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Negotiating the diagnostic uncertainty of contested illnesses: physician practices and paradigms

Debra A. Swoboda
City University of New York, USA

ABSTRACT In the absence of scientific consensus about contested illnesses such as Chronic Fatigue Syndrome (CFS), Multiple Chemical Sensitivities (MCS), and Gulf War Syndrome (GWS), physicians must make sense of competing accounts and develop practices for patient evaluation. A survey of 800 United States physicians examined physician propensity to diagnose CFS, MCS, and GWS, and the factors shaping clinical decision making. Results indicate that a substantial portion of physicians, including nonexperts, are diagnosing CFS, MCS, and GWS. Diagnosing physicians manage the uncertainty associated with these illnesses by using strategies that enhance bounded rationality and aid in thinking beyond current disease models. Strategies include consulting ancillary information sources, conducting analytically informed testing, and considering physiological explanations of causation. By relying on these practices and paradigms, physicians fit CFS, MCS, and GWS into an explanatory system that makes them credible and understandable to them, their patients, and the medical community. Findings suggest that physicians employ rational decision making for diagnosing contested illnesses, creating a blueprint of how illnesses lacking conclusive pathogenic and etiological explanations can be diagnosed. Findings also suggest that patients with contested illnesses might benefit from working with physicians who use these diagnostic strategies, since they help manage the complexity and ambiguity of the contested illness diagnostic process and aid in diagnosis. In addition, findings provide a window into how emerging illnesses get diagnosed in the absence of medical and scientific consensus, and suggest that diagnosing physicians advance the legitimacy of controversial illnesses by constructing the means for their diagnosis.

KEYWORDS *contested illnesses; decision making; diagnosis; physicians; uncertainty*

ADDRESS Debra A. Swoboda, Department of Behavioral Sciences, York College of The City University of New York, Jamaica, NY 11451, USA. [Tel: +1 718 262 2686; fax: +1 718 262 2675; e-mail: dswoboda@york.cuny.edu]

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Introduction

The social process by which new illnesses get placed on the public health agenda is a complex one. Most emerging illnesses begin as a set of identifiable symptoms whose significance is not understood nor appreciated. At some point, however, those suffering from these symptoms, as well as doctors and medical researchers, come to see these conditions as illnesses with organic causes. Many illnesses that later become accepted as biomedical diseases are first the source of uncertainty and dispute (Roueche, 1988). A substantial body of work describes how illness legitimation occurs when researchers and health professionals identify a new disease, or when sufferers advocate for recognition of symptoms that cannot be explained in terms of existing conditions. The impact of physician diagnosis of contested illnesses on illness legitimation has received less attention.

Gray's (1999) notion of 'postmodern medicine' points to the ambiguities of many modern illnesses. Uncertainties regarding the legitimacy of these illnesses make it hard for sufferers to receive a clear diagnosis, calling into question the ability of common medical practices to understand patients who have these problems. In addition, as lay people use information and technology to develop their own illness expertise, arriving at a diagnosis that conforms to the patient's experience of illness becomes more problematic. Understanding how physicians arrive at a diagnosis has long been central to medical sociology, although the way physicians manage uncertainty and reduce error in complex cases demands more examination. This article describes how physicians diagnose three similar contested illnesses and the clinical practices and paradigms that shape their decision making. Investigating this diagnostic process provides a window into understanding how doctors make sense of complex, emerging illnesses, and the impact of diagnostic incidence on public health.

Background

Chronic Fatigue Syndrome (CFS), Multiple Chemical Sensitivities (MCS), and Gulf War Syndrome (GWS) are emergent, contested illnesses because they share a number of characteristics: (1) their symptoms are broad and nonspecific, and differ in kind and severity among individuals, even among those with similar exposures and histories (Meggs, 1999); (2) their pathogenic mechanisms have not been identified (Pall, 2007); (3) their causation is disputed as to whether it is psychological, biological, or both (Shorter, 1992); and (4) their treatment involves competing therapies (Wessely et al., 1998). While CFS, MCS, and GWS have different degrees of medical and

public acceptance as legitimate illnesses, all three lack conclusive biomedical status. They are also linked to each other in another way: these three illnesses share similar symptoms and are often diagnosed as comorbid conditions or in place of one another (Proctor, 2000).

Clinical use of the term 'CFS' first surfaced in the 1980s in the United States of America (USA) (Ware, 1992). In 1998, the Centers for Disease Control and Prevention (CDC) developed a case definition, identifying CFS as a condition characterized by fatigue as well as other somatic complaints (Holmes et al., 1988). A movement towards medicalization of CFS began when the US National Institutes of Health initiated a research program on CFS and the Social Security Administration designated CFS as a disabling condition acceptable for compensation. While diagnostic guidelines have been developed (Jason et al., 2001), dispute over an appropriate name for the condition continues. In the UK, the illness is called Myalgic Encephalomyelitis (ME) (Cooper, 1997). CFS is more accepted as a biological illness in the USA, where the term 'Chronic Fatigue Immune Dysregulation Syndrome' is more often used, reflecting a bias toward immunological explanation (Wessely et al., 1999). Scientists continue to search for a biomedical explanation for CFS and a definitive set of diagnostic indicators. Researchers who reject the identification of CFS as an organic disorder describe it as a psychological illness, an immune disorder, or a neurological condition (Komaroff and Buchwald, 1998). Competing claims by clinicians from different medical specialties also fuel the scientific debate (Broom and Woodward, 1996). Hence, skepticism about the legitimacy of CFS as a biomedical disorder continues to exist in parallel with efforts by sufferers and other vested communities to increase its diagnostic legitimacy.

