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Multiple Chemical Sensitivities: Stigma and Social Experiences

Multiple Chemical Sensitivity (MCS), an intolerance to everyday chemical and biological substances in amounts that do not bother other people, is a medically contested condition. In addition to symptoms and the ongoing difficulties of living with this condition, this hidden and stigmatized disability strongly impacts social relationships and daily life. Based on an ethnographic study, this article introduces the context of MCS in terms of cultural themes, the media, and the economic power of industries that manufacture the products that make people with MCS sick. Participants' experiences with family members and friends, in work and school settings, and with physicians exemplify the difficulties of living with MCS. I dedicate this article to Joan Ablon, my professor and mentor, whose work has always inspired my thinking and research topics. [multiple chemical sensitivities, environmental illness, stigma, hidden disabilities, medically contested diagnoses]

An estimated 15 percent to 20 percent of U.S. residents have a disabling condition that interferes with life activities (Davis 1997; National Organization on Disability/Louis Harris and Associates 1998). However, the Disability Agenda (1999) noted that while "the so-called 'visible disabilities,' like wheelchair use and visual disabilities, dominate the demographics of disability . . . the 'invisible disabilities' are far more prominent" (e.g., activity-based disabilities, such as diabetes, asthma, heart conditions, or back problems).

Hidden or invisible disabilities are not easily seen or measured, hidden from currently available standard diagnostic tests so that the legitimacy of the condition is in doubt, and can be hidden by choice by persons with the disability (Fitzgerald and Paterson 1995). Hidden disabilities impose such difficulties as social and work restrictions; having to explain or defend one's condition to others; having others doubt, blame, or trivialize one's symptoms; and being misunderstood or having one's behavior misinterpreted (Taylor with Epstein 1999). With regard to

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others' perceptions, "hiddenness" has at least three different aspects: (1) sensory invisibility—it is not manifested in differences that others can see, hear, or smell; (2) cognitive invisibility—observers' mind sets or bias block understanding or believing that someone has problems; and (3) absence—others do not see the person when he or she is not feeling well enough to be out (Lipson 2000). These three situations color the lives and relationships of people with Multiple Chemical Sensitivities (MCS), also called Environmental Illness.

This article is based on an ethnographic study of MCS that began in late 1997 and on other findings published on self-care and MCS as a hidden disability (Lipson 2000, 2001). In this article, selected findings describe stigma and social relationships in the context of having a hidden disability that is also medically contested. First, cultural and economic influences are described as the context that reinforces the stigma experienced by people with MCS. Then, participants' words exemplify the themes of stigma and relationship issues with friends and family, in work and school settings, and in the health care system.

Multiple Chemical Sensitivities

MCS is a condition in which a person has become intolerant to normal levels of everyday chemical and biological substances that pose little or no problem to the general population (Ashford and Miller 1998). This condition has become increasingly prevalent in the context of the explosive growth in the manufacture and use of synthetic chemicals, energy-efficient buildings, poorer nutrition, and endocrine-disrupting chemicals (Millar and Millar 1998). Examples of problematic substances are fragrances in cosmetics, body products, cleaning products and air fresheners, office machine "exhaust," new construction materials, fresh paint, solvents, new carpeting and adhesives, automotive exhaust, tobacco smoke, pesticides, and molds. Because such substances are everywhere, this condition creates significant life disruptions (Gibson, Reed, Cheavens, and Warren 1996).

MCS is a medically contested diagnosis (Kroll-Smith and Floyd 1997) and the subject of heated controversy as to whether it has a psychogenic or an organic etiology.¹ Major problems in diagnosing and studying MCS are its extremely varied presentation² and lack of a generally accepted case definition. Although symptoms can appear in any bodily system, the neurological, respiratory, and gastrointestinal systems are commonly affected.

A number of physiological hypotheses have been posited to explain how people become hypersensitive to chemicals and why symptoms can appear in many organ systems. Among these hypotheses are detoxification system damage, neurogenic inflammation, limbic kindling, and immune system problems. Rea (1992–1996) suggests that those who have become chemically sensitive maintain a "total body load" of pollutants that overwhelms the body's detoxification systems; the result is that exposures to even minute amounts of any substance may trigger symptoms. Underlying such damage is disrupted enzyme systems, especially from chemicals that are fat soluble and remain in the body (Rogers 1990). It may be that MCS is more prevalent in women because of hormonal systems more vulnerable (Lax and Henneberger 1995) to the large number of endocrine-disrupting chemicals in pesticides and plastics that mimic estrogen (Millar and Millar 1998).

