

Running head: MULTIPLE CHEMICAL SENSITIVITY

Invisible Disabilities and Social Action: The Case of Multiple Chemical Sensitivity

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Abstract

Multiple chemical sensitivity (MCS), also known as environmental illness (EI), and chemical injury (CI), is a condition in which persons experience illness reactions from low levels of exposure to chemicals such as perfumes, pesticides, solvents, paints, and formaldehyde. The majority of civilians with MCS/CI appear to be women although Gulf War veterans report similar symptoms. The purpose of this study is to explore and understand environment-related social activism in a sample of persons self-identified with this invisible disability. This paper profiles activist involvement in a sample of 209 persons, 82% women, using an instrument designed specifically for this study (The MCS Activism Scale). Persons in the study had done personal reading ($n = 207$), attended support groups ($n = 117$), engaged in letter-writing campaigns ($n = 117$), organized others on environmental issues ($n = 67$), been officers in support groups ($n = 48$), advocated for legislation ($n = 47$), and edited newsletters ($n = 27$). Significant educational materials, as well as considerable legislative actions, have appeared as a result of work by those who experience MCS/CI. An abundance of support groups and networks have also been founded. MCS activists have used a variety of resources and channels to communicate their works and accomplishments in order to increase public awareness of environmental hazards in spite of considerable opposition from dominant patriarchal structures that construct chemicals as safe and delegitimize persons injured by such.

Invisible Disabilities and Social Action: The Case of Multiple Chemical Sensitivity

Introduction

Multiple chemical sensitivity (MCS), also known as environmental illness (EI), and chemical injury (CI), is a condition in which persons experience illness reactions from low levels of chemical exposure. Common incitants include perfumes, pesticides, solvents, paints, formaldehyde and many others. Reactions vary from mild to life-threatening, and can effect any bodily system. Currently, MCS/CI is recognized as a disability by the Social Security Administration, the Department of Housing and Urban Development, and the Americans with Disabilities Act.

Medical research concerning MCS is in its infancy, and much controversy exists in the literature regarding the nature, prevalence, and etiology of this condition. There are currently multiple theories as to etiology including limbic kindling (Bell, 1992; Bell, Miller, & Schwartz, 1992; Miller & Ashford, 1992), increased airway resistance (Meggs & Cleveland, 1993), immunological mechanisms (Meggs, 1992), damaged detoxification pathways (Rogers, 1990), acquired porphyria (Baker, 1994), and psychological mechanisms (Black, Rathe, & Goldstein, 1990; Brodsky, 1983; Simon, Katon, & Sparks, 1990; Terr, 1989). However, acceptance of MCS as a legitimate physical disorder/disability by the conventional medical community has yet to occur. Consequently, persons with MCS are left to cope on their own with a poorly understood, progressively disabling condition. The necessity of avoiding chemicals (Ziem, 1992) often dictates a life of isolation with decreasing access and increasing difficulties at work and in social relationships (Gibson, Cheavens, & Warren, 1996; Gibson, Cheavens, & Warren, under review).

For reasons that are poorly understood, the majority of civilians with MCS appear to be women (Cullen, Pace & Redlich, 1992; Gibson et al., 1996; Heuser, Wojdani & Heuser, 1992; Kipen et al., 1992; Meggs et al., 1996; Ross, 1992), although Gulf War veterans report similar symptoms (Miller, 1996). Consequently, there is a growing community of predominantly women who report very serious illness for which legitimization, support, and medical interventions are lacking. In our industrial, chemical-dependent culture, governmental legislation, the orientation of the medical community, and information supplied to the media and public are dictated by corporate interests. The result is that those harmed by chemical technologies receive neither relevant information nor treatment. Glendinning (1990) has identified persons injured by chemicals as survivors of technology, along with veterans of atomic warfare, victims of industrial accidents, and users of the Dalkon Shield. Glendinning has traced the journey of the technology survivor who experiences loss of hope, loss of help from others, loss of faith in previously respected institutions, and even loss of a personal sense of heroism since personal response to and control over life become so limited. But Glendinning has described ways in which technology survivors transform their dramatic losses into valuable experiences of helping both self and others. Once

these survivors come to terms with what they cannot change, they begin to accept their condition, to an extent. With this acceptance, they can begin to care for and help themselves. According to Glendinning, the first step for most technology survivors is to educate themselves about their injury and its causes. Once an understanding is reached, survivors then tend to form social networks in order to educate and support one another. Manzo and Weinstein (1987), found that those who were harmed by the environment were more likely to become activists. By virtue of having the chemical injury thrust upon them, the person with MCS has a perspective that may engender advocacy for and empowerment of others. The actions taken by this marginalized group are vital elements in providing public awareness regarding the dangers of everyday chemical exposures that effect our entire population.