First identified in the 1980s, MCS is characterized as an illness in which multisystem symptoms result from chemical exposure at doses below thresholds causing effects in the general population. While groups of physicians, researchers, and sufferers advocate for the recognition of MCS as a debilitating disease, it has not received wide acceptance as a unified organic illness (Locke, 2006). Medical reports describe MCS as a set of symptoms too unique and varied among individuals for syndrome identification (Zavestoski et al., 2004). In the UK, acceptance of MCS as a legitimate disorder is resisted by the medical establishment, with some notable exceptions. The British Society for Allergy, Environmental and Nutritional Medicine, for example, recognizes MCS as an organic illness that can be diagnosed and treated. In the USA, the American Academy of Allergy and Immunology, the American College of Occupational Medicine, and the American College of Physicians officially reject the status of MCS as a physical disorder and caution physicians 'not to treat patients as if the disease existed' (Kroll-Smith and Floyd, 1997: 28). In the meantime, researchers offer conflicting explanations of MCS, including psychological distress, odor intolerance, conditioned response, and a combination of

psychological and biological mechanisms (Leznoff, 1997; Ducatman, 1998). In spite of these conflicting findings, advocacy groups continue to lobby for the recognition of MCS as a diagnosable entity by modifying institutional policies, passing legislation, and creating treatment commodities to assist the environmentally ill (Kipen and Fiedler, 2000).

In comparison to the scientific debate about the nature of CFS and MCS, greater agreement exists among researchers that the symptoms of GWS are real. A consensus that these symptoms constitute a diagnosable syndrome, however, is lacking. Recognition of GWS emerged from efforts by Gulf War veterans to obtain viable treatment for physical symptoms (i.e. nausea, fatigue, lack of muscle control, irritable bowel, headaches, rashes) developed as a result of military service (Chalder et al., 2001; Nicolson et al., 2003). Veterans in the USA reacted to the Veterans Affairs (VA) stance that these service-related symptoms were stress-related or psychological by pressuring federal agencies such as the Department of Defense and the CDC to conduct epidemiological studies of Gulf War related illnesses. Subsequent investigations identified exposure to toxicological substances, intake of multiple vaccines, and interactions with various environmental factors as possible explanations for veterans' health problems (Storzbach et al., 2000). Although few researchers argue for a syndrome definition of Gulf War related illnesses (Haley et al., 1997), veterans continue to fight for recognition of GWS as a diagnosable illness. When the VA expanded the definition of a 'qualifying chronic disability' in 2001 and GWS was not included, many veterans received a psychiatric diagnosis or a diagnosis of CFS in lieu of being diagnosed with GWS, and others obtained a diagnosis of GWS from non-VA physicians (National Gulf War Resource Center, 2003). In the UK, Gulf War veterans have been able to claim disablement pensions because of the syndrome (Roberts, 2005).

Diagnostic negotiation

Although the political and social forces described shape the identification of emerging illnesses, new illness identification also occurs in doctor–patient interactions (Aronowitz, 1998). Diagnosis is essential to medical practice, since it provides descriptive information, treatment possibilities, and causal explanations. Case studies of individuals with CFS, MCS, and GWS indicate that receiving a contested illness diagnosis involves a series of diagnostic negotiations (Raine et al., 2004; Dumit, 2006). Sufferers in these studies often have encounters with physicians who interpret their symptoms as psychological problems or as forms of malingering rather than as indicators of an organic illness (Deale and Wessely, 2001; Nettleton et al., 2004). Some sufferers encounter physicians who reject the existence of a contested illness in assigning any diagnosis or treatment (Hyden and Sachs, 1998; Cohn, 1999). Others receive a diagnosis of an illness of unknown origin or of a somatoform disorder (Malterud, 2000; Nicolson et al., 2003). Still others encounter physicians who remain uncertain or refer them to

medical specialists for further evaluation (Engel et al., 2002). Finally, some sufferers consult physicians who apply a contested illness diagnosis (McCormick, 2000; Swoboda, 2006). For some of these individuals, diagnosis of a contested illness is provided by a general practitioner, whereas others obtain a diagnosis from a physician who is a self-designated contested illness expert (Munson, 2000; Tucker, 2004). Studies suggest that most individuals eventually obtain a diagnosis of a contested illness from a physician (Clarke, 2000; Goldstein, 2004). These results indicate that while some physicians evaluate patients' conditions as psychological in nature or fail to identify their symptoms as indicative of these conditions, other physicians apply a contested illness diagnosis. What are physicians who diagnose a contested illness doing differently in clinical decision making from those who do not diagnose these illnesses?

The diagnostic process

As Balint (1972) discusses, when physicians are confronted with a set of symptoms that are unclear or mysterious, they attempt to arrive at an 'organized illness'. Diagnosis is a process that begins with the patient's illness history and culminates in a result that can be categorized. Diagnostic criteria are valid for groups of patients with a specific disease, while diagnostic work requires accounting for individual particularities in disease manifestations. Physicians use pattern recognition to assign diagnosis (Groopman, 2007), generating provisional hypotheses based on patient symptoms and then matching these against information drawn from the patient's medical history, physical exam, empirical tests, and other sources (Tierney et al., 2005). Diagnostic decision making depends on the physician's fund of medical knowledge, experience, and familiarity with the presenting problem (Del Mar et al., 2006). Diagnostic performance also depends on factors such as: (1) the complexity of the particular disease; (2) the likelihood the disease is presenting in a typical way; (3) the presence of coexisting medical conditions; and (4) the information and tests available to derive accurate conclusions. Experienced physicians are more likely than novices to form provisional diagnostic hypotheses early in the medical encounter, relying on heuristics and tacit knowledge to do so (Garb, 1989).

Despite these tenets, diagnostic reasoning usually focuses on pathophysiological mechanisms (Nardone, 1990), and the primary concern is to affix disease causality (Friedman et al., 2005). The more detectable and consistent the abnormality, the easier the disease is to diagnose. Clinical medicine is rarely an exact science, however, since many diseases lack an identified pathogenic mechanism. As a result, diagnosis of many diseases involves a substantial degree of uncertainty.

