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Skin Lesions and Crawling Sensations: Disease or Delusion?

by Ginger Savely, NP, and Mary M. Leitao

I first began seeing patients with a constellation of odd symptoms in 2002. Several patients with chronic, debilitating illnesses alerted me to their nonhealing skin lesions. These patients also reported crawling and stinging sensations under the skin. Fiber-like strands and granule-like objects were associated with their skin lesions.

With a hand-held digital microscope, I was able to see a network of blue fibers under the skin and blue and white fibers protruding from their lesions. On several occasions I attempted to remove the tough, white filaments and found these to be quite resistant to extraction.

A colleague informed me that the Morgellons Research Foundation had described a disease matching what I observed in my patients. I contacted the foundation and learned that my state, Texas, was second only to California in the number of reports of this bizarre condition, which the foundation designated Morgellons disease.

Signs and Symptoms

Patients with Morgellons disease typically experience sensations of insects crawling on, stinging and biting their skin. Their skin lesions can be minor or disfiguring. These lesions often contain fiber-like material that can be removed as single strands or what appear to be balls of fibrous material.

Patients frequently describe this material as "fibers," "fiber balls" or "fuzz balls." Granules removed from patients' skin and viewed under a microscope often appear to have one or more fibers attached at the ends. Patients often describe these granules as "seeds," "eggs" or "sand." Many report material they describe as "black specks" or "black oil." Some patients have intact skin with the crawling sensations. The fibrous, granular or black material is the only visible indicator of disease.

According to the Morgellons Research Foundation, most patients (95%) report symptoms of disabling fatigue and self-described "brain fog" or problems with attention. Patients report a high incidence (50%) of fibromyalgia, joint and muscle pain and sleep disorders. Other common symptoms are hair loss, rapid visual decline, neurological disorders and, occasionally, healthy teeth that appear to disintegrate. Most patients are unable to continue working, and those who do work report that they do not function optimally.

Psychological Complications

The majority of patients with Morgellons disease have been diagnosed with a psychosomatic illness. The average patient seeks help from between 10 and 40 providers and reports that symptoms are not taken seriously.

Patients report that most providers do not even perform a thorough exam. Instead, they make an instant diagnosis of delusions of parasitosis, a psychiatric disorder in which patients mistakenly believe that they're infested with a parasite.^{1,2} These providers attribute the obvious open sores on patients' skin to attempts at self-mutilation.

One patient described his experience with Morgellons in this way: "I have had this disease for 20 years. I spent the first 10 years going from doctor to doctor for help. I spent the last 10 years just living with it, knowing that no one would ever help me."

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A high incidence of psychopathology confounds the clinical picture for these patients. Mental illness appears to be directly attributable to this disease: As patients seek validation for an insidious infectious disease that defies logic, some of them exhibit obvious symptoms of mental illness. It appears that the underlying infectious disease, which has been unrecognized and untreated, can cause psychopathology in many patients.

Epidemiology and Transmission

California, Texas and Florida appear to have the highest number of reports of Morgellons disease, with primary clusters in Los Angeles, San Francisco, and Houston, Dallas and Austin, Texas. All 50 states and 15 nations, including Canada, the United Kingdom, Australia and the Netherlands, have documented cases of the disease. The total number of registrations to the Morgellons Research Foundation Web site is currently 1,700, which the foundation believes to be a fraction of the actual number of cases.

The two main occupational groups reporting symptoms of Morgellons disease are nurses and teachers. Nurses outnumber teachers 3 to 1, but both occupational groups represent a significant percentage of patients with this disease. It is unclear what the risk factors might be, but researchers are exploring the possibility of casual transmission.

There is some evidence that skin lesions and fibers may not be readily apparent on all people with this disease, and family members of patients often report similar systemic disease symptoms without skin symptoms. Whether the disease is transmissible by human contact is unclear. Although affected people are fearful of infecting family members, families with multiple cases are likely to have had simultaneous mutual exposure.

