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WORK AND COMMUNITY ACCESS FOR PEOPLE WITH  
MULTIPLE CHEMICAL SENSITIVITY

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## Abstract

Multiple chemical sensitivity (MCS), a condition in which persons have symptomatic reactions to low levels of environmental chemicals, is an example of a poorly understood condition likely engendered through environmental exposure. Prevalence studies suggest that MCS affects 12-15% of the U.S. population and that it crosses age, SES, and racial lines. Some of the consequences of experiencing MCS include difficulties with health care, housing, relationships, and work. Gibson, Cheavens and Warren (1996) found that only a quarter of persons self-reporting MCS were still employed, the remainder having lost or left their jobs because of inability to tolerate chemical exposures in the work setting. In addition, persons with MCS often do not have access to community resources such as libraries, health care, grocery stores, or community meetings due to chemical barriers. Consequently, persons experience significant isolation. We examined work and community access in 100 persons with self-reported MCS. Two illness variables (course of illness and symptom severity) and three work/community access variables (employment status, workplace harassment, and level of access to community resources) were explored in terms of their influence on quality of life as measured by the Satisfaction with Life Scale. Results are discussed in terms of the importance of community integration for persons with hidden disabilities.

## WORK AND COMMUNITY ACCESS FOR PEOPLE WITH MULTIPLE CHEMICAL SENSITIVITY

Chemical stressors have yet to be integrated into models for understanding work, stress, and health. Although there is growing understanding of the importance of exposure to toxins for child growth and development, there has been little interest in or understanding of conditions in adults that suggest an environmental etiology. Multiple chemical sensitivity (MCS), in which persons have symptomatic reactions to low levels of environmental chemicals, is an example of a poorly understood condition likely engendered through environmental exposure. Prevalence studies suggest MCS to be fairly widespread, affecting 12.6% of the population, and cutting across lines of gender, race, education, and socioeconomic status (Caress & Steinemann, 2003). However, MCS is still largely unrecognized and delegitimized, leaving sufferers to cope with the physical and emotional impact of chronic illness without adequate assistance or support.

There are several definitions of MCS in the U.S., but all share the requirement that the person has become sensitized to low levels of incitants in ambient air, that illness reactions then occur with subsequent exposures to the chemical to which the person has sensitized, that sensitivities exist to more than one chemical or class of chemicals, and that the reactions affect more than one organ system, e.g., respiratory and digestive, or neurological and respiratory ("Multiple chemical sensitivity," 1999). Reactions can range from mild to life threatening and affect any bodily system, including respiratory, digestive, neurological, endocrinological, musculoskeletal, or cardiovascular. Common incitants include organic solvents, pesticides, cigarette smoke, cleaning products and fresh paint. Symptoms can last from hours to days and may include headache, fatigue, nausea, dizziness, confusion, irritability, muscle pain, asthma, and even a loss of consciousness (Gibson, Cheavens, & Warren, 1996). In what is described as the spreading phenomenon, the constellation of incitants often expands over time to include other chemicals, foods, medications, natural substances such as molds and pollens, and/or electromagnetic exposure (Gibson, Placek, Lane, Brohimer, & Lovelace, 2005).

A number of theories have been proposed to explain the etiology of MCS, including both physiological and psychological explanations. The most common cause is thought to be sensitization resulting from one large chemical exposure or gradual, repeated exposures over time, most often experienced in the workplace or during home renovations. Several biological markers have been noted, including abnormal immune function (altered helper/suppressor cell ratios, presence of chemical antibodies) (Heuser et al., 1992; Levin &

Byers, 1992), abnormal EEG and MRI patterns (Dudley, 1993; Heuser et al., 1992), detoxification pathway dysfunction (McFadden, 1996; Rogers, 1990), damage to the nasal mucosa allowing toxins closer proximity to deeper tissues (Meggs, 1995), and measurable levels of pesticides within the blood (Rea et al., 1992). Probably the most respected physiological theory currently is neural sensitization where neurological tissues become oversensitive and overactivated as a result of continued chemical exposure, consequently causing the symptoms associated with MCS (Bascom, 1989; Bell, 1992; Miller & Ashford, 1992). Miller has referred to this as Toxic Induced Loss of Tolerance or TILT (Miller, 1999). Rossi (1996) hypothesized that intracerebral localized kindling could best account for the tendency of MCS to spread over time to new incitants and to worsen even in the absence of continued exposures. Most recently, Pall (2003) has extended the neural sensitization (kindling) hypothesis and postulated that MCS is the result of an inflammatory feedback loop involving elevated nitric oxide and a more permeable blood brain barrier sensitized by pesticides or organic solvents. To date, Pall's theory is the most broad-based, and accounts for the largest number of characteristics of MCS of any theory.

