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The Phenomenology of Multiple Chemical Sensitivity at Four Levels of Severity

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Paper presented at the annual convention of the American Psychological Association, August 15–19, 1997, Chicago, Illinois. In P. Gibson (Chair). Multiple Chemical Sensitivity: An Emerging Social, Environmental and Medical Issue.

This study explored chemical incitants, symptoms experienced, and sickness-related behavioral dysfunction as measured by the Sickness Impact Profile (SIP) in 254 persons self-identified with Multiple Chemical Sensitivities (MCS). Chemicals rated as causing the most symptomatology in respondents were pesticide, formaldehyde, fresh paint, new carpet, diesel exhaust, perfume, and air fresheners. The five most commonly cited symptoms in this sample were tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties, and long-term fatigue. Overall mean SIP score was 25.25%, showing serious impairment in comparison with other chronic conditions, with the most serious dysfunction in the categories of Work (55.36%), Alertness Behavior (53.45%), and Recreation and Pastimes (45.20%). Respondents rated themselves as to level of severity of their condition using an instrument designed for use with MCS. Results are discussed in terms of environmental, social, and medical issues.

Introduction

Even though initial population studies in the U.S. find that between 15 and 33% of persons report having chemical sensitivities (Bell, Schwartz, Peterson, & Amend, 1993; Meggs, Dunn, Bloch, Goodman, & Davidoff, 1996), and large numbers of people contact education and advocacy groups each week for information about their own reactions to chemicals, the problem remains understudied and poorly understood (Ashford & Miller, 1991). Because reactions to chemicals can be so debilitating, people with sensitivities attempt to avoid exposures, thereby limiting their contact with other people and their access to vital resources such as work, leisure, and medical care (Gibson, Cheavens, & Warren, 1996).

We conducted this study in order to examine the life-altering impacts of chemically induced illness and to identify the symptoms and behavioral limitations of MCS at four levels of severity. Data available using the Sickness Impact Profile (SIP) allowed us to compare the impacts of MCS with better understood and more readily accepted medical conditions, and SIP subscales allowed examination of any pattern of functioning that may occur in MCS. In addition, we hoped to educate professionals and the public about the psychosocial aspects of a poorly understood health condition.

Method

Participants

Participants are 254 self-identified persons with Multiple Chemical Sensitivity.

Procedure

Participants were initially gathered through advertisements in newsletters and publications geared toward people with MCS, physicians' offices, and MCS support groups, and by contacting a random sample of the membership of the Chemical Injury Information Network, an educational and advocacy group relating to chemical injuries. Participants completed a confidential mail survey.

Measures

We used results from other studies to generate a list of 29 chemicals affecting persons with MCS (Bell et al., 1993; Meggs et al., 1996; Miller & Mitzel, 1995). These chemicals included pesticides, auto exhaust, smoke, perfume, and others. Persons rated the severity of their illness reaction to each chemical on a 4-point scale from 1 = 'no reaction' to 4 = 'very ill.' A list of 31 symptoms was generated in the same manner (Bell, et al., 1993; Meggs, et al., 1996; Miller & Mitzel, 1995). Symptoms experienced were rated similarly on a 4-point scale from 1 = 'not at all a problem' to 4 = 'severe problem.'

Severity of condition was measured by a 4-item scale designed specifically for MCS (E.I. Disability Classification, 1987). Respondents read descriptions of increasingly severe MCS and rated themselves as mild, moderate, severe, or totally disabled (Table 1).

