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Morgellons:
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Background

General Information

Morgellons is a controversial disease of unknown cause and unknown transmission. It was labeled as such in 2001, when one mother, Mary Leita, watched as her son developed an unexplainable rash and additional symptoms. As a concerned mother and biologist by training, Leita investigated this illness and formed the Morgellons Research Foundation in 2002 to help bring together Morgellons patients from all over the world. [20]. According to Leita, there are currently over 10,000 cases in the world right now, with most of them occurring in the United States [13].

The symptoms of Morgellons vary in their severity and distribution, but they are characterized by a feeling of infestation by some sort of biting insect, as well as the presence of fibers. [20] These fibers are a very important aspect of the disease, although they are currently not well studied, so little is known about their composition or origin. [20] Additionally, there is a striking central nervous system component to the illness of many patients, which Leita described as "neurological symptoms which don't just involve the brain. These are not just crazy people who like that they are infected with bugs; these people are very ill" [13].

The Morgellons Research Foundation has a board of Medical Advisors, composed of seven top health care professionals, including Dr. William T. Harvey, the Chairman of the MRF Board of Directors. Together the Medical Advisory Board has drafted a case definition for Morgellons, which can be found under the Case Definition tab of www.morgellons.org. Some of the most important aspects of this definition are:

- The characteristic filamentous fibers

- Skin lesions

- Central Nervous System symptoms, including cognitive dysfunction and emotional changes, brain fog

- Aerobic limitation

Additionally, the Morgellons Research Foundation has published pictures of people with Morgellons lesions and fibers under their skin, as well as magnified pictures of the characteristic fibers. These images can be found on their website www.morgellons.org under the images tab.

Timeline of Morgellons

1674: In a monograph entitled, "Letter to a Friend" Sir Thomas Browne coins the term Morgellons when he writes of a disorder afflicting children as "that **endemic** distemper of children in **Languedoc**, called the morgellons, wherein they critically break out with harsh hairs on their backs."

1682: Dr. Michel Ettmuller documents microscopic objects associated with what was then described as a worm infestation of children. He produces a drawing that the Morgellons Research Foundation believes appears similar to microscopic views of present-day Morgellons [x].

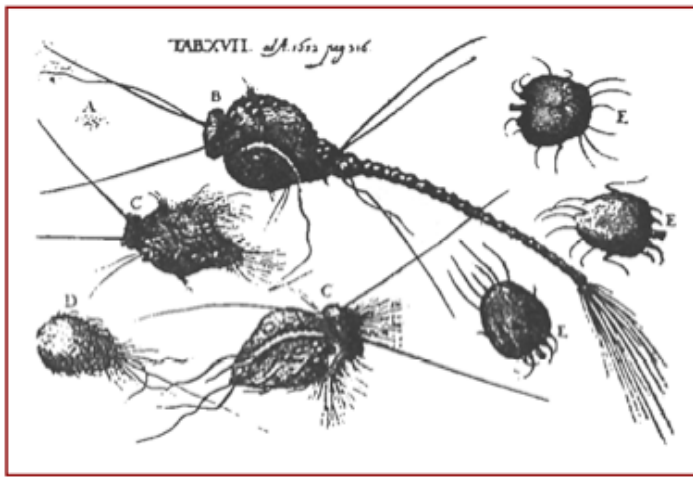


Figure 1: Etmuller's Drawing, taken from morgellons.org, permission pending.

1935: British physician C.E. Kellet publishes a paper entitled, "Sir Thomas Browne and the disease called the Morgellons" in which he equates the word morgellons as deriving from the term masclous, meaning "little flies".

2002: Mary Leitaio founds the Morgellons Research Foundation; she is the executive director. [20]

June 2005: Senators Dianne Feinstein and Dick Durbin contact the CDC, requesting that the organization formally investigate Morgellons [6].

June 2006: CDC Morgellons Task Force, chaired by Dan Rutz, first meets.

August 2006: Three executive board members of the Morgellons Research Foundation resign over a financial dispute after a disagreement with Leitaio about the use some charitable donations.