Medical decision making is prone to error, especially in complex clinical cases. Errors occur when diagnostic decisions are made on the basis of factors irrelevant or incidental to the clinical case. Diagnostic reasoning errors can be classified on principles of cognitive psychology (Goroll and

Mulley, 2000). One form of error involves faulty information gathering, which is linked to errors in understanding patient complaints, applying relevant information, assessing disease prevalence, and interpreting clinical data (Maudsley and Strivens, 2000). A second form of medical error, faulty verification, occurs when physicians fail to ensure that all symptoms are explained by the assigned diagnosis and that no other diagnostic probability exists. Verification error is most likely to occur when test results are inappropriately used to confirm or reject diagnostic hypotheses, or when the predictive limitations of tests are not acknowledged. Accurate verification of complex diseases is difficult to achieve through testing since diagnostic tests are indirect measures of disease and must be standardized against some best estimate of disease (Sackett et al., 1996). Faulty context formation produces a different type of medical error, where focus is placed on a particular diagnosis and other explanations are not considered. Context errors often result as a function of typicality, when physicians attempt to explain symptoms in terms of what is most typical rather than what is possible (Bakken, 2002).

Overcoming diagnostic uncertainty

Certain physician practices appear to enhance diagnostic certainty and reduce error, especially in difficult cases. One of these practices is obtaining the best available information (West and West, 2002). The more knowledge physicians have about an illness, the better they are at deciding how to act. In contrast, physicians who are less well informed are more likely to reduce uncertainty by focusing on psychological symptoms, stressing caution in the diagnostic process, or emphasizing their gatekeeper role (Kassirer, 1989; Siriwardena, 2006). Clinicians whose knowledge includes familiarity with existing diagnostic protocols are more likely to diagnose a contested illness (Bowen et al., 2005). Using sources of information in addition to articles in peer-reviewed journals also increases knowledge acquisition, although the degree of 'interpretive flexibility' applied to this information is a factor (Collins, 1983). Conducting a critical appraisal of the literature, including evaluating standards of proof, questioning the validity of mainstream science, and examining alternative channels of information are components of interpretive flexibility. The availability of computer databases and the Internet also make it possible for physicians to communicate and retrieve information at a new level of sophistication (Jordan, 2002). Obtaining the best available information can also include obtaining information and assistance from patients. Studies indicate that patient collaboration improves diagnostic certainty (Ghosh, 2004a) and patient satisfaction (Edwards and Elwyn, 2006), especially in difficult cases (Scheibler et al., 2003). Diagnostic certainty is improved when patients are asked to be 'co-producers' of diagnostic practices (Parascandola et al., 2002), although physicians find it more difficult to collaborate with patients if they fear somatic disorders are involved (Kroenke, 2003).

Use of a thorough evaluation process also enhances diagnostic certainty. Diagnostic uncertainty typically results in increased test-ordering (Zaat and van Eijk, 1992; Ghosh, 2004b), although empirical tests are most useful when used as a tool to augment clinical opinion (Ishida et al., 1994) or when linked to other forms of diagnostic information (Salmon, 2000). Use of an evidence-based approach may include application of therapeutic alternatives, even if their outcomes cannot be fully known (Engel et al., 2002; Apkon, 2003). The diagnostic value of testing is nonetheless dependent on appraisal of the predictive limitations of tests and on connection of test results to patient self-report (Schiff et al., 2005).

Research suggests that while etiological certainty is not required for illness diagnosis, physicians may develop their own explanations of illness origin (Csabai and Szili, 2006). Physicians may be more likely to diagnose an illness whose etiology is not known if they suspect the illness has an organic and not psychological cause (Mayou and Sharpe, 1997; McCormick, 2000). In this vein, Richardson et al. (2001) find that physicians are more likely to diagnose contested illnesses if they believe these illnesses are the result of viruses, bacteria, or exposure to toxins, than if they believe these illnesses are 'mental disorders'. Thus, regardless of whether causation can be definitively established, diagnostic certainty may be increased if physicians reject psychological causation and consider other explanations of illness etiology.

Problem statement

Research addressing contested illness classification and the diagnostic process suggests that contested illness evaluation involves diagnostic negotiation. Diagnosis of contested illnesses is problematic: physicians must take steps to account for broad illness symptomology, explain absent biological markers, and understand the similarity of these illnesses to each other and to other conditions. How do physicians evaluating patients with these conditions explain the diagnostic process? The medical literature indicates that physicians generally use pattern recognition to assign diagnoses, developing provisional hypotheses that are then matched against the physician's knowledge base and information gathered from the patient and testing procedures. Errors are not uncommon in this process – especially in complex clinical cases, and typically involve incomplete information gathering, unfounded use of tests to verify diagnosis, or failure to consider other plausible diagnoses. The medical literature also indicates that certain physician practices improve diagnostic certainty. These include obtaining the best available information, conducting analytically informed testing, and developing physiological explanations of causation. Given this information, it is expected that physicians diagnosing contested illnesses such as CFS, MCS, and GWS differ from physicians who reject or fail to assign these diagnoses in the types of diagnostic strategies they use. Use of practices

that aid in managing uncertainty and error may help explain diagnosis of contested illnesses. Building on this information, a study was undertaken to examine the practices and paradigms that physicians use for evaluating CFS, MCS, and GWS, and the impact of these practices on diagnostic incidence.

Hypotheses

To examine the clinical decision making involved in diagnosing CFS, MCS, and GWS, a survey of practicing US physicians, a portion of whom have contested illness expertise, was conducted. Questionnaire items were developed based on findings in the literature about the medical controversies associated with CFS, MCS, and GWS. The survey examined three hypotheses about the physician practices and paradigms associated with diagnosis of CFS, MCS, and GWS: (1) physicians who diagnose these illnesses are more likely than nondiagnosing physicians to obtain the best available information for evaluating illness legitimacy; (2) physicians who diagnose these illnesses combine the results of several evaluation tools for determining diagnosis; (3) physicians who diagnose these illnesses reject psychological causation for other explanations of illness etiology.

