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“I Never Wanted to Be a Quack!”

The Professional Deviance of Plaintiff Experts in Contested Illness Lawsuits:
The Case of Multiple Chemical Sensitivities

When medical practitioners act as expert witnesses for the plaintiff in contested illness lawsuits, they can be stigmatized by their professional community. Drawing on ethnographic research surrounding the condition multiple chemical sensitivities (MCS) in Australia, this article focuses on: how plaintiff experts specialize; their rationale for deviance from the professional norm; and structural constraints to medical advocacy. By diagnosing and treating the condition as organic, these experts oppose the accepted disease paradigm of the medical community and therefore face professional isolation and peer pressure. They rationalize their continued advocacy within a moral discourse, which includes a professional aspiration toward altruism, an ethical commitment to “truth,” and the explicit emphasis that financial gain is not a motivation. For their deviance the experts have been confronted with professional disillusionment and emotional drain. Ultimately, the medical profession is disenfranchising experts who may be vital characters in the quest for understanding about environmental illnesses.

Keywords: [multiple chemical sensitivity, contested illness, toxic torts, medical community, professional deviance, peer pressure]

The MCS Controversy

More than 20 years after a cluster of symptoms was first labeled as multiple chemical sensitivities, or MCS (Cullen 1987), a debate still rages worldwide about what causes the condition. Insurance companies fight with MCS claimants in the courts, and scientists continue to argue with scientists in medical journals over whether the illness is an organic injury caused by toxins in the body (Ashford and Miller 1998; Colburn et al. 1996; Donohoe 2005; Winder 2002), or if it is a psychosomatic condition related to paranoia about chemicals (see Black 2000; Lacour et al. 2005; Staudenmayer 1999). Also termed *environmental illness* and *idiopathic environmental intolerance*, MCS is an extraordinary sensitivity to everyday chemicals that the rest of the population has little problem with, such as those emanating from painted walls, perfume, and recently laid carpet. After exposure to chemicals, people with MCS can experience ongoing symptoms, including chronic fatigue, fainting,

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headaches, and memory loss. These exposures can be very debilitating for the chemically sensitive and can impede them from living a normal life (Kroll-Smith and Floyd 1997; Lipson 2004). However, the alleged chemical burden in the chemically sensitive body is not evidenced in pathological test results, which renders the possibility of a toxicological causation objectively immeasurable. This explanation thus contradicts biomedical science paradigms regarding the localization and measurability of disease (see Romanucci-Ross and Moerman 1991:368).

Far from being a purely objective debate over competing medicoscientific theories, there is much at stake in the conflict over the causation of MCS; if it becomes officially recognized as a genuine organic condition, the parties liable to lose are small-business employers, insurance companies, governments, multinational corporations, and the entire chemical industry (Ashford and Miller 1998; Dumit 2006). Moreover, if the condition is deemed toxogenic, it challenges some historically entrenched beliefs of the medical profession about the way in which bodies react to the environment (Kroll-Smith and Floyd 1997). Although it is difficult to determine whether support for people with MCS is increasing in the clinical medical profession, my research concurred with previous findings that physicians in general tend to be skeptical of the disease (Dumit 2006; Kroll-Smith and Floyd 1997). Some insightful work in the social sciences examines the discrepancy between lay and expert models regarding environmental illness (Brown 1992; Dumit 2006; Engel with Adkins and Cowan 2002; Kroll-Smith and Floyd 1997), expert disagreement regarding contested illnesses (Asbring and Närvänen 2003; Donnay 1998; Reid and Reynolds 1990), and the burgeoning environmental health movement (see, e.g., Brown 2007). However, more attention needs to be paid to the experiences of those in the alternative medical community of supportive experts who advocate for sufferers of a controversial illness, and the treatment these experts receive from their professional community for challenging the disease paradigm of their field. This article addresses this gap in the literature by focusing on a group of experts in Australia who act as plaintiff experts for the chemically sensitive on a regular basis, specifically the process of specialization, how they rationalize their decision to deviate from the professional norm, and structural constraints to advocacy. The objective is to give an ethnographic account of how the medical profession treats proponents of deviant scientific theories, how this treatment can impact patient advocacy, and what this can mean for those with emergent conditions.¹

Like supportive experts, skeptical practitioners desire a compassionate and socially effective method of dealing with people who have a contested illness. Most skeptics of MCS qualify that a psychosomatic causation makes a condition no less genuine (see, e.g., Staudenmayer 1999). However, the chemically sensitive nonetheless interpret this diagnosis as implying that they are “just plain crazy” (Dumit 2006) and, thus, like those with chronic fatigue syndrome (CFS), they “argue vehemently [...] against being labeled as mentally ill” (Cooper 1999:229). It is for this reason that I refer to medical advocates of MCS as supportive specialists, because they reinforce the toxic etiology offered by most people with MCS, whereas the skeptical experts are reluctant to accept these “lay epistemologies” (Kroll-Smith and Floyd 1997) as legitimate.

