

# Morgellons disease?

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**ABSTRACT:** Morgellons disease, a pattern of dermatologic symptoms very similar, if not identical, to those of delusions of parasitosis, was first described many centuries ago, but has recently been given much attention on the internet and in the mass media. The present authors present a history of Morgellons disease, in addition to which they discuss the potential benefit of using this diagnostic term as a means of building trust and rapport with patients to maximize treatment benefit. The present authors also suggest “meeting the patient halfway” and creating a therapeutic alliance when providing dermatologic treatment by taking their cutaneous symptoms seriously enough to provide both topical ointments as well as antipsychotic medications, which can be therapeutic in these patients.

**KEYWORDS:** delusions of parasitosis, Morgellons disease, therapeutic alliance

## A case

A 60-year-old female patient presented to the psychodermatology clinic of New York Presbyterian Hospital armed with stacks of sheets of paper with “samples” that had fallen off of her body. She had taped them onto the pages with specific labels indicating where they came from on their body, such as “front of scalp,” “lining of skirt – itchy,” “back of neck – keeps coming back,” and “white stuff from buttocks.” The patient vividly described the “white spots” and “black spots” and became increasingly anxious as she described her fears of other family members catching the organism that was infesting her. Her husband reported that she had refused even to spend time with her grandchildren out of fear of contagion. She described sensations of pruritus and formication that impacted her quality of life enormously and caused her to suffer greatly. Showering several times a day and thoroughly cleaning her home provided her with some relief, but did not cure her problem. As she continuously excoriated her scalp, arms, and chest while in clinic, she told us that she was certain of

her diagnosis because of reading she had done on the internet describing a disease consistent with her symptoms. Our patient was certain that her diagnosis was Morgellons disease, and she had printouts from the internet to prove it to us.

## Signs and symptoms

Patients claiming to have Morgellons disease are a complicated and multidisciplinary challenge not only for modern medicine, but also for dermatologists attempting to treat them.

Descriptions of patients claiming to have the disease are strikingly similar, and their symptoms are consistent with that of those diagnosed with delusions of parasitosis (1–4). The primary symptom is a cutaneous dysesthesia that causes patients to pick at their skin continuously in order to “extract” an organism or “foreign body” they believe they have. The cutaneous findings that result from these patients’ attempts to dig out the suspected parasites or “foreign body” range from normal skin to minor excoriations, prurigo nodularis, and frank ulcerations. The cutaneous symptoms may be asymmetrical because of the effect of the dominant hand. Patients develop elaborate and complex stories associated with their condition.

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The authors of this paper knew of a patient who provided a very elaborate commentary on the sex lives of the organisms. As was the case in the 60-year-old patient initially described, these patients often collect “samples” in bottles or jars or on paper or slides of what is often lint, hair, debris, fuzz, dead skin, “fibers,” and even bugs found in the home. Such behaviors are known as the “matchbox sign”: patients closely document their syndrome to then use these “specimens” to provide evidence to physicians of the underlying cause of their condition. Morgellons patients claim to have observed that their skin exudes such fibers. Interestingly, the present patient did not report fibers exuding from her skin in her self-diagnosis of Morgellons even though it is considered a hallmark of the disease. Her reporting is an example of the confusion surrounding the term “Morgellons disease.” Patients also observe obsessive cleansing rituals by showering often, scrubbing their bodies to the point of self-mutilation to try to remove the suspected microbes or “foreign material,” and cleaning their living environment excessively. Patients also often hire exterminators to come frequently to their homes. These patients often go to many physicians, such as infectious disease specialists as well as dermatologists, and are frustrated when these doctors seem unable to bring them much relief and do not believe their claims.

Such a spectrum of symptoms has also been described as an example of a delusional disorder, somatic type (known also as a monosymptomatic hypochondrial psychosis) because the symptoms focus on the delusion itself and do not involve delusions or thought disorder relating to other issues. The effects on quality of life are tremendous and can be so consuming that patients are often unable to work and are too anxious about infesting others to spend time with family and friends. The level of suffering from these skin sensations is immense, and has broad ramifications on the patient’s quality of life. It is thus very difficult for patients to accept that the cause of their pathology is in the mind or the central or peripheral nervous systems (5).

