no cause for alarm from a public health standpoint, as the malady is not considered in any way contagious."********* The local paper quoted Dr. E. Giddings of Willard Parker Hospital in New York City to assure survivors of the influenza pandemic that they were not in danger. Giddings claimed blood tests had "yet disclosed the presence of any such" connection between encephalitis and influenza. Moreover, the paper covered Giddings' discussion of a novel treatment involving music: M. Haffman, a young male violinist, approached Giddings to play the violin for Mrs. Dora Mintz of the Bronx who had been in a continuous sleep for twenty days at Willard Parker. Haffman had read that violin music could stimulate certain nerve centers that laid inactive, causing the patient to rouse. Giddings allowed the experiment because Haffman was "most sincere and earnest about it and the experiment was at least a perfectly harmless one…."††††††††† The inclusion of music therapy in the title of the article gave an impression of a disease that was peaceful and restful, not dangerous and deadly. Public health officials also tried to alleviate anxiety by providing public health measures to stop the spread of the disease. At the federal level, newly appointed Surgeon General Hugh Smith Cumming sought to soothe fears by stoking the fires of xenophobia, blaming Europeans for the disease. This "mysterious disease," he claimed, was "brought from Europe" where this "plague" continued to spread. The US could avoid an epidemic, he continued, if US health officers at ports of entry were vigilant against immigrants coming from "infested European centers" where "sleeping sickness" had "become epidemic."‡‡‡‡‡‡‡‡‡ This blaming of "the other" for disease has a long and continuous history in the United States, from blaming Jews for typhoid in the late nineteenth century, African Americans for tuberculosis in the early twentieth century, Haitians for AIDS in the 1980s, to Asians for Covid-19 in the 2020s. At the state level, Dr. A. McR. Crouch,

†††††††† "Suspected Case May be Sleeping Sickness," *The Twin-City Sentinel*, 1 February 1922, p. 5; "Suspected Case," *The Western Sentinel*, 3 February 1922, p. 5; "Gradually Rousing from His Sleepiness," *The Western Sentinel*, 10 February 1922, p. 7; "Gradually Rousing from his Sleepiness," *The Twin-City Daily Sentinel*, 9 February 1922, p. 5

‡‡‡‡‡‡‡‡ "Sleeping Sickness Appears in London," *Winston-Salem Journal*, 29 February 1920, p. 19.

§§§§§§§§ "Italian Scientist on Sleeping Sickness: Thinks Keeping Body Strong is Best Way to Keep Immune to Disease—Germ has not yet been Discovered," *Winston-Salem Journal*, 19 February 1920, p. 11.

********* "Suspected Case May be Sleeping Sickness," *The Twin-City Sentinel*, 1 February 1922, p. 5.

††††††††† "Music is Tried as Cure in 'Sleeping Sickness'," *The Twin-City Daily Sentinel*, 8 November 1919, p. 25.

‡‡‡‡‡‡‡‡‡ "Must Put Bars Up Against Disease: Surgeon General Cumming Says Immigrants Should be Watched Closely to Keep Out Infections Maladies," *Winston-Salem Journal*, 8 March 1920, p. 1; Editorial," Sleeping Sickness Spreads," *Winston-Salem Journal*, 6 March 1921, p. 4.

the North Carolina State Epidemiologist, sent letters to all physicians requiring them to report cases in an effort to ward off a "threatened epidemic." They should treat this "new" disease as a "germ" case and keep patients isolated. With no known treatments, he recommended keeping the patient comfortable, well nourished, and free of indigestion that often accompanied the "sleeping sickness."§§§§§§§§§ Local doctors informed the community that this "malady" often started with a "bad cold" that was "not likely" to cause "serious result unless persons neglected to take the usual precautions" when battling a cold. To evade the disease, people should "avoid persons suffering from colds, . . . stay in the open air as much as possible, . . . dress warmly, and . . . mingle in crowds no more than necessary. Washing the hands and mouth in disinfectants after being in a crowd is also recommended."********** Public health notices warned people to be vigilant, watching for symptoms of dizziness, aching, drooping eyes, drowsiness, sore throat, or loss of strength or mobility, and report them immediately to the Winston Salem Board of Health.†††††††††† By following these "simplest means," the community would be safe from this new and little understood disease.‡‡‡‡‡‡‡‡‡‡

Almost as quickly as it came, encephalitis lethargica nearly disappeared by the late 1920s. In 1927, William J. Matheson established a Commission to research the disease. Matheson had contracted influenza in 1918, followed by a leg tremor that no one could explain. One neurologist diagnosed him with Parkinson's disease, but another concluded it was encephalitis lethargica. Matheson used his fortune made from chemical manufacturing to establish a six-member committee composed of neurologists and public health officials to centralize research. He believed his commission would find a cure within two years.§§§§§§§§§§ His estimate was wrong as there is still no cure for it. Decreasing cases by the mid to late 1920s led researchers to shift their focus to other more prevalent diseases. The North Carolina Board of Health made no further mention of encephalitis lethargica in its records other than a brief reference in 1930 in a list of diseases that would prohibit a person from traveling on any common carriers.**********
While North Carolina was not an epicenter of the disease in the early 1920s, the public was aware of the severity of it through newspaper coverage and public health announcements. These sources of information kept the public informed about the latest scientific theories, outbreaks, and means to avoid the disease, thereby hoping to quell public panic. They assured the community that proper nutrition, adequate sleep, and avoidance of sick individuals would prevent them and their families from this new and frightening illness. In many ways, public health reactions to encephalitis lethargica resembled those a century later when Covid-19 swept the globe. Both illnesses sparked widespread fear and major public health responses, and both highlighted the limits of medical understanding in their times. Each left behind a cohort of patients with chronic disability: post-encephalitic Parkinsonism versus long Covid. While encephalitis lethargica remains an enigmatic epidemic of the past with unresolved etiology, teams of researchers confirmed the viral etiology of Covid-19, leading to vaccines and

§§§§§§§§§ "Requests Reports of Sleeping Cases," *The Western Sentinel*, 4 April 1919, p. 3.
********** Editorial, "Sleeping Sickness," *The Union Republic*, 20 March 1919, p. 1.
†††††††††† Editorial, "Sleeping Sickness," *The Union Republic*, 20 March 1919, p. 1.
‡‡‡‡‡‡‡‡‡‡ Editorial, "Sleeping Sickness," *The Union Republic*, 20 March 1919, p. 1.
§§§§§§§§§§ Kroker, "Epidemic Encephalitis," 2004, pp. 132-33.
********** "Transportation of Persons Having or Thought to be Suffering With a Communicable Disease," *Twenty-Third Biennial Report of the North Carolina State Board of Health*, Vol. 23 (July 1928 – June 1930): 219.

antiviral therapies that provided some semblance of protection and security to people in the 2020s that those living in the 1920s were unable to achieve.

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