

5 – APPROACHING MORGELLONS: A FORMER SUFFERER’S PERSPECTIVE

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“Patients with DI pose a truly interdisciplinary problem to the medical system”
(Freudenmann and Lepping 2009).

“I’m not crazy. I’m sick”

I had symptoms from the Morgellons spectrum, recovered and documented my experience (see Keleher 2008a). Since overcoming my symptoms, I have tried to help those still suffering from this horrific condition through published research, blogging and other communications. Recently I reviewed the approach to Morgellons patients outlined in Freudenmann and Lepping 2009; their perspective of Delusional Infestation (which they suggest Morgellons falls within) is based on a number of suggested truths. After discussing some of the article’s framework, I introduce an alternative approach built on communication between patient and medical practitioner and avoiding delusional terminology.

Suggested Truth #1- Morgellons is delusional

*“The aim of this work is to sum up the current knowledge on delusional infestation (DI) or—
using the narrower but more commonly used term—delusional parasitosis”*
(Freudenmann and Lepping 2009)



“Ninety-five percent of Morgellons patients are diagnosed with delusional parasitosis, a psychological disorder, and given antipsychotic medication as treatment.” (Ezra, accessed 8/22/11). If the medical world is a democracy, then those considering Morgellons a true condition (myself included) are presently losing. It isn’t though and understanding this condition does not rely on numbers or percentages, it relies on facts. I suggest professionals and sufferers alike consider recent studies; they have provided physiological parameters defining the condition (Harvey, et. al. 2009), have found, “fibers under the skin of 100% of those thought to be sufferers” (Wymore, accessed 7/27/11), and have provided patients’ input on defining the condition (Amin 2010). These studies and the endless personal accounts of sufferers confirm Morgellons as a true medical condition with severe symptoms and extreme suffering.

Many consider Morgellons Disease a new name for Delusion of Parasitosis. The most notable symptoms often used to self-diagnose this condition include crawling sensations on or under the skin, lesions, and fibers projecting from the skin. Historically this symptom set has been referred to as Ekbaum Syndrome and many other names (see Kellett 1935); I have suggested historic names are referring to variations of the same condition (online article titled “Rethinking DOP” accessed 10/19/11). Recent names associated with this symptoms set include NeuroCutaneous Syndrome (Amin, various publications from 2001 to present), HyperToxicity Syndrome (Springstead, accessed 7/28/11), and, of course, Delusional Infestation (Freudenmann and Lepping 2009). While I prefer Morgellons as the name for this varied set of symptoms, the final name chosen might be descriptive but should not be judgmental.

Having had these symptoms, I know, as only someone who has had them can, they are not delusional. It is truly shocking sufferers are still confronted with this substantial hurdle. As we grow in understanding this condition through research and documentation, a clear means for clinical diagnosis (other than patient self-diagnosis and symptomatic descriptions) is certain to develop.

Suggested Truth #2- Physical evidence provides no information

“Although the real nature of the specimen can be identified readily, the material should be analysed”
(Freudenmann and Lepping 2009)

The context and wording of the above statement stands in contradiction to recent studies of Morgellons’s fibers; recent studies by the FBI could not find a match among their library of fiber samples (Wymore 2009). It also suggests medical professionals rely on their acting abilities. Patients do not benefit from theatrics, they benefit from medical professionalism connecting symptoms to cause.

Fibers

Many of the studies on Morgellons relate to fibers found projecting from the skin and lesions (see studies by Randy Wymore and associates of Oklahoma State University Center for Health Research). A tertiary analysis of these fibers by untrained and unqualified often results in labels of lint, hair and textile fibers. “However, a more thorough analysis of the fibers performed by the Federal Bureau of Investigation forensics laboratory has revealed that the fibers do not resemble textiles or any other manmade substance. In fact, the fibers are virtually indestructible by heat or chemical means, making analysis difficult by conventional methods.” (Wymore R. Personal communication. May 4, 2009 from Savely and Stricker 2010).

Lesions

While it is stated, “Lesions are usually limited to body parts within easy reach.” (Freudenmann and Lepping 2009), the pattern of lesion distribution could be better understood. Some sores may be caused partially or wholly by scratching, which is a common reaction when crawling sensations are present, however scratching does not account for all. Historic documentation of lesion and fiber distribution reported (Kellett 1935) and reviewed (Keleher 2008b) suggest some location patterns which may relate to the central nervous system or causation (as in the hatbands of boys in London described in Crocker 1884 and others). Documenting body distribution of lesions within the Morgellons community could add to our understanding.