The Sickness Impact Profile (SIP) (Bergner et al., 1976a; Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976b) was used in order to obtain a personal, subjective assessment of the influence of MCS on the daily lives of individual respondents. The SIP is a "behaviorally based self-report measure" (de Bruin, de Witte, Stevens & Diederiks, 1992) developed for the purpose of measuring health status. It is meant for use in health surveys, program planning and policy implementation, and in monitoring patients' progress in terms of illness (de Bruin et al., 1992). The instrument consists of 136 items grouped into 12 categories. The categories of Ambulation, Mobility, and Body Care and Movement measure the physical limitations of an illness. Four other categories, Social Interaction, Communication, Emotional Behavior, and Alertness Behavior, measure the psychosocial dimension related to a chronic illness. The remaining independent categories include Eating, Work, Sleep and Rest, Household Management, and Recreation and Pastimes. Because the SIP shows satisfactory test-retest reliability, high internal consistency, and good content, criterion, and construct validity, it is known as a valid and reliable measure of health status and daily functioning (de Bruin et al., 1992). Scores are yielded for total dysfunction, physical functioning, psychosocial functioning, and 12 categories as percentages of the maximum possible dysfunction.

Completed surveys were returned by 254 persons. Respondents were 82% women, primarily Caucasian, had a mean age of 49, and developed chemical sensitivity at a mean age of 33. Only 32% were employed. Mean personal annual income for the sample was \$18,300. Annual personal income had declined \$26,000 following the development of MCS. When asked to rate the severity of their condition, 11% of participants rated their condition as mild, 29% as moderate, 43% as severe, and 11% as disabled. Causes of chemical sensitivity were attributed to one large chemical exposure for 21%, a series of low level exposures for 53%, and a physical illness for 6%, and were unknown for 15%. Sample characteristics are shown in more detail in Table 2.

Chemicals rated as causing the most symptomatology in respondents were pesticides, formaldehyde, fresh paint, new carpets, diesel exhaust, perfumes, and air fresheners. Table 3 lists all 29 chemicals and participants' mean illness response for each.

The five most commonly cited symptoms in this sample were tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties, and long-term fatigue. Of the 15 symptoms receiving 2.5 or higher ratings on the 4-point scale, 8 were clearly central nervous system related, 2 were musculoskeletal, and 2 were gastrointestinal. All symptoms and their ratings are listed in Table 4. Interestingly, the five most highly rated symptoms are all major symptoms of CFIDS, suggesting considerable overlap between the two conditions.

Total Sickness Impact Profile scores are shown in Figure 1 for this entire sample in comparison with samples with other illnesses. Overall mean SIP score for this sample was 25.25%. Patrick and Deyo (1989) summarized the literature on the use of the SIP with a number of chronic illnesses. Comparing our data with that of Patrick and Deyo, we find that our respondents demonstrated more dysfunction than persons with Angina, Crohn's Disease, Rheumatoid Arthritis, Chronic Lower Back Pain, and Oxygen Dependent Chronic Obstructive Pulmonary Disease. The only conditions in Patrick and Deyo's data bank showing more dysfunction than MCS on the SIP are Non-responding Chronic Pain and Anterior Lateral Sclerosis.

The most serious impairment among our respondents was shown in the categories of Work (55.36%), Alertness Behavior (53.45%), and Recreation and Pastimes (45.20%). Considerable impairment was also shown on Sleep and Rest (31.50%), Social Interaction (30.66%), Home Management (28.86%), Emotional Behavior (26.45%), and Mobility (24.91%). Least impaired were Communication (15.20%), Ambulation (13.57%), Body Care and Movement (9.58%), and Eating (8.96%). The physical dimension mean score was 13.61%, and the psychosocial dimension score was 31.63%. The category and dimension scores are shown in Figure 2.

Respondents' scores for their reactions to individual chemicals were totaled to create an overall sensitivity score. Likewise, symptom scores were totaled for each respondent to create an overall symptom score. These overall scores were then used along with overall SIP scores to compare respondents in the mild, moderate, severe, and disabled categories. Chemical, symptom, and SIP scores showed progressively more serious dysfunction as level of self-rated severity increased. Three one-way ANOVAs revealed statistically significant differences for total symptom, chemical, and SIP scores between all groups except the severe and disabled. Table 5 lists demographic and SIP variables for respondents at four levels of severity of MCS.

