Chemical Sensitivity/Chemical Injury and Life Disruption

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This paper describes life disruption associated with chemical sensitivity using data collected in an ongoing study of 305 persons (80.3% female) self-identified as having environmental illness (EI), multiple chemical sensitivity (MCS), or chemical injury (CI). Having MCS was associated with reported difficulty in work, finances, quality of available medical services, access to public space and resources, relationships, and considerable personal distress. Many of the respondents reported experiencing the loss of livelihood, home, and mobility due to living with an unrecognized illness/disability with little medical or social support. Helping professionals are in positions to offer their clinical skills to provide help and support to this population, so a discussion of clinical implications is provided.
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Introduction

The impact of our chemical environment on women's health is a new and poorly understood area of study. In this area, as in many others, health conditions that challenge existing paradigms for understanding illness are often controversial. This is true in the case of multiple chemical sensitivity (MCS), also referred to as environmental illness (EI), chemical hypersensitivity, chemical injury (CI), 20th century disease, and other labels. Although there is disagreement as to how narrowly or broadly this condition should be defined for research and treatment purposes, MCS/EI or CI is a chronic multi-sensory disability caused by negative reactions to environmental incitants modified by personal susceptibility and specific adaptation (Ashford & Miller, 1991; Bascom, 1989; Bell, 1982; Randolph & Moss, 1982; Ross, 1992). Persons vary in the constellation of substances to which they react, and in the specific symptoms triggered by the exposures. Symptoms may relate to any organ system (e.g., respiratory, cardiovascular, digestive, central nervous), and may include reactions such as rhinitis, fatigue, nausea, dyspepsia, increased or decreased heartrate, dizziness, confusion, irritability, and headache. Susceptibility in an individual may change over time, may worsen, and may be affected by whether or not the person is presently in an "adapted" state (Randolph & Moss, 1982).

Substances that may trigger negative reactions can include all modern chemicals in addition to foods and pollens traditionally recognized as incitants. Chemicals most commonly described as causing reactions include petrochemicals, pesticides, household cleaners, exhausts, air fresheners, dry cleaning odors, smoke, perfumes, and others substances (Ashford & Miller, 1991; Lewith & Kenyon, 1985; Randolph & Moss, 1982; Rogers, 1990).

Disagreement among medical practitioners surrounds this condition, and so patients are often left to fend for themselves.

About three quarters of persons affected by this condition are women (Cullen, Pace & Redlich, 1992; Heuser, Wojdani & Heuser, 1992; Kipen et al, 1992; Ross, 1992) although it is not
clearly understood why. Miller (1992) has discussed the preponderance of female patients, pointed out that a number of conditions including connective tissue diseases seem to affect women more than men, and suggested that "because the maternal immune system is challenged with paternal antigens during pregnancy, its immunologic repertoire and responses may somehow make it more vulnerable to chemical exposure" (p. 186). Other possible factors in the seeming gender imbalance in regard to chemical sensitivity may include the fact that many chemicals are hormone mimickers (particularly estrogen) (Paulsen, 1993), and the indoor air pollution levels in the the average home.

There is little knowledge regarding the psychosocial impacts of living with a health condition that is not only unrecognized by our society, but, given the need to avoid exposure to chemicals, requires a substantial degree of isolation for survival. Among the preliminary work which has been done is Rippere's (1983) book addressing the psychosocial aspects of severe allergy, the work of Davidoff (1991), Ziem and Davidoff (1992), Fiedler and colleagues (Fiedler, Maccia, & Kipen, 1992), and Gibson's (1993) discussion of the secondary effects of the stresses of coping with MCS/CI.

