Learning from Morgellons

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I - Introduction

Morgellons disease is both chronic and contested. Neither of these qualities are particularly straightforward. ‘Chronic’ refers to the persistence or recurrence of symptoms over a significant period of time. Whilst health organisations and medical textbooks describe chronic diseases as noncommunicable conditions that are generally incurable and last longer than three months, the significance here is social.¹ Does the persistence of your illness affect your job? - your relationships? - your sense of self? Then it is chronic.

Many diseases are contested.² Arguments about precise aetiology, measurement of symptoms, proper treatment all occur frequently in even the most established of conditions. The ‘contested’ element in Morgellons is more fundamental; it is about the legitimacy of the disease itself. This delegitimisation is a composite of controversies regarding Morgellons’ aetiology, diagnosis, symptoms, prevalence, treatment and history. This means that Morgellons ‘has no general medical acceptance as a disease entity’.³ Its almost totally disputed nature places it alongside conditions such as Chronic Fatigue Syndrome (CFS), Gulf War Syndrome and Chronic Lyme Disease.⁴ It shares many features with these illnesses, most notably a lack of clinical consensus regarding its aetiology, friction between patient and doctors’ conceptualisation of the disease and a highly politicised lay community. Because of this, looking at Morgellons can offer valuable insights into how similar conditions operate.

In this essay I will discuss how the vague and non-specific symptomatic features of Morgellons leads to a conflict between doctors and patients over different aspects of disease and what meanings we should attach to them. It is an informative example of how disease advocacy groups organise and politicise themselves, utilising the internet and more traditional networks to further their aims. This condition also represents a failure of the biomedical model to adequately address the concerns of those suffering from chronic illnesses of this type. A breakdown in trust has taken place, with serious consequences for those involved and medicine more widely. As such, I will ask and answer the following questions:

¹ World Health Organisation: http://www.who.int/topics/noncommunicable_diseases/en/ visited 21/08/14; The Center for Managing Chronic Disease; http://cmcd.sph.umich.edu/what-is-chronic-disease.html visited 21/08/14


⁴ Note the many similarities these diseases have with the contested status of Morgellons: Swoboda, D. A. ‘The social construction of contested illness legitimacy: a grounded theory analysis’ in Qualitative Research in Psychology, 2006, Vol. 3. pp. 233-251
- In what ways does Morgellons represent ‘failure’?
- How does the Morgellons ‘community’ operate and what does this tell us about contested illness patient groups?
- How can we improve outcomes for individuals who suffer chronic, contested illnesses?

My methodology is deliberately holistic, though it may seem at times to be slipshod. Rare is it to find a subject small enough to be able to adopt this kind of approach, and Morgellons presents one such an opportunity. I have looked extensively at the majority of published literature on Morgellons, as well as developed a solid understanding of the delusional infestation research which has obvious and sometimes explicit crossovers. I have explored chronic illness narratives, looked at patients’ experiences of pain and delved into contested disease debates. From the social sciences I have appropriated work on oppositional consciousness and advocacy groups. What I have also done is tried as far as possible to recognise the many platforms where this disease expresses itself. This means using advocacy websites, patient blogs, doctor’s guidance sites, video clips and radio shows. It also means looking at newspaper reports, science blogs and discussion forums. These non-traditional sources do present their own problems, notably varying accuracy and partisanship, but it was important that I used them. They are where the disease lives and breathes. I feel strongly that their influence, their feedback into people’s perceptions, is as important to understanding the social existence of this disease as any journal article.

Below is a brief introduction to ‘Morgellons’. This section is not intended to be exhaustive, and many points will be returned to later. It is my intent that this section will establish a clear and understandable basis from which to proceed, because it is impossible to discuss what Morgellons is without first knowing its basic pathology, controversial aspects and interested groups.

A short history of Morgellons

Morgellons sufferers report a diverse range of physiological complaints. The various symptomatic constellations that are formed from different sources give a strong impression of what might constitute Morgellons, but diagnostic uncertainty persists due to the variety of sufficient but unnecessary symptoms. This ambiguity has led to Morgellons patients being described as ‘a complicated and multidisciplinary challenge’.

The primary locus of the disease is on, in, or under the skin, where patients report painful and frustrating sensations of stinging, crawling and itching, accompanied by raw cutaneous lesions which do not heal. It is argued by patients that these feelings and sores are caused by the ‘distinguishing feature’ of the condition, the existence of

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protruding material from the skin. Often described as ‘fibres’ or ‘filaments’, these ‘protruding’ items can normally only be viewed through a microscope. Patients have reported these fibres as being of varying length, colour and transparency. There is a high incidence of related conditions that Morgellons patients also suffer from including chronic fatigue, depression, OCD, ADHD, fibromyalgia, joint pain, sleep problems, hair loss and neurological disorders as well as anxiety and substance abuse/dependence. The number of patients who suffer from comorbid psychological conditions has been reported as high as 75%. The direction of the causal link between these co-morbid features and Morgellons is disputed. Most doctors believe that the relationship with other conditions is correlative, not that they are symptomatic of Morgellons, which is often the patient’s view.

In clinical settings, Morgellons sufferers have largely been diagnosed as having delusions of parasitosis, a psychological condition where patients believe there to be insects or unidentifiable objects about their person which cause considerable discomfort. Under the delusional interpretation of Morgellons favoured by doctors, the open wounds are self-inflicted by patients attempting to relieve their symptoms, the fibres are extracts of clothing and the co-morbidity with other conditions indicates a predisposition towards mental rather than physical illness. The frequency of this condition across populations is unknown, with the few estimates that do exist putting the number in the tens of thousands. It is important to recognise though that all Morgellons organisations maintain that the condition is under-diagnosed to a large extent. The majority of reported cases come from the western world, and women are more likely to suffer.

6 http://www.thecehf.org/about.html visited 19/08/14
7 http://morgellonsdiseaseawareness.com/morgellons_photo_galleries/morgellons_fibers_in_skin visited 20/08/14
10 Ibid., p. 264
11 Ibid., (Authors treat delusional infestation and Morgellons as synonymous)
12 Delusions of parasitosis can be called delusional infestation, delusions of infestation and is also known as Ekbom syndrome.
14 Ibid.
Much has been written chronicling the development and progress of Morgellons over the last decade or so. To say that a ‘history’ has been established would be false; a series of contentious points have been raised and in turn disputed, sometimes vehemently, across a variety of mediums by a diverse set of contributors. Establishing a clear narrative in this claustrophobic environment is a difficult task. This is made all the harder because one section of those involved is as keen to establish Morgellons as a historical and distinct condition as the other is to deny this. Those who wish to discredit a Morgellons ‘history’ are normally those from the medical community who believe it to be or probably be a spurious illness that is simply delusions of parasitosis under a new moniker.

However, some sense can be made of what has happened. To make this as clear as possible I will split the narrative between what occurred in the first decade or so of this millennia and the claims made by some that Morgellons should be considered a long-standing condition.

The first strand of the Morgellons story begins in 2001 when Mary Leitao, a biologist from Pennsylvania, became concerned about a sore on her two year old son’s lip, which was apparently struggling to heal. Treatment from healthcare professionals proved ineffective, and she began to notice that fibres appeared to be coming from the wound. After examining her son under a microscope, she became convinced that this was the case, though in her effort to convince her doctors likewise she was diagnosed with Munchausen by proxy. In 2002 she founded and became executive director of the Morgellons Research Foundation (MRF), which would become the primary patient advocate group for Morgellons sufferers throughout the 2000s. Utilising the internet and publicity campaigns on television and in the press, membership of the research foundation grew to the point where the MRF claimed it had over 10,000 ‘registered families’. It is largely as a result of such efforts that a research community was assembled around (and against) Morgellons, and journal articles began appearing from 2005. The internal developments of this require closer attention and are examined in the next section and in later chapters.

Other patient support organisations around the world formed in the latter part of the decade, alongside numerous blogs and online comment pieces devoted to the topic and university departments specialising in Morgellons research. Although the MRF has now ceased to exist, other organisations have filled the void, such as the Charles

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15 Munchausen by proxy is a mental illness where a parent or caregiver exaggerates or fabricates medical complaints on behalf of their children. See: http://kidshealth.org/parent/general/sick/munchausen.html visited 22/08/14


17 Oklahoma State University’s Center for Health Sciences is committed to furthering Morgellons research under Dr. Randy Wymore http://www.healthsciences.okstate.edu/morgellons/index.cfm visited 24/07/14
E. Holman Morgellons Disease Foundation (CEHF), which funds research, galvanises patients and organises annual conferences and events.\(^{18}\)

The second aspect of a Morgellons ‘history’ that must be considered is its novelty, or lack thereof. The appellation ‘Morgellons’ was chosen by Leitao because of the similarity of her son’s symptoms to those described in a 17th century work by Sir Thomas Browne. It was intended to be a short-term solution, in her words a ‘placeholder’.\(^{19}\) The many thousands who would assemble themselves under that placeholder did not always see it that way however.

Some writers have traced the disease further beyond the Browne piece to Leonellus Faventinus de Victoris, writing in 1544, and argued that it continued under various monikers until the first half of the 20th century, where it was last described in 1935.\(^{20}\) This schema, which assumes that Morgellons is a rare, under-diagnosed condition that has been misdiagnosed or ignored in the past is a difficult one to swallow, given the troublesome nature of retrospective diagnosis and the lack of modern medical continuity. Even the now famous Browne letter, where Leitao got her appellation, does not strictly describe something we would recognise as ‘Morgellons’.