Purpose, Goals, Objectives

The purpose of this study is to explore and understand environment-related social activism in a sample of persons self-identified with this invisible disability. These persons represent a new subculture of environmental activists who engage in education and advocacy in spite of, in some cases, monumental personal obstacles. This paper profiles activist involvement in this sample using an instrument designed specifically for this study (The MCS Activism Scale). We also explore correlates of activism and display products of MCS activists including pamphlets, books, newsletters, and educational manuals. In order to maintain confidentiality for our research participants, some materials are prepared by persons in this study and some are the work of others.

Methodology

Participants

Participants are 209 persons self-identified with MCS/CI who responded to ads requesting persons to complete a mail survey relevant to their condition. Notices were sent to support groups, physicians' offices, and to newsletters and other publications aimed at persons with MCS.

Measures

Demographic indicators (including gender, ethnicity, income, employment status, and relationship status) and illness characteristics (including severity of condition, years ill, course of illness, and age became ill) were collected as part of a larger, ongoing study. Also measured was level of activism on an 18-item scale designed for this study (see Table 1). Included were items ranging from reading about MCS and attending support groups to more intensive types of work such as doing research, establishing support groups, and editing newsletters and books.

Procedure

Respondents returned mail surveys that were handled in a confidential manner by removing all identifying information and storing names and addresses in a locked closet accessible only to

the researchers. Careful measures were taken in order to insure the safety of participants by packing the surveys in baking soda before use to remove any chemicals or odors produced through photocopying. Data were analyzed using SPSS.

Results

Respondents are 82% women, primarily Caucasian but include 10 Native Americans, 2 Latina/Latinos, and 2 Asians. Persons had been ill a mean of 14.7 years, and had a mean personal income of \$13,900. Ninety-nine reported that their injury resulted from one identifiable chemical exposure, and 60 reported that this occurred in the workplace.

Mean activism score for this sample is 6.9 ($SD = 3.9$) on the MCS Activism Scale. Scores ranged from 0 to the highest possible score of 18. Most persons had done personal reading ($n = 207$), over half had attended support groups ($n = 117$) and engaged in letter-writing campaigns ($n = 117$). More intensive advocacy included organizing others on an environmental issue ($n = 67$), being an officer in a support group ($n = 48$), advocating for legislation ($n = 47$), and editing a newsletter ($n = 27$). Table 1 lists the percentage of respondents who engaged in each activity. Level of activism was not significantly related to age, gender, income, length of illness, or course of illness. Activism correlated significantly positively with education ($r = .24$, $p = .000$), severity of condition ($r = .25$, $p = .000$) with persons more severely injured engaging in higher levels of activism, and with having lived in unusual circumstances such as a tent, trailer, porch, or car ($r = .24$, $p = .001$). Activism correlated significantly negatively with working outside of the home ($r = .25$, $p = -.17$), with persons able to work being less active than those unable to work.

Participants engaged in activities aimed toward educating the public about chemicals in ambient air, passing legislation to protect the public from negative effects of common chemicals, mandating education of medical personnel in regard to toxicology, improving health care service delivery for persons with chemical sensitivities, and, most importantly, acquiring both recognition of the condition chemical sensitivity/injury in the mainstream medical community and training physicians regarding treatment of the problem.

Discussion

Our work indicates that significant educational materials, as well as considerable legislative actions have appeared as a result of work by those who experience MCS/CI. An abundance of support groups and networks have also been founded. Activists who have experienced first-hand the harm to health from toxic chemical exposures are in positions to advocate for prevention of further spread of this condition, and to in some cases make the toxicology literature accessible to the greater public. MCS activists have used a variety of resources and channels to communicate their works and accomplishments in order to increase public awareness of environmental hazards. Some examples of channels used include web sites, radio

spots, and television interviews. For the ever-growing population of MCS survivors the lesser activism among those employed outside the home may be accounted for by most of their available energy being channelled into maintaining jobs that involve ongoing exposures and other challenges relating to their disabilities. The relationship between level of activism and severity of condition is consistent with the finding by Manzo and Weinstein (1987) that those who are harmed by the environment are more likely to be active. Some persons find new motivation and make significant contributions through becoming politically active in the emerging grassroots movement of persons with chemical injuries. As Glendinning has stated, these technology survivors first become empowered through self-education, and then extend this educational process to others.

