The MCS Debate: A Medical Streetfight

by Eric Nelson

The Free Press

Often labeled an "emerging" health issue, Multiple Chemical Sensitivity (MCS) simply has yet to be legitimized by the "old-guard" medical establishment and the state medical-insurance institutions.

Because the illness has only been recognized in the last decade or so, and its effects are unpredictable, few diagnostic tests are considered "meaningful" by mainstream medicine. Even though immunological tests and brain scans show abnormalities caused by chemical exposure and subsequent sensitivity, they are not considered "reliable" indicators by the medical establishment. The result is that MCS is not a "real" objective diagnosis.

However, a growing body of evidence and literature - rarely cited by the proponents of psychological explanations for MCS - indicates that neurotoxic chemicals can irreversibly disrupt the central nervous system.

Those who suffer from MCS have no doubt about its realness.

"I've had to deal with a lot of self-seeking ignorance and lack of ethics on the part of public officials," said Bonnye Matthews of Seattle, who became an MCS activist after she was exposed to styrene in carpet glue while working for the Army Corps of Engineers. She is the author of Chemical Sensitivity (McFarland & Co., 1992).

Chemical sensitivity can take a number of forms. Someone may be exposed to a very high dose of chemicals once or twice. Or the person may be exposed to "low levels" of chemicals for a long period. In either case, he or she may become sensitized to the first chemical, plus a range of other unrelated chemicals.

MCS patients commonly suffer headaches, chronic fatigue, memory lapses, dizziness, stomach problems, rashes, hives and disturbed vision. Researchers attribute many central nervous system disorders to a form of brain damage called toxic encephalopathy (brain inflammation due to poisons).

"I feel like I have the flu all the time," said Wendell Boggs, a former Boeing worker at Auburn who has worked with chemicals for the better part of 30 years.

"There are lots of things around the home I have to watch. No colognes or perfume. I quit shopping," Boggs said. "Once, I went into the Fred Meyer toy section and picked something up and it really set me off. I have just about eliminated all the things I have to stay away from."

Taking Sides

Just how chemical exposure can irrevocably change people's health and sensitize them to a wide range of chemicals - be it gasoline, newspaper ink or perfume - is a matter of intense debate. In fact, it is the closest thing the medical profession has to a streetfight.

- One side is doing complex research on neurological reactions to chemical exposure. In their various fields, Dr. Iris Bell, Dr. Thomas Callender and Johns Hopkins Professor Linda Davidoff are studying how chemical exposure and sensitivity can affect brain chemistry
and cause emotional and central nervous system disorders. Dr. Gordon Baker, a Burien allergist, backs their theories and also believes chemical exposure can leave tell-tale immunological "markers."

- The other side is composed of a network of occupational health researchers, some of whom double as industry consultants, such as Seattle toxicologist Dr. Patricia Sparks. These researchers propose a scenario - strongly contested by MCS activists - in which "low-level" chemical exposure, workplace stress and previous psychological problems create chemical sensitivity. Emphasizing the level of uncertainty in MCS research, they do not recommend that MCS patients avoid chemicals. They believe psychiatric treatment can offer relief.

Scientists on the cutting-edge of MCS research have proposed an "olfactory-limbic model" to explain how chemicals affect memory and the central nervous system. Among them are Dr. Iris Bell of the University of Arizona, who theorizes that chemical molecules enter the olfactory bulb, where smells are processed. They then progress to the brain's limbic lobe, where emotions lie and information is organized into broad topic files - a sort of card catalogue.

In the limbic lobe, that card catalogue gets toppled, causing memory lapses and upsetting emotions.

This process has been dubbed "kindling." The result is that memory and central nervous system disorders can be provoked through "repeated low-level stimulation of an irritant chemical [or by one high exposure]," Dr. Stephen Schacher of Seattle notes in a newsletter to his MCS patients. Once sensitized, an individual could experience progressively worse reactions from exposures that are too low to affect unsensitized people.

Related to kindling are "cross sensitization" and "time-dependent sensitization," which mean that other substances will produce a like effect, perhaps long after the initial exposure.

Research also shows more people than previously thought report "cacosmia," in which an altered sense of smell is combined with illness, such as headaches and nausea. According to Bell, 66 percent of a sample group of college students reported cacosmia when exposed to new carpet, pesticides, car exhaust and paint. Women report more sensitivity than men.

'No Time To Dry Out'

But can these findings actually be measured in the body? Baker, an allergist who has seen more than 400 Boeing workers since the Auburn crisis, says a battery of immunological and neuro-psychological tests are helpful.

Many Auburn workers were diagnosed with brain damage due to chronic exposure to phenol formaldehyde. "At Boeing, these people were working seven days a week - they had no time to dry out," Baker said.