November 2006: The American Journal of Dermatology publishes a letter and two opinion pieces on Morgellons. The Journal's stance is that dermatologists should treat Morgellons patients, not for a parasitic infection but with Pimadoline, an anti-psychotic used to treat Delusional Parasitosis.

March 28, 2007: CDC removes their page on Delusional Parasitosis from their website's section on Parasitic Diseases. [26]

May 10, 2007: In an interview with KGW News, Dan Rutz says that the CDC's Morgellons research is beginning, but that he has "a pretty good idea that there is not an infectious process here. There is nothing to imply there is one, but our mind is open to everything, including that remote possibility." [22]

Development of the Controversy

Morgellons Advocates

From the case reports available, it seems clear that anyone who has ever suffered from Morgellons, or has a family member that suffered, it is an intensely painful condition, which currently has no real treatment options. Additionally, the disease is characterized by a struggle to find doctors or other health care providers who believe the patient is truly suffering from some sort of parasitic disease. Most commonly, Morgellons patients are diagnosed with Delusional Parasitosis, a condition which is characterized by the feeling of having live bugs crawling on one's body, in the absence of any real living organism. [8] According to the Morgellons Research Foundation, 31% of registered Morgellons patients have been diagnosed with Delusional Parasitosis. [13]

However, many Morgellons patients and advocates argue that doctors are too hasty to give this diagnosis, and do not properly examine the specimen brought in by patients or demonstrated under the patient's skin. Some patients become so upset and desperate that they turn to self-treatments which are often dangerous and toxic, such as insecticide baths and herbal supplements. [3] Additionally, the emotional stress endured by these patients is immense, and patients often self-identify as suicidal [3].

Patients and families with Morgellons are hoping that the CDC task force, formed in June of 2006, will provide some answers about the condition, and hopefully give them a real name for their disease. However, things are moving very slowly with the investigation. Some people, like Mary Leitaio, believe that this delay is due to the bureaucracy of the CDC, but also due to their lack of belief in an infectious agent in Morgellons. Leitaio explained the CDC's skepticism of parasites by saying that "If they thought what we thought, they would be moving very fast" [13]. In a phone interview LAUREN CITATION HERE, Dr. Randy Wymore also expressed doubt over when the CDC Task Force on Morgellons will actually begin its investigation as it has been delayed for over a year now, but said he would gladly collaborate with the epidemiological researchers should they desire to see some samples or make use of the OSU Morgellons research center's extensive online registry with a database of more than 10,000 Morgellons patients. The delay in the CDC's epidemiological investigation is distressing for Morgellons sufferers such as an Alabama woman who thinks it's because "Sometimes the government doesn't want to panic people until they can figure out a definitive cause. They're trying to figure out if this is going to be an epidemic. I hate to tell them, but it already is". [3]

Recent research, performed by two Oklahoma State University physicians, may also show promise for the future of Morgellons. Intrigued by Morgellons fibers, Dr. Wymore and his peers took fiber samples from Morgellons patients and sent them to the forensic laboratory of the Tulsa Police Department where they were analyzed. The fibers were compared against other specimen of fabrics and other materials, but they were not matched when compared to a database of over 800 known synthetic fibers. Additionally, they were not unable to identify the samples in chemical testing, although additional chromatography analyses are pending. [3]

In a phone interview with Mary Leita, she expressed that there were two important things that she would like to say to the people who are skeptical about Morgellons. First,

that "the ideological agent of Morgellons is filamentous, not imaginary, not clothing fibers, etc." Secondly that "Physicians could serve their patients best if when a physician is told by a patient that they have Morgellons, they need to look at the fiber specimen under lighted magnification of at least 30 power. (Looking with the naked eye or a simple magnifying glass will do nothing.) Maybe then they will see something that will give them good information." [13]

See our *Analysis* section for more details.

Morgellons Skeptics

Morgellons skeptics are generally divided into two groups. First, there are those who believe there is a pathology associated with Morgellons and accept it preliminarily as a "disease" with admittedly unknown cause—however they do not believe there is sufficient evidence to assume that it is caused by an infectious microorganism. A second, more extreme group of critics contests Morgellons demarcation as a category of distinct symptoms at all. Those of this viewpoint suggest that the Morgellons phenomena is best understood as a psychosis or mass-shared delusion. Physicians and scientists are representative members of both paradigms and levy various claims against Morgellons, all of them disputing its contested and as yet unproven status as an infectious disease.