## History of Morgellons disease

Morgellons disease was first described by the writer and physician Sir Thomas Browne in a passage in his work *A Letter to a Friend*, which was first published posthumously in 1690. He described, “Hairs which have most amused me have not been in the face or head, but on the Back, and not in Men but Children, as I long ago observed . . . called the

Morgellons, wherein they critically break out with harsh Hairs on their backs, which takes off the unquiet symptoms of the Disease, and delivers them from Coughs and Convulsions” (6) (p. 467–468). The condition was in fact described by a different name even earlier when, in 1544, Leonellus Faventinus de Victoriis in the book, *Diseases of Infants*, wrote, “[T]here exists in little children certain living principles having the appearance of worms that are called by the common folk Dracontia. They settle especially to the muscular parts of the body, to wit the arms and legs – the calves especially . . . they must be positively shaken into coming out into the open . . .” (p. 469–470). Browne’s term “Morgellons” comes from “mouscouloun,” meaning the hook that is attached to the end of a spindle. “Mouscouloun” comes from the Latin, “muscula,” which means little fly (p. 474).

Throughout its history, the disease had been given many titles, including Les Crinons, Masclous, Masquelons, and Morgellons. The disease continued to be written about in the medical literature well into the late 1800s, although it was, at times, difficult to assess if the writers were actually describing the same condition because of notable differences in the symptoms described. Indeed, some of the patients described may have, in fact, had a frank parasitic infection. Throughout the writings on Morgellons, the disease seemed fraught with controversy. In 1721, in *A Natural and Medicinal History of Worms*, Le Clerc wrote on Morgellons, “From the fountain of Error indicated in the second place to wit from things inanimate, are also bred a certain species of Worms which are cutaneous and called Cridones or Crinones, if they are only Hairs . . . Ettmuller indeed challenges us to the Test of Experience, and affirms by the Assistance of the Microscope he had seen those Crinons, that is, true Worms; but since Leuwenhoek by using the same Instrument did not discern them to be Worms, but Hairs or Bundles of Hairs, and an inanimate Matter, it remains that the present authors make a Judgment to themselves which of the two to believe, and which not” (p. 475).

The modern description of the symptoms of Morgellons seems different than those of the “worms” described several centuries ago. It is indeed unfortunate that this historically controversial disease was chosen in the current century as the name of the disease thought to be responsible for the symptoms that a mother observed in her son. This mother, Ms. Mary Leitao, founded the Morgellons Research Foundation in 2002. Between 1935 and Ms. Leitao’s using the term in 2002, there were no published reports on Morgellons

disease of which the authors of the present paper are aware.

With the start of this foundation and its public relations efforts, there has been much public and media attention drawn to this disease. A Google search, as of December 2007, will produce approximately 56,500 hits on Morgellons disease compared to approximately 15,400 hits in November, 2006 (7). At that time, the Morgellons Research Foundation claimed 3300 registrants compared to the 11,019 as of December 2007 along with over one million hits reported. The foundation also has a medical advisory board composed of six physicians (none of whom is a dermatologist) and two registered nurses, a board of nursing composed of three additional registered nurses, and a scientific advisory board composed of six individuals with PhDs. The foundation has developed a working case definition on its web site with seven common signs and symptoms for diagnosis including skin lesions, cutaneous movement sensations, “filaments” in or on skin lesions (these “filaments” have also been described as “fibers”) musculoskeletal effects, aerobic limitation, cognitive dysfunction, and emotional effects. The web site contends that Morgellons signs and symptoms are “far broader” than delusions of parasitosis, and that it is likely “that DP [delusions of parasitosis] is a prematurely assigned label to an organic, rather than purely psychiatric disease” (8).

The foundation has sponsored research to better understand this “newly emerging infectious disease.” Savely, Leitao and Stricker, all members of various boards of the Morgellons Foundation, described that the pathophysiology is either “nonspecific” or “an inflammatory process with no observable pathogens” and reported that “Morgellons fibers are made of cellulose” (9) (p. 3–4). These authors also provided a reason as to why Morgellons might be confused with delusions of parasitosis. They claimed that some of the associated manifestations that are psychiatric in nature – disabling fatigue, life-altering cognitive decline, and mood disorders – are caused by this dermatologic condition and should not be confused as a primary psychiatric condition. Other potential pathogens implicated are fibers with “autofluorescence,” *Strongyloides stercoralis*, *Cryptococcus neoformans*, and various other bacteria, although there has not been published information on a positive confirmatory test (5). More recently on the foundation’s web site there has been the claim of *Agrobacterium* as a possible pathogen.