The extent to which MCS is considered a valid, compensable condition varies from country to country. In Australia, for example, the condition is not categorized

as an official disease and is not included in diagnostic manuals for permanent impairment (see, e.g., WorkCover 2008). However, under certain jurisdictions in the United States, the chemically sensitive have been granted disability status (Kroll-Smith and Floyd 1997). Austria has recently followed Germany's lead in officially categorizing MCS as a physiological, and specifically not psychological, condition (Müller 2009). More generally, some scholars have suggested that the environmental health movement—an international movement encompassing the environmentally ill, lay activists, sympathetic academics, and scientific professionals—is enabling a shift in scientific understanding of environmental risk and facilitating more widespread acceptance of illnesses like MCS (Brown 2007; Hess 2005). Yet, although movement dynamics and cultural shifts are certainly playing a part in the MCS controversy, medicoscientific contestation is nonetheless a powerful barrier to legitimacy for people with the condition. Experts working in the field are thus integral to the social treatment of the chemically sensitive and are consequently a vital group for analysis.

Methodology

The research for this article stems from an ethnographic exploration into the medicolegal process surrounding chemical injury lawsuits. Over three years I investigated the claims of eight workers alleging to have contracted chemical sensitivity in the workplace in Australia—seven that involved contested diagnoses of MCS and the final one implicated a similarly controversial toxic brain injury. For the one claim that was ongoing at the time of study, I undertook participant-observation with the chemically sensitive litigant and his legal team before, during, and after three court hearings over three years. In each case, discourse analysis was undertaken of all relevant documents to which I was given access, including medical, legal, media, and parliamentary texts. Further, 35 semistructured interviews were conducted with chemical injury litigants; their friends, family, and members of the community who acted as advocates or gave evidence during the litigation; medical and public health expert witnesses; legal practitioners; and political representatives.

Accurate data on the percentage of professionals who support a chemical explanation of MCS in Australia is unavailable, although anecdotal evidence suggests that the number is small, and the number of practitioners who vocally support MCS plaintiffs is even smaller. As this article aims to give voice to medical advocates for MCS, the quotes in this article are predominantly drawn from six supportive specialists living around Australia. Although this number prevents making generalizations regarding the global community of supportive experts, it is notable that all six experts are known nationally (and some of them internationally) as being significant characters in the quest for the condition's legitimacy, and their experience consequently offers an important insight into contested illness advocacy. The group includes an occupational physician, a genetics expert, a general practitioner (GP), a toxicologist, an occupational therapist, and a clinical psychologist. The various disciplines of the supportive expert informants differ vastly; however, I conceptualize each of them as working in the medicoscientific field because they are all in the practice of treating and diagnosing MCS patients, there are striking similarities

between their untraditional approaches to MCS, and their practice is regulated and controlled by the broader biomedical community.

In workers' compensation suits, solicitors tend to engage medical experts who are not only renowned for their expertise but are also likely to support their client's claims. This phenomenon fosters adversarial proceedings wherein arguments given by plaintiff and defense experts are usually oppositional. This inherent polarization means that expert opinions about MCS in the litigation context do not accurately represent the range of beliefs about the condition that may exist in the broader biomedical community. For this very reason, however, the courtroom does provide a critical site for the contested illness researcher, a hub of activity wherein the most skeptical experts collide with the most supportive. It is therefore a useful site for researching how renowned supportive experts in the field of contested illness both experience and rationalize their deviance.

One of the limitations to this research is that although the plaintiffs and their supportive medical practitioners were enthusiastic interviewees, only two members of the defense teams responded positively to my invitation to be interviewed. My research objective to better understand the controversy surrounding MCS promotes further research into the condition (incl. the perspective of the chemically sensitive), which may be deemed unnecessary by experts who feel it is a psychosomatic and largely individualized condition. Further, skeptical experts can sometimes face attack from special interest groups (Deyo and Psaty 1997), which might discourage them from being involved in contested illness research when these groups are also participating. Consequently, besides two insightful interviews with a skeptical toxicologist and infectious disease specialist, defense experts are underrepresented in the interview data, although not in participant-observation or discourse analysis.

