

## **She's Not Disabled - She Plays Tennis**

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An estimated 15% to 20% of U.S. residents have a disabling condition that interferes with life activities making this the largest minority group in the United States (Davis, 1997; National Organization on Disability/Louis Harris and Associates, 1998). Minority status is based on restricted access to education, full employment, and other resources. People with disabilities are often stigmatized and marginalized based on their being visibly different in appearance or behavior from the range of "normal." However, the Disability Agenda (1999) noted that while "it is a common perception that the so-called 'visible disabilities,' like wheelchair use and visual disabilities, dominate the demographics of disability ... the 'invisible disabilities' are far more prominent." The 1998 N.O.D./Harris Survey asked 1000 Americans with disabilities which disabling condition most limited them. Forty-four percent were most limited by activity-based disabilities, such as diabetes, asthma, heart conditions, or back problems, while 35% were most limited by mobility impairments (spinal problems, missing or paralyzed limbs, or arthritis) (Disability Agenda, 1999).

In her recent book, Taylor (1999) described eight criteria for hidden disabilities: (1) impairment in functioning; (2) decrease in quality of life; (3) restricted lifestyle, especially in social and work realms; (4) a daily focus on pain, fatigue and/or disability; (5) feeling defensive, having to explain or defend your condition to others; (6) if the disability is stigmatized, people doubt or blame one or trivialize one's symptoms; (7) a chronic or progressive disorder; and (8) feeling misunderstood or one's behavior being misinterpreted, e.g., the person whose chronic fatigue is accompanied by memory loss is "flaky," the pain sufferer who gains weight is lazy.

Readers with personal and/or professional disability expertise can see that my perspective and experiences are typical of someone with a recently acquired disability, particularly the identity issues reflected in many of my examples. In thinking about hidden disabilities, I have come up with three types of invisibility: (1) sensory invisibility - others can't see, hear, or smell any difference; (2) invisibility because of absence - others do not see someone in public when he or she is not feeling well enough to be there; and (3) cognitive invisibility - the observer's perception or bias blocking his or her hearing, believing or understanding the disability. These types thread through MCS.

### **What is MCS?**

Multiple Chemical Sensitivity (MCS), also called Environmental Illness, is a condition in which one has become intolerant to normal levels of everyday chemical and biological substances that pose little or no problem to the general population. Because such toxic substances are everywhere, people with MCS are forced change their lifestyles, sometimes radically, to protect their health as much as possible. Frequent problematic substances are fragrances in cosmetics, body products, cleaning products and air fresheners, poor indoor air quality from office machines, new construction materials, fresh paint, solvents, new carpeting and adhesives, automotive exhaust, tobacco smoke, molds and pesticides. Many people become intolerant to various foods and medications. Although each person has a unique constellation of symptoms, exposure may result in such typical symptoms as headaches, dizziness, fatigue, nausea, breathing difficulties, tightening of the throat, diarrhea, brain fog, memory loss, learning disorders, eczema, painful joints and muscle pain (Millar & Millar, 1998; Ashford & Miller, 1998).

MCS is a medically contested diagnosis. Sufferers are often told they are depressed

or their symptoms are a manifestation of stress, similar to the history of such recently contested disorders as carpal tunnel syndrome and chronic fatigue syndrome. It is interesting that these conditions are much more common in women. However, MCS may continue to be blamed on psychological problems because of enormous political and economic pressures from pharmaceutical and chemical industries. These industries stand to lose billions should the fact that people can become permanently disabled from their products become widely accepted. Whether MCS should be considered under the Americans with Disabilities Act is also controversial. The ADA does not list specific disabilities that are covered in every instance. The majority of MCS court and workers compensation cases have been lost and highly disabled people have great difficulty getting SSI unless they over-accentuate their mental symptoms and accept a psychiatric diagnosis.

### **My Study and Personal Experience**

I developed chemical sensitivities during the time my university department was being extensively remodeled. In early December, 1996, I caught a cold, which progressed to wheezing and then pneumonia. During my first class in January, I was particularly bothered by the strong odor of new carpet and adhesive and I felt quite disoriented. I told the students that I thought something from the remodeling was making me forget words, and asked them to bear with me. After a few weeks of no improvement, my department chair insisted that I file an "incident" report. That started the workers' compensation process and from then on I was labeled "the injury sustained 2/7/97." During the next six months, my symptoms increased despite reducing my hours in the department. I began reacting to such other substances as auto exhaust, bathroom air fresheners, laundry and dishwasher detergent, and even the unfinished plywood floor of my home office adjacent to our bedroom. I had to sleep on the living room couch until my husband installed non-toxic flooring. Such exposures cause cognitive and concentration problems after which I develop headaches, body aches, and overwhelming fatigue that last at least until the next day.

