

Morgellons

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Morgellons (also called **Morgellons disease** or **Morgellons syndrome**) is a name that was given in 2002 by Mary Leita^[1] to a proposed condition characterized by a range of cutaneous (skin) symptoms including crawling, biting, and stinging sensations (formication); finding fibers on or under the skin; and persistent skin lesions (e.g., rashes or sores). Doctors,^[2] including dermatologists^[3] and psychiatrists,^[4] regard Morgellons as a form of delusional infestation (also called delusional parasitosis), i.e. the belief that there is a pathogenic infestation despite contrary medical evidence.^[5]

Despite the lack of evidence that Morgellons is a novel or distinct condition and the absence of any agreed set of diagnostic symptoms,^[6] the Morgellons Research Foundation and self-diagnosed Morgellons patients successfully lobbied members of Congress and the U.S. government's Centers for Disease Control and Prevention (CDC) to investigate the proposed condition.^{[2][7]} The CDC researchers issued the results of their multi-year study in January 2012, indicating that there were no disease organisms present in Morgellons patients, the fibers found were normal clothing fibers, and suggested that patients' sensations were manifestations of "delusional infestation".^{[8][9]}

Morgellons Disease

Classification and external resources

MeSH D055535

(http://www.nlm.nih.gov/cgi/mesh/2012/MB_cgi?field=uid&term=D055535)

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History

Mary Leita^[1] and the MRF

In 2001,^{[1][10]} according to Mary Leita^[1], her then two-year-old son developed sores under his lip and began to complain of "bugs."^[11] Leita^[1], who graduated with a bachelor of science in biology and worked for five years at Boston hospitals as a lab technician before becoming a stay-at-home mother, says she examined the sores with her son's toy microscope and discovered red, blue, black, and white fibers.^{[1][12][13]} She states that she took her son to see at least eight different doctors who were unable to find any disease, allergy, or anything unusual about her son's described symptoms. Fred Heldrich, a Johns Hopkins pediatrician with a reputation "for solving mystery cases," examined Leita^[1]'s son.^[1] Heldrich found nothing abnormal about the boy's skin, wrote to the referring physician that "Leita^[1] would benefit from a psychiatric evaluation and support," and registered his worry about Leita^[1]'s

"use" of her son.^[1] *Psychology Today* reports that Leitao last consulted an unnamed Johns Hopkins infectious disease specialist who after reviewing her son's records refused to see him, suggesting Leitao herself might suffer from "Munchausen's by proxy, a psychiatric syndrome in which a parent pretends a child is sick or makes him sick to get attention from the medical system."^[13] This opinion of a potential psychological disorder, according to Leitao, was shared by several medical professionals she sought out:^[14]

(Leitao) said she long ago grew accustomed to being doubted by doctors whenever she sought help for her son, who is now 7 and still suffering from recurring lesions. "They suggested that maybe I was neurotic," Leitao said, "They said they were not interested in seeing him because I had Munchausen Syndrome by Proxy."^[15]

Leitao says that her son developed more sores, and more fibers continued to poke out of them.^{[11][13]} She and her husband, Edward Leitao, an internist with South Allegheny Internal Medicine in Pennsylvania, felt their son suffered from "something unknown."^[1] She chose the name *Morgellons disease* (with a hard *g*) from a description of an illness in the monograph *A Letter to a Friend* by Sir Thomas Browne, in 1690, wherein Browne describes several medical conditions in his experience, including "that endemial distemper of children in Languedoc, called the morgellons, wherein they critically break out with harsh hairs on their backs."^{[13][16]} There is no suggestion that the symptoms described by Browne are linked to the alleged modern cases.

