

<http://somatosphere.net/?p=12696>

## The social framing of diagnoses and empathetic listening

2016-08-05 05:00:00

By Aaron J. Jackson

The account that follows depicts a visit with my neurologist. The visit was one of many within a five-month period of navigating various medical spaces to get to the bottom of the illness that was ailing me. It speaks to the systemic and cultural dimensions of illness that threaten to undermine medical understandings, diagnosis and treatment, alongside personal narratives of suffering.

I need a body to live and my current one is harbouring a ghost. To medical professionals, its idiopathic guise makes it seemingly innocuous. But it's not. How do I know? Because it's already stripped me of valuable time with my children. Because I'm the one embodying these curious ailments. My muscles twitch. My hands ache. There's an old guy sitting to my right in the waiting room, plaid shirt and jeans, who's called in for his appointment. He has more bounce in his step than I do. I feel like I'm living an 80's body swap comedy. But my body hasn't been swapped. It's the same white body I've always had. It just feels different. I'm envious of his seventy-five-year-old vitality.

Finally, Professor Mead – let's call him that for purposes of anonymity – calls my name. The office atmosphere feels stiff and lifeless. He tells me to lie down on the bed. My shorts and t-shirt provide unencumbered access to my body's flesh. A needle electrode is inserted into my muscles to record the electrical activity at rest. The monitor declares the electrodes findings through a series of wavy and spiky lines.

Small fasciculations are recorded in my left foot. They're nothing like the twitching that distracts me in the evening, but he assures me that they're benign. And then, with a mingled look of confidence and haughty nonchalance he asks, "Anything stressful going on at the moment?" I know stress can trigger fasciculations, but I've been asked this question too many times over the past months and, frankly, I find it irritatingly misguided in light of my embodied suffering.

I tell him that I have been experiencing weakness in my left arm. He begins pulling and pushing on my arms, asking me to apply resistance. My feelings of weakness are subjective, he asserts, a distortion of what's

happening. They are incongruent with his objective measures – his sophisticated pulling and pushing – which reveal no loss of strength. I could easily argue that the knowledge I have of my body after thirty-five years is more objective than his pushing and pulling, which seems to me to be a more subjective measure: Based on whose standard of strength? And certainly interpretively vulnerable to personal bias.

I stare at the EMG monitor and the waveforms that represent the ‘benign’ complaints that deprive me of sleep and time spent with my family. Given my age, Prof. Mead defaults to a diagnosis of ‘Post Viral Chronic Fatigue Syndrome’ (CFS). He quickly rattles off a list of other aliases the condition is known by, including Myalgic Encephalomyelitis and Post Viral Fatigue. He tells me that it usually arises after a bout of Glandular Fever. The problem is, I haven’t had glandular fever.

It’s a “wastebasket diagnosis.” Not because CFS isn’t real – it couldn’t be more real for those debilitated by the condition. It’s a wastebasket diagnosis because it offers an explanation, in the absence of one. I get off the bed and slip my shoes back on. I leave feeling disoriented and farther from understanding my body and personal narrative of suffering. Dr. Richard Horowitz (2013) identifies time restrictions and missing out on important symptoms as potential candidates that interfere with making a diagnosis. I suspect the medical literature is also at fault, making listening on the part of the physician more imperative.

## **Bedfellows**

CFS is often used interchangeably with [Benign] Myalgic Encephalomyelitis (ME). The relationship (if any) between CFS and ME is a contested one. There are a vast number of proponents from within the medical community advocating for the abandonment of CFS as a diagnostic label and a return to the name Myalgic encephalomyelitis, which is believed to speak more directly to the condition’s underlying pathophysiology (see, 2011 International Consensus Criteria). The term CFS does no more than describe a primary feature of the disease, overlooking the many complex dysfunctions of the condition. Jodi Bassett, the founder of The Hummingbird’s Foundation for Myalgic Encephalomyelitis contends that CFS isn’t a distinct diagnosis, it defines a “mixed population of people with various misdiagnosed psychiatric and miscellaneous non-psychiatric states which have little in common but the symptom of fatigue” (2011:20). Persons displaying what are perceived to be vague and ubiquitous symptoms are often lumped under the umbrella term CFS, for which there is no known aetiology or treatment. They are dismissed and urged to seek treatment on their own. The ways these conditions are institutionally recognised and framed within the World Health Organization’s International Classification of Diseases (ICD)

reveals a primary source for much of this ongoing confusion.