Several psychosomatic theories have also been proposed in recent years. Common arguments suggest that symptoms related to exposure are simply behaviorally conditioned responses (Black, 1996; Bolla-Wilson, Wilson, & Bleecker, 1988; Simon, 1994); a result of preexisting psychopathology, such as depression, anxiety, or personality disorders (Simon, Katon, & Sparks, 1990); an amplification and exaggeration of negative sensations (Simon, 1994); or even a result of failed defense mechanisms used to suppress childhood trauma (Selner & Staudenmayer, 1992). However, these theories are either not well developed or supported or fail to account for the fact that many reactions occur to substances that have no early warning properties (meaning that they have no odor). Although many chemicals do produce psychiatric symptoms as primary reactions (such as personality changes and panic attacks related to organic solvent exposure), a link has not been consistently shown between MCS and preexisting psychopathology. Rather, any psychiatric symptoms are likely to be a direct result of exposure or of the stress and loss related to coping with a chronic illness. Caress and Steinemann (2003) asked participants about psychiatric problems before and after developing MCS and found that 37.7% had developed emotional problems since their illness began, compared to only 1.4% who reported having these problems beforehand. In addition, testing of these psychological theories can be a significant ethical concern, as they often include purposefully exposing sensitive individuals to chemicals, which may lead to serious reactions and illness. The current resistance and disagreement over chemical sensitivity is reminiscent of past questions about lupus, MS, chronic fatigue

syndrome, and endometriosis (Heuser et al, 1992; Klonoff & Landrine, 1996), all which are now generally accepted as being truly physiological conditions. And recently Saito, Kumano, Yoshiuchi, Kokubo, Ohashi et al. (2005) demonstrated that persons with MCS have no more physiological or psychological symptoms than controls when not in the midst of exposures.

Individuals with MCS often experience significant life disruption and difficulties with work, finances, and participation in activities and hobbies as a result of coping with an illness which requires substantial isolation to survive. Disruption in work is common in people with sensitivities. Gibson et al. (1996) found that of a sample of 268 persons, most (76.8%) reported having lost their jobs or being forced to quit due to chemicals in the workplace. Only 7% of respondents were currently working in conditions that they considered safe for their health. Mean income of participants was barely above the poverty line. This can be particularly devastating when financial burdens are already high. For instance, participants spent an average of almost \$6,000 on medical care in the previous year, and an estimated average of almost \$35,000 over the course of their illness. Medical benefits are often difficult to obtain, and many report being forced to spend their life savings in order to survive.

Of respondents who attributed their illness to one large chemical exposure, over half reported that it had occurred in the workplace. People suffered declining motivation for work and increased stress in relationships with co-workers as a result of their attempts to avoid workplace chemical exposures. Co-workers often resisted accommodating the sensitive worker preventing the worker from creating a safe workspace (Gibson et al., 1996). Those who are able to continue working often experience considerable harassment from coworkers, and reluctance from management to provide appropriate accommodations, such as the use of less toxic cleaners or a desk space near windows that open (Gibson, 2003).

If the worst happens and people are no longer able to work, in addition to financial and social losses, they must adjust psychologically to being perceived as unproductive in a culture that measures its worth through work. Thus chemical exposure is a work stressor needing research attention.

In addition to work, many individuals are also forced to give up hobbies, travel, education, and community involvement in order to avoid exposures. People lose access to public buildings, the homes of friends and family members, places of worship, malls, restaurants, continued education, and even medical and dental offices (Gibson et al., 1996). The effects of this isolation have been described by some patients as traumatic. People are not only forced to live lifestyles not of their own choosing, but are denied basic services taken for granted by most of the population.