Methods

A 12-item questionnaire was developed by the investigator consisting of three attitudinal, five practice, and four demographic questions. The survey instrument and study proposal were approved by the Institutional Review Board at the investigator's institution. The four-page survey instrument was designed so that physicians who believed a particular contested illness was legitimate but that another contested illness was not, could complete the portion of the survey for the illness believed to be legitimate, and skip the section(s) pertaining to another illness. The first section of the survey asked questions that all respondents could complete. Respondents were asked to use a three-point Likert scale (1 = agree, 2 = disagree, 3 = don't know) to indicate whether they believed sufficient knowledge existed for determining the legitimacy of CFS, MCS, and GWS, and whether they believed each illness existed, regardless of knowledge sufficiency. Respondents were asked to identify, using a list of items, the illness information sources they used. They were then asked to use a three-point Likert scale (1 = very familiar, 2 = somewhat familiar, 3 = not familiar) to indicate their level of familiarity with existing diagnostic protocols for each illness. Respondents who indicated they did not believe an illness existed were directed to skip the second and third sections of the questionnaire for that illness. In the second section, respondents were asked to report the number of individuals they had diagnosed with each illness.

The third section posed questions regarding physicians' diagnostic practices and beliefs about illness etiology. They were asked to rate the importance of diagnostic tools from a list of items using a three-point Likert scale (1 = very important, 2 = somewhat important, 3 = not important). Diagnostic tools rated by physicians included 'treatment efficacy', 'psychological evaluation', 'empirical tests', 'physician consultation', 'patient collaboration', 'contributing illnesses', 'differential diagnosis', and 'medical history'. Tools listed were selected from principal sources – CDC *Diagnosis of CFS criteria* (2005), American Academy of Environmental Medicine *Practice guidelines* (2004), CFS/ME Working Group *Report* (2002), and US Department of Defense/Veterans Health Administration *Clinical practice guidelines* (2002) – identifying CFS, MCS, and GWS diagnostic tools. Examples of each diagnostic tool were provided. These items included, but were not limited to: neuropsychological evaluation and depression/anxiety screening for 'psychological evaluation'; drug therapy and nutritional supplements for 'treatment efficacy'; somatoform disorders for 'differential diagnosis'; and blood/serological tests, skin tests, urinalysis, liver/pulmonary function tests, and brain function tests (e.g. Positron Emission Tomography) for 'empirical tests'. Respondents were also asked to identify, using a list of items, the etiology they believed best explained each illness. Etiologies listed included 'organic factors', 'immune mechanisms', 'neurological mechanisms', 'psychological actors', and 'unclear'. Etiologies listed were selected from sources, including journal articles and conference proceedings, identifying possible CFS, MCS, and GWS explanations. Respondents were asked to provide demographic information and additional comments in the final section of the survey.

The self-administered survey was mailed in March 2006 to a total of 800 physicians practicing in the USA. The first mailing to all physicians in the sample consisted of the questionnaire, a cover letter describing the goals of the study, and a self-addressed business reply envelope. Twice, at four-week intervals, reminder letters were sent, accompanied by another questionnaire and a business reply envelope. The sample included 200 physicians randomly selected from the *Official ABMS directory of board certified medical specialists* (American Board of Medical Specialties, 2005). Fifty surveys were mailed to physicians certified in each of the following areas: Family Practice (FP); Internal Medicine (IM); Allergy/Immunology (AI); and Primary Medicine (PM). These medical specialties were selected because available studies indicate that individuals are most likely to be diagnosed with CFS, MCS, and GWS by a physician certified in one of these areas. The sample also included 600 physicians randomly selected from a list of physicians who had been identified as having expertise in CFS, MCS, or GWS and who were certified in one of the four medical specialties. Since there is no expert certification that physicians with knowledge of CFS, MCS, and GWS can earn, illness experts were identified from two sources. A portion of the expert pool was obtained from resource lists maintained

by CFS, MCS, and GWS patient advocacy groups such as Co-Cure, the Health Environmental Action League, and the National Gulf War Resource Center. Physicians on these lists were referred by organization members based on their record of contested illness diagnosis and advocacy. Physicians in this case were identified as having expertise because they met the standards of illness sufferers. The remaining pool of experts was obtained from membership lists maintained by institutions and groups conducting research on CFS, MCS, and GWS such as the International Association for CFS, the Chemical Injury Information Network, the Environmental Sensitivities Research Institute, and the War-Related Illness and Injury Study Center. Physicians in this case were identified as having expertise because they had demonstrated knowledge of CFS, MCS, or GWS through research and publication. All physicians in the pool of experts had been on these lists for four or more years and were currently practicing and/or conducting research to maintain and upgrade their skills.

Analyses

Statistical analyses were performed using the SPSS program (v.11.0). Following data entry, survey items were recoded to exclude missing data. Univariate descriptive analyses were used to initially examine the frequency distribution of the study variables. Nominal data were evaluated by chi-square analyses. Continuous variables were transformed into dichotomous variables to compute Pearson correlations. Two-tailed bivariate comparisons were performed on outcome measures and covariates for physician groups. Multivariate regression analysis was used to explore indicators of physician propensity to diagnose CFS, MCS, and GWS. In all statistical analyses, a probability level of $p \leq .05$ served as the criterion for statistical significance.

Results

Of the 800 physicians to whom questionnaires were mailed, 445 returned scoreable questionnaires. Eighteen questionnaires were returned as undeliverable. An additional nine physicians responded to disqualify themselves for various reasons (i.e. no longer practicing medicine, no longer seeing patients, insufficient knowledge). Consequently, the overall response rate was 59 percent. The response rate for the survey of physicians described in this study is typical for that of a physician mailed survey (Kellerman and Herold, 2001).

Limitations of survey results should be recognized. While experts and nonexperts surveyed returned questionnaires at comparable rates, physicians in these cohorts who responded may have been more likely to do so because they believe CFS, MCS, and GWS are legitimate illnesses. It

is possible that nonrespondents would have different attitudes and would have responded to certain questions differently than respondents. Thus, a response bias toward contested illness existence and diagnosibility may be reflected in questionnaire results, and generalizability of survey findings consequently may be limited.