My impetus for beginning an ethnographic study of living with MCS was noticing that some people responded to me in an odd way when I explained why I moved away from their perfume. The study evolved into a feminist experiential analysis of the kind so well explicated by Shulamit Reinharz (1981). I did participant observation in two treatment centers, a support organization, and an Internet chat-room. I informally interviewed MCS sufferers, activists, and educators in California, Texas, Vancouver and Halifax. I interviewed 33 people with MCS recruited to reflect as broad a range as possible in age, ethnicity, education and illness severity (Lipson, in review). Sharing our mutual experiences bolstered my sagging self-esteem and participants advised me about self-care. In the context of the negative media images of MCS, interviewees seemed grateful to be interviewed by someone who understands our life challenges and is committed to publishing our real stories. However, this study is also quite personally threatening. Most interviewees were severely ill, some completely disabled and only five were able to work. I identified with their experiences and alternated between feeling fortunate and frightened of becoming more ill, especially since most of them warned me to get out of my workplace. I recorded such feelings in a field note journal which became an additional source of data.

Most of the experiences I describe here are my own because of the focus of this panel, but I also quote some interviewees on the following themes: not being believed, work slights, relationship changes, and symbols reflecting identity. The three types of invisibility thread through them.

### **Themes**

**Not Being Believed.** Cognitive invisibility is a universal experience among people with MCS. Before considering research, I faced one of the most frustrating problems encoun-

tered by nearly all people with MCS - not being taken seriously by physicians. My first worker's compensation medical examination resulted in a letter that informed me that "after careful consideration of all available information, we deny all liability for work-related injury or illness." The physician was an over-70 allergy retired university faculty member who focused only on my asthma symptoms. He did not seem to hear me when I stated at least twice that I could deal with the breathing problems - it was the cognitive problems that most bothered me as an academic. Brain fog is invisible, noisy breathing is not. In actuality, he was perceiving only the symptoms that fit his biomedical categories, and MCS does not fit. At that time, I did not know that most physicians do not believe that MCS has a physiological basis. I had been completely honest and, in retrospect, naive and his not hearing me left me betrayed and angry.

My protest of the worker's compensation denial led to a second worker's compensation physical. By then I was more wary, but unfortunately I was also more sensitive to more chemicals, including the strong chlorine odor that permeated the elevator to this internist's office. It left me too spaced out to be assertive. He ended the examination by telling me:

You are a scientist, you should know that we can't test for this, therefore it's not really accepted. I don't really believe this. How can you live in this world? There are chemicals everywhere, you can't even walk on the street.

Based on his letter, worker's compensation immediately cut off paying my acupuncturist. His letter said:

This diagnosis is a diagnosis that is not accepted universally by mainstream medicine ... it is felt by many to be an illness of fashion, an illness that is in vogue and written about often, unfortunately, in the lay press. Dr. Lipson does very well playing tennis ... she is not disabled. It is my opinion that this patient does not suffer from a true multiple chemical sensitivity syndrome but in fact may have been transiently intoxicated, because there are chemicals everywhere, including on a tennis court. No treatment other than reassurance would be recommended.

In my journal I expressed my anger and dismay at the hands of "this condescending know-it-all bastard whose medical opinion gives him such power over my situation. He is not in my body, he doesn't know how I feel, how upsetting this is, and what it has done to my work and my life. I wish he could be in my shoes." Every person I interviewed had similar stories of how they were treated by the doctors they consulted. Fortunately, my third worker's compensation examination by a state-appointed "qualified medical examiner" was much better. His specialty is occupational medicine and he had written a chapter on MCS. His report resulted in a "12% permanent disability," whatever that means, for which I needed accommodations at work.

A number of people I interviewed described various ways in which the medical model creates cognitive perceptual invisibility, such as "doctors don't see your problems if it doesn't fit in their categories." One woman said: "the doctor told me there is nothing wrong with me, but I knew something was very wrong. After a year, when I had a bad lupus attack, I finally talked the doctor into giving me a test, and it showed up. He couldn't believe it, he thought it was all my imagination." A man in his early 30s said: "I was shocked and disappointed in medicine. They couldn't understand my complaints. They were looking for simple answers... the thumb doctor looks at the thumb, and the toe doctor looks at the toe, and they

don't see that they have the same disease, or they are connected."

Work issues. I am not generally paranoid, although the following examples may sound like it. They exemplify both sensory invisibility and that caused by absence. I currently try to minimize my exposures by mostly working at home. When I come into my department two or three half days a week, I am either teaching or hiding out in my office with its open window and air purifier. Like many environmentally ill people, I do not look ill in a relatively clean environment and I leave when I can feel a reaction starting. A careful observer might notice some changes in my appearance which can sometimes happen quite rapidly. For example, in a committee meeting in a conference room in which I smelled something unpleasant, I began to feel the usual tightness in my head that may be swelling mucous membranes and the chair saw my face redden and my eyelids droop and asked if I was OK. I was grateful to be acknowledged and left the meeting.