Not surprisingly people with MCS often score poorly on quality of life indicators. In our lab we have found low levels of hope, social support, and life satisfaction. The mean score on the Satisfaction with Life Scale (SWLS) in 209 persons was 14.9, lower than scores reported in the literature for populations of university undergraduates (24.54) (Coutinho & Woolery, 2004), medical outpatients (23.5) (Arrindell, Meevvesen, & Huyse, 1991) and elderly persons (24.2), and only slightly higher than populations of male prison inmates (12.3) and veterans hospital inpatients (11.8) (Pavot & Diener, 1993). In the same study life satisfaction was significantly correlated with the illness variables course of illness and fatigue, leisure satisfaction, income, and being in a romantic relationship.

In this study, we were interested in the impact of work, workplace harassment, and community access variables on the quality of life measure life satisfaction. In particular, we were interested in whether work, workplace harassment, and community access variables would exert an influence on quality of life as measured on the Satisfaction with Life Scale over and above illness variables in persons self-reporting MCS. We predicted that work experience, harassment, and community access would be more important predictors of life satisfaction than actual severity of symptoms reported.

## Method

### *Participants*

Participants were 100 persons self-identified as having MCS gathered through notices in newsletters and on websites of MCS advocacy and support groups.

### *Procedure*

Notices asked specifically for people with MCS who were either currently employed or had been employed while having MCS. We used the research definition of MCS published in the May/June 1999 issue of Archives of Environmental Health. Potential respondents were invited to participate in the study if they experienced sensitivities and negative reactions to chemicals, and their condition met these 6 criteria:

- 1) Their symptoms should be reproducible with repeated chemical exposure.
- 2) Their condition should be chronic.
- 3) Their symptoms should occur from low levels of chemical exposure [lower than they previously tolerated or than other people tolerate without problems].
- 4) Their symptoms should improve or resolve when the chemical incitants are removed.
- 5) They should have symptoms to multiple chemically unrelated substances.

6) Symptoms should involve multiple organ systems, (for example digestive and respiratory.)

People who met these criteria were invited to request either a hard copy or e-mail attachment survey and to return it through e-mail or regular mail. Volunteers received and completed a survey that included informed consent. Surveys received were coded with a number and all identifying information was kept separately in a locked cabinet.

### *Measures*

Participants answered questions about basic demographics, work experiences (including accommodations requested or received), and harassment experienced in the workplace. Respondents indicated whether their health condition had improved, stayed the same, or deteriorated in the past two years; and categorized their level of MCS-induced disability according to a 4-point scale originally published in the Human Ecology Action League (HEAL) newsletter ("E.I. Disability," 1987). They also completed the Satisfaction with Life Scale (SWLS) that measures global life satisfaction on five questions using a 7-Point Likert-type scale. The SWLS has good internal (.87) and test-retest reliability (.82). Possible scores on the scale range from 5 to 35, and researchers have found means of 23 to 24 in a variety of samples including college students, single women without children, and medical outpatients (Arrindell, Meeuwesen, & Huyse, 1991; Diener et al., 1985; Pavot & Diener, 1993). Respondents were also asked whether or not they experienced 45 different symptoms described in the MCS-related literature and to rate the severity of each on a 4-point Likert-type scale. We also inquired as to participants' ability to access community resources that most healthy persons take for granted, including communities of worship, grocery stores, health food stores, community meetings, public libraries, homes of extended family members, homes of friends, and offices of dentists and medical doctors.

### Results

Of the 100 respondents, 88% were women. Participants had a mean age of 50, an annual household income of \$52,000, and a personal income of \$32,000. Fifty-eight persons were employed and 42 were not. The majority of respondents were Caucasian (N=97), but also included were one African American, one Native American, and one Latin American.

Twelve percent reported mild disability, 57% moderate, 25% severe, and 3% reported being completely disabled by the condition. When asked what they thought caused their sensitivities, 27% blamed a series of low level exposures over time, 9% one large chemical exposure, 1% a preceding physical illness, and 11% other causes. Forty-three

percent believed the cause to be a combination of several factors, and 7% reported not knowing the initial cause.

