# Multiple Chemical Sensitivity, Culture, and Delegitimization: A Feminist Analysis

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# ABSTRACT

The condition referred to as multiple chemical sensitivity (MCS), chemical injury (CI), environmental illness (EI), twentieth century disease, toxic encephalopathy, and other names has generated controversy because victims' claims of harm from low levels of chemicals in the environment conflict with general mainstream belief in the safety of these substances. Mainstream culture's response to persons with MCS/CI has interacted with sexism, served to delegitimize victims thereby reducing their power, reduced the victim's context (because of forced isolation), and jeopardized jobs and relationships. This paper will analyze the situation of the chemically injured person and culture's response from a feminist perspective, and discuss cultural delegitimization as a process used by a chemical culture to neutralize the message of the person with MCS/CI, i.e., that the environment is unsafe for her/him, and, by extension, for others.

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## INTRODUCTION: CHEMICAL SENSITIVITY AND REACTIVITY

Persons who report serious negative health reactions to levels of chemicals commonly present in the environment have been labeled as having multiple chemical sensitivity (MCS), chemical injury (CI), environmental illness (EI), twentieth century disease, or toxic encephalopathy. There is agreement on neither the name nor the mechanism for such reactions. The reactions themselves occur in response to petrochemicals, cleaners, pesticides, fragrances, formaldehyde, and others, and can include symptoms of distress in respiratory, digestive, cardiovascular, central nervous, or other bodily systems. Examples of described reactions are rhinitis, increased or decreased heartrate, dyspepsia, confusion, dizziness, depression, joint pain, headache and others (Ashford and Miller, 1991; Bascom, l989; Bell, l982; Randolph and Moss, l982; Ross, l992). Reactions range from mild to debilitating, and tend to occur in response to more and more chemicals as the condition progresses (Ashford and Miller, l991; Randolph and Moss, l982). For some, just a few-second exposure to perfume, for example, may trigger serious headaches and confusion. Many reactions last as long as several days or more, leaving the person debilitated much of the time, resulting in a forced choice between well-being and access, since chemicals are in common use in almost any work or social context. Consequently, persons alternate between sickness and isolation. A woman who participated in my research on life impacts of MCS described this fluctuation:

> I am unable to travel, unable to do grocery shopping, laundry is done in the bathtub. I am unable to work, socialize, unable to have long term contact with the public unless I know prior to that the environment is 'safe'. And still then, one wrong turn

> and I can be literally on the ground for days. The best precaution I can take is complete avoidance although this certainly is not within my person. Thus, often times I do what I am able and sometimes push myself mentally and physically past a healthy point, my body reacting wildly in exchange for my own stubbornness.

Although it may be tempting to dismiss the problem as one affecting only a very small portion of the population, initial studies suggest otherwise. The National Academy of Sciences has estimated that 15% of the population may be affected by chemical sensitivity (Davidoff, l989). Meggs et al. (l996) found that 33% of a rural population reported illness from chemical odors with 3.9% experiencing daily symptoms. If Meggs et al.'s sample is representative, this means that over ten million persons in the United States are becoming ill from chemicals on a daily basis. Of those affected, the majority appear to be women (Cullen, Pace and Redlich, l992; Gibson, Cheavens and Warren, l996; Heuser, Wojdani and Heuser, l992; Kipen et al., l992; Meggs et al., l996; Ross, l992), although Gulf War vets report similar symptoms (Miller, l996). Reasons for the apparent preponderance of women in civilian populations may include women's smaller body size in relation to men, their greater proportion of body fat in which chemicals accumulate, the interactions of chemicals (particularly pesticides) with estrogens (Paulsen, l993), differences in the female immune system as as result of contact with paternal antigens in pregnancy (Miller, l992), and women's lower body concentrations of alcohol dehydrogenase (Freeza et al., l990). For example, women in the Freeza et al. study broke down under one fourth the amount of alcohol broken down by men participants. This may be relevant to MCS/CI in that these same enzymes detoxify chemicals (Rogers, l990). Non-biologically-based factors relating to gender asymmetry in MCS may include women's greater use of chemical cosmetics and fragrances, and the stratification of women into

low-paying clerical jobs with poor air quality due to the presence of photocopy fumes, pesticides, carbonless paper, and others' fragrances.

Much controversy has surrounded discussion of the validity of such MCS-related complaints, possible causal mechanisms, appropriate treatment, and fair accommodations for affected individuals.

