

Multiple Chemical Sensitivity and Rehabilitation Planning Implications  
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Multiple chemical sensitivity (MCS) is a chronic illness that affects multiple organ systems and presents numerous barriers to independent living and employment. However, individuals with MCS represent an underserved population that could benefit substantially from rehabilitation services. The purpose of this manuscript is to (a) provide an overview of the literature to familiarize readers with the medical characteristics of MCS, (b) explore the psychosocial and vocational impact of this illness, and (c) suggest considerations for rehabilitation planning.

#### Multiple Chemical Sensitivity and Rehabilitation Planning Implications

Multiple chemical sensitivity (MCS), also referred to as multiple chemical intolerance (MCI), chemical injury (CI) or environmental illness (EI), is a chronic, and often progressive, illness that affects multiple organ systems and presents a wide range of problems from mild reactions to severely disabling symptoms (Lamielle, 2003). Although some individuals with MCS experience symptoms that only moderately interfere with their daily functioning, many others are precluded by their illness from meeting even their most rudimentary needs (e.g., housing, employment, education, recreation, socialization, transportation, access to basic goods and services; Gibson, Cheavens, & Warren, 1996; Lamielle, 1996). Compounding such problems, these individuals represent an isolated and underserved population that is often misunderstood and stigmatized by society. Given an absence of health care and rehabilitation providers who are knowledgeable about MCS, individuals with this illness are often precluded from receiving rehabilitation services (Zavestoski et al., 2004). The purpose of this paper is to (a) provide an overview of the literature to familiarize readers with the medical characteristics of MCS, (b) explore the psychosocial and

vocational impact of this illness, and (c) suggest considerations for rehabilitation planning.

#### Characteristics of MCS

MCS is an acquired disorder associated with multiple recurrent symptoms triggered by exposure to low level chemicals that are well tolerated by most individuals (Lamielle, 2003). Agents that trigger symptomatic responses vary by individual and may include pesticides, disinfectants, automobile exhaust fumes, paint, solvents, new carpet, and perfumed products (Levy, 1997). In addition, some individuals experience reactions to food, medications, and natural substances. Others experience reactions triggered by exposure to electrical devices and frequencies.

Many people with MCS report the onset of the condition as following an initiating exposure event (Lamielle, 2003). Others report prolonged, repetitive, or cumulative low level exposures in environments with poor air quality and insufficient ventilation as causing their condition, and some are unable to identify a specific source of their illness. After an initiating exposure event, reactions are triggered by both the original chemical at decreasing levels of exposure and additional chemicals.

Among the general population, prevalence estimates range from 3 to 16 percent, and the majority of individuals with MCS are women (Gibson, Cheavens, & Warren, 1998; Labarge & McCaffery, 2000; Morton, 2003). The average age at symptoms onset ranges from 30 to 50 years, and women who acquire MCS tend to be well-educated and from middle class backgrounds (Labarge & McCaffery, 2000; Zavetoski et al., 2004). However, prevalence estimates and demographic characteristics may not accurately represent the actual characteristics of this population because estimates are based on research samples, and self-selection introduces bias because the criteria for sample selection in most studies only require self-reports of MCS. Also, characteristics of those who chose to participate in research studies may be different than the characteristics of those who chose not to participate, making it difficult to generalize research findings to the larger population of people with MCS (LaBarge & McCaffrey, 2000). Furthermore, controversy among health care and medical professionals regarding the condition makes it likely that many individuals with MCS remain unidentified.

The diagnostic criteria for MCS include: (a) the symptoms are reproducible with repeated chemical exposure, (b) the condition is chronic; (c) low levels of exposure [lower than previously or commonly tolerated] result in manifestation of the syndrome; (d) the symptoms improve or resolve when the incitants (chemicals) are removed; (e) responses occur to multiple chemically unrelated substances; and (f) symptoms involve multiple organ systems (Cullen, 1994). These systems include respiratory, neurocognitive, gastrointestinal, cardiac, circulatory, immune, sensory, musculoskeletal systems (Donnay, 2000). People with MCS can experience a vast array of symptoms that tend to vary by individual. In a study involving 200 individuals with MCS, the most commonly

reported symptoms included headache, fatigue, confusion, depression, shortness of breath, arthralgia, myalgia, nausea, dizziness, memory problems, gastrointestinal symptoms, and respiratory symptoms (Labarge & McCaffrey, 2000). Other frequently reported symptoms included anxiety, irritability, food cravings, sleep disturbance, and skin irritations. Table 1 includes a comprehensive list of the organs potentially affected and common symptoms.