From "Mainstream" Practitioner to Medical Maverick: The Specialization Process

Being faced with patients who have an anomalous and contested condition presents a professional challenge for all medical practitioners (Asbring and Närvänen 2003). As students of medicine specialize, they are taught within a rationalist tradition of knowledge, both in their formal education and in informal social interaction with their professional colleagues (Romanucci-Ross and Moerman 1991). Medical students consequently learn to value certain kinds of information over others, such as the measurable from the immeasurable, the factual from the nonfactual, and the probable from the possible. Anything that cannot be measured "is deemed, more or less, not to exist; at best it is ignored in any notions of causality" (Romanucci-Ross and Moerman 1991:368). As ever greater and more sensitive medical technology is developed to assess minute physiological abnormalities, the elusive nature of chemicals in MCS pathological test results renders the patient's chemical explanation increasingly perplexing. The unresolved debate surrounding the condition's etiology means that professional medical associations such as the American College of Occupational and Environmental Medicine offers little definitive guidance regarding the diagnosis or treatment of MCS (see position statement of the American College of Occupational and Environmental Hygienists [ACOEM], which, since its release in 1999, has remained noncommittal). Despite the relatively equal split

between supportive and skeptical researchers in the medicoscientific community (Donnay 1998), the clinical medical profession remains predominantly skeptical (Dumit 2006; Kroll-Smith and Floyd 1997), or at least hesitant to accept a chemical explanation without more proof.

Considering the professional controversy surrounding MCS, it is pertinent to question how these supportive practitioners come to specialize in treating the condition as genuine and organic at a time when a vast proportion of their colleagues disagree. The acquirement of expertise is often explained through the process of specialization whereby a professional uses “a circumscribed body of knowledge and skills to gain particular productive ends” (Freidson 2001:18). Specialization is usually studied by investigating what differentiates one profession from another, such as medicine versus nursing (Malka 2007), or contrasting different areas of specialization within the same profession (Weisz 2006). However, the disparity in expert opinion regarding contested conditions even within the same discipline group highlights the extent to which the specialization process and the definition of expertise can be problematic. In this section, I reveal the process through which the supportive experts specialize in the controversial field of MCS and demonstrate how their title as expert is questioned by the broader medical community.

Although Freidson’s definition of specialization above implies a choice to narrow one’s focus, the supportive experts in this research only pursued an interest in MCS after they had unintentionally attracted a large number of similarly afflicted patients who had a history of chemical exposure. One physician, a GP, emphasized that her reputation as a specialist in both CFS and MCS in Western Australia was purely by accident. An extraordinary number of patients with CFS began to seek consultation with her when she was erroneously included on a list of specialists in CFS disseminated by a local politician. In 1991, she was consulted by a patient who had all the symptoms of CFS but also had work-related exposure to petrochemicals from her workplace. The GP then started to identify a link between long-term chemical contact and continued ill health. Then, as the doctor explains, “the jungle drums beat, and someone else comes, and someone else comes, and before you know it, it kind of snowballs.”

Another expert who specializes in genetics followed a similarly unplanned career path. After conducting an epidemiological study on pregnancy and lifestyle, her team stumbled on an unforeseen connection between chemical exposure and fertility in males. The study received unprecedented media attention, and as a consequence, she explains, “being involved in toxicity, I sort of found myself being referred to a lot of people who were ill from chemicals.” These experts, like all of those interviewed, then became renowned specialists in MCS who have since treated up to hundreds of chemically sensitive patients.

The group of supportive experts I studied developed their beliefs about the etiology of MCS based largely on observations in clinical experience, in conjunction with Cullen’s (1987) criteria for diagnosis. One supportive occupational physician explains that his experience with MCS challenged his professional training:

When you go to medical school, an absolutely essential part of your training is to go to the pathology course where there are bottles with diseased hearts, brains, joints, all there to see [...] And modern medical reasoning and

science is based on the fact that there is a pathological basis for disease [...] MCS is different. MCS is, it seems, a biochemical disease [...] And given that MCS lacks the nice heart-attack-heart-in-a-bottle-that-you-can-see, given that it lacks overt physical findings [...] The evidence that is of the most importance in thinking about the patient with MCS is the patient themselves. It is the symptoms they've got. It is their story. It is their history. It is what they tell you of their experience. It's the experiential data that is absolutely crucial... the defense in the system will say evidence presented by the patient is not necessarily valid. In this particular case, in my opinion, it is the only evidence that is valid.