This work gives attention to the voice of a marginalized group consisting primarily of women, who have been either ignored, or delegitimized with mental health labels by patriarchal health care systems. Persons who experience chemical injuries are the most qualified persons to help others understand the condition. Yet, in the case of MCS/CI, powerful dominant interests purposely counter messages from this disabled community with false assurances of safety, and situate the chemically injured as somaticizers. Economic interests dictate that in order to continue a chemical-dependent lifestyle, we must not acknowledge culpability for negative health effects from chemicals. Conventional medicine is unable to help because it is part of the dominant economic/industrial structure that adopts and supports technologies in the name of production, regardless of the consequences of those technologies. Some of these technologies (e.g., nuclear power) are associated with consequences that will be salient for thousands of years (Mander, 1991; Mies, 1993). Persons disabled by chemicals are thus in conflict with the dominant epistemology that values only measurable commodities, transmuting human effort into "labor", the natural world into "natural resources" or "raw materials", and acts of caring for others into "women's work." Health is measured against profit in "risk assessment", and human health and natural ecosystems are seen as fair trade-offs for convenience and increased production.

A socialist feminist analysis reminds us that ways of thinking depend upon mode of production. One needs only to observe media advertisements for chemicals to see that, in the West, they are constructed as bringing convenience, saving lives, and improving our ability to provide and transform "resources" ("ADM, supermarket to the world"). Thus any construction of chemicals as problematic in any way, let alone as causes of illness is proscribed.

Consequently, the far-reaching influences of the chemical industry have rendered those suffering from chemical injuries as some of the only voices able and willing to provide information and motivate others to fight for a healthy, non-toxic environment. The mounting consequences brought about by thousands of volatile chemicals (many poorly tested with

unknown side effects) call for immediate action to insure our safety in the future. This process of activism was articulated by Wilkinson and Kitzinger (1994) who cited Winnow (1992) in relation to breast cancer prevention: "Real prevention would mean changing fundamental social structures. It would mean going after the tobacco industry, stopping the pollution of our environment, providing quality food" (p. 136).

The person injured by chemicals experiences first hand the unforeseen consequences of a Western industrial colonizing culture. Chemical sensitivity/injury is thus a warning to and a critique of the Western obsession with production and profit. Ironically, this is a condition that prohibits any continuance of a chemical-laden lifestyle for those who experience it. A feminist future must include respect for invisible as well as visible disabilities, regardless of whether they challenge dominant economic paradigms. Chemical injuries deserve to be included in feminist study, and require the questioning of practices that have been made invisible through their normalization in an industrial culture. Social action by persons with MCS/CI facilitates this goal and promotes a healthier environment, as described in the following example:

Toni Temple was attending college and receiving good grades, working full time as management director for three state trade organizations, raising her children, and participating actively in her community. After an exposure to zinc chloride through furnace ductwork in her home, Ms. Temple's life changed drastically. Although she is totally disabled, suffers from afflictions other than MCS, and can only leave her home with a respirator, she still manages to remain active in the MCS community. She is currently trying to head a National Campaign called "Healthier Hospitals on the Horizon," which came about from her publication "Healthier Hospitals" (Temple, 1996). Ms. Temple founded the Ohio Network for the Chemically Injured, and is currently active in the National Coalition for the Chemically Injured. She has written numerous articles for newsletters and other publications, such as "New Meaning for Access," and has also appeared on television and radio shows to speak about MCS. Although the bill was not passed, Ms. Temple lobbied on behalf of Ohio House Bill 389, which would have mandated that physicians receive education in toxicology and nutrition. She has filed a complaint with the EPA and is currently in the process of proving that her local water system is being contaminated by an oil company situated near the source of their water supply.

Persons harmed by substances generally regarded as safe face severe obstacles in being heard. But education, community, resolve, and a sense of urgency combined with a desire to help others avoid future suffering have created a new and growing group of activists like Toni Temple, who, though suffering themselves, manage to make paradigm-challenging contributions that the dominant culture would like to ignore.

