

Running head: SOCIAL SUPPORT IN CHEMICAL SENSITIVITY/CHEMICAL INJURY

Social Support in Persons with Self-Reported Sensitivity to Chemicals

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Abstract

We examined social support in 305 persons with multiple chemical sensitivity using The Personal Resource Questionnaire 85 (PRQ85) (Weinert, 1987) and qualitative descriptions of respondents' social interactions. PRQ85 scores were lower than those of healthy populations, but similar to samples with chronic illness. Participants needed but were prevented from receiving support for personal difficulties due to their limited public access, their need for chemical avoidance including fragrances, and others' lack of information and negative attitudes regarding chemical sensitivities. Respondents drew some support and validation from support groups and from romantic relationships. Fatigue level, being in a romantic relationship, contact with a support group on a monthly or greater basis, chemical avoidance in the home, gender, and an improved course of illness predicted 19% of the variance for perceived social support. Qualitative data are used to illustrate particular problems of persons in this sample, and suggestions are made for practitioners who encounter this population.

## Social Support in Persons with Self-Reported Sensitivity to Chemicals

One health condition to gain recent attention is that of self-reported illness from exposure to low levels of chemicals in the environment. Symptoms vary with individuals, but can involve any bodily system, and commonly affect respiratory, digestive, neurological, cardiovascular, and musculoskeletal systems. Anaphalaxis, rhinitis, altered or irregular heartbeat, joint pain, fatigue, headache, alterations in orientation or memory, depression, panic, and skin reactions are examples of commonly reported symptoms. Chemical sensitivity has been referred to variously as multiple chemical sensitivity (MCS), environmental illness, chemical hypersensitivity, and chemical injury by differing groups who study the problem from various perspectives.

The prevalence of chemical sensitivity has been estimated at about 15% of the general population (National Academy of Sciences, cited in Davidoff, 1989). Bell, Schwartz, Peterson, and Amend (1993) found that 66% of college students reported illness from at least one of five listed chemicals (pesticide, auto exhaust, paint, new carpet, and perfume), and 15% from at least four of the chemicals. Meggs, Dunn, Bloch, Goodman, and Davidoff (1996) found in a random household sample of 1,027 persons that 33% reported chemical sensitivity, with the major incitants being perfumes, pesticides, cigarette smoke, and fresh paint. Chemical sensitivity was present in all age, income, race, and education groups, was as common as allergy, and was reported to cause daily symptoms in 3.9% of respondents. Despite the prevalence of MCS, little is known about how persons cope with this condition and, in particular, the role of social support in their adaptation.

Although exact ratios vary depending upon sample source, the majority of civilians with chemical sensitivity appear to be women. Clinical samples studied by Cullen, Pace, and Redlich (1992), Heuser, Wojdani, and Heuser (1992), Kipen et al. (1992), Lax and Henneberger (1995), and Ross (1992a) were predominantly women. Meggs et al. (1996) found in their large representative household population study that 39% of women and 24% of men reported

chemical sensitivity, and Bell et al. (1993) found more illness from chemicals in women undergraduates than in men.

Fundamental problems in examining the concept of chemical sensitivity are the lack of knowledge pertaining to this condition and the lack of a generally accepted definition of MCS. Ashford and Miller (1991) proposed an operational definition, claiming that an MCS patient "can be discovered by removal from the suspected offending agents and by re-challenge, after an appropriate interval, under strictly controlled environmental conditions" ( p. 29). Medical researchers have uncovered biological markers of chemical sensitivity, including immunological abnormalities, abnormal EEGs, and abnormal MRI (Heuser et al., 1992), nasal abnormalities (Meggs & Cleveland, 1993); damaged detoxification pathways (Rogers, 1990); pesticides in the blood (Rea et al., 1992); and abnormal evoked potentials upon chemical challenge (Dudley, 1993). Immunological findings include abnormal helper/suppressor ratios (either too high or too low), and high levels of chemical antibodies (Heuser et al., 1992). In addition, there is some suggestion that chemically sensitive patients may eventually develop autoimmune disease (Heuser et al., 1992; Levin & Byers, 1992).

A hypothesis receiving some serious attention is that of limbic kindling through the olfactory system (Bell, 1994; Bell, Miller, & Schwartz, 1992). Because of the ubiquitous nature of present-day chemical exposures in ambient air, some individuals are thought to have sensitized or "kindled" to low-level chemicals that then trigger serious reactions mediated through limbic pathways. Because of the limbic system's connections to and involvement in regulating many bodily systems, including autonomic, endocrine, immune, cognitive, and affective, it is well situated hypothetically to initiate the variety of symptoms reported by MCS patients (Bell, 1994; Bell et al., 1992).

Alternatively, a considerable percentage of persons with MCS or chemical injury evidence damaged enzymatic pathways (Rogers, 1990). Baker (1994) reported that about half of his chemically-injured patients tested positive for porphyria, a deficiency in enzyme systems that synthesize heme, a component of hemoglobin which carries oxygen to all tissues. Acquired

porphyria may be caused by drugs, chemicals, infections (including Hepatitis C), and malnutrition.