Patients have also reported symptoms in their pets. Most reports involve dogs, but cats appear to be increasingly affected. Several horse owners, using lighted 30x handheld microscopes, have observed fibers associated with skin lesions on their animals.

Pathophysiology

Skin biopsies of Morgellons patients — even samples with fibrous material — typically reveal nothing specific. At most they suggest an inflammatory process with no observable pathogens. In general, pathologists look for signs of known diseases and may miss clues of this disease in biopsies.

Some preliminary research shows that the fibers in Morgellons disease are made of cellulose, but this observation has never been formally studied. Studies have identified fibers composed of a cellulose-protein complex as a minor constituent of mammalian connective tissue. One study found increased amounts of these fibers in tissue from patients with scleroderma and other pathological skin conditions.³

Morgellons and Lyme Disease

Many patients with Morgellons disease have positive Western Blots for *Borrelia burgdorferi*, the causative agent in Lyme disease. There may be a connection between the two infectious diseases, with one agent possibly predisposing the patient to the second agent. Whether all patients with Morgellons disease also have Lyme borreliosis remains to be seen. The etiologic agent(s) of Morgellons disease is unclear.

Treatment and Prognosis

Until a formal study of Morgellons disease is launched, the cause, transmission and treatment of this disease are uncertain. As the number of documented cases rises, the Morgellons Research Foundation hopes that government health authorities will begin to take note and support investigation into the cause and epidemiology of the disease.

I now have 31 patients who fit the criteria for Morgellons disease. These patients have come to me from all over Texas, desperate for answers. I continue to be impressed with the consistency of their stories. All but one of these patients have tested positive for Lyme borreliosis, so I am currently treating them with antibiotics and seeing some remission in Morgellons symptoms. The antibiotics I've used are doxycycline (Periostat), clarithromycin (Biaxin), metronidazole (Metroloction), sulfamethoxazole/trimethoprim (Bactrim), and IM ceftriaxone (Rocephin). Any kind of topical ointment can provide symptomatic relief of the lesions — I've found that the primary benefit is in providing a protective barrier.

As NPs, we must strive to look beyond what we have been taught when confronted with new and puzzling symptoms in patients. Rather than being quick to pigeonhole these patients into a psychiatric diagnosis, we owe it to them to thoroughly investigate the cause of their symptoms. Morgellons disease is a reminder that we have much to learn by really listening to the patient.

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Ginger Savely is a family nurse practitioner at South Austin Family Practice Clinic in Austin, Texas. She has a special interest and training in the treatment of tickborne diseases. Mary Leitao is founder and executive director of the Morgellons Research Foundation, which is dedicated to her son Drew, who has Morgellons disease.

COMMENTS

I am understanding more each day about this horror I suffer every day. My concern is lack of awareness. I notice most posts are outdated. Please don't give up For the sake of our grandchildren we must move forward and force awareness on society. We desperately need funding to help with research on this disease. Can we strive for a national awareness day, posts on facebook, and every social network out there. Ask our family and friends to post something or do fundraisers to help fight this disease. Together we can move mountains. I will do everything in my power to help our cause. Please email me with your ideas.We can do this.....
kmiranda@ptd.net

KATHY MIRANDA, NOT AT THIS TIME October 09, 2012
GULFPORT, FL

Just this morning I was watching Discovery Health and watched the episode regarding Morgellons and got your name from there. Long story short I have what I believe to be Morgellons. I am no different than others, diagnosis of delusional parasite, self infliction but in the beinging with each visit with Doctors they were treating me with fungus meds and perimithine. I have been battling this condition for two years. Moved out of the house where it first started found out the new tenants total 7 occupants have the same leisons and rash that I have

So my question is is there a Doctor that is closer to me than you (Columbus GA) any help you can give me I would be so grateful. My fund are limited or I would come to see you. Sincerely, Belinda Sandoval

Belinda Sandoval, N/A December 21, 2010
Columbus, GA

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