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

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Abstract

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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Introduction

> More and more people are slipping through normalized gaps in the social safety network. (Beck, 1992, 135)
>
> We don't even have a code for this disease, so we're not going to pay you. (Johnson, 1996)

Access to healthcare in the US is increasingly restricted through bureaucratic means. Doctors, the traditional adjudicators of whether or not someone is sick and in need of care often must listen first to what an employer, health maintenance organization, or insurer decides is a coverable event before rendering a judgement (Scott, 2000; Starr, 1982; Walsh, 1987). In the case of emerging uncertain illnesses like chronic fatigue syndrome (CFS) and multiple chemical sensitivity (MCS), the resulting judgement may be that despite symptoms, there is no care that can be offered. This judgement in turn impugns the person's legitimacy to make a claim and to be suffering, denying them the sick role altogether (Clarke & James, 2003; Glenton, 2003; Matthews, 1998; Simon, Katon, & Sparks, 1990).

Based on fieldwork, newsgroup postings, and published discussions on CFS and MCS, this article examines ways in which sufferers, doctors, and institutions use facts in situations where judgements of illness take place. First I analyze the contexts in which institutional codes and doctor–patient interaction combine to produce "symbolic domination" (Melucci, 1996a), especially as discussed on the internet. Patients experience these encounters as a system in which they must "prove" their illness and their suffering through mobilizing facts. Doctors, government and insurance agencies appear to patients to be unable to hear their claims, denying them a social sick role and rendering

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them “just plain crazy.” I then turn to collective action online, to track how the very systemic nature of healthcare denial can be archived, discussed, and used to create tactics of the weak in response to symbolic domination. These tactics include collective perseverance, creative use of existing categories, and deploying available counter-facts within the rules of the system. This is not a general solution, but allows some suffers to live better within current institutions some of the time.

In each of these situations, biomedical facts play crucial roles in persuading participants how to render judgements. At the same time, because of the pervasive uncertainty of the illnesses, the facts themselves are susceptible to being framed and reframed by the participants (Kroll-Smith, Brown, & Gunter, 2000; Gabe, Kelleher, & Williams, 1994; Brown & Mikkelsen, 1990) Facts, in other words, because they are supposed to settle matters of who is sick and what care is appropriate, become instead forces deployed by participants in attempts to emplot and counter-emplot each other (Dumit, 2000; Good, Munakata, Kobayashi, Mattingly, & Good, 1994).

CFS (Sabin, 2003; Wessely, Hotopf, & Sharpe, 1998) and MCS (Kroll-Smith & Floyd, 2000; Matthews, 1998) are each clusters of illnesses whose status varies historically and by country and institution. They are characterized as “distinguished by great uncertainty regarding aetiology, diagnostics, treatment and prognosis” (Asbring & Narvanen, 2003, on CFS). They are emergent illnesses in the sense that they are researched, discussed, and reported on, but no aspect of them is settled medically, legally, or popularly. They are serious, fraught conditions not only for the persons afflicted, but also for the thousands of physicians, families, researchers, corporations, insurance and administrative agencies having to deal with them. Thus despite the very different character, histories, and meanings, CFS and MCS share a number a number of cultural, political and structural characteristics that should be separated and studied (adapted from Dumit, 2000):

1. They are chronic conditions and share with other chronic conditions the difficulty of fitting acute disease models of treatment, the sick role, and the determination of health care costs (Cassell, 1997; Glenton, 2003).
2. They are “biomental”: their nature and existence are contested as to whether they are primarily mental, psychiatric, or biological. They are causally undetermined: their etiology is likewise contested as to social, genetic, toxic and personal possibilities (Shorter, 1992; Showalter, 1997; Heuser, Mena, & Alamos, 1994; Hyde, Goldstein, & Levine, 1992).
3. They are therapeutically diverse: the nature and reimbursement of competing therapies, including alternative medicine is wide open (Wessely et al., 1998).
4. They have fuzzy boundaries and are each cross-linked to other emergent illnesses as subsets, mistaken diagnosis, and comorbid conditions.
5. They are legally explosive: each condition is caught up in court battles, administrative categorization and legislative maneuvering. Disability status, for instance, is haphazardly applied. Therefore they are highly contested: the stakes are high, and many of the players have significant resources (Matthews, 1998).

A key concern in research on contested, uncertain illnesses is the intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, sufferers are at risk of being denied social recognition of their very suffering and accused of simply faking it (Clarke & James, 2003; Jackson, 2000; Lillrank, 2003; Ware & Kleinman, 1992). They require tremendous amounts of “hard work” by patients to achieve diagnosis and acknowledgement (Werner & Malterud, 2003). The amount of constant struggle suggests that these emergent, contested illnesses can best be described as “illnesses you have to fight to get.” Social studies of medicine have discussed this contest in terms of medicalization (cf. Conrad, 1992), and now biomedicalization (Clarke and James, 2003), each of these terms denoting a field of contention (Crossley, this issue) best summarized by Klawiter:

> From three decades of scholarship on medicalization, we know that medicalization is a contested process, that it involves collective organizing and strategic claims-making across multiple arenas, and … a wide array of social actors… Medicalization is not an absolute—not an either/or process—but a matter of degree, and that it quite often results in hybrid syndromes, or conditions, that are medicalized along one dimension but not along others. (Klawiter, 2002, p. 313)

CFS and MCS are both incompletely biomedicalized and the degree varies greatly in the US, by state, company, and institution (Dumit, 2000; Kroll-Smith & Floyd, 2000; Matthews, 1998; Wessely et al., 1998). With these emergent, contested illnesses, the social problem is the apparently intractable uncertainty at each dimension. There is often not enough research and at the same time too many facts. The fights over definitions, diagnosis, response and prevention thus depend disproportionately on this small amount of research, much of it underfunded. “Everyone is calling for more studies: the ones that are done have many problems, most attributable to the fact that there has been limited funding and they have been done on ‘shoestring’ budgets” (Miller, 1994, p. 266). Different parties read

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