

1999 MCS consensus statement

This article was published in the May/June 1999 issue of Archives of Environmental Health, Vol. 54, No. 3, pp. 147–149.

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Multiple Chemical Sensitivity:
A 1999 Consensus

ABSTRACT.

Consensus criteria for the definition of multiple chemical sensitivity (MCS) were first identified in a 1989 multidisciplinary survey of 89 clinicians and researchers with extensive experience in, but widely differing views of, MCS. A decade later, their top 5 consensus criteria (i.e., defining MCS as [1] a chronic condition [2] with symptoms that recur reproducibly [3] in response to low levels of exposure [4] to multiple unrelated chemicals and [5] improve or resolve when incitants are removed) are still unrefuted in published literature. Along with a 6th criterion that we now propose adding (i.e., requiring that symptoms occur in multiple organ systems), these criteria are all commonly encompassed by research definitions of MCS. Nonetheless, their standardized use in clinical settings is still lacking, long overdue, and greatly needed—especially in light of government studies in the United States, United Kingdom, and Canada that revealed 2–4 times as many cases of chemical sensitivity among Gulf War veterans than undeployed controls. In addition, state health department surveys of civilians in New Mexico and California showed that 2–6%, respectively, already had been diagnosed with MCS and that 16% of the civilians reported an “unusual sensitivity” to common everyday chemicals. Given this high prevalence, as well as the 1994 consensus of the American Lung Association, American Medical Association, U.S. Environmental Protection Agency, and the U.S. Consumer Product Safety Commission that “complaints [of MCS] should not be dismissed as psychogenic, and a thorough workup is essential,” we recommend that MCS be formally diagnosed—in addition to any other disorders that may be present—in all cases in which the 6 aforementioned consensus criteria are met and no single other organic disorder (e.g., mastocytosis) can account for all the signs and symptoms associated with chemical exposure. The millions of civilians and tens of thousands of Gulf War veterans who suffer from chemical sensitivity should not be kept waiting any longer for a standardized diagnosis while medical research continues to investigate the etiology of their signs and symptoms.

AS RESEARCHERS AND CLINICIANS with experience in the study, evaluation, diagnosis, and/or care of adults and children with chemical sensitivity disorders, we support the stated goal of the National Institutes of Health 1999 Atlanta Conference on the Health Impact of Chemical Exposures During the Gulf War “to fully characterize the nature of multiple chemical exposures

within the Gulf War veteran population and to relate this characterization to what is known about Multiple Chemical Sensitivity (MCS) and related conditions and disorders within civilian populations.”(1) Based on research conducted by state and federal government agencies, we already know that MCS is one of the most commonly diagnosed chronic disorders in civilians and the most common—but still largely undiagnosed—disorder of any kind in Gulf War veterans of the United States.

In statewide telephone surveys of randomly selected adults, conducted by health departments in California in 1995 and 1996 and New Mexico in 1997, investigators found that 6% of adults in California(2) and 2% of adults in New Mexico(3) indicated that they had already been diagnosed with MCS or Environmental Illness, whereas 16% in both states said they were “unusually sensitive to everyday chemicals.” When randomly selected adults in other states were asked if they were “especially sensitive” (instead of “unusually” sensitive), one-third consistently maintained that they were. (4–6)

Among Gulf War era veterans, data from the largest random survey presented by the U.S. Department of Veterans’ Affairs (VA) in 1998 (based on questionnaires completed by 11 216 deployed to the Gulf and 9 761 nondeployed) show that 5% reported chemical sensitivity among the nondeployed personnel and 15% reported the same among the deployed.(7) Other VA researchers report much higher rates—but the same 3-fold difference—in a smaller random sample of VA hospital outpatients: 86% of ill veterans deployed to the Gulf complained of chemical sensitivity, compared with 30% of undeployed ill veterans.(8) In the only study in which MCS was specifically assessed among veterans selected randomly from the VA Registry, investigators found 36% of 1 004 met common research criteria for MCS.(9) Among randomly selected Department of Defense (DOD) personnel who remain on active duty, two larger studies by the Centers for Disease Control found slightly lower—but still significant—2.1- and 2.5-fold increases in the prevalence of self-reported chemical sensitivity among those deployed to the Gulf, compared with those who were not deployed. In the “Iowa” study, in which the prevalence rates for deployed and nondeployed individuals were 5.4% and 2.6%, respectively, investigators used a detailed questionnaire to assess “probable MCS.” (10) In the “Pennsylvania” study, (11) in which prevalence rates were 5% versus 2%, respectively, only one “yes/no” question was asked about chemical sensitivity. Canadian Gulf War veterans reported only approximately one-half the prevalence of MCS (2.4%), but nevertheless this was 4 times more than their controls. (12) Even in the United Kingdom where MCS is little known, Gulf War veterans report being diagnosed with MCS at 2.5 times the rate of military controls. (13)