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Controversy exists among medical professionals and researchers regarding the cause of MCS and the best way to treat it. Disagreements surround whether MCS is an organic disorder, a psychological disorder, or some combination of both (Labarge & McCaffrey, 2000). Increasingly, patients with MCS are being evaluated by neuropsychologists and researchers have begun to identify biomarkers of the illness, some of which are neurological (Sorg & Newlin, 2002). Regardless of etiology, however, individuals with MCS experience considerable disability and disruption to their daily lives. Although the diagnostic criterion that removal of incitants leads to improvement in symptoms would seem to suggest that the condition is not severe in nature, the vast array of chemicals present in the environment make it extremely difficult for individuals to avoid chemical exposure, especially in public spaces where they have little control of the environment. The legitimacy of MCS is now recognized by Worker's Compensation, the Social Security Administration, and the Americans with Disabilities Act (ADA; Tranquillo, 1998). However, people with this condition still encounter negative attitudes and resistance when seeking treatment from health care providers and other helping professionals (Labarge & McCaffrey, 2000; Zvestoski et al., 2004).

MCS presents itself symptomatically as different conditions to different specialists, and recommended treatment regimens vary substantially depending on the specialist that the individual with MCS is treated by (Miller & Prihoda, 1999). Many traditional treatments (i.e. medication, surgery, advise to expose oneself to chemicals in order to "cure" one's irrational fears) have been reported by people with MCS to exacerbate, rather than alleviate, symptoms (LaBarge & McCaffrey, 2000). In a recent ethnographic investigation of the experiences of living with this condition, participants indicated that they managed their symptoms through three main avenues: prevention/avoidance of chemical exposure, detoxification (i.e. protocols such as herbal and nutritional supplements or saunas that assist in the elimination of chemicals from the body), and emotional self-care (Lipson, 2001). The creation of chemical-free home, community, and work environments is advocated by environmental physicians (also referred to in the literature as clinical ecologists) and people with MCS as the primary means to prevent and treat this condition (Donnay, 1999; Tranquillo & Lowman, 1998).

Psychosocial Impact of MCS

Given the pervasiveness of chemicals in the environment combined with the vast array and severity of symptoms that may occur as a result of exposure, MCS can lead to substantial disruption in every life arena including personal finances, employment, activities of daily living, family and social relationships, hobbies, recreation, transportation, housing, health care, and education (Gibson et al., 1996). Such extensive disruptions can result in psychological distress. Symptoms can vary on a daily basis, and uncertainty regarding chemical exposure and the physical effects which will accompany the exposure can produce anxiety. In addition, symptoms can mimic those caused by fear, stress, depression, and panic disorder (Lundberg, 1998). Both depression and fatigue, common symptoms of MCS, make it difficult for individuals to participate in psychosocially fulfilling activities. In many instances, they must relinquish valued hobbies, recreational pursuits, social activities and other interests because all their energy is used to carry out activities of daily living. Psychological disorders that accompany MCS can occur as both a symptomatic response to environmental exposure and as a reaction to the disruption it causes in one's life (McCarty, 1998).

Diagnostic uncertainties and skepticism on the part of medical providers can further compound the psychological distress that is associated with these disruptions. The stress of struggling to achieve recognition of one's illness in order to receive medical treatment can exacerbate symptoms (Zavestoski et al., 2004). In an investigation of the psychosocial impact of MCS, Gibson (1999) found in her sample of 305 survey respondents with self-reported MCS that 7.5 years was the average length of time it took to identify their condition. By the time they were diagnosed, respondents had seen an average of eight physicians, spent large sums of money, and endured extensive and intrusive medical tests.

Access to the social supports that could mitigate the negative impact of MCS on psychosocial functioning is a problematic issue as well. Individuals with MCS must often lead socially ostracized lives, avoiding opportunities for psychosocial contacts and involvement in community activities because of the risk of exposure to harmful chemicals (Gibson et al., 1996). The social ostracism experienced by people with MCS is further compounded by the skepticism of others who refuse to believe that chemicals are the cause of symptoms and are unwilling to make requested accommodations (e.g., refrain from use of perfumed products). These individuals view and treat people with MCS as malingerers or hypochondriacs. One individual with MCS describes how even disability advocates have ostracized her: "One of the most painful things that [people] with MCS have to deal with is the fact that most people with disabilities exclude us, discriminating against us in their non-air-filtered, carpeted independent living centers filled with [people] who have dosed themselves in perfume, disinfectant, hairspray, and the like" (Platt, 2003, p. 27).

Individuals with MCS may rely on support groups for assistance with coping with the psychosocial, cognitive, and physical demands of their illness.

