

# The Hidden Marginalization of Persons With Environmental Sensitivities

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## Abstract

*This paper constructs persons with environmental sensitivities as comprising a hidden, marginalized group in technological culture that is paying a large price for our industrialized lifestyle. Due to the polluted nature of most public venues, this population is robbed of a sense of “place” necessary to maintain personal relationships. This population is marginalized by health-care providers and shunted into mental health categories, as our current health paradigms are not adequate to frame and categorize health problems caused by our toxic industrial lifestyle. The problem is discussed within the context of the pressures of capitalism, and examples are given of persons with environmental illness receiving mental health diagnoses (an attempted colonization) when they attempt to access mainstream health-care providers who lack knowledge or expertise regarding toxic-induced illness. Key Words: Environmental sensitivities—Multiple chemical sensitivity—Electrical hypersensitivity—Chemical intolerance—Chemical sensitivity—Chemical hypersensitivity.*

Persons with environmental sensitivities (ES) comprise those with chemical sensitivities (CS) and/or electrical hypersensitivities (EHS). The dilemma of what to label such conditions evidences the etiological controversy. “Chemical sensitivity,” “multiple chemical sensitivity,” “environmental illness,” and “electrical hypersensitivity” reflect an environmental etiology, while “idiopathic environmental intolerance” suggests a more random, individually situated condition that paves the way for psychologizing people’s illness and maintains denial regarding the presence of the condition.

Persons with ES experience both differential exposure and differential vulnerability to toxics. A large number attribute their condition to one large chemical exposure or to a combination of moderate to high exposures (differential exposure). After this initial sensitization experience, people are no longer able to tolerate previously “benign exposures” (differential vulnerability). For example, large numbers of veterans from Desert Storm are unable to tolerate exposures they once ignored (Johnson & Starzman, 2000). Exposures implicated among civilians with chemical intolerance include pesticides, formaldehyde, paint, new carpet, diesel exhaust, perfume, and air fresheners (Gibson & Vogel, 2009). Subsequently, a “spreading phenomenon” occurs in CS, where the sensitivity generalizes, first to other related and later to unrelated chemicals. Though substantial numbers of persons report having ES in several developed countries, many persons, and particularly health-care providers, remain ignorant regarding the conditions. Thus persons with ES are marginalized and extruded from access to modern resources in their own communities (Gibson, 2010).

What factors account for the successful marginalization and extrusion of 12.6% of the US (Caress & Steinemann, 2003), 19% of the Swedish (Johansson et al., 2005), 27% of the Danish (Berg et al., 2008), and 32% of the German (Hausteiner et al., 2005) populations?

The life impacts of having sensitivities include extrusion from one’s occupation, damaged social relations (Gibson, 2015; Gibson et al., 1996), delegitimization (Gibson, 1997), and even homelessness. Most poignant, perhaps, is the loss of place. Chalquist (2009) talks of “place” and its importance for a homecoming, or a “re-ensouling our relationship with the world place by place” (p. 81). In a former interview study in my lab, we actually set out to study relationships but found that place trumped relationships, simply because people were unable to share the space required to form and maintain relationships (Gibson et al., 2011). Thus persons with sensitivities can become refugees in terms of place. Though some managed to turn this tendency on its head by connecting strongly to a natural place, most were severely limited in habitable venues.

There is a parallel to colonization in general, which involves taking another’s resources for one’s own advantage: desecration of

place—land stolen or poisoned, long hours in uncomfortable sweatshops, development on sacred sites, logging of one's forest home, or other. For those with ES, most all space is desecrated by the ubiquitous presence of toxics. Where in the "developed" world can one find a space unspoiled by pesticides, petrochemicals, or electromagnetic frequencies? The town without Wi-Fi in West Virginia notwithstanding (Gaynor & Cogan, 2015), it is an almost impossible task. As lands are denigrated and pollution increases, persons are expected to adapt to more and more artificial aspects in their milieu (Kahn, 2011). This "adaptation" has required sacrifice zones, where people endure differential exposure for the sake of others' comfort (or greed). For example, the Louisiana coastline is nicknamed "Cancer Alley" because it hosts hundreds of petrochemical plants that take an exorbitant toll on human health. The growing numbers of venues destroyed by "fracking" are also zones where people no longer have healthy options for living.

