

Morgellons: an exercise in medical validation

Introduction

Morgellons may or may not be a modern affliction, but the circumstances in which it exists are distinctly specific to the 21st century.¹ The existing literature is both sparse and voluminous. Medical journal work is lacking, whilst patient-written material stretches all over the internet.² Almost totally absent is an academic effort which tries to document what has happened from a social constructivist position, taking account of both accredited literature and otherwise. In the following piece I hope to go some way towards filling this gap, and so I will now briefly outline my point of view. I do not believe it is necessary to engage in complex and often circular debates about aetiology. Remove this dangerous temptation and what is left is the processes: who is made to feel how and by what means; what makes a 'disease', what is 'medical authority' and how does it exercise said authority? These are the questions I hope to answer. Neutrality is impossible, but hopefully by aiming towards it I can achieve something close to meaningful analysis as a byproduct of such efforts. To this end I have attempted to regard both academic and non-academic sources as valuable. 'Sticking to the literature' in this case would I believe prove myopic and do a disservice to the heterogeneity of the actors involved.

In short, I am not concerned so much with the symptoms and the various causal debates, but rather with the way that Morgellons illustrates power structures between patients and the medical community. In this essay I will attempt to navigate the contentious territory of disease definition, framing and legitimisation in relation to a very contemporary phenomenon. Tracing Morgellons through the last decade and elucidating the contours of the debate is an informative exercise for anyone interested in the operation of contemporary medical. It is an age that enables the collective organisation of once spatially and socially disparate individuals, though the results are perhaps unexpected. There is no large-scale awakening of critical awareness, no metaphysical dissatisfaction with the tenets of science, no coherent rejection of norms. Rather, there is a desperate desire of patients to be recognised by traditional medical authority, and further to that a deep and profound sense of displacement

¹ For lengthy expositions on how Morgellons manifests, see Frudenmann, R. W. & Lepping, P. 'Delusional Infestation' in *Clin. Microbiol. Rev.* 2009, 22(4) pp. 693-709; or Savely, V. R. & Stricker, R. B. 'Morgellons disease: Analysis of a population with clinically confirmed microscopic subcutaneous fibers of unknown etiology' in *Clinical, Cosmetic and Investigational Dermatology* 2010, 3 pp. 67-68; or Middelveen, M. J., Rasmussen, E. H., Kahn, D. G. & Stricker, R. B. 'Morgellons Disease: A Chemical and Light Microscopic Study' in *Journal Clin. Exp. Dermatol. Res.* 2012, 3:1 p. 1

² To put this in perspective, a PubMed search of 'Morgellons' returns 45 results, Jstor just 9, whilst Google and YouTube will provide you with about 929,000 and 58,600 respectively.

when these desires are unfulfilled.

I will argue that Morgellons teaches us much about the position of medicine within society.³ In order to do so I will briefly explore the evolution of Morgellons and discuss the various ways that patient groups have tried to control its framing; through the use of history; a struggle of semantics; the hierarchy of internal medical framing between psychological and somatic explanations and the value of scientific validation in relation to the legitimisation of the condition. Then I will describe what happens when such tactics fail.

I will conclude that, whilst remaining strictly ambivalent on the aetiological status of Morgellons, this case exists as a fascinating reassertion of the prevailing power of medical science, and a disheartening glance at the alienation of patients that rejection can endeavour. It also demonstrates both the strength and the limitations of the internet as a tool for transferring power from traditional institutions to individuals and newly generated advocate communities. Ultimately it shows that much more than organisation and communication are required to win a game of disease definition in which the cards are stacked so firmly against you.