Meggs and Cleveland (1993) hypothesized that airborne insults cause chronic inflammation of the mucous membranes, which leads to “neurogenic switching” in which nerve impulses move and cause symptoms in other parts of the body. The limbic kindling hypothesis suggests a direct path from the nose, where chemicals are inhaled, to the limbic system in the brain, which governs such functions as sleeping, eating, and mood. Kindling means sensitization to very low levels of chemicals, which also explains the “spreading phenomenon” in which sensitivities to new substances develop with no or little exposure (Bell, Miller, and Schwartz 1992).

Immunological hypotheses describe abnormal ratios of helper/suppressor cells in MCS (Heuser, Wojdani, and Heuser 1992). Those who acquire MCS may create antibodies to chemicals, and some people also develop autoimmune responses that may progress to such conditions as arthritis, lupus, or multiple sclerosis.

Estimates of MCS prevalence range from 4 percent to 34 percent of the population. A large population based telephone survey ($n = 4,046$) found that 6.3 percent of California respondents reported physician diagnosed “environmental illness” or “multiple chemical sensitivity,” and 15.9 percent reporting being “allergic or unusually sensitive to everyday chemicals” (Kreuzter et al. 1999). In a random sample of 1,582 people in Atlanta, 12.6 percent reported a hypersensitivity to common chemicals, and 1.8 percent had lost their jobs because of their hypersensitivity (Caress and Steinemann 2003). It is generally agreed that women are more commonly affected, and a recent study found that women of child-bearing age are significantly easier to sensitize to odors than are men or women of other ages (Dalton, Doolittle, and Breslin 2002).

There is limited research on how MCS impacts the lives of those who acquired the condition. Gibson’s survey research, which includes qualitative analysis of answers to open-ended questions, is the richest body of literature to date (Gibson 1993, 1997, 1999; Gibson et al. 1996, 1998). In addition, there are several books that portray the lives of selected people whose disabling MCS has led to drastic life changes, such as homelessness (Johnson 2000; McCormick 2001; Zwillinger 1998).

Social, Cultural, and Economic Contexts

Disability and Stigma

As a chronic illness in which physical impairments can be accompanied by cognitive and emotional symptoms, MCS can limit several major life activities and can range from mildly to totally disabling. While eight states now officially recognize MCS for workers’ compensation claims (Blank 1998), the great majority of Americans with Disabilities Act (ADA) court cases and workers compensation cases have been decided against individuals with MCS, even with sufficient evidence to prove that they have a disability that would be covered under the ADA (Saab 1999).³ People with MCS who are completely disabled have great difficulty obtaining Supplemental Security Income (SSI) unless they overaccentuate their mental symptoms in order to receive a psychiatric diagnosis.

These legal difficulties are related to the controversial aspects of MCS, its general invisibility until divulged, and that “most disabled persons, whatever their

condition might be, are faced with significant social and attitudinal barriers as well as logistic ones" (Ablon 1999:11). Ablon's rich research on social and family issues experienced by people with dwarfism and neurofibromatosis 1 demonstrates the stigma that accompanies disability. "American values contain significant cosmetic and social prescriptions for 'beauty,' 'ugliness' and good health, which are systematically portrayed in the media and through selection in social, economic and political dimensions of life" reinforce negativity toward the physical and mentally different (Ablon 1984, 1999:12).

Cultural Themes

Underlying social problems of people with MCS in North America is the strong emphasis on individual "rights" rather than an emphasis on group or community well-being. People assert their right to express their own individuality through the way they dress and the cosmetics they wear; sometimes they do so with vehemence and occasionally through cruel assaults, as will be seen in a later example. When someone with MCS mentions a problem with someone else's fragrant body product, quite often that person will say or think "You can't be serious!" instead of examining what he or she is wearing. Even those who are careful not to apply cologne or scented hand lotion rarely think about such odors as dry-cleaned clothing, hair spray, or deodorant. It is difficult for unaffected people to realize the extent to which "we share the air," and that fragrance remains in the area long after the person wearing it has left.

A second theme is the common view that nice smells are better than no smells and, of course, nice smells are *much* better than bad smells. The fragrance industry spends millions of dollars to reinforce this theme through advertising and film stars' endorsements. Fragrances are added to cleaning products and infused into public spaces, a continuing challenge for people with MCS. While people with MCS have difficulty traveling because of others' body and hair products in enclosed places, airports themselves are now becoming more inaccessible (e.g., a news item a few years ago announced that London's Heathrow Airport was planning to pipe the smell of fresh-cut grass through the ventilation system to decrease international travelers' stress). The difficulty of locating a bathroom that does not smell of chemical air "fresheners" is an ongoing problem for people who risk getting sick when they need to use a toilet in a workplace, department store, library, or restaurant.