Although my department generally tries to accommodate me, including moving me to another floor for two years, the invisible character of my problem results in ongoing subtle slights. Some colleagues and students merely "forget" about my problem, others do not understand how serious it can become, and a few people do not take it seriously. First example: this academic year, monthly department meetings were held in the department lounge, a room in which I still smell carpet adhesive and formaldehyde. In good faith I attended the September meeting in a mask and sat in the open window, five stories up. I still had to leave after 45 minutes and I informed the administrator that I could not attend meetings until they were held in an accessible place. Finally, the February meeting was scheduled in a classroom and I was determined to attend. When I entered the room, I smelled something nasty. The receptionist had just sprayed the counter with a chemical cleaner and a colleague explained that they had to clean it up because "it was a sticky mess." I put on a mask and moved to the open doorway at the other end of the room. Next, a visiting scholar entered the room and when she saw me she said "Oh, Juliene, I'll stay away from you, I'm wearing perfume." Either nobody had bothered to tell her about the School of Nursing's voluntary fragrance-free policy or she did not take it seriously. I had to leave after 20 minutes.

The second example involved my being scheduled to receive a new computer to replace one that was hopelessly outdated. "Computer exhaust" bothers me and I use an exhaust fan behind my computer at home. Because brand new computers put out especially toxic chemicals, I requested that my new computer be left on for three or four months to allow it to "off-gas" in my old office until I moved back into the department. After carefully specifying exactly what I wanted on my new computer and it had arrived, I was informed by e-mail that my new computer would be given to someone else; a new one would be ordered for me when I moved back upstairs. The administrative person who transmitted this message, who is knowledgeable about occupational health, also said, "I know of no off-gassing that occurs with computer products. If you have any science to support this, I would be willing to review it." I shot back an e-mail offering my own research findings and said "your note implies that you do not consider my own experience valid, please look at new studies showing high cancer rates in Silicon Valley line workers."

Changes in Social Relationships. As with any marginalized or stigmatized group, people are divided into those who are "like me" or understand me and those who are not or do not. As I struggle to incorporate my health condition into my identity, I find myself dropping some old friends and making some new ones. Most new friends have MCS or other disabilities. People I no longer associate with do not take my problem seriously, can not remember to avoid fragrances in my presence, or avoid me because I have changed. I am sure that my constant concern with my environment and health is boring or maybe it is my lower energy and inability to go to various places. One of my favorite interviewees said this:

I find myself hating people because they have perfume on, or a "G.D."

cigarette in their mouth, you know, and they're 30 feet away and I can still smell it, because I'm downwind. And these poor people who are....new people ... they might be really lovely, and I'm already pissed at them, and I don't want them near me.

Symbols, Invisibility and Identity. Typical of hidden disabilities, people with MCS can choose whether to make themselves visible by means of equipment. The power of a symbol hit me about ten years ago when I flew to Canada with a professor colleague who has MS. On the way to the check-in desk, he used a cane. As soon as he got into a wheelchair, airline staff began to talk to me about what he could do or not do rather than asking him (Lipson and Rogers, 2000). Disclosing one's disability can result in being discredited, particularly when the condition is medically contested or stigmatized. Some interviewees choose not to wear a mask even when it would be helpful because they do not want to be seen as "weird" or "crazy;" others wear it to signal that they are not "safe" in situations in which people are wearing fragrances or are smoking. One articulate woman explained that:

When I go outside, I use a mask and oxygen, occasionally I use a wheelchair. People respond differently to these things. The mask scares them, they think I have something contagious, they stay away. People relate to people in a wheelchair in a friendly way. With oxygen, it's more like "you poor thing, you're sick." I'd rather be scary than pitied....

When I am in public or a relatively clean environment, I rarely wear a mask. However, I always wear one in my department. The obvious reason is cutting down exposure, but an underlying reason is keeping my disability visible in the place where I got sick. In other words, wearing a mask may not totally reflect what is in the environment, but may also reflect my vacillation between acceptance and denial. However, my change in appearance definitely reflects the changes in my identity: weight gain, avoiding makeup, and tending to mostly wear the same old comfortable cotton clothes.

In conclusion, writing this paper was quite difficult but personally useful in examining my adjustment to a hidden disability. Now, where does tennis come in? I have played regularly for 15 years. When I returned to playing after developing MCS, I noticed that tennis was the only thing that made me feel better and over time I have thought about why this might be. Initially, I thought that pounding the ball was helping me release some of my anger related to my health condition. Then I realized that it was the exercise and laughing with my tennis friends. Then I learned that sweating helps lower one's toxic load and is also physiologically therapeutic. The other day, however, I realized that my competence in tennis was one of the few things that remained the same during a time when I have had to lower my expectations in most other areas of my life because of a condition that restricts my freedom and energy. Perhaps keeping parts of one's identity while changing others is what adjusting to any disability is all about.

NOTE: This paper was part of a symposium entitled "Hidden Disabilities: Personal Encounters" presented at the annual meetings of the Society for Applied Anthropology, March 24, 2000, San Francisco, CA.

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