The main objection to those who advocate for the existence of an infectious agent behind Morgellons comes from physicians who argue that Morgellons symptoms are psychosomatic in nature. The most common differential diagnosis for those who present claiming Morgellons is delusional parasitosis. Those who suffer from delusional parasitosis believe, mistakenly, that they are afflicted with a parasitic infection or infestation with bugs and vehemently resist physician's attempts to persuade them otherwise with contrary medical evidence. Often, seeking to persuade physicians of the legitimacy of their claims, parasitosis patients will come to the medical clinics with pieces of skin, scabs, hairs, and other samples from their body to present to their doctor as proof of infection— this is widely known among dermatologists as the "matchbox sign" (or, more contemporarily as the "ziplock bag" sign).



Figure 2: Pictures of a patient treated by Dr. D. Scott Smith for Delusional Parasitosis, presenting with the "Ziploc bag" sign and featuring skin-lesions of unknown origin.

The vast majority of physicians who treat patients with Morgellons prescribe Pimadizone, an anti-psychotic used to treat the delusions of infestation with bugs that characterizes delusional parasitosis. Obviously this is a frustrating suggested medical intervention for those with Morgellons symptoms who firmly believe that they are not delusional. In the November 2006 Journal of American Academy of Dermatology, the editors published a letter encouraging its member physicians to continue to "treat" Morgellons by allowing patients the validation of the using the term "Morgellons" but prescribing the anti-psychotic risperidone. Essentially, the American Academy of Dermatology suggests that physicians acknowledge to the patient that they suffer from "Morgellons" but then suggest treatment to relieve the symptoms with anti-psychotics. In the letter to the editor, the contributing authors emphasized the "importance of clarifying to all delusions of parasitosis patients that their condition is not a result of an infectious agent. However, we found the term [Morgellons] to be of paramount importance in establishing patient confidence and in developing patient-physician rapport throughout this patient's care." [Murase].

Dr. Noah Craft, a dermatologist and assistant professor at Harbor-UCLA Medical Center expressed his frustration that patients have been presenting for decades with complaints of parasitic infections,

but now aided by the Internet hype surrounding Morgellons they desire a diagnosis of Morgellons. Notably, Craft also believes that the CDC's pending epidemiological investigation into the clusters of Morgellons symptoms in Southern California and Texas is laudable; even if an infective microorganism doesn't cause the disease, further scientific investigation appears to be warranted.

Many physicians, especially dermatologists who often first see patients with Morgellons lesions, believe that Morgellons websites, personal blogs, and conspiracy theorists on the Internet are primarily to blame for the rise in Morgellons patients. It is notable that widespread reports of Morgellons cases— nationally and internationally—have only spiked since the symptoms were first described online at www.morgellons.com in 2002 by Mary Leita of the Morgellons Research Foundation. The information available online has fueled what some psychiatrists believe is a classic case of shared delusion, or "folie a deux" on a remarkable scale. "It seems to be a socially transmitted disease over the Internet," said Robert E. Bartholomew, an Australian sociologist who specializes in studying mass delusions [Healy LA Times]. Dr. Mary Seeman, an emeritus professor of psychiatry at the University of Toronto is concerned that the Internet and our increasingly wired online global village has changed the typical dynamics of the "folie a deux" phenomenon, and the result is a shared delusion of unprecedented size and geographic distribution [New York times article]. "When a person has something bothering him these days, the first thing he does is go online," says Dr. Seeman [nytimes article]. Bartholomew and Craft are not alone in their assessment: many believe that the information widely available on the worldwide web has encouraged a subset of truly delusional patients to cling to the "diagnosis" of Morgellons.

Dr. Randy Wymore, an assistant professor of pharmacology at Oklahoma State University and former Morgellons Research Foundation board member is nationally renowned for his scientific pursuit for answers about Morgellons fibers. Dr. Wymore