The media reinforces the stigma faced by people with MCS. Newspaper or TV reporters focus on its most dramatic manifestations, such as describing the extreme measures required for survival for the most sensitive and ill people. Many of these people can rarely leave their houses and some reporters have labeled them "bubble people." An MCS activist described the media at public demonstrations:

They (reporters) always show up painted to the hilt. When you tell them they have perfume on and to please back away they say, "Well, I need this interview," and they push you out of the way. I've picketed. (Reporters) go to the rallies and they *purposely* take pictures of the most weird looking people. I've been on the front-page of the newspaper wearing a huge respirator.

A key event that still angers people with MCS after some five years was a segment of the television show "20/20" on MCS, produced and narrated by

John Stossel.⁴ He and the show were perceived to have publicly discredited and humiliated some residents of Ecology House, an apartment building in northern California constructed especially for people with MCS. MCS activists initiated a letter-writing campaign to ABC News officials, its corporate owner, and legislators to protest slanted reporting and irresponsible journalism, particularly Stossel's reliance on so-called experts paid by the chemical industry. In addition to increasing the stigma of MCS by portraying people with MCS as psychologically disturbed rather than being legitimately sick from chemical products, this kind of program downplays the health effects of environmental pollution.

Economic Influences

The corporate profit motive also reinforces the stigma attached to MCS. People with MCS and the physicians who treat them strongly believe that "hired guns" in the chemical, pharmaceutical, and cosmetic and pesticide industries help them dispute or suppress information that might hurt sales, such as publications that question the safety of their products. In major conferences on MCS, attendees include representatives of these industries and "industry-supported physician-apologists" whose agenda is to discredit MCS. Some highly paid "research organizations" are actually industry mouthpieces and some other organizations provide expert witnesses to attorneys who defend corporations in product liability lawsuits on health risks and damage from various products (Radetsky 1997). MCS activists also state that federal agency "foot-dragging" in developing an MCS research case definition, necessary for research funding, is partially due to how "industry fought so hard for so long to keep MCS from getting one," because a case definition "should slow down industry research abuses" (Locke 2002:3, 4). These cultural, media, and economic themes emerged in the fieldwork described below, contributing to the stigma faced by people with MCS.

To summarize, sources of stigma include cultural themes of individual rights to express oneself through clothing and cosmetics, the desirability of nice smells, corporate efforts to discredit MCS because of the potential to lose trillions of dollars should this condition become "legitimate," and lack of basic medical/biologic knowledge of chemical sensitivities because research is hampered by the lack of a case definition for the illness (Wilson 2002). These interacting sources are shown to operate in the lives of the informants to be described in this article.

Methods

This ethnographic study was conducted in northern California and included short field trips to Vancouver, British Columbia, Halifax, Nova Scotia, and Dallas, Texas. I was a participant observer in monthly meetings of an MCS support organization, accompanied activist members when they testified at public "access" hearings, and socialized with residents of Ecology House, an apartment building especially constructed for low-income residents disabled by MCS. I observed for a week in each of the two North American environmental health clinics (Halifax, Nova Scotia and Dallas, Texas). In each setting, I informally interviewed people and took detailed field notes.

I conducted 36 individual semistructured, audio-taped 90–120 minute interviews, recruiting participants through snowball sampling, referral from MCS educators, clinic volunteers or professional colleagues, or directly in the Dallas clinic testing room. All interviewees signed a consent form promising confidentiality. Interview questions elicited the history of illness, a typical day, changes in one's home, relationships, activities and sense of self, health care experiences, medical treatments and self-care, and finally, "What would you most like to tell health providers about this condition?" Thirty interviews were face-to-face, and six were by telephone.

I sampled for variation in severity and length of illness, demographics, and geography. Seventy-eight percent were women between 28 and 65 years, and 89 percent were white. More than half lived with spouses, partners, or parents, and the rest lived alone. Fifty percent had college or graduate degrees, and 39 percent worked, but only 16 percent were well enough to work full time. In this sample, 53 percent were severely ill or disabled, and 14 percent had mild MCS. They had been ill from one to more than 21 years (31 percent from eight–12 years), and 62 percent attributed their illness to sick buildings or workplace chemicals.

To describe the context of MCS, I collected newspaper articles, examined the lay and professional literature, and subscribed to three MCS newsletters. I viewed videotapes and TV programs on health and the environment and followed policy discussions and decisions. I participated in an on-line weekly MCS chat room for a month to note the issues of most interest to participants. Data were analyzed for categories and themes with the help of a word processor and later the NUD*IST program.

