COMMENTARY

The challenge of Morgellons disease

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Two letters that describe patients with "Morgellons disease," appearing in this month's issue of the *Journal*, serve to remind us that the spectrum of those with cutaneous dysesthesia is broad indeed. Though we cannot yet delineate the pathway exactly, some of the mechanisms by which the itch sensation is generated and transmitted are now understood,[1-3] and we feel that we have some sort of a grip on winter itch, itching in the elderly, the infant with atopic dermatitis,[4,5] or urticaria, lichen planus, and others of the recognized pruritic dermatoses.

Less well understood are other sensations that patients may describe to us, such as crawling, biting, stinging, pricking, burning, shooting, and so forth. These sensations may be focal or generalized, and while some patients may present to us with no visible change in the skin—those with brachioradial pruritus,[6] for example—others, reporting that the discomfort is relieved only by picking, squeezing, or pulling hair, present with neurotic excoriations, prurigo nodularis, or trichotillomania.[7,8]

A separate group of patients are those unfortunate few who have an inherent need to "know" and to understand what is going on with their skin. These patients, made very anxious by the vacuum in their knowledge, and perhaps also by their inability to attain relief from professionals will, with great ingenuity, "create" a "cause" for their symptoms, which makes logical sense to them, and with which they can be comfortable. Because of the nature of the sensation, many of these patients believe themselves to have an infection or infestation, and we are of course all familiar with the syndrome of delusions of parasitosis, or Ekbom's disease,[6,9-12] as is described in the two letters.

This condition[12] has recently reverted to the name given by Sir Thomas Browne in 1674, to an apparently identical symptom complex, Morgellons disease.[15] What is remarkable in Sir Thomas Browne's description, in the literature references over the past 75 years,[6,11-14] and in the complaints of our patients today, is the extraordinary similarities that they all describe—in the quality of the sensory changes experienced, in the level of the patient's distress, in the various and ingenious interpretations of what may be happening in the skin, and in the ongoing and desperate search for relief. The patients are virtual carbon copies, one of the other.

The clinical picture is unmistakable. The patient is intensely anxious, is obsessively focused on his or her symptoms, brings "specimens" of the offending agent, or agents, and is unshakable in his or her belief as to the cause. Usually there will be a logical explanation of exactly how the infection or infestation was contracted, and the patient will have resorted to the most extreme measures both to eradicate it and to prevent contagion.[6,9-12] Furniture is discarded, clothing burned, and close physical contact denied. Tragically, grandmothers will not touch their grandchildren—for although the condition may occur at any age, and in both sexes, elderly women living alone are the most common demographic.

It is important for us to realize that, just as the patient describes, the sensation that is experienced is in the skin. It is understandable, therefore, that the patient is not open to the idea of pathology in the mind, the nervous system, or the brain. It is also important for us to distinguish delusional beliefs from phobic concerns or obsessional worries, a distinction that caused some confusion in the past[13] and that is important, because both the psychopathology and the treatment are different between the three.[11]

The syndrome may be seen in association with a number of psychiatric conditions, including bipolar disorder, paranoia, schizophrenia, depression, and abuse of drugs, such as cocaine, amphetamines, or ritalin. In the past, a delusion of parasitosis was often considered to be a monosympomatic hypochondriacal psychosis,[13] but it has been my experience that this is a rather restricted view, and that psychiatric comorbidity, such as depression, anxiety, or personality disorder, can usually be uncovered during a careful interview, when more florid psychopathology is not

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evident. The syndrome has also been reported in association with a number of medical conditions that are characterized by itching, such as renal disease, malignant lymphoma, hepatic disease, etc.[6,11]

Today, the informed dermatologist may be anywhere from doctor number five to number ten or more in this patient's search for relief, and the patient will, in the interim, have raised both heaven and hell in a frantic attempt to solve the problem that has literally taken over his or her life. Today, the internet further complicates an already difficult situation, as we see in the two letters in this *Journal*, as our patients share every facet of their condition, every theory as to cause, and every attempt at relief, however far-fetched, with their fellow sufferers.

This sharing, and a tremendous amount of suffering, have given rise to the formation of "The Morgellons Research Foundation," an organization devoted to "researching an emerging infectious disease,"[16] with a medical board that boasts five MDs and an RN. Interestingly, none are dermatologists. An internet search for "bugs in the skin" will bring one to the Foundation's Web site,[16] and as Murase et al[17] point out, the information therein may be very misleading to someone who suffers from delusions of parasitosis. One reads of cellulose fibers, fibers with "autofluorescence," fuzz balls, specks, granules, strongyloides stercoralis, cryptococcus neoformans, "alternative cellular energy pigments," and various types of bacteria for which potent antibiotics are prescribed, in the ever broadening spectrum of possible "pathogens." In no case does one read of positive confirmatory tests, though many tests are undertaken. As Murase et al[17] note, one also reads of numerous associated medical and psychiatric disorders that are attributed to, rather than co-existent with, or causative of the distressing symptoms. Frustration is extreme and suicidality is not unknown.

Clearly, as more and more of our patients discover this site, 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.[17] It behooves us, therefore, as dermatologists, not only to be aware of this phenomenon, but also each to develop an effective way to work with these patients, and so enable the patients to be able to accept one of the medications that we know to be effective. This is a challenge indeed—so often the patient, feeling "brushed off" or not understood, simply does not follow through either with medication or with psychiatric referral.

If one is to succeed in helping these patients, it is important that one acknowledge to the patient that what the patient describes is exactly what that patient is experiencing. One can then empathize, as did Murase et al, with the patient's pain and discomfort, their anger and frustration with dismissive doctors, and the devastating changes wrought by the condition in the patient's life, and so develop a therapeutic relationship. With regard to causation, Morgellons disease may be an acceptable appellation, but it may also be that the touted "mysteries" of this disease only prove stimulus for further research by the patient. So, perhaps without going too far into the difference between a disease with a definite cause and a syndrome that may have different ones, it may be reasonable for us to refer to the symptom complex in question as "Morgellans syndrome" rather than disease.

My own approach has been to explain to the patient that from my examination, biopsy, and tests, I have been unable to find evidence to support any of the possible causes put forth by either the patient or the Web site, though I in no way doubt the patient's experience. I explain that though we cannot explain exactly what is going on, we believe that, in part, certain neuropeptides are involved. This then opens the way either to refer the patient to a psychiatrist with whom one can work—as someone familiar with these specialized pathways—or to prescribe appropriate medication oneself. It is very important also, I believe, to pay attention to the skin in a positive way, with baths, emollients, and the like. Of the psychotropics, I still find that pimozide, in a dose of anywhere from 0.5 mg to 2 mg once daily, works more quickly and more reliably than others of the atypical antipsychotics, perhaps because of its known action on opioid pathways,[6,10] although risperidone and aripiprazole are also reportedly effective.[18,19] It is very important to tell the patient at the outset that medication may be needed for months to years, and to stress the need not to discontinue, unilaterally—so often once control has been lost, it is hard to regain it. Coexisting psychomorbidities such as anxiety and depression must also be addressed.

Although it is clear that one must always keep an open mind, it would seem to me to be appropriate for the treating physician to wait until the tried and true drugs, such as those mentioned above, prescribed in an adequate dose, and for an adequate period of time, have failed in a particular case, before one becomes too involved in ascribing a pathogenic function to cellulose fibers and the like, as is currently being suggested.[20]

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