There seem to be parallels between the global colonization of mental health categories and the internal marginalization and attempted colonization of those for whom high technology is not viable. Mills (2013) speaks of "colonial subject formation" as our Western diagnostic mental health nomenclature is exported to create greater numbers of drug-dependent customers for pharmaceutical companies. Just as this diagnostic nomenclature travels the seas to colonize China and India, it inserts itself into populations "at home" where a resonant diagnostic home for physical illness is lacking, thus further enlarging its scope. So psychiatry can delegitimize and then colonize as patients those who react to products of technology in ways that others do not. Even laypersons are unable to conceptualize the dilemma of the person with ES, for, as Jensen (2004) points out, we cannot really encounter a person constructed as "the other" (p. 223). One of the best descriptions of the consequences of this hegemonic thinking that I have seen is in Kahn and Hasbach (2011), who, when discussing the paranoia toward wildness in the form of predator animals say, "With the paranoia comes the drive to eradicate the source of the fear: we kill the animal/other ... In so doing, we damn ourselves to encounters with the 'Others' who are merely reflection of ourselves" (p. 215).

Just as the mental health paradigm is used inappropriately (and sadistically) with Indian farmers who commit suicide because their sustainable way of life is obliterated by Western agricultural and trade policies, it is used "at home" in the colonial "North" with survivors of chemical and electrical injuries. There appears to be "no shame" in these actions, as US veterans are labeled with somatization disorder, even when disabled severely enough to require wheelchairs (Johnson & Starzman, 2000). In 1995 the picture of a child born

without legs to a Gulf War veteran graced the cover of *Time* magazine (Hudson et al., 1995). With chemical sensitivity, one could up to that point have wondered whether it had been ignored because of its invisible nature. Yet this picture of the child without legs permanently laid to rest the assumption of any innocent motivation for the neglect of technologically induced conditions and put it clearly on economics.

Many persons are victimized in the global rush for ever-expanding markets for goods and resources. The Indian farmer who once saved his or her own seed, the veteran who served in Iraq and/or Afghanistan, and the civilian with ES are all evidence that we need an entirely new (or rather an old) way of living on the earth—a way that values individual lives, allows for true diversity, and reverses the genocide of indigenous people by intensive resource-grabbers. Though one could hope for science to bring an understanding of the dangers of toxic exposures and thus contribute to a mitigation of these aggressive resource extraction tactics, even studies in the tradition of Baconian science are ignored in the current race for resources. Andy Fisher (2012) would say that without a different society we will not pay *attention* to the science base, as science itself is carved up and accepted or rejected, depending upon its convergence with the mainstream economic system.

For the "system" it is better that those with ES be disenfranchised and relegated to the mental health industry where they can then at least be subsumed in presently validated categories (and feed the current problematic system). Thus psychiatry first delegitimizes/marginalizes and then attempts to colonize as patients those who react to products of technology in ways others cannot. It is easy to ignore the suffering of those whose bodies are speaking to them of the damage done to them with common chemicals. Morrison (2009) says that we live under a "collective illusion—the belief that this planet is composed of a collection of unrelated and independent objects, rather than interrelated and interdependent subjects that make up a fragile and miraculous web of life" (p. 104). Thus we maintain denial and survive by separating ourselves from others' pain. I once expressed horror to a colleague regarding the terrible suffering of Maher Arar, a dual citizen of Canada and Syria, who, in 2002, was deported by the United States to Syria through "extraordinary rendition," where he endured unspeakable torture. My colleague's suggestion to me was "don't think about that."