Characteristics of physician respondents are presented in Table 1. The percentage of nonexperts, CFS experts, and MCS experts who returned scoreable questionnaires far exceeded the percentage of GWS experts who responded with scoreable questionnaires. Another difference was that GWS experts were significantly more likely than other respondents to practice in an institutional than in a group or solo setting ($\chi^2 = 28.982$, d.f. = 2, $p < .001$). Respondent groups did not differ significantly from one another with respect to medical specialty. Respondents were predominantly male (75.3%) and their mean years in medical practice was 21.4 ± 8.9 (SD).

Diagnostic incidence

Approximately one-half of all physicians (51%; $n = 229$) had diagnosed one or more individuals with CFS, 42 percent ($n = 187$) of physicians had diagnosed one or more individuals with MCS, and 16 percent ($n = 71$) had diagnosed one or more individuals with GWS. Not surprisingly, CFS, MCS, and GWS experts were found to be 2.6–3.7 times more likely than physicians who were not illness experts to diagnose these illnesses. Nonetheless, a significant portion of physicians who were not experts in any of these illnesses was also found to have diagnosed patients with CFS, MCS, or GWS. Thirty-one percent ($n = 34$) of nonexperts had diagnosed one or more individuals with CFS, 24 percent ($n = 26$) of them had diagnosed one or more individuals with MCS, and 7 percent ($n = 8$) had

Table 1 **Characteristics of physician respondents**

	All *N = 445* *%*	*Nonexperts* *N = 108* *%*	*CFS experts* *N = 129* *%*	*MCS experts* *N = 119* *%*	*GWS experts* *N = 89* *%*
Respondents	100.0	24.3	29.0	26.7	20.0
Practice setting					
- group	43.3	41.7	51.2	46.2	32.6
- solo	32.8	31.5	34.1	40.3	22.5
- institution	23.4	26.8	14.7	13.5	44.9
Medical specialty					
- family practice	25.6	27.8	31.8	20.2	21.3
- internal medicine	27.6	25.0	23.2	30.2	33.7
- allergy immunology	25.4	22.2	24.0	31.1	23.6
- preventive medicine	21.4	25.0	21.0	18.5	21.4
Males	75.3	75.9	76.0	74.8	74.2

Table 2 **Odds ratios on diagnosing CFS, MCS, and GWS by respondent groups**

Criterion	*Odds ratio*	*< p value*
CFS		
- CE v GE	4.0	.01
- CE v NE	3.0	.05
- ME v GE	2.3	.01
- CE v ME	1.8	.05
- ME v NE	1.7	.05
- NE v GE	1.3	.05
MCS		
- ME v GE	9.3	.01
- CE v GE	4.7	.01
- ME v NE	3.7	.05
- NE v GE	2.5	.05
- ME v CE	2.0	.05
- CE v NE	1.7	.05
GWS		
- GE v NE	3.1	.05
- ME v NE	2.6	.05
- CE v NE	2.6	.05
- GE v CE	1.1	.01
- GE v ME	1.1	.01
- CE v ME	1.1	.05

CE = CFS experts, ME = MCS experts, GE = GWS experts, NE = nonexperts.

diagnosed one or more individuals with GWS. Odds ratios for comparisons among respondent groups diagnosing at least one individual with CFS, MCS, or GWS are shown in Table 2.

Also notable is that a significant portion of physicians with expertise concerning one of these illnesses had diagnosed one or more individuals with another contested illness. Among CFS experts, 47 percent ($n = 56$) had diagnosed at least one individual with MCS and 24 percent ($n = 25$) had diagnosed at least one individual with GWS. Among MCS experts, 56 percent ($n = 4$) had diagnosed at least one individual with CFS and 21 percent ($n = 20$) had diagnosed at least one individual with GWS. A different pattern emerged concerning GWS experts. GWS experts were almost as likely to have diagnosed an individual with CFS (25%, $n = 22$) as with GWS (20%, $n = 18$), suggesting that CFS is assigned as an alternative to or more acceptable diagnosis than GWS by GWS experts. Rates of diagnosis were highest among CFS and MCS experts. More than 84 percent of physicians in both groups had diagnosed more than 10 individuals with the illness in their area of illness expertise, and some portion of CFS experts (6.7%, $n = 8$) and MCS experts (5.9%, $n = 7$) had diagnosed more than 100

individuals. These findings suggest that while contested illness expertise is associated with increased diagnosis of CFS, MCS, and GWS, a significant portion of all physicians – regardless of illness expertise – had diagnosed these illnesses. Some physicians provided diagnosis of more than one of these illnesses in their practices, and some physicians diagnosed one of these contested illnesses in place of another.

Knowledge and diagnostic propensity

In order to test the study's first hypothesis, the data were examined for evidence that physicians diagnosing CFS, MCS, and GWS are more likely than nondiagnosing physicians to obtain the best available information for evaluating illness legitimacy. Table 3 shows the frequency of belief in knowledge sufficiency, familiarity with diagnostic protocols, and use of information sources among diagnosing versus nondiagnosing physicians.

Results indicated that physicians who had diagnosed one or more individuals with CFS, MCS, or GWS were on average twice as likely as nondiagnosing physicians to believe that sufficient knowledge exists for determining the legitimacy of these illnesses. Physicians who had diagnosed one or more individuals with CFS, MCS, and GWS were also significantly more likely than nondiagnosing physicians to be somewhat or very familiar with diagnostic protocols for these illnesses.