It also controverts claims that Morgellons is a new, *emerging* disease with a potential environmental cause.\(^{21}\) Proponents of this ‘novel’ view maintain that the condition is a modern phenomenon, which is why it is important that further research is conducted in order to explain exactly how this disease came to appear. Many of the research papers also describe Morgellons as an ‘emerging condition’, but it is unclear precisely what is meant by this.\(^{22}\) Put simply, it cannot be both centuries old and also a new condition.

Some patients appear to hold both views simultaneously. This may be most clearly understood by saying that many feel like they suffered with Morgellons for years before being able to reconcile their symptoms under a new label and fashion an identity therewith. In this sense then, Morgellons, or the Morgellons label, is ‘new’. But because they *had* suffered in silence and ignorance, they consider this condition to have had a much longer dormant existence. The confusion and contradiction in this exposition serves to underline what is a constant in any Morgellons narrative: uncertain assertions in the face of the unknown.

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\(^{18}\) See [http://www.thecehf.org](http://www.thecehf.org) visited 23/07/14


\(^{20}\) Accordino, R. E., Engler, D., Ginsburg, I. H., Koo, J., 2006, p. 9

\(^{21}\) Sometimes the historical and novel line are followed in the same article, see Dovigi, A. J., ‘Intraoral Morgellons Disease or Delusional Parasitosis: A First Case Report’ in *The American Journal of Dermatopathology*, 2010, Vol. 32, No. 6, pp. 603-604

Research

Considering the short time period and limited incidence of the disease, there is a fairly large amount of research that has been conducted. Still, peer-reviewed journal research on Morgellons that collects data on significant numbers of patients is rare. A PubMed search returns 48 results, which includes one literature review and one medical ethics piece. As Hylwa et al note, few of the pieces focus on physical biopsy specimens or on artifacts obtained through patients themselves. The result of this is that on the whole, studies rely on case reports and short reviews of literature, offering comment on symptoms, diagnosis and best practice.

These tend to assume epistemic diagnostic authority and normally state that to a certain or absolute degree the authors believe Morgellons to be delusional. They believe that claims of fibres causing distress are spurious or likely to be spurious. The effects of and reaction to this conviction will form an important point of discussion in later chapters.

The Centre for Disease Control and Prevention (the CDC) is the only body that has conducted large-scale research on Morgellons. In 2012, after four years of work, they published a project which was described by the authors as ‘the most comprehensive...study of persons who have symptoms consistent with the unexplained dermopathy referred to as Morgellons’. Whilst inconclusive, the research eliminated environmental causes, and purported that there was no evidence of a contagious component to the disease. The overriding thrust of the report was to suggest that Morgellons may be a modern incarnation of delusional infestation, ‘with which it shares a number of clinical and epidemiological features’. However, it could not be conclusively linked.

This does not encompass all of the work that has been done on Morgellons. There is research that has been published which from the outset is committed to the somatic ‘reality’ of the condition. In these instances the causality of the disease has so far proved elusive and potential treatment solutions are ‘rarer and less consistent’.

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23 Retrieved 29/08/14


27 Ibid.

28 Ibid.

29 Söderfeldt, Y. & Grob, D., 2014, p. 73
number of scientists publishing papers of this ilk is quite small, often calling for larger and more in-depth studies to be carried out. Of the speculative findings, there is some suggestion that a connection with chronic Lyme disease might hold the key, meaning that Morgellons can potentially be considered a contagious disease.\textsuperscript{30} Chronic Lyme disease itself is not free from disputation, which makes this link somewhat troublesome. Other research has identified myiasis as a potential cause, which again suggests a contagious element to Morgellons.\textsuperscript{31} This is in direct contrast to what the CDC report concludes.

Overall, a quite clear split can be discerned in the research conducted. One camp assumes an ontological position of skepticism towards the legitimacy of Morgellons. By casting doubt on the disease concept, their work serves to discredit or reframe the symptoms as the patient’s would like them to be understood. Those conducting this research have undertaken better funded, larger scale projects than the ‘other side’ and I would argue that their findings represent the views of the majority of the medical profession. Clashing with this work, implicitly but sometimes directly, is that which takes Morgellons as an unexplained but fundamentally biological condition. They remain determined to further their research agenda, spark debate about aetiology and as a result discover possible treatments on the basis of somatic rather than psychological discord.

The various papers published have been discussed in frank terms, both in and outside of the normally formal and at least \textit{prima facie} reverent sphere of journal politics. Little love has been lost between sufferers, researchers, journalists and other observers of developments in Morgellons. Almost all research that has been conducted which does not point towards a somatic origin for this condition, that labels sufferers as delusional or that considers Morgellons a phenomenon best dealt with through psychiatry, meets fierce resistance from patient groups and research advocates. For example the CDC report was criticised heavily upon publication by this faction. The choice of health maintenance organisation, Kaiser Permanente, was said to be an inappropriate choice which in many ways pre-determined the outcome of the study.\textsuperscript{32} Both the methodology and the interpretation of results have also been queried by prominent members of Morgellons advocacy groups, with the feeling that their long campaigned for ‘big study’ amounted to the end rather than the beginning of debate. It must be noted that these ringing condemnations straddle various publications, opinion pieces and internet forums. Assessing their credibility and disinterestedness is a difficult task. The level of personal investment in the topic from most of the commentators is high.

\begin{footnotesize}

\textsuperscript{31} \url{http://www.morgellonsuk.org.uk/micromyiasis.htm}

\textsuperscript{32} Some felt that the CDC ignored existing (pro)Morgellons research and should not have chosen an health insurance provider to assist the study: \url{http://www.rense.com/general80/fraudf.htm}
\end{footnotesize}
On the other side of the divide, the research which has been conducted that presupposes a somatic, discoverable cause for Morgellons has been dismissed as ‘dangerous pseudoscience’ by those in the medical establishment.\(^{33}\) It has been noted that the research being done on Morgellons from this stand-point emanates from the same small group of researchers, whose credentials and personal integrity has been questioned (see Chapter IV).\(^ {34}\) This criticism varies. There are those who believe the Morgellons infrastructure, with its advocacy groups, forums and researchers to be an extension of their delusional physical selves, who suffer from ‘Morgellons Syndrome, a disease that was invented in 2002’ [my emphasis].\(^ {35}\) A more empathetic strain of critics are those who are committed to improving patient’s lives and view any research that feeds their beliefs to be a barrier to effective treatment.\(^ {36}\) It is worth observing that there is a significant professional imbalance between those who believe Morgellons to be psychological in origin and those who don’t, the medical community vastly falling in the former camp. The greater amount of research being conducted with a psychological cause in mind has led to fairly predictable clinical guidance. The advice given to dermatologists and physicians on the whole is to regard Morgellons as a psychological issue and a potential by-word for delusional infestation. The disparity described above between researchers who believe Morgellons to be psychological and those who subscribe to a potentially somatic cause has been compared to the proportion of scientists who do not believe in Darwinian evolution.\(^ {37}\) It has been suggested that journalists both favouring an ‘underdog’ medical story and papers wanting bizarre human interest features have fueled a misrepresentation of the totality of scientific certainty on the topic.\(^ {38}\)

As this short overview of some of the research conducted into Morgellons so far demonstrates, nothing is straightforward, and consensus, if such a thing can be achieved, is possible only amongst certain groups. To borrow terminology employed by the Contested Illness Research Group at Brown University, what the variety of research and social action surrounding Morgellons shows quite clearly is how ‘contestation amongst various actors’ interacts to shape the ‘dominant

\(^{33}\) Steven Salzberg, McKusick-Nathans Institute of Genetic Medicine, John Hopkins University School of Medicine, USA responding to Middelveen, M. J., Stricker, R. B. et al, 2013

\(^{34}\) Mnookin, S. The Panic Virus: The True Story Behind the Vaccine-Autism Controversy, 2012, Simon & Schuster, USA, p. 90; or for a more informal attack see http://scienceblogs.com/whitecoatunderground/2010/05/13/bad-science-done-badly-its-bad/

\(^{35}\) Ibid, p. 88


\(^{37}\) Mnookin, S., 2012, p. 92

\(^{38}\) Ibid, pp. 92-95
epidemiological paradigm’. 39 This is described as ‘an embedded set of institutional structures, beliefs and actions of academia, government, industry, nonprofit organisations, health voluntaries and the media’. 40 Though it stretches the traditional definition of ‘epidemiology’, it does so in a useful, social way, encompassing the factors which contribute to the complex meanings behind beliefs about diseases, their causes, and diagnostic strategies. In this case, despite outcry and consternation from numerous sources, the established opinion on Morgellons, that which is disseminated throughout those with diagnostic authority, repeated in the media and played out regularly in local clinical settings is one of skepticism and concern for the psychological rather than the somatic aspects of this condition. The struggle by patients to change that outlook and to temper its consequences will form a large part of my piece.

39 Brown, P., Morello-Frosch, R. & Zavestoski, S. Contested Illnesses: Citizens, Science, and Health Social Movements, 2012, University of California Press, USA, p. 84

40 Brown, P., McCormick, S., Mayer, B., Zavestoski, S., Morello-Frosch, R., Altman, R. G. & Senier, L. ‘A Lab of Our Own’: Environmental Causation of Breast Cancer and Challenges to the Dominant Epidemiological Paradigm’ in Science, Technology & Human Values, 2006, Vol. 31, No. 5, p. 500
II - Failure

Any disease can put a strain on a number of relationships. The interplay between patient and doctor, but also between patient and their family, friends and employment become of paramount concern and are often redefined and reconstituted by serious illness. More fundamentally, a person’s relationship to their own body, sense of self and the society they live in can become compromised. This is especially true in the case of chronic diseases, where existence can become a struggle to ‘maintain control over the defining images of self and over one’s life’. In this chapter I will document how Morgellons patients participate in this struggle, and outline the many pressures that come to bear upon them in the process. I will also look at the relevance of the CDC report and at how patients and doctors have been dangerously driven to try and subvert their traditional relationship.