Like this practitioner, each of the supportive experts emphasized the importance of the patients' history for understanding a condition that reveals no pathological leads. The occupational therapist, for example, explained that her method of diagnosis is to spend hours with each patient as they carry out everyday activities, watching behavior and "putting two and two together." Although these experts are keen to demonstrate that they are nonetheless discerning—as one practitioner said, "it's very easy to pick up someone who's genuine and not genuine"—the temporal link between exposure and symptoms within the patient's history is deemed to be the most useful clue to diagnosing chemical sensitivity.

This approach goes against the standards of proof usually required in the biomedical disease paradigm because, when confronted with a patient's narrative they deem to be genuine, supportive experts accept that a condition may be physiological even if it cannot be proven by objective measures. They are engaging with an experiential form of truth in contrast to the empirical data privileged by their skeptical colleagues. Although skeptical experts in my research did seek an exposure history from MCS patients, in the absence of measurable test results the patient's account of the chemical link to their illness was largely negated. Basing a diagnosis on the narrative of the patient is seen by these professionals to be inconsistent with the scientific rigor that traditionally characterizes biomedical science. One skeptic noted, for example, that much "unreason" ran through discourses surrounding MCS and that, in patient consultations, he often finds his "bullshit-o-meter running off-scale." Another highlighted that he attended a lecture by the aforementioned Professor Cullen and was not convinced: "he didn't actually have any evidence that [MCS] existed. The thing about chemical sensitivity is that there's not a scientific basis for it."

Professional Isolation and Peer Pressure

Often broadly defined as "clinical ecology," the supportive position on environmental illness is considered by many to be "junk science" (Huber 1991; see also Jasanoff 1995). Many skeptics feel that this supportive school of thought exacerbates psychomorbidity and paranoia about chemicals and, thus, constitutes a dangerous practice. This perception of their work has significant implications for the supportive experts. For identifying with the alternative community of clinical ecologists and for their deviance from the orthodox approach to MCS, supportive specialists often have their expertise undermined and challenged by their colleagues. The following

excerpts are from medicolegal reports that were written about supportive experts by their skeptical contemporaries in one of my chemical injury case studies:

Ms. [*Supportive Psychologist*]’s reliance upon a now aged, qualitative and quite impressionistic interpretation . . . would appear to be poor scientific practice . . . Her quotation from Tulsy is erroneous. Whilst it is probably a typographical error . . . these errors suggest [she has] had little if any experience with the [psychological test she used].

The reasoning of Dr [*Supportive GP*] seems to go from consistency to conclusion without much in the way of evidence or experienced rational analysis in between.

Professor [*Supportive Occupational Physician*]’s report includes factual differences to the information acquired at my assessment . . . The bulk of evidence in my opinion in clinical toxicology is against the existence of a neuropsychiatric syndrome arising from chronic occupational inhalation . . . a view that [the patient’s] symptoms reflect a solvent-induced neuro-psychiatric condition therefore lies outside of credible toxicological opinion.

Although the adversarial nature of the litigation context encourages experts to discredit each other, these quotes nonetheless reflect the feelings of distrust among the broader medical community regarding the scientific credentials of supportive professionals.

Specializing in this contested area and being labeled a proponent of junk science has implications not only for the reputation of these people as scientific experts but also in their daily professional lives. The supportive specialists all acknowledged that they were isolated by their colleagues for taking an unorthodox viewpoint about MCS. A supportive toxicologist notes that: “the monolithic refusal of certain sections of the medical industry to agree that there is in fact [a] condition is enormous.” The practitioners consequently have few allies in their immediate disciplinary group. Consider, for example, the following excerpt of an interview with the supportive occupational physician:

Interviewer: Do you have many colleagues who share [your] belief about the condition?

Professor: [*Smiling*] No.

Interviewer: Any?

Professor: Some, to varying degrees. I’ve got one who I think agrees with me, I’ve got one or two others who I think are sympathetic, but who I think would hold strongly to the view that I’m wrong [. . .] and ah, will make a bit of a joke of it really. But in essence, I am in a minority.

In conjunction with their marginality, a common theme identified in the supportive experts’ discourse was the stigma they experienced from their colleagues after developing a reputation in the MCS area. The clinical psychologist remarked:

I find that I've been almost blacklisted as a person who's sympathetic to the cause. [...] You find that if you're sympathetic to the worker that is affected by chemicals [...] you're almost like a leper in the community because you take the stance that you do.