The emergent picture of the person with mild MCS was one with an adequate income of about \$37,000, with 64% of persons still employed. Total dysfunction on the SIP was under 12%, chemical sensitivity total score was 69, and symptom total score was 59. Persons with mild MCS generally did not report severe social disruption, e.g., SIP social dimension score was only 13%. At the moderate level, mean income was reduced by about one-third (mean income was \$23,000), with 62% employed. SIP total score was 21%, almost double that of persons in the mild category, chemical sensitivity total score was 89, and symptom total score was 74. Social disruption is more marked in this group as evidenced by a SIP social dimension score of 28%. Examining the severe category, we see that income has dropped to under \$11,000, less than one-third of that in the mild category. Only 10% of respondents in the severe category were employed. SIP total score was 30%, almost 3 times that of the mild category, chemical

sensitivity total score was 102, and symptom total score was 82. Social disruption was considerable here with a mean SIP social dimension score of 37%. For the disabled category, annual income was about \$18,000 due to greater variability in this category than in the severe category. No one in this category was able to work. SIP total score was 32%, chemical sensitivity total score was 107, and symptom total score was 90. Both chemical sensitivity and symptom scores increased 50% over the mild category. Social disruption in this category was comparable to that of the severe category.

Interview Summaries

In order to better understand the personal impact of MCS and how it varies as a function of severity level, we interviewed one respondent at each level of severity. Each of the following descriptions was compiled from survey and interview data, and was read to and okayed by the respondent prior to this presentation. Names have been changed in order to maintain privacy.

Linda is a 75-year-old woman living with mild MCS. She began noticing symptoms due to chemicals when she was a child living near a coal mine. She attributes her sensitivities to daily exposure to the toxic air and she recalls clean laundry being contaminated with a layer of soot when hung outside to dry. It wasn't until age 25, however, that Linda attributed her illness to these childhood experiences. She describes MCS as "slowing up" her everyday life. Linda has to be very careful and "think twice" about what she is doing at all times. For example, she had to postpone the painting of her house until the weather was warm enough for complete ventilation, and she had to leave the house for hours at a time while the painting was taking place. MCS did not have an effect on her employment status and she is now retired because of personal choice. Although most of her family is supportive, Linda has certain relatives who do not understand her condition and frequently mock her and her illness. She has limited contact with these family members. Linda also has a few colleagues/friends with whom she has lost contact due to their refusal to understand her need for a chemical free environment. She is also limited in some of the social activities she enjoyed in the past. For example, she has not seen a movie in years, she

cannot go to various restaurants, malls, or grocery stores, or any place filled with cigarette smoke, perfumes, soaps, or other chemicals to which she is sensitive.

Kate is a 51-year-old woman living with moderate MCS. Kate received an MCS diagnosis in November of 1992; however, she has experienced sensitivities to detergents and various other products all her life. A few major reactions occurred in 1990 when her apartment was redecorated and polyurethane was used on the floors, and also when she was exposed to asbestos-removing solvents in the same year. Kate is currently an assistant professor of philosophy at a state university. Because of MCS she can spend only 12 to 15 hours at the university each week and can no longer teach summer classes. As a result, her annual income has declined by about \$15,000. Most of Kate's co-workers are sympathetic to her chemical sensitivities. However, her superior recently admitted to her that had he known MCS was so "severe" he would not have hired her. Overall MCS has affected Kate's life in many ways. Her relationship with her sister has virtually ended because of this disorder. They can no longer meet because her sister shows only a vague interest in and understanding of Kate's injury and lives in a new house that is toxic to Kate. Other than her sister, Kate has no close family relationships. MCS has virtually eliminated her social life. She had been performing on stage all her life and was a playwright and poet for 15 years. Before being afflicted with MCS, Kate saw all the plays in her area, was actively involved in monthly poetry meetings, and had in her words a "wonderful social life." MCS has taken all of this away from Kate, and her only remaining recreational activities are walking alone in the woods and talking to friends on the telephone. She feels she has lost "half" of her life. She describes herself as hypervigilant and says she is constantly aware of her body since she is in pain 50% of the average day. Kate says she sometimes thinks about and longs for death when she is reacting to chemicals. One positive result of Kate's new life is that it has prompted her to do more writing.