There also are writers who have postulated that MCS is a psychological illness (Black, Rathe, & Goldstein, 1990; Brodsky, 1983; Simon, Katon, & Sparks, 1990; Terr, 1989), although much controversy surrounds this research. Those treating MCS as a psychological disorder have been criticized on ethical grounds by physicians who treat MCS as a physiological disorder and who prescribe avoidance of the offending chemicals in order to avoid further deterioration in the health of their patients. However, this advice is contradicted by practitioners who do not believe that MCS has physiological origins. Many physicians have written against the practice of assuming a psychologic origin for MCS (Levin & Byers, 1992; Ross, 1992; Ziem, 1992), and Ziem (1992) has reported that several of her patients were made worse by advice not to worry about chemical exposures.

Levin and Byers (1992) believe that MCS has a psychological overlay that can distract health providers from the the organic origins of the disease. For example, Morrow, Ryan, Goldstein, and Hodgson (1989) showed personality disturbance in solvent-exposed workers, and Dager, Holland, Cowley, and Dunner (1987) discussed panic disorder as a result of exposure to organic solvents. Heuser et al. (1992) note that patients with systemic lupus erythematosus often exhibit psychiatric symptoms. They further speculate, on the basis of their findings of abnormal neurological functioning in a high percentage of MCS patients, that psychiatric symptoms exhibited in MCS may be neurologically-based. In an attempt to tease out physiological from psychological indicators, Bell, Peterson, and Schwartz (1995) examined self-reported illness from odors in a non-clinical population and found that it was predicted by physiological as opposed to psychological illnesses in close family members. Miller (1996) has made a cogent theoretical argument for the construal of chemicals as broad-based causal factors in illness, bolstering her case with historical examples of medical facts that were ignored due to their failure to coincide with then current medical paradigms.

The controversy and confusion regarding the etiology of MCS translates into poor medical diagnosis and treatment for patients. In an earlier paper we reported that persons with MCS reported seeing a mean of 8.2 physicians each, waiting 7.5 years for a diagnosis, spending a considerable amount of money on their health, receiving misdiagnoses, and suffering iatrogenic harm (Gibson, Cheavens, & Warren, 1996). Combining with these medical difficulties are severe disruptions in multiple life areas (Gibson, 1993). Specifically, persons with MCS report that having MCS causes problems in maintaining an income, using household products, pursuing hobbies, using public transportation, seeing families and friends, and living in traditional housing (Gibson et al., 1996; Lax & Henneberger, 1995; Miller & Mitzel, 1995).

For purposes of this study, MCS is conceptualized as a chronic physiological rather than psychological condition. It is expected that there will be life consequences that both overlap with and are unique from those present in other chronic illnesses (Strauss, 1984).

One important area of study in relation to any chronic health problem is that of social support. The link between between low levels of social support and a high incidence of morbidity and mortality in the chronically ill is well established (House, Landis, & Umberson, 1988; Shumaker & Hill, 1991). Berkman and Syme (1979) found an association between social ties and mortality that remained significant even after the effects of SES, health behaviors, physical activity, obesity, and preventive health care utilization were removed. Uchino, Cacioppo, and Kiecolt-Glaser (1996) reviewed studies of the influence of social support on physiological processes and found associations with improved cardiovascular (blood pressure), endocrine (catecholamine level), and immune function (cellular and humoral immunity). Social support also is a robust predictor of psychological well-being (Friedman & King, 1994; Primono, Yates, & Woods, 1990; Wineman, 1990), with perceived support having a greater effect than actual support received (Barrera, 1986), though it is not known exactly how perceived support effects its influence upon health (Shumaker & Hill, 1991; Thoits, 1995).

Few researchers have investigated social support as a dependent variable, yet the construct has been shown to be influenced by illness characteristics and, sometimes,

demographics. Age and gender have been studied as demographic variables, with inconsistent findings. Willey and Silliman (1990) found that older age was associated with smaller networks and less social activity in cancer patients. On the other hand, McColl and Friedland (1995) found that any effects of age were no longer significant after accounting for type of disability. Investigations of gender also are inconclusive. McColl and Friedland (1994) found gender unrelated to perceived social support in persons who had experienced strokes or spinal cord injuries. In Willey and Silliman's study (1990) gender was unrelated to network size, level of social activity, or resilience of social support. In contrast, Gulick (1994) observed higher levels of perceived social support in men than in women with multiple sclerosis, while Turner (1994) found higher levels in women.