These separated/marginalized people, though "square pegs," can then be placed into the "round holes" available in the mental health industry. To gain the client's cooperation in this process, therapists are advised, by disbelieving writers, to first earn the patients' trust and then encourage them to resume normal chemical exposures—a

medically imperialist and damaging move. Barnes, Mercer, and Shakespeare (2005) have cited Freidson (1970, 1971), who challenged that “The medical profession has first claim to jurisdiction over the label of illness and anything to which it may be attached, irrespective of its capacity to deal with it effectively” (p. 60).

Somatization is a label that was previously given to those who manifested symptoms lacking a medically recognized cause. With the advent of DSM-5 (American Psychiatric Association, 2013), it is no longer even necessary to have an absence of physical findings to receive the diagnosis, now named “somatic symptom disorder.” With this revision of the category, one may have an illness that is deemed physical but may devote too much energy or attention to the illness, or to communicating about it, in the judgment of a “mental health expert” with hegemonic categories. Dumit (2006) has taken on the diagnostic industry in his article about illnesses you “have to fight to get”: “One must have laboratory signs in order to be suffering: one must suffer in code in order to be suffering in fact, or one does not suffer at all” (p. 580).

Despite physiological findings of inflammation (Belpomme et al., 2015), hypoperfusion in the temporal lobes upon chemical exposure (Orriols et al., 2009), a change in the permeability of the blood brain barrier specifically for EHS (Johansson, 2015), and other findings, ES remain marginalized and treated only by environmental physicians, who themselves are marginalized by mainstream medical “science” for their efforts.

Eight persons with ES who had endured psychological “evaluations” submitted them to my lab for research purposes (Gibson & Bryant, 2009). Four of the eight mental health providers gave the clients purely psychological diagnoses. Two saw the problem as a mixture of both psychological and physiological causes. Two acknowledged patients had Chemical Sensitivity, and one of these diagnosed depression as a *result* of CS. The psychological labels conferred included somatization, delusional disorder, conversion disorder, mixed personality disorder, depression, and anxiety (some received multiple diagnoses). In most cases, including those with previous diagnoses of CS, the chemical intolerance was downplayed, and clients received psychological, as opposed to physiological, diagnoses.

Three of the eight diagnoses were categorized as problems of somatization. In these cases the somatization classification was due to clients’ past diagnoses (“she has been considered to have possible somatization tendencies in the past”), the clients’ acknowledged physiological symptoms consistent with anxiety (“points towards a somatization of emotional distress”), or a believed “conversion reaction” from cognitive and emotional disturbances as a result of CS reactions (“a profound conversion reaction”). Somatization has its

roots in Freudian psychology, as Freud postulated that some persons possessed “somatic compliance,” the ability to manifest psychological conflicts in the body.

One client in particular requested an evaluation in attempt to return to work. He wore a mask to the appointment to minimize reactions to toxics in the office. Although the examiner acknowledged that he had previously been diagnosed as having chemical and electrical sensitivity, the current diagnoses given on Axis I were delusional disorder, somatoform disorder, and conversion disorder. The client was seen as delusional for believing that he suffered sensitivities to chemicals and electricity. In addition, it was suggested that fictitious disorder (faking the sick role) be ruled out for this man. The global assessment of functioning score was said to be between 41 and 50 (on a scale of 100 with 100 being highest) and his prognosis said to be poor. This client was again diagnosed as having both delusional disorder and conversion disorder 2 years later by another examiner. Yet another 2 years later, he was said to have “no evidence of delusions” but again retained the diagnosis of somatoform disorder. One year later yet another evaluator returned his diagnosis of delusional disorder and retained the somatoform disorder. The client had worn his mask to all the evaluations. Finally, the last examiner stated, “There is little chance that his psychosis would improve after this number of years.” My own knowledge of this person is that he is highly skilled, functional, and intelligent. Yet the very presence of a mask and the assertion that he is sensitive to what others deem normal was enough to relegate him to the ranks of the dysfunctional and even the psychotic.

