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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.



## Keywords

Chronic illness; Chronic fatigue syndrome; Multiple chemical sensitivity; Uncertainty; Social movements; United states; Access to care

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