Level of disability and length of illness represent illness characteristics that may be important in regard to access to social support. Peters-Golden (1982) noted that social support was related to longer survival of cancer patients, but the greater the disability the less social support one was likely to receive. White, Richter, and Fry (1992) found similar results in their examination of diabetes patients whose levels of perceived social support diminished with poorer health. Willey and Silliman (1990) reported that pain, impaired function, and spending time in bed all related to lower frequency of social visits. Similarly, Fitzpatrick, Newman, Archer, and Shipley (1991) found that greater disability was associated with poorer social support in diffuse (as opposed to intimate) relationships in persons with rheumatoid arthritis. Other investigators have found contrasting results (Douglas et al., 1994; McColl & Friedland, 1994; Willey & Silliman, 1990). Thus, the relationship between illness characteristics and social support remains unclear, and may result from complexity in the concept of disability (McColl & Friedland, 1994), variability in instrumentation, differential characteristics of the conditions under study, or the use of general as opposed to specific measures of social support.

Theoretical frameworks proposed for understanding possible reductions in social support in illness have included stigma associated with illness (Peters-Golden, 1982) and the social activity hypothesis (Bloom & Kessler, 1994). Peters-Golden (1982) found that women with

breast cancer received inadequate support, particularly in contrast with what well persons expected they would receive should they become ill. In addition, a substantial portion of Peters-Golden's healthy respondents said that they would avoid persons with cancer, and that they perceived it as a sign of maladjustment for sick persons to discuss their illness, thus providing support for the position that stigma interfered with social interactions for this population. Twelve years later, Bloom and Kessler (1994) concluded that stigma no longer operated in relation to breast cancer. Instead, the authors offered as an explanation for reduced social support in illness the social activity hypothesis which posits that persons lose social interaction opportunities both as a result of role change (with the ensuing loss of portions of identity), and reduced ability to engage in customary activities. With reduced energy, discretionary activities disappear first as the person struggles to maintain obligations such as work. Increasing time must be spent resting in compensation for energy used in work or other necessary activities, and the social activities that may engender supportive exchange cannot occur.

In the case of MCS, we reasoned that both stigma and social activity might operate to limit opportunities for social support. Persons with chemical sensitivity in particular may be at risk for problematic interactions with others due to their unusual requests for chemical-free contexts, and the poorly understood nature of MCS. If others are likely to stigmatize persons with physical conditions such as cancer, they may be all the more likely to avoid persons with a condition that is seen by some as psychological. Thus, persons with MCS may be avoided or become the targets of negative attributions by others. In addition, social activity would be reduced by some characteristics of the condition (i.e., the inability to tolerate many public settings due to chemicals, the attendant fatigue), hereby threatening the person's opportunity for social exchange. The present study was undertaken to examine the relationship between these covariates and social support in persons with chemical sensitivity in order to understand some of the phenomenology of MCS as a chronic disability. It is not the purpose of this paper to demonstrate that social support influences well-being. This already has been adequately

demonstrated, although some methodological problems remain (Barrera, 1986; Dean, Holst, Kreiner, Schoenborn, & Wilson, 1994; Rook, 1984; Shumaker & Hill, 1991; Schwartzer & Leppin, 1991; Stewart, 1989). Rather, the purpose is to examine perceived social support, its determinants, and sources of and satisfaction with social support in persons with multiple chemical sensitivity.

Social support was measured with the Personal Resource Questionnaire 85 (PRQ85) (Weinert, 1987) as both perceived social support and satisfaction with support, because adequacy of support has been shown to be more important than mere availability (Fitzpatrick et al., 1991), and because comparison samples were available for other chronic health conditions (Foote, Piazza, Holcombe, Paul, & Daffin, 1990; Weinert, 1987; White & Richter, 1990, personal communication). Gender, age, and employment status were included as demographic variables. As married persons have been found to have higher levels of support than single persons (McCull & Friedland, 1994), being in a romantic relationship was included as a variable of study. Fatigue was included because it is a major symptom of chemical sensitivity that limits activity and may affect perceptions at time of data collection. Support group contact was included to explore whether this type of networking actually increases perceptions of being supported. Course of illness, length of illness, and severity were included as illness characteristics to explore the relationship between intensity of condition and social support. Safety level of the home was included as a variable unique to MCS because physicians prescribe chemical avoidance for their patients attempting to cope with MCS, and we reasoned that a safer home might allow patients to feel better and, thus, be better able to pursue social contact.

The research questions addressed were a) how do persons self-reporting MCS rate their perceived social support compared to persons with other illnesses, b) what is the relationship of gender to social support, c) how do persons with MCS perceive treatment by family members, d) who have they depended on for help, and e) what particular support needs have they encountered? We also were interested in exploring the relationship of social support to illness characteristics, demographics, and relationship variables.

## Method

Sample

The sample consisted of 305 self-identified persons with multiple chemical sensitivities. Participants were recruited through advertisements in national publications targeted to this group, through support groups, and through offices of physicians. Additionally, a convenience sample was drawn from the Chemical Injury Information Network, a national education and advocacy group, and questionnaires were mailed to these participants. Physician validation of diagnosis was not required, as physicians who currently diagnose MCS are in a minority, and there is currently no agreed upon definition or diagnostic procedure relating to MCS that is seen as valid across medical specialties. Participants were asked to rate their own level of severity of sensitivity using a 4-point scale adapted from the E.I. Disability instrument (1987; see Table 1 for an abbreviated version of the instrument used in this study).