Leitao started the Morgellons Research Foundation (MRF) in 2002 (informally) and as an official non-profit in 2004.^{[13][17]} The MRF states on its website that its purpose is to raise awareness and funding for research into the proposed condition, described by the organization as a "poorly understood illness, which can be disfiguring and disabling."^[18] Leitao stated that she initially hoped to receive information from scientists or physicians who might understand the problem, but instead, thousands of others contacted her describing their sores and fibers, as well as neurological symptoms, fatigue, muscle and joint pain, and other symptoms.^[13] The MRF claims to have received self-identified reports of Morgellons from all 50 US states and 15 other countries, including Canada, the UK, Australia, and the Netherlands, and states that it has been contacted by over 12,000 families.^[18]

In 2012 the Morgellons Research Foundation closed down, and directed future inquires to Oklahoma State University.^[19]

Media coverage

In May 2006, a CBS news segment on Morgellons aired in Southern California.^[20] The same day the Los Angeles County Department of Health services issued a statement saying, "No credible medical or public health association has verified the existence or diagnosis of 'Morgellons Disease'," and "at this time there is no reason for individuals to panic over unsubstantiated reports of this disease."^[21] In June and July 2006 there were segments on CNN,^[22] ABC's *Good Morning America*,^[23] and NBC's *The Today Show*. In August 2006, a segment of the ABC show *Medical Mysteries*^[11] was devoted to the subject. The disease was featured on ABC's *Nightline* on January 16, 2008,^[24] and as the cover story of the January 20, 2008 issue of the *Washington Post Magazine*.^[25]

The first article to propose Morgellons as a new disease in a scientific journal was a review article co-authored by members of the MRF and published in 2006 by the *American Journal of Clinical Dermatology*.^[26] An article in the *San Francisco Chronicle* reported, "There have been no clinical studies" (of Morgellons disease).^[27] A *New Scientist* article in 2007 also covered the phenomenon noting that people are reporting similar symptoms in Europe and Australia.^[28]

In an article published in *The Los Angeles Times* on April 22, 2010, singer-songwriter Joni Mitchell claimed to be a sufferer of the condition, stating:

"I have this weird, incurable disease that seems like it's from outer space, but my health's the best it's been in a while, Two nights ago, I went out for the first time since Dec. 23: I don't look so bad under incandescent light, but I look scary under daylight. Garbo and Dietrich hid away just because people became so upset watching them age, but this is worse. Fibers in a variety of colors protrude out of my skin like mushrooms after a rainstorm: they cannot be forensically identified as animal, vegetable or mineral. Morgellons is a slow, unpredictable killer – a terrorist disease: it will blow up one of your organs, leaving you in bed for a year. But I have a tremendous will to live: I've been through another pandemic – I'm a polio survivor, so I know how conservative the medical body can be. In America, the Morgellons is always diagnosed as "delusion of parasites," and they send you to a psychiatrist. I'm actually trying to get out of the music business to battle for Morgellons sufferers to receive the credibility that's owed to them."^[29]

On 13 June 2011, the Australian Broadcasting Corporation's 'Radio National' broadcast *The mystery of Morgellons* with guests including the Mayo clinic's Professor Mark Davis.^[30]

On February 3, 2012, the Russian Channel One popular *Let Them Talk* show hosted by Andrey Malakhov, in the programme entitled

"The Curse of The World's End" featured several alleged victims of the disease in the studio some of whom provided home-made footage. According to one of the guests, Valentina Serova, in Rostov oblast where she came from, the spread of Morgellons has gained epidemic proportions and is totally ignored by the state.^[31] Among theories and hypothesis aired, one dealt with the possible result of bacteriological weapons testing (Salsk Steppes, in particular, were rumoured to have served as sites for such testings in the USSR). One of the invited experts, Irina Ermakova, head of the National Genetic Security Association of Russia, linked the possible origins of Morgellons directly to the production of GMO, claiming that of the 15 thousand families afflicted by the disease around the world, the majority live nearby fields where transgenic plants are being produced.^[31]

Former Major League Baseball pitcher Billy Koch and his entire immediate family have been noted in the media to be sufferers.^{[32][33]}