Although some contend that chemical sensitivity/injury is psychologically based, support for physiological concomitants is mounting. MCS/CI samples have demonstrated immunological problems (Heuser, Wojdani and Heuser, l992); pesticides in the blood (Rea et al., l992); nasal abnormalities (Meggs and Cleveland, l993); nonviable detoxification pathways (Rogers, l990); and neurological signs including abnormal EEGs and MRIs (Heuser, Wojdani and Heuser, l992). Dudley (l993) demonstrated that chemical exposure triggers abnormal evoked potentials in persons with MCS.

Consequences for Victims

Rippere (l983) documented through interviews the life consequences of having allergies (including some chemical sensitivities), and stressed others' negative reactions to the sufferers which included ostracism and denigration. Focusing specifically on sensitivity to and injury from chemicals, Gibson et al. (l996) found considerable life disruption in a sample of 305 persons (80% women) self-identified with chemical sensitivity or injury. Participants reported job loss and accompanying nullification of work/professional identity (two-thirds lost or were forced to quit their jobs due to chemical exposures in the workplace); reduced income (participants' annual income declined by a mean of $17,000 since becoming sensitive); multiple moves in residence to find safe houses; unusually high medical expenses; and loss of hobbies and social interaction. In addition, many had lived in highly unusual circumstances such as tents, cars, porches and horse trailers, or were homeless altogether due to inability to tolerate the chemicals in the construction and maintenance of conventional housing. In fact, a new

sub-class of poor persons disproportionately women may be forming, as 66% of the Gibson et al. sample had lived in these unusual circumstances at some time during the course of their condition.

Forced to live outside the conventional health care system because of that system's disbelief in their condition, persons with chemical sensitivity use alternatives, care for themselves, or go without care (Gibson et al., l996). Many report avoiding health care altogether since many conventional mainstream providers see their claims as unfounded (Engel et al., l996). Rippere found that conventional medicine was seen as beneficial by allergy patients (including chemical allergy) only about one fourth of the time. When emergencies deem they must seek conventional help, they are powerless to avoid exposures from medical offices due to perfumes, pesticides, cleaning chemicals, etc.

Persons who are poor or of ethnic minority origin may be even more seriously impacted and have less power as a result of chemical-induced illness. Native Americans in particular suffer from an elevated incidence of many health problems, including chemical injury. Hansen and Lurie (l995) have discussed the repeated pesticide spraying of the reservation town of Mission, South Dakota and the reported health problems that ensued. Residents were given no warnings prior to the sprayings, and endured repeated contamination of everything in their homes including their food, as they were unable even to close their windows because of the heat (and the inability to afford air conditioners).

## IN CONFLICT WITH CULTURE

Once a person identifies her or himself as injured by or sensitive to chemicals, she or he faces the daunting tasks of finding appropriate medical help, financing necessary life changes to minimize chemical exposures (which may include job change, move to a safer residence, purchase of air purifiers and other aids), and maintaining social contact in spite

of inability to tolerate ubiquitous chemicals such as fragrance, cleaners, and pesticides. Since very little medical help is available, often chemical victims fend for themselves, self-educating through reading what scant research exists, attending self-help groups, and avoiding exposures in any way possible. Minimizing chemical exposure is an extremely difficult task yet necessary for survival (Ziem and Davidoff, l992), and so the process plays out often in a public manner as persons with chemical sensitivities interact with conventional practitioners, wear masks, request accommodations, and experience debilitating reactions in public. In essence the person with chemical injury is at odds with industrial society. Since persons with MCS include such a disproportionate number of women, sexism compounds other negative attitudes toward this population.

Ignoring or misconstruing women's health complaints is not new. MCS is emerging in a cultural/historical context in which women's health problems have been understudied, women have been underrepresented in research, and where treatments for women's health problems have often been inappropriate, irrelevant, or harmful. Nineteenth century medicine saw women's ills, including tuberculosis as caused by renegade uteri or ovaries (Ehrenreich and English, l994). Laurence and Weinhouse (l994) discuss the removal of even healthy ovaries to cure problems such as "troublesomeness, eating like a phoughman, masturbation, attempted suicide, erotic tendencies, persecution mania, simple 'cussedness' and dysmenorrhea" (17). Fleiss' operation on Freud's patient Emma Eckstein's nose to cure her hysteria (seen by Fleiss as caused by masturbation) is a particularly flagrant example of folly posing as medical treatment (Masson, l986).