Because talking about one's experience reveals illness, suffering, and stigma themes, this article relies heavily on quotes from the interview narratives to illustrate the themes that were found also in participant observation and document review. As this article will show, stigma and suffering was experienced in interactions with family and friends, with colleagues in work and school settings, and at the hands of physicians.

Invisibility and Misunderstanding

Family and Friends

Because people with MCS usually appear to be healthy, most participants stated that acquaintances or friends do not understand the seriousness of their condition. Being sickened by perfume, for example, sounds sufficiently bizarre to either be ignored or even elicit hostile behavior, especially if the chemically sensitive person is assertive. When participants acquired MCS, relationships changed or became impaired and people often became quite isolated. Linda⁵ described friends' insensitivity to her needs:

I went off to the mall with some friends; I told them I can't have those fragrances and stuff. They said, "We are going to try this perfume." I said "Yeah, just don't spray it on you." Then I saw them back there spraying away. Now my eyes were swelling; I was so mad I couldn't even think, my eyes hurt; everything hurts. And so they said, "We're sorry. We won't do it again." I said, "Don't worry because I ain't going with you all no more."

Jane described the impact of her illness on her closest relationships:

When I found out it was my husband's work (pesticides on clothing), I wanted him to quit his work, and that was just too much for him. My sister, my closest friend and another friend, and my husband, they left me, just couldn't stand my illness. I just don't contact other friends; some of them smoke and I can't . . . and I also have nothing to say to anybody anymore, I was too busy dealing with life. I have an isolated life and it's real hard to share experiences. [When I was sickest] I didn't want any close friends, because it hurt, because I remember the loss.

Sometimes participants sacrificed their well being to preserve a relationship, such as Mary:

My girlfriend wears chemicals but she tried not to wear any that day. But see, she still has it on her clothes . . . the washing stuff she uses. And we went down to town and we did a little bit of yard-saling. And her laundry soap was really bothering me, but I didn't say anything to her 'cause she's real sensitive and I didn't want to hurt her feelings. And everywhere we went there were chemicals. I kept reacting all day to everything.

Linda, who is very involved in her church, described:

We're like family. But it got to a point, I can't even stay in the congregation. Now I'm forced to stay in there (dining hall with TV monitor), I can't be around people. But they understand, they've been really considerate. [Q: Do people stop wearing fragrance?] No, they don't stop wearing it, but they start lightening up on what they're wearing. But I do hate being separate from the congregation because the whole purpose of even being in church is to be a part and you all learning as one.

Work or School

The majority of participants became chemically sensitive from remodeling, sick buildings, or exposure to chemicals in the workplace. Most had to quit their jobs and many had become too sick to work at all. A few interviewees worked part time if they could arrange flexible schedules in safe conditions or with accommodations and a few returned to school. However, they still faced exposures, often unexpected, for example, arriving to find that a classroom had been painted or pesticide had been sprayed outside an entrance.

Amy's "normal" appearance was associated with work colleagues' not taking her condition seriously or understanding the extent of her sensitivity. A nurse who eventually became disabled from clinic remodeling and from coworkers' fragrances, Amy first tried a different work position in the same clinic: "The staff was more compliant [with not wearing fragrances], but [the office] was literally 100 feet down the hall from where I had been. The offenders wore such strong fragrances and would walk around, so it could be 100 feet away and I was still going to get them. I was having a miserable. . . . It never ended. Administration wouldn't deal with it."

In their former or current work or school settings, most participants had informed supervisors, teachers, or colleagues about their problems with specific substances, mainly fragrances. Informing ranged from mentioning it to requesting accommodations such as a different office or fragrance-free environment. Responses

ranged from cooperation and support to frank cruelty, which was experienced by three participants. When Amy returned to college to get her Bachelor's degree in nursing, she faced an even worse situation with colleagues "testing" and even assaulting her: "I struggled all over again for two years, at school, with professors refusing to not wear fragrance; some students threw fragrances on me; one sprayed my backpack with Windex."

Hostility and assault⁶ from coworkers and minimal support from supervisors were continuing problems for Carl. He described one incident in which he was sickened by retaliatory perfume spraying on his office door the day after he reported smoking outside his office window (no-smoking area). His division chief also minimized the seriousness of his condition: "He told me at one point that people do little things to get other people annoyed and I shouldn't let it get a rise out of me. Hmm [sarcastically], I think next time I visit my parents I'll see if my father's really diabetic and drop some sugar in his diet coke and see if he can tell the difference."