The ICD provides international classifications and standards for diagnosis, health management and epidemiology. ME has been recognised and classified by the ICD since 1969 (Hooper 2006). CFS, on the other hand, didn't gain institutional recognition until its listing in the alphabetic index of the ICD in 1992, and coding in 1998 (CDC 2001). Bassett (2011) argues that the creation of CFS as a diagnostic label was politically motivated. She goes on to describe that with an increase incidence of ME in the late eighties, insurance companies were involved in creating CFS as a means of expediently denying long term disability claims based on "tiredness" (p. 19). Bassett (2009) outlines the industry that has sprouted up around CFS, and the vested political and financial interests key players have in perpetuating it as a legitimate unexplained medical condition: governments, medical insurance companies, doctors, psychiatrists, chemical and vaccine industries, health industry.

The shifting coding and arranging of these conditions in various versions of the ICD compounds the turbid confusion present in medical and public realms. For example, in the tenth edition of the ICD, Postviral Fatigue Syndrome (PVS) shares the same code with ME (G93.3) under diseases of the nervous system (ICD-10 2015). CFS is also indexed to (G93.3), alongside ME and PVS. This has no doubt facilitated the conflation of these diseases within the medical community under one rubric: Chronic Fatigue Syndrome. In recent editions, however, it appears chronic fatigue syndromes indexed associations with the G93.3 code have been removed due to its similarities with PVS, leaving only a nondescript chronic fatigue under the subcategory 'Not Otherwise Specified', under ill-defined conditions (R53.82) (Schweitzer 2015; ICD-10-CM 2016). This may be seen as progress for those who supported the separation of CFS/ME. For those with a CFS diagnosis, however, it could work to further alienate their experiences of suffering. Online blogger Mary Schweitzer (2015) describes this as a slap in the face to those suffering from a disease as debilitating as MS or end-stage renal disease.

The way that Professor Mead used each of these terms interchangeably to describe my condition illustrates the reach of misunderstanding within the medical community. I found myself wondering about the impact these diagnoses have had on medical guidelines and practice. How many others had Professor Mead dismissed prematurely in favour of a CFS (mis)diagnosis? How many other medical professionals are complicit in this negligence? Despite their best intentions, the medical strategies employed by physicians are undermined by the medical literature.

An article in the guardian dating back to 2002 suggests that more than 60% of patients diagnosed with CFS/ME in the UK are unhappy about the

way the medical profession has treated them (Burne 2002). The various criteria and definitional usages of CFS (e.g. Fukuda, Oxford, Australian, etc.) add to this quagmire. These criteria overlap in some areas and depart in others, further obfuscating understandings of what CFS is. If CFS comprises a mixed-bag of definitions and is applied indiscriminately, how can reliable research be conducted among CFS populations to find the causative nature of these conditions? Carruthers et al. (2011) suggest a more clearly defined phenotype would aid in the selection of homogeneous groups of patients, leading toward improving diagnosis and treatment.

The premature and indiscriminate application of CFS amounts to increased rates of misdiagnosis and systemic neglect. The internet is replete with varied testimonies depicting the profound disturbances and debilitating effects of CFS/ME that go untreated. In a time when medical information is more accessible online, many individuals are forced to research their own conditions, if they are to have any hope of finding treatment.

Much of this points to the historical, cultural and institutional contingency of diagnostic labels. Annemarie Goldstein Jutel (2011) has documented in detail the intersecting social, political, commercial, institutional and technological factors that sustain diagnostic labels or lead to their collapse. It is important to recognise that these categories do not have a natural and independent existence but are social categories that “organise, direct, explain, and sometimes control our experience of health and illness” (145).