Of the total participants, 245 (80.3%) were women. The sample was made up of 92.8% Caucasians, 4.9% Native Americans, 1% Latina/Latino descent, and 0.7% Asian Americans. The majority of returned questionnaires were from the Chemical Injury Information Network (32%), a newsletter ad (19%), and the ad in the national publication (16%). Thirty two percent responded from various other sources, and 0.7% left blank the question about where they had learned of the study. Over half of respondents (53.8%) were married, 5.2% were living with a partner, and 41% were living alone. Mean age was 46.8 years ( $SD = 10.67$ ), with a range of 23 to 79 years. Participants rated their level of disability (Table 1) as mild (12.8%), moderate (31.1%), severe (39.3%), or totally disabled (15.7%).

Measures

Social Support. The Personal Resource Questionnaire 85 (PRQ85) (Weinert, 1987) Part 1 measures support needs in the last 6 months, persons who were contacted for help with these needs, and satisfaction with support received (see Table 2). Participants are asked to mark any and all of the sources that they would turn to for help in 10 life situations, and to mark their level of satisfaction with help received on a 6-point scale ranging from very dissatisfied to very

satisfied. Perceived support was measured by part 2 of the PRQ85, which is based on Weiss's (1969, 1974, cited in Weinert & Tilden, 1990) relational function model. This model conceptualizes perceived support as embodying attachment, social integration, opportunity for nurturant behavior, reassurance of worth (both personal and in regard to accomplishments in roles), and access to informational, emotional, and material assistance. Factor analysis of the PRQ85 Part 2 identified three factors — intimacy/assistance, integration/affirmation, and reciprocity — that accounted for 43.4% of the variance (Weinert, 1987). The instrument has 25 items rated on a 7-point scale; internal consistency ranges of .87 to .91 have been reported (Weinert & Tilden, 1990). Internal consistency in the present study was .91.

Other variables. Severity of condition was measured as mild, moderate, severe, or disabled with a 4-item scale designed specifically for MCS (E.I. Disability Classification, 1987). Other variables measured include employment status, level of fatigue, and course of illness. In addition we included the interpersonal support variables of relationship status, level of supportiveness of a romantic partner, whether the partners believed the respondents were truly environmentally ill, whether or not the respondents had experienced a romantic break-up since becoming sensitive to chemicals, if any break-ups were perceived to be caused by the illness, whether the respondents had contact with support groups, and whether the respondents felt ostracized or mistreated by family members other than spouses as a result of their health conditions. For ease of presentation, these variables and coding schemes used are listed in Table 3.

### Procedure

Participants were asked to complete and return a questionnaire which consisted of 169 multiple choice and open ended questions. All responses were confidential and informed consent was obtained with the return of the completed questionnaire. This study is a cross-sectional analysis of the initial data collected from a longitudinal study.

Relationships between variables were examined using correlation analyses, *t*-tests, and analysis of variance and covariance. To protect against type 1 error risks when multiple tests are conducted, only results significant at or beyond the .01 level are reported. Hierarchical

multiple regression was used to explore the relative contribution of study variables to perceived social support.

### Results

Respondents scored between 58 and 174 on perceived social support with a mean of 125.9 ( $SD = 25.6$ ). Means were lower and more variable than the samples in Weinert's data bank, which lists means ranging from 139 to 149 in middle-aged and older adults ( $SD = 13.9$  to 14.9). Foote et al. (1990) found PRQ means of 141.13 in 40 persons (32 women; 8 men) with multiple sclerosis (mean age = 48.2). On the other hand, White and Richter (1990; personal communication) found a mean of 131.3 ( $SD = 20.09$ ) in a sample of 134 women with diabetes mellitus who were similar in age to the present sample ( $M = 46.2$  years, range 20 to 86 years).

There was no significant relationship between perceived social support and having gainful employment. However, the correlation between safety level of the work environment and social support for those who were employed approached significance. Perceived social support scores were not significantly related to age.

Level of fatigue correlated negatively with perceived social support ( $r = -.19$ ;  $p = .001$ ). Perceived social support was higher in persons who reported an improved course of illness compared to those whose conditions had reportedly worsened,  $t(226) = -3.40$ ,  $p = .001$ ; those who said they had improved in their health had a mean of 131.18 ( $SD = 24.34$ ) and those who reported deterioration had a mean of 119.69 ( $SD = 27.56$ ). Neither severity nor length of illness were associated with perceived social support.

