



[[back to articles & presentations](#)]

Articles and Presentations

Delusions of Parasitosis versus Morgellons Disease: Are They One and the Same?

By Ginger Savely, RN, FNP-C and Mary Leitao, Director of the Morgellons Foundation
(www.morgellons.org)

This article will be published in ADVANCE for Nurse Practitioners

Primary Author:

Ginger Savely, FNP-C
South Austin Family Practice Clinic
4534 Westgate Blvd Suite 108
Austin, TX 78745
Fax: (512) 899-8460
Email: savely@austin.rr.com

Ginger Savely is a family nurse practitioner working in a family practice clinic in Austin, Texas. She has bachelors degrees in both Psychology and Nursing and graduated summa cum laude in her nursing class at the University of Texas where she was named Outstanding Graduating Senior. She has masters degrees in both education and nursing. Ginger has a special interest and training in the treatment of tick-borne diseases and is recognized nation-wide for her work in this area. She is a member of ILADS, a prestigious group of world experts on the treatment of Lyme and other tick-borne diseases. Ginger was honored by her peers by being selected to receive the 2004 Texas Nurse Practitioner of the Year Award.

Secondary Author:

Mary M. Leitao, BS
Executive Director Morgellons Research Foundation
101 Cedar Brook Ct McMurray, PA 15317
Email: morgellons@aol.com

Mary Leitao is the founder and Executive Director of the Morgellons Research Foundation. This foundation is dedicated to her six year old

son, Drew who has Morgellons Disease. She graduated Magna Cum Laude from the University of Massachusetts at Boston with a BS in Biology. She has worked at Massachusetts General Hospital and the University of Massachusetts Medical Center as an Electron Microscopist and an Immunohistochemist.

Introduction:

Delusions of Parasitosis (DOP), also known as Delusional Parasitosis (DP), or Eckbom's Syndrome, is a psychiatric disorder in which patients mistakenly believe they are infested with a parasite.[1,2] When two people both describe symptoms of DP, the condition is termed Folie à deux (madness of two).[3] There is also Folie à trois (madness of three), and Folie à quatre (madness of four). Delusional Parasitosis affecting all members of a family is considered Folie à Famille (madness of family).[4]

Patients often refuse to accept a psychiatric diagnosis for their skin symptoms and findings, continuing to insist they are infested. In medical school, physicians learn of the "matchbox sign" of DP, so-called because patients carry samples of "hair," "lint," or "fuzz" to the physician in a matchbox, in a desperate attempt to provide evidence of the agent responsible for their torment. Antipsychotic medications such as Pimozide (Orap) are often prescribed for these patients.[5]

The Problem:

The philosopher Thomas Kuhn proposed that scientific communities operate within a rigid set of assumptions and therefore are not susceptible to a paradigm shift when confronted by an anomaly.[6] In medicine we form differential diagnoses based on what we already know and when unusual symptoms do not fall within those boundaries we doubt both the symptoms and the patient. Suppose that we in the medical world are overlooking an important and previously unrecognized skin condition, dooming patients to unending frustration and suffering by not validating or attempting to treat a devastating infection? The few medical professionals who have become involved with the diagnosis and treatment of this disorder are becoming increasingly convinced that these patients have been unfairly treated and are actually suffering from a puzzling disease, which causes horrific symptoms and psychiatric sequelae in some individuals.

I first began seeing patients with symptoms of DOP in my clinical practice in 2002, when several patients with chronic, debilitating illnesses alerted me to their non-healing skin lesions. These patients also experienced crawling and stinging sensations under the skin, as well as the presence of fiber-like strands and granule-like objects associated with skin lesions. With a hand-held digital microscope I was able to visualize a network of blue fibers under the skin of these patients, as well as blue and white fibers protruding from their lesions. On several occasions I attempted to remove the tough white filaments that I saw protruding from the lesions, 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 had observed in my patients. I contacted the foundation and was informed that my state, Texas, was second only to California, in the number of reports of this bizarre disease, which they had chosen to call Morgellons Disease.