Achieving medical legitimacy in the 21st century

In 2001, Mary M. Leitao became aware that her son was suffering from an open sore on his lip, which failed to heal over time and appeared to produce 'bundles of fibres'.⁴ Initially dismissed by doctors as eczema and then as Münchhausen syndrome by proxy on behalf of Leitao herself, so began a long journey to achieve validation for what she believed to be a debilitating and potentially contagious illness.⁵ She settled on the term 'Morgellons' to describe what she was witnessing, forming the now defunct 'Morgellons Research Foundation' to bring attention to the disease. Many others soon followed and the internet became awash with manifold organisations, ranging from dubiously qualified charlatans to largely non-scientific supportive patient communities to university departments devoted to Morgellons research.^{6 7} The years 2001-2013 have seen both an enormous growth in the

³ The main bulk of my work has concerned the US and the UK, so I think it would perhaps be more accurate to say *Western* society. Cases of Morgellons have to my knowledge been reported across Australia, the US and Europe but not in Asia, South America or Africa.

⁴ Frudenmann, R. W. & Lepping, P. p. 708

⁵ Münchhausen syndrome by proxy refers to a condition whereby a sufferer repeatedly attempts to draw medical attention to the non-existent symptoms of another in order to gain sympathy.

⁶ I use the word 'organisations' loosely. I am referring to groupings of people around a general topic and on a shared space, in this case 'Morgellons' and the internet, rather than necessarily established institutions or exclusive collections of people.

⁷ For recognised research department see

<http://www.healthsciences.okstate.edu/morgellons/index.cfm>; for individual

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number of Morgellons sufferers, who were now able to reconcile their previously unacknowledged symptoms under the new label, and the diverse range of tactics employed by sufferers in an attempt to receive medical validation. There is not enough space here to unpick exactly why such legitimisation is important for any individual or group but needless to say I have not taken it as self-evident. The amount of validation required undoubtedly varies from person to person but is important not just for an individual's psychological well-being but for generating future research infrastructure, changing physician practice and establishing an accepted basis for suffering. In short, it is about being taken seriously.

Important to realise is that all of the processes of legitimisation I have observed are constricted by their promoters' determination to stay firmly within the confines of the Western scientific context in which disease defining is conventionally achieved. Rarely did I see attempts to justify Morgellons with reference to mystical or religious authority: it is never a 'curse' or a 'plague' from God. Although, it is true, references to 'nanotechnologies' and 'chemtrails' abound, I believe that this kind of conspiratorial speculation only gains currency once traditional channels have been exhausted.⁸ It is also worth noting that many sufferers prefer to subscribe to an open-minded stance that rejects conspiracy and argues that because we do not currently know what the cause is does not mean that we never will.

Over the last decade, numerous ways of framing Morgellons have been attempted by patients. The end-goal is always its establishment as a legitimate, biological disease with an internal history present in medical literature that requires further scientific attention. As it stands, the current discourse strongly implies that Morgellons is not a distinct condition but rather a new name for delusions of parasitosis, a long acknowledged condition. It is argued that the internet has facilitated a reconceptualising of the old psychological condition by allowing patients to self-diagnose and ignore expert advice.

The first contention with the mainstream medical narrative is that this is not an emerging disease or an existing condition with a new name.⁹ Starting with Mary Leitaoherself, who

practitioners working on the disease see <http://www.drwayne.com/Lyme.htm>; for large-scale support networks see <http://www.morgellonsuk.org.uk>; for individuals offering pseudoscientific explanations see <http://morgellonsthe truth.com> all visited 15/11/13

⁸ For a sample of nanotechnology theory proponents, see http://www.bibliotecapleyades.net/ciencia/ciencia_morgellons19.htm or <http://timothytrespas.wordpress.com/2013/01/27/morgellons-is-a-man-made-nanotechnology-a-bio-weapon-created-with-form-functions-from-all-3-branches-of-life/>, for writings about chemtrails see <http://loveforlife.com.au/content/09/12/27/morgellons-disease-silicone-nanotechnology-it-not-parasite-research-how-polymers-ar> or <http://www.morgellonsexposed.com/Chemtrails&Morgellons.htm> all visited 15/11/13

⁹ The World Health Organisation defines an emerging disease as: 'one that has appeared in a population for the first time, or that may have existed previously

