

Running head: MULTIPLE CHEMICAL SENSITIVITY

Multiple Chemical Sensitivity, Illness, and Culture: On the Margins of Health Care

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Introduction

A condition sharing some overlap with fibromyalgia, and considerable overlap with CFIDS (Buchwald & Garrity, 1994), but which is even less understood, less accepted, and more lacking in treatment options, is that of multiple chemical sensitivity or MCS. This condition is also referred to as chemical injury, and environmental illness. In MCS, the person through the process of induction, becomes sensitized to particular chemicals or classes of chemicals. Triggering then occurs when the person is re-exposed to these chemicals and negative symptoms are elicited (Ashford & Miller, 1991; Miller, 1996; Randolph & Moss, 1982). Over time the reactions spread to other classes of related chemicals and the experiencer may thus be caught in a cycle of increasing sensitivity and decreasing personal resources. Classes of chemicals implicated include solvents, perfumes, paints, pesticides, vehicle exhausts, and others (Bell, Schwartz, Peterson, & Amend, 1993). Reactions may be mild, but often are severe or even life-threatening. Included are reactions commonly recognized as allergic such as rhinitis, dermatitis, and anaphylaxis, but also neurological symptoms such as headaches, confusion, dizziness, irritability, and others. Digestive, endocrine, and neuromuscular effects are also reported.

Chemical poisoning is not new to toxicologists nor to practitioners of occupational medicine. Indeed some persons with MCS have been victims of industrial accidents or other large toxic exposures. Others, however, do not report one known exposure, but develop symptoms after chronic low level exposures, working in a sick building, or having a physical illness.

Two 1995 reports document MCS as a worldwide problem and one U.S. study (Meggs et al., 1996) found that 33% of a rural representative household population reported having illness symptoms from low level chemical exposures, with 4% reporting becoming ill every single day as a result.

Research on MCS is in the early stages, but several etiological hypotheses are being discussed in the medical literature. These include neurogenic inflammation, limbic kindling, compromised detoxification pathways, immunological dysregulation, and psychosomatic mechanisms. In limbic kindling, probably the dominant physiological hypothesis, persons are seen as having sensitized to low levels of chemicals through the olfactory nerve (Bascom et al., 1997; Bell, 1994; Bell, 1996; Bell, Miller, & Schwartz, 1992; Bell, Schwartz, Baldwin, & Hardin, 1996). Because of the ubiquitous nature of chemicals, the olfactory nerve eventually fires at levels of stimulation below the normal threshold for a response. Thus some persons may be responding through the olfactory system to chemicals not previously thought to have physical or behavioral effects at low levels. The unwanted limbic system stimulation could then dysregulate any number of bodily functions because of its involvement in emotion, eating, mood, immune competence, digestion, and other functions.

Detoxification pathways also may be a mechanism for MCS, as these persons often have damage to these pathways (Rogers, 1990) and chemicals are capable of disabling enzyme systems. In fact, some pesticides are designed with detox pathway damage as a goal in order for the toxin to remain in the bug's body long enough to do damage. An example of this would be the addition of piperinol butoxide which disables liver enzymes, to pesticides such as rotenone.

A variety of physiological hypotheses are supported by the research to some extent. No one clear pattern of harm has emerged across all patients. However, MCS samples have shown immune damage including altered T-cell ratios (Heuser, Vojdani, & Heuser, 1992), nasal pathology including inflammation and damage to the epithelium (Meggs, 1997; Meggs & Cleveland, 1993), pesticides in the blood (Rea, 1992), amino acid imbalances (Galland, 1987), autoimmune problems (Levin & Byers, 1992), sleep disturbances (Bell et al, 1996), and neurological indicators (Dudley, 1993; Heuser, et al., 1992).

The experience of MCS is one of progressive loss of functioning resulting in stifling limitations in lifestyle. Access diminishes as sensitivities spread to more and more substances, and persons participate in fewer activities and live in more restricted contexts as the condition progresses. The need for vigilance regarding exposures causes a loss of spontaneity, and makes any social interaction or outing cumbersome. Damaged social relations often result for several reasons. First, the person spends considerable time ill from exposures. Second, the need for chemical avoidance significantly reduces activities in contexts where exposures could occur. Third, friends, loved ones, acquaintances, and professionals often display ignorance and disbelief regarding the condition, further alienating the sufferer.