Further, the GP feels she has been labeled by a number of colleagues in the medical community as being a physician who will too readily diagnose MCS. She has developed this opinion largely after her role in a parliamentary inquiry surrounding a well-publicized incidence of MCS among workers at a mine site. She diagnosed tens of workers and local residents with chemical injuries and some with MCS, which sparked skepticism among the mining company's management and skeptical medical practitioners. A number of people publicly noted that all of the MCS complainants seemed to consult the same doctor [the GP] and receive the same diagnosis. Consequently, the GP feels she has been labeled a "quack."

When they are accused of being "outside credible toxicological opinion"—or treated as *quacks* or *lepers*—terms that imply they are suspect, are of dubious character, and should be isolated, these specialists are clearly being marginalized for "straying too far from the encoded clinical perspective" (Romanucci-Ross and Moerman 1991:368). According to some members of the mainstream professional community, the motivations of plaintiff experts in contested illness lawsuits are questionable. Huber, for example, refers to clinical ecologists among other "junk scientists" as "cranks" and "mavericks," and he qualifies that:

Not every investigator who has fallen hard for pathological science is weak-minded, sloppy, or inclined to fraud. Some are seduced simply because they are irrepressible rebels, compulsively driven to dispute orthodox views, whatever they may be. [Huber 1991:31]

To some extent, these practitioners are mavericks in the way that Huber accuses them—radicals who challenge the long-established disease paradigm of the medical profession. Although the term *maverick* can imply deliberate and self-assured dissent, the above examples demonstrate that these specialists have not sought this role initially but, rather, have found themselves in such a position. Unlike Huber's accusation of "irrepressible rebellion," the GP exclaimed: "I never wanted to be a quack! I want to do just good medicine. Mainstream, good medicine."

In response to positivist notions regarding science, Karl Popper (1963) asserted that the scientific endeavor is based on conjecture and refutation. Scientists put forward theories to explain phenomena and, if the theories withstand attempted refutation from colleagues, they will be given peer-review approval. Philosopher Thomas Kuhn (1962) rejected the openness and cooperation implied by Popper, asserting that scientists are inherently reluctant to change their fundamental ideas or the core paradigm of their field. According to Kuhn's theory it is unsurprising that novel and unorthodox theories such as those put forward by supportive experts about MCS would meet with intense scrutiny and attempted refutation by the medicoscientific community.

However, the experiences of the expert informants to this research illustrate that a more complex social dynamic is at play. They are not merely having their

theories contested in a scientific or legal forum but are instead experiencing a case of the “power of the norm” (Foucault 1982). The stigma experienced by the supportive experts for dissenting and their contradictory desire to conduct “mainstream medicine” is testament to the normative forces that exist within the medical community. Their treatment highlights the existence of sanctions imposed to keep doctors adhering to the accepted framework of practice (Daniel 1998). Notably, none of these supportive experts have lost their licenses to practice or been denied membership to professional societies. They are not openly ostracized at professional gatherings (but they at times feel alienated from those who attend). As the final section of this article illustrates, the sanctions imposed on them are more subtle, but nonetheless disenfranchising. For now, however, it suffices to say that by specializing in a field of contested medicine, these experts have been faced with increasing social pressure for their divergence from the hegemonic medical view about MCS.

“Crusading for Truth”: How Contested Illness Experts Rationalize Their Deviance

Despite the fact that their reputation in MCS was initially unintended, all of the supportive experts have chosen to act as an expert witness for chemically sensitive plaintiffs and entered an advocate’s role for the chemically sensitive. Some have publicly opposed mining operations where cases of MCS have been reported; most have published research on the organic nature of the condition (although the results are not published in top-tier medical journals); and all of them continue to provide assistance for people with MCS who are embroiled in litigation. How then do these experts rationalize their decision to continue to deviate despite the marginalization they experience for nonconformity? Theorizing why dissenters challenge the status quo, Turner notes:

There is always something altruistic about such a symbolic breach; always something egoistic about a crime [...] A dramatic breach may be made by an individual, certainly, but he always acts, or believes he acts, on behalf of other parties, whether they are aware of it or not. He sees himself as a representative, not as a lone hand. [1974:38]

Aside from the difference in evidence standards that they articulated above, all of the supportive specialists I spoke to rationalized their continued advocacy for the chemically sensitive through a discourse of altruism, which they articulated in a moral discourse of three parts.

The first moral overtone in the practitioners’ reasoning related to the concept of “truth.” The genetics expert, for example, rationalized her decision to continue acting on behalf of MCS patients:

I think that in my case I’m a crusader for truth. And if I believe something and I can look for evidence to prove it, you know, I’ll go with it. That’s just the way I am [...] It doesn’t always win you friends, you know.