History:

The name "Morgellons Disease" was based on a disease described in the 1600s by Sir Thomas Browne. Dr. Michel Etmüller's later microscopic drawings of objects, associated with what was then believed to be a worm infestation of children, appear similar to microscopic views of fibers from present-day sufferers of this disease.[7]

The Morgellons Research Foundation began accepting registrations from people with symptoms of this unrecognized disease in 2002. The original focus of the foundation was on skin symptoms, but it soon became evident that other consistencies within this patient group, such as disabling fatigue, life-altering cognitive decline, joint pain, and mood disorders, were of much greater concern.

Symptoms:

Patients with Morgellons Disease typically have symptoms which include insect-like sensations: i.e. crawling, stinging, and biting sensations, as well as skin lesions, which can be minor to disfiguring in their appearance. Fiber-like material can often be removed from skin lesions as either single strands or what appear to be balls of wound fibrous material. Patients frequently describe this material as “fibers,” “fiber balls,” or “fuzz balls.” Granules removed from the skin of patients can often be seen microscopically to have one or more fibers attached at the ends. Patients often describe these granules as “seeds,” “eggs,” or “sand.” Many individuals report material described as “black specks,” or “black oil.” Some patients have no observable skin lesions, and have intact skin, with the skin sensations and fibrous, granular or black material being the only visible indicator of this disease.

According to statistics from the Morgellons Foundation, the majority (95%) of patients 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, as well as sleep disorders. Other symptoms reported frequently are hair loss, rapid visual decline, neurological disorders and occasionally teeth which, despite the lack of caries or gingivitis, appear to disintegrate. Most patients are unable to continue working, and those who do work report that they do not function optimally.

The vast majority of patients with this disease have been diagnosed with a psychosomatic illness. Typically, patients have sought help from between ten and forty physicians and report that their symptoms are not taken seriously. Patients report that physicians do not even do a thorough exam but make an instant diagnosis of DOP, and attribute the obvious open sores on patients’ skin as attempts at self-mutilation. One patient described his experience with this disease in this way: “I have had this disease for twenty years. I spent the first ten years going from doctor to doctor for help. I spent the last ten years just living with it, knowing that no one would ever help me.”

The high incidence of psychopathology, which appears to be directly attributable to this disease, confounds the clinical picture for these patients, as they seek validation for an insidious infectious disease that defies logic, while sometimes exhibiting 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:

The states of California, Texas and Florida appear to have the highest number of reports of this disease, with primary clusters noted in Los Angeles, San Francisco, Houston, Dallas, and Austin, Texas. All fifty states and fifteen nations, including Canada, the UK, Australia and the Netherlands report cases of Morgellons. The total number of registrations to the Morgellons Research Foundation website is presently 1200, which is believed by the foundation to be a fraction of the actual number of cases.

The two main occupational groups reporting symptoms of Morgellons are nurses and teachers. Nurses outnumber teachers 3:1, but both occupational groups represent a significant percentage of patients with this disease. It is unclear what the risk factors for these two occupational groups might be, but the possibility of casual transmission of infectious agents has been entertained.

There is some evidence to suggest that skin lesions and fibers may not be readily apparent on all individuals with this disease, as family members of patients often report similar systemic disease symptoms, without skin symptoms. Whether the disease is transmissible by human contact remains unclear. Although most sufferers are fearful of infecting family members, families where all are affected are ones where simultaneous mutual exposure is suspected.

Patients have also reported symptoms of this disease in their pets. The majority of reports involve dogs, but cats appear to be increasingly affected. There have also been recent reports of horses with skin lesions fitting the description of Morgellons lesions. Several horse owners have observed fibers associated with skin lesions on their animals, by using lighted 30x handheld microscopes.

Pathophysiology: what little we know

Skin biopsies of patients typically reveal nothing specific, or describe an inflammatory process with no observable pathogens. Several biopsies have shown fibrous material along with skin tissue. In general, pathologists are looking for signs of known diseases, and thus may miss clues of this disease in biopsies.

