Notes of A.M.I.C.A. for the Australian NICNAS Working Draft Report

NICNAS Working Draft Report:
http://www.health.gov.au/internet/main/publishing.nsf/Content/ocs-mcs-draftreport-cnt.htm

The Role of NGF

In the NICNAS Working Draft Report we couldn't find any quotations of the studies that underline the role of NGF, VIP and SP in the diagnosis of MCS.

In particular in Sweden, at the Karolinska Intitute, Dr Eva Millqvist uses regularly the NGF challenge test to diagnosticate the respiratory chemical sensitivity.

Eva Millqvist, Ewa Ternesten-Hasséus, Arne Ståhl, and Mats Bende, Changes in Levels of Nerve Growth Factor in Nasal Secretions after Capsaicin Inhalation in Patients with Airway Symptoms from Scents and Chemicals, Environ Health Perspect. 2005 July; 113(7): 849–852.
Full Text: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1257644&blobtype=pdf

Also in Japan Dr Kimata noted an increase of NGF, VIP and SP in the nasal lavage fluid of self-reported MCS sufferers.

Hajime Kimata, "Effects of Exposures to Organic Volatile Compounds to the levels of NGF (Nerve Growth Factor) and Histamine in Patients with Self-reported MCS", International Journal of Hygiene and Environmental Health, vol. 207 (2004).

Most interestingly, the same scientist found out that the exposure to electro magnetic fields, such as the one from mobile phones, can increase the dermatological allergic responses. This can explain, for example, the intermittence of symptoms, since the multi-factorial exposures to chemicals, EMF and other stressors can trigger in a different way the symptoms.

Kimata Hajime, Enhancement of allergic skin wheal responses by microwave radiation from mobile phones in patients with atopic eczema/dermatitis syndrome, International archives of allergy and immunology 2002;129(4):348-50.

The increase of NGF is observed also in atopic dermatitis which may explain the dermatological symptoms in MCS patients.

M. Toyoda , M. Nakamura , T. Makino , T. Hino , M. Kagoura and M. Morohashi, Nerve growth factor and substance P are useful plasma markers of disease activity in atopic dermatitis, British Journal of Dermatology, Volume 147 Issue 1, Pages 71 - 79, 3 Jul 2002
Full Text: http://www3.interscience.wiley.com/cgi-bin/fulltext/118938473/PDFSTART

WHO and Idiopathic Environmental Intolerance (IEI)

The NICNAS Working Draft Report quotes several times (p. 9, 14, 58) the definition of Idiopathic Environmental Intolerance (IEI) as it was suggested by the World Health

Organization or by the IPCS. Actually, we read on the Report written by Nicholas Ashford and Claudia Miller for the State of New Jersery, which is published under the title of "Chemical Exposures: Low Levels and High Stakes", 2nd Edition (Hardcover - Jan 8, 1998), that the MCS Workshop in Berlin was signed by a great controversy for the presence of experts with a heavy conflict of interest.

The new definition of IEI was supported only by some – and not all - participants of the workshop and it was not a general consensus. At the end of the workshop, about 80 researchers (not of clinical ecology) wrote to the IPCS asking to stop the writing of the conclusions of the workshop and the IPCS noted on the final report that "The document does not reflect the decision or the position of the UNEP, ILO or WHO; that it can not be considered an official publication and, thus, it can not be criticized, summarized or quoted without the written permission of the Director of IPCS".

Soon afterwards, the WHO wrote a note to the participants of the workshop that the new definition of MCS was not supported by WHO. Nonetheless, the conclusions presenting the new definition of MCS, Idiopathic Environmental Intolerance (IEI), were published as Anonymous by Regulatory Toxicology and Pharmacology, whose editorial direction admitted that received such conclusions by the Environmental Sensitivities Research Institute (ESRI), an organization financed by the industry (source: Nicholas Ashford and Claudia Miller's book).

So we believe it is very important to quote the facts as they are: the WHO does not support the IEI definition.

Conflict of Interest

Very similarly, we, as organization of MCS patients, strongly react when we see the quotation of studies and researches done by doctors who have a conflict of interest. The NICNAS Working Draft Report quotes, for example, Staudenmayer on pag. 11, 19, 20, 30, and Sparks on pag. 13, 16, 21, 24, 25, 26, 36, 38 without any disclosure about their financial interests.

We read on Nicholas Ashford and Claudia Miller's book and on several articles that such doctors worked as consultants of the industry in the legal actions promoted by MCS sufferers who ask for compensation for the chemical injury caused by exposures at work or by exposures to products containing toxic or sensitising chemicals.