### *Descriptives and Frequencies*

#### *Illness Variables*

Approximately 40% of participants (N=37) reported considerable or slight decline in their symptoms over the last two years, approximately the same number (N=39) reported slight or considerable improvement, and approximately 20% (n=22) respondents reported a mixed course or no change. In addition to their chemical sensitivities, 24 respondents also reported experiencing electrical sensitivities.

We created a symptom composite variable by summing respondents' scores for each individual symptom. Possible scores ranged from 0 to 135. Respondents' composites ranged from 16 to 120 with a mean of 61 and a standard deviation of 24. Symptoms rated the most problematic out of a maximum rating of 3 (range 0-3) were tiredness/lethargy (2.08), difficulty concentrating (1.97), stronger sense of smell (1.97), headache (1.95), memory difficulties (1.85), and muscle aches (1.82).

#### *Community Access and Work Variables*

##### *Job Variables*

Job harassment was reported by 54% of respondents. Thirty eight percent did not experience harassment and eight percent did not answer the question. Examples of harassment included eye-rolling, disgusted looks, verbal abuse, perfume spraying outside of the respondents' doors, being "tested" in various ways to see if chemicals really did make them sick, laughter when they wore masks, and ostracism. Humiliation was common and in one case the head physician in a medical facility said openly at a meeting with the MCS worker present that he thought MCS was a mental illness. Four unemployed respondents said that co-workers had thought of them as "crazy." In addition, a few respondents described more aggressive incidents that qualified as assaults. For example, one person reported that a manager had sprayed cleaning solution in the worker's face, and another that a hostile co-worker poured aftershave into a typewriter that the worker needed to use.

##### *Community Access*

Even though participants were asked to respond to each of the nine community access variables dichotomously (yes or no), there were so many qualifying comments that we decided to code each as no access, partial access, or fairly good access given MCS-related limitations. There is often no complete access in most settings for persons with MCS



and virtually all settings asked about had many caveats. For example, in many settings, people could often stay only a short time, or had to use air purifiers. Frequencies for our coding for each of the nine settings are shown in table 1.

Table 1

*Community Access for 100 Persons with MCS*

	NO ACCESS	PARTIAL ACCESS	FAIRLY GOOD ACCESS	NO RESPONSE
Community of worship	45%	19%	18%	18%
Grocery store	13%	28%	59%	
Health food store	8%	11%	80%	1%
Community meetings	40%	30%	30%	
Public library	19%	33%	46%	2%
Homes of extended family	29%	31%	37%	3%
Homes of friends	24%	43%	31%	2%
Dentist	24%	11%	65%	
Medical doctor	12%	21%	66%	1%
Total Access Score (0-18)	Mean= 11.31	SD=4.25		

*Satisfaction with Life Scale (SWLS)*

Satisfaction with Life Scale mean score was 14.9 of a possible 35 (SD=8.1). This is the exact same mean that our lab previously found in a sample of 209 persons with self-reported MCS. Other researchers using the SWLS have reported scores ranging from 23.5 to 25.8 for medical outpatient and elderly samples respectively (Arrindell et al., 1991; Diener et al., 1985; Lewis & Borders, 1995). Our respondents with MCS are scoring approximately 10 points lower on this measure than other ill populations or elderly persons. Our previous study found significant gender differences on the SWLS, with women scoring higher than men. In this study, although women scored slightly higher than men (15.06 vs. 13.94), the differences were not significant.

### Correlations

Both measures of community involvement - employment status and community access total - correlated negatively at the  $p < .01$  level with symptom total ( $r = -.289$  and  $-.352$  respectively). Having experienced harassment in the workplace correlated negatively with current household income ( $r = -.248$ ;  $p < .05$ ) and with a current working status ( $r = -.335$ ;  $p < .01$ ). It correlated positively with symptom total ( $r = .270$ ;  $p < .01$ ), and negatively with course of illness ( $r = -.220$ ;  $p < .05$ ).