Given the reported difficulties for this population, it is important for social scientists to begin to understand the psychosocial impact of MCS/CI, and for therapeutic interventions to be tailored specifically to the needs of this population. Some suggestions from the Expert Panel on Multiple Chemical Sensitivity convened by the Agency for Toxic Substances Disease Registry (ATSDR) ("Expert Panel", 1993) for studying MCS populations included conducting neurological research, doing prevalence studies, constructing an environmental control unit to observe patients' reactions to substances, conducting educational workshops, and developing a data base of self-identified persons with MCS. The present research has used the later method to describe life impacts of living with chemical sensitivity from data collected in an ongoing study of persons self-identified with MCS/CI.
Method

Participants

Participants for this study were drawn from several sources. Ads requesting participation from persons with multiple chemical sensitivities were placed in one national publication and one newsletter for chemically sensitive persons. Several leaders of support groups for persons with chemical sensitivity distributed questionnaires at support meetings. In addition, questionnaires were mailed to a random sample of about one-third (n=412) of the membership of the Chemical Injury Information Network, a nationally recognized organization that aims to support and educate persons around the issues of chemical injury. Questionnaires were also placed in offices of several physicians who specialize in treating chemical sensitivity. No physician validation of diagnosis was required, as few physicians treat MCS/CI. There is currently no agreed upon definition or diagnostic procedure relating to MCS that is seen as valid across medical specialties, and we believe that it is important to give credibility to our respondents' stories.

Procedure

Information was collected in two parts from persons who either phoned or returned request-to-participate forms printed in newsletters. Those drawn from the CIIN membership list were simply mailed questionnaires with requests to participate. When questionnaires were returned, any identifying information was removed.

Measures

In round one, participants were asked to respond to a 25 page questionnaire that included both closed and open-ended questions addressing variables such as demographics, relationships, severity of symptoms, and details about coping with their levels of chemical sensitivity.

Round two followed up on participants’ comments regarding financial difficulty including declining income, worker’s compensation and disability claims, costs of creating safe living spaces, and medical costs. Respondents were also asked to report on the number of medical and mental health providers seen and rate their effectiveness. Finally, because it appeared from the results of round one that a substantial number of women respondents did not have children,
we asked whether or not chemical sensitivity had affected these participants' decisions not to have children.

This article gives a general overview of life impacts of chemical sensitivity/injury with emphasis on practical variables such as finances and availability of medical and psychological help. Suggestions for supportive psychotherapy are offered.

**Results**

Of the 305 first round questionnaires returned, 32% were from the Chemical Injury Information Network, 19% were from a newsletter ad, 16% were from the ad in the national publication, 7% were from The National Center for Environmental Health Strategies, 6% were from support groups, and 2% were from physicians’ offices. Eighteen percent learned of the study from other sources (probably from others with MCS/CI), and 0.7% did not respond to the question asking where they learned of the study. The final convenience sample of 305 self-identified persons had a mean age of 46.8 years (ranging from 23–79). Women comprised 80.3% of the sample (n=245). Of these total respondents, 288 persons volunteered to participate in further research and were mailed the round two questionnaire six months later. Of these, 268 returned the round two questionnaire in time to be included in these analyses, a 93% return rate. Therefore, some of these data are based on 305 participants in round one, and some on 268 participants from the second round. Participants reported having symptoms caused by chemicals for a mean of 15 years (SD=13.6), but did not attribute their suffering to MCS for a mean of 7.5 years (SD=10.2). Participants include 282 Caucasians, 15 Native Americans, 3 Latina/Latinos, 2 Asian Americans, and 2 "other." Respondents reported experiencing varying levels of chemical sensitivities including mild (12.8%), moderate (31.1%), severe (39.3%), and totally disabled (15.7%). There is no way of determining whether this sample is representative of the population of persons with chemical sensitivity, as there is presently no agreed upon definition of this condition.
Job/Work

Less than a third of participants reported working outside of the home. Over half of those who reported an initial known exposure that damaged their health reported that it occurred in the work environment. Of the 268 round two participants, 205 (76.5%) reported having lost their jobs or having had to quit their jobs because they were unable to tolerate the chemicals in their work environment. Of 305 round one participants, only 22 (7%) are currently working in conditions that they consider safe for their health. Declining motivation for work and increased stress in relationships with co-workers were commonly reported experiences as participants attempted to avoid workplace chemical exposures. Co-workers were often not receptive to requests to discontinue fragrances or other personal care products that were a source of difficulty for the workers with chemical sensitivities.