In 2006, the Centers for Disease Control announced that it would launch an epidemiological investigation to better define Morgellons disease

(10). This led to published commentary by the dermatologic community arguing that Morgellons disease is really one and the same as delusions of parasitosis (5,7,11,12). Murase et al. (7) described Morgellons as a potential rapport-enhancing, trust-building title for delusions of parasitosis that enables doctor and patient to communicate more easily about the patient’s disorder, which can usually not be named during treatment. Although they did use the term “Morgellons” with the patient these authors described, they reassured the patient that they had observed no evidence of a bacterial, fungal, or parasitic infection. They further emphasized that the use of the term was not a validation of its proposed infectious disease process.

### **What’s in a name? A discussion**

As Murase et al. (7) eloquently described, the use of the term, “Morgellons disease” to converse with patients about their condition does allow for ease of communication, particularly when the patients believe that an infectious microbe is the cause of their suffering. Another rapport-enhancing term for delusions of parasitosis, however, could be chosen instead of one that is so charged and controversial. One wonders if using the term “Morgellons disease” in clinical practice may bring about a slippery slope of using patient-created diagnostic terms to describe conditions with no empiric support of their existence in the medical literature. It is also important to note that for patients with delusions of parasitosis who are already being treated with antipsychotic medications, information on Morgellons can be confusing and may negatively affect patients’ adherence to their treatment plans. The use of the term may complicate an already complicated scenario of treatment. Nevertheless, for patients who have assessed their symptoms and found information on Morgellons on the internet after physicians explain what they mean by the term (i.e., that they do not believe that the patient is experiencing an infectious process), using it may be beneficial to patient care through building trust.

### **Meeting the patient “half way” and creating a therapeutic alliance: A discussion of treatment**

Trust is central to success with these patients especially in attempting to start them on antipsychotic medications (5,13). To build this trust, it is

imperative that the dermatologist thoroughly examine these patients and carry out a detailed medical history to exclude a frank skin condition or other possible organic conditions that may be the cause such as substance abuse (such as cocaine), neurological (such as multiple sclerosis), endocrine (such as diabetes mellitus), hematologic/oncologic (such as lymphoma), nutritional (such as B12 deficiency), infectious (such as AIDS), cardiovascular (such as congestive heart failure), or renal. (For a full listing of all organic conditions that should be included in the differential for delusions of parasitosis, please see Dunn et al., 2007 (2).) It is also important that the dermatologist collaborate with a psychiatrist, either through a combined clinic (feasible at an academic medical center) or referral. Through taking a thorough psychiatric history, the physician may exclude other psychiatric conditions that may be the cause of the delusions, such as schizophrenia or psychotic depression (3). Collaborative treatment with a psychiatrist is often challenging at first because patients may deny their need for a psychiatrist and often refuse to see one. At the psychodermatology clinic at the New York Presbyterian Hospital, the present authors have worked with patients who have refused to interact with the psychiatrist during sessions, choosing to look only at the dermatologist. Nevertheless, as Driscoll et al. (1) wrote, this multidisciplinary care is ideal for patients with such conditions.

For the dermatologist treating a patient claiming to have Morgellons disease, there is not only an issue of nomenclature, but also one of action. Regardless of what the disorder is called, dermatologists must acknowledge to their patients that they know that their sensations and suffering are real and that they will do everything they can to help. The physician should then explain that the dysesthesia that the patient is experiencing is mediated, in part, by neuropeptides, and that symptoms are often improved when patients go on certain known medications that act on these neuropeptides. Koblenzer (11) reported that pimozone, with its powerful antipruritic action, has been shown to be particularly effective with Morgellons patients. Koblenzer (5) also suggested that for those patients who reportedly do not respond to pimozone, a higher dose, for a different period of time or, perhaps, a different antipsychotic (such as risperdal) should be tried. (For a discussion of psychotropic medications for patients with delusions of parasitosis, please see the Lee *et al.* article in this edition of the journal.) If patients are reluctant to take a psychotropic medication, it may be helpful to emphasize to them that these medica-

tions have worked well with patients with similar symptoms and that in light of how miserable they are, they have nothing to lose in trying the medication. It may also be beneficial to “meet the patient halfway” by prescribing a benign ointment, such as crotamiton cream, which is a parasitic medication used for scabies that also has antipruritic effects.