This specialist expresses that she weathers the ostracism she has been exposed to in her career for supporting people with MCS because of a commitment to “truth,”

which she privileges over maintaining acceptance from her professional community. Similarly, the clinical psychologist mentioned she was “prepared to take a stand” for the chemically sensitive because:

I’ve seen so many people now who’ve suffered so much [...] and I’ve interviewed many, many people and I’ve seen how adversely chemicals [...] have affected a person’s overall functioning. Not only neuropsychologically, but emotionally, physically, and in a number of ways [...] they can’t live a normal lifestyle. They withdraw themselves from society really. And I’ve seen them firsthand. I’ve visited them in their homes, and know how much they suffer. So that’s why I’m prepared to take a stand.

Here, the psychologist similarly engages with a notion of “truth”—in this case a “firsthand” understanding of her patient’s reality—and identifies it as responsible for her continued advocacy for chemically sensitive litigants. The quest for truth could perhaps be seen as characteristic of the scientific endeavor in general—most scientists would presumably state that their professional objective is to make a contribution to the fact base of their field. However “truth” as these supportive experts refer to it is more of an ethical conviction than a professional aspiration.

The second aspect of the experts’ moral discourse lies in what they perceive as the altruistic element of the practitioner’s role. The occupational physician, for example, said:

[When] I speak to an individual and I feel that I’m talking to a genuine human being who has got a real problem and who is worthy of medical help, that’s where the support is. And it comes from the . . . it’s like distilled whisky. It’s pure. You see the patient who is not phony, who is not trying to manipulate the system, who is not dishonest, who has got an absolutely genuine problem, who has got something which is not their fault, and who is receiving all sorts of opposition to getting what any normal person under calm circumstances would feel is the logical right thing to do; namely, help someone who is sick.

Another expert, a toxicologist, noted:

I do it to help people. I actually would *like* to think there is something sort of special we can find and then look forward to a cure [but] I actually don’t think there is. I think if there was we would have found it by now.

Essentially, these experts are engaging with the notion of altruism and its link to patient advocacy, which is a common rhetorical feature in discussions about medical education and practice (Bishop and Rees 2007; Pearson 2000). The expectation that physicians should “advoca[te] for the patients’ best interests [above] all other considerations” can seem contradictory to politicoeconomic pressures to ration health care (Pearson 2000). However, these practitioners explicitly state that “helping people” remains their primary professional goal.

Part of the cultural capital ascribed to medical practitioners is the accumulation of wealth generally acquired throughout their careers. However, by specializing in representing people with a controversial illness (most of whom cannot afford high medical fees), some supportive practitioners have to forego this privilege to some extent. Skeptical physicians often argue that supportive experts have developed financially lucrative practices by attracting and treating patients who believe they have rare environmental conditions, thereby exacerbating the iatrogenic problem. This phenomenon was not evident in my research however. The occupational physician, for example, describes the way in which he receives no financial support for his choice to care for chemically ill people.

In the main, the support comes from the absolute grass roots. And it usually is not financial or monied in any way. And it is weak in terms of major resources and things.

By contrast, skeptical experts who are engaged by the defense in compensation cases often receive immensely higher remuneration than those experts who act on behalf of the plaintiff. In one of my compensation cases, for example, the total cost for the worker to consult all of his supportive medical specialists, of which there were six, was approximately \$1,500. The cost of the defense specialists' fees, however, of which there were also six, was approximately \$15,000. My research demonstrated that for most defense specialists the financial benefits were not necessarily a causal factor to their skeptical position but, rather, a bonus. It must, however, be noted that such remuneration does continue to legitimate their viewpoint and provides little incentive for change. The supportive experts emphasize that their decision to support the chemically sensitive in contrast to the majority of their colleagues is an altruistic one that sees financial gain as insignificant.

By reporting the moral discourse engaged by the supportive expert informants, I am not meaning to imply that those practitioners who are skeptical of MCS, and moreover those who testify against MCS litigants in compensation cases, are acting immorally. Rather, skeptical experts have a different and more empirical approach to truth. According to them, the scientific basis behind the claims of the chemically sensitive is unsound, their illness does not stem from chemical exposure, and, therefore, the condition does not require treatment or assistance as if it were an organic injury. Indeed, in their insightful discussion about the role of medical ideology in repetitive strain injury litigations in Australia, Reid and Reynolds (1990) assert that both skeptical and supportive experts in fact use a scientific façade to mask strong moral overtones in their arguments. According to the authors' findings, skeptical experts merely employ medicoscientific discourse to conceal their moral outrage at people who seek compensation when, according to these experts, they do not deserve it. Supportive experts, however, use opposing scientific theories that act as a thin objective veil for compassion for the patient. Both, therefore, have an underlying moral impetus to their work; however I emphasize here that the supportive experts' explicitly appropriate a moral discourse to justify their position on MCS.