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Table 1

MCS Activism Scale Results in a Sample of 209 Persons with Self-Reported MCS/CI

Sometimes having an illness or a disability leads to involvement with others around educational or advocacy issues. In response to your condition, have you:

	% answering yes
1. done personal reading of books, articles, newsletters, or other materials to educate yourself regarding MCS/CI.	99%
2. attended any meetings of a support group?	56%
3. taken an active role in a support group?	43.5%
4. joined an organization that published a newsletter that dealt with MCS/CI (e.g., CIIN, HEAL, NCEHS, NYCAP, etc.)?	84.2%
5. supported other people with MCS/CI in a non-professional capacity?	89.5%
6. written an article for a newsletter/publication?	36.8%
7. engaged in letter-writing campaigns in relation to MCS-related issues?	56%
8. organized other citizens to take a stand on an environmental issue that was related to MCS?	32.1%
9. been an officer of a support/advocacy group for those with MCS/CI?	23%
10. spoken publicly about MCS-related issues?	34.9%
11. done a media interview in relation to MCS?	28.7%
12. advocated for legislation beyond letter-writing that would affect those with MCS?	22.5%
13. engaged in original research (data-gathering and collating and reporting) in relation to environment or MCS?	32.5%
14. written a book/technical report on the topic of MCS/environment?	9.1%
15. worked with others with MCS in a professional capacity (as a physician, consultant, counselor, etc.)?	15.3%
16. started/headed a local advocacy or support group for MCS?	18.2%
17. started/headed a national advocacy/educational/support group for MCS?	4.8%
18. edited a newsletter or publication devoted to MCS/environmental issues?	12.9%

Appendix I: World Wide Web Sites Relating to Chemical Sensitivity/Chemical Injury

<http://www-rohan.sdsu.edu/staff/lhamilto/mcs/>

<http://www.snowcrest.net/lassen/mcsei.html>

<http://www.aehf.com/chemsens/html>

<http://www.teleport.com/~elliott/mcs-ei.html>

<http://www.teleport.com/~elliott/alissa.html>

<http://home.earthlink.net/~hesolutions/index.htm>

<http://home.earthlink.net/~hesolutions/20-20-1-97.htm>

http://bcn.boulder.co.us/health/chn/mcs/mcs_main.html

<http://www.ehcd.com/index.html>

<http://www.ehcd.com/chemsens.html>

<http://EnvPrevHealthCtrAtl.com/mcs-ei.htm>

<http://appa.org/publish/REGULA.HTM>

<http://www-hsl.mcmaster.ca/tomflem/envir.html>

http://www.ul.cs.cmu.edu/books/multiple_chem/multiple.htm

<http://www.best.com/~immune/>

<http://www.pic.net/~enviromd/resources/>

<http://www.crisny.org/not-for-profit/nycap/mcs.htm>

<http://www.supernet.net/~jackibar/mcs.html>

<http://www.accesssnewage.com/articles/health/Chemical.htm>

<http://www.lifelines.com/libry1html#Chemical>

<http://unix.adept.net/~mcsinfo/>

<http://www.gulfwar.org/uk/index.html>

<http://www.dtic.dla.mil:80/gulflink/>

Appendix 2: Chemical Injury Resource/Information Providers List

Chemical Injury Information Network, P.O. Box 301, White Sulphur Springs, MT 59645 Phone: (406) 547-2255

CIIN is a non-profit organization dedicated to education regarding the negative effects of chemicals on health. Special features of each newsletter include summaries of recent relevant research. The newsletter is "Our Toxic Times" published monthly by editor Cynthia Wilson. There is no specified membership fee, but donations are requested/appreciated to fund the publication.

Chemical Sensitivity Disorders Association (CSDA). P.O. Box 24061, Arbutus, MD 21227

Newsletter is, *The Chemical Sensitivity Connection*. This is the Baltimore Area EI/MCS Support/Advocacy Group.

The Chicago-area EI-MCS Support Group, 1404 Judson Avenue, Evanston IL 60201

Newsletter is "Canary News" published monthly by Lynn Lawson coordinator and editor (also author of "Staying Well in a Toxic World"). Membership is \$15 yearly for individuals or families. Send to Nancy Westrom, ON342 Sunset Ave., West Chicago, IL 60185. In case of hardship, send a letter or card along with what you can afford.

Citizens Clearing House for Hazardous Waste, P.O. Box 6806, Fall's Church, VA, 22040 Phone: (703) 237-2249

Executive Director: Lois Marie Gibbs

Ecological Health Organization And Action Coalition, P.O. Box 281116, East Hartford, CT 06128-1116

ECHO is an affiliate of NCEHS, and "is a statewide non-profit advocacy, support and referral organization for people who have Multiple Chemical Sensitivity (MCS) and others who care about preventing this illness." Newsletter is published bi-monthly by editor Elaine Tomko. Membership is \$15.

Environmental Access Research Network, Director, Cindy Duehring: P.O. Box 426, Williston, North Dakota, 58802 Branch Office: 315 7th Ave. W., Sisseton, South Dakota 57262 Phone: (701) 859-6367

Write: *A Referenced Compendium of Chemical Injury*.