Finances

Although household income for our sample averaged about $35,000, mean personal income for participants was a little over poverty level. Most persons suffered a drastic decline in income since becoming chemically sensitive, and the mean reported decline in annual income was $17,761. Of the 151 persons (of 268 in round two) who sought disability, 85 were successful, 26 were denied, and 43 currently had cases pending. The mean disability award was $12,019, and took an average of two years to obtain. Participants reported that the mean cost of obtaining disability was $2,509. Some respondents gained disability for a diagnosis of chemical sensitivity. Others felt so desperate for benefits that they allowed their attorneys or physicians to use psychiatric diagnoses in order to obtain compensation for them even though they disagreed with those labels. Others obtained compensation, but did not know what label was used to gain benefits.

Medical Care

Medical care was particularly troublesome because few physicians are familiar with environmentally related disorders. The 268 round two participants reported seeing a mean of 8.6 medical practitioners each. Of these practitioners, 27% were described as being helpful.
Respondents reported spending a mean of $5,784 on medical care in the last year, and a mean of $34,783 over the course of their illness. Over one quarter of the sample still did not have a doctor knowledgeable about chemical injury at the time of data collection. The 220 participants who felt that they had doctors educated about chemical sensitivity saw practitioners in clinical ecology/environmental medicine (37.7%), general practice (11.5%), homeopathy (6.6%), chiropractic medicine (5.6%), occupational medicine (4.3%), psychiatry (2.6%), and immunotoxicology (2.3%).

Persons perceived severe difficulties in getting help and being taken seriously by the medical profession. Many participants reported that physicians and other health professionals refused to investigate their claims that they were being made ill by chemicals, and that in many cases they were even encouraged to expose themselves to chemicals as part of an effort to "deprogram" them from their belief that chemicals were making them ill. Many respondents believed that they had suffered iatrogenic harm due to unnecessary medical treatments based on faulty diagnosis. Respondents believed that they had suffered harm from drug effects (n=161), delay in diagnosis (n=48), treatment for the wrong condition (n=28), invasive medical tests (n=31), one unnecessary surgery (n=36), two or more unnecessary surgeries (n=5), three or more unnecessary surgeries (n=7), and electric shock treatments (n=4). Only 32% of respondents received their initial MCS diagnosis from a physician. Many (47%) reported having self-identified their chemical sensitivities before receiving an MCS-related diagnosis and treatment.

Contact with mental health practitioners was felt to be particularly troublesome. A total of 549 mental health providers were contacted by the 187 of our respondents (of the 268 persons in round two) who sought psychological help. Of these 549 providers, only 92 (16.8%) were seen as being educated about chemical sensitivity, and 197 (35.9%) as being in any way helpful. Respondents felt harmed by mental health providers in various ways, including having their symptoms of chemical sensitivity ignored or de-emphasized (n=119), receiving psychiatric labels (n=102), being given psychoactive medications (n=83), having psychiatric hospitalization
suggested (n=33), and being psychiatrically hospitalized for what they believed were symptoms of chemical sensitivity (n=28).

**Housing**

Participants attempted avoidance of chemical exposures through replacement of household items such as carpets, formaldehyde board, plastics, and others. But, for many, income decline accompanied the growing perception that living conditions were unsafe. Consequently, many respondents reported either continuing to live in unsafe conditions, or spending their life savings to redo their homes and purchase air purifiers or other necessities. Participants reported spending a mean of $27,816 to redo their homes. Many had moved repeatedly in search of safe homes in which to reside. When asked how safe their current home was, 5% of participants replied that their home was "very safe," 35.6% said it was "mostly safe," 43.9% said it "should be better," 10.9% said it was "mostly unsafe," and 4.6% said it was "not at all safe." Some respondents reported being unable to tolerate any traditional housing due to chemicals used in construction, and they lived in very unusual conditions. For example, one respondent had lived in her horse trailer for a year. Others described being homeless or living in their cars, in RVs, in one purified room in their house, or in tents. Sixty-six percent of participants reported living in highly unusual conditions such as these at some point in order to avoid chemical exposures.