Moreover, medical labels confer identities upon persons, which can be problematic if the label is incongruent with one’s own experiences of suffering. In these cases, persons are prevented from constructing a coherent narrative around the suffering that has interrupted their experiences, enhancing their distress. The historical baggage attached to labels and the cultural settings in which they are applied may also work to reinforce clinical assumptions and observations around one’s symptoms, preventing appropriate diagnosis and treatment.

### **Empathetic listening**

Reflecting upon my consultations with Professor Mead, I can see how our cultural setting and the social meanings different bodies are saturated with may have mediated his interpretations of my illness. Contemporary western life has been marked by the growth of the commercial fitness industry. Jutel notes that fitness centres are part of a fifteen billion dollar per annum industry in the United States (2011:100). Various forms of body work (dieting, exercising, cosmetics, etc.) reflect our consumerist

practices. As Mansfield (2011) explains, bodies are perceived as projects to be worked on in the pursuit of happiness and pleasure and a more marketable self. Indeed, these are the kinds of messages touted by the media and the fitness industrial-complex, that permeate our most private spaces. The body beautiful is linked to themes of youth, energy, health, romance and freedom (Mansfield 2011). The omnipresent depiction of body ideals in our image-saturated culture enhances our awareness of other bodies, the ways bodies conform and the ways they don't. Bodies become saturated with social meanings: revered, wanted, desired, pitied or stigmatized.

I wondered, what kinds of meanings did Professor Mead assign to my flesh? What kinds of stories did my white body, hardened from years of running and Thai boxing, call forth? Various comments were made during our consultations regarding my body's appearance. At one time I was asked if I used performance enhancing drugs. Another time he asked if I had experienced atrophy. Before I could I answer he followed cynically with "It doesn't look like you've experienced any." And he brazenly quipped that I was a worrier after the EMG found no motor or nerve abnormalities.

Did my physical embodiment and presumed health somehow cohere with medicine's institutional attitude towards CFS/ME? I think back to Mead's goodbye: "I hope I don't see you again". In *Pulse* magazine, Dr Mary Church, a member of the British Medical Association's Medical Ethics Committee, is reported writing:

"Never let patients know you think ME doesn't exist and is a disease of malingerers. Frustrating though it is...certain members of the profession are true believers. Never advise an ME patient to make a review appointment. At the end of the consultation, I say goodbye, not au revoir. Always refer ME patients to a local expert. It's a wonderful way of passing the buck" (Marshall and Williams 2005).

On Prof. Mead's table, I felt devoid of any experiential knowledge. In the absence of clinical evidence my experiences and symptoms were subordinate to the presumed cause of my condition (my anxieties), reinforced by my young and healthy-appearing body.

The value of listening to a person's illness experiences, or "empathetic witnessing" as Arthur Kleinman (1988) calls it, has been well documented in the social sciences over the last three decades. Kleinman defines this as an existential commitment to the ill person that helps them make sense of their embodied suffering and gives value to their experiences (ibid:54).

Arthur Frank (1995:66) writes, “the ideological work of medicine is to get the patient to accept this diagnostic identity as appropriate and moral”. Our encounter failed to produce this effect.

This failing, however, is not identical to any one of these things: Prof. Mead, my body, our culture of consumption, the institution of medicine, the clinical gaze, or the social framing of diagnosis. Rather, it’s a failing that emerges from a fleeting intermingling of all of them. The outcome of this clinical encounter emerged through a mixing together of medical and cultural practices, disciplinary knowledges, intimate thoughts and relations that are brought to the encounter from beyond the physical boundaries of the room, an austere consulting room with fluorescent lighting, bodies, EMG machines, waveforms, twitchings, and last-minute appointments. They are these arrangements that give birth to a range of propositions – “He’s anxious and he’s wasting my time,” or, “He’s in good health, this can’t be serious.”