Women have not fared much better as research participants. When they have been included, it has often been in less than ethical circumstances, with some present studies no exception. Lappe (l991) has discussed the "progress" of studies of high and low doses of estrogen for birth control complete with cover-ups of cancer risks. Both Laurence and Weinhouse (l994) and Paulsen (l993) have criticized the current tamoxifen study which

puts large numbers of women participants at risk for blood clots, endometrial and ovarian cancers, depression, and eye disorders in order to investigate the drug as a breast cancer deterrer. Where women have identical maladies as men, they may still be treated differently. Goudsmit (l994) has cited two studies that found that women coronary patients were offered fewer interventions than were men, even though, in one study, the women patients evidenced greater disability. At times women's health problems are not addressed at all. Goudsmit (l994) has provided examples of cases where women's physical problems of diabetes and irritable bowel syndrome (IBS) were dismissed as the results of hysteria and stress respectively. The condition of MCS may serve as a particularly appropriate case example of the delegimization of the health concerns of women and other persons constructed as nondominants. Though health providers often do not use economic, ecological or political variables when assessing conditions of those considered 'deviant', in the case of MCS this may be a fatal oversight. Conventional medicine is firmly embedded within and interdependent with the economic/industrial structure where decisions to adopt technological innovations are made by an elite few and consequences are not considered until these technologies are developed and applied. In the case of many of these technologies (e.g., nuclear power) the consequences are so devastating that they will be felt for thousands of years (Mander, l991; Mies, l993c). And by the time consequences are understood, these same technologies are so embedded in our economies that an honest and objective assessment is impossible. Persons with chemical injuries are in the unenviable position of asking for this impossible after-the-fact assessment of our chemical-dependent lifestyle from the general culture and from their health providers.

But, being context-dependent, health providers are unable to offer this assessment. Physicians work in a system that educates in an allopathic paradigm valuing heroic cures over prevention, where drug companies sponsor research, and in which their publications

are subject to peer review thus insuring difficulty for those espousing variant views. Theron Randolph himself (now considered to be the major founder of environmental medicine) was dismissed from his post as faculty at the Northwestern University School of Medicine early in his career for being a heretical influence upon students (Randolph and Moss, l982). Randolph's model for chemicals as causes of disease conflicted with accepted rules of practice. Kroll–Smith and Ladd have characterized the contrast between the beliefs of those with chemical sensitivity (and the practitioners of environmental medicine who treat them) and those of conventional medicine which will inspect the body and label it "healthy or sick in a manner that reflects what the medical establishment is willing to concede and what the state is willing to compensate" (l993: 11) as a paradigm conflict in the Kuhnian sense. This conflict, then, leads to efforts on both parts to assert one's position, and invalidate the views of the other. These efforts can be conceptualized as performances.

Feldman (l995), in her discussion of interpretation of qualitative data, has discussed dramaturgical analysis of a performance for an audience. In the case of the person with chemical injury, the power structure puts on a performance of power/knowledge/control/assurances of safety/lack of "hysteria" in the face of increasing complaints from sufferers – thus forcing those with disabilities for which they receive neither recognition nor treatment to enact performances of protection. The performance of protection includes such visible props as masks, air purifiers, etc., that in turn guarantee stigma to the users (Goffman, l963). The performance of protection also includes violating agreed upon rules and assumptions in order to avoid chemicals. E.g., Women with chemical injuries cease to use chemical cosmetics, hair dyes, polyester clothes etc., thus violating culturally/industrially prescribed norms for women, failing to participate in consumption, and threatening mainstream efforts to maintain the shared reality that chemical exposures are not a threat. Ironically, this performance of protection

is routinely stigmatized as "maladaptive", both by those responsible for the environmental hazards from which sufferers are protecting themselves, and by those designated by culture as 'healers'.

But, increasingly, it is chemical exposures, and by extension, technology and industrialization that have themselves come under critique. Vandana Shiva said "The environmental crisis was precipitated by the view that nature was inadequate and that technology could improve on it" (l993a: 273). Particularly, criticism is leveled at our apparent inability to learn from mistakes and change course when there is evidence that we should do so: "Now it seems that the dominant view is to pose the disease as the medicine, and 'technology transfer' has become the magical cure for every ecological illness" (Shiva, l993a: 273). In discussing the effect of technology on humans, Jerry Mander has said:

> With the Industrial Revolution, many things began moving at mechanical speeds. As the natural environment was paved over, and as human life moved into human-made environments, the natural rhythms of our reactions gave way to industrial rhythms. We learned to interact with mechanical speeds, as assembly-line workers and most auto drivers know. Now that machines move at electronic speeds, the wheel of activity turns even faster, with us on it (l991: 65).