In only one of the eight cases was the client determined to actually experience environmental intolerance as the *primary* problem. The client experienced severe eye irritation, symptoms of depression and anxiety, and unemployment as a result of work-related toxic exposures, and saw a mental health professional for disability determination. In this case the practitioner concluded that mood disorder was secondary to chemical sensitivity.

This tendency toward the somatization of CS remains despite the fact that the direct effects of toxics on mental health are well known. For example, solvents are able to engender panic attacks (Dager et al., 1987), and the physiological sequelae of pesticide exposure include a large number of nervous system effects up to and including convulsions (Sherman, 1995), Parkinson’s disease (Allen & Levy, 2013), and many types of cancers (Carozza et al., 2008). Yet in the cases that I reviewed, past diagnoses of CS and organic bases for illness were usually disregarded by evaluators.

Psychological diagnoses are agreed-upon constructs that change with evolving cultural and professional thought. They lack stability,

in that the DSM is periodically revised at the whim of those with power in the American Psychiatric Association. Persons diagnosed with any of four personality disorders (dependent, histrionic, schizoid, and paranoid) almost found themselves no longer diagnosable, as the DSM-5 committee originally planned to discontinue the four labels. However, these plans were scrapped at the last minute, and the “disorders” are still included in the nomenclature. Despite this malleability of mental health diagnostic categories, these categories are seen as immutable by many and serve to prevent the diagnostic industry from having to face its failures, accept feedback, and re-vision itself in congruence with modern technology-induced illness/disability.

Barnes et al. (2005) discuss “risk discourse” that pushes people to minimize their health risk through diet, exercise, and other personal behaviors but ignores the visible and not so visible threats over which citizens have no control, such as vehicle exhaust, pesticide in public places and in drift from agriculture, toxics used in medical treatment, and others. Both Abberley (1987) and Thomas (2004) have stressed the need to recognize industrial capitalism’s contribution to disability. The expectation that people’s bodies can easily accommodate daily doses of common poisons in their home and work environments constitutes an example of what Johnstone (2001) was referring to when he said,

in a capitalist society profit and wealth through participation in the market are primary objectives, and the economics of disability service provision is dependent upon the continuation of prosperity and acquisition for those who are powerful and wealthy. Disability rights are conditional to capitalist economics. (p. 100)

Mainstream psychology and psychiatry have prevented themselves from understanding or accepting that illness can be caused by chemical technologies by their failure to integrate research from outside their fields (even Baconian research) and their firm reliance on psychosomatic paradigms rooted in Freudian psychology. Indeed they are conservative disciplines, serving under capitalism and colonialism. So how can the Western health paradigm get outside itself and see modern problems with a new lens when it itself is part and parcel of Western industrialism?

It is not sensible economically to make ill and extrude numerous groups of people in ways that will devastate future economies (e.g., lowered IQ in children exposed to lead, extreme disability in Gulf War veterans, endless searching for medical answers among those with chemical intolerance). But Nandy (2010) has said “The political economy of colonization is of course important, but the crudity and insanity of colonialism are principally expressed in the sphere of psychology” (p. 2). The cultural approach to CS is thus more emo-

tional than rational and extrudes with enthusiasm those who threaten to impede technological growth.

Though the perceived disorder in those with ES is actually only a by-product of a society-wide disorder that includes excessive faith in and reverence for technology and industry, technological stressors *must* be ignored, by not only health-care providers but by others, to meet the capitalist goal of limitless growth. Of course it is widely recognized that this goal *cannot* be met, as it would be physically impossible for our earth to support the high level of industrial consumption “enjoyed” in the most highly “developed” nations (Merchant, 2005; Mies, 1993; Porritt & Nadler, 1991). Fisher (2012) cites Berry’s (1977/1986) claim that the goal of the system is to separate people from “sources of life,” give these sources to corporations, and then “sell them back to us at highest profit” (p. 102). But the transformation of these “sources” almost always makes them toxic (pesticided food, chemically treated clothing, formaldehyded wallboard) such that persons with CS cannot use them.