Clearly, there is a significant need for a standardized clinical definition of MCS and a comprehensive clinical protocol that VA, DOD, and other physicians can use to evaluate it. We recommend to our colleagues and the sponsors of the Atlanta Conference—the Department of Health and Human Services’ Office of Public Health and Science, the Centers for Disease Control and Prevention, the National Institutes of Health, and the Agency for Toxic Substances and Disease Registry—that MCS be formally defined for clinical purposes by the top 5 “consensus criteria” identified in a 1989 survey of 89 clinicians and researchers who had extensive experience in MCS but who also held widely divergent views about its etiology.(14) Included were 36 specialists in allergy, 23 in occupational medicine, 20 in “clinical ecology,” and 10 in internal medicine and otolaryngology. We would add only that symptoms associated

with chemical exposures must involve multiple organ systems, thus distinguishing MCS from specific single-organ system disorders (e.g., asthma, migraine) that also may meet the first 5 criteria.

Consensus Criteria for MCS

The following consensus criteria for the diagnosis of MCS were gleaned from the study by Nethercott et al. (14) (funded in part by grants from US NIOSH and US NIEHS):

1. “The symptoms are reproducible with [repeated chemical] exposure.”
2. “The condition is chronic.”
3. “Low levels of exposure [lower than previously or commonly tolerated] result in manifestations of the syndrome.”
4. “The symptoms improve or resolve when the incitants are removed.”
5. “Responses occur to multiple chemically unrelated substances.”
6. [Added in 1999]: Symptoms involve multiple organ systems.

Given the only other explicit consensus ever published on MCS—the 1994 statement of the American Lung Association, American Medical Association, U.S. Environmental Protection Agency, and U.S. Consumer Product Safety Commission, that “complaints [of MCS] should not be dismissed as psychogenic, and a thorough workup is essential” (ALA 1994)—we recommend that MCS be diagnosed whenever all 6 of the consensus criteria are met, along with any other disorders that also may be present, such as asthma, allergy, migraine, chronic fatigue syndrome (CFS), and fibromyalgia (FM). MCS should be excluded only if a single other multi-organ disorder can account for both the entire spectrum of signs and symptoms and their association with chemical exposures, such as mastocytosis or porphyria, but not CFS or FM, which are not so associated.

To assist physicians who are unfamiliar with the evaluation of MCS, we recommend that clinical protocols include validated questionnaires for screening and characterizing chemical sensitivity,(15,16) a list of overlapping disorders to consider in the differential diagnosis of MCS, and a list of signs and test abnormalities associated with MCS in the peer-reviewed literature (summarized by Ashford and Miller(17) and Donnay(18)). Although no single test is yet considered diagnostic of MCS, those suggested by signs, symptoms, or history may be helpful in treating and tracking the disorder.

The presentation of MCS may vary greatly among cases and over time. Some individuals are totally disabled by severe symptoms suffered on a daily basis, for example, whereas others are disabled only minimally by mild symptoms suffered occasionally. We, therefore, recommend that any clinical diagnosis of MCS be characterized and followed over time using quantitative and/or qualitative indices of life impact or disability (e.g., minimal, partial, total); symptom severity (e.g., mild, moderate, severe); symptom frequency (e.g., daily, weekly, monthly); and sensory involvement (identification of which sensory pathways—olfactory, trigeminal, gustatory, auditory, visual and/or touch, including perception of vibration, pain and heat or cold—show altered (+/-) sensitivity and/or tolerance for normal levels of stimuli, either chronically or in response to particular chemical exposures).

For research purposes that require greater homogeneity, we encourage investigators to refine the consensus criteria for MCS with whatever additional inclusion or exclusion criteria they believe are needed to test their hypotheses. The indices and domains that are used to characterize and select both cases and controls in MCS research should be fully reported so that results from different studies can be compared and their broader applicability assessed.

Given the significant overlap in clinic populations of MCS with both CFS and FM, as well as the need to better understand the relationships between these disorders,(19–21) we recommend that all “solicitations” and “requests for applications” issued by federal agencies for human research into any one of CFS, FM, or MCS direct investigators to screen for all three (regardless of their selection criteria, which need not be affected) and to report their results in these terms. There is a precedent for this: The National Institute of Arthritis and Musculoskeletal Disorders routinely requires that in studies of fibromyalgia investigators must screen for and report any overlap with temporo-mandibular joint disorder. CFS, FM, and MCS research could all benefit from greater collaboration, and so we welcome the Congressional initiative of Senator Tom Harkin to earmark \$3 million of the DOD’s 1999 Gulf War illnesses research budget for multidisciplinary studies of CFS, FM, and MCS together (solicitation 074&&&-9902-0005 issued 2/12/99) to better understand both their overlaps and differences. We recommend that such three-way studies be solicited by all federal agencies funding CFS, FM or MCS research.

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