Women with chemical sensitivities are stepping off the industrial wheel. Their retreat, which suggests the unsuggestible — viz., that our modern industrialized world is destroying human health — subjects them to others' incredulity, even scapegoating. Through processes of renouncing chemicals, leaving culturally entrenched jobs, discontinuing chemical clothes and cosmetics, women who are chemically injured, whether by choice or necessity, shun all that an industrialized patriarchal society sanctions.

Regardless of whether they mourn these changes (and many do), they have, in a sense, decolonized themselves as Ward Churchill (l994) has suggested members of imperialist cultures must do. Maria Mies has described this decolonization and would have the colonized "overcome the fascination exerted by the colonizer and his (sic) lifestyle and re-evaluate what he/she is and does" (l993a: 56).

This re-evaluation leads directly to a consideration of consumptive patterns and treatment of environment. Karen Warren (l987) sees the four pillars of patriarchy as being sexism, racism, classism, and naturism. As a descriptor of present day gender arrangements, patriarchy and capitalism have been theorized to be both related to and independent of one another by different writers; there is no general agreement among feminists regarding the exact relationship between the two. Most would agree that the systems of capitalism and patriarchy do share characteristics, however. "[S]ystems of inequality such as patriarchy and capitalism, depend on the success of a few at the expense of the majority" (Stacey l993: 65). The link between industrialized capitalism and patriarchy is conceptual in that both espouse domination and power ethics, misappropriating the resources of those with less power while concurrently offering a rhetoric justifying such behavior. This rhetoric uses the power to name to distance from entities conceptualized as "resources," and a paradigm of colonization is perpetuated as all communication about nature thus becomes pedagogy for "use." Examples include the construal of human effort as "labor," the transformation of the natural world into "natural resources" or "raw materials," the designation of caring for others as "women's work," and the blatantly degrading references to women as sexual objects for men's consumption. The socialist feminist analysis is relevant here and adds that ways of thinking depend upon mode of production. A chemical-dependent economic machine dictates against any construction of chemicals as problematic in <u>any</u> way, let alone as causes of illness.

Thus, although more women than men may be affected by MCS/CI, men also suffer when they develop this condition which says the unspeakable about our chosen industrialized chemical-dependent lifestyle. Our industrial/capitalist culture may be patriarchal in terms of its power structure, but it punishes men who break rules for men's behavior much as it punishes women. The man with MCS, for example, is "unmasculine" in his plea for clean air in the workplace, in his acknowledgement of his vulnerability, and his failure to appreciate the products of our capitalist economy. He, too, becomes a willing or unwilling critic of a consumer culture and its attendant consequences. Shiva (l993c) has described the push to uniformity in the patriarchal model that destroys diversity in its move toward monocultures. The man with chemical injury, like the woman with CI, has become uncooperative in that by virtue of having "special needs" he can no longer participate in the mandatory homogeneity of this evolving monoculture. Women and men injured by chemicals are an inconvenience. They slow down the machine through their need for "special consideration" - by requiring us to think/consider what we have taken for granted, much as they have been forced to do.

As persons with chemical injuries re-evaluate their experiences, out of the text "I am a sick individual" emerges the subtext "I have been poisoned and we are all at risk." This counter-dominant assertion puts its messengers in further conflict with culture by locating "the origin of sickness in a culture committed to the production and use of synthetics, and makes a strong case for the need to change the basis of production to prevent disease" (Kroll-Smith and Ladd, l993: 24). Because this message threatens the very underpinnings of a capitalist industrialized culture, culture retaliates in attempt to silence, delegitimize, and pathologize the messenger.

The Delegitimization Process

Soine (l995) has charged that gender bias prevents practitioners from taking injury from sick buildings seriously. The treatment of victims of sick building syndrome (SBS), some of whom go on to develop MCS, provides a recent relevant case example of the interaction of sexism and capitalism/industrialism. SBS is overrepresented among women, and primarily among women with lower status occupations such as clerical workers (Soine, l995). Despite the facts that the research associates high levels of volatile organic compounds (VOCs) with SBS, that there are known adverse health effects of VOCs, and that the effects of exposures to mixtures of VOCs have not been investigated, initial response to complaints of SBS blamed the problem on psychological causes, i.e., "mass hysteria," and attempted to construct a psychological profile of the victim of SBS. But "subsequent research findings indicated that there was no common psychological profile of the victim of SBS" (Soine, l995: 54).