The social cost of Morgellons

The study of chronic illnesses in recent decades has led to some much needed meditation on the broader effects of disease in society. Far more accounts which incorporate patient experience have appeared and the willingness to engage in wider notions of just what can reasonably be placed under the mantle of studying disease is encouraging. My approach to Morgellons follows this tradition, in that it takes illness to be far more than simply a straightforward somatic phenomenon that can be understood purely or largely from a bio-medical (or indeed strictly psychiatric) perspective. As to whether it is correct to classify Morgellons as a chronic illness, on this point I think the evidence is unequivocal. Morgellons patients can suffer various symptoms for years with little improvement in wellbeing, existing in a state of ill-health and unease. To not view this as a chronic illness is to disregard and deny the reality of the pain of those who live with it.

The social cost to an individual who suffers from this condition can be high. For some, almost all aspects of their life can become compromised. As Accordino et al write:

‘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.’

Charmaz, K. Good Days, Bad Days: The Self in Chronic Illness and Time, 1993, Rutgers University Press, USA, p. 5 (Note that though this work explores the changing notions of selfhood experienced by those with other chronic conditions, I found the descriptions so similar to those reported by Morgellons that I thought it fair to use them as synonymous explorations of the cost of disease).

With a desire to avoid a lengthy, well-trodden discussion on the distinction between disease and illness, I have treated them as synonymous. That is to say, someone who is ill and someone who has a disease are one and the same.

The difficulties of simply ‘carrying on’ whilst suffering from a chronic illness are visible in many of the Morgellons case studies, and their sick-role trajectory will be familiar to anyone who has studied or experienced chronic conditions. As described in the quote above, unemployment is often the price paid by patients, especially those with little sick leave provision or inflexible employers.\textsuperscript{44} For those who are seeking employment, the confidence required to go through the necessary steps required to get a job may be drained by living with the condition, combined with finding themselves ‘ignored, rejected and stigmatised’.\textsuperscript{45} Evidently, the fallout from unemployment can make matters worse, as sufferers face financial hardship. For many who have worked all their life, this is a demeaning and demoralising situation, and so it is understandable that some react with anger and panic.\textsuperscript{46} Morgellons patients have variously reported losing their jobs and struggling to find new employment, enduring marital and familial breakdown, becoming housebound, developing anxiety issues and depression. Suicide is also a possible outcome.\textsuperscript{47} Much has been written about how patients deal with pain in chronic illnesses, and in the case of Morgellons aetiology is irrelevant; sufferers have to learn to deal with varying degrees of pain.\textsuperscript{48} A strong support network of friends, family and work colleagues is in many cases required to help people struggling with a condition like Morgellons to get through day to day life. However, often these relationships can begin to deteriorate over time under the pressure, or in some cases were not there to begin with. People ‘come to feel abandoned’, whether it be by their doctors, their familiars or by their past, healthy self.\textsuperscript{49} Often sufferers are driven away from traditional safety nets and into the arms of online and international patient communities. Alongside these pastoral forums lurk opportunists looking to profit. This overall ‘community’ is an important aspect of Morgellons, and I will explore the positive aspects of this at length in the next chapter. What should be noted here though is the way in which marginalisation, pseudoscience and exploitation can play off against each other to cause serious damage. Disaffection can lead some individuals to a point of despondency. It is these individuals most at risk from the shady characters that have at times inhabited the Morgellons world, proffering treatments which are at best non-effective, at worst

\textsuperscript{44} Charmaz, K., 1993, p. 154
\textsuperscript{45} Ibid, p. 109
\textsuperscript{46} Ibid, p. 187
\textsuperscript{47} Many Morgellons sites mention suicide as an outcome, for example http://www.morgellons-research.org or http://scienceblog.com/14703/another-morgellons-victim-commits-suicide/#mpZSi72dYrz6pQ97 visited 12/08/14
\textsuperscript{48} For writings on chronic illness and pain, see the introduction to Miles, A., Curran HV, Pearce S \textit{et al} ‘Managing constraint: the experience of people with chronic pain’ in \textit{Social Science and Medicine}, 2005, Vol. 61, pp. 431-441
\textsuperscript{49} Molyneux, J., 2008, p. 26
dangerous and never cheap.\textsuperscript{50} One such person is Dr. Hildegarde Staninger, who sold infra-red ‘saunas’.\textsuperscript{51} Although she made high claims as to their effectiveness, finding any evidence from people she may have helped is virtually impossible. Though it appears as if Dr. Staninger has retreated from the Morgellons scene, her and others like her remind us of the dangers of excluding people from traditional avenues of support and treatment. Vulnerable individuals, driven to accept bizarre rationalisations of their pain, are willing to part with large sums of money because they feel like they have run out of options.

Morgellons is also an issue of gender. It has been claimed that over 70\% of patients are female.\textsuperscript{52} This is important not only in considering the aetiology of the condition, but also in analysing doctor-patient relations and chronic illness. Studies of how women struggle with disease, use healthcare and how their roles in the home and at work interact with a chronic condition have shown that women’s experiences cannot be ‘subsumed under those of men’.\textsuperscript{53} This is particularly pertinent with a condition such as Morgellons, where fatigue is regularly reported as a symptom. In part because it is difficult to define, invisible, subjectively variant and nonspecific, fatigue has for some time been a troublesome symptom for patients and doctors. Putting a value on fatigue is hard. As it is also present in the population as a whole, fatigue is often undervalued and not treated with severity by physicians who prefer more objective ways to examine their patients. In the case of women with Morgellons, complaining of fatigue as well as other difficult to operationalise symptoms feeds into traditional and damaging stereotypes of female patients as being prone to hypochondria, neurosis and wasting doctors’ time with trivial complaints.\textsuperscript{54} Given that a larger number of women than men still perform caregiving and home-based family roles, suffering from Morgellons may force a retreat from these responsibilities, with all the ensuing feelings of further isolation and marginalisation. Patients often report feeling trapped between an image of someone who is too ill to work and one who is still

\textsuperscript{50} For a case in point, see DeBonis, K. & Pierre, J. M. ‘Psychosis, Ivermectin Toxicity, and ‘Morgellons Disease” in Psychomatics, 2011, Vol. 52, No. 3, pp. 295-6

\textsuperscript{51} Dr. Staninger’s links with Morgellons appear to have been severed some time in 2010, and it is difficult to find any information directly from her. This profile is based on numerous forum discussions of her products, service and background, for example: http://morgellonsgroup.proboards.com/thread/3514/dr-staninger-unlocks-mystery-morgellons?ixzz2jhKnYm7=undefined, http://drhildy.proboards.com, http://curezone.com/forums/am.asp?i=1669899 & http://cassiopaea.org/forum/index.php?topic=1453.165 visited 14/08/14


\textsuperscript{54} Montali, L., Frigerio, A., Riva, P. & Invernizzi, P. ‘It’s as if PBC didn’t exist’: The illness experience of women affected by primary biliary cirrhosis’ in \textit{Psychology & Health}, 2011, Vol. 26, No. 11, p. 1431
compelled by gender roles to keep a clean home and look after loved ones.\textsuperscript{55} This is compounded by a desire to do things and forge as normal a life as possible without being forced to give up their ‘sick’ role because they appear too healthy.

A large part of the issues described above stem from medical diagnosis, or lack thereof. Whilst some doctors and dermatologists are willing to give a diagnosis of ‘Morgellons Disease’, these are few and far between, and tend themselves to be well known advocates of the condition. The reported experience of using local medical services, at least in the US, the UK and Australia is almost universally similar: Morgellons patients are diagnosed with a psychiatric disorder, normally delusions of parasitosis. A recent literature review by Söderfeldt and Groß argued that suggested treatments presented in those works which assume Morgellons to be some form of delusion are often similar.\textsuperscript{56} Almost always, one or more of the following treatments is recommended: antipsychotics, psychiatric referral or the creation of a treatment team which incorporates a dermatologist.\textsuperscript{57} Alongside this we must place limited evidence that antibiotics, hypnosis and even orthopedic casting can relieve symptoms.\textsuperscript{58} The effect that a delusional diagnosis can have manifests in several ways. For patients, being diagnosed is about achieving legitimacy for your pain and being recognised as having a right to suffer. It is also about having access to resources, and being able to justify withdrawing from certain societal responsibilities. Being diagnosed by a medical professional not only allows a person to be taken seriously by health workers but also by their employers and their family. As we live in societies where people often take a doctor’s word more seriously than that of their long-term partner, parent or child, medical opinion is vital in shaping the perceptions of others. Simultaneously, it acts as a ‘gateway to health services, welfare benefits, unemployment certification, worker’s compensation claims, and pensions’.\textsuperscript{59} In the case of Morgellons, a psychiatric diagnosis does not fulfil this promise, and frequently causes the patient more aggravation and trauma.