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selected the moniker 'Morgellons' from a 17th century English text written by Sir Thomas Browne, many have attempted to establish a longer timeline for the condition than is often given.^{10 11} A multitude of links have been discovered in medical literature from as far back as 1558, although very little was written in the 20th century.^{12 13} Historical arguments are important in legitimisation processes because they allow proponents of different viewpoints to promote their positions with hundreds of years of evidence. An important component in forwarding the AIDS debates of 1980s, for example, was indeed historical: homosexuality was not new, so how could AIDS be caused by it?¹⁴ This criticism of the prevailing portrayal of the crisis helped to loosen the grip on medical consciousness that AIDS was a gay-only disease. In the case of Morgellons the medical, historical argument would be that nothing in the environment has changed, and this condition does not seem to be contagious, so therefore it is most likely a new name for an existing condition (implied to be delusions of parasitosis) or a new disease (which is very unlikely given the first two tenets of the argument). Uncovering convincing historical evidence is therefore an important reply to this logic, as it rejects the less likely hypothesis of an emerging disease in favour of a rare but chronically under-diagnosed condition.

Nomenclature is also a battleground of arguments and it has often been seen that ideas of validity are tied inexorably to the semantics of naming diseases. In the first instance, giving a collection of symptoms a title is absolutely vital in organising patient consciousness around a disease concept. Mary Leitaos resurrection of Morgellons from the annals of medical history served this purpose well, and, whether she appreciated it consciously or not, something as simple as 'having a name for a disease' contributes greatly to its 'relification'.^{15 16} However, numerous journal articles on the subject of Morgellons argue against the use of 'Morgellons

but is rapidly increasing in incidence or geographic range.'

http://www.who.int/topics/emerging_diseases/en/ visited 14/11/13

¹⁰ She found it through reading Kellett, C.E. 'Sir Thomas Browne and the disease called the Morgellons' in *Ann Med Hist.* 1935; 7: 467–79, though the only print copy of the reference I can find is Browne, T. 'Religio Medici, Hydriotaphia, and the Letter to a Friend', Sampson Low, Son, and Marston, London 1869 p. 172

¹¹ Many journal articles state that it came into being *with* Leitaos in the early 2000s, for example see: Freudemann, R. W. *et al* 'Delusional Parasitosis and the Matchbox Sign Revisited: The International Perspective' in *Journal Compilation Acta Dermato-Venereologica* 2010, p. 517

¹² Montuus, H. (1558), *De infantum febribus, etc.* Lugduni, tornaesius & Gazius, p.13.

¹³ For a summary see http://www.morgellonsuk.org.uk/morgellons_history.htm visited 14/11/13

¹⁴ Epstein, S. 'Impure Science: AIDS, Activism and the Politics of Knowledge', University of California Press, London 1996 p. 56

¹⁵ Collins, H. & Pinch, T. *Dr. Golem: how to think about medicine*, University of Chicago Press, USA, 2005, p. 123

¹⁶ Stein, B. 'The Need to Operationally Define 'Disease' in Psychiatry and Psychology' in *Ethical Human Psychology and Psychiatry*, Vol. 11, Issue 2, 2009, p. 122

disease', in an attempt to undermine the causal inferences that come from using such terminology. A typical such discussion goes like this:

'...it may be reasonable for us to refer to the symptom complex in question as "Morgellons syndrome" rather than disease.'¹⁷

Often, the use of 'Morgellons' is dismissed altogether:

'In order to reduce confusion, we have proposed a set of minimal criteria and suggested using the name "delusional infestation". This underlines the overarching delusional theme "infestation" and incorporates variations of the delusional theme over time, including newly emerging imaginary pathogens such as the so-called "Morgellons."¹⁸

Or:

'Compared with the 1980s...Inanimate material, fibres and so-called "Morgellons" become more frequent...This supports our recommendation to use the term "delusional infestation" rather than "delusional parasitosis."¹⁹ (Emphasis in the original).