Early stages of MCS are often marked by a frantic search for medical care. Respondents in my ongoing study saw a mean of 8.6 physicians, and only a quarter of these were deemed to have been at all helpful by patients. Participants reported spending exorbitant amounts of money, experiencing considerable iatrogenic harm, and being perceived as not credible by both medical and psychological providers. Access to medical care is limited because of the perfumes, pesticides, and other chemicals present in medical facilities. This means that MCS patients are often unable to find help either for the MCS symptoms or for unrelated health problems should they occur. Respondents in my research reported difficulty finding physicians educated about MCS, safe offices, or someone to take their symptoms seriously. Consequently, many avoided any medical treatment, and 20 persons delayed treatment until their conditions had become medical emergencies.

The person coping with MCS may experience considerable emotional upset which may occur as a primary response to exposures (e.g., anxiety following exposure to solvents) (Dager, Holland, Cowley, & Dunner, 1987), or as secondary effects of loss (e.g., depression as a result of loss of job, friends, and hobbies). Confusion can result from misattributions, e.g.,

irritability as a result of an exposure may be attributed to a social variable with ensuing damage to personal relationships (Gibson, 1993).

The future is uncertain with a poorly understood condition that tends to spread, and for which persons often become disabled enough to be completely unable to work. Consequently, anxiety and fear regarding outcome are common elements of the MCS experience.

Why Do More Women than Men Get This Diagnosis?

Although men also have MCS, and particularly Gulf War veterans report these symptoms, there is an apparent preponderance of women among civilians diagnosed with or self-reporting MCS (Cullen, Pace & Redlich, 1992; Gibson, Cheavens, & Warren, 1996; Heuser et al., 1992; Kipen et al., 1992; Lax and Henneberger, 1995; Ross 1992). There are several possible explanations for this. Women are known to have less alcohol dehydrogenase, an enzyme that detoxifies alcohol as well as chemicals (Freeza et al., 1990). Women also have a mean smaller body mass than men, and, as allowances for chemicals in water and air are calculated for the "average person," smaller persons may be more vulnerable. In addition, women use more cosmetics and fragrances containing ingredients with known neurotoxic effects. For example, camphor, found in nail polish, perfumes, and other compounds, can damage the central nervous system, eyes, skin, and respiratory system. Women's work conditions in pink collar jobs expose them to high levels of these chemicals in co-workers' personal care products, as well as to high levels of xerox fumes, carbonless paper, pesticides, and chemical cleaners. A Danish study of work-related health complaints in over 4000 workers found gender, job category, photocopying, VDT use, and use of carbonless paper to be significantly associated with a high level of symptoms (Skov & Valbjorn, 1987, cited in Ashford et al., 1995).

Perhaps most salient of all in regard to gender is that dioxin-like chemicals such as pesticides and PCBs are known hormonal disruptors. At the cellular level they may be estrogen agonists or blockers, or testosterone blockers (Colborn, Dumanoski, & Myers, 1997). They thus affect women differently than men, and behave differently depending upon the

particular point in a hormonal cycle at time of exposure. Additionally, these chemicals are potentiative, as a recent study showed estrogen mimickers to be 1000 times as potent when two chemicals were combined (Arnold et al., 1996). Thus the hormone-disrupting activity of many common chemicals may place women at risk for effects that are both different from and more intense than those experienced by men.

What Is Missing from Our Knowledge Base?

Almost everything! We currently have no validation across studies of a physiological mechanism underlying MCS. Perhaps there are a variety of pathways through which the body sustains damage, with MCS as the final common pathway. Or perhaps some causal mechanism such as chemical exposure may trigger a variety of types of illness with MCS as only one possibility.

We have no long-term studies of persons with MCS to detail the phenomenology or course of the condition. We know nothing regarding who is at risk to develop MCS or why some persons with MCS improve while others deteriorate. This knowledge is needed in order to prevent the spread of MCS and to offer secondary and tertiary prevention to those who are already sensitized.

Also missing in regard to this condition is adequate toxicological information on most of the chemicals currently in use. Many substances in use have not been tested at all for health effects, almost none have been tested for combination effects, and very few have been looked at in relation to neurological effects. There are no toxicity data at all for over 39,000 commercial chemicals (Wilson, 1995, p. 2).