This is because of the crucial distance between the validation Morgellons patients hope to get from doctors and the actual explanation that is given to them upon reporting their symptoms. The stigma attached to mental illness, which is certainly


\textsuperscript{56} Söderfeldt, Y. & Grob, D., 2014 pp. 71-76

\textsuperscript{57} Ibid. p. 72


how delusions of parasitosis is conceptualised in the Morgellons community and beyond, weighs heavy on almost all involved. A toxic combination of factors exacerbates the impact of a psychological diagnosis. Morgellons is a visual, visceral condition, but its lack of legitimacy amongst medical professionals and the limited exposure that the general public have to it mean that patients often find it difficult to regularly explain and justify themselves. This can and does lead to the curtailment of normal activity. As with other conditions, the imposition of a psychiatric diagnosis serves to shift blame to the patients themselves, which is often what is resisted most. Young and middle-aged patients are particularly at risk, as suffering from Morgellons goes against what is expected of them in terms of health, work, socialising etc. Revealing their illness can be ‘grossly uncomfortable, often painful, often embarrassing’, and though sometimes it occurs in subtle ways, this marginalisation should not be discounted.

There is a lot of resistance amongst patients to a delusional diagnosis. Time and time again it is reported on forums and patient websites that ‘Morgellons is real!’, ‘People who suffer from Morgellons disease are NOT delusional’, ‘Our condition is real’ etc., as well as more focused anger on the doctors themselves who ‘refuse to see reality’ by giving patients a delusional diagnosis. In many ways these arguments are similar to those had between patients and practitioners in other contested or once-contested diseases such as ADHD, CFS and RSI. Such is the anger directed at the medical community that in the case of Morgellons the level of ill temper and distrust can become outright conspiratorial. It is to be noted that despite strongly rejecting the label given to them by practitioners, the desire is to change the diagnosis, not the diagnoser. Morgellons patients don’t want to push away medicine, they feel pushed away by it. Understanding this hope is key to appreciating why for many the breakdown in trust between patients and those trying to treat them is so painful. As mentioned above, diagnosis can serve practical purposes as well. Although Morgellons is not classified as a condition that can receive benefits on the Social Security Administration list of impairments, if a patient can prove they have severe enough dermatitis then they may be able to claim disability payments. They can also try and claim welfare under mental disorder listings. Some Morgellons websites offer advice about how to claim social security and suggests professionals who can help.

60 Brown, P., Morello-Frosch, R. & Zavestoski, S., 2012, p. 94; Jamison, L., 2014, p. 41
63 Söderfeldt, Y. & Grob, D., 2014, p. 74
64 http://www.disabilitybenefitshome.com/common-disabilities/morgellons-disease visited 12/08/14
diagnosis of delusion and the detrimental effect that Morgellons can have on patients’ ability to work means that sufferers regularly find themselves without employment or access to health-related welfare. This situation is unlikely to change unless there is a major shift in the general medical stance on Morgellons, which would in turn change the diagnostic frame and affect policy.

In short, the problems faced by Morgellons patients are similar to those suffering other chronic illnesses with unknown aetiologies and variant, nonspecific symptoms. They struggle to gain legitimacy for their pain from the medical establishment, which feeds back into their workplace and familial environments. They fight to maintain routines and stay housed and fed, as well as to do simple things they used to enjoy. They endure an endless battle with themselves over the person they formally were, the person they see themselves as now and the person the world views. These are not trivial concerns.

The CDC report

As mentioned in Chapter I, to date the only large-scale study conducted on Morgellons was undertaken by the Center for Disease Control and Prevention (the CDC), which published its report in 2012. That it embarked on such a research project was the result of well-organised and persistent lobbying, a movement which incorporated practitioners, the media, local and national politicians. The study, a population-based examination of potential Morgellons sufferers, was to a degree inconclusive. It strongly suggested that there was no contagious element to the condition and eliminated environmental causes but did not come down totally in favour of a delusions of parasitosis diagnosis, refusing to be fully drawn on the issue:

‘We were not able to conclude based on this study whether this unexplained dermopathy represents a new condition, as has been proposed by those who use the term Morgellons, or wider recognition of an existing condition such as delusional infestation, with which it shares a number of clinical and epidemiologic features. We found little on biopsy that was treatable, suggesting that the diagnostic yield of skin biopsy, without other supporting clinical evidence, may be low. However, we did find among our study population co-existing conditions for which there are currently available therapies (drug use, somatization).’

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66 Will Storr reports on a patient in the UK made unemployed by Morgellons and unable to claim any sick-related remuneration [http://www.theguardian.com/lifeandstyle/2011/may/07/morgellons-mysterious-illness](http://www.theguardian.com/lifeandstyle/2011/may/07/morgellons-mysterious-illness) visited 18/08/14


69 Ibid.
However, despite this uncertainty, the fallout from the report has been definite and damaging to those hoping for further well-funded research into Morgellons. The effect of the CDC report was to largely end speculation and subdue tones of open-mindedness in medical journals regarding the condition. Groups who might be associated with providing care for sufferers such as nurses would write in 2007 that:

‘As psychiatric nurses we need to be aware of this disease so we are not too quick to side with the skeptics...even though there is no evidence yet of what causes these strange and unrelenting symptoms, the CDC and other reputable scientists have taken on the challenge to uncover the mystery and provide answers.’

Following the report, such passages as those above disappear completely from the discourse, excepting those pro-Morgellons researchers. It is true that throughout the last decade there were always articles that strongly promoted a delusion of parasitosis label for Morgellons. What is also true however, is that following the report, those other articles, those calling for more research, or describing Morgellons as something unexplained, no longer get written. It was also reported in the press and online that the CDC had concluded that ‘Morgellons exists only on the patients’ minds’. The CDC report in many ways closed the book on speculation that Morgellons could be something somatic, and became the go-to piece of evidence for those who believe and always believed otherwise. The most important piece of research conducted on the condition, despite being inconclusive, has been treated as if it is the final word. It is indeed true that the CDC were being cautious, that they found no positive evidence for the claims made by Morgellons sufferers, but it does not mean that the study can go without critical appraisal. Although expensive and lengthy, the research only clinically evaluated 41 people. Furthermore, since the population was selected by criteria other than self-identification it has been argued by critics of the study that some of those included did not have or even consider themselves to have Morgellons. The validity of these criticisms may rest on somewhat pedantic points, but what is certainly true is that an awful lot of reading between the lines has been passed off as something more substantial. It is also unlikely that any more large-scale studies of Morgellons will be conducted in the near future and so to the frustration and chagrin of many patients the CDC report is the closest thing they have.

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70 Paquette, M. ‘Morgellons: Disease or Delusions?’ in Perspect Psychiatr Care. 2007 Apr; 43(2): p. 68

71 For example: http://news.yahoo.com/study-freakish-mystery-illness-finds-no-cause-220159892.html visited 13/08/14; http://guardianlv.com/2014/04/14-thousand-people-have-morgellons-disease-but-cdc-says-it-doesnt-exist/ visited 13/08/14; though this is not representative of the entire media response, which was slightly more varied. For a long list of media stories following the report, see http://morgellonswatch.com/2012/01/25/cdc-report-on-morgellons/ visited 13/08/14


73 Subjects for the study were initially selected by a systematic search for key words in their medical records which might indicate the presence of Morgellons.

74 For a particularly angry response to the report by a patient, see http://www.rense.com/general80/fraud.htm visited 13/08/14
Trust

I now move to a third area in which I feel that some form of failure has occurred in the way that medical mechanisms are intended to operate. This is the way in which patients are supposed to interact with doctors, what the expectations are on both sides and how these interactions have been subverted in a negative way. Although I do not have the space here to go into the various literature on sick-roles and doctor patient relations, it is clear that in the case of Morgellons something is seriously wrong.\(^75\) This manifests in several key ways, all related to trust.

Morgellons patients do not trust their doctors and do not feel that they are performing their jobs adequately. A major aspect of this is that the diagnosis they receive is not what they expect or are willing to accept. Patients who strongly believe that what they are experiencing is physiological react to a psychiatric diagnosis extremely negatively. Ambiguity or uncertainty on the part of the physician or dermatologist, whilst entirely understandable, sometimes gets interpreted as a wilful denial of the sufferer’s reality. This is often exacerbated for patients who have gone to their doctor in order to gain validation for a condition they already know the name of. In these situations, anything other than a diagnosis of ‘Morgellons’ spells disappointment and disbelief. More often than not, it also means a trip to another doctor in search of a more palatable explanation. ‘Doctor-hopping’ is common amongst sufferers and many will go to great lengths to find one who will believe them, i.e. one who will diagnose them with Morgellons and reassure them that their pain is ‘real’.\(^76\)

Diagnostic legitimacy for contested diseases tends to vary across specialities, and it has been suggested that seeking out a dermatologist may increase the chance of a delusions of parasitosis diagnosis, so they are sometimes avoided.\(^77\) Many are willing to travel in search of legitimisation. As one poster on a forum writes upon finding another whose doctor was apparently sympathetic:

‘I would be interested in meeting with your doctors. What state are they in, I live in Missouri but would travel just to get some validation and sanity back.’\(^78\)

However, this is not simply about being unable to obtain a clear or desired diagnosis of what they are suffering from. In many cases patients have reported being dismissed, talked down to and generally not taken seriously by those they have

\(^75\) For a good overview of these concepts and work see Frank, A. W., ‘From sick role to practices of health and illness’ in *Medical Education*, 2013, Vol. 47, pp. 18-25; Williams, S. J., ‘Parsons revisited: from the sick role to…?’ in *Health*, 2005, Vol. 9, No. 2, pp. 123-44

\(^76\) ‘Doctor-hopping’, ‘doctor shopping’ or ‘double doctoring’ is where a patient rejects an initial diagnosis and approaches different practitioners until they return a diagnosis that they agree with.