This is of marked contrast to the (limited) pro-Morgellons journal literature, which often describes the condition as 'Morgellons disease (MD)'.^{20 21} At the heart of this war of words is a desire to lay claim to the implicit meanings behind descriptive terms. Just as it has been noted that patients prefer the use of myalgic encephalomyelitis (ME) to chronic fatigue syndrome (CFS) because 'a biomedical label' underlines the 'realness' of their complaints', Morgellons sufferers feel vindicated in their pain when it is recognised as a disease, more so than as a syndrome and it certainly offers more relief than being labelled delusional.²²

To this end, the vast majority of pro-Morgellons internet sites on the subject refer to the condition solely in disease terms. What is interesting is that in some cases where arguments are put forward to change the name of the illness, they are done so in order to claim *more* validity from nomenclature. So for instance, Peter Mayne's work argues 'the more correct terminology for MD would be 'borreliac dermatitis', whilst independent researcher Jo

¹⁷ Koblenzer, C. S. 'Commentary: The challenge of Morgellons disease' in *J Am Acad Dermatol* 2006; 55 p. 921

¹⁸ Frudenmann, R. W. & Lepping, P., p. 724

¹⁹ Frudenmann, R. W. *et al*, p. 518

²⁰ It is crude to categorise groups as 'anti' and 'pro' Morgellons, but it does serve the purpose of allowing me to succinctly group those who believe it to be of psychological origin, and most probably a pre-existing condition, and those who believe it to be a new, distinct disease whose cause is yet to be established.

²¹ For example, see Middelveen, M. J., Rasmussen, E. H., Kahn, D. G. & Stricker, R. B., p.1

²² 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

Simmons suggests that 'Micro-Myiasis' might be of more semantic accuracy.^{23 24}

Distinct trends can be seen in the above discussion. The psychological shift from being the passive recipient of a biological disease to being labelled delusional is painful for sufferers, thus the strong resistance to adopting anything but a label that strongly asserts an underlying somatic causality.²⁵ What is more, the attempts to rectify this trauma all operate with a *reference to* rather than a *rejection of* scientific norms: in trying to imply causality from appellations, Morgellons sufferers are grafting to be accepted on science's terms. They want a name which holds within its terms a hint at biomedical aetiology because this changes not just how they are able to view themselves and their condition, but how doctors, researchers, pharmaceuticals and the mainstream media do as well.

Implicit and integral to this struggle is the hierarchy of physiological and mental illness in popular consciousness. Huge stigma still exists around the latter whereas the former is seen as a game of chance: anyone can get ill but you have to be crazy to be crazy. The framing of a disease as either psychological or somatic can therefore have a significant effect on how patients are treated by the world around them: not just in the medical environment but among friends and family. A biological diagnosis can certainly reduce stigmatisation, and therefore it is not surprising the attitude certain Morgellons activists take towards the issue.²⁶ Sentences like 'People who suffer from Morgellons disease are NOT delusional' and 'Morgellons, THE DISEASE IS REAL' are not uncommon ways of broaching the subject on numerous websites.^{27 28} Others are more conservative in their language, certainly, but the central message remains that regardless of what Morgellons is; it is *real*, it is *not* psychological. These debates mirror arguments inside the narratives of other 'contested diseases' such as ADHD, Chronic Fatigue Syndrome and RSI. Critics suggest that they are 'socially constructed' and potentially dangerous for patients. I would posit that all diseases are constructed in so far as they are reflections of the dominant explanation system of the time. Though there is not enough space here to give a full and fair description of this debate, it is important to note that Morgellons is another in a long line of conditions that some regard as the diluting of proper

²³ Mayne, P. *et al* 'Morgellons: a novel dermatological perspective as the multisystem infective disease borreliosis' in *F1000 Research*
<http://www.f1000research.com/articles/2-118/v1#article-comments> retrieved 16/11/13