Tests confirmed the presence of antibodies that fight off chemicals such as formaldehyde, benzene and isocyanate. Baker says MCS patients also are more likely to develop autoimmune antibodies such as those in rheumatism and multiple sclerosis patients. In sum, Baker said, "You find a 'turned-on' immune system."
The neuro-psychological tests given to MCS patients carry names like Quantitative Electroencephalogram (QEEG), Positron Emission Tomography (PET) and Single Photon Emission Computer Tomography (SPECT). The complex tests measure brain function and can actually "map" certain lobes. When exposed to chemicals, such as a perfume, "The scans show decreased blood flow (to some areas of the brain)," Baker said.

Baker's assertions are backed by top researchers in the field. A 1991 report prepared by an American Psychiatric Association task force, for example, noted QEEG's success in detecting abnormalities involving gross central nervous system disorders.2

Another group, studied by Callender of the Environmental and Occupational Medical Research Institute in Lafayette, La., and Dr. Lisa Morrow of the University of Pittsburgh, developed toxic encephalopathy after being exposed to pesticides, solvents and other toxins. When given SPECT scans, 93 percent had apparent brain function abnormalities.3 PET scans are considered even more sensitive.

But the state Department of Labor and Industries (DLI), which oversees workers' compensation claims for Boeing and other self-insurers, won't accept these tests as proof of an MCS diagnosis. No formal diagnostic code has yet been established for MCS. And a committee of the Washington State Medical Association has advised DLI not to cover the brain scans or immunological tests.

In a letter to DLI director Mark Brown last year, the WSMA warned that the tests "are not considered by most physicians and professional bodies as clinically meaningful for the diagnostic evaluation of a patient given the label of MCS."

How did the WSMA come to this determination? By referring to the conservative American Medical Association (the same group that advises silicon-gel breast implants are still safe, if monitored).4

WSMA also followed the recommendations of Dr. Patricia Sparks, a Seattle toxicologist who heads the Occupational Health Services program at Providence Medical Center. Sparks serves as a consultant and independent medical examiner for Boeing, and until recently consulted for DLI on MCS cases. Sparks could make as much as $330,000 under her two-year consulting contract with the state.

'A Strong Odor'

Following the outbreak of illness at Auburn, Sparks headed a team of researchers hired by Boeing. They found that the workers did receive phenol formaldehyde exposure at "low levels," but that their health problems stemmed largely from "psychosocial factors" at work and in the community.

Writing in a slew of medical journals between 1990 and 1992,5 Sparks and her colleagues drew conclusions of a psychosomatic nature. Sparks dismissed any immunological explanation, concluding instead that the workers had prior psychological problems, and that exposure to chemicals, combined with stress and labor-management strife, all led to "mass hysteria."

"Phenol formaldehyde does have a strong odor, as do other agents in the workplace. The irritant symptoms coupled with a fear of toxicity may produce a state of autonomic arousal leading to a panic attack. The belief that they were being 'poisoned' was reinforced by health providers...
Dr. Patricia Sparks concluded that workers had prior psychological problems, and that exposure to chemicals, combined with stress and labor-management strife, led to "mass hysteria."

"In summary," Sparks wrote, "our study suggests strongly that psychiatric morbidity explains much of the illness and disability by this group of workers."6

In letters to DLI, Sparks said she is concerned about "the application of invalid or misapplied clinical tests by a handful of practitioners to inform patients they have disease or damage when they don't - or at least the tests mentioned cannot be relied upon to demonstrate damage if it does exist."

In her papers, Sparks also has attacked the methodology of immunological labs used by Baker, adding that the tests are expensive and therefore profitable to the labs. Baker has since switched labs and said he finds the same results.

Sparks was contacted for comment, but did not return calls. In a recent article in the Seattle Post-Intelligencer, she observed that she has become the "Great Satan" of the chemical sensitivity movement.

In response to pressure from WSMA and DLI's medical advisors, the state's new "interim policy" on MCS requires "prior authorization" for certain tests, including the QEEG, PET and SPECT scans. In other words, the state won't cover them. And, without an "objective" diagnosis, DLI will not grant benefits to a disabled worker.

But literature suggests that without brain scans, some patients are diagnosed incorrectly. Callender and Morrow cite a patient accidentally exposed to the chemical tetrabromoethane who exhibited signs of MCS and emotional disorders. Routine neurologic tests and a CT scan all proved negative and the patient was initially diagnosed with major depression.

"Without a subsequent PET evaluation, which diagnosed various anomalies in brain function, this patient would have been left with a psychiatric diagnosis."7

**Simon Sez...**

Despite clear findings that psychological disturbances are consequences, not causes, of MCS, contradicting studies funded in part by chemical-intensive industries continue to generate controversy. They also capture the interest of attorneys who defend corporations against MCS cases.