A significant problem for those who were working or in school was deciding how and when to divulge their problem. Some participants needed to or chose to identify themselves by wearing a mask or carrying oxygen to use when needed. Others described more subtle changes in their appearance, which were noticed by only the most supportive colleagues, such as a facial expression of distress, color changes, or swelling eyelids, or such behavior as leaving abruptly or backing away from someone who "smelled."

Like people with other chronic illnesses that do not leave visible signs on the body, supervisors, colleagues, or instructors were often surprised when someone with MCS could not meet their expectations. They may have been unable to complete their work in a timely manner because of limitations in activities or problems with access, general low energy, or an upsurge in symptoms following a large exposure. A few participants described being cited for too many absences or not given time extensions to complete course requirements, and a few were fired.

Interactions with Physicians

Most physicians do not understand MCS or how to treat it. Sources of problems include (1) standard tests like blood counts, urinalysis, EKGs, etc., are usually normal in people with MCS; (2) people with MCS do not fit into standard biomedical categories; and (3) pharmaceuticals rarely work and often make the patient worse because he or she has become sensitized to them. Because most physicians believe that every health problem can potentially be treated with a pharmaceutical, if the medications are ineffective, they blame the patient's psyche rather than the medicines themselves. Helen, another nurse, described how she was treated during her many emergency room visits:

Why can't anybody tell I'm sick? Why aren't those blood tests showing? . . . I'm, I'm, you know, I'm dying! And dealing with a doctor who would often be cruel—stand there and say "There's nothing wrong with you." In the ER, [they're] saying, "Do you work?" I said, "Well you know, I'm ill, I'm not working right now." And just write it down, "Psychiatric." This is very sad . . . having been a medical professional, you think, "Please support me." "You are my colleague, please understand," and they didn't, because they didn't have the information. . . . Even

for me as a medical practitioner—I'd look in all my books, I'd look on the Internet . . . where am I in these textbooks? How come I'm not here?

Jane was required to see a therapist for documentation to obtain intravenous gamma globulin, which she needed on a twice-weekly basis:

She treated me as if I was depressed and as if I was denying. I got sicker and sicker while I was seeing her. (My husband) came home from work at 4 or 5 and sometimes I would be just getting up. Then he would have to cook and clean and take care of everything, and he was getting fed up with this. So, by trying to focus on my early childhood she was saying, indirectly, that all of these problems were caused by my depression and by my attitude, and if I would only look at them and also analyze the relationship with my husband I would be better.

Irene left mainstream medical care because it was ineffective and she was not believed:

My doctor, because I wasn't getting better, would send me from one specialist to another, to another. And then she started getting doubts about me. It was like I was not telling the truth because nobody could find anything. The symptoms are from head to toe, my heart palpitations were going like crazy, and my knees had turned in, my tendons were just pulling all the time, you know . . . and muscle cramps and groggy head. I mean, it was just miserable, and then she got into this snit. And I thought, "This is it, I've got to get away from these doctors."

Other physicians were very insensitive to their patients' needs, like Rhonda's:

I can't wear my mask with this doctor because he's really egotistical. He was covered with after-shave and I've been sick all day. Doctors say "There's nothing wrong with you—go see another doctor and you'll be fine." If somebody says "I'm allergic to fragrance" or "Don't put Betadine on me"—just believe them. The Hippocratic Oath says, "Do no harm." It doesn't say, "You're crazy. If you just believed differently, it wouldn't be real." You know, that's been the hardest thing, watching doctors "put us down" like we were "crap."

In other cases, physicians' inability to believe or comprehend chemical injury spoiled their patients' chances for workers' compensation, like Paula's experience:

I had reading problems, memory problems really bad. I described it like a record running on the wrong speed. I had foot drop, I was shuffling like a person with Parkinson's. And the neurological stuff was very obvious, even to my husband, who's just a construction person. However, one worker's comp neurologist who checked me over really fabricated his report and said that it was all in my head. It's been horrible. He said, well, I was just faking it.

However, physicians who treat MCS are often themselves marginalized because they treat a condition in which many mainstream physicians do not believe and because a general lack of effective treatment may necessitate innovative treatments. For example, a San Francisco allergist's⁷ license was suspended by the California Medical Board for using "unorthodox" treatments for seemingly intractable conditions. Some physicians are secretive because they fear the consequences should their treatment be brought to light (e.g., a participant's doctor

asked her not to submit receipts for her multiple nutritional supplements to workers' compensation because he feared investigation). Before being diagnosed with MCS, Kathy described an encounter with an allergist in a large health maintenance organization:

The fumes from my neighbor's carpet cleaner continued to come into our apartment and I got so sick from it—shaking and dizziness and trembling. I told my allergist about it. He said, "I'm going to tell you a secret, but you must never mention it around here because I'll get into trouble. I think you're chemically sensitive. It means you have to be really, really careful around chemicals." But that's all he told me. He didn't dare go on to tell me what could possibly happen.