The problem of environmental intolerances, then, poses a challenge that industrial culture *cannot* meet. To truly understand the genesis of and the stresses posed by chemical and electromagnetic intolerances requires a reflexive construction of the context in which our very systems are situated. Whether or not *any* systems within industrial capitalist societies can truly grapple with the implications of these “contested” conditions remains to be seen. Meanwhile the level of medical resources used by persons with CS is many times that of persons with better-understood conditions, though most of these services are rated by users as not helpful (Gibson et al., 2003). Neither do we have cures for Gulf War syndrome, the disabling symptoms experienced by persons near ground zero on 9/11, or illness in EPA personnel caused by the renovation of the EPA’s Waterside Mall (Johnson, 2008).

Mills (2013) cites Nandy (1983), who writes of non-Western people being so colonized that Western categories of knowledge pervade even their dialogues with one another. Psychiatry would like to do this with persons with ES, but grassroots support has offered a strong paradigm for reading the environment and acting in accordance with one’s own body. People with ES have become savvy regarding these moves and hence control what information they share with providers who cannot understand true diversity (Gibson et al., 2016). Thus people resist true colonization, and a new category of illness may eventually emerge from this phenomenon into hegemony.

Though psychology prides itself on integrating diversity, to understand true diversity, one must understand indigenous ways of being—ways not addicted to technology. Jensen (2004) said, “If we cannot perceive others in a diversity of ways, we will destroy the diversity we cannot perceive” in the interest of

monolithic control, toward production—which, after all, is nothing but the turning of the living (forests) into the dead (two-by-fours), the living (mountains) into the dead (aluminum cans)—toward the annihilation of all that is different. In other words, it calls for the annihilation of life. (pp. 419–420)

This is all possible through the externalization and objectification of nature (Merchant, 2005) that in the 16th century created an internal psychology (Fisher, 2012) with humans thus de-contextualized (Gibson, 1997). The result demands that our technological environment is not and cannot be responsible for personal harm, as psychology concerns itself only with what happens between the ears. Thus our own difficulties have internal causes, and we receive the deserving diagnoses. It is no wonder that persons with ES report that contact with mental health providers is highly negative (Gibson et al., 2016).

People with ES are a fairly new group (though many have been sick for 30–40 years) that has been rendered irrelevant to mainstream economic commerce. How many more demographics will industrial conglomerates destroy before the very principle of growth at any cost is questioned and, more importantly, replaced by a sustainable paradigm? Shiva (1989) extensively documents the plight of indigenous women, excluded from the economic “plans” for India because their work is sustenance-related, does not produce cash crops, and is congruent with natural cycles. They are deemed irrelevant by Western water/environment managers who compartmentalize problems and are unable to see the connections between deforestation and drought, cash-cropping and poverty, fish-farming and salinization of water. That Indian women know how to purify water without chlorine (that becomes chloroform or another trihalomethane when hot water is run) is an iconic example of a heavy-hitting, toxic, industrial process trampling a community-centered sustainable one. Like Indian women, those with ES are not deemed as reliable sources of information. Those sensitized/damaged by chemical culture and thus painfully aware of the consequences are labeled as mentally ill—like the Indian farmers who commit suicide due to lost livelihoods.

Western science has ignored natural consequences of heavy chemical use and unsustainable practices to the destruction of lifestyles of those in the Gulf of Mexico (BP), fisherpeoples in Alaska (Exxon/Valdez), Gulf War veterans, and numerous racial minority communities who inhabit heavy industrial zones (Bullard et al., 2007).