However, their interactions with other support group members are often limited to phone or e-mail contacts because of inaccessible public and private buildings (Gibson et al., 1998). Those who seek out psychosocial support from healthcare and mental health professionals often find that the treatments recommended only serve to undermine their physical and psychological well-being. Interventions such as psychotropic medications or surgery have been reported by people with MCS to exacerbate symptoms (Gibson, 1999).

#### Vocational Impact

For many individuals with MCS, symptoms first develop as a result of exposure to chemical incitants in the workplace (Gibson 1999). In an investigation of the vocational and psychosocial impact of MCS, Gibson et al. (1996) found that 205 of the 268 participants in her sample had been terminated from or forced to quit their jobs because of their inability to tolerate chemicals in the workplace. Of these individuals, 151 eventually sought disability compensation.

Requesting accommodations from employers can be an anxiety-provoking prospect for those who would like to continue working. Requests for accommodations are often perceived by employers as unwarranted or inconvenient (Gibson et al., 1998). In addition to encountering resistance from employers, the need for some individuals with MCS to avoid exposure to perfumes may lead to strained interactions with co-workers who take offense at requests to refrain from wearing scented products. In fact, individuals with MCS have reported a variety of negative reactions from co-workers ranging from ignoring their requests to actual harassment (Gibson, 1999). Subsequently, they may delay requests for accommodations until the point that their health has been seriously compromised or attempt to continue working without accommodations. They then become so ill that they must quit their jobs or are forced to leave because their job performance has declined.

For those who then apply for disability compensation, the process can be quite taxing. In her research, Gibson et al. (1996) found it took a mean of two years for individuals with MCS to acquire disability compensation, cost approximately \$2000.00 to obtain, and the mean award was a mere \$12,000 per year. Often, a psychiatric label was used to qualify them for compensation. Gibson et al. attribute these difficulties in accessing disability compensation to the general lack of knowledge about MCS among disability evaluators such as judges and physicians.

Gibson (1999) effectively summarizes the negative consequences for both society and the individual that result from the stigma surrounding MCS and subsequent failure to validate and address the job accommodation needs of people with this condition:

When we do not accommodate sensitive populations or when accommodations fail, we dislodge large numbers of productive persons from the work force. This displacement from the workforce begins a negative life trajectory for the dislodged worker that includes suspension of benefits such as

health care, life insurance, and retirement; loss of financial security; and isolation (p.2).

In her research, participants with MCS included professionals such as nurses, professors, clerical workers, teachers, chemists, and photographers who had become unable to continue working because of their illness. Given the valuable contributions that society misses out on when such highly skilled professionals disengage from the labor force as well as the negative consequences that this disengagement can have on their overall quality of life, these individuals stand to benefit substantially from the provision of rehabilitation services.

#### Rehabilitation Counseling Implications

Medical research has demonstrated that patient empowerment techniques, where patients are active participants in their care, are more effective treatments for individuals with controversial disorders such as MCS than more disease-oriented strategies (Zavestoski, 2004). Because this finding is consistent with rehabilitation philosophy that emphasizes active consumer involvement, it stands to reason that rehabilitation counselors are in a strong position to partner with people with MCS to remove barriers to health care and social services, healthy housing, and suitable employment. Rehabilitation planning with individuals with MCS is likely to include a combination of psychosocial support, independent living services, and accommodations planning using an interdisciplinary team approach. In an effort to assist rehabilitation counselors to effectively address the needs of this challenging and underserved population, the following guidelines are offered:

1. Keep in mind that, because of the stigma and misunderstanding associated with MCS, individuals may be understandably wary about meeting with a new service provider. Therefore, it is imperative that, upon initially meeting the client and in all subsequent interactions, rehabilitation counselors communicate respect and validation rather than judgment and skepticism regarding their condition (Gibson et al., 1998). In fact, a significant cause of treatment failure among people with MCS has been identified as the premature dismissal by clinicians of the individual's symptoms (e.g., implying that symptoms are "all in the patient's head;" Labarge & McCaffrey, 2000). It is further advised that rehabilitation counselors refrain from letting their own assumptions about etiology be the moving force behind decision-making and planning and, instead, focus on the functional aspects of this condition. As noted by Labarge and McCaffrey, similar etiology debates to those surrounding MCS have also surrounded conditions such as lupus and multiple sclerosis, and individuals should not be denied access to services simply because medical professionals have not yet identified the cause of their illness.
2. When scheduling initial appointments or intake interviews, ask clients with MCS if your office building is accessible to them. If they have concerns, try to arrange a safer meeting location or break up sessions into shorter meetings. Some clients will need to meet out-of-doors, especially if your building is new or newly

renovated, if it was recently treated with pesticide, if staff or other clients wear fragrances, or if there are problematic cleaning products (Gibson, 1999).