Table 2  
Correlations between Illness, Community Access, and Work Variables

	Satisfaction With Life Score	Course of Illness	Symptom Total	Work Status	Harassment on Job	Community Access Total
Satisfaction with Life Score	1.0	.229	-.327**	.225*	-.177	.159
Course of Illness		1.0	-.325**	.119	-.234	.234*
Symptom Total			1.0	-.289**	.260	-.352**
Work Status				1.0	-.277	.401**
Harassment on Job					1.0	-.214
Community Access Total						1.0

\*\* . Correlation is significant at the 0.01 level

\* . Correlation is significant at the 0.05 level

### Multiple Regression

Satisfaction with Life Scale results were positively skewed with a mean of 14.88 and a bunching of scores on the lower end (skewness = .846). Examination of normal probability and detrended normal probability plots revealed significant deviation from normality. We therefore transformed the data using the LOG10 of the SWLS scores with significant improvement in the appearance of the variable.

Symptom total was somewhat positively skewed (skewness = .486) and exhibited negative kurtosis (.286). Examination of a histogram revealed only mild to moderate departure from normality. These scores were therefore used in their original form.

Community access data were somewhat negatively skewed (skewness = -.370) and exhibited negative kurtosis (-.582). Because departure from normality was moderate and because reflecting and transforming to the logarithm did not appear to improve the appearance of the histogram, we retained the original scores.

A scatterplot of residuals indicated that the assumption of multivariate normality was not violated. We therefore conducted a hierarchical multiple regression using SPSS with the LOG of the Satisfaction with Life Scale scores as the dependent variable. We entered the illness variables course of illness and symptom total as the first block and the community involvement variables employment status, having experienced harassment in the workplace, and community access total as the second block. Illness variables explained 9% of the variance ( $R^2 = .09$ ) with only symptom total contributing significantly to the model. Community access variables did not add significantly to predicting life satisfaction ( $\Delta R^2 = .021$ ). Our hypothesis that community access as measured in this study would predict life satisfaction was not supported.

## Discussion

Our hypothesis that community access and employment status would predict life satisfaction seemed reasonable given the qualitative reports that discuss isolation in this population (Gibson, Placek, Brohimer, Lane, & Lovelace, 2005). However, our data did not bear out this association. Our measure of community access was essentially an additive list of where persons can go in their communities. However, simply being able or unable to access stores, libraries, and meetings may not in and of itself bring life satisfaction as long as people have others who can access problematic places for them (e.g., grocery stores). Also persons place differing importance on various resources. For example, a number of people told us that they were not able to go to church, but that they didn't care. Future measures should incorporate the value that someone places on a resource rather than simply measuring accessibility. Additionally, the willingness of family and friends to visit the person in their home may lessen the importance of accessing other settings.

The limitations to community access for this population are important and bear comment. Access to medical and dental care was poor for one third of respondents. What many persons take for granted is available only under severe hardship for some people with these hidden disabilities. Previous research in our lab has found that unmet medical needs

are a severe problem for people with MCS and that some persons had gone without care, sometimes even enduring severe pain (e.g., failing to treat an abscessed tooth), due to either lack of access to medical buildings because of chemical barriers or the possibility of a negative/allergic reaction to the procedure itself (Engel, Gibson, Adler, & Rice, 1996). Anesthesia in particular can be problematic and place persons with MCS at severe risk.

The variable of having experienced workplace harassment has some interesting associations that may merit further examination. The significant negative correlations between reported workplace harassment and both income and working status suggest that those who lose their employment due to MCS may experience more workplace harassment than those who remain in the workplace. Future research could address the possible role of harassment as a possible causal variable in driving people with these types of disabilities out of the workplace. The significant positive correlation with symptom total and significant negative correlation with course of illness suggests that those who are the sickest and on a downward trend in their health may experience more harassment from co-workers; this also can be examined in prospective studies. Our measure was a dichotomous one and future measures could assess not only the presence, but the level of workplace harassment. Better measures could yield more useful data.

Future research should address the need for community integration for people with hidden and poorly understood disabilities such as MCS. Models for including disabled persons in the workplace while keeping interpersonal conflicts and harassment to a minimum need to be developed. Access to necessities such as medical care as well as other activities and recreational facilities needs to be studied and improved as well. Education and interventions regarding disabilities and chronic illness need to expand to include "emerging" disabilities that marginalize and isolate many people. The refusal to actively confront and understand the conditions and experience of those currently suffering must be addressed.

Weaknesses of this study include the moderate number of participants, the use of volunteers, the measures of access, and symptoms created for this research, and the summative approach to community access that failed to take into account the value placed on each resource by the participants.

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