Stigma, Suffering, and Fighting Back

People with MCS face a double burden of stigma and invisibility. As if it were not enough to experience pain, brain fog, fatigue, breathing difficulties, and the like following an exposure or on a daily basis, being treated as weird or crazy, shunned by family members or friends, or considered "crocks" by physicians and freaks by the media adds suffering to stigma.

Those with invisible stigmas may reveal themselves through their behavior; control of behavior and visibility appear to be important variables in others' reactions to the stigmatized person (Frame 2000). Having the ability to pass, however, comes at a cost (Kimpson 2000); people may suffer if they "pass" and suffer differently if they identify themselves. In the case of MCS, asking for accommodations may be met with hostility, scapegoating, or harassment. Yet bearing one's discomfort in silence and staying in odorous situations risks a more severe reaction that takes longer to clear. Individuals who leave settings in which they are becoming symptomatic may be perceived by others as irresponsible or they face disappointment or anger from friends and families who expect them to function as any well person does.

MCS is also characterized by psychologization of what is primarily a "women's disease." Seventy to 80 percent of individuals with MCS who are not part of an exposed cohort⁸ are women (Ashford and Miller 1998; Miller and Mitzel 1995). Being told that "there is nothing wrong with you, all your tests are normal; you are probably under stress or depressed" seems a clear example of a male-oriented biomedical viewpoint in which female illness is disproportionately attributed to psychiatric contributors (Richman, Jason, Taylor, and Jahn 2000). There are striking similarities in the experiences of people with other conditions in which women are affected much more than men are. These conditions are not easily diagnosed because they exist in multiple bodily systems, exhibit widely varying presentations, or have no widely accepted tests to diagnose them.

In experiencing a combination of symptoms, ongoing environmental anxiety, and being disbelieved or discredited, some people do become depressed. They insist, however, that they are depressed because they are sick, not sick because they are depressed. Others cope with their daily challenges through support from peers, in person or phone if possible, or on Internet chat rooms. Knowing that others experience similar social experiences makes one feel less "crazy" and alone. Still others have found meaning in their suffering through their activism: educating

others, addressing ADA access issues, and providing input into federal reports on MCS or the U.S. Food and Drug Administration on such issues as ingredient labels for perfumes. People in the MCS subculture refer to the old practice of taking canaries into coal mines to check for poisonous gasses, calling themselves modern-day canaries, the first victims of a growing epidemic of environmental illness. They are committed to warning others of the dangers of our increasingly polluted environment (Lipson 2001).

Conclusion

It is important to recognize that people with MCS face the same challenges as do those who have other invisible, delegitimized conditions. People with stigmatizing disabilities face significant social and attitudinal barriers as well as logistical ones (Ablon 1999), and people with MCS exemplify well such barriers. In this study, it became strongly evident that economic, medical, and social and cultural contexts interact to produce and increase the stigma experienced by people with MCS, such as corporate profit motives and valuing individual rights to self-expression and smelling nice. Within this context, family, friend, physician, and work or school relationships and performance were negatively affected, increasing the social suffering of people with MCS, which was felt by those with MCS to be as bad or worse than the physical suffering.

Ultimately, the findings of this study suggest, as do those of Gibson et al. (1996, 1998) and other MCS researchers, that what is needed in addition to reducing environmental pollution and the use of toxic substances in food, water, homes, and workplaces is research that supports MCS as a legitimate medical condition. We also need public health education about risks and prevention, such as the current campaign against second-hand smoke, a useful analogy in pointing out that "we share the air."

NOTES

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1. Examples of psychological theories include psychological-behavioral conditioning, pre-existing depression/anxiety, childhood trauma, or odor conditioning (Gibson 2000). These are not elaborated on in this article because the participants in this study are upset by the implications that the problems are in their psyches rather than their bodies.

2. The picture is further complicated by the fact that MCS, Chronic Fatigue Immune Disorder Syndrome, fibromyalgia, and Gulf War Syndrome share symptoms and occur together in approximately one-third to two-thirds of all cases (Donnay 1998).

3. This situation is beginning to change. For example, *Davis vs. Utah State Tax Common* (May 8, 2000) was decided in favor of an employee claiming MCS triggered by coworkers' use of perfume and strong-smelling hand lotion; the employee was considered to have an ADA-covered disability (Holland and Knight, LLP, 2000).