Published last year, the "Simon Study" was authored by a team of UW researchers led by psychiatrist Dr. Gregory Simon, who's now at Group Health. Simon had previously co-authored a number of articles with Sparks. Another author, Dr. Hal Stockbridge, is now DLI's associate medical director.
Simon's study found little, if any, relation between MCS and positive immunological responses. Baker and others, however, contend the study used flawed methodology and exhibited ethical breaches.

With funding from Boeing's Health and Safety Institute and the UW, Simon's team began a study in 1989 of 41 patients seen by Baker who did not work at Boeing. Baker told the researchers he believed only a portion of the group had chemical sensitivity and wished to compare results to sharpen his diagnostic techniques. Simon never came back with his results, Baker said.

Critics of the Simon Study say the research team assumed Baker had diagnosed all of the group as having chemical sensitivities, when in fact he had not.

The study also placed these patients against control participants suffering from back injuries. This created a "confused" control group, Baker said, because their back injuries could have been related to autoimmune diseases such as rheumatoid arthritis and lupus.

Baker said a proper study should have compared 100 Boeing workers having chemical sensitivities, 100 Boeing workers without chemical sensitivities, and 100 people from the community at-large.

Simon found few if any immunological differences between the MCS patients and the controls with back injuries. Brief neuropsychologic tests also proved negative. "Psychologic distress," Simon wrote, "was the only factor that clearly distinguished" the two groups.

The study concluded that MCS patients would benefit from psychological treatment, warning that actively avoiding chemicals "may only reinforce social withdrawal and disability without actually preventing any biological injury."8

Simon said he stands by his study and believes that the immunological explanation for MCS is "barking up the wrong tree." He does, however, believe that studying kindling and other neurological models will lead to progress.

Simon also stressed that he does no consulting or expert-witness work. "I don't believe you can maintain your objectivity."

Eyebrows raised when a draft of the Simon Study was released in 1991 to Seattle attorney Gary Keehn, who was defending Boeing in a chemical exposure case. The study wasn't published in medical journals until 1993.

Simon admitted it was an ethical violation, but explained that it happened when a member of his team gave Boeing's Health and Safety Institute a progress report on the study. A copy of a draft found its way to Keehn. "We made our objections about this quite clear," Simon said.

Baker maintains a wry sense of humor about the matter. "They (Boeing) might as well have seen it - they paid for it."

There is little humor, however, in the threatening letters being sent to Baker and other physicians who treat MCS patients from the state Department of Licensing, asking why they are prescribing "unapproved" immunological and neuro-psychological tests. Baker's patients believe he is being persecuted. "The man has put his neck out for us," said MCS sufferer Heidi Guevara, a former Auburn worker.
"L&I has undertaken a pattern and practice of trying to attack physicians over a difference of opinion," said Baker's attorney Randy Gordon, who notes that the state's inquiries do not stem from patient complaints.

"A clear motive is to stifle scientific inquiry and well-founded viewpoints for the purpose of advancing the litigation position of major employers in the state of Washington."

**Working In Tandem?**

That some researchers in the medical community work with industry is not a radical proposition.

In exploring these relationships, Johns Hopkins clinical psychology Professor Linda Davidoff writes that established standards for exposure to many chemicals are outdated and were developed by a "flawed scientific process that was heavily influenced by financially interested parties." Just because workers are exposed to "low levels" of chemicals, she says, doesn't necessarily mean they are safe.

Davidoff added that other chemically related illnesses were explained away in the past by "facile psychologic hypotheses," including an early analysis of sick building syndrome as a "mass psychogenic illness."

Davidoff and fellow researcher Grace Ziem explain that because of the financial stakes surrounding chemically related illnesses, industry and its insurers are supporting research that focuses on psychological explanations. "Such studies," Davidoff and Ziem write, "likely have influenced the thinking of professionals on this problem.

"Industry-funded studies, moreover, come to negative conclusions about occupational disease more frequently than do studies funded by other sources. If only psychologic and psychiatric problems arise from chronic [low-level] exposures, industry avoids expensive changes in manufacturing and marketing strategy, and insurers avoid liability."**10**

1 Archives of Environmental Health, Jan./Feb. 1993, 48/1, 6-12.
3 Environmental Research, Feb. 1993, 60/2, 295-319.
5 See, for example, Western Journal of Medicine, July 1990, 28-33.
8 Annals of Internal Medicine, July 15, 1993, 19/2, 97-103.
10 Archives of Environmental Health, Jan./Feb. 1992, 47/1, 88-91.