2. In terms of vocational planning, early intervention is critical, particularly when assisting individuals who are still employed at the onset of symptoms. In the early stages of MCS, the effects are still reversible, but if left untreated, symptoms are likely to worsen and develop into a permanent disability (Gibson, 1999). Thus, immediate changes to the work environment through proactive accommodations planning could enable the employee to continue working and prevent more severe symptoms from developing. Disability management specialists who work in industrial settings are in key positions to facilitate the mobilization of proactive services when an employee complains of symptoms.

3. It is imperative to evaluate the scope and severity of the client's sensitivities in order to formulate a realistic rehabilitation plan. The *Quick Environmental Exposure and Sensitivity Inventory* (QEESI; Miller & Prihoda, 1999), a standardized assessment tool listed in the resource appendix, may be an aid in this process. If a client is relatively newly diagnosed or has never had the opportunity to have a home environment that is truly free of irritants, he or she may underestimate the scope of his or her sensitivities. The client may then experience unanticipated barriers when entering a training or employment situation, necessitating the need to periodically revisit and revise the rehabilitation plan.

4. Realize that gaining accommodations in the workplace may involve ongoing negotiation and changes in the accommodations plan as the workplace will, at times, acquire new barriers in the form of new equipment, new coworkers, or remodeling to the building. Roessler and Rumrill (1995) offer pragmatic guidelines to assist with this process. Accommodations that have been identified as helpful to workers with MCS include allowing employees with MCS to work near open windows, replacing carpeting with vinyl tile, using nontoxic cleaning materials, establishing fragrance and indoor air quality policies, and allowing employees to work at home (Tranquillo & Lowman, 1998). Make sure that employers are aware of this need. Employers should also be briefed about the possibility and nature of harassment that is sometimes incurred by those with MCS at the hands of coworkers or supervisors.

5. According to data collected by Gibson et al. (1996), less than a third of those with MCS were able to work outside the home, and as few as 7% viewed their workplaces as non-detrimental to their health. Thus, rehabilitation counselors should support clients with developing skills and strategies to achieve self-employment or home-based employment.

6. Traditional methods of retraining and education may involve too many barriers to offer a workable environment. In these instances, rehabilitation counselors should support alternative methods of training such as distance education or individual mentoring where the chemically sensitive client will not encounter harmful chemicals that could be present in traditional learning environments.

7. Assist the chemically sensitive client in connecting with support groups. If there are none that meet in the client's community, suggest participation in one or more of the Internet-based groups where he or she can communicate with hundreds of others who have first-hand experience with the many dilemmas unique to this disability (see Appendix for a resource list).

8. Adjustment services similar to those that benefit individuals with other chronic illnesses may also benefit people with MCS. These services include stress management education, relaxation training, fatigue management and energy conservation, role/identity appraisal, and family/couples counseling (McReynolds, Koch, & Rumrill, 1999).

9. If the client has not secured a relationship with a medical practitioner who specializes in treating persons with this medical condition, encourage and help him or her to find one. Mainstream practitioners may not have had training to direct them in meeting the needs of these patients. Physicians who are board certified through the American Academy of Environmental Medicine are likely to have ongoing clinical experience with chemically sensitive patients and can best advise them.

10. Be aware that making a recommendation for any type of psychological counseling may be received with some reluctance and even hostility. Those with MCS often have had to fight long and hard with family, friends and society to gain recognition that their medical needs are legitimate and that their illness is not a "phobia" or other psychosomatic response. Thus, clients may see any participation in professional psychological support as opening themselves up to the withdrawal of hard won accommodations and benefits. If providers of psychological services are not knowledgeable about MCS, sessions are likely to become an exercise in educating the provider rather than assisting the client. However, providers who are sensitive to the needs of this population and are flexible enough to arrange accessible counseling locations can provide valuable supportive relationships.

11. The leadership of rehabilitation counselors can be a boon to the advocacy efforts of people with MCS. Because they are often too ill to advocate for themselves and most public spaces contain many barriers, they tend to become invisible in their communities. Initiate discussion among local rehabilitation providers about how to implement outreach and quality services to this underserved population. The advocacy skills possessed by rehabilitation counselors may be highly useful and effective in organizing task forces, initiating research projects, and implementing pilot programs directed at the chemically sensitive population.

