

The Orphan Patient

A Plea to Fellow Health Care Providers

by *Ginger R. Savely, RN, FNP-C*

Travis had a way with words. A gentle, timid soul, he was not particularly adept with people but was expressive and insightful on the written page. He was very bright, so much so that despite his young age of 22 he often became inpatient with the ineptitude of his fellow humans and the inconsistencies of an irrational world.

Why he developed a mysterious disease that consumed him and made him lose his way is beyond comprehension. Bugs, worms or things that he couldn't describe were infesting his body and his brain, tormenting him with itching, biting and stinging sensations. Strange things were occurring that made no sense to his rational mind: fuzz balls, fibers of different colors and black pepper-like dots were emanating from his pores and making his skin feel like it wasn't his own. He couldn't sleep, he couldn't concentrate, he couldn't work or enjoy life in any way. From doctor to doctor he went in desperation, seeking to discover the cause of his misery, hoping to find a diagnosis to explain his bizarre symptoms. He hoped that even if none could diagnose his malady, someone might at least listen, look, and try to understand and help him.

Hope slipped away with each succeeding office visit. He appeared pale, thin, covered with open sores, anxious and fearful. Immediate diagnoses of "delusions of parasitosis", "self mutilation" or "methamphetamine abuse" were conferred upon him without giving him the respect of a proper history or physical. Health care providers would shake their heads in judgmental haste and refer him on to a psychiatrist.

Was he crazy? It sure seemed that way. But his craziness didn't cause the illness. The illness caused the craziness. He became obsessed with every little detail of his hygiene and of his surroundings. He tirelessly scrutinized every inch of his body, looking for signs of his invader and hoping to extract the instruments of his torture. He felt terribly sick emotionally and physically. He had to drop out of school and quit his job as a pharmacy technician. The lesions that covered his body were an eyesore. He was embarrassed to be seen in public for fear that others would think he was contagious or unclean. For over a year he stayed locked up in his room, hiding from

the world, unable to live a normal life or look forward to a promising future. His only connections to the outside world were the web blog that he faithfully maintained and the chat groups he was a part of.

Then he read an article that I wrote about the mysterious skin condition known as Morgellons disease. As he read, he gasped as he recognized every one of his symptoms. For the first time in several years he felt a glimmer of hope. Finally someone would take



him seriously and would treat him with the respect that he deserved. He came to see me and after a thorough history and exam I informed him that he fit the criteria for this unusual and little-known disease, a disease for which there was no test or cure, a disease that, although described over 300 years before, was not even recognized by the Centers for Disease Control and Prevention (CDC) or state health departments.

Validation of his illness was a huge step but there were more obstacles to overcome. Since no one has discovered the causative agent of Morgellons disease, its treatment is a shot in the dark. The patient surrenders himself as lab rat, willingly taking different concoctions of antibiotics that have been helpful to others with the same affliction, but never knowing whether he will be one of the lucky ones who respond. Some patients with Morgellons, especially those with long-standing illness, have worsening symptoms with treatment. Their condition becomes aggravated and their sensitivities sharpened. Anxiety peaks, discomfort heightens and the unusual objects flow forth with a vengeance.

This was the case with

Travis. His response to treatment was such an intensification of symptoms that on several occasions his mother took him to the local psychiatric hospital, not knowing how to handle his agitation and his inability to cope with the pain. After stopping treatment his manic episodes would disappear but the return to baseline was a return to the same lonely life of despair. From past experience I knew that our only hope was to treat aggressively with antibiotics,



but his reaction to treatment was so insupportable that it was difficult to know how to proceed. I believed that his case was too complex for me to handle, but there were no doctors within hundreds of miles who would know what to do or even take his disease seriously.

We seemed to be caught between a rock and a hard place. We'd take one step forward and two steps back. Meanwhile, other Morgellons patients of mine were having symptom flares but getting past them and going on to notice marked improvement. But without improvement there was no hope. And eventually life with pain, fear and misery and without dignity, joy or hope seemed pointless and unbearable.

One Sunday afternoon the horror of it all became too much for Travis to bear. Longing for sound sleep and relief from the pain, he took a large quantity of sedating medications and slipped away from his earthly prison. His mother found him a few hours later and through the shock and sorrow, she couldn't help but notice that it was the first time in several years she had seen a peaceful look on his face. A strange mix of feelings overcame her - the gut-

wrenching agony of a mother losing her only precious son, mixed with a protective sense of relief that his suffering was finally over.

What happened to Travis should make all of us in the medical field pause and consider the ways that we let patients down. Patients deserve to be listened to and taken seriously. To confer a hasty psychiatric diagnosis when a patient's symptoms seem too unusual to categorize is as much a transgression against humanity as it is medical malpractice. There are many more "orphan diseases," as they've come to be known, with "orphan patients" abandoned because they didn't have the good fortune to come down with a known and socially acceptable condition. Throughout the history of medicine we have seen this patient mistreatment due to ignorance on the part of the medical team - patients with tertiary syphilis locked away and put in straightjackets, epileptics believed to be possessed by the devil, gastric ulcer patients advised to learn relaxation techniques because they were inflicting their ailment upon themselves.

As practitioners, let us never forsake our patients. Let us take the time to really listen and look. May we never abandon a patient by discarding him into a lonely, bleak existence of despair. May we not disregard his concerns, ignore his feelings, nor discount his suffering. That is not the way that we would want to be treated nor would we want that kind of disrespect for the ones we love. *pha*

For More Information About Morgellons Disease
www.morgellons.org

Suggested reading:

1. Savely, GR, Leitaio, M. Skin Lesions and Crawling Sensations: Disease or Delusion? *ADVANCE for Nurse Practitioners*, May 2005, 16-17.
2. Savely, GR, Leitaio, M, Stricker, RB. The Mystery of Morgellons Disease: Infection or Delusion? *American Journal of Clinical Dermatology* 2006; 7(1):1-5.

Address all correspondence to:

Ginger R. Savely, RN, FNP-C
Director, TBD Medical Associates
450 Sutter Street Suite 1504
San Francisco, CA 94108
lymesf@gmail.com
Phone: 415-786-9090
Facsimile: 415-399-1057