In a cultural context viewing poverty as the absence of Western consumption patterns (Mies and Shiva l993), and the ability to work as a natural resource, a pro-industry bias in health care insures that psychological causes of illness be sought before chemical-related causes. But, given the unknowns regarding the effects of chemicals, this is perilous for the health of all concerned. The National Research Council reported that under 10 percent of the 70,000 commercially-used chemicals have ever been tested for neurotoxicity (cited in Duehring and Wilson, l994). Additionally Duehring and Wilson stated:

> According to an NAS study in l987, none of the chemicals used in cosmetics and only 17 percent of the chemicals used as food additives had been tested for neurotoxic effects, and none of the tests conducted was considered adequate (l994: 5).

Even when chemicals are assessed for toxicological effects healthy young white males are the standard research participants, and studies do not consider "the possible synergistic, additive, cumulative, and potentiated effects of different chemical combinations" (Duehring and Wilson, l994:19). This is despite the fact that recent evidence suggests that the combined toxicity of chemicals is more likely to be potentiative than additive (Abou-Donia, Wilmarth, Jensen, Oehme, and Kurt, l996).

Laxity in the search for knowledge of chemical effects has been instrumental in bringing us to our current state of environmental contamination. Mies and Shiva have discussed the dilemma of health in an industrialized society framing pollution and ill-health within an ecofeminist perspective:

> Ecofeminism is about the connectedness and wholeness of theory and practice. It asserts the special strength and integrity of every living thing. . .We see the devastation of the earth and her beings by the corporate warriors, as feminist concerns (l993: 14).

Birkeland says that ecofeminism "offers a political analysis that explores the links between androcentrism and environmental destruction" (l993:18). Ecofeminism has been attacked by some as "essentialist", and Birkeland acknowledges that some feminists of various types, including ecofeminists, believe that women are closer to nature than are men. But, given the interconnectedness of all nature, and the cultural mediation of our experience of nature, Birkeland cites and agrees with Joan Griscom who said "The very idea of one group of persons being 'closer to nature' than another is a 'construct of culture'" (cited in Birkeland, l993: 22). Birkeland thus rejects the essentialist accusation as itself an outgrowth of patriarchal dualistic thinking. Similarly, Gaard has said: " . . it's

not the similarity between women and animals that is interesting to ecofeminists per se, but rather the similarity in the conceptual operation which justifies their subordination" (l996: 440). Thus, "[b]y showing how the oppression of women and of animals are conceptually similar, ecofeminists hope to direct our analysis to the functioning of oppression itself" (Gaard l996: 441). Salleh (l992) explains:

> Under patriarchal culture, the program of repression that has treated women and colored peoples as resources, from the beginning of recorded history, has also been the ideology that plunders nature (204).

It is impossible to completely understand or address chemical injuries without addressing the exploitation that is at the core of industrialized cultures where only priced commodities are valued. In such systems activities such as homemaking, subsistence farming, and the provision of social support, as well as nondominant peoples, and the natural world are not valued. Calculated risks are seen as justified to produce more commodities, even if those risks involve human health and include upsetting natural ecosystems, and using extensive amounts and types of chemicals for convenience and increased production.

Mies and Shiva sum up this predicament: " . . . all women and all men have a body which is directly affected by the destructions of the industrial system" (l993:20). Those with MCS/CI may be joining plants and animals in succumbing to pollution generated by this industrial system long-predicted to devastate the natural balance (Carson, l962). Yet, in health assessments, this chemical context is ignored. For example, few practitioners are trained in toxicology in spite of the widespread nature of chemical exposures. Ellyn Kaschak has talked about the process of drawing an artificial boundary around an individual or figure in question, thus effecting a separation from ground or context: " . .

.an artificial boundary is drawn between the figure and the context such that we come to believe that the figure exists separately from the context. Similarly the context fades from awareness . . . " (Kaschak, l992: 31). In the case of MCS, health providers are then free to assess the woman made ill by chemicals without considering the source of her illness. Without context, her health problems neither make sense, nor do they seem legitimate. "Most important, perhaps, is that whoever gets to draw this line, to create the boundary, is the owner of the context, and, as such, holds the power to define reality, to say what matters and what does not" (Kaschak, l992: 31).

In a culture that has medicalized women's bodily functions, MCS defies medicalization. As no treatments are universally effective, experts are revealed to be inexpert, and the experiencer is forced to manage and understand her own body. But, because of the cartesian split between the objective knower and the object, the voices of those who experience the condition are not seen as viable sources of information about the condition. As Mies (l993a) has said, we should not abdicate our senses as sources of knowledge. However, with persons with MCS/CI silenced as a source of information, we are led to believe we must wait for answers from the same technological establishment that brought us radioactive waste, Love Canal, and Chernobyl.

