

Scientific Studies:

Illnesses You Have to Fight to Get

**“Imagine
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sick!”**

No one wants to be sick. Now imagine having to fight to prove you really are sick! A study by Joseph Dumit, Assistant Professor of Anthropology and Science & Technology Studies at Massachusetts Institute of Technology, was published in *Social Sciences and Medicine* entitled *Illnesses You Have to Fight to Get: Facts as Forces in Uncertain Emergent Illnesses* (Dumit, 2006). In the article he discusses the ever familiar repertoire that sufferers of multiple chemical sensitivities (MCS) and chronic fatigue syndrome (CFS) face - they must fight for their symptoms to be recognized and diagnosed by doctors while they are often delegitimized by medical providers.

The introduction opens with the statements “More people are slipping through the normalized gaps in the social safety network. We don’t even have a code for this disease, so we’re not going to pay you” (Dumit, 2006).

Dumit tells of the difficulty patients with MCS and CFS have obtaining health care and having that health care covered by insurance. He expertly describes how these patients often are dismissed, as despite their

symptoms, no care can be offered due to the lack of proven etiology, which denies them what he refers to as the “sick role”.

This study was especially interesting as Dumit and his researchers engaged in UseNet discussion groups to learn what people who suffered with MCS and CFS discuss in support group settings. Users who posted in these groups were not consulted or notified that they were being studied. Rather, users were under the impression of being in support and information sharing groups.

In these groups, Dumit learned a substantial amount about how day-to-day life with chronic illness interferes with one’s ability to function, apply for disability benefits, and cope with delegitimization. He also learns how and why these patients become lay experts on the system and gains insight into why it often appears these patients overuse the medical system.

Dumit (2006) describes MCS and CFS as “emergent illnesses in the sense that they are researched, discussed, and reported on, but no aspect of them is settled medically, legally, or popularly.” In essence there is cultural, political, and structural disagreement. Dumit acknowledges that sufferers are at risk of being denied social recognition and are often accused of “faking” simply because of lack of medical acceptance. It is for



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this reason that Dumit describes these illnesses as “illnesses you have to fight to get” since most sufferers find themselves in a battle to prove they have a legitimate biomedical illness. Patients and doctors alike become engaged in battles over under funded research studies and hotly debated disagreements definition, diagnosis, response, and treatment for these illnesses.

We are reminded that the American biomedical system requires diagnostic codes before compensation and treatment, therefore control of the codes creates a “no code” situation in which patients are delegitimized and kept out of reach of social supports needed when ill and disabled. This often results in the patient being treated as though “it’s all in their head” by physicians and family alike. The reason for lack of codes is the lack of conclusive biomarkers, tests, and objective criteria to define these conditions.

Without these codes and biomarkers sufferers are engaged in a battle to obtain disability benefits, often being repeatedly denied until the Federal District Court is appealed. Many cases are overturned at this point if the sufferer has the energy and resources to go that far. Sadly, the Social Security Administration does not have to abide by these overturned cases as precedents for future claimants, so each claimant must struggle through this long process to obtain benefits.

Dumit discusses the fact that there are no biomarkers for any mental

illnesses, except Alzheimer’s, yet various codes exist and mental illnesses are fully accepted as legitimate.

The study focused on small groups of USENET newsgroups with a total of 180,000 postings over a three year period. They found that sufferers deploy facts to offer entry into debate. For sufferers, truth is wanted so care is obtainable. For corporations, profit is wanted and truth is secondary. Sufferers often experience exclusion and lack of care due to lack of codes and perceived irrelevance of their condition. Patients are forced to learn to maneuver within bureaucratic systems in order to survive. While corporate strategies delay and defer the patients suffer. The Internet allows patients who have difficulty engaging face-to-face due to being fatigued, agitated, in pain, or unreliable to communicate more normally. The resources obtained on the Internet also allow for sharing to make life more livable. Discussions form a basis for tactics, relationships, identities, therapies, friendship, referrals, and emotional support.

All in all, despite concern over the lack of informed consent to participate in the research study, this study was nicely done and expressed the real challenges MCS and CFS patients face as they deal with chronic illness.

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References

Dumit, J (2006). *Illnesses You Have to Fight to Get: Facts as Forces in Uncertain Emergent Illnesses*. Social Sciences and Medicine. 62:577-590.

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Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses.

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Chronic fatigue syndrome and multiple chemical sensitivity are two clusters of illnesses that are pervaded by medical, social and political uncertainty. This article examines how facts are talked about and experienced in struggles over these emergent, contested illnesses in the US. Based principally on a large archive of internet newsgroup postings, and also on fieldwork and on published debates, it finds that (1) sufferers describe their experiences of being denied healthcare and legitimacy through bureaucratic categories of exclusion as dependent upon their lack of biological facts; (2) institutions manage these exclusions rhetorically through exploiting the open-endedness of science to deny efficacy to new facts; (3) collective patient action responds by archiving the systematic nature of these exclusions and developing counter-tactics. The result is the maintenance of these very expensive struggles for all involved.

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