It is important for the dermatologist to treat secondary skin changes in these patients. By doing so, the dermatologist will help forge a therapeutic alliance with the patient by acknowledging that there are skin issues to be treated. Dermatologists should recommend soothing moisturizers, oatmeal baths and low potency topical steroids. The dermatologist should encourage these patients to stop irritating their skin by over-scrubbing when washing and, in particular, not to apply rubbing alcohol to their skin. The patient should be advised to avoid wool and to wear soft, loose, cotton clothing or fleece. Another cutaneous symptom that should be addressed is relief of patients' itch with agents such as antihistamines, including those with soporific effects.

With the prescriptions for both psychotropic medication as well as cutaneous treatment, the patient will feel that the physician listened to the patient's concerns, did not brush them off, and took them seriously. The patient will thus be more likely to adhere to the antipsychotic medications prescribed.

A peculiar finding is that patients have been reported to have recovered through the use of antibiotics (14). These antibiotics may have worked because of the placebo effect or their anti-inflammatory action. However, unless there is evidence of a secondary infection, it is not advisable to prescribe antibiotics to these patients. When antibiotics elicit positive results, patients may become increasingly convinced that their condition is the result of an infectious microbe, and use this as further evidence of infestation. They may also want more antibiotic when they run out. If their condition declines after the perceived positive effects of antibiotics, then the patient will believe that only the antibiotics made them better. The prescribing of antibiotics to these patients may thus reinforce the wrong ideas.

Lyell (4) (p. 193) wrote, “You can only help the patient by keeping in touch.” Dermatologists should be aware that these patients initially require long-term, in-depth care that may not fit into the normal structure of a dermatology clinic's typically efficient patient visits, and that work with these patients requires a multidisciplinary collaborative approach.

Once treatment starts to work, however, it can more easily fit into a normal dermatologic practice.

## Summary

Morgellons disease has recently been given much attention on the internet and in the mass media. The present authors believe that many of these patients may benefit from being treated as those with delusions of parasitosis, but that there is some utility in the use of the diagnostic term. The present authors discussed the potential benefit of using the term as a means of building trust and rapport with patients to maximize treatment benefit. They also suggested a therapeutic paradigm of “meeting the patient halfway” and creating a therapeutic alliance when providing dermatologic treatment by taking their cutaneous symptoms seriously enough to provide both topical ointments as well as antipsychotic medications, which can be therapeutic with these patients. Lastly, the present authors are aware of the importance of keeping their minds open to the possibility of yet undefined organic conditions that may exist. It is the present author’s hope that suggestions in this paper prove useful for the care and treatment of these patients.

## References

1. Driscoll MS, Rothe MJ, Grant-Kels JM, Hale MS. Delusional parasitosis: a dermatologic, psychiatric, and pharmacologic approach. *J Am Acad Dermatol* 1993; **29**: 1023–1033.
2. Dunn J, Murphy MB, Fox KM. Diffuse pruritic lesions in a 37-year-old man after sleeping in an abandoned building. *Am J Psychiatry* 2007; **164**: 1166–1172.
3. Koo J, Lee CS. Delusions of parasitosis. A dermatologist’s guide to diagnosis and treatment. *Am J Clin Dermatol* 2001; **2**: 285–290.
4. Lyell A. Delusions of parasitosis. *J Am Acad Dermatol* 1983; **8**: 895–897.
5. Koblenzer C. The challenge of Morgellons disease. *J Am Acad Dermatol* 2006; **55**: 920–922.
6. Kellett CE. Sir Thomas Browne and the disease called the Morgellons. *Ann Med Hist* 1935; **7**: 467–479.
7. Murase JE, Wu JJ, Koo J. Morgellons disease: a rapport-enhancing term for delusions of parasitosis. *J Am Acad Dermatol* 2006; **55**: 913–914.
8. Morgellons Research Foundation Web site. Available at: <http://www.morgellons.org/>. Accessed September 14, 2007.
9. Savely VR, Leitao MM, Stricker RB. The mystery of Morgellons disease: infection or delusion? *Am J Clin Dermatol* 2006; **7**: 1–5.
10. Marris E. Mysterious “Morgellons disease” prompts US investigation. *Nat Med* 2006; **12**: 982.
11. Koblenzer C. Pimozide at least as safe and perhaps more effective than olanzapine for treatment of Morgellons disease. *Arch Dermatol* 2006; **142**: 1364.
12. Waddell AG, Burke WA. Morgellons disease? *J Am Acad Dermatol* 2006; **55**: 914–915.
13. Paquette M. Morgellons: disease or delusions? *Perspect Psychiatr Care* 2007; **43**: 67–68.
14. Harvey WT. Morgellons disease. *J Am Acad Dermatol* 2007; **56**: 705–706.