Thus we have conventional medical practitioners (untrained in toxicology), and chemical companies (with a vested financial and legal interest) drawing the boundaries between patients and chemical context with the result that women who re-experience the salience of the chemical context are defined as deviant and unbalanced. Conventional medical practitioners hired by chemical companies are hence the "owners" of the context and can provide "expert testimony" in disability hearings and product liability suits regarding the authenticity/validity (or lack thereof) of the woman's claim. The values inherent in these epistemologies are not questioned as they function as tools for the delegitimization of women's health experiences. A participant in my research, herself a

practicing health professional, described a declining health spiral that was precipitated by chemical exposure in the workplace and culminated in psychiatric hospitalization. In her words:

> The following eight days spent in the psyche facility were condescending and demeaning. The throat burning and insomnia continued and all medication used to treat these symptoms had adverse reactions. Regardless of my pleas to concentrate on my physical symptoms, the hospital staff focused their efforts on my mental status.

One is reminded of Baker-Miller's (l976) discussion of cultural dominants constructing the characteristics of subordinates. Those who are in dominant positions are thus free to characterize as they see fit the chemical sensitive person, who is subordinate by virtue not only of being a woman (or a man who has broken rank by complaining about exposures) but through having a disability. Dominant perceptions are legitimized and bolstered by professional credentials of the labelers, and congruence with the majority culture's lack of attention to the health effects of chemicals. Western health and behavior cannot be understood except within the context of a capitalist, industrialized, chemical-laden patriarchal culture. But context having been erased and epistemologies set within a medical model, industrial paradigms serve to construct these women as not believable. Support is forthcoming from psychosomatic, psychoanalytic traditions which remind us that women are unconscious of their true urges and subscribe to Freud's doctrine of "somatic compliance" which presumably allows psychic disturbance to manifest in the body. Thus Freud was able to attribute Dora's symptoms of loss of voice and cough to her desire for oral sex with her father (Freud, l963). One woman in my research described the attribution process run amok in her interactions with physicians:

> I have found that, rather than paying close attention to what I tell them, they either chalk things up to depression, or 'female hysteria' or merely say 'this can't be'! Some have lectured me about getting on with life, in front of my husband. One even said I had played with too many frogs (an infectious disease specialist). One suggested wine and chocolates and a walk in the park.

Dora's stressors were social and her label hysteria, but her case offers a striking parallel for the experience of the chemically injured. Women with chemical sensitivity/chemical injury may be our modern-day "hysterics" in the institutional sense — that is, women held hostage by professionals who seek to quell, study, and label them as their bodies speak in a language not decipherable within an old paradigm. It may indeed once again be trauma at the base of this new "hysteria"— not psychological trauma as in Freud's day, but a physiological trauma made up of more chemical exposures than the body can tolerate. Yet impinging stressors are ignored and women are once again accused of using the body for secondary gain – the hysteric for attention, the chemical injured for attention, work avoidance, and compensation. Often women's disorders may become magnets for negative cultural attributions about women in general. This may be what led Micale to assert that " the history of hysteria may . . . be read as an exercise in cross-gender representation. For centuries, hysteria has served as a dramatic medical metaphor for everything that men found mysterious or unmanageable in the opposite sex" (l989: 320).

The behavior of those with MCS may be even more of a threat than hysteria in that it violates and exposes many shared assumptions/myths of western, technological, chemical society. (See Lappe, l991, for a discussion of ten myths that an industrial culture uses to minimize concern regarding environmental contamination.) Yet the efforts

to maintain those assumptions and thus the economic structures dependent upon them are monumental. The focus of the research and rhetoric in regard to chemical injury, and thus critique, must be kept on the victim rather than on the structures that are the object of the victim's critique. Feldman (l991) has discussed the assumption of ethnomethodology that all deviations from the accepted norm are motivated. In the absence of an understanding of the health effects of chemical exposure, dominants are at a loss to explain the behavior, for example, of the woman wearing a respiratory mask, and therefore impute psychological motivations. Psychological explanations (which do not threaten our economic status quo) are a useful way of dismissing her claims that she needs the mask in order to breathe safely in public.