\(^77\) [http://www.thecehf.org/appointment-tips-for-morgellons-patients.html](http://www.thecehf.org/appointment-tips-for-morgellons-patients.html) visited 14/08/14

Some even speak with fear of being institutionalised as a result of trying to pursue a Morgellons diagnosis. Unfortunately, and it can be hard to tell, some sufferers conflate the first part of this (not getting a clear, physical diagnosis) with doctors being ignorant of their symptoms and unwilling to help them get better. Going from doctor to doctor in search of a diagnosis that fits is nothing particularly new and whilst not desirable, is not entirely indicative of a breakdown of trust between doctors and patients. The result of their experiences with doctors and health care providers has not simply led to doctor-hopping though, but to a wholesale development of appointment strategies which from their very beginnings rely on deceit and mistrust.

Variants are published on different websites and forums, but I will use as my main source of information the CEHF’s ‘Appointment Tips for Morgellons Patients’ page as this is where much of the other information is consolidated. It advises that doctors may not be aware of Morgellons, and that if they follow standard procedure (i.e. a literature review) then they will not be in a better position to treat you. It is suggested that dermatologists be avoided, as they have a seeming history of superficial or non-existent examination of patients and more frequently give delusions of parasitosis as their assessment. Visiting emergency rooms or walk-in clinics is similarly warned against. Sufferers are told by this website and others to avoid describing their symptoms in detail, and to exercise restraint in using certain words, no matter how apt they appear to be in describing what is happening. Patients are advised to refrain as far as possible from presenting samples (known by doctors as ‘the match-box sign’) of things they have found on or in their skin. General guidance is also offered in regards to composure and conduct, in order as far as possible to assure the doctor of your sanity.

The recommendations mentioned above are echoed in other sources. A woman who runs a Morgellons helpline similarly states:

“The most important advice I give? Don’t take specimens in. That’s the number one rule...otherwise they’ll think you’re crazy”

And on a blog devoted to Morgellons:

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79 For example http://www.sfgate.com/health/article/Nasty-disease-or-is-it-delusion-Thousands-2495736.php visited 14/08/14

80 It is been claimed that this has happened to some (http://www.morgellonsexposed.com/LivingWithANightmare.htm, http://www.thecehf.org/appointment-tips-for-morgellons-patients.html visited 14/-8/14) but I have been unable to verify this

81 http://www.thecehf.org/appointment-tips-for-morgellons-patients.html, for another, more subjective example see http://morgellonscanada.blogspot.co.uk both visited 14/08/14


83 ‘Rita’ quoted in Jamison, L., 2014, p. 33
‘The only advice about doctors is to ask right off the top if they’ve heard of Morgellons. If they’re dismissive, leave!’

Randy Wymore, a pro-Morgellons researcher, suggests that sufferers take a stock letter with them to their practitioner (see Appendix). Some patients have entirely given up trying to get doctors to help them on the basis of Morgellons and resort to lying outright about what symptoms they have to receive what they view as necessary treatment. Of course this is only effective if you already know that you react well to a certain prescription.

The intention of these kinds of guidelines, and the context necessary for it to emerge, is quite clear: Patients felt that doctors were being unduly offhand about their condition, and have developed ways around the system. The success of these strategies is debatable, as patently people are still struggling greatly to get what they want from the system. What is less debatable, I feel, is the obvious contravention of good doctor-patient relations that these tactics represent. Any situation where a body of ill people feel compelled to systematically lie to their health care providers, conceal symptoms and distort their lived experience of sickness is in itself seriously unhealthy.

In their case study about chronic illness, Anderson, Blue and Lau describe a subject as a ‘model patient’ on the basis that she is well informed about her disease (diabetes in this case), is willing and able to put it first and believes strongly in self-care and individual responsibility. Many Morgellons sufferers fit this description, yet because of a fissure between their expectations and the actuality of their visits to the doctor, sometimes inflamed by the attitudes and approaches of practitioners, they find themselves at the other end of the scale: troublesome, time-consuming, insane.

This is not a one way process either. In direct response to the growth of patient strategies like those outlined above, there are many examples to be found in the medical literature of counterpart tactics employed by doctors. Over time, pragmatic methods have evolved with the hope of delivering a diagnosis that reduces patient resistance and hopefully makes them more open to treatment. Some doctors are acutely aware of the presence of Morgellons support organisations, their agenda and the likely forms that a Morgellons patient might take. Ironically then, the widespread expansion of lay literature on the subject has in some cases made sufferers’ lives more difficult by establishing Morgellons as a by-word for delusions of parasitosis.

The different ways in which authors have suggested that Morgellons can be tackled by health providers can involve deceit to varying degrees, questionable use of therapeutic privilege and raises serious concerns about the role of consent. One approach used emphasises compassion, inclusion of family and warning of insensitivity leading to a guarded and unresponsive patient. It also posits that a potentially effective way to get a sufferer to agree to antipsychotic medication is by focusing on their co-morbid features, and trying to demonstrate to them how treating these secondary conditions

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84 [http://morgellonscanada.blogspot.co.uk](http://morgellonscanada.blogspot.co.uk) visited 15/08/14

85 Jamison, L., 2014, p. 31

86 Much of the following section draws on Söderfeldt, Y. & Grob, D., 2014, pp. 73-74
would be beneficial to their wellbeing. Invocation of vague, ‘scientific’ explanations such as a hypersensitive nerve fibre network which appeals to the sick person’s pre-existing conception of their condition is also encouraged. Of course, this is simply a way to mask the physicians belief that the patient is delusional and prescribe the drugs they would do for someone who accepted they had that condition.

Another technique is to use Morgellons as a ‘rapport-enhancing’ term in order to offer a pharmaceutical solution, by replacing delusions of parasitosis in the discourse with something more accepted by the patient. This approach requires the practitioner to acknowledge the belief that Morgellons is a disease with an unknown cause, even though they don’t actually consider that to be the case. Indeed, it is made explicit that whilst this is a stratagem that can wield positive effects, it must be used conservatively so as not to imply too heavily an organic cause for the condition. They are thus encouraged to use familiar Morgellons lexicon as a way of gaining confidence and compliance, which makes it easier to suggest that certain therapies may help with certain symptoms. The intention throughout is to establish a ‘trusting relationship’ by means of a ‘supportive, non-confrontational approach’.

A third method put forward involves using euphemistic or medically specific terminology, such as describing the medicine as neuroleptics as opposed to antipsychotics. This also involves telling patients that the medicine is for their dermatological symptoms, which can be justified by arguing that some antipsychotics contain antipruritic agents, with obvious benefits for the patient. Pimozide in particular is recommended on this basis, and several doctors have reported success by using it.

All of these are pragmatic responses intended to help treat those who are sometimes difficult to reach, but all also involve a degree of deceit. It is important to recognise that there is no malevolent intent behind these suggested strategies. They are attempts to get around patients who resist and reject what doctors might regard as a more ‘honest’ approach. However, this does not stop them running the risk of ‘harming the

88 Ibid., p. 703
individual doctor-patient relationship, as well as confidence in medicine overall’.\textsuperscript{94} This is because non-disclosure of the true nature of medicines is easily revealed by independent internet research. Given that large numbers of Morgellons sufferers are clearly competent at using the internet, and considering the somewhat hostile and by turns suspicious community, it is not hard to envision how behaviour like that described above might have a negative effect. Being ‘lied to’ by someone who may have been their personal physician for many years can cause an irreversible disintegration of trust.

Issues of consent are also salient. Would patients consent to psychopharmaceutical treatment programmes if they were aware of their actual contents? Patients have the right to refuse treatment, even if the consequences to themselves are grave. The American Medical Association severely restricts the occasions where information may be withheld from a patient. It is permissible to refrain from informing a patient of something if that knowledge will demonstrably worsen their condition, but it cannot be kept a secret \textit{ad infinitum}.\textsuperscript{95} In the UK, consent only exists if the patient ‘genuinely knows and understands’ the treatment being offered to them, excepting cases covered under the mental health act.\textsuperscript{96} In either case, the patients’ right to be informed about what is being recommended is not being respected to the extent that it should be.

That being said, it is clear that many doctors are still ignorant of Morgellons as patients continue to report dismissive and unproductive visits to surgeries and clinics. One thing that this does suggest is that there is a distance between what is being recommended in the literature and the actual experiences of patients, who feel neither comforted nor tricked, but rather simply rejected.

\section*{Conclusion}

In this chapter I have outlined some of the ways in which Morgellons can be viewed as a failure of modern medicine to reconcile the issues faced by sufferers within the current framework of care. Morgellons shares features with many other contested diseases, and patients suffer a variety of chronic symptoms that interfere greatly with their quality of life. The research into this disease has stalled significantly since the CDC report in 2012, and what is written by those outside of the community is almost completely conceptualised as delusions of parasitosis literature. What is perhaps most worrying is the level of mistrust that has developed between patient and doctor. Issues of legitimacy on a more global level are being fed by innumerate small collapses of confidence in a local setting. It is fairly easy to trace the pattern of events that led to this situation, but that does not detract from the fact we are viewing a total inversion of desirable practice. Patients are being encouraged to carefully plan their interactions with health care professionals, hide their symptoms and generally present a false image of their illness in order to obtain a diagnosis and treatment that

\textsuperscript{94} Söderfeldt, Y. & Grob, D., 2014 p. 74

\textsuperscript{95} Ibid, p. 73

\textsuperscript{96} Visited 25/08/14
favourably agrees with their predisposed disease conception. Doctors for their part have been accused of acting with disdain and lack of compassion. In the medical literature, several methods are suggested which, though driven by good intentions and potentially effective on a case-by-case basis, stretch the limits of therapeutic privilege and risk doing deeper damage.