Following on from the compassion-versus-moral outrage finding by Reid and Reynolds, the supportive and skeptical experts in MCS litigations are in fact

variously identifying with two different facets of the medical practitioner's role. The supportive experts I interviewed are articulating their profession as one that is ultimately altruistic and intended to help people who are sick. The skeptical experts, however, are enacting a more regulatory medicine that polices the social body in the Foucauldian vein (1973); in this case, to act as a gatekeeper to workers' compensation and the "secondary gains" of the sick role (Parsons 1951). This is in part because of the politicoeconomic context in which the workers' compensation scheme plays out, which, as psychologist Lisa Neimeyer suggests, constitute "unique pressures" that may be "serving to transform the traditional role of healer into that of 'medical police'" (1991:251). Nevertheless, the supportive practitioners I have studied here believe that the moral values guiding many of their skeptical colleagues are inadequate. These accidental mavericks discursively situate themselves in a minority moral community that states its priorities as "truth," altruism, and the irrelevance of financial gain.

Although these supportive experts feel professionally isolated within their local discipline groups, they are valued members of the environmental health movement described above. At international MCS conferences and in email contact with the chemically sensitive and other dissident supportive professionals around the world, these experts receive widespread respect for challenging the medical profession's status quo and acting on behalf of those believed to be "genuinely injured people." It is notable, therefore, that even though they forego some forms of capital, such as career success, reputation within the broader professional community, and certain financial benefits, their decision to advocate for the "underdog" accrues to them a different form of kudos. Nevertheless, this is grassroots support from an alternative community that has little influence in the mainstream medical profession.

Constraints to Medical Advocacy

There remain fundamental structural constraints that can inhibit supportive practitioners from continuing to act as expert witnesses for plaintiffs with emergent and controversial condition like MCS. In conversations with experts themselves, there was a palpable sadness that arose when they discussed their experiences with people who suffer from MCS. Essentially, despite the sources of motivation they identified, they seemed at times jaded with the cause. As I reveal below, these feelings stem from three sources of pressure they face in the advocate's role.

First, even though most of the supportive experts devalued monetary gain compared to helping people and "crusading for truth," financial logistics nevertheless played a pivotal role in their ability to practice. This element of professional life is illustrated in the following story of one specialist who developed a controversial technique for identifying MCS in the body. Her laboratory stopped receiving funding because the evidence she produced was too contentious and "upset some very powerful people." She says:

Basically they sent me out of business. I have got beaten down because I lost all my money [. . .] I haven't been able to do the things I used to do so I've dropped right back.

Although she was unable to tell the “whole story behind this” because she was “too frightened of being sued for defamation,” these snippets nonetheless show the infrastructure that is needed by researchers—particularly in a field of science that is in its infancy—which includes financial and often institutional support. If and when that assistance is not forthcoming or is terminated—irrespective of whether one sees financial gain as unimportant in principle—the practical implications are that one may be forced to “drop right back” in attempting to act on behalf of people with MCS.

A further constraint that the supportive specialists articulated was a form of professional disillusionment, which developed over a number of years after receiving little institutional support for their work in the MCS field. An anecdote narrated by one expert is particularly pertinent here: each year, it is compulsory for members of professional communities to attend conferences and workshops to further their career, for which they receive a certain amount of points for “professional attainment.” Some of the supportive specialists I spoke to have attended a number of conferences of the Australian Chemical Trauma Alliance (ACTA), a not-for-profit organization where sufferers convene with advocates and experts, including environmental, occupational and toxicological scientists, to discuss recent findings about chemical injuries. The expert in question said ACTA conferences are among the best and most informative conferences to which he has ever been. By contrast, he explains that he has never learned “one single thing useful about chemical injury” from the various conferences in his own discipline that he has attended. Nevertheless, when he applied to his representative college of medicine to receive professional attainment points for attending the ACTA conferences, he was promptly notified by letter that such meetings would not accrue points because they did not further his medical knowledge. This case study typifies the positive and negative sanctions that exist in the medical profession (Daniel 1998) that are designed to ensure doctors think within the accepted medical framework. This authority can manifest in formal stipulations, such as those that dictate that a professional will only be rewarded in his career for attending conferences that reinforce the medical community’s current beliefs.