Expediently, other shared assumptions (not necessarily relating to chemicals) can then be used to bolster the claim that the woman is somehow psychologically deviant. Dominants commit the fundamental attribution error (Ross, l977) and attribute the behavior of the person seeking to avoid chemicals to some characterological flaw. Standard classifications, themselves the products of flawed political processes (read Caplan l995 for a detailed description of the inner workings of the processes by which diagnostic categories are created) are then used to categorize women who threaten to upset our world views. Rippere has said of this labeling process: "This sort of 'explanation' is very convenient for the professional 'helper' who offers it, because it virtually ensures the prompt disappearance of all but the most thick-skinned sufferer from the surgery or clinic" (l983:21). The resulting anguish for the labeled is described by this woman in my research sample:

> Once a psychological diagnosis was placed on me, I began to question my own sanity and talked in depth with medical personnel and my parents about being

committed for treatment. I could not understand how overnight, I went from feeling fine to being unable to do simple tasks.

When old categories do not suffice, new ones are coined, as in the use of the term "chemophobia" to dismiss a patient's concerns in regard to exposures. A woman in my research was diagnosed as having "olfactory delusions" simply because she could smell chemicals that others could not. This is in spite of the fact that Bell, Peterson and Schwartz (l995) have identified cacosmia (increased ability to detect odors) as a not rare phenomenon, and as predicted by physiological as opposed to psychological disturbances in family health histories. Another woman who contacted me was diagnosed as having Munchausen by proxy when she attempted to get help for her chemical sensitive child who had been affected by silicone breast implants through breast-feeding.

In addition to the psychological harm of delegitimization, delays and misdiagnoses engender iatrogenic harm in persons already suffering. One participant in my study said: "I believe I have been harmed more by the dragging of feet and the reluctance to look at the possibility that I react to my environment. Each specialist appointment resulted in a 2-3 month wait, weeks for results, and then on to a new theory."

Mies (l993a: 49) has said "The violence of the scientist is mainly the power of definition." Feminists have discussed this power of naming in relation to those who have nondominant status, and with MCS the use of language further contributes to the stigmatization. One woman said: "The medical profession will not call poisoning poisoning if you know the poisoner, typically a large corporation. However, my medical records of my suicide attempt with pills, use the word poisoning freely."

New age philosophies can be invoked by dominants to further delegitimize persons through emphasis on total personal responsibility for illness to the exclusion of external social and economic contextual variables. Wilkinson and Kitzinger said "In the twentieth century, capitalist economy, redolent with Thatcherite values, health as one's personal

responsibility (and moral duty) is a very convenient rhetoric" (l994:134). Wilkinson and Kitzinger critique the new age exhortation to think away illness by stepping out of the victim role: "By contrast, a feminist analysis of health and illness begins by acknowledging that we ARE victims — victims of a patriarchal world and a heterosexist health system, which, as feminists, we struggle against" (l994:138). MCS/CI sufferers, positioned against their will as victims in a chemical culture, have thus invoked the power of naming, through rejecting the terms 'sensitivity' and 'MCS' for the term 'chemical injury' in order to better reflect the origin and causality of the condition.

In addition to espousing unacceptable views, and failing to think themselves well, victims of chemical injury have had the "bad form" to look emotional in the process. The woman diagnosed as having Munchausen was extremely upset, as custody of her child was at stake. Diagnosticians, by contrast, have the luxury of appearing calm and "objective". Similarly, battered women are upset in court while the well–dressed, calm batterer appears balanced and rational. The woman with chemical sensitivities, with each ensuing loss and the increasing isolation, may be strained to the edge of her coping skills. But she is up against "the epistemology of a dominant group (which) can be made to appear neutral, and its value base invisible, since it coincides perfectly with what appears to be society in some generic, universal form" (Kaschak, l992, 10). The fact that we may look for emotion more in women whether or not it it present (Shields and MacDowell, l987) further places the woman who is incongruent with her culture at risk of being stigmatized. One woman spoke of the challenge of emotional restraint when in conflict with the health system:

> The psychological damage from the medical personnel and the denial of the existence of MCS has caused incredible stress over the years. The monumental insensitivity of the medical profession tests my faith more than anything, but I've

learned a great deal from confronting this challenge and so far I haven't strangled any M.D.s, which is something for which I give myself five stars!

The research on chemical sensitivity/injury may be used to delegitimize those with chemical injury much as is practice, yet in a more abstract sense. It is not surprising then that the research to date includes looking for mental illness as concomitant, attempting to fit the condition into already established paradigms such as odor-conditioning, or any variety of paradigms that ignore the environmental connection. Even work by sympathetic researchers who are not strangers to the realization that pollution is the cause of MCS/CI, proceeds to try to locate the imbalance within the person rather than the context through the search for "biological markers" of chemical sensitivity (although some are looking for direct environmental damage). It is assumed that if such markers can be identified, then perhaps they can be corrected in such individuals. The condition is still a disease to be treated, with the implication of deficiency in the individual rather than the environment. A true holistic approach would have to address our larger contextual problems of environmental contamination and degradation which are fueled by economic and political philosophies. Wilkinson and Kitzinger (l994) cite Winnow (l992) regarding 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" (l994:136).