4. Originally planned to be part of a series on "junk science" and canceled because of a lawsuit, the program was aired anyway. Those who were interviewed complained that the "slanted reporting" including Stossel asking "How does it feel to be getting money (SSI) for a nonexistent condition?" and splicing answers to his questions into different questions.

5. All names are pseudonyms.

6. Vigh (2002) described a nurse who became the “office laughingstock for supervisors and colleagues, some of whom continued to bathe in their perfumes even after she told them it made her sick.” He also quoted Mary Lamicelle, executive director of the National Center for Environmental Health Strategies, who said that she often hears stories about employees harassing coworkers who suffer from asthma attacks or other respiratory problems or health effects from fragrances.

7. Dr. Robert Sinaiko’s license was suspended by the California Medical Board, despite his argument that every innovative treatment he uses is well within the range of appropriate innovation (Winokur 1998). His patients and others with MCS around the United States supported his case with letters to protest his suspension and raised a small fund to help with legal fees.

8. As an example, interviewees in Halifax, Nova Scotia, described the 1991 disaster in Camp Hill Hospital in which some 800 of the 1,100 employees had gotten sick. Of these, 380 had to leave work for some time, and by 1998, there were still 80 employees on permanent disability (Interviewee #13). Another interviewee said that the new hospital building had a closed ventilation system and that “the disaster began in the kitchen where sodium hydroxide used in the dishwashers was being vented back into the kitchen and the kitchen workers were getting profoundly sick. After it was handled, there was a reoccurrence and then there was sabotage. Somebody put something down an air vent, which sickened people in the rest of the hospital, and ‘it gave them a grand opportunity to say that that’s what was wrong in the first place’” (Interviewee #11).

REFERENCES CITED

Ablon, Joan
1984 Little People in America: The Social Dimensions of Dwarfism. New York: Praeger Publishers.

1999 Living with Genetic Disorders: The Impact of Neurofibromatosis 1. Westport, CT: Auburn Books.

Ashford, Nicholas, and Claudia Miller
1998 Chemical Exposures: Low Levels and High stakes, 2nd edition. New York: Van Nostrand.

Bell, Iris R., Claudia Miller, and Gary Schwartz
1992 An Olfactory-Limbic Model of Multiple Chemical Sensitivity Syndrome: Possible Relationship to Kindling and Affective Spectrum Disorders. *Biological Psychiatry* 32:218–242.

Blank, D. M.
1998 A Growing Sensitivity to What Is in the Air. *New York Times*. Feb. 12: BU 11.

Caress, Stanley M., and Anne Steinemann
2003 A Review of a Two-Phase Population Study of Multiple Chemical Sensitivities. *Environmental Health Perspectives* 111(12):1490–1497.

Dalton, Pamela, Nadine Doolittle, and Paul Breslin
2002 Gender-Specific Induction of Enhanced Sensitivity to Odors. *Nature Neuroscience* 5(3):199–200.

Davis, Lennard
1997 Introduction. In *The Disability Studies Reader*. Lennard Davis, ed. Pp. 1–6. New York: Routledge.

Disability Agenda: A Quarterly Publication of the National Organization on Disability
1999 The Distribution of Disability, 3(4). Electronic document, available online at: <http://ssdba.calstatela.edu/Abstracts/SOC0120.htm>), accessed October 2002.

Donnay, Albert
1998 *Overlapping Disorders: Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Multiple Chemical Sensitivity and Gulf War Syndrome*, 4/4/98 edition, Baltimore: MCS Referral and Resources.

Fitzgerald, Maureen F., and Kathy Paterson
1995 The Hidden Disability Dilemma for the Presentation of Self. *Journal of Occupational Science (Australia)* 2(1):13-21.

Frame, Melissa J.
2000 What's Wrong with Her? The Stigmatizing Effects of an Invisible Stigma. *Disability Studies Quarterly* 20:243-253.

Gibson, Pamela Reed
1993 Multiple Chemical Sensitivities/Environmental Illness: Invisible Disabilities. *Women and Therapy* 14(3/4):171-185.
1997 Multiple Chemical Sensitivity, Culture and Delegitimization: A Feminist Analysis. *Feminism and Psychology* 7(4):475-493.
1999 Social Support and Attitudes toward Health Care Delivery as Predictors of Hope in Persons with Multiple Chemical Sensitivity. *Journal of Clinical Nursing* 8(3):275-283.
2000 MCS: A Survival Guide. Oakland, CA: New Harbinger Publications.