I have tried as far as possible in this section to present the ‘broken’ side of Morgellons without diverging too far into analysis, blame and solutions. This I will discuss in my final chapter, once I have explored the notions of community and offered a defence of the actions of health professionals in this case.
III - Community

Community is a loose term, one that is frequently employed but difficult to define. In disease studies the word is equally tricky. Do sufferers of the same disease automatically form a community? What about their doctors or family members? Or researchers working on the condition? - and so on. With Morgellons this issue is compounded by the problematic nature of the disease itself, and the fact that the Morgellons ‘community’ is so frequently referred to. I think it is best to draw a line around those who suffer from and are interested in the disease and communicate, educate and support each other. Whether it be online, in local projects or through international gatherings such as the annual conference organised by the CEHF, individuals reach out to each other, share stories and offer advice about the disease. They also politicise and organise themselves as a group that, whilst not by any means homogenous, can agree largely on goals. In this section I will outline what I believe to be the two main functions of the Morgellons ‘community’. Firstly, it acts as a support mechanism for those who believe they have the condition. Secondly, it performs an advocacy role, trying to challenge and change the dominant epidemiological paradigm. I think that studying the way that this group operates, alongside looking at the condition as it exists in people’s lives and in clinical settings, can give insights into how contested diseases operate in an era of mass communication.

Support

As is no doubt clear, living with this condition can be difficult for a number of reasons. Networks of individuals with this disease who communicate and console each other have grown over the last decade, passing through distinct transitions to reach the stage we are at today. To understand the role that these groups can play in people’s lives it is useful to briefly examine how they came into existence. One of Mary Leitao’s initial aims in creating the now closed Morgellons Research Foundation was to raise awareness about the condition and attract the attention of interested scientists or indeed anyone who could help. The actual result of her taking her concerns online was a deluge of communication from people claiming that they were having similar health problems. A combination of factors, including the arrival of Randy Wymore, the first credible scientist to take an interest in Morgellons, and the contracting of a professional communications consultant to increase the disease’s media profile, led to an enormous growth in Morgellons coverage. This spanned talk shows, documentaries and newspaper articles, all with the intention of reaching more people who might have Morgellons. Apparently a successful strategy, the

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98 Mnookin claims that Leitao launched a ‘national PR blitz’ in 2006: Mnookin, S., 2012, p. 88
number of patients registered on the website grew massively and a more general online presence was reported.99 Although the MRF is no longer operational, the CEHF has effectively picked up where it left off, offering a space where pro-Morgellons information can be found, stories of other sufferers shared and research disseminated. Alongside this exist manifold blogs, personal websites and forums from many different countries.100 How do these platforms offer emotional and practical support to sufferers? First and foremost they serve to remind and reassure patients that they are not alone and that they don’t have to endure their personal health issues in isolation. This is an extremely common motif on Morgellons websites, perhaps due to the marginalising effect of the disease, dispiriting encounters with doctors and the relief of discovering others in the same situation. Many feel like they have fought an unknown condition for years in frustrating ignorance and confusion, writing things like ‘In the first three years I suffered with Morgellons disease I was totally on my own’.101 Therefore phrases such as ‘you are not alone’ surface repeatedly and provide emotional algiatry for the previously isolated. This was not always the case with rare or fringe conditions, and so this high level of support and information is fairly new. Charmaz, writing in 1991, says:

‘People who have esoteric illnesses seldom could get facts from fellow patients, mainly because they did not know anyone else with the same condition.’102

Not being alone is far from the only reoccurring theme of Morgellons support networks. They also exist to provide an alternative framework through which to conceptualise the experience of disease. This is largely an exercise in providing validation on the basis of an understanding of Morgellons that diverges from what sufferers are told by their doctors, by their companions or that which they might read in the paper. The somatic understanding of Morgellons that underpins the community forums manifests not only in formal assertions of its biological aetiology by pro-Morgellons researchers and other interests. It shows through on a much more emotive, personal level, in the repeated assertions that ‘this is real’ and that patients ‘are not crazy’. The opening lines on a Morgellons website say the following, and sum up more or less the thematic essence of the majority:

‘You are not alone. Nor are you delusional or is this self-inflicted...I have suffered the seemingly unrelenting torment. There is hope...So always remember you are not alone.’103

99 Ibid, p. 89

100 For example, Canada: http://morgellonscanada.blogspot.co.uk, the UK: http://www.morgellonsuk.org.uk, Turkey: http://tuhafhastaliklar.blogspot.co.uk/2013/12/morgellons-hastalik.html, Germany: http://www.morgellons-research.org/morgellons/ all visited 15/08/14

101 http://www.morgellonsexposed.com/Throwback.htm visited 12/08/14

102 Charmaz, K., 1993, p. 18 (This edition is a reissue).

103 http://morgellonsaid.wordpress.com visited 15/08/14
Online, the limits on what can be said and who might be given a voice are far less restricting than in everyday social life. As a result, almost unconstrained communication can take place, which in some parts leads to or at least facilitates the growth of conspiracy theories and unfettered anger. That some are drawn to these kinds of explanations demonstrates more of a desperation for answers than any widespread devotion to blaming the government, chemtrails, nanotechnology etc. In fact, many patients deeply resent the implication that they might subscribe to such theories because of how much they feed into the notion that a Morgellons sufferer is not a sane, rational individual. Nonetheless, this community, like all communities, has blurred edges. Beyond initiating and housing emotional convalescence, Morgellons organisations and patient-led groups swap tips and strategies on coping with their condition. In this respect it is no different to other patient groups who discuss such things in relation to their illness. Effectiveness of treatments are debated and a multitude of suggestions are exchanged that might make life more bearable for one another.

**Advocacy**

Before it ceased operations, the MRF argued that one of its primary functions was ‘taking a disease, which was unnamed and largely misunderstood, from obscurity into the world of science.’ Its work, along with that of others, has not achieved this, or at least not achieved this to a degree they would deem desirable. What they have been able to do to some extent is push back against the ‘ambiguous, flexible, historically changing, contextually variable, internally inconsistent and sometimes disputed’ boundaries of modern science. At their highest, most organised and most politicised level, the Morgellons community have attempted repeatedly to challenge the dominant epidemiological paradigm that frames their disease. Their success has been limited, but it is demonstrative of the difficulties faced by any group trying to attack the realities presented by science. As Mansbridge writes: ‘the dominant group has so much control over the ideas available to other members of the society that the conceptual categories required to challenge the status quo hardly exist.’

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105 Fair, B., 2010, p. 604


The various strategies they have employed revolve around fighting for legitimacy regarding their version of the disease concept. Nomenclature is one such battlefield. It has been noted that in the first instance having a name for a condition at all contributes to its validity and ‘realification’. From here, a fight over semantics takes place, with many doctors and scientists strongly resisting the communities attempt to secure the label ‘Morgellons disease’, preferring to label it a syndrome or advocating the removal of the term from discourse all together. As with many other contested diseases, Morgellons sufferers tend to seek a ‘biomedical’ label because it is this that to a greater extent emphasises the ‘reality’ of their condition. They feel that their experiences are exonerated by this which is why Morgellons ‘disease’ is employed by pro-Morgellons researchers and campaigners.

Another function performed by organisations such as the MRF and lately the CEHF is to politicise their members and to encourage collective action at a local level. By providing stock letters and addresses of relevant persons, patients are encouraged to contact health professionals, politicians, celebrities - anyone who could help the cause. The clear intention of this lobbying is to establish control over the dominant epidemiological paradigm and to recruit scientists who are able to validate and elucidate the somatic model of Morgellons. It is as a result of this work that the CDC investigated Morgellons in the first place, though such activity appears to have been curtailed following the publication of the report. The presentation of Morgellons in the literature, the aetiology given and the proposed medical treatments remain stubbornly difficult for outsider groups to change. However, limited success has been achieved through the work of a few individual researchers, who have been able at least to give Morgellons patients some aetiological possibilities which they can accept and support as an alternative epidemiological view of the disease. The two functions of the Morgellons community described above (support and advocacy) combine in order to create what is known as ‘oppositional consciousness’.

This is the growth of a collective identity that comes out of ‘shared grievances that might result from discrimination, structural dislocation, shared values, or other social constructions’. Morgellons patients have come to view themselves as members of a group who see their situation as unjust and believe that perhaps

110 There are many parallels with CFS in this regard, see Huibers, M. J. H. & Wessely, S. ‘The act of diagnosis: pros and cons of labeling chronic fatigue syndrome’ in Psychological Medicine, Cambridge University Press, 2006, p.2
111 The Morgellons community fits the criteria for having developed oppositional consciousness, as described by Groch, S. ‘Oppositional Consciousness: Its Manifestation and Development: The Case of People with Disabilities’ in Sociological Inquiry, 1994, Vol. 64, No. 4, p. 371
112 Brown, P., Morello-Frosch, R. & Zavestoski, S., 2012, p. 109
through collective action this injustice may be reconciled.113 In many ways, their identity is defined by what they don’t have, i.e. something psychological or stress related, in common with many other contested diseases.114 Overall, they are able to harness communication tools and create supra-individual identities that combine a commitment to a distinct disease concept, a resistance to the imposition of non-somatic explanations and produce a variety of networks offering support and pastoral care.