The psychogenic origin of MCS

In particular, there is a strange coincidence that doctors, with conflict of interest, support the psychogenic origin of MCS. In Nicholas Ashford and Claudia Miller's book we read on that many studies supporting this pathogenesis have been strongly criticizes for the design and methodology used.

In particular, we read that Staudenmayer and Selner concluded that MCS has a psychiatric origin using challenge tests without explaining:

- if the cases were in a dis-adaptation state (in order to exclude the false positive outcomes or the false negative ones caused by precedent exposures to similar compounds to the ones used in the challenge test);
- if there were confirming tests to distinguish the placebo challenge and the chemical challenge;
- and if there was enough time laps (one week at least) between one challenge test and the next one in order to prevent the false negative caused by the adaptation state.

Ashford and Miller also remind us that Black was criticized by Galland (1990) because many of the chemically injured patients he visited had never shown any psychological symptom before the Environmental Illness onset. Moreover, according to Galland, Black's study did not consider that who looses his/her own job or who is hospitalized for any kind of illness shows a higher score of psychopathologic symptoms, compared to healthy subjects.

We also would like to stress the importance of two studies you quoted by Ann Davidoff and Linda Fogarty who found out that the use of Psychological/Psychiatric test, such as the Minnesota Multiphasic Personality Inventory (MMPI), is not useful in determining the pathogenesis of MCS. The discovery of any Psychological/Psychiatric symptom, in fact, could be explained both as the effect of an organic illness both as the impact of an organic illness on the quality of life. At the same time, the presence of any Psychologic/Psychiatric symptom before the onset of MCS could be explained as early manifestation of the organic illness or as a predisposition factor. These two researches were reviewed and commented by the Journal of Occupational and Environmental Medicine, which is the official publication of the American College of Occupational and Environmental Medicine (ACOEM).

Given this evidence, your project for a longitudinal study is very important in the understanding of the illness, but, in our opinion, it also needs to be coupled by a toxicological assessment of the chemical exposures during life and by the genetic polymorphism of the metabolism of xenobiotic compounds.

A.L. Davidoff et al., *Psychiatric Interferences from Data on Psychological/Psychiatric Symptoms in Multiple Chemical Sensitivity Syndrome*, archives of Environmental Health, May-June 2000, vol.55 n.3.
A. Davidoff e L. Fogarty, *Psychogenic Origins of Multiple Chemical Sensitivities Syndrome: a Critical Review of the Research Literature*, archives of Environmental Health (1994) 49(5):316-325.

Recently the Research Advisory Committee on Gulf War Veterans of Boston University School of Public Health, created by the Congress, recognized the Gulf War Syndrome as a physical illness and it has many features in common with MCS.
The full report is available on the Internet:

http://sph.bu.edu/insider/images/stories/resources/annual_reports/GWI%20and%20Health%20of%20GW%20Veterans_RAC-GWVI%20Report_2008.pdf

The Genetic Polymorphism

Regarding the role of the genetic polymorphism in MCS, we strongly recommend Dr Haley's research on the Gulf War veterans.

Haley, RW, Billecke, S, & La Du, BN, Association of low PON1 type Q (type A) arylesterase activity with neurologic symptom complexes in Gulf War veterans, Toxicology and Applied Pharmacology (1999), 157(3):227-33. http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6WXH-45FK0P4-53&_user=10&_rdoc=1&_fmt=&_orig=search&_sort=d&view=c&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=b1edfdc210134b1cc841feb1bb4c732d

In 2007 we promoted a pre-study about the genetic polymorphism in 35 Italian patients with diagnosis of MCS. The tests were performed by Dr Gabriella Scordo of the University of Uppsala and the outcomes are not published yet, but we offer you the results of the texts in attachment. You can clearly notice the prevalence of slow acetylators.

Systemic Lack of Knowledge of Toxicology and of Environmental Factors in Medicine

In our experience the medical practice, at least in Italy, doesn't consider enough the knowledge of environmental medicine, toxicology and especially neuro-toxicology. Even when the physicians have a certain competence in acute poisonings, it's much more difficult the recognition of the effects of a past exposure or of a chronic poisoning.

All modern medicine is designed to treat the symptoms rather than to find the causes of illnesses, mostly because medical research is founded by the chemical industry. This social condition of scientific progress poses a serious concern in the capacity of our society to deal with chemical related injuries, such as MCS.