Survey respondents were asked to report the sources of information they used to understand CFS, MCS, and GWS. Information sources evaluated by respondents included 'articles in medical journals', 'conference proceedings', 'patient-provided information', 'media reports', 'the Internet', and 'physician consultation'. Findings showed that respondents identified 'articles in medical journals' more often than any other source of information about CFS, MCS, and GWS. This finding was true for both diagnosing and nondiagnosing physicians. Physicians diagnosing CFS, MCS, and GWS were significantly more likely than nondiagnosing physicians, however, to use additional sources of information. Diagnosing physicians were significantly more likely than nondiagnosing physicians to use 'conference proceedings' as a source of illness information, especially physicians diagnosing CFS ($\chi^2 = 46.300$, d.f. = 1, $p < .001$). Diagnosing physicians were also significantly more likely than nondiagnosing physicians to use 'patient-provided information' as a source of illness information, especially physicians diagnosing MCS ($\chi^2 = 42.891$, d.f. = 1, $p < .001$). In addition, physicians diagnosing CFS and MCS were significantly more likely than nondiagnosing physicians to use 'the Internet' as a source of illness information, and physicians diagnosing GWS were significantly more likely than nondiagnosing physicians to use 'physician consultation' as a source of illness information. These findings suggest that, compared to nondiagnosing physicians, physicians diagnosing CFS, MCS, and GWS are more likely to believe they have sufficient knowledge for determining illness legitimacy because they use sources of information beyond medical

Table 3 **Frequency table for knowledge sufficiency, protocol familiarity, and information source variables (*N* = 445)**

	CFS				*MCS*				*GWS*			
	Diagnose < 1		*Diagnose 1 +*		*Diagnose < 0*		*Diagnose 1 +*		*Diagnose < 1*		*Diagnose 1 +*	
	N = 216		*N = 229*		*N = 258*		*N = 187*		*N = 374*		*N = 71*	
Variables	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Knowledge sufficiency	87	40.2	183	79.9*	76	29.4	121	64.7*	134	35.8	54	76.0*
Protocol familiarity	71	32.8	180	78.6*	67	25.9	150	80.2*	207	55.3	60	84.5*
Information source												
- medical journals	141	65.2	185	80.7	122	47.2	122	65.2	165	44.1	51	71.8*
- conference proceedings	71	32.8	168	73.3*	85	32.9	119	63.6*	131	35.0	45	63.3*
- patients	77	35.6	149	65.0*	66	25.5	115	61.4*	86	22.9	41	57.7*
- media reports	28	12.9	92	40.0*	44	17.0	53	28.3	98	26.2	30	42.2
- the Internet	57	26.3	106	46.2*	63	24.4	82	43.8*	90	24.0	26	36.6
- physicians	78	36.1	98	42.7	65	25.1	75	40.1	77	20.5	29	40.8*

* Difference between diagnosing and nondiagnosing physicians for this variable is significant at .001.

journals. Diagnosing physicians thus appear to reduce uncertainty and reduce error by using a wider set of illness information.

Multivariate regression analyses were performed to identify the impact of illness expertise, knowledge sufficiency, information sources, and protocol familiarity on propensity to diagnose CFS, MCS, and GWS. Findings show that propensity to diagnose CFS is best explained by a combination of belief that sufficient knowledge exists for determining the legitimacy of CFS, use of conference proceedings as a source of CFS information, and CFS expertise ($R^2 = .365, p > .05$). In the case of MCS, 38 percent of the variance in diagnosis was due to a combination of MCS expertise, belief that sufficient knowledge exists for determining the legitimacy of MCS, use of patient-provided information as a source of MCS information, and MCS expertise ($R^2 = .376, p > .01$). In the case of GWS, 21 percent of the variance in GWS diagnosis was explained by familiarity with GWS protocols and belief that sufficient knowledge exists for determining GWS legitimacy ($R^2 = .214$, $p > .01$). These results suggest that physician propensity to diagnose CFS, MCS, and GWS is associated with belief that sufficient knowledge exists, which is linked to use of information beyond medical journals.

Diagnostic practices

To test the study's second hypothesis, the data were examined for evidence that physicians diagnosing CFS, MCS, and GWS combine the results of several evaluation tools for determining diagnosis. Survey results showed that physicians who had diagnosed one or more individuals with CFS, MCS, or GWS use similar tools for diagnosing all three illnesses, although some illness experts believe additional tools are also important. Comparisons of mean ratings of diagnostic tools by illness experts and other diagnosing physicians for each illness are shown in Table 4.

Diagnosing physicians across all three illnesses, regardless of illness expertise, rated 'treatment efficacy' first and 'psychological evaluation' second in importance for diagnosing CFS, MCS, and GWS. These findings suggest that since no consensus exists regarding how to conclusively diagnose CFS, MCS, and GWS, diagnosing physicians use both patient reaction to associated treatments and psychological evaluation to rule out other conditions. In addition, diagnosing physicians – especially illness experts – rated additional diagnostic tools such as 'empirical tests' and 'patient collaboration' as important for evaluating all three illnesses. In the case of CFS, both CFS experts and other diagnosing physicians rated differential diagnosis and patient collaboration as next in importance behind treatment efficacy and psychological evaluation, although CFS experts also rated 'empirical tests' as important. These findings suggest that in the absence of definitive tests or biological markers, physicians diagnose CFS by ruling out other causes of fatigue using a patient-centered clinical method, with CFS experts using empirical tests to augment this process. In the case of MCS, both MCS experts and other diagnosing physicians rated medical

Table 4 **Mean ratings of diagnostic tools by diagnosing physicians**

	CFS experts N = 119	*Other physicians N = 110*			*MCS experts N = 96*	*Other physicians N = 91*			*GWS experts N = 18*	*Other physicians N = 53*		
	x	*x*	*F*	*p*	*x*	*x*	*F*	*p*	*x*	*x*	*F*	*p*
Treatment efficacy	1.17	1.47	10.637	.001	1.29	1.60	24.389	.001	1.00	1.50	6.828	.001
Psychological evaluation	1.28	1.66	19.340	.001	1.63	1.67	.356	.701	1.40	1.50	2.476	.062
Physician consultation	1.95	2.09	1.942	.145	2.43	2.35	.497	.152	2.30	2.38	1.035	.378
Contributing illnesses	2.01	2.08	.452	.636	2.90	2.76	3.065	.068	1.59	1.93	4.260	.006
Empirical tests	1.94	2.49	22.729	.001	1.83	2.14	17.767	.004	2.00	2.29	5.936	.001
Patient collaboration	1.50	1.89	12.631	.001	2.23	2.40	5.183	.006	1.60	2.03	3.811	.011
Medical history	2.50	2.58	3.485	.069	1.81	1.91	5.713	.004	2.80	2.71	1.134	.336
Differential diagnosis	1.43	1.73	24.104	.001	2.55	2.53	.183	.146	2.60	2.57	1.426	.235