## GAINING STRENGTH AND HOPE FROM ADVERSITY

Women no longer available as nurturers or sexual objects (Lott, l985), (as all personal resources come to be taken up with survival), and thus lacking in social support (Gibson et al.,under review), do by necessity what women have been disallowed — self care. This self-care, with time, may evolve and become political. Initially, the isolation may bear a resemblance to the nineteenth century rest cure except that it is self-imposed and

necessary for chemical avoidance. And the resulting anguish is the same, as the woman is relegated to the invisible realm of her 'safe' house. But women with chemical injuries are educating and energizing themselves to become advocates and agents of change. Women with chemical injuries have defied their own predicaments to supervise their own medical treatments (often relying on alternatives), to advocate for environmental legislation, and to educate others in regard to chemical injury. Similarly, men with CI defy the masculine stereotype to report vulnerabilities, accept their special needs, and come to grips with a "masculine" identity that it outside that of the instrumental provider and commodity exploiter prescribed by industrialized culture. Persons with MCS/CI, those with children made ill by chemicals, and concerned others head support groups and national organizations, edit newsletters, and write books. Several manuscripts and books accessible to laypersons have documented the consequences of a chemical lifestyle (Duehring and Wilson, l994; Wilson, l993). An example is Lawson's (l993) detailed and well-documented review of the challenges to living safely in a very polluted world which discusses scientific, political, and legal issues in relation to chemical contamination and has even been heralded as "the Silent Spring of the 90s" (Canary News, 26: 2).

Shiva (l993) has said ". . . across different contexts, . . . in ecologically eroded zones and polluted places, women identify with the interest of the earth and their children in finding solutions to the crisis of survival" (p. 85). Women with chemical injuries and others with concern for this issue who are becoming politically active are joining this web of activists who recognize how truly crucial our ecological condition has become. Glendinning (l990) conceptualizes persons with chemical injuries (she uses the term environmental illness) as survivors of technology along with atomic veterans, users of the Dalkon Shield, and victims of industrial accidents. She discusses their many-faceted losses that nonetheless, for some, lead to positions of strength in which they are able to

eventually help not only themselves, but others. Included in Glendinning's sample are environmental leaders, such as Lois Gibbs (Love Canal), who emerged through the seemingly insurmountable rhetoric of the dominant system to protect and educate others about contaminated communities. Similarly, in one of my own studies, of 209 persons self-identified with MCS/CI, 56% had attended support group meetings, 89.5% had engaged in lay support of other victims, 56% had engaged in letter-writing campaigns, 32.1% had organized other citizens on an environmental issue relating to MCS, 34.9% had spoken publicly about MCS-related issues, 18.2% had started or headed a local support group for MCS, and 4.8% had started/headed a national advocacy/educational/support group (Gibson, Rice and Stables, l997). This process of activism was articulated by Wilkinson and Kitzinger who described " . . . campaigns and community action: to change current medical, social, and political approaches to cancer, and to provide information and support for all who need it. That is what 'stepping out of the victim role really means. That is what we mean by a feminist approach to breast cancer" (l994:138)

Chemical injuries, likewise deserve to be included in the purview of feminist health concerns, and require the questioning of practices that have been made invisible through their normalization in an industrial culture.

## CONCLUSION

Vandana Shiva (l993b) has discussed the consequences of a global market economy for women in "developing countries" who are often robbed of resources such as water, land, and sustainable lifestyles by the resource-intrusive commodity production approach of Westernization with its emphasis on the GNP, and accompanying de-emphasized and hence unseen consequences of impoverished ecosystems. Chemical sensitivity/injury may be a wake-up call hitting closer to home and a critique of our Western obsession with production which speaks through the poisoning of the bodies of the colonizers. The

person with chemical injuries experiences first hand these de-emphasized consequences as her/his condition makes unviable any semblance of a "normal" (in the Western sense) lifestyle. Similarly, Shiva (l993b) has discussed Hardin's (l974) view that the planet's poor are a surplus population who drain world resources and who could be shed to leave the world better off. Persons with chemical injuries may be perceived in a similar way by corporate polluters unappreciative of the chemically injured community's message. 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 who, though suffering themselves, manage to make paradigm-challenging contributions that the dominant culture would like to ignore.

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