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Some respondents were able to construct or arrange safe housing, but then felt like prisoners in their homes while trying to avoid outside exposures. Participants reported staying inside to avoid neighbors' use of pesticides and herbicides, paints, fabric softeners in dryers, construction chemicals or other contaminants. Being housebound by some degree was a common experience. Some respondents (7%) reported becoming ill from taking walks outside near their homes due to outside chemicals such as petrochemical exhausts and pesticides. At the time of our study, 8% were totally housebound. Even if the immediate area surrounding the constructed safe house was viable, venturing into the larger community was a reported hazard
for many respondents. Many participants volunteered that they had to avoid church (11%), malls (25%), movies (8%), and restaurants (19% cannot go at all and 23% go only rarely and with extreme care). Almost half of the sample said they were unsafe in any public areas in which perfume was likely to be encountered, and many reported being so sensitive to personal care products that they were unable to have visitors in their homes if those persons had used perfume. Participants said they had lost access to continued education (24%), involvement in hobbies (e.g., painting) (33%), travel (22%), socializing (17%), and visiting family (9%). Relationships

Sixty-one percent of the 305 participants said that they were in romantic relationships, and 82% of those in relationships said that their partner was either somewhat or very supportive. A majority, 77%, said that their partners believed "fairly strongly" or "very strongly" that chemicals were the cause of their symptoms. Ninety-four persons or 31% of the sample reported experiencing a romantic breakup since becoming chemically injured. When we asked those who suffered a break-up to what extent their health contributed to it, only 26% said that the illness contributed "not at all" or "very little." Although most persons did not report the loss of romantic relationships, almost three quarters of those who did suffer break-ups believed that their illness contributed to ending the relationships. Many women with MCS/CI in the sample had decided not to have children for health-related reasons. Of the 245 women respondents, 64 said they did not have children. When asked whether chemical sensitivity had been a factor in their decision not to have children, 35 replied that it had. Of these 35 women, 10 felt that their health was too impaired to carry a child, 19 said they feared it would worsen their own health to carry a child, 18 said they were unable to go to medical offices due to the chemicals in those environments, 18 reported they were unable to financially provide for a child due to their health, and 24 said they feared their children would inherit chemical sensitivity. Some persons reported more than one reason.
Personal Distress

Many respondents reported on surveys and during telephone conversations that they had experienced severe stress and trauma due to the life changes and losses that occurred as a result of their chemical sensitivities. Many persons were living without necessities such as housing, medical care, and public access. Others had access to necessities, but reported other kinds of losses such as career advancement, education, travel, hobbies, and community involvement. Further personal distress was reported to occur as a result of the lack of attention and concern for this health problem by the medical profession and the public in general. For some, stresses had become overwhelming. One fifth of the sample of 305 had seriously considered suicide, 8.2% had made a plan, and 3.3% had attempted suicide.

Discussion and Treatment Implications

Severe life disruption was reported by participants in this study as a result of living with chemical sensitivity/injury. Persons reported losing access to jobs, medical care, housing, family contact, and children. Loss of livelihood was reported by a majority of our respondents due to the level of chemical exposures in the average workplace. Serious financial loss followed loss of livelihood, and drastic declines in income and/or savings were reported. Many persons reported using all of their own financial resources and having to depend upon family while they waited for worker's comp or disability claims to be processed. A decline in income was paired with an increase in medical costs for most persons in the sample. The shortage of medical experts seems to lead persons with MCS to search from one doctor to another until they locate someone helpful. Women participants expressed considerable anger at not being taken seriously by primarily male physicians who were in positions to evaluate them. Our study shows that persons with chemical sensitivity may be so severely impacted as to be insolvent, homeless, jobless, and without social support systems. Many persons in the sample reported living marginal lives while struggling to secure what healthy persons or those with better understood health problems take for granted: safe housing, basic necessities, meager social support, and
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Therapeutic Considerations

In spite of the fact that pioneering work in the area of illness caused by chemicals was done in the fifties, there is still no agreement regarding causality, treatment, or compensation regarding this problem. Participants expressed anger over the emphasis on individual behaviors such as smoking, diet, and other person-controlled variables which calls attention to personal responsibility for health maintenance, but offers no help to persons who suffer health effects from chemical exposures over which they have no control. With little medical, legal, or economic aid available, individuals with chemical sensitivity/injury constitute a hidden population (Gibson, 1993) of persons who suffer severe life disruption as a result of chemically-related health problems.