The role of the internet

An aspect of Morgellons that is oft-referenced and little explored is the functional role of the internet in the development of the condition. It has been suggested that in some sense, Morgellons is a disease that has ‘spread’ online.115 The argument is that the reason so many people have self-diagnosed themselves is because the internet allows the unregulated dissemination of medical information without the traditional checks on validity that have historically restrained such a flow. The widespread reach of the internet means that an unprecedented number of individuals have access to this information, and the combination of the two developments creates a unique and modern context for contested illness groups to flourish and widely propagate their ideas. It has been posited that Morgellons can best be understood as a ‘meme’ or a ‘folie a internet’ which challenges conventional definitions within society, because ‘the psychological appeal of an idea...not necessarily its validity, can be more valuable to its success’.116 This notion of mass hysteria which spreads online is based upon the assumption that the internet is the only place in which patients may come to conceptualise themselves as Morgellons sufferers.

This is not viewed as a positive phenomenon, as the widening of medical sources is argued to create unnecessary tension between doctors and patients, undermine diagnostic authority and dilute the effectiveness of medical care. Certainly, some are concerned, arguing that ‘one potential negative consequence is the dissemination of information with minimal or no supporting evidence that is incorrectly portrayed as factual’ through an internet presence ‘may facilitate the dissemination of bizarre beliefs’.117 The danger of patient to patient interaction is not a new worry. It has been reported that in some cases doctors advise patients against seeking out others in their condition, for fear that this will do more harm than good. However, whilst in the past


115 http://www.mostlyodd.com/morgellons-imaginary-epidemic/ visited 18/08/14


this involved joining a self-help group, seeking out specialist publications and procuring information in a sometimes complicated and time-consuming way, the internet allows the individual to achieve the same aims with far more limited resources. Doctors are concerned that in the case of Morgellons, patients are falling for ‘cyberchondria’, where an ‘unfounded medical fear’ is severely worsened by use of the internet.¹¹⁸

Morgellons patients strongly reject this view, arguing that the internet allows the spread of information and the organisation of sufferers, not a proliferation of false self-diagnosis. It is repeated many times that individuals felt that they had been suffering with an unknown condition for long periods of time (decades in some cases) before they were alerted to the possibility they may have Morgellons. These people feel strongly that the internet has given them a name for their condition, but in no way changed the way they personally experience their symptoms. Some found their way to a Morgellons diagnosis through way of friends, the media or sympathetic health care professionals. Under this schema, the internet is just one of a multitude of mediums through which information is spread and people are reached, rather than being the site of a geographically and socially diverse form of mass hysteria. It is also important to remember the real institutional features that characterise Morgellons: the research foundations, university departments, telephone helplines and conferences. In short, too much can be ascribed to the power of the internet and such an explanation is overly simplistic.

Away from the epidemiological sphere, the case of Morgellons does demonstrate how pivotal the internet can be in advocacy campaigns. As a concentrated online contested illness community can draw on wider social and cultural resources, cutting across multiple fields in its political efforts, Morgellons patients have used the internet to communicate and organise, raise money and lobby.¹¹⁹ Again though, this is a case of the technology being a facilitating factor rather than the cause of any activity.

In this section I have looked at how ‘community’ functions in relation to Morgellons. I have found it to have a dual purpose. It serves to offer emotional support and reassurance through communication and repetition of simple messages of legitimacy. It also acts as a political body which organises itself to challenge science and pursue a distinct agenda.

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¹¹⁸ White, R. W. & Horvitz, E. ‘Cyberchondria: Studies of the Escalation of Medical Concerns in Web Search’ in ACM Transactions on Information Systems, Vol. 27, No. 4, p. 1

Morgellons is a disease with a split narrative. So far I have endeavoured to paint a vivid picture of one side of this discourse. But the other side remains to be told. It would be doing a grave disservice to the health care professionals involved to blithely ignore how their view of this condition can be justified. In this section I will explain the reasonable actions of doctors, nurses and dermatologists who find themselves unwilling to give a diagnosis of Morgellons and unable to help their patients. I will then discuss the somewhat chequered past of the pro-Morgellons researchers and the problems with such a small number of individuals producing almost all of the work on the subject.

Reasonable doctors

A doctor facing a Morgellons patient is one with a difficult task. Symptoms are varied and vague and it is hard to establish a complete picture of what is happening within the body of the individual. The literature that you have read tells you that much of the behaviour you are witnessing and the issues reported by the patient fit into the established pattern of delusions of parasitosis. Perhaps you have experience of such a condition and have seen cases before. You also know that there exist case studies which demonstrate the effectiveness of antipsychotic medication as a treatment. So, in this situation, what is the reasonable course of action?

Notwithstanding the accounts of patronising and ill-judged interactions between doctors and patients, many do try to be compassionate, to make it clear that they understand the pain and uncomfortable nature of the patient’s position and to find a solution that may offer some relief. So far in this piece I have focused on the negative aspects of the way Morgellons patients are treated, and I want to make it clear that this is not the whole story.

For a start, it is apparent that we cannot for one moment treat medicine as a homogenous mass. Morgellons is a disease reported across different continents, encompassing thousands of people interacting in a multitude of settings, so to treat doctors as one is an obvious and dangerous mistake. The literature available to physicians recommends a variety of different methods of dealing effectively with Morgellons patients, and recognising the manifold forms these take is important. Söderfeldt and Groß present and analyse a number of these in their review which draws from many other sources. There are also doctors who are ‘willing’ to treat Morgellons, and who form a small minority of health care professionals. In clinical practice, indulging a false belief might present numerous problems for a patient. It is well known that often ill people can develop sometimes obsessive routines which help them cope with their condition. In the case of Morgellons this manifests

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120 Söderfeldt, Y. & Grob, D., 2014
121 One such example is Dr. Anthony Bewley, a consultant dermatologist in London
122 Charmaz, K., 1993, p. 150
in cleaning regimes, the use of creams, specialised diets and regular removal of fibres from the skin. This can be taken to dangerous levels by sufferers desperate for relief, sometimes to the point where people use bleach or similar substances to try and alleviate their symptoms.\textsuperscript{123} If a doctor acknowledges and validates the patient’s own conception of Morgellons, then subsequent action based on that conception becomes further rationalised and legitimate, and dangerous attempts at self-medicating may be attempted.

Furthermore, it is likely that contributing to this belief system from the authoritative position that a doctor holds will solidify convictions in others. So the dangers of doing so extend beyond simply an individual patient, but potentially across a whole range of people. Looked at this way, it is irresponsible and unprofessional for a doctor to try and treat Morgellons in a manner which accords with the patient community’s conceptualisation of the disease.

Then there is simply the matter of honesty and integrity. As discussed above, doctors have developed numerous strategies to try and more effectively help Morgellons sufferers, with troublesome results for patient consent. The other side of this is when doctors adopt a policy of full disclosure. That is, they have examined all the relevant evidence and the patient and come to the conclusion that in their professional opinion the individual is suffering from a well established and documented psychiatric condition.

The balance of research

I have discussed the research that has been done on Morgellons in many passages above and briefly touched on the fact that the vast majority of academic interest in the area has concluded that Morgellons is or is most likely to be a modern incarnation of an established psychological condition. This is research and comment from scientists, psychologists, dermatologists, nurses and physicians published in largely respectable, peer-reviewed journals. In short, under normal circumstances, it would amount to fairly absolute and certainly workable clinical certainty.\textsuperscript{124} The research done which presents Morgellons as somatic or of unknown origin, however, could not be seen as so straightforwardly credible. To begin with the actual number of researchers undertaking work on Morgellons is small. The papers tend to emanate from the same group of scientists and reference each other and themselves.\textsuperscript{125} Whilst this is not necessarily a problem, it is easy to see how a comprehensive and credible-looking research programme could be constructed on the basis of a small amount of actual work. It is worth noting though that many fields operate in a similar way to this, given the heavily specialised nature of modern research.

\textsuperscript{123} Apparently with some success: \url{http://www.quantumbalancing.com/morgellons.htm} visited 18/08/14; \url{http://msjdy3.hubpages.com/hub/I-USED-TO-HAVE-MORGELLONS} visited 18/08/14

\textsuperscript{124} I include the caveat ‘under normal circumstance’ because ordinarily such a context would not produce so antagonised a patient community.