Emily is a 62-year-old woman with severe MCS. She began noticing symptoms around the age of 35. These symptoms can be traced back to the natural gas and fossil fuel that was used to heat her home since childhood. During the time that Emily began developing MCS, she

was employed as a teacher. Her symptoms became so severe that she spent more time at home than in the classroom, forcing her to give up teaching. Consequently, her personal annual income fell from \$9,000 to 0. Although Emily lost her job due to her illness, she feels fortunate to have a supportive husband and understanding children. Also, Emily has found that over the years her in-laws have become more sensitive to her needs. On the other hand, despite her neighbors' knowledge of her sensitivities, they continue to use fertilizers and herbicides which have a negative effect on Emily's health. Suffering from MCS has drastically changed Emily's social life. Her sense of self has been directly affected because she can't go into crowded areas or enjoy public functions, like church or the library because of the levels of perfumes and other chemical substances present. Emily's interactions with persons without MCS have been limited due to their lack of knowledge of her need for a chemical free environment. Overall, Emily's life has been dramatically changed because of her illness. Too sick to leave her bed, Emily was housebound for an extended period of time. The most significant impact that MCS has had on Emily's life is the loss of her job as a teacher.

Pat is a 57-year-old woman disabled from her chemical sensitivities. In March of 1989, Pat was diagnosed with MCS related to pesticide poisoning. This poisoning was the result of coming into contact with improperly mixed Diazinon. Both Pat's personal and household incomes have dramatically declined due to her illness. Although Pat achieved an extensive education and aspired to become an administrator, she is collecting social security and teacher disability. Because of Pat's lack of employment and the necessity for her husband to take care of her, her household income has dropped from \$85,000 to \$21,000. Although Pat's husband has been extremely supportive, the illness has caused a major strain on their marital relationship. Her husband is only able to leave her for a few hours at a time, causing him to live as though he is also suffering from MCS. Communication with the rest of her family has decreased, causing a feeling of loneliness and isolation for Pat. Her children don't believe she is suffering from MCS and do not visit because of the restrictions placed on them to be free of chemicals. This lack of interaction is so severe that she has never seen her four grandchildren. Social interactions are

limited to her husband and two other individuals with MCS. Pat's interest in both leisure and social activities has declined significantly. On those rare occasions when she does go out into public areas, she must use an oxygen tank to supply herself with uncontaminated air. Pat's greatest life impact from MCS is that she lived for a period totally isolated in the wilderness, without water or electricity. The disabling nature of her illness has caused her to travel 100,000 miles to live in a "safe" trailer, on oxygen 24 hours a day. In addition to having unusual living arrangements, Pat's IQ has tested 30 points lower than it did before the onset of MCS, suggesting some loss of neurological functioning as well.

Discussion

This research demonstrates that illness related dysfunction from MCS can occur on a continuum from mild to more serious life disruption. Some persons' lives are so seriously disrupted that they lose jobs, relationships, public access, and any kind of personal comfort. The more serious the disruption, the more likely the person is to become invisible because of isolation, given that this is a problem our culture generally ignores.

Respondents in this study showed more medically related dysfunction on the SIP than persons with most other illnesses investigated. The chemicals cited as causal in this dysfunction, such as perfume, pesticide, paint, and new carpet, are ubiquitous in our environment and impossible to avoid. One important point that should be made here is that respondents in this study have been sick a mean of 17 years. Thus we may be seeing the health effects of past environmental conditions 15–20 years ago. It is impossible to know what will be the future effects of the constantly increasing number of chemicals introduced into our environment. Colborn, Dumanoski, and Myers (1997) suggest that the effects of hormonal disruptors such as dioxin, PCB, and many pesticides are so serious that we are already compromising the reproductive integrity of both animals and humans.