CDC investigation

Following a mailing campaign coordinated by the Morgellons Research Foundation in which self-described sufferers clicked on the foundation Web site and sent thousands of form letters to members of Congress, a Centers for Disease Control and Prevention (CDC) task force first met in June 2006.^{[2][34]} In July 2006, Dan Rutz, MPH, a communications specialist for the CDC, said, "We're not ready to concede there's a new disease, but the volume of concern has stepped up because a lot of people are writing or calling their congressmen about it."^[35] By August 2006, the task force consisted of 12 people, including two pathologists, a toxicologist, an ethicist, a mental health expert and specialists in infectious, parasitic, environmental and chronic diseases.^[36] In May 2007, KGW-TV Newschannel 8's Laural Porter asked Rutz if he had any information about the nature of the fibers. At that time Rutz said, "None. We don't know. We haven't studied them in a lab yet. There is nothing to imply there is [an infectious process], but our mind is open to everything, including that remote possibility."

In June 2007, the CDC opened a website on "Unexplained Dermopathy (aka 'Morgellons')".^[7] By November 2007, the CDC had announced an investigation process, stating that, "The primary goals of the investigation are to better describe the clinical and epidemiologic features of this condition and to generate hypotheses about possible risk factors."^[7] Kaiser Permanente in Northern California was chosen to assist with the investigation, which began after the scientific protocols and review board structure had been prepared and approved. Investigators planned to report on the geographic distribution of the illness, and estimate rates of illness in affected communities. The investigation involved skin biopsies from affected patients, and characterization of foreign material such as fibers or threads obtained from patients to determine their potential source.^{[7][37]} In January 2008 it was reported that the CDC was enlisting the aid of the U.S. Armed Forces Institute of Pathology and the American Academy of Dermatology "to conduct 'immediate' and 'rigorous' research."^[38]

On 4 November 2009, the CDC issued a preliminary report based on an external peer review of the project.^[39] As of 24 March 2011 the CDC said "We recently completed the data analysis. A final report has been submitted for publication in a peer-reviewed scientific journal."^[40]

On 25 January 2012 the CDC released the results of the study finding no infectious or environmental links.^{[8][9]} The study consisted of skin biopsies, blood tests, and interviews of over 100 Morgellons patients, and yielded no evidence of an infection (bacterial, fungal, or otherwise) or common environmental factor causing the problems.^[8] Laboratory analysis of the threads found by participants revealed nothing unusual, but consisted of cotton and other materials likely to be found in clothing.^[8] The researchers could not find any explanation for sensations participants reported under their skin and suggested these could be "delusional infestation," wherein people falsely believe their bodies are being invaded by small organisms.^{[8][9]} Various Morgellons groups responded to the results of the studies by saying it confirmed their expectations that the government-run study is trying to cover up larger issues.^[9] Jan Smith, owner and operator of "Morgellons Exposed", a site which hosts her theories on the cause of Morgellons (including alien nano-technology implants), believed the problem was more than a medical condition and responded, "There's something being hidden."^[9]

Mayo Clinic study

A study conducted of 108 patients at the Mayo Clinic was published in *Archives of Dermatology* on May 16, 2011. The study failed to find evidence of skin infestation despite doing skin biopsies and examining specimens provided by the patients. The study, which was conducted between 2001 and 2007, concluded that the feeling of skin infestation was delusional parasitosis.^{[41][42][43]}

Symptoms and diagnosis

Morgellons is not recognized as a unique disorder, so there is currently no list of symptoms or differential diagnosis for Morgellons that is generally accepted by the medical community. Patients usually self-diagnose based on media reports and information from the internet.

The 2007 *Atlas of Human Parasitology* covers the proposed condition in its section on "Pseudoparasites and Artifacts":

Many dermatologists refute the suggestion that this is an actual disease but instead indicate that many of these patients have psychological problems or other common skin disorders. Given the large numbers of individuals who feel that they have this affliction, it will be most helpful over the coming years to have a valid scientific assessment of Morgellons disease and its possible etiology (or etiologies). One of the chief criticisms by many patients has been that they feel the medical community and other scientists consulted have not been open to the idea that there is possibly an as yet unidentified infectious or physiologic causation for the disease. However it is certainly true that many expert parasitologists, medical entomologists and other microbiologists have in fact carefully examined fibers and other materials expressed or extracted from such patients and found that biological organisms are not present. Although an apparent association of the condition with the presence of Lyme disease has been reported (Savely et al., 2006, *Am J Clin Dermatol*, 7:1–6), further research will be needed to help resolve the validity of Morgellons disease. Until then, whether Morgellons disease is another name for delusional parasitosis or a real disease entity with a biologic or physiologic basis will remain up in the air.^[44]