Neuro-Toxicology

A study by Satoshi Ishikawa and Mikio Miyata stresses the importance, in the diagnosis of MCS, of several neurophysiological tests that show a damage in the central nervous system: pupillographic test, visual contrast test, slow-motion pupillographic test. This study was sponsored by the Ministry of Health who promoted the collaboration of the Japan Commission for MCS with the Environmental Health Center of Dallas of Dr William J. Rea. The same study underlines the importance of toxicological tests on the patient and in his/her house.

Satoshi Ishikawa, Mikio Miyata, *Chemical Sensitivity and Its Clinical Characteristic in Japan*, Asian Medical Journal 43(1): 7-15, 2000.

In the NICNAS Working Draft Report we can not find some relevant studies about the use of the SPECT Scan in the diagnosis of cerebral damage in chemically injured patients.

Simon TR, Hickey DC, Rea WJ, Johnson AR, Ross GH. Breast implants and organic solvent exposures can be associated with abnormal cerebral SPECT studies in clinically impaired patients. Radiology (1992) 185:234

Callender TJ, Morrow L and Submaranian K. Evaluation of chronic neurologic sequelae after acute pesticide exposure using brain SPECT scans. Journal of Toxicology and Industrial Health (1994) 41:275-284

Heuser G, Mena I and Alamos F. Neurospect findings in patients exposed to neurotoxic chemicals. Toxicology and Industrial Health (1994) 10 (4/5):561-571
Ross GH. Neurotoxicity in Single Photon Emission Computed Tomography brain scans of patients reporting chemical sensitivity. Toxicology and Industrial Health (1999) 15:415-420

Immunological tests

We also would like to remind a collection of studies about the role of allergy to metal in chemical sensitivity. The Lymphocytes Transformation Test LTT-Melisa shows the reaction of Lymphocytes to metals. This kind or systemic allergy can explain both MCS and autoimmunity disorders.

Stejskal J, Stejskal V., The role of metals in autoimmunity, Neuroendocrinology Letters 1999; 20:351-364 http://www.melisa.org/pdf/Mercury-and-autoimmunity.pdf

Stejskal, V, et al., Metal-specific lymphocytes: biomarkers of sensitivity in man, Neuroendocrinology Letters 1999; 20:289-298 http://www.melisa.org/pdf/biomark.pdf

Regland B, Zachrisson O, Stejskal V, Gottfries CG., Nickel Allergy Is Found in a Majority of Women with Chronic Fatigue Syndrome and Muscle Pain- And May Be Triggered by Cigarette Smoke and Dietary Nickel Intake, Journal of Chronic Fatigue Syndrome, Vol. 8(1) 2001
http://www.melisa.org/pdf/cfs_nickel.pdf

Another study by Alberto Migliore from Rome shows a co-morbidity between MCS and Sjögren's syndrome.

Migliore A, Bizzi E, Massafra U, Capuano A, Martin Martin LS., (Department of Rheumatology at San Pietro-Fatebenefratelli Hospital and Centro Ricerche, Association Fatebenefratelli for Research, Rome), *Multiple chemical sensitivity syndrome in Sjögren's syndrome patients: casual association or related diseases?*, Arch Environ Occup Health. 2006 Nov-Dec;61(6):285-7.

Recognition of MCS in the World

The claim of the NICNAS Working Draft Report that “MCS is not recognised as a classified disease identity in any country in the world”, leaves us dubious because we know that MCS is recognized by several governmental agencies, local states and administrations in USA, as we read on Dr. Albert Donney’s website: http://www.mcsrr.org/factsheets/mcsrecog.html and http://www.mcsrr.org/fedmcsgroup/fedmcsrec.html

Moreover, since 1998 several Governors of U.S. States sign the Proclamation of May as the Month for the Awareness and Education about MCS and year by year they are always more, as you can read on the website: http://www.mcs-america.org/index_files/proclamations.htm

In Italy MCS was recognized in 2005-2006 as an illness identity by four regions, until last September the National Council of Health, the scientific arm of the Italian Ministry of Health, gave a negative opinion about such recognition for the lack of a specific test. Now we do not know what will happen to the local recognitions. We suspect problems of conflict of interest in some of the doctors who were called to decide about MCS. In Italy, as many will know, the law about conflict of interest is very weak so this is mainly a moral, rather than a legal, problem.

In our experience MCS is a descriptive diagnosis just like other descriptive diagnosis, such as Chronic Headache or Autism, and the legal recognition of it as the disabling condition – for a compensation legal action or for a disability pension - considers all the chronic illnesses and complaints that it is possible to demonstrate with tests.

So, in our opinion, the lack of recognition of MCS is mainly a political issue that is influenced by financial interests because the practice - in medical, insurance and legal terms - already considers MCS as real illness on an individual basis.

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