²⁴ For Simmons' posited link between Morgellons and myiasis, see
<http://www.morgellonsuk.org.uk/micromyiasis.htm> viewed 16/11/13

²⁵ For a good discussion of this process in relation to ME/CFS see Aronowitz, R. A. 'From Myalgic Encephalitis to Yuppie Flu' in Rosenberg, C. E. & Golden, J. *Framing Disease: Studies in Cultural History*, Rutgers, United States, 1997, pp. 167-172

²⁶ For the power of a somatic evaluation over a psychological one see Stolzer, J. M. 'ADHD: Valid medical condition or culturally constructed myth' in *Ethical Human Psychology and Psychiatry*, Vol. 11, Issue 1, 2009, p. 11

²⁷ <http://www.morgellonsexposed.com> visited 16/11/13

²⁸ <http://www.morgellonsmedicalcenter.com/morgellons.html> visited 15/11/13

medical and nosological practice.²⁹

When constructing a timeline of this disease, an important date is unarguably January 25th, 2012. This is the day that the Centre for Disease Control and Prevention published a large-scale study into Morgellons that had been four years in the making³⁰. The study was the result of years of lobbying on behalf of advocates who demanded scientific investigation and petitioned practitioners, local politicians, Congressmen and media outlets. I do not have the space to fully examine the contents of the report, which was described as ‘the most comprehensive, and the first population-based, study of persons who have symptoms consistent with the unexplained dermatopathy referred to as Morgellons’, but this concluding paragraph gives a good sense of the outcome:

‘We were not able to conclude based on this study whether this unexplained dermatopathy 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).’³¹

Sticking tightly to the text induces very little in the way of concrete conclusions, but in this case the real-life results revealed the inherent prejudices of the medical community. I believe that there have been two outcomes from this study. The first is the ‘blackboxing’ of Morgellons within the medical community as a by-word for delusional parasitosis, an occurrence with widespread consequences for clinical diagnosis and popular conception of the disease.³²

²⁹ For a selection of papers debating the definitions of ‘disease’, including criticism of ‘socially constructed’ conditions see Boorse, C. ‘On the Distinction between Disease and Illness’ in *Philosophy & Public Affairs*, Vol. 5, Issue 1, 1975 pp. 49-68; Conrad, P. & Barker, K. K. ‘The Social Construction of Illness: Key Insights and Policy Implications’ in *Journal of Health and Social Behaviour*, Vol. 51, 2010, pp. 67-79; Cooper, R. ‘Disease’ in *Studies in History and Philosophy of Biological and Biomedical Sciences*, Vol. 33, Issue 2, July 2002, pp. 263-282; Ereshefsky, M., ‘Defining ‘health’ and ‘disease’ in *Studies in History and Philosophy of Biological and Biomedical Sciences*, Vol. 40, Issue 3, September 2009, pp. 221-227

³⁰ It was also criticised on that basis: the final report was significantly different in both scale and scope to the original proposition.

³¹ Pearson, M. L., Selby, J. V., Cantrell, V., Braden, C.R., *et al* ‘Clinical, Epidemiologic, Histopathologic and Molecular Features of an Unexplained Dermatopathy’ in PLoS ONE 7(1): e29908. doi:10.1371/journal.pone.0029908 p. 11

³² ‘Blackboxing’ is by now a common term in STS literature, and I use it in a loose sense to describe something taken as ‘matter of fact’ by scientists and doctors on the basis of convoluted and potentially inconclusive studies. For a fuller exposition of the slightly slippery concept, see Latour, B. *Science in Action*, Harvard University Press, United States, 1987

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The second ramification of this study would appear to be the quickening of a process already present before it was published: the consolidation, politicisation and ultimately, heightened desperation of the Morgellons community.