The main purported symptom of Morgellons is "a fixed belief" that fibers are embedded in or extruding from the skin.^[4] The Morgellons Research Foundation claims patients have reported additional – though unsubstantiated – symptoms,^[45] including:

- formication, the sensation of insects "moving, stinging or biting" beneath the skin
- skin lesions, both spontaneous and self-inflicted
- musculoskeletal effects and pain, including joints, muscles, tendons and connective tissue
- disabling fatigue
- cognitive and emotional effects

William T. Harvey, director of the MRF medical advisory board, claimed in 2007 that Morgellons patients exhibit laboratory findings including increased levels of inflammatory cytokines, increased insulin, and antibodies to three bacterial pathogens, but did not provide evidence for these claims.^[46] Many Morgellons patients have symptoms that are also consistent with chronic fatigue syndrome, depression, obsessive–compulsive disorder, and attention deficit disorder.^[47] Rhonda Casey, chief of pediatrics at OSU Medical Center, while working with the OSU-CHS for the Investigation of Morgellons Disease, stated that her Morgellons patients looked ill with neurological symptoms, which included confusion, difficulty walking and controlling their feet (foot drop), and a sagging mouth when speaking.^[13] The OSU-CHS has issued a list of symptoms similar to that of the MRF.^[48]

Causes and pathophysiology

Delusional parasitosis and other neuropsychological disorders

Most dermatologists, psychiatrists, and other medical professionals view Morgellons as a new name for a well established condition, delusional parasitosis,^[49] also known as "delusions of parasitosis" (DP or DOP) and *Ekbom's Syndrome*: Morgellons is "a pattern of dermatologic symptoms very similar, if not identical, to those of delusions of parasitosis,"^[49] and "the vast majority"^[26] (elsewhere, 95%)^[50] of Morgellons patients are diagnosed with delusional parasitosis or another psychosomatic illness. This explanation is, however, "unpopular among individuals identifying themselves as having Morgellons disease."^[51]

In delusional parasitosis, patients hold a delusional belief that they are infested with parasites. They may experience formication, a sensation similar to that of insects crawling on or under the skin. Individuals suffering from this condition may develop elaborate rituals of inspection and cleansing to locate and remove "parasites" and fibers, resulting in a form of self-mutilation; they injure themselves in attempts to be rid of the "parasites" by picking at the skin, causing lesions, and then pick at the lesions, preventing them from healing.^[4] Patients with delusional parasitosis often present at the doctor's office with what MDs term the "matchbox sign"^{[26][52]} – a medical sign characterized by the patient making collections of fibers and other foreign objects supposedly retrieved from the skin^[4] – and, because of "unshakeable delusional ideation", strongly reject diagnoses that do not involve parasites.^{[26][53]} A significant minority of DP cases occur in groups of two, three, or more individuals in close proximity, even families, known by the French terms *folie à deux*, *folie à trois*, and *folie à famille*.^[26] Delusional parasitosis, with symptoms that have "extraordinary similarities" to Morgellons, has been described in the medical literature for over 75 years.^[54] Dr. Noah Craft, a dermatologist at the Harbor-UCLA Medical Center, Torrance, CA, has seen a handful of Morgellons patients and biopsied their skin lesions, but found

only normal skin and inflammation, as one would find in a bump that has been picked at.^[13]

Some cases of delusional parasitosis have organic causes other than those associated with neurological/psychological conditions of unknown etiology. For example, formication, the sensation that bugs are crawling under one's skin, can be caused by allergies, diabetic neuropathy, menopause, skin cancer, demodex mites, stimulant drug abuse or herpes zoster. Both dementia and mental retardation have been reported in association with DP.^[55] Symptoms associated with delusional parasitosis, including urticaria (hives), paresthesia (unexplained tingling sensations in the skin), and pruritus are common side-effects of many prescription drugs or drug abuse.^[56] The sensations are real, but the attribution of the sensations to unknown parasites and the collection of fibers is part of the delusion.