A little over half ( $n=168$ ) the participants (53% of women and 63% of men) stated that they had some contact with a support group. Of those with support group contact, 22% had at least weekly contact and 15% had a minimum of monthly contact. The difficulties of access to public and private buildings limited many respondents to phone contact with other support group members. Perceived level of social support was not affected by merely having contact with a support group. When those with high levels of contact (monthly or greater) were compared with the remainder of the sample, the results approached, but did not reach,

significance. There was a weak correlation between severity of condition and high support group contact ( $r = .17, p = .003$ ).

Other support available to some participants occurred in partner relationships. Of the 187 participants who were involved in romantic relationships, 99 (48.8%) said that their partners were very supportive and 68 (33.5%) stated that their partners were somewhat supportive. Only 26 (12.8%) stated that their partners were either somewhat or very unsupportive. Just over three quarters (77.3%) of those in romantic relationships said that their partners believed "fairly strongly" or "very strongly" that their symptoms were caused by chemicals. However, some reported that their partners believed "not at all" (3.4%), "very little" (2.9%), or "somewhat" (16.4%) that their illness was caused by chemicals. Respondents commented spontaneously that they found it particularly stressful to be disbelieved when they asserted that chemicals made them ill. Perceived social support scores correlated positively with having a supportive partner ( $r = .28, p < .001$ ), and having a partner who believed that chemicals were making the respondent sick ( $r = .27, p < .001$ ), and negatively with having suffered a romantic break-up since becoming sensitive to chemicals ( $r = -.21, p < .001$ ), and believing that MCS was the cause of the break-up ( $r = -.19, p = .03$ ).

Perceived social support scores were significantly affected by being in a romantic relationship. Those in relationships perceived higher levels of social support,  $t(300) = -4.39, p < .001$ . Persons who rated their partners as being very supportive perceived higher levels of social support than those who rated their partners as being somewhat supportive or less,  $t(201) = 3.18, p = .002$ .

One way analysis of variance revealed that women reported higher levels of perceived social support than did men,  $t(303) = 2.47, p = .014$ . Women had a mean of 127.7 ( $SD = 25.5$ ) on Part 2 of the PRQ85; for men the reported mean was 118.6 ( $SD = 24.8$ ). Because some researchers have found greater benefit of married status for men than for women (Berkman & Syme, 1979; House et al., 1988), we investigated the relationship between gender and relationship status with a 2-way ANOVA (gender x having a romantic partner). There were

significant main effects for both gender and relationship status, but no 2-way interaction; therefore, we concluded that in this sample these variables operated independently.

Participants reported experiencing considerable difficulties in the past 6 months on support needs and satisfaction with support (PRQ Part 1) (Table 2). On the PRQ-85, Part 1 the mean number of situations in which respondents reported turning to various support sources were: friends ( $M = 4.7$ ), spouses ( $M = 4.5$ ), professionals ( $M = 2.9$ ), children ( $M = 2.3$ ), other kin ( $M = 2.9$ ), spiritual advisors ( $M = 1.6$ ), support groups ( $M = 1.2$ ), neighbors ( $M = 1.0$ ), and no one ( $M = 0.6$ ).

#### Relationship of Social Support to Covariates

Variables that correlated highly with PRQ85 scores were entered into a hierarchical multiple regression in order of strength of correlation. Variables entered into the model were (in order of entry) fatigue, being in a romantic relationship, contact with a support group on at least a monthly basis, perceived safety level of the home environment, gender, and reported course of the condition. Perceived safety of the home (rated on a 5-point scale) was included in the model due to its moderate correlation with PRQ85 scores,  $r = .23$ ;  $p < .001$ . Gender, being in a romantic relationship, course of illness, and level of contact with a support group were dummy coded. One dummy variable was constructed for each two category variable ( $p - 1$ ). Course of illness included categories for getting worse, getting better, mixed course, staying the same, and a missing data category. Four dummy variables were created for getting worse, getting better, mixed course, and missing data. The missing category allows examination of whether data are selectively, rather than randomly, missing (see Cohen & Cohen, 1983). Staying the same was used as the comparison group. With  $E$  to enter set at .05 and  $E$  to remove set at .10, all 6 predictor variables were entered into the equation yielding a multiple  $R$  of .44, and an  $R^2$  of .19. (Table 4). On step 6, of the four course of illness variables, only an improved course predicted social support.

#### Qualitative Data

Qualitative information from the open-ended questions was analyzed to illustrate the particular types of difficulties our respondents reported in obtaining social support. Many respondents provided examples in response to our question regarding whether they felt that they were ostracized or otherwise mistreated by family other than partners, and responses were categorized and tallied by the first author for type of mistreatment.