Starting with the former, an analysis of the literature being published pre-2012 puts on show scientific confirmation in action. Tentative estimates at potential aetiologies, calls for more research and a general tone of skeptical uncertainty lightly pervade, alongside admittedly much more numerous self-assured papers arguing for delusions of parasitosis or a similar diagnosis. However, it cannot be denied that throughout the academic and popular literature, a certain undercurrent of open-mindedness persists, for example Mary Paquette stated in 2007:

‘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.’³³

In another article of the same year:

‘Morgellons disease remains a medical mystery...Rather than being quick to pigeonhole Morgellons patients into a psychiatric diagnosis such as DP, practitioners should take patient complaints seriously and keep an open mind about this potentially novel infectious disease.’³⁴

and Elizabeth Devita-Raeburn, again in 2007, wrote ‘until then [the CDC report], the Morgellons mystery continues’.³⁵ Following the study, this willingness to entertain unorthodox ideas about Morgellons disappears from the discourse, and only articles funded and published by advocate research organisations remain to challenge the mainstream medical view. This is somewhat alarming. It should have been noted for example that questions have been raised about the validity of the CDC research. Criticism has variously been levelled at the choice of health maintenance organisation, preexisting biases amongst researchers, the methodology used and the interpretation of the data, but none of this is represented in journal articles.^{36 37} For something that may well be considered a ‘fringe’ but serious condition, this

³³ Paquette, M. ‘Morgellons: Disease or Delusions?’ in *Perspect Psychiatr Care*. 2007 Apr; 43(2): p. 68.

³⁴ Savely, V. R. & Stricker, R. B. ‘Morgellons disease: the mystery unfolds’ in *Expert Review of Dermatology*, 2007 2(5): p. 589

³⁵ Devita-Raeburn, E. ‘The Morgellons Mystery’ in *Psychology Today* 2007, <http://www.psychologytoday.com/articles/200702/the-morgellons-mystery> visited 21/11/13

³⁶ The health maintenance organisation, chosen to assist the study by providing patient data, was Kaiser Permanente, based in Oakland California, and it has been implied heavily by some that this was an inappropriate choice that pre-determined outcomes. For a diatribe on the subject see

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study did not represent the beginning of a debate or the further highlighting of their condition; it was the end-point, the 'last nail in the coffin'.³⁸

The second outcome of the study is the effect it had on sufferers. It is hard now to find an advocate group who do not make at least a passing reference to it. Some of the responses were vitriolic:

'[The CDC report] is little more than under-funded pork, a shuck, a jive, political chicanery and, at worst, a cynical lip service...'³⁹

Or:

'The CDC is a completely bankrupt and amoral organisation. They're scientifically and morally bankrupt.'⁴⁰

Some are more circumspect, talking of the report as 'extremely damaging' and 'not a positive step', but all recognise the issues that have arisen from its publication.⁴¹ The CDC report is now regarded as the go-to study when justifying diagnosis, to such an extent that sufferers discuss in detail how to avoid being labelled delusional when seeking help.⁴² Symbolically it represents the moment when mainstream medical science singed the different threads of possible Morgellons explanations and settled upon a response which was not only viewed as incorrect by advocates but one of worrying influence.

So far in this section I have focused on particular methods of legitimisation employed and how events can change the discourse. What has not been discussed is what many consider to be the defining feature of Morgellons: the influence of the internet as a proxy vector, morphing the disease into a phenomenon far bigger and more wide-reaching than it would have been otherwise.

Within the popular media, the idea that Morgellons is a 'disease spread by the internet' permeates, and academic sources have also debated the role it may have played in the 'rise' of this condition.⁴³ What is implied by this contention is that the internet enables people to self-diagnose and organise themselves around that diagnosis in a manner that until this point was impossible. Alternate and new arenas of communication allow historical norms to be

<http://www.rense.com/general80/fraudf.htm> visited 25/11/13

³⁷ These criticisms have been voiced in personal correspondence by prominent members of Morgellons advocate organisations.

³⁸ Personal correspondence.

³⁹ <http://www.rense.com/general80/fraudf.htm> visited 20/11/13

⁴⁰ Cliff Mickelson speaking with Jeff Rense

<http://www.youtube.com/watch?v=IGrSAqRluw4> visited 18/11/13

⁴¹ Personal correspondence.