The final and strongest demand on these professionals occurs at an emotional level. The occupational physician feels that fighting for this cause can sometimes deny him emotional “nourishment”:

Now one area of support does not come from getting success in these cases—success in winning the case—because mostly you *don't* win the case. Most of the people I see with MCS and with other conditions, there is in some concrete way a loss that they sustain, and therefore I can't get any nourishment as a doctor from waiting or seeing their recovery and their success in all of this. So one thing I do not do is have any attachment to a successful outcome. I have commitment to trying to help them. And doing what I can and knowing that I've done what I can, and then I try and let it go. Because if I don't, I'll sink, because I see one person, two people, three people, twenty people, etc. And they all have difficulties.

In acting on behalf of the chemically sensitive, medical specialists are fighting for a cause that is usually unsuccessful in two respects: the patients sustain a lifelong and

largely incurable injury, and further they most frequently lose their medicolegal claims. These losses deny practitioners a sense of professional satisfaction and amount to an emotional “wearing down,” which was identified by all of the specialists I interviewed. One response to this exhaustion is to emotionally distance themselves such that they are desensitized toward the outcome. Just as the occupational physician tries to “let it go [or] I’ll sink,” the toxicologist remarks:

In my early days it was grueling, because I found I was trying to help the plaintiff. I was involved in a class action . . . and the lawyer there said, look, you’re not here to help the clients, you’re here to help the court. So now I just go in and just say what I think. I was in court last week . . . and the [plaintiff lawyer] didn’t ask the right questions so I couldn’t help her. And I wanted to say, “no, don’t ask that, ask this!” But it’s not my problem. Yes it was my problem because I wanted to help her [. . .] but I don’t worry about it anymore. I used to in the past, but I don’t anymore.

Thus, the combination of financial restrictions, professional disillusionment, and emotional pressure is clearly having an impact on the supportive experts’ choice to advocate on behalf of people with MCS: financial constraints can inhibit the professional’s mode of practicing—be it a laboratory that loses funding or a practice forced to close; emotional pressures can deny experts the sense of professional satisfaction that can make their jobs worthwhile; and a lack of institutional reward can make them feel professionally disillusioned. With one of my informants having “dropped right back,” a number of them choosing “not to worry about it anymore,” and all of them feeling disenchanting with their role, these deterrents decrease the likelihood of the continuing involvement of supportive specialists in the quest for legitimacy of illnesses like MCS.

Conclusion

By specializing in treating an emergent and immeasurable condition as though it is organic, experts who deviate from the accepted framework of their field can find themselves marginal and stigmatized by their professional community. The informants to this research rationalized their decision to breach the professional norm by conceptualizing themselves as part of a minority moral community that prioritizes an ethical commitment to “truth” and helping those who suffer. Their experiences illustrate however that there are structural constraints that can—on a practical level—impede their ability to continue to assist the chemically sensitive in their struggle for recognition.

It is understandable that the biomedical community scrutinizes and attempts to falsify theories that explain emergent phenomena in nonconformist ways. Not only is the very concept of science based on hypothesis and refutation (Kuhn 1962; Popper 1963), but also the Western medical profession is endowed with the cultural authority to monopolize and regulate its field of expertise (Daniel 1998; Willis 1983). Clearly the public would start to lose its trust in the profession if more and more “quacks” and “irrepressible rebels” were given the authority to practice. However, the extent of the resistance faced by the practitioners featured in this

article evidences a deeply held medical distrust of that which is emergent, uncertain, and immeasurable, which has widespread implications. Supportive specialists are being deterred from continuing to research the field of MCS not because they feel their theories have been legitimately falsified but, rather, because of the social, financial, emotional, and professional constraints they are faced with for deviating from the professional norm.

Because the field of MCS continues to be an area of great uncertainty and little consensus (see ACOEM 1999), I would argue that the more practitioners working in the area, the better. As Kroll-Smith and Floyd (1997:18) note with regard to MCS, “stories are all we have at the moment because there are no agreed upon criteria for defining [it].” As the supportive experts in this article have specialized—albeit unintentionally initially—in treating MCS patients, they are listening regularly to such narratives and are therefore important and motivated players in the quest for understanding the condition. By disenfranchising these experts, the medical profession may be inhibiting advancements in emergent illness medicine.

Note

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1. Although MCS—or similar manifestations of chemical injury—have been documented since the 1930s (Shorter 1997), “emergent” refers not to its infancy but, rather, to the fact that “no aspect of the condition is settled medically, legally or popularly” (Dumit 2006:578).

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