MCS is thus an environmental issue because, although many illnesses have environmental causes or contributions, more than any other condition MCS suggests a direct causal link

between chemicals and illness. MCS illustrates the human cost of environmental contamination and use of substances about which we have very little knowledge.

MCS is an emerging social issue because of the life consequences for those who experience it, because of the controversy it engenders in a culture where chemicals are ubiquitous, because of the challenge to our conventional views regarding the causes of illness, and because of the lack of public acknowledgement of MCS as a valid chemical injury.

MCS is also a medical issue because in spite of the serious dysfunction involved, medical care is almost nonexistent. In an earlier study we found that persons with MCS had seen a mean of 8.6 physicians, only a quarter of whom were described as helpful, and had spent a mean of \$5,800 on medical treatment in the previous year. Respondents reported receiving misdiagnoses, unnecessary invasive medical tests, and considerable iatrogenic harm (Gibson et al., 1996).

MCS takes us in a new direction in regard to the study of the cause of illness. In fact, Miller (1996) has suggested chemical sensitivity as a mechanism for a broad spectrum of chronic illnesses including asthma, migraine, depression, and chronic fatigue. If so, we need new directions for research and health care that take environmental etiologies into account. And MCS needs to be conceptualized not as a marginalized condition, but as one that holds broad implications for the reconceptualization of the illness process itself.

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Table 1

Categorical guidelines for levels of disability

Level	Description
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Mild Able to work. Frequently has many symptoms, some of vague nature. May find petrochemicals and other environmental exposures such as auto exhausts cigarette smoke, and cleaning materials to be unpleasant or produce uncomfortable feelings, but able to work effectively.

Moderate Able to work at home or with controlled environment at work place. May have to use gas mask or charcoal mask and air purifier filter system. Exposure to inciting agents causes acute symptoms which may alter functional capacity (severe headache, muscle pain, poor concentration, memory loss, etc.). May have to change job or work conditions if environmental pollution is severe enough.

Severe Unable to work effectively, even with environmental control, using avoidance, masks or filters. On some days, may be able to work 30 to 60 minute shifts several times a day if in a very controlled environment. Reacts to chemicals such as insecticide, phenols, chlorine, formaldehyde, perfume, petro-chemicals, etc. Has severe mental and physical symptoms which may or may not clear. Public exposures such as church, post office, movie or shopping are not tolerated. Visitors to home must clean up significantly. Can usually care for self in a home situation. May be able to drive if automobile made free of inciting agents, sealed, and has charcoal air filters. Has difficulty with other family members or guests in home who bring in aggravating exposures on clothing, printed material, hair, etc. Adversely reacts to many medications. May have to move if existing home has uncontrollable outdoor pollution, is new and has not outgassed, or has other significant problems of mold, flooring, or other incitants. Requires a clean room, carpet-free, cleared of inciting agents, special heating and air filtering. Must wear natural fiber clothing specially laundered.

Disabled Requires assistance to function in rigidly controlled home environment. Reactive symptoms have spread to virtually all environmental agents including chemicals, foods, pollens, and molds. Has mental and physical symptoms that are incapacitating, although frequently not structurally described. Total and very restrictive environmental control required in home and vehicle. Cannot tolerate family or help who have outside exposures with even small contamination of clothing or hair with odors. Visitors usually are too toxic to be tolerated indoors. Usually requires several moves to different areas of the country to find tolerable climate which is also chemical free. May require unusual and extensive measures to make a tolerable clean refuge area to sleep in. Has difficulties with virtually everything in environment (universal reactor).

Note. From "E.I. Disability Classification", 1987, The Human Ecologist, No. 35, P. 13. Material relating to food sensitivities was deleted.

Table 2

Characteristics of 254 sample respondents with self-reported chemical sensitivity.