Specks

While specks or dots are commonly documented in association with lesions and fibers, I have not seen any study related to them. Again, here is a piece of evidence which could prove fruitful in better understanding Morgellons.

Further examination of fibers, specks and lesion locations may provide a better understanding of cause and treatment. Other physical evidence could include but not be limited to: body temperature recorded over extended timeframe, testing for neurotoxicity, health history reviewed and baseline testing for toxins.

Suggested Truth #3- Morgellons Patients Simply Need Psychological Assistance

“It is stunning to see that patients are otherwise entirely mentally healthy and argue rationally if they discuss issues other than infestation.”

(Freudenmann and Lepping 2009)



There is an interesting paradox in the quote above. While implying psychological assistance is needed, it also suggests patients are mentally sound and there is patterning in behavior. As I myself would like to pursue counseling to sort through my life experiences (including Morgellons), I think finding this kind of assistance may be helpful. Certainly these symptoms have stress connected to them and reduction could be assisted by sharing with a trusted professional. Still, I do not think of psychology as the primary need for sufferers. Symptoms, while often related to thinking and processing, are not limited to the brain (see Harvey

et. al. 2009) and patient documentation (including my own) suggest the condition is systemic.

They further state sufferers are, “...reluctant to see psychiatrists”. This is true. Some would see visiting a psychiatrist as a kind of defeat or admission of being crazy. There are also concerns these symptoms would simply be approached with antipsychotic drugs and potentially create new health problems. While I believe the symptoms are primarily neurologic and due to toxins (keeping in mind the brain is part of the nervous system), the overwhelming stress, lack of sleep, and fear of the unknown cause psychological trauma.

On a personal note, my sister-in-law, a PhD and professor of biology, discussed Morgellons with me when I was still in the thick of symptoms. She said, “I watched a news special on it and they’ve figured it out. It’s all in your head.” I responded with, “Yes, it’s all in my head, my arms, my legs, and the rest of my body”. I was quick to forgive her.

I do recommend the sufferer find a trusted therapist to help through this trauma. The symptoms are horrific. Many live in isolation. The trauma is deep and whole. Ideally, a patient needs access to a professional team able to assist in healing of body, mind and spirit.

Suggested Truth #4- Morgellons Sufferers cannot contribute to the understanding of this condition

“Patients often put down notes, pseudo-scientific essays, and drawings with lay theory”

(Freudenmann and Lepping 2009)

It feels like the scene from Monty Python’s Meaning of Life where a woman about to give birth says to a preoccupied doctor, “What do I do?” To which he replies, “Nothing, dear, you’re not qualified”.

For myself I have been extremely fortunate in finding my voice within the Morgellons world. I have had my thoughts, theories, and research online as well as in peer reviewed articles. I have been thanked by patients and medical professionals. I am very lucky to have overcome these symptoms but also to have an audience for my words whether written or spoken. I do feel I have made significant contributions towards understanding this condition. While it is impossible to distance and have an objective view towards these symptoms while suffering, discounting patient observations and insights is counterproductive. Morgellons Disease sufferers need to be listened to and can make a difference!

Suggested Truth #5- The Internet Has Caused the Growing Amount of Morgellons Sufferers

“At present, Morgellons appears to be one of the first ‘internet transmitted diseases’”

(Freudenmann and Lepping 2009)

The internet is a lifeline for support and information to those suffering these symptoms. The condition lends itself to isolation and has often resulted in self inflicted home imprisonment. The medical community poorly understands these symptoms. Where else can a sufferer seek answers? The message boards, blogs, and websites allow many who are house bound access to other sufferers and concerned individuals. While the credibility of Morgellons related information is mixed and varies greatly (ironically, my favorite sources for online medical information pubmed.gov contained Freudenmann and Lepping’s research), credible well researched medical insight is lacking. Sadly, it is also a source of endless misinformation and “snake oil salespeople”. Slightly over four years ago, when I was experiencing these symptoms, I was able to connect to the information and individuals who brought me back to health. Without the internet, I suspect I would never have recovered. Implying the internet is the cause of Morgellons is based on faulty logic; it does not account for all of the documentation of these symptoms prior to the existence of the internet, nor does it account for my own and many others’ development of these symptoms before even hearing of Morgellons. Given the growing online presence of sufferers, the internet could be a means for better understanding patterning and reliable information to assist in managing and recovery of Morgellons.