Thus people with ES must endure illness for the current economic model to continue. They and other groups absorb a portion of the costs of our highly technological, resource-extractive business model that benefits a small number of persons. Mental health diagnoses keep this population in check so that complaints about toxics are not

taken seriously. On the other hand, “If you become so delusional that you no longer see trees, human beings, a living planet, but, instead, dollar bills, workers, resources—far from being put away, you may find yourself well-rewarded, perhaps the CEO of a corporation” (Jensen, 2004, p. 224). In his conversation with his friend Richard Drinnon, Jensen (2004) hears that we must “tame” those who are closer to the body or who live close to nature. People who get in touch with the damage chemicals cause them are therefore dipping dangerously close to crossing the line into savagery and must be managed, or dispensed with.

Dispensable groups in the United States may include veterans with health needs, those with ES, small farmers, minorities, people with disabilities, the elderly, the “undocumented,” and the poor, among others. Once one tallies the numbers in each of these groups, how many remain who are truly indispensable? The economic system of capital is working for only a small, temporary, elite. Some hang on at the margins, many fall off, and some are outright destroyed. As Shiva and others have pointed out, when problems are acknowledged, nature-destroying “solutions” are proposed. Mander (1991) reviewed several ludicrous examples of proposed techno-fixes, including covering the oceans with polystyrene chips to reflect sunlight, releasing the pollutant sulfur dioxide from jumbo jets to block sunlight, and shooting ozone bullets into the stratosphere to correct ozone holes. More evidence that we have learned nothing is in the proposals for numerous “natural” gas pipelines in the United States to export gas to Japan, made energy-poor by the meltdown at Fukushima, and for the corporate forced industrialization of India.

What role can ecopsychology play in acknowledging marginalized and colonized people (and nature)? Fisher (2009) charges that without a “critical theory of society,” the politics of ecopsychology will “remain undeveloped and default in the direction of psychologism” (p. 63), as evidenced in psychology’s treatment of those with ES. A few years ago I spoke at a holistic health fair with the help of my Dalmatian-mix, Fred. I pointed out that dogs like Fred were being euthanized in high numbers at shelters all over the United States, at the same time that we were entertaining ourselves with Dalmatian movies, stuffed animals, calendars, statues, posters—all substitutions of the unreal for the real. Though a Dalmatian calendar may not at first glance appear to qualify as Kahn, Ruckert, and Hasbach’s (2012) perverted instantiation of a relationship with nature, it nonetheless fools us into ignoring the true perversion in the form of pervasive killing of the real embodiment. With our awareness focused on the calendar and not the real, “Our collective lens is object focused and cast at the near point” (Sewall, 2012, p. 269), and we thus atrophy our sensory abilities to focus on and experience the natural (Sewall). Thus

it is a part of the perversion of a relationship with this form of nature (Kahn et al., 2012). The unreal can never satisfy us completely. Yet a new generation of people is growing up with a firm focus on the unreal. My students tell me that their younger siblings become angry when forced to go play outside. Without early training in interacting with the real, generational amnesia threatens to override any attempts to improve our way of encountering either nature (Kahn, 2011; Kahn & Hasbach, 2012) or the “other” in the form of one made different by our neglect and remaking of all that is natural. Shepard (1998) said that the child, as a result of missing the 8- to 10-year period of growing up in nature that is normal in indigenous societies, and living in a “fabricated environment,” comes to feel that “non-livingness is the normal state of things” (p. 102) and perhaps that all life is machines or that people comprise the only living things. If the world is not alive to communicate with the child, the only choices are to be “a spectator or an exploiter.”

I do not believe that the concepts of chemical or electrical hypersensitivity can ever be addressed in isolation from the generational slide in the acceptance of unreal environments. Whether we will stop this slide is questionable, though Kahn (2011) suggests that we must immerse our children in nature and help them understand that they are seeing a degenerated version of the world. For my part I will attempt to teach this to my students. Even persons with CS sometimes report having been “asleep” in regard to environmental issues before the onset of their illness. The very occurrence of ES may well be a mechanism by which persons, not initially aware of the deteriorated state of their context, are grabbed violently by the world and shaken. Once shaken, they threaten the “made world” (Shepard, 1998) and become marginalized in the process.

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