The MRF's William Harvey has written that non-healing "Morgellons lesions" have been found on infants' bodies in locations that the infants cannot themselves reach to scratch.^[46]

Some cases of Morgellons have been diagnosed as "cutaneous dysaesthesia".^[57]

Role of the Internet

Morgellons patients usually self-diagnose based on information from the Internet and find support and confirmation in on-line communities of people with similar illness beliefs.^{[51][58][59]} In 2006, Waddell and Burke reported the influence of the Internet on their self-diagnosed Morgellons patients: "physicians are becoming more and more challenged by the many persons who attempt self-diagnosis on-line. In many cases, these attempts are well-intentioned, yet wrong, and a patient's belief in some of these oftentimes unscientific sites online may preclude their trust in the evidence-based approaches and treatment recommendations of their physician."^[60] Dermatologist Caroline Koblenzer specifically faults the MRF website for misleading patients: "Clearly, as more and more of our patients discover this site (MRF), there will be an ever greater waste of valuable time and resources on fruitless research into fibers, fluffs, irrelevant bacteria, and innocuous worms and insects."^[54] Vila-Rodriguez and MacEwan said in the *American Journal of Psychiatry* that the Internet is important in spreading and supporting "bizarre" disease beliefs, because "a belief is not considered delusional if it is accepted by other members of an individual's culture or subculture."^[58]

The *LA Times*, in an article on Morgellons, notes that "(t)he recent upsurge in symptoms can be traced directly to the Internet, following the naming of the disease by Mary Leita, a Pennsylvania mother."^[59] Robert Bartholomew, a sociologist who has studied the Morgellons phenomenon, states that the "World Wide Web has become the incubator for mass delusion and it (Morgellons) seems to be a socially transmitted disease over the Internet." According to this hypothesis, patients with delusions of parasitosis and other psychological disorders become convinced they have "Morgellons" after reading internet accounts of others with similar symptoms.^{[61][62]} A 2005 *Popular Mechanics* article stated that Morgellons symptoms are well-known and characterized in the context of other disorders, and that "widespread reports of the strange fibers date back" only a few years to when the MRF first described them on the Internet.^[57]

The *Dallas Observer* writes that Morgellons may be spread via the Internet and mass media, and "(i)f this is the case, then Morgellons is one in a long line of weird diseases that have swept through populations, only to disappear without a trace once public concern subsides."^[17] The article draws parallels to several mass media-spread mass delusions. An article in the journal *Psychosomatics* in 2009 similarly asserts that Morgellons is an Internet meme.^[63]

In 2008 the *Washington Post Magazine* reported that Internet discussions about Morgellons include many conspiracy theories about the cause, including biological warfare, nanotechnology, chemtrails and extraterrestrial life.^[64]

Known skin conditions

Some cases of self-diagnosed Morgellons disease are actually other recognized skin disorders, including allergic dermatitis, contact dermatitis, idiopathic urticaria and infestation with the parasite scabies. There are also case reports of patients submitting self-dissected superficial nerves.^[3] ^{[54][65]}

Hypotheses about the fibers

Randy Wymore, a former research director of the MRF and presently director of the Oklahoma State University Center for Health Sciences' Center for the Investigation of Morgellons Disease, claims that Morgellons patients have submitted masses of dark fibers visible at 60x magnification under the unbroken skin, while unaffected individuals do not.^[3] Wymore sent samples of fibers, none of

which was collected by biopsy, to the Police Crime Lab in Tulsa, Oklahoma, for analysis. A forensic scientist at the Tulsa Police Crime Lab in Oklahoma searched the FBI's national database, but the Morgellons sample did not match any known fiber in the database.^[11] Lab director Mark Boese said the fibers were "consistent with something that the body may be producing," adding, "These fibers cannot be manmade and do not come from a plant. This could be a byproduct of a biological organism."^[11]