What is the Cultural Perception and Response to MCS?

Women as nondominants have had to struggle to have their narratives and health complaints taken seriously. But, some elements of the cultural response to MCS may be unique to this condition. Those injured by chemicals that are an integral part of U.S. economics face both gender relevant and additional obstacles. It is impossible to study chemically-induced illness as long as the greater culture maintains that low-level exposure

to chemicals cannot and does not induce illness. MCS is a health condition embedded in and subject to a chemically-dependent culture, with increasing dependence upon technology, less emphasis on the individual, and industry control of health care. Cultural response to MCS necessarily parallels response to issues of environment. Kidner (1994) has argued that the field of psychology has been mute about the environmental crisis because psychology is rooted in and sustained by the same paradigmatic understanding of the natural world that has engendered ecological damage in the first place – one that fosters a firm separation of person from context. Environment is generally ignored by psychologists, and normalcy in terms of personality is seen as behavior that is "congruent with the needs of the economic system" (p. 373). Numerous studies and publications document the human cost of environmental degradation, e.g., hormone mimickers such as found in pesticides may cause serious alteration in biology and behavior for many species of animals (Colborn et al., 1997). Yet psychology has failed to integrate this knowledge in spite of its relevance for human behavior. It is now recognized that it would be impossible for the earth to sustain worldwide the level of commoditization of resources now practiced by industrialized nations (Clark, 1995). In addition, the Western capitalist lifestyle requires the colonization of persons in poorer cultures in order to sustain its current standard of living (Shiva, 1993). Yet psychology has offered no critique of this lifestyle.

Given that a contextualized understanding of MCS requires the consideration of these broader issues, it is not surprising that health care providers may ignore, dismiss, or pathologize MCS. Detractors have dismissed MCS as chemophobia, depression, a symbolic blaming of chemicals for the angst of modern civilization, and somatoform disorder; heated controversy over etiology continues (Black, Rathe, & Goldstein, 1990; Brodsky, 1983; Davidoff, 1991; Davidoff & Fogarty, 1994; Simon, Katon, & Sparks, 1990; Terr, 1989).

Some progress, however, has been made in spite of this seemingly impossible situation. The Social Security Administration, Housing and Urban Development, and the Americans with

Disabilities Act do recognize this condition. Thus MCS is receiving validation outside of and in spite of conventional medical care. However, large scale change required that this condition be understood by the dominant culture, and we have many of the pieces in place for this to occur. For example, although chemicals have not been viewed as causes of human illness at levels in ambient air, many are known toxicants. Even traditional science that views itself as separate from and superior to environment must come to terms with results of its own accumulating research that suggests we are poisoning ourselves.

Where Does This Leave Us in Terms of Treatment?

There is currently no treatment for MCS that is seen as valid across medical specialties. Persons with MCS see a variety of practitioners depending upon illness characteristics, e.g., Heuser et al. (1992) report that a considerable number of their MCS patients have developed autoimmune disease, thus immunologists are consulted. Pulmonary specialists consult when primary symptoms are respiratory. Generally, physicians who believe that MCS is physiologically caused believe in chemical avoidance to delay the spread of sensitivities (Ross, 1992b; Ziem, 1992). Those who believe it is psychologically caused dispute this and encourage the patient to re-expose herself to chemicals in order to prevent social isolation and lifestyle change. A heated discussion of the ethics of this approach has occurred in the literature.

In the absence of an agreed upon protocol for treatment, patients self-care and consult alternative practitioners. Alison Johnson (personal communication) has studied treatments tried by persons self-reporting MCS, and results show that, other than chemical avoidance, generally no one treatment helps more than about a quarter of patients. Given the current state of knowledge and the cost of experimenting, Johnson has suggested that it might be prudent for patients to save their money until a truly effective treatment comes along. In the meantime we have a large number of debilitated people whose medical needs remain unmet by the conventional medical system.

Prevention would be a wiser strategy regarding MCS than is injuring people and fighting over how to treat them. However, as Winnow (1992, as cited in Wilkinson & Kitzinger, 1994)

has said of breast cancer prevention "Real prevention would mean changing fundamental social structures. It would mean going after the tobacco industry, stopping pollution of our environment, providing quality food" (p. 136). Preventing MCS requires the same, but conflicts with the economic goals of an industrialized culture. 9

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