Characteristic	%
Gender	
% women	81.9
% men	18.1
Ethnicity	
Pacific Islander	1.2
African American	.8
Latin American	1.6
Native American	2.0
Caucasian	83.4
Asian American	.4
Other	5.9
Education	
Less than 12 years	1.2
12 years	12.6
12-15 years (including trade school)	36.2
16 years (bachelors degree)	26.4
Masters degree or beyond	23.2
Partner status	
Single	13.8
Married	50.0
Divorced/separated	24.4
Living with partner	8.3
Widowed	3.5
Employment status	
Employed	32.3
Not employed	67.3
Attributed cause of injury	
One large chemical exposure	21.3
Series of low level exposures	52.8
Physical illness	6.3
Unknown	15.4
Severity of condition	
Mild	11.0
Moderate	28.7
Severe	42.9
Disabled	11.0

Table 3

Level of illness reported from exposure to common chemicals in persons with self-reported chemical sensitivity.

Chemical	Mean Illness Rating*
Pesticide	3.67
Formaldehyde	3.56
Fresh paint	3.53
New carpet	3.51
Diesel	3.46
Perfume	3.45
Air freshener	3.42
Fresh asphalt/tar	3.39
Moth balls	3.39
Nail polish remover	3.31
Phenol	3.31
Nail polish	3.25
Fabric softener	3.24
Furniture cleaner/polish	3.24
Dry cleaned clothes	3.22
Hair spray	3.22
Cigarette smoke	3.21
New vinyl shower curtain	3.16
Chlorine bleach	3.14
Fabric stores	3.13
Propane	3.08
Auto exhaust	3.05
Laundry detergent	3.04
Scented deodorant	3.02
Felt-tipped markers	2.99
Natural gas	2.95
Glass cleaner	2.94
Shampoos/conditioners	2.82
Newsprint	2.55

Note. * Ratings were made using a Likert-type scale with 1 = no reaction, 2 = mildly ill, 3 = moderately ill, 4 = very ill.

Table 4

Symptoms reported from chemical exposure in persons reporting chemical sensitivity.

Symptom	Mean Extent of Problem*
Tiredness/lethargy	3.13
Difficulty concentrating	2.99
Muscle aches	2.93
Memory difficulties	2.92
Fatigue > 6 months	2.89
Problems digesting food	2.78
Joint pain	2.73
Headache	2.71
Irritability	2.66
Tenseness/nervousness	2.64
Spacey feelings	2.63
Trouble sleeping at night	2.59
Depressed feelings	2.58
Difficulty making decisions	2.57
Head fullness/pressure	2.56
Bloating	2.56
Runny/stuffy nose	2.48
Grogginess	2.42
Eye irritation	2.42
Clumsiness	2.42
Problems focusing eyes	2.40
Dizziness/lightheadedness	2.40
Slow response	2.35
Ringing in ears	2.08
Chest pain	2.07
Constipation	2.05
Tingling fingers/toes	2.03
Nausea	2.01
Loss of motion	2.00
Rashes	1.98
Hives	1.62

Note. * Ratings were made on a 4 point Likert-type scale with 1 = not at all a problem, 2 = minor problem, 3 = moderate problem, 4 = severe problem.

Table 5

Demographic and illness variables at four levels of severity of MCS.

Variable	Mild	Moderate	Severe	Disabled
Annual Personal Income ^a	37.48	23.33	10.57	17.65
Percent Employed	64.30%	62.20%	10.10%	0.00%
SIP total	11.66%	21.21%	30.07%	32.48%
SIP-Physical Dimension	5.48%	10.65%	16.56%	19.48%
SIP-Social Dimension	13.16%	28.21%	37.20%	38.83%
Chemical sensitivity total ^b	69.44	89.07	101.72	106.55
Symptom total ^c	59.27	74.04	81.62	89.72

Note. ^a in thousands. ^b possible scores ranged from 29 to 116. ^c possible scores ranged from 31 to 124