history and empirical tests as next in importance behind treatment efficacy and psychological evaluation, although MCS experts also rated patient collaboration as important. Thus, physicians appear to diagnose MCS by performing a complete medical history and conducting tests to evaluate exposure history, with MCS experts using patient collaboration to augment this process. Regarding diagnosis of GWS, both GWS experts and other diagnosing physicians rated contributing illnesses, patient collaboration, and empirical tests as next in importance as diagnostic tools behind treatment efficacy and psychological evaluation. Physicians diagnosing GWS thus appear to balance evaluation of existing chronic illness symptoms with patient input and the results of empirical tests.

These results support the study's second hypothesis. Regardless of whether physicians are diagnosing CFS, MCS, or GWS, they overcome uncertainty and reduce error by chaining together the results of several diagnostic tools that by themselves have limited predictive power. Practices for determining diagnosis include evaluating therapeutic applications, conducting psychological evaluation, performing empirical tests, and seeking patient collaboration. In order to account for absent biological markers, physicians organize the results of these measures to eliminate alternative diagnoses and build an evidence-based conclusion regarding the presence of a contested illness. Physicians who are illness experts rate these tools as more important than nonexperts do, suggesting that expertise is associated with use of these diagnostic strategies.

Etiological paradigms

To test the study's third hypothesis, data were examined for evidence that physicians who diagnose CFS, MCS, and GWS reject psychological explanations of their etiology. Table 5 shows the frequency of etiological explanations of CFS, MCS, and GWS among diagnosing physicians.

Among all physicians diagnosing CFS, MCS, and GWS, very few (1.6–2.9%) identified 'psychological factors' as the cause of these illnesses. Regarding CFS etiology, more diagnosing physicians (51%, $n = 117$) identified 'organic factors' than any other as the cause of CFS, a finding true for both CFS experts and other diagnosing physicians. Nonetheless, nonexperts were 7.7 times more likely than CFS experts to believe CFS etiology is unclear. These findings indicate that although some consensus exists among diagnosing physicians that CFS is an organic disorder, many nonexperts diagnosing CFS do not believe etiology is clear. In the case of MCS, diagnosing physicians – regardless of illness expertise – were split over whether MCS is an immune or an organic disorder. This suggests that while physicians diagnosing MCS reject psychological explanations for the illness, they disagree about its root cause. Regarding GWS, diagnosing physicians shared some consensus (49%, $n = 35$) that GWS is an organic disorder, although the vast majority of GWS experts (78%, $n = 14$) reported they

Table 5 **Frequency table of etiological explanations by diagnosing physicians**

	All physicians N = 229	*CFS experts N = 119*	*Non-CFS experts N = 110*	*All physicians N = 187*	*MCS experts N = 96*	*Non-MCS experts N = 91*	*All physicians N = 71*	*GWS experts N = 18*	*Non-GWS experts N = 53*
Organic	51.2	54.6	48.2	36.8	28.4	47.3*	49.4	22.0	58.8*
Immune	23.0	34.5	10.1*	37.4	45.3	27.6*	4.2	0.0	3.6
Neurological	3.4	4.2	2.7	7.8	9.5	7.0	5.6	0.0	7.5
Psychological	2.9	2.5	3.6	1.6	0.0	2.2	2.8	0.0	5.5
Unclear	19.5	4.2	35.4*	16.4	16.8	15.9	38.0	78.0	24.6*

* Difference between illness experts and non-illness experts for this variable is significant at .001.

believe GWS etiology is 'unclear'. The findings therefore suggest that GWS experts and nonexperts disagree about whether GWS has clear causation.

These results indicate that even though consensus is lacking regarding a dominant etiological explanation for each illness, diagnosing physicians replace psychological explanations with other physiological explanations of illness etiology, thus supporting the study's third hypothesis. Not all physicians diagnosing CFS embrace an organic explanation for CFS, physicians diagnosing MCS are split over whether MCS is an immune or organic disorder, and many physicians diagnosing GWS believe GWS etiology is unclear. In addition, wide differences exist between experts and nonexperts concerning etiological explanations given for each illness. At the same time, results confirm that etiological certainty is not necessary for CFS, MCS, or GWS diagnosis.

Conclusions

Even though disputes remain regarding the authenticity of and means for diagnosis of contested illnesses such as CFS, MCS, and GWS, study findings indicate that a significant portion of physicians in the USA are diagnosing these illnesses. While experts are more likely than nonexperts to diagnose these illnesses, nonexperts are also diagnosing these illnesses, and a significant portion of physicians are diagnosing more than one of these illnesses. Study findings provide a window into the practices and paradigms that physicians use to arrive at a contested illness diagnosis. Results indicate that physicians diagnosing CFS, MCS and GWS use different decision-making strategies from physicians who do not diagnose these illnesses. Diagnosing physicians appear to mange uncertainty and reduce error via what Simon (1982) termed 'bounded rationality' – reasoned decision making based on informed assessment of all possibilities. This bounded rationality involves employing strategies that aid in thinking beyond current disease models (Stein, 2000). One strategy diagnosing physicians use is to develop their own 'expert knowledge' (Couch and Kroll-Smith, 1997) by consulting sources such as existing diagnostic protocols, conference proceedings, information provided by patients, and the Internet. By increasing their fund of information beyond conventional sources, diagnosing physicians are more likely to believe they have sufficient knowledge to diagnose CFS, MCS, and GWS. A second diagnostic strategy involves tolerating diagnostic and therapeutic uncertainty via use of an evidence-based medicine approach for illness evaluation. To compensate for the absence of biological markers and evidentiary standards for CFS, MCS, and GWS, diagnosing physicians draw on a broad set of evaluation tools, which include empirical testing, psychological evaluation, treatment efficacy, and patient collaboration. A third diagnostic strategy entails active consideration of physiological explanations of contested illness causation. By assuming that CFS, MCS, and GWS are not psychological illnesses and instead are explained by biological

mechanisms and etiologies not yet determined, diagnosing physicians are able to advance an 'etiological paradigm-in-formation' for these illnesses (Brown et al., 2001: 249).

