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Chemical Sensitivities:  
Patients' Views for Improved Access in a Technological Society

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Multiple chemical sensitivity (MCS), also known as environmental illness (EI) and chemical injury (CI), is a little known disease. Most people are familiar with allergies, but few are aware of the serious reactions of some persons to common chemicals in our environment. Reactions to chemicals include headaches, cold or flu-like symptoms, skin reactions, muscle and joint pain, and serious neurological symptoms (Ashford & Miller, 1989; Bell, 1982; Lewith & Kenyon, 1985; Randolph & Moss, 1982; Rogers, 1986, 1988, 1990). People who are affected by these reactions vary across the spectrums of socioeconomic status, type of employment, age and ethnic background. The majority of persons identified with MCS are female. Pace and Redlich, Kipen et al., Ross ("Proceedings", 1992) and Heuser, Wojdani, and Heuser (1992) have all described samples that were made up primarily of women.

The types of reactions and the chemicals that MCS patients react to are innumerable. In the book Clinical Ecology (1982), Bell provided lists of both symptoms and common chemical stressors. Bell listed the skin, ears, nose, throat, eyes, muscles, respiratory system, cardiovascular system, gastrointestinal system, genitourinary system, and nervous system as areas both mildly and severely affected by the onset of MCS. Damage or complications in any of the areas may occur independently or in connection with problems in another area. Some common symptoms of MCS and reactions to chemicals include warmness, coldness, sweating behind the neck, nasal congestion, post nasal drip, hoarseness, intermittent deafness, blurring of vision, shortness of breath, pounding heart, weakness of muscles, and depression (Ashford & Miller, 1989; Bell, 1982; Lewith & Kenyon, 1985). Reactions can be caused by any number of chemicals, including those found in everyday substances such as perfume, smoke, pesticides, gasoline, carbonless paper, cleaning products, clothing detergent, plastic, medications, carpeting, and countless other seemingly necessary items.

The lack of knowledge about this disease affects the attention given to both the disease and the patients. A vicious cycle has begun with this lack of knowledge leading to a lack of publicity regarding the problem. Without publicity and research in this area, the general public, as well as the medical profession, remains uninformed about the causes and the effects of MCS. Consequently, little attention is given to the needs of the chemically sensitive. The prescribed advice of those treating the patients afflicted with MCS/EI/CI is often to avoid the chemicals and/or substances that result in reactions. Unfortunately, the universality of chemicals in the environment that potentially cause harm to this population makes avoidance difficult, if not impossible. Therefore, the choice for patients afflicted with MCS becomes to weigh the cost of painful physical and psychological reactions with the benefits of access to grocery stores,

shopping malls, restaurants, human contacts, and anything else that puts them at the risk of encountering a chemical stressor.

While the issue of access is a political and personal issue for persons with all types of handicapping disabilities, the lack of understanding of MCS/EI compounds the issue for this population (Gibson, in press). Specific solutions to problems cannot be put into effect or even proposed until the problem itself is accepted as valid. Until MCS is acknowledged and accepted as a true illness, this population will not have the opportunity to have their voices heard and their needs met on a level afforded to patients afflicted with other chronic illnesses. In addition to this obstacle, the denied access due to chemicals in the environment is so far reaching that the problem of avoiding or eliminating the offending substances becomes one so massive and difficult that it is often easier to leave this population to fend for themselves.

In her book The Allergy Problem: Why People Suffer and What Should Be Done, Rippere (1983) gathered comprehensive information on the lives of 85 severe allergy sufferers. In one of the chapters Rippere specifically looked at sufferers' views on social changes needed to alleviate some of the strain resulting from their condition. The three most common suggestions given by the participants in Rippere's study were more publicity in the media, greater public understanding and sympathy, and education of doctors and other professionals. Rippere concluded that respondents were aware of the need for social understanding as a precursor for social action.

The present study collected a comprehensive database on 305 self-identified MCS patients. The study sought to examine several variables including social support in MCS patients, limitations of MCS patients, and patients' views on what should be done in order to improve their current conditions. The question specifically asked was, "What do you think should be done in order to make life less difficult for those with MCS?". When questionnaires were returned, the responses were coded and summed. The results of the responses to this specific item represent the minimum number of participants for which these suggestions are an issue. Due to the open-ended formatting of the question, only those participants who specifically mentioned each suggestion voluntarily were included in the summation of the responses.

The most commonly mentioned response to this question was to educate the public and physicians. MCS patients reported being negatively impacted, and in some cases, discriminated against because of the lack of knowledge regarding their condition. The second most commonly mentioned response in our study was to acknowledge MCS/EI as a true illness. This was followed by compensation for victims of MCS. Other frequently mentioned suggestions included banning perfume, smoking, and pesticides in public; having the medical profession and others such as employers, friends, and family listen to victims of MCS; making public buildings and housing safe; having more research on MCS; providing more media coverage; and providing for notification of pesticide use (See Table 1).