Many respondents reported feeling painfully isolated from families, especially in instances where family members had been asked to be chemical free in order not to endanger the respondent. Respondents said that their families did not understand the nature of their sensitivities (15%), relatives would not refrain from wearing perfume (12%), and that family members did not believe that the respondent had a true physical illness (7%). Other reported behaviors by family members included refusing to discuss the chemical sensitivity with the respondent (3%), excluding the respondent from family get-togethers (2%), calling the respondent a malingerer (2%) or a hypochondriac (2%), being verbally abusive (2%), refusing to visit (2%), making the respondent the target of humor (1%), cutting off communications entirely (1%), and deliberately exposing the respondent to chemicals (1%). One person said, "It is much easier not to include me – no one has to change their lifestyle. Few visit me because of rules." Another said, "I suffer many lonely hours mourning for a family who just can't bother." Still another offered, "I have been isolated by my immediate family. It is my opinion that they do not know how to deal with it, so they don't." One specific incident involved a woman with severe sensitivities who reported being unable to enter her family's home due to chemicals present. Yet, to relieve loneliness, she travelled a long distance to see them for the holidays. She did not feel safe entering their home for fear of having an illness reaction, and so plates of food including her holiday dinner were brought out for her to eat in her van.

Many people described having to live in extreme circumstances, as even their own homes made them ill. Respondents reported living totally housebound for long periods (38%), living in cars (4%), in tents (3%), in trailers or campers (2%), on patios (1%), in cleaned-out garages (1%), in a community of porcelain trailers (1%), and totally outdoors (1%). Living quarters

described by one person each included the back of a covered pick-up truck with a cotton mattress, a glass room in the woods, an 8' x 10' hut, and a van. Thus, for some the inability to live in conventional housing necessitated physical separation even from immediate families. In other cases older adolescents chose to move out of the homes of their chemically sensitive parents rather than forego the use of fragrance or ask friends to visit the house fragrance-free.

Some respondents reported going to extreme efforts to insure social interaction. One person described creating a new family outside of biological connections. One woman who had an extremely positive attitude in spite of severe limitations — she had lived in her horse trailer for a year — only felt safe socializing outdoors and so organized trail rides in the mountains, because, as she put it, "life ain't no spectator sport." This respondent reported finding a way to overcome her perceived limitations and maintain a social group, and some others mentioned loving and helpful partners, families, and friends. Another participant felt that she received support from the lesbian community that might not otherwise have been available to someone with MCS within mainstream structures.

### Discussion

The results of this exploratory study suggest that persons self-identified with chemical sensitivity feel considerably disabled and affected in the realm of social support. Scores on a measure of perceived social support were lower than those of well samples and lower than those of most other ill samples, and showed considerable variability.

A substantial portion of this sample received at least some support from romantic partners. In fact, because of limited access to work, community activities, and sometimes extended family, partners and friends seemed to provide the bulk of what support was available. However, both the quantitative and qualitative data suggest that when MCS patients do receive support in life situations that arise in conjunction with the illness/disability, they are not wholly satisfied with that support. Explanation for the low levels of perceived social support and the lack of satisfaction with support received may lie partially in the long-term chronic nature of

MCS. Persons in this sample had been ill for an average of almost 15 years. It has been suggested by several researchers in the field of social support that, while an acute stressor or illness may mobilize support, the responses of others to illness of a chronic nature may erode with time (due partially to caregiver burnout), leaving support resources depleted (Barrera, 1986; Thoits, 1995). In addition, we believe that there are unique stressors operating for those with MCS that seem to support both the stigma and social activity hypotheses, although due to the exploratory nature of this work we did not test any specific hypothesis. These stressors revolve around diminishing access for the person with MCS, and the present attitudes and knowledge of others regarding the condition.

Access to both persons and places diminishes for several reasons. First, physicians who specialize in MCS often recommend chemical avoidance (Levin & Byers, 1992; Ross, 1992b; Ziem, 1992). Patients comply with medical advice to improve physical health and reduce sources of illness reactions. However, this results in separation from previous sources of support and stability, and consequent reduced roles and activities. Second, many persons were confined to small geographic areas due to chemical exposures in automobiles or airplanes, thus family contact and support were diminished. Third, even within a geographic area, persons with MCS report losing public access due to the chemicals present in public buildings. Therefore community service, public outings, shopping, and other public contacts diminish. The need to avoid fragrances in some persons is a reported source of difficulties in personal interactions, as others may take offense at the request to refrain from wearing scented products.

The attitudes of others serve to place further distance between persons with MCS and potential sources of support. Since MCS/CI is still a largely unrecognized and often refuted chronic condition, many of our respondents reported that they simply were not believed by laypersons or physicians, or that their requests for accommodations were perceived as unnecessary or inconvenient demands. The views of health professionals, in particular, have an influence on how a condition is seen and/or treated and, when persons with MCS receive psychiatric labels for what they perceive to be physical problems (Gibson et al., 1996), the

attribution of the disease as "all in your head" isolates the victims from spouses, family, friends, and especially doctors (Rippere, 1983). Therefore, the lack of validation by others may be a significant obstacle to perceived social support for this population.