There is preliminary information that the fibers are made of cellulose, but this information has neither been formally studied, nor confirmed. Studies by Hall, et al identified fibers, composed of a cellulose-protein complex, as a minor constituent of mammalian connective tissue. Hall found increased amounts of these fibers in tissue from patients with Scleroderma and other pathological skin conditions.[8]

Co-infection of Lyme Disease?

Many patients with Morgellons Disease have positive Western Blots for *Borrelia burgdorferi*, the causative agent of Lyme Disease. It appears that there may be a connection between the two infectious diseases, with one agent possibly predisposing the individual to the second agent. Whether all patients with Morgellons Disease also have Lyme borreliosis remains to be seen. There is some recent information that the fibrous, and other, material associated with skin lesions may be caused by an unknown viral agent or agents.

What next?

Until a formal study of Morgellons Disease is instituted, the cause, transmission, and treatment of this disease are uncertain. The Texas Department of Health (TDH) was alerted by the foundation to the occurrence of this disease in Texas first in 2002. The TDH dialogued with the Executive Director of the foundation in 2004, at which time the TDH conferred with the CDC (Centers for Disease Control and Prevention). To date, neither the TDH nor the CDC has initiated a program or study to investigate this disease. As the number of documented cases rises, it is the hope of the authors that governmental health authorities will begin to take note and support investigation into the cause and epidemiology of the disease.

I now have 25 patients in my practice that fit the criteria for Morgellons disease. These patients have come to me from all over the state of Texas, desperate for answers and willing to go anywhere to be treated with dignity and taken seriously. I continue to be impressed with the consistency of their stories. All but one of these patients have tested positive for Lyme borreliosis by Western Blot through IGenEX Laboratories in Palo Alto, California. When I treat these patients with antibiotics for their Lyme disease, I am seeing remission in Morgellons symptoms in most.

The Hungarian physician, Ignaz Semmelweiss, was ridiculed in the 1850's in Vienna for suggesting that childbed fever was caused by an infectious agent. Syphilis patients were put in straight jackets in mental institutions before it was realized that they were suffering from an infectious disease. Throughout history the medical world has been reluctant to adopt new paradigms, or conceptions, of disease. 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 take their complaints seriously and investigate the cause of their symptoms.

Sir William Osler, one of the greatest physicians, humanitarians and teachers of the 19th century taught that "Medicine is learned by the bedside and not in the classroom." Recognition of Morgellons disease will serve as a reminder to us in the medical world that we have much to learn by really listening to the patient.

References:

1. Ait-Ameur, A, Bern, P, Firoloni, M. P, Menecier, P. Delusional parasitosis or Ekbom's syndrome. *La Revue de Medecine Interne*. 2000; 21:182-186.
2. Koo J, Lee CS. Delusions of parasitosis. A dermatologist's guide to diagnosis and treatment. *Am J Clin Dermatol* 2001;2:285-90.
3. Bourgeois ML, Duhamel P, Verdoux H. Delusional parasitosis: folie a deux and attempted murder of a family doctor. *Br J Psychiatry* 1992;161:709-711.
4. Daniel E, Srinivasan TN. Folie a Famille: Delusional parasitosis affecting all the members of a family. *Indian J Dermatol Venereol Leprol* 2004;70:296-297.
5. Koo J, Gambla C. Delusions of parasitosis and other forms of monosymptomatic hypochondriacal psychosis. General discussion and case illustrations. *Dermatol Clin*. 1996 Jul;14(3):429-38.
6. Kuhn TS. *The Structure of Scientific Revolutions*. 2nd ed. Chicago: University of Chicago Press; 1970.
7. Kellett CE. Sir Thomas Browne and the Disease Called the Morgellons, *Annals of Medical History*, n.s., VII 1935; 467-469
8. Hall DA, et al. Oriented Cellulose as a Component of Mammalian Tissue. *Proceedings of the Royal Society of London. Series B, Biological Sciences*, 1960. 151 (945): 497-516.

[\[top of page\]](#)

[\[back to articles & presentations\]](#)



PO Box 341461 Bethesda MD, 20827-1461
Phone: 301.263.1080 Fax: 301.263.0776
lymedocs@aol.com