

Mystery skin disease Morgellons has no clear cause, CDC study says

By JoNel Aleccia, NBC News
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plos.org A patient shows the scarring scabs attributed to the odd skin disease Morgellons, in which victims say fibers and other material extrudes from sores on their skin.

A strange disease in which sufferers say they find fibers, fuzz and other debris sprouting from sores on their skin is not contagious and has no clear cause, the largest-ever study of the condition called Morgellons has found.

Government health officials on Wednesday released the results of a four-year, nearly \$600,000 review that found no infectious or environmental link to Morgellons, which reportedly plagues thousands of people in the United States and other countries.

“It’s a negative, but it really limits and narrows down the field of possibilities,” said Mark L. Eberhard, director of the division of parasitic diseases and malaria at the Centers for Disease Control and Infection. “By removing a couple of the big players -- infections and the environment -- that still leaves some wide-open

territory about what could be the causes.”

The new study should reassure sufferers who worried about infecting family and friends, he added.

Researchers studied 115 people who reported Morgellons-like symptoms from the Kaiser Permanente health system in Northern California from July 2006 to June 2008, amounting to a rate of 3.6 cases of the disorder per 100,000 people. They conducted extensive interviews, tested patients' blood and urine, and studied biopsies of skin samples. It's considered the first detailed, population-based analysis of “unexplained dermatopathy,” which is how researchers describe Morgellons.

The CDC and Kaiser Permanente initiated the study in January 2008, after CDC officials received hundreds of calls and e-mails about an odd, fiber-sprouting skin disease. By the time the study was launched, the agency had heard from some 1,200 people. The mysterious disorder was dubbed Morgellons in 2002 by a Pennsylvania mother of a toddler who reportedly suffered from the disorder first identified in 17th century France.

But scientists writing in the journal PLoS ONE also found nothing remarkable about the threads and fuzzballs patients reported emerging from lesions on their skin, which laboratory analysis showed were cotton or other fibers, possibly from clothing. They also couldn't explain the creepy-crawling, tingling or pins-and-needles feeling that many sufferers said they experienced before rashes, sores and ulcers emerged. No parasites or mycobacteria were detected.

The scientists suggested that Morgellons victims may suffer from a condition similar to “delusional infestation,” in which people imagine bugs or other critters invading their bodies.

“No common underlying medical condition or infectious source was identified,” wrote Eberhard and his colleagues.

But people who believe they suffer from Morgellons said that was exactly the result they expected from a government agency trying to cover up a larger problem.

“I’m pretty sure they’ll say we’re all delusional,” said Jan Smith, 62, a Concord, N.H. woman who runs the website “Morgellons Exposed,” which details her 15-year battle with the perplexing disorder. Her theories include fears that Morgellons is caused by alien beings implanting nano-technology in humans.

“There’s so much more to this than a medical condition,” Smith said. “There’s something being hidden.”

Betsy Curry, 65, of Palm Bay, Fla., said she has endured sores and scabs all over her body for eight years, lesions that she said have extruded threads or fluff. She didn’t expect the government report to offer any more help than the dermatologists and other doctors who dismissed her complaints.

“I’ve had years of doctors telling me something was wrong with me, I was crazy, I was too fat,” said Curry, whose condition was described on Inspire, an online support community.

“After eight years, it’s just something I accept.”

Morgellons sufferers were mostly white, middle-aged women, more than half of whom reported they were in poor health, the study showed. Like Curry, about 70 percent of the victims also suffered from chronic fatigue syndrome and more than 60 percent reported ongoing bodily aches and pains.

About 60 percent showed problems with cognitive functioning. About half had evidence of drugs in their system, including drugs to control pain, and nearly 80 percent reported exposure to solvents, the study showed. About 40 percent had skin lesions or abrasions that appeared to be caused by self-inflicted rubbing or scraping, researchers found.

But the study shouldn’t be interpreted to conclude that the problem is all in sufferers’ heads, Eberhard stressed. Instead, it should be a baseline for future research and encouragement for patients and their doctors to work together, harder, to find a cause.

“These people are definitely suffering from something,” Eberhard said. “It has impacted their lives greatly.”

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