Our findings in regard to women having higher levels of perceived social support than men are in contrast to the work of other researchers (McCull & Friedland, 1994; Willey & Silliman, 1990) who found no gender effects on social support, and that of Gulick (1994), who found that men with multiple sclerosis perceived higher levels of social support than did women. More congruent with our findings are those of Turner (1994), who found that gender related to network contact, confidant relationships, empathy in relationships, and emotional disclosure, with differences favoring women. These four variables, in turn, were associated with perceived social support and Turner believes that, because women are encouraged to behave in a more communal manner than are men, they may be better at both giving and receiving social support. Women's intimacy training may be an advantage in MCS. In Turner's study, men had fewer confidants than women and were much more likely to have none or only one person in which to confide. With an awkward and poorly understood condition like MCS, it may be only close confidants who are willing to make requested changes such as forgoing the use of fragrances. This is supported by the many comments written in the margins of our questionnaire reporting that respondents had lost many contacts, but found out "who their real friends were".

Instrumentation may partially account for these differing results (Gulick used the Norbeck Social Support Questionnaire), rather than illness or gender characteristics. One of the difficulties in drawing conclusions from the research on social support and health is that researchers have had to summarize across various types of conditions and measures. The reasons for lower support experienced by men than women in this sample are not clear and should be validated and explored in future work. Both men and women with MCS are at risk for verbal and other kinds of abuse as a result of having a little understood health problem. Both fail to fulfill expectations of others in terms of quantity and types of activities in which they are able to engage. Both defy gender role expectations, women in their inability to engage in the

types of nurturing behaviors we have come to expect from women, and men for their "weakness" embodied in their reactions to chemicals and their difficulties regarding financial provision. However, it is possible that women with MCS are able to acquire more social support. There is some suggestion that men with MCS may be more stigmatized than women. Cheavens and Winstead (1996) found that college students perceived MCS complaints in women (as presented in a vignette) as more physiologically-based than identical complaints in men.

One final note regarding gender differences in social support in the present study is that we should be cautious in assuming that the higher perceived support for women will necessarily be health-protective. Shumaker and Hill (1991) concluded from their review on gender and social support that the relationship between social support and physical health for women is "weaker and somewhat more complex" (p. 106) than that for men, and discuss sex differences in caregiving roles as one possible mitigating factor.

The lack of association between severity of condition and social support is consistent with work by Douglas et al., (1994) and McColl and Friedland (1994), but inconsistent with that of Fitzpatrick et al., (1991), Peters-Golden (1982), and White et al., (1992), to the extent that results can be compared across conditions and instruments. Willey and Silliman (1990) found no effects of spread of cancer, but did find that pain and impaired function were associated with less social contact.

A clean home environment was moderately correlated with social support in this sample. An unsafe home for the MCS patient means chronic exposures to incitants that will continue to degrade health and induce fatigue, and thereby reduce opportunities for social interaction.

The lack of association between gainful employment and level of social support is of interest, given the opportunities for social and personal contact in the workplace. However, for persons with MCS, work may be a source of both support and stigma. Negative responses of co-workers to complaints regarding fragrances and other chemicals may counterbalance any opportunities for support, and account for the very low correlation between work and support. Alternatively, because the correlation between a safe work environment and social support was

much higher, it may be that the problems generated by attempting to maintain a job that provides too many chemical exposures mitigate against feeling supported. In an unsafe workplace, it may be that relationships with co-workers degenerate as the employee has increasing difficulty functioning. Conversely, those who are able to secure safe employment may be better able to tap into workplace support.

Practitioners may encounter patients reporting MCS in an institution not necessarily prepared to serve this population. Although family and friends are important sources of social support, the roles of health care providers should not be underestimated. Dunkel-Schetter (1984, cited in Primomo et al., 1990) reported that advice and information concerning illness were viewed as more helpful when offered by health care providers than by family and friends, and that failure of these professionals to give this type of support was detrimental to health. Despite the limited etiological information regarding MCS, a sympathetic practitioner can provide respect, validation, and comfort, as well as helpful advice for persons experiencing this problem. Frangrances on helping professionals often limit access to medical care for those with MCS. Practitioners can refrain from wearing perfumes and other odors to allow patients to interact with them safely. Also, they can advocate for increased accommodations for MCS patients in hospital contexts. Temple (1996) has documented the needs of the person with MCS in the hospital environment and offered guidelines for delivery of safe medical services through limiting exposures to chemical cleaners, fragrances, pesticides, and other irritants. Some knowledge and a sympathetic attitude on the part of the practitioner will allow patients to state their needs and receive health care in a setting that does not further endanger them. Patients can be asked whether they are believed and supported by their families, whether they have access to support groups, and about the safety level of their homes (if they even have homes). Referrals should be made to medical providers who study and treat this condition.

Limitations to generalization from these data include the use of volunteers, self-report, retrospective data for some variables (e.g., length of illness), and possible sampling bias. Although gender ratios and problems reported are congruent with what little work has been

published to date on this topic, it is not known how the use of advertising for volunteers affected the sample. The robustness of these findings will only be determined by future research. As exploratory research, however, the data make a contribution to the understanding of a poorly understood condition.