⁴² See <http://www.thecehf.org/appointment-tips-for-morgellons-patients.html> for a detailed discussion of this visited 20/11/13

⁴³ Paquette, M., p. 67

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inverted, and it is argued that geographical location is irrelevant; broadband has globalised what would previously have been far more local concerns.

Taking this argument at face value is tempting. The internet is overflowing with different Morgellons groups, organisations, forums etc., and the likelihood is that such virtual infrastructure is self-perpetuating. Non-accredited diagnosis evidently takes place, and no doubt the online Morgellons presence represents an auxiliary source of validation, rationalisation and comfort for sufferers. This is dangerous because it is open to widespread abuse and in the view of some, works against patients getting the appropriate treatment. Essentially, the medical establishment argument goes, without the confirmation that the internet offers, sufferers would accept their delusional diagnosis, doctors would not be questioned and money would not be wasted investigating a disease that 'does not exist'.

However, this is rather blunt analysis that fails to convince. To begin with, there have always been alternative sources of medical authority- patient grouping and advocacy is patently not a new phenomenon. Perhaps, the internet enhances an already established process. It is not that groups form and communicate with each other because of the internet, but rather that the internet offers slightly easier means of doing so than traditional schemas.

It has to be noted too that some sufferers have neither access to nor awareness of the internet, having been referred to patient organisations by dermatologists or doctors who were familiar and sympathetic with the condition. So to say that this is a condition 'transmitted by the internet' is misleading. What the internet has done is added to a complex feedback of different factors leading to the growing awareness of the condition, the foundation of which being that numerous people believe strongly that they are physically ill. It is very easy to make the argument that Morgellons would never have become what it is without the internet, but to attribute such prominent a role ignores both the *real* organisations associated with it - the research foundations, hospital departments, conferences, support groups - and the truly central facet, the people themselves.

In this section I have discussed the various tensions that exist within a modern struggle for medical legitimacy. Let us now turn to the troubling outcomes that emerge as a result of this struggle.

The dangers of ostracisation

As discussed above, a multitude of different methods have been employed by the Morgellons community, aimed at framing the condition as a somatic disease and legitimating it in the eyes of the medical establishment and the wider public. Evidently, this has not been entirely successful. What I am concerned with here is the fall-out from this process: how does alienation and reject affect populations on a psychological and economic level?

A significant amount of personal stress can emerge from the feeling that your illness is not legitimate. Those in the Morgellons community argue that a whole host of secondary

conditions result: depression, fatigue, personality change. These are explained in the academic literature as being co-morbid factors, though the causality is disputed. For example, Mayne states 'while these patients do suffer from psychiatric morbidity it is most often in the depressive and anxiety disorders spectrum and not likely a primary psychotic process'.⁴⁴

What is certainly seen outside the clinical setting is a loss of self-esteem and a draining of power from the individual: unemployment, relationship breakdown, stigmatisation, bankruptcy, alongside the ever-present physical symptoms of the condition. A label of 'delusional' on medical records can prevent people from finding employment in some situations. In extreme instances, sufferers have taken their own lives as a response to the misery of their situation.

Alongside this is the intertwining of pseudoscience and exploitation. Disenfranchised by mainstream science, some sufferers seek any rationalisation they can find, whether this be through blaming governments, chem-trails, nano-technology etc. A select few individuals proffering 'cures' emerge and charge extortionate prices for treatments that are at best non-effective and at worst dangerous. An example of this is 'Dr' Hildegard Staninger, whose authority would appear to be almost entirely based upon falsehood and deception. In the late 2000s, she sold infra-red 'saunas' for thousands of dollars, claiming to have 'cured' Morgellons.⁴⁵ Her qualifications have been called 'self-described, self-created and self-congratulatory' and there are many accounts of sufferers paying through the nose for smoke and mirrors that relieve their bank balance more than their symptoms.⁴⁶ The same theme cuts through all those like her: helpless, vulnerable people are driven to accepting bizarre explanations as a method of validating their pain and as a result are susceptible to pay significant amounts of money to opportunistic quacks. This process is a direct result of removing people from orthodox channels of support and treatment.