After several more weeks of insomnia, fatigue, arthritic pain, seizures, and twitching I finally got to the bottom of my embodied debilitating curiosities and decided to send a letter to Professor Mead to voice my concerns:

Bill,

Listening is a moral act, essential to appropriate treatment and care. In my mind, clinical assessments should be a joint venture: A combining of distinct pieces of knowledge (experiential and clinical) in a collaborative effort to find the underlying cause of one’s ailments. Had I not pushed for further testing with my GP, I would have remained ailed by Lyme Disease for an indeterminate amount of time. I write this to you as one patient hoping to appeal to your sense of judgement, with the hope of improving ethical medical practice. I believe better treatment and care could have been provided by adhering to age-old medical principles: obtaining a thorough medical history, conducting a thorough clinical examination and following up with appropriate investigation. I would also add listening to the list.

*Aaron J. Jackson is a doctoral candidate in anthropology at the University of Melbourne. His primary interest is in families and disability, with a focus on fatherhood and community.*



## Bibliography

- Bassett, J. (2009). "Who benefits from 'CFS' and 'ME/CFS'?" The Hummingbirds' Foundation for M.E. <http://www.hfme.org/whobenefitsfromcfs.htm>
- Bassett, J. (2011). *Caring for the M.E. Patient*. Lulu.com Publishing
- Burne, J. (2002, March 30). Battle Fatigue. *The Guardian*.  
<http://www.theguardian.com/society/2002/mar/30/health.lifeandhealth>
- Centers for disease control and prevention. (2001). *A Summary of Chronic Fatigue Syndrome and Its Classification in the International Classification of Diseases*. [http://www.institutferran.org/documentos/ICD\\_code.pdf](http://www.institutferran.org/documentos/ICD_code.pdf)
- Frank, A. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: The University of Chicago Press.
- Hooper, M. (2006). *The Terminology of ME and CFS*. National Alliance for Myalgic Encephalomyelitis.  
<http://www.nameus.org/defintionspages/DefHooper.htm>
- Horowitz, R. (2013). *Solving the Mystery of Lyme & Chronic Disease*. New York: St. Martin's Press.
- ICD10Data.com. Accessed January 1, (2016).  
<http://www.icd10data.com/Search.aspx?search=chronic+fatigue>
- Jutel, A.G. (2014). *Putting a name to it: Diagnosis in Contemporary Society*. Baltimore, Maryland: Johns Hopkins University Press.
- Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Mansfield, L. (2011). "Fit, Fat and Feminine? The Stigmatization of Fat Women in Fitness Gyms". In *Women and Exercise: The Body, Health and Consumerism*, edited by Eileen Kennedy and Pirkko Markula, 81-101, New York: Routledge.
- Marshall, E., Williams, M. (2005). *M.E. – who is attacking whom? m.e. support-norfolk*:  
<http://www.sayer.abel.co.uk/MESNORFOLK/Attacking.html>
- Schweitzer, M. (2015). Welcome to ICD-10-CM (blog post).

<http://slightlyalive.blogspot.com.au/2015/10/welcome-to-icd-10-cm.html>

World Health Organisation. (1992). *International Statistical Classification of Diseases and Related Health Problems*, 10th Revision (ICD-10). Geneva: WHO. <http://apps.who.int/classifications/icd10/browse/2015/en#/G93.3>

#### **AMA citation**

Jackson A. The social framing of diagnoses and empathetic listening. *Somatosphere*. 2016. Available at: <http://somatosphere.net/?p=12696>. Accessed August 5, 2016.

#### **APA citation**

Jackson, Aaron J.. (2016). *The social framing of diagnoses and empathetic listening*. Retrieved August 5, 2016, from Somatosphere Web site: <http://somatosphere.net/?p=12696>

#### **Chicago citation**

Jackson, Aaron J.. 2016. The social framing of diagnoses and empathetic listening. *Somatosphere*. <http://somatosphere.net/?p=12696> (accessed August 5, 2016).

#### **Harvard citation**

Jackson, A 2016, *The social framing of diagnoses and empathetic listening*, *Somatosphere*. Retrieved August 5, 2016, from <<http://somatosphere.net/?p=12696>>

#### **MLA citation**

Jackson, Aaron J.. "The social framing of diagnoses and empathetic listening." 4 Aug. 2016. *Somatosphere*. Accessed 5 Aug. 2016.<<http://somatosphere.net/?p=12696>>