It was hypothesized that the results gathered by Rippere (1983) on sufferers' views on needed social changes would be similar to the results gathered in this study on patients' views of what should be done. As shown in Table 2, the results of the two studies do parallel one another. There tends to be more focus on restrictions involving chemicals in the responses offered by the MCS patients, but this difference is easily understood when examining the nature of the illnesses. Chemicals introduced into the environment are the major cause of physical and psychological reactions of MCS victims. In fact, many victims were initially unaffected by chemicals in the environment until they were exposed to either massive amounts of a chemical or lesser amounts over a longer period of time. This explains some of the calls for greater restrictions and bans on harmful chemicals by MCS patients as opposed to allergy sufferers.

Several of the respondents reported their strategies for surviving in the current polluted environment. Of the 305 participants, 24% reported avoiding chemicals and harmful substances as a coping mechanism. Several others said that they posted signs or asked others to refrain from wearing perfumes, aftershaves, and other scented personal hygiene products in their presence. Another 17% said that the maintenance of a special diet such as a rotation diet was helpful in maintaining a standard of health. Many of the respondents claimed that a positive mental attitude or a sense of humor was essential to their survival and mental health. Some took more drastic measures. For example, a number of respondents reported sleeping outside in tents or shelters for some or all of the year, regardless of weather conditions. Some reported breathing through masks, respirators, or handkerchiefs to filter the air in unsafe areas.

One factor repeatedly mentioned was the need to prioritize activities. Chronic illness often limits activity level (Strauss, 1984), and our respondents reported the inability to complete tasks at the desired rate. Patients suggested handling this situation by prioritizing, and not overwhelming themselves. One respondent reported using an energy allotment technique with five or ten minutes of activity interspersed with rest periods. Another patient felt the need to become self-reliant in as many areas as possible including learning to grow her own food and sew her own clothing in order to avoid polluted urban areas.

Only 4% voluntarily mentioned more support groups in response to the question "What should be done in order to make life less difficult for those with MCS?". This, however, is misleading when considering the importance of support groups for patients with MCS. One reason this practice may have been overlooked by respondents is the prevalence of support groups in MCS communities and the networks of communication established by MCS patients within this population.

While the suggestions as to what should be done were numerous and widespread, the majority of people responding to the questionnaire (63%) voluntarily mentioned the need for

education of the public and of practicing physicians. This outcry for education by a chronically ill population should spark the interest of physicians and laypeople alike. Education, in combination with validation of the illness, can be relatively simply implemented, and can fulfill the main concern of the MCS population. Although not all of the suggestions and requests would be practical or possible to concede to, listening to the voices of the MCS population is the first major step toward a solution or cure for this "invisible" illness (Gibson, in press). Without the input of the sufferers themselves, the fundamental aspects of this illness will remain both unexposed and misunderstood by the medical profession and the general public.

## References

- Ashford, N.A., & Miller, C.S. (1989). Chemical sensitivity: A report to the New Jersey State Department of Health.
- Bell, I. R. (1982). Clinical Ecology: A new medical approach to environmental illness. Bolinas, CA: Common Knowledge Press.
- Gibson, P. [1993]. Multiple chemical sensitivities/environmental illness: Invisible disabilities. Women and Therapy, 14, 171-185. Also printed as a chapter in M.E. Willmuth & L. Holcomb (Eds.). [1993]. Women with disabilities: Found voices. NY: Haworth Press.
- Heuser, G., Wojdani, A. & Heuser, S. (1992). Diagnostic markers of multiple chemical sensitivity. In Multiple chemical sensitivities: Addendum to biologic markers in immunotoxicology. National Research Council. Washington, D.C.: National Academy Press. (pp. 117-138). Proceedings of the Association of Occupational and Environmental Clinics (AOEC) Workshop on Multiple Chemical Sensitivity. (1992). (Special issue). Toxicology and Industrial Health, 8(4).
- Randolph, T. G., & Moss, R. W. (1982). An alternative approach to allergies. New York, NY: Harper & Row.
- Rippere, V. (1983). The allergy problem: Why people suffer and what should be done. Wellingborough, Northamptonshire: Thorsons Publishers Limited.
- Rogers, S. A. (1986). The EI syndrome. Syracuse, NY: Prestige Publishers.
- Rogers, S. A. (1988). You are what you ate. Syracuse, NY: Prestige Publishers.
- Rogers, S. A. (1990). Tired or toxic? Syracuse, NY: Prestige Publishers.
- Strauss, A.L. (1984). Chronic illness and the quality of life. St. Louis, MO: C.V. Mosby Company.

Table 1  
Patients' Suggestions on What Should Be Done  
In Order to Make Life Less Difficult  
for MCS Patients

Educate public and physicians	63%
Acknowledge MCS as a true illness	30%
Compensation for victims	21%
Ban perfume in public	19%
Ban pesticides	16%
Make public buildings safe	16%
Ban smoking in public	15%
Provide safe housing	13%
Increase media coverage	11%

Based on 305 self-identified MCS patients.

**Table 2**  
**Comparison Between Suggestions of Allergy**  
**Sufferers and MCS Victims' Suggestions for What Should Be Done**

Suggestion	% of Rippere's allergy sufferers	% of our MCS respondents
Education of physicians and others	21%	63%
Acknowledgement as a true illness	9%	30%
Increase in media publicity	34%	11%
Government ban on dangerous products	7%	17%
Support groups	2%	4%

Based on 305 self-identified MCS patients and 85 allergy patients as identified in Rippere's book The Allergy Problem: Why people suffer and what should be done. (1983).