What is pertinent is not necessarily who is right, but that there is more to the diagnostic process than achieving clinical certainty. There is much to be criticised about the 'scientific' side of Morgellons advocacy, and at the present time it is not particularly convincing.⁴⁷ However, without an acknowledgment of the messy and layered processes that constitute a patient's narrative we will only ever get one half of the story. Whilst some of the academic

⁴⁴ Mayne, P. *et al* 'Morgellons: a novel dermatological perspective as the multisystem infective disease borreliosis' in *F1000 Research*
<http://www.f1000research.com/articles/2-118/v1#article-comments> retrieved 26/11/13

⁴⁵ This description has been pieced together from many forums discussing her. Her official internet presence almost completely disappeared in 2010 and it difficult to find anything still out there directly from her.

⁴⁶ <http://curezone.com/forums/am.asp?i=1669899> visited 20/11/13

⁴⁷ For a brief description of some of the dubious connections and unscrupulous journal practices present in pro-Morgellons literature see
<http://scienceblogs.com/whitecoatunderground/2010/05/13/bad-science-done-badly-its-bad/>

literature does try and broach this sensitively, the majority has very little concern for the subjective realities of those suffering.⁴⁸

A more positive outcome that can be observed is the remarkable ability of human beings to organise themselves and construct support networks even in arduous circumstances. The 'most important thing' about Morgellons organisations is the pastoral re-enforcement and sense of community they disseminate.⁴⁹ A typical Morgellons website may contain something like the following:

'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.'

⁵⁰

When all attempts at legitimisation have failed, the collective solidarity of sufferers leaves them one last plane on which to find acceptance on their own terms. This is an area in which medicine becomes irrelevant, the very emotional zone of knowing that your suffering is not solitary, and the limited comfort that this knowledge brings.

Conclusion

Throughout this essay, my aim has always been to cast a critical eye over the institutionalised processes that we laud as sophisticated products of an advanced and compassionate society. Thus we have seen how entrenched the authority of medicine is, how difficult it is to shake its influence and how sometimes something that at heart is an inconclusive study becomes the basis for widespread diagnostic certainty. What I think is pertinent about this work is two-folded. Firstly, the presupposed eminence of the internet as a factor is, I believe, overstated and in need of revision. The internet helps individuals to communicate, it did not invent communication. Sufferers sought out Morgellons online communities because of the symptoms they were experiencing, not because the internet somehow 'gave' them the disease by confirming their delusional psychosis. There are so many more factors to consider when constructing the history and framing of Morgellons than explaining it away as a product of modern technology.

The second is that Morgellons does not show us the weakness of medicine. It does not show us that the internet is an empowering tool which has enabled thousands of people to construct elaborate rationalisations and form a credible non-medical power-base. It demonstrates clearly that individuals in modern society still crave medical legitimisation, and this search for validation goes right to the heart of the various approaches outlined above. Medicine is powerful because if it does not believe you, neither do your employers or your husband or

⁴⁸ For a piece which at deals with Morgellons sympathetically whilst retaining a DI line see Frudenmann, R. W. & Lepping, P., pp. 690-732

⁴⁹ Personal correspondence.

⁵⁰ <http://morgellonsaid.wordpress.com> visited 19/11/13

family, and this case outlines that starkly.

What remains at the very core of this issue is the belief that medicine is a vital institution that exists to help people and for the most part does so adequately. At every stage sufferers grasped for scientific approval and were denied. For a long time now critics have outlined the fallibility of modern medicine, and I think that this condition is interesting evidence to add to that debate. Morgellons is an example of systematic break down and where once was trust lies suspicion, where once was deference lies defiance and where once was hope lies deep-seated and profound disappointment.

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