The combination of neurological signs, physical symptoms, life disruption, and lack of resources can present a confusing picture to both patient and practitioner, and many of our respondents either sought services from or were referred to mental health providers. Overall, respondents were very dissatisfied with the help they received, as less than one fifth of the mental health providers consulted were described as being educated about chemical sensitivity. It is vital to give some attention to considerations regarding therapy and advocacy for this group. Without a knowledge of and sensitivity to MCS/CI issues, a therapist has little chance of providing the much needed support that may make the difference between the client's coping with a difficult chronic health condition, and breaking down totally under the stress and loss inherent in the condition.

Therapy with the chemically sensitive/chemically injured client

The chemically sensitive woman has her already nondominant status re-emphasized by virtue of her inability to tolerate chemicals in a culture where they are ubiquitous. The chemical sensitivity will compound and be compounded by other demographic variables such as ethnicity, race, and class; thus the therapist is challenged to continue her own nondomination training (Brown, 1994). The therapist is challenged to apply the principles of feminist therapy to a
problem area that may be new to her. "Feminist therapy theory defines clients as
the experts about the meaning of their lives and their pain, the goals of their therapy, and
success of their treatment" (Brown, 1994, p. 115). Therefore the first rule must be to listen and
learn from the client. Many persons with MCS/CI have had to develop considerable medical
knowledge in order to survive, and thus are often in good positions to educate others regarding
their condition. But this does not mean that they cannot benefit from the validation and
empathy that would characterize good feminist therapy.

Understanding that the level of sensitivity will determine much about the lifestyle. There
will be great differences in the necessary lifestyle modifications between those with mild
sensitivities and those whose sensitivities have become severe. Many persons without
sensitivities are able to understand mild or isolated reactions, but draw a blank when confronted
with someone who is virtually unable to tolerate any exposures. Some persons are unable even
to be around others who will secondarily expose them to odors they have picked up from others
on their clothing or hair. It is probably in reaction to their misunderstanding of those with severe
sensitivities that critics charge "chemophobia" and suggest "desensitization."

Expecting some reactions that mimic "psychiatric" symptoms. Chemical sensitivity/ injury
may create severe stress, anxiety, and depression both as primary reactions to exposures and
as secondary reactions to loss and disintegration of previous lifestyle. Critics have used the
presence of neurological reactions as grist for suggesting that chemical sensitivity is a
psychiatric disorder. However, petrochemical exposures can cause depression (Randolph & Moss,
1982), anxiety, and even panic attacks (Dager, Holland, Crowley & Dunner, 1987). In fact, many
persons with MCS/CI report developing phobias after the onset of the chemical sensitivity, but
no research has directly addressed this. At the same time, any pre-existing or unrelated mental
health needs should not be ignored. Certainly, other concerns do not disappear just because a
person has developed sensitivities. Deciphering when the MCS is relevant can be a shared task
with the client, and will require a good working knowledge of MCS-related issues as well as a
sensitivity to the dynamics operating with a specific client in a specific context.
Being flexible about the time and place of meeting and fee. Some clients will need modifications in the office setting. Small modifications might include getting rid of air fresheners, potpourri, perfumes, and other odors in the office. Some clients will be unable to go to the office even with these modifications (perhaps due to the heating system, pesticides, or perfumes used by other clients) and may best be seen in their homes. Additionally, with these clients, cancellations are more likely to be the result of erratic energy levels and illness due to unavoidable exposures than to resistance or lack of follow through. Financial difficulties may prevent many with MCS/CI from obtaining therapy unless some flexible arrangements can be made.

Helping the client plan for how to care for herself when in a reaction. In between exposures, clients may need help making plans for themselves as to what they will do when they know they have suffered a debilitating exposure. As some exposures entail mental confusion as well as physical illness, clients may do well to plan for them before the confusion sets in. Some of the special needs during reactions may include needing to ask for physical assistance, getting away from the offending chemical, taking any particular remedy that mitigates ill effects, taking special care to control irritability brought on by the exposure, etc.