What else could be causing the growing numbers of people having Morgellons? Given my experience, I feel strongly the condition relates to issues of toxicity. Our world is becoming more toxic day by day and the number of sufferers is likely to increase into the future. As the toxic soup within our bodies mixes in new exposures each day, the likelihood of developing health issues increases.

An Appropriate Approach

First, I ask those suffering not be overly angry with Freudenmann and Lepping. Their understanding and sharing reflects on current trends in the medical world towards processing and dealing with this mysterious condition. That's all. They are not alone in their thoughts. They have given something to respond to. I thank them for sharing their perspectives online and in an easily accessible manner.

As a former sufferer of Morgellons and an online source of the condition, I have communicated with numerous patients and heard their stories. While I will not share specifics of individual cases, there are many suggesting abuse by medical professionals. This is unacceptable. The diagnoses of Delusion of Parasitosis (DOP) or Delusional Infestation (DI) themselves carry an implied label of mental instability and needs, in relation to Morgellons, to be rethought, retired and replaced.

Treatment of Morgellons Disease patients needs to change. I have suggestions which I believe will be beneficial to both the patient and the medical professional. These include: research current approaches which reduce or eliminate symptoms (while not simply being the means to cover underlying symptoms), give patients a voice, treat patient as a sufferer of symptoms, and end delusional labeling.

Know the current successful approaches – The question to needing to be asked is, *Which approaches appear to successfully reduce, diminish or eliminate symptoms without causing harm?* If there appears to be patterning in success, it is with approaches dedicated to reclaiming internal environment; my recommendation is to focus on understanding these approaches while having a general understanding of all approaches. There have been suggestions of successful approaches with antipsychotics (Koblentz 2006, Reid & Lio 2010); as some believe Morgellons to be the result of neurotoxicity (see Amin 2001 to present and also Keleher 2008 to present), I wonder how these drugs might affect neurologic symptoms (could these potent drugs simply be covering symptoms and not treating the condition?).

While there has been some progress in understanding Morgellons Disease, there are still disturbing trends seemingly designed to question all patient input and keep to the diagnosis of delusional. In reviewing the content of medical research found on Pubmed.gov, presently there are only 31 articles found under the search of Morgellons Disease (accessed 8/22/11- for comparative purposes, searches under the topics of “face lift”, “botox”, and “tattoo removal” resulted in counts of 2637, 1129, and 215 respectively). With further research, the label of “delusional” is certain to be unceremoniously buried.

Given the low amount of research on Morgellons, it is surprising The Kaiser Foundation was awarded a contract by the CDC to investigate it. The research was performed several years ago and is still to be released. As of 24 March 2011 the official CDC statement was, “We recently completed the data analysis. A final report has been submitted for publication in a peer-reviewed scientific journal”. For comparison, I as a writer with the daytime job of teaching and no background in medicine have had eight professional publications (two in a peer reviewed medical journal) during the same time-frame. While I understand the difficulties of getting published, it is unbelievable the CDC with such credibility would be so greatly delayed. Whether the Kaiser research assists in developing a successful approach to treatment or not, those making decisions on the extremely slow release of this tax funded research need to be held accountable.

A solid understanding of the research and approaches towards treatment of Morgellons will help the professional in assisting those suffering. Sufferers come to understanding this condition from a different angle as their lives depend on it.

Give patients a voice – Listening to patient input makes sense no matter what they are suffering from. Morgellons is unique in the lack of understanding and communication between the medical world and sufferers; labeling a group as “crazy” creates much strain in communications. While the professional should take time to discuss the symptoms with a patient, a questionnaire designed specifically for Morgellons sufferers could provide individual information while assisting in building a growing data base for this condition.

Treat patients as suffering from real symptoms – Having experienced symptoms, I cannot voice the need for empathy more. Not only are these people suffering severely, but they are suffering with the knowledge that the majority of the medical world feel they are somehow crazy (justifying the same judgment by the general population). It is a very tough road! Listen to what they are experiencing; document the symptoms you can, and be kind. Calling this set of symptoms delusional is false and greatly disturbing to those who are suffering. Calling it Morgellons, until a better name appears, is more appropriate.

Final Thoughts

The approach toward interacting and treating Morgellons patients need to be updated to fit the current understanding of this condition. The dangers of past approaches is a patient may lose faith in medical professionals, move towards self treatment (some which are extremely dangerous), chose to isolate themselves, or, in some cases, consider suicide. The suffering in this condition is extreme. The medical world needs to help the patient shed light into a very dark place. A nonjudgmental, positive, informative and knowledgeable approach will help patients and medical professionals alike.

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