Further work is needed with samples with verified diagnoses (although this is difficult at this juncture) and for whom there are documented exposures. This is complicated by the fact that few resources are available for tracking those who do have documented exposures. In addition, those who are involved in litigation are being advised by lawyers not to participate in research studies due to the "discoverable" nature of the research data.

Future research could address the functions and effects of MCS support groups, as contact was weakly associated with higher levels of perceived social support. The weak correlation between severity of condition and high support group contact may suggest that persons with more serious conditions self-select for contact with support groups; life difficulties may be so significant for these individuals that the perceived effects of contact are negligible. In addition, the partner relationships of persons with MCS should be explored, as many respondents reported receiving more support from partners than from other sources. Social support as an independent or mediating variable could be examined through prospective studies addressing the consequences of poor social support for course of illness and quality of life in MCS.

It is hoped that this research will stimulate an interest in uncovering ways to meet the social support needs of persons with chemical sensitivity, a chronic health condition associated with unique needs and difficulties. If health professionals are to contribute to the well-being of this population, much more needs to be understood regarding the difficulties of coping with chemical sensitivity, and those who experience the condition must be seen as viable sources of information about what needs are unaddressed.

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Table 1

Categorical Guidelines for Levels of Disability

Level	Description
Mild	Able to work. Frequently has many symptoms, some of vague nature. May find petrochemicals and other environmental exposures such as cigarette smoke to be unpleasant or produce discomfort 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	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 time a day if in a very controlled environment. Reacts to many chemicals such as insecticide, formaldehyde, perfume, petro-chemicals, etc. and has severe mental and physical symptoms which may or may not clear. Public exposures such as church or shopping are not tolerated. Visitors to home must clean up significantly. Requires a clean room, carpet-free, cleared of inciting agents, special heating and air filtering. Needs 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 others who have outside exposures with even small contamination of clothing or hair with odors. Has difficulties with virtually everything in environment.

Adapted and abbreviated from E.I. disability classification. (1987). The Human Ecologist, No. 35, 13. Material relating to food sensitivities was deleted.

Table 2

Percent of Respondents Reporting Support Needs in the Last 6 Months and Satisfaction Level with Help Received

Situation	% answering "yes"	level of satisfaction with help received <sup>1</sup>
Had a crisis?	62%	4.23
Needed help caring for an extended family member?	17.4%	4.26
Had a concern about a relationship with spouse, partner, or intimate other?	40.3%	4.01
Needed advice for a problem with a family member or friend?	52.1%	4.49
Had financial problems?	53.8%	3.76
Felt lonely?	77.0%	4.43
Been sick and unable to carry out usual activities for a week at a time?	55.4%	4.31
Been upset and frustrated with the conditions of your life?	80.3%	3.96
Had problems with work in or out of the home?	54.4%	3.77
Needed someone to talk to about day-to-day personal concerns?	87.5%	4.59

<sup>1</sup> 6= greater satisfaction, and 1=lesser satisfaction.

Table 3

Study Variables other than Social Support and Severity of Condition, and Method for Coding

Variable	How Measured/Coded
Employment	1 = <u>employed</u> , 0 = <u>employed</u>
Fatigue level	1 = <u>not at all</u> to 5 = <u>extremely</u>
Course of illness	worsened, stayed same, mixed course, improved
In romantic relationship?	1 = <u>yes</u> , 0 = <u>no</u>
Support from partner	1 = <u>very unsupportive</u> to 5 = <u>very supportive</u>
How much does partner believe respondent has MCS?	1 = <u>not at all</u> to 5 = <u>totally</u>
Had romantic break-up since developing MCS	1 = <u>yes</u> , 0 = <u>no</u>
How much did MCS contribute to break-up?	1 = <u>not at all</u> to 5 = <u>totally</u>
Ostracized by family members because of health?	1 = <u>yes</u> , 0 = <u>no</u>

Table 4

Summary of Hierarchical Regression Analysis for Variables Predicting Perceived Social Support as Measured on the Personal Resource Questionnaire 85 (PRQ85) for Entire Sample (N=305)

Variable	Multiple R	R <sup>2</sup> change	beta	Semi-partial	F	Sig F
Fatigue level	.19	.04	-.13	-.12	5.51	.02
Romantic	.31	.06	.22	.22	17.05	<.01
Contact	.34	.02	.16	.15	8.29	<.01
Homesafe	.38	.03	.16	.15	8.54	<.01
Gender	.40	.02	.13	.12	5.47	.02
Course	.44	.03				
Worsened			.04	.02	.17	.68
Up & Down			.10	.07	1.91	.17
Improved			.23	.11	4.68	.03
Missing			.10	.07	1.55	.21

Note. Romantic = currently in a romantic relationship. Contact = contact with a support group. Homesafe = level of perceived safety of home environment. Missing = data missing for course of illness. R = .04 for Step 1; .10 for Step 2; .12 for Step 3; .15 for Step 4; .16 for Step 5; .19 for Step 6.