Environmental Health Network, P.O. Box 1155, Larkspur, CA 94977

EHN focuses on "the issues and developments relating to the health and welfare of the environmentally sensitive." Newsletter "The New Reactor" is published bi-monthly by editor Susan Molloy, M.A. Membership is \$15/\$7 low income.

Environmental Research Foundation, P.O. Box 5036, Annapolis, MD 21403-7036

Phone: (410) 263-1584

Newsletter is *Environment and Health Weekly*, Peter Montague Ph.D., Editor.

Greenpeace USA, 1436 U. Street N. W., Washington, D.C. 20009

Well-known, environmental activist group.

Human Ecology Action League, Inc., P.O. Box 49126, Atlanta, GA 30359-1126

Phone: (404) 248-1898

HEAL is a nonprofit volunteer organization designed to serve and provide information to those whose health has been adversely affected by the environment. Emphasis is on support rather than advocacy. They publish "The Human Ecologist" quarterly. Membership is \$20/\$15 low income. HEAL can inform you of local HEAL support groups in your area.

MCS Referral & Resources, 2326 Pickwick Road, Baltimore, MD 21207-6631

Phone: 410-448-3319

This organization is overseen by Grace Ziem, MD, Dr.PH, and facilitated by Albert Donnay, MHS. They focus on "professional outreach, patient support, and public advocacy devoted to the prevention, diagnosis, treatment, and accommodation of Multiple Chemical Sensitivity Disorders (including porphyria) . . . and offer referral and research services and medical literature for MCS professionals (physicians, health educators, social workers, attorneys, etc.) as well as MCS patients, elected officials and the media".

**The National Center for Environmental Health Strategies 1100 Rural Avenue,
Voorhees, NJ 08043 Phone: (609) 429-5358**

NCEHS is a non-profit, organization committed to education, research, support, and advocacy services on environmental and public health issues including environmentally and occupationally-induced illnesses. They publish "The Delicate Balance" which provides very current updates regarding legislation, research, and advocacy efforts related to EI/MCS. Editor is Mary Lamielle. Membership is \$15/\$10 low income.

**National Coalition Against The Misuse of Pesticides, (NCAMP), 701 E Street S.E.,
Suite 200 Washington, D.C. 20003 Phone: (202) 543-5450**

Newsletter is *Pesticides and You*.

**National Ecological and Environmental Delivery System, 527 Charles Avenue 12A,
Syracuse, NY 13209 Phone: 1-800-634-1380**

This is a private business providing products for the allergic and chemically sensitive. We include them not necessarily to encourage your business, but because they have a message service. When you order, you receive their newsletter which is partly advertisement, and partly messages from fellow EIs. Anyone can submit a message free of charge. This message then goes to everyone who order from NEEDS for the next few weeks (or longer). This is how I recruited some folks for my research. You can request a catalog to purchase products.

**New York Coalition for Alternatives to Pesticides, 353 Hamilton St., Albany, NY
12206-0005 Phone: (518) 426-8246 or 9331**

NYCAP "is a citizens organization committed to public education and advocacy to reduce the pesticide hazards." NYCAP News is their quarterly newsletter edited by Tracy Frisch. Membership is \$25 (suggested)/\$6-10 minimum poverty.

**Northwest Coalition for Alternatives to Pesticides (NCAP), P. O. Box 1393, Eugene
Oregon 97440 Phone: (503) 344-5044**

Newsletter is *Journal of Pesticide Reform*, Caroline Cox ed., Norma Grier, Dir.

**Pesticide Action Network (PAN), 116 New Montgomery Street, # 810, San
Francisco, CA 94105**

Newsletter is *Global Pesticide Campaigner*, Monica Moore, Dir.

Pesticide Education Center, P. O. Box 420870, San Francisco, CA 94142-0870

Phone: (415) 391-8511

President: Marion Moses, MD.

Pesticide Watch, 116 New Montgomery Street, Suite 530, San Francisco, CA

94105 Phone: (415) 543-2627

Newsletter is *Pesticide Watch*, Joan M. Clayburgh, Dir.

Public Citizen, 1600 20th Street, N. W., Washington, D.C. 20009 Phone: (202)

833-3000

Founder: Ralph Nader

Rachel Carson Council Inc. 8940 Jones Mill Road, Chevy Chase, MD 20815 Phone:

(301) 652-1877

Newsletter is *Rachel Carson Council News*, Diana Post, Dir.

Share, Care & Prayer, P.O. Box 2080, Frazier Park, CA 93225

This is a Christian organization that attempts to serve the needs of the chemically sensitive.

Contact is Janet Dauble.