Dermatologists say many fibers are from clothing embedded in self-imposed sores and the fibers patients bring in bags are textile in nature.^{[13][66]} The fibers may also be peripheral nerve endings.^[65]

One self-diagnosed sufferer, who happened to be a general practitioner in England, was able to extract tropical rat mites from his skin. "What these mites do is go in through the hair follicles and find a blood vessel at the bottom. That's where they sit and that's what the 'fibres' are – their legs folded back."^[67]

Bacterial hypothesis

Three members of the Morgellons Research Foundation, including Raphael Stricker, Director and former President of the International Lyme and Associated Diseases Society (ILADS), and Ginger Savely, also an ILADS member,^[68] authored an article about Morgellons published by the *American Journal of Clinical Dermatology* in early 2006. The authors wrote that "Morgellons disease may be linked to an undefined infectious process," and reported that many patients with Morgellons disease have positive Western blots for *Borrelia burgdorferi*, the causative agent of Lyme disease, and treatment with anti-bacterials appropriate for Lyme disease leads to remission of Morgellons symptoms in most patients;^[26] however, no methodology or clinical data are provided in support of any of these claims.

Treatment

Treatment for delusional parasitosis

Many dermatologists treat Morgellons as delusional parasitosis. After a thorough medical examination to rule out known organic causes for the symptoms, delusional parasitosis patients are typically prescribed one of several typical antipsychotic drugs.^{[69][70]} In the past, pimozide was the drug of choice; in addition to antipsychotic activity, it also has antipruritic activity, meaning it inhibits the sensation of itching.^[71] However, pimozide requires frequent electrocardiographic monitoring.^[70] Currently, atypical antipsychotics such as olanzapine or risperidone are used as first line treatment.^[70] Antipsychotics are effective at treating delusional parasitosis at doses as low as one-fifth to one-tenth the dose typically prescribed for schizophrenia.^[70] It is common for patients who believe they have Morgellons to reject a physician's diagnosis of delusional parasitosis. It has been suggested that the term Morgellons should be adopted by dermatologists to enhance their rapport with their patients, allowing them to overcome this resistance.^[72]

Treatment for infectious disease

People who say they have Morgellons frequently reject the diagnosis of delusional parasitosis,^[57] "report that their symptoms are not taken seriously,"^[26] and refuse psychotropic medicine. Randy Wymore, a former MRF director, has claimed on his website that some Morgellons patients who test positive for Lyme disease obtain symptom relief using aggressive, long-term antibiotic treatment. Virginia Savely, a nurse with the MRF and member of the International Lyme and Associated Diseases Society (ILADS), claims to have similar unpublished results.^[26] The antibiotic treatment is not curative, because when it is discontinued, the symptoms return.^[47] Dermatologists say that these positive effects of antibiotic use for some patients are likely the result of a placebo effect or anti-inflammatory actions of the drugs. They advise against prescribing antibiotics, which may reinforce the patients' delusions instead of addressing what these doctors consider the core problem: delusional parasitosis.^[49] In addition, long-term antibiotic use can have serious side effects.

Self-treatment

Persons with Morgellons symptoms may turn to alternative remedies described on web sites and discussion groups. Some treatments are dangerous, however, and have included the use of bleach, veterinary medicines intended for deworming horses, and industrial insecticides.^[36]

See also

- Conspiracy theory
- Medicalization
- Münchhausen syndrome
- Quaternary prevention
- Somatoform disorder

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Further reading

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External links

- Unexplained Dermopathy (also called "Morgellons") (<http://www.cdc.gov/unexplaineddermopathy/>) from Centers for Disease Control and Prevention (USA)
- Morgellons Research Foundation (<http://www.morgellons.org/>)
- Morgellons Watch (<http://morgellonswatch.com/>)

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