Helping the client to validate her own knowledge. Even clients who are considerably educated about their condition can forget that they are the experts in regard to how chemicals and the illness/sensitivity process affects them. For some, avoidance may even be a matter of life and death. Yet, persons with this condition are in a position of having to be assertive about something that few people understand or respect.

Helping the client face planning for a future that may include some disability. Although some persons with MCS/CI recover to some extent, and a small number report recovering completely, many do not. Considerable fear may be associated with an unknown course of illness (Gibson, 1993). The client may need help making plans to confront work problems, financial difficulties, and perhaps more physical disability. Another aspect of long term planning includes helping the client let go of earlier goals that are now unattainable. Since the
sensitivities dictate what environments are feasible, there will be roles that must necessarily be abandoned or never attained.

**Resisting pressuring the client into one's own choice of cures.** Esten and Willmott (1993) have written of the therapist's need to "cure" the client of having a disability: "With all good intentions the therapist tells the client of diets, snake venoms treatments, special exercise programs, and vitamin regimes that will rid them of the problem" (p. 31). This is not to say that there are no helpful interventions for MCS. On the contrary, many participants in this study reported obtaining help from a variety of treatments. However, it is the client who must make the decision to try yet another type of therapy. These decisions must be viewed in the context of knowing that the client has probably already spent considerable funds, time, and energy trying various treatments.

**Helping the client come to terms with constant challenges/changes in regard to identity.** Each increase in the level of sensitivity as the condition progresses poses new challenges for the chemically sensitive woman. If new sensitivities develop, further life restrictions may ensue. Feminist psychologists have struggled to place persons in context in order to understand behavior, but the client with MCS is in the unique position of having her contextual background shrink with increasing limitations until much of what she identified with as "self" is no longer available. One respondent in this study dealt with this by actually giving herself a new name, as she felt that her old self was "dead" now that she was forced to live an entirely new and isolated lifestyle. Although family members were upset by this, for her it represented a tangible way of naming her experience and going forward. Other clients may struggle with the need to be ever-vigilant regarding exposures and mourn the loss of a spontaneous lifestyle. Clients with MCS, perhaps much like those with MS, need to confront, integrate, and mourn each new loss or change in self that occurs as functioning slowly diminishes. Friedman (1993) has discussed the tremendous personal shock of becoming quadriplegic in an instant as a result of a car accident. Conditions like MCS, in contrast, *may* have the "advantage" of spreading slowly over time thus giving a therapist the opportunity to offer support as one stable element in the process.
Even though changes come slowly, the loss of access and functioning is likely to be cause for shame and embarrassment. Barshay (1993) has said:

We try to "pass-for-well", sometimes in order to avoid the hatred and disbelief of others, sometimes to avoid our own shame and self-hatred. It is as irrational to be ashamed of being sick as to be ashamed of being raped or beaten, but there it is, that deep and ancient women-shame in another form. . . . So it is possible that you may ask how I am, and you may have recognized and put aside your disbelief and hatred, and I still won't be able to tell you right away because I'm too ashamed of myself and what my life has become. (p. 168)

**Supporting the client's move to the political.** If possible and if the client desires it, helping her to connect with advocacy organizations may urge her to a new level of growth. Many MCS sufferers have made serious contributions to public education and legislative advocacy in relation to MCS and the environment. For many clients, this will happen naturally as they learn of legislative and educational projects. Others may need to be made aware of the major organizations that have been formed to deal with MCS-related issues. Therapists should be familiar with major organizations that address MCS-related issues in order to provide resources and remain current on political and legal discussions in the area. Many health providers with an interest in the area join a number of these organizations for self-education and to procure resources. A list of these can be obtained from the first author.

This is necessarily a brief introduction to therapy considerations with persons with chemical sensitivities/injuries. More will be learned by listening to persons who tread the path of the impossible – living in the modern world while it is poisoning them. Feminist therapists, by virtue of their belief in respect for and validation of the client are in excellent positions to lead other therapists into an understanding of the therapeutic needs of this group of persons.
References