\textsuperscript{125} Mnookin, S., 2012, p. 90
The repute of the advocate researchers has also been called into question, as has their qualification for the role. Dr. Raphael Stricker, author of numerous papers on Morgellons, is no stranger to accusations of unprofessional behaviour. In 1993, he was found to have falsified data for a grant application and was banned from applying for grants or serving on PHS advisory committees for three years.\textsuperscript{126} His co-author on many papers, Ginger Savely’s competence has been questioned because her training is in nursing, not biology or dermatology. The work they have completed together has been discredited by some, as has the journal it was published in, which ‘would appear to value rapid communication over quality’.\textsuperscript{127} Savely has also had trouble in the past. In 2006, she was forced to move from Texas to San Fransisco (to work with Stricker) because she was unable to find a doctor willing to supervise her practice.\textsuperscript{128} She had been prescribing long-term courses of antibiotics to those diagnosed with chronic lyme disease, which contravened the Texas Medical Board’s regulations.\textsuperscript{129} She claims to have been harassed and discriminated against because she was willing to treat patients with ‘cutting edge methods’.\textsuperscript{130} It has however been suggested that since she offers Morgellons patients the same treatments, she is making her living promoting and then profiting from a model of disease she also propagates in her research.\textsuperscript{131}

Other Morgellons researchers are not free from criticism, and nor are their modes of publication. Randy Wymore, a supposedly-leading Morgellons scientist, has actually published very little on the subject, and nothing of real repute or insight. The articles that have made it into journals in recent years have been published largely online and disputed heavily once there. For example, Mayne, English and Kilbane et al, 2013, was published on F1000 Research, and only approved by one individual who worked in a department noted for its links to pro-Morgellons research.\textsuperscript{132} The work is described as ‘seriously flawed’ by Steven Salzberg, similar to criticism given to their previous work, which ‘should never have been published’.\textsuperscript{133} One further shadow that hangs over much of the pro-Morgellons research is the connection that many of the


\textsuperscript{127} \url{http://scienceblogs.com/whitecoatunderground/2010/05/13/bad-science-done-badly-its-bad/} visited 18/08/14

\textsuperscript{128} Her account of what happened: \url{http://www.gingersavely.com/More-Bio.html} visited 19/08/14

\textsuperscript{129} \url{http://www.standupforlyme.org/getinformed/statesman_20060330.html} visited 19/08/14

\textsuperscript{130} Ibid

\textsuperscript{131} \url{http://morgellonswatch.com/2006/05/14/follow-the-money/} visited 19/08/14


\textsuperscript{133} Steven Salzeberg is a Professor in the Departments of Medicine, Biostatistics and Computer Science at John Hopkins University School of Medicine (\url{http://ccb.jhu.edu/people/salzberg/Salzberg_Salzberg_Lab_Home.html}); \url{http://f1000research.com/articles/2-118/v1}; \url{http://f1000research.com/articles/2-25/v1}#article-comments, both visited 19/08/14
researchers have with chronic lyme disease, itself a highly controversial and disputed condition.\textsuperscript{134}

I do not wish this section to read like an \textit{ad hominem} attack of those who research Morgellons. Being in trouble with the medical authorities in the past is no sure indicator of current trustworthiness, and plenty of research is disputed and discredited by individuals for a variety of professional and personal reasons. It is just important to recognise that these criticisms do exist and that to the average practitioner who has no stake in this either way they probably make a difference. I return then to the question I posed at the beginning of this section. As a doctor, nurse or dermatologist faced with a Morgellons patient, having taken the steps you normally would, the steps you have been trained to take, what is the reasonable course of action?

I think it is perfectly acceptable to concede that in the majority of cases doctors are simply ‘doing their job’ and that Morgellons presents challenges that are not readily reconciled by following best practice. That is to say, doctors are not necessarily the problem in this case.

In this essay I have endeavoured to show how instructive this case can be in demonstrating the functioning life of a modern, contentious, chronic disease. Morgellons teaches us lessons about how conflict plays out between patient communities and health care professionals, and how those communities perform a second (though not secondary) pastoral role. The internet facilitates discourse and connection but does not necessarily fundamentally change the way that patient advocacy operates.

Ultimately, what I have tried to convey is that Morgellons represents ‘failure’. It is a failure because of the social cost of the disease, which remains largely unmediated by medical action. It is a failure because the doctor-patient relationship in this case has been bent out of shape by conscious deception on both sides. And it is a failure because despite over a decade of research and campaigns, individuals are still struggling without respite from this condition. The longer this continues, the more embittered and defensive the community will get and the less likely it is that progress could be made.

It is easy to argue that it is the patients that are at fault here. Indeed, they are the ones who apparently resist treatment, who ignore the ‘facts’. They are the ones who supposedly crave medical help yet refuse to listen to medicine when it talks. And they are the ones who talk to each other and the press, furthering rationalisations of their condition that have potentially dangerous consequences if they convince people to reject help.

What I’m getting at is deeper than this. Neither doctors nor patients are to blame for this situation, if blame is even the right word. Our understanding of health as it relates to clinical intervention with chronic illnesses of this type is blunt, outdated and ineffectual. Over thirty years ago, George Engel wrote that medicine suffers badly from ‘adherence to a model of disease no longer adequate for the scientific tasks and social responsibilities of either medicine or psychiatry.’135 Whilst psychiatry, and the task of biospsychosocial psychiatrists, has moved on, it is hard to argue that medicine has done the same.136 It is clear, and the experience of Morgellons strongly reinforces this point, that a move away from the biomedical model is necessary to adequately treat individuals with chronic diseases. The narrow, reductionist view of disease currently employed ignores the ‘social and medical consequence’ that accompanies doctor patient relations.137 This feeds into societies where ‘the notion of biophysical facts [have] primacy over humanistic interpretations’, and a medical diagnosis or lack

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136 Ghaemi, S. N. ‘The rise and fall of the biospsychosocial model’ in The British Journal of Psychiatry, 2009, Vol. 195, pp. 3-4; Though in recent years there have been some promising signs, see Johnson, S. B. ‘‘Medicine’s paradigm shift: An opportunity for psychology’ in The American Psychological Association, 2012, Vol. 43, No. 8, p. 5

of one has far-reaching effects on a patients’ rights, both on a personal and professional level.\textsuperscript{138}

That patients feel stigmatised and unable to accept a psychological diagnosis is a direct result of this ideological base. By the same token, that doctors are unwilling to provide more holistic, less operationalised responses also follows on from this thinking.

In one case, a doctor noted that antibiotics appeared to be effective in treating some Morgellons patients. However, this was dismissed as a ‘peculiar finding’ that should not be entertained further for fear it might incubate incorrect ideas about the nature of the condition.\textsuperscript{139} Whilst there are good reasons why a doctor might not want to prescribe drugs without being certain as to why they are effective, this dismissive, steadfast commitment to a mind/body divide is standing in the way of treating people effectively.

Morgellons is symbolic of the ‘emergence of diseases that have psychological, social and environmental components’ which challenge the ‘hegemony of biomedicine’.\textsuperscript{140} Without looking at them in depth we will have no insight into the problems they pose and the solutions they might hold. Fundamentally both doctors and patients generate their own realities about what is happening in their bodies and minds. Equally fundamentally neither of them understand this or many other chronic illnesses like it.

Our current tools of analysing and aligning the needs of mind and body are unable to do so to any recognisable and desirable degree, and it is in this disconnect, this space, that we are left asking ‘what kinds of reality are considered prerequisites for compassion’?\textsuperscript{141}

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\textsuperscript{139} Accordinho, R. E., Engler, D., Ginsburg, I. H. & Koo, J., 2006, p. 11
\textsuperscript{140} Mehta, N. ‘Mind-body Dualism: A critique from a Health Perspective’ in Mens Sana Monographs, 2011, Vol. 9, No. 1, pp. 202-209
\textsuperscript{141} Jamison, L., 2014, p. 39
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May 15, 2006

Re: Morgellons Disease

From: Randy S. Wymore, Ph.D., Department of Pharmacology & Physiology
Rhonda Casey, D.O., Department of Pediatrics
Oklahoma State University Center for Health Sciences
Tulsa, Oklahoma

Dear Practitioner,

This letter concerns a patient population that manifests a particular set of symptoms we have encountered with increasing frequency, and that OSU-CHS is actively researching. The condition has been labeled as Morgellons Disease and it is unclear if this is a single disease or a multi-faceted syndrome. Until recently, most of these patients have been grouped as a subset of the diagnosis of Delusions of Parasites (delusional parasitosis; DOP). After obtaining careful patient histories and thorough physical exam, we have determined that Morgellons patients have several important distinctions ruling out the diagnosis of DOP.

This population of patients frequently exhibit the following symptoms:

• Distinct and poorly healing skin lesions with unusually thick, membranous scarring upon eventual healing.
• Moderate to extreme pruritis at sites of lesions as well as un-erupted skin.
• Microscopic examination of these lesions will most often reveal the presence of unusual fibers, which may be black, blue or red. These fibers, which many healthcare providers initially thought to be textile contaminants, are often present in the deep tissue of biopsies obtained from unbroken skin of individuals with this condition. Careful examination of these fibers further reveals that they are frequently associated with hair follicles, and are definitely not textile in origin.
• Most of these patients suffer from a host of neurological symptoms which can vary in severity from mild to severe. These neurological symptoms include peripheral tingling, paresthesias and varying degrees of motor involvement; which appear to progress.
• Intermittent cognitive and behavioral status changes are often observed and also seem to progress with the severity of disease. This is often referred to as “brain fog” by the patient as they experience a waxing and waning of this symptom.
• Laboratory findings in these patients are variable, but often reveal eosinophilia and elevated levels of Immunoglobulin E.
• Other symptoms of varying severity and frequency have been described, and are included in the attached case definition.

Continued…
Morgellons patients differ from classical, delusional parasitosis patients in several areas. They do not respond to antipsychotics, and new lesions continue to appear upon complete cessation of manual excoriation.

Due to the sensation of foreign material in their tissue, that has been described as sharp, stinging and/or splinter-like, the patient may have discovered the fibers prior to seeking medical care, and may bring them to your office for examination. Please do not assume that the patient's problem is purely psychological based on this propensity.

Many of these patients may appear skeptical of traditional medical care due to frequent dismissal of their symptoms in the past. The combination of suffering from a chronic disease with distressful symptoms and no known cause or cure can cause some patients to appear anxious or agitated.

We encourage you to take the time to carefully interview any patient who may fall into this category, perform any testing you may deem appropriate, and most importantly treat the patient with compassion and dignity.

Sincerely,

Randy S. Wymore, Ph.D.
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Morgellons Research Foundation
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