One implication of these findings is that the practices used by physicians to diagnose CFS, MCS, and GWS appear to be based in rational decision making, not rush-to-judgment decisions in the absence of proof. Diagnosing physicians appear to be developing best practices for evaluating the existence of these contested illnesses, creating a blueprint of how diagnoses of illnesses lacking conclusive pathogenic and etiological explanations should take place. Diagnosing physicians seem to take the position that because CFS, MCS, and GWS are characterized by nonspecific symptoms, inconsistent symptom patterns, absent biological markers, and similarity to each other and other conditions, diagnosis via standard pattern recognition and hypothesis testing alone will not suffice. Instead, they attempt to make sense of competing accounts and develop alternate or additional practices for clinical decision making. In addition, diagnosing physicians appear to believe that questioning the application of current disease models to CFS, MCS, and GWS is an important component of the diagnostic process. They apparently value the clinical approach that many modern diseases require tolerance of uncertainty while pathogenic and etiological evidence is being discovered, and that developing appropriate diagnostic tools in the interim will benefit both physicians and patients. As a result of using these practices and paradigms, diagnosing physicians are able to fit CFS, MCS, and GWS into an explanatory system that makes them more credible and understandable to themselves, their patients, and the medical community. Claims leveled against physicians diagnosing CFS, MCS, and GWS for purported tendencies to misdiagnose or ignore scientific evidence should be evaluated in light of these findings.

A second implication of study findings involves patients who have been diagnosed with CFS, MCS, and GWS as well as those seeking diagnosis and treatment for these illnesses. The results suggest that patients might benefit from working with physicians who use the clinical decision-making strategies described here, regardless of whether or not these physicians are known as contested illness experts. This is because physician practices such as obtaining ancillary illness information, conducting analytically informed testing, and questioning dominant paradigms of illness explanation help patients (not just physicians) understand the complexity and ambiguity of the diagnostic process, and aid in CFS, MCS, and GWS diagnosis. These practices are also associated with greater doctor–patient collaboration, a practice found to increase patient satisfaction and confidence in medical encounters. Results indicate that while contested illness expertise is associated with use of these strategies, nonexperts who employ these strategies also diagnose and treat CFS, MCS, and GWS. Thus, the way a physician thinks about disease and the diagnostic process may be

as important a criterion for physician selection as the doctor's diagnostic experience or illness expertise.

Study findings also have relevance for understanding how widespread diagnostic incidence of emerging illnesses occurs, even in the absence of medical and scientific consensus. It appears that diagnosing physicians use strategies for evaluating CFS, MCS, and GWS that allow them to challenge the 'dominant epidemiological paradigm' of contested illnesses (Brown et al., 2004) and negotiate diagnosis in the face of conflicting illness accounts. Application of these decision-making strategies helps explain why diagnosing physicians believe CFS, MCS, and GWS exist, and – since these methods are assigned more importance by experts – why diagnostic incidence is greater among experts than nonexperts. Study results show that physicians who do not diagnose CFS, MCS, and GWS, in contrast, are less likely to use information from ancillary information sources. Research cited earlier in the article suggests that, in addition, physicians who do not diagnose contested illnesses are more likely to accept psychological explanations of illness causation and emphasize their gatekeeper role. This comparison suggests that contested illness diagnosis occurs because physicians decide to tolerate uncertainty and think beyond current disease models.

An implication of these findings is that physician diagnosis of CFS, MCS, and GWS may further the medical acceptance and public acknowledgment of these illnesses as legitimate health problems, regardless of whether or not conclusive scientific and medical consensus for diagnosibility is attained. When an illness and its causation are controversial, new expert consensus can produce a change in public perception of illness authenticity (Brown et al., 2000). Another implication is that the decision-making process that physicians use to diagnose CFS, MCS, and GWS may provide a working model for evaluating other contested illnesses. This may help explain study results concerning the propensity of physicians who primarily diagnose either CFS, or MCS, or GWS to also diagnose other illnesses in this group.

Understanding how to evaluate emerging illnesses is a fundamental issue in modern medicine, particularly in the way this understanding affects interactions between physicians and their patients. A body of research documents the advocacy efforts of illness sufferers and health researchers in advancing the legitimacy of contested illnesses (Packard et al., 2004), but the impact of physician diagnosis on contested illness legitimacy has received less attention. The findings of this study address this gap by documenting the practices and paradigms that physicians use to diagnose CFS, MCS, and GWS, and the effect on diagnostic incidence. These findings have relevance for evaluating physicians who diagnose CFS, MCS, and GWS, and for directing patients seeking diagnosis of these conditions. In addition, findings provide a window into how emerging illnesses get diagnosed in the absence of medical and scientific consensus, and suggest that diagnosing physicians advance the legitimacy of controversial illnesses by constructing the means for their diagnosis. While potential response bias may color the

generalizability of survey findings presented here, results help to explain how physicians perceive the legitimacy of CFS, MCS, and GWS and create a clinical framework for negotiating diagnostic uncertainty.

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Author biography

DEBRA A. SWOBODA is Associate Professor of Psychology in the Department of Behavioral Sciences at York College of The City University of New York. She has published in journals such as *Qualitative Research in Psychology* and has a chapter on women with contested illnesses in the edited volume *Dissonant disabilities: Women with chronic illnesses theorize their lives.* Her research focuses on the construction of contested illness legitimacy in different arenas including sufferer narratives, electronic community discourse, public accommodations, and physician practices.