Gibson, Pamela Reed, Jennifer Cheavens, and Margaret Warren
1996 Chemical Sensitivity/Chemical Injury and Life Disruption. *Women and Therapy* 19(2):63-79.
1998 Social Support in Persons with Self-Reported Sensitivity to Chemicals. *Research in Nursing and Health* 21:103-115.

Heuser, Gunnar, Aristo Wojdani, and S. Heuser
1992 National Research Council Multiple Chemical Sensitivities: Addendum to Biologic Markers in Immunology. Washington, DC: National Academy Press, pp. 117-138.

Holland and Knight LLP
2000 (Nov.) Sensitivity to Odors and Lotions Justifies ADA Claim. *Employment, Labor and Benefits*, 10(6). Available online at: <http://www.hklaw.com/Publications/Newsletters.asp?ID=163&Article=775>

Johnson, Allison, ed.
2000 Casualties of Progress, Brunswick, ME: MCS Information Exchange.

Kimpson, Sally A.
2000 Embodied Determinism: Constructing a Transgressive Self. *Disability Studies Quarterly* 20:319-325.

Kreuzter, Richard, Raymond Neutra, and Nan Lashuay
1999 Prevalence of People Reporting Sensitivities to Chemicals in a Population-Based Survey. *American Journal of Epidemiology* 150:1-12.

Kroll-Smith, Steve, and H. Hugh Floyd
1997 Bodies in Protest: Environmental Illness and the Struggle over Medical Knowledge. New York: New York University Press.

Lax, M., and P. Henneberger
1995 Patients with Multiple Chemical Sensitivities in an Occupational Health Clinic: Presentation and Follow-Up. *Archives of Environmental Health* 50:425-431.

Lipson, Juliene G.
2000 She's Not Disabled: She Plays Tennis. *Disability Studies Quarterly* 20:340-346.

2001 We Are the Canaries: Self-Care in Multiple Chemical Sensitivity Sufferers. Qualitative Health Research 11:103-116.

Locke, Stevie
2002 MCS Case Definition Still Needs Support. Our Toxic Times: A Publication of Chemical Injury Information Network 13(10):3-8.

McCormick, Gail
2001 Living with Multiple Chemical Sensitivity: Narratives of Coping. Jefferson, NC: McFarland and Company.

Meggs, William J., and C. Cleveland
1993 Rhinolaryngoscopic Examination of Patients with the Multiple Chemical Sensitivity Syndrome. Archives of Environmental Health 48:14-18.

Millar, Heather, and Myrna Millar
1998 Environmental Health Nursing. Vancouver, BC: NICO Environmental Health Strategies.

Miller, Claudia, and Howard Mitzel
1995 Chemical Sensitivity Attributed to Pesticide Exposure versus Remodeling. Archives of Environmental Health 50(2):119-129.

National Organization on Disability/Louis Harris and Associates
1998 N.O.D. /Harris 1998 Survey of Americans with Disabilities. Available online at: <http://www.nod.org>

Radetsky, Peter
1997 Twentieth Century. Boston: Little Brown and Company.

Rea, William
1992-1996 Chemical sensitivity, Vols. 1-4 Boca Raton, FL: Lewis Publishers.

Richman, Judith A., Leonard A. Jason, Renee R. Taylor, and Susan C. Jahn
2000 Feminist Perspectives on the Social Construction of Chronic Fatigue Syndrome. Health Care for Women International 21:173-185.

Rogers, Sherry A.
1990 Tired or Toxic? Syracuse, NY: Prestige Publishing.

Saab, Tracie DeFreitas
1999 Work-Site Accommodation Ideas for Individuals Who Experience Limitations Due to Chemical Sensitivity or Environmental Illness (EI), Electronic document, <http://www.jan.wvu.edu/media/MCS.html>,

Taylor, Stacy, with Robert Epstein
1999 Living Well with a Hidden Disability. Oakland, CA: New Harbinger Publications.

Vigh, Michael
2002 Scent-Sensitive Nurse Sues LDS. *Salt Lake Tribune*. October 15. Electronic document, <http://www.sltrib.com/2002/oct/10152002/utah/7273.htm> accessed February 2003.

Wilson, Cynthia
2002 An Overview of Multiple Chemical Sensitivity. Our Toxic Times (Chemical Injury Information Network) 13(9):5-9.

Winokur, Scott
1997 Allergist's License Is Revoked. *San Francisco Examiner*. August 9: D1.

Zwillinger, Rhonda
1998 The Dispossessed: Living with Multiple Chemical Sensitivities. Paulden, AZ: The Dispossessed Project.