## Conclusion

MCS is a complex and controversial disorder that can introduce multiple barriers to psychosocial functioning, daily living, and employment. Because individuals with this disorder are frequently misunderstood by health care and rehabilitation professionals, they represent an underserved population who stand to vastly benefit from independent living and vocational services. Given

the fact that growing numbers of individuals in the United States are reporting chemical sensitivities to toxic home environments and "sick" buildings (Kelly, 1998), it behooves rehabilitation counselors to better equip themselves with the attitudes, knowledge, resources, and skills to address the unique needs of this population. Although debate still exists in the medical literature regarding the cause and most effective treatments for MCS, rehabilitation counselors must set aside their own biases and be willing to acknowledge and address the many obstacles to quality of life that are experienced by this generally highly skilled population who have a great deal to offer society. In their delivery of services to this challenging population, they must also keep in mind that "those who experience the condition must be seen as viable sources of information about what needs are unaddressed" (Gibson et al., 1998, p. 113).

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Table 1

*Symptoms that Occur with Chemical Sensitivity*

Organ System	Symptoms
Cerebral/ Neurological	Headache Migraines Dizziness

	Vertigo Nausea Short term memory difficulties Difficulty concentrating Spaciness (often called “brain fog”) Irritability Mood swings Fatigue Muscle spasms Tingling, twitching or numbness in extremities
Respiratory	Asthma Sinusitis
Gastrointestinal	Acute gastrointestinal pain Bloating and indigestion Diarrhea Food intolerances Constipation
Musculo-skeletal	Joint pain Muscle pain and stiffness
Immune	Frequent infections
Sensory	Sensitivity to light, sound, scents, heat or cold Pain or irritation of eyes, ears, or nasal tract
Other	Intolerances to caffeine, drugs and medication Skin rashes Irregular heartbeat Tinnitus

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References: Bell, Schwartz, Peterson, & Amend, 1993; Donnay, 1999; Lamielle, 2003; Meggs, Davidoff, Dunn, Bloch, & Goodman, 1996; Miller, 2001; Randolph & Moss, 1993.

#### Appendix: Resources for Rehabilitation Counselors

##### Books:

— Gibson, P.R. (2000). *Multiple chemical sensitivity: A survival guide*. Oakland, CA: New Harbinger Publications.

\_ McCormick, G. (2000). *Living with multiple chemical sensitivity: Narratives of coping*. McFarland Publications.

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#### Free Publications:

\_ Gibson, P.R. (2002). *Understanding and accommodating people with multiple chemical sensitivity in independent living*. Houston, TX: Independent Living Research Utilization (ILRU). Contact the ILRU at (713) 520-0232 for a copy.

\_ The Labor Institute (1993). *Multiple Chemical Sensitivities at Work: A Training Workbook for Working People*. NY: Author. Contact The Labor Institute, 853 Broadway, Room 2014, New, York, NY at (212) 674-3322 for a copy.

#### Newsletters:

\_ *Our Toxic Times*. Published monthly by the Chemical Injury Information Network, P.O. Box 301, White Sulphur Springs MT 59645 ([www.ciin.org](http://www.ciin.org)).

\_ *The Human Ecologist*. Published quarterly by The Human Ecology Action League, P.O. Box 29629, Atlanta, GA 30359. E-mail: [HEALnatnl@aol.com](mailto:HEALnatnl@aol.com).

\_ *Canary Times*. Published quarterly by the Chronic Fatigue Syndrome, Fibromyalgia, & Chemical Sensitivity Coalition of Chicago, P.O. Box 277, Wilmette, IL 60091 ([www.chicagocfs.org](http://www.chicagocfs.org)).

#### Videotapes and CDs:

\_ *Multiple Chemical Sensitivity: How Chemical Exposures May Be Affecting Your Health (Volumes 1, 2, & 3)*. These films feature interviews with MCS patients and medical researchers. A special edition is available featuring an interview with the director of HUD discussing legal responsibilities of landlords.

\_ *Gulf War Syndrome: Legacy of a Perfect War*. This film demonstrates the prevalence and nature of chemical sensitivity in the Gulf War Veteran population.

#### Internet Resources:

\_ The National Center for Environmental Health Strategies, Inc. () provides technical assistance, training, workshops, and publications.

- \_ *MCS Referral and Resources ()* provides advocacy and education.
- \_ The *Chemical Injury Information Network ()* keeps a list of regional support groups throughout the United States and Canada, provides advocacy and education, and publishes a monthly newsletter.
- \_ The *American Academy of Environmental Medicine ()* identifies medical professionals trained in the treatment of MCS.
- \_ The *Environmental Health Network of California ()* provides education and advocacy.
- \_ The *Environmental Illness Society of Canada ()* provides education and advocacy.

*Assessment Instruments:*

- \_ The *Quick Environmental Exposure and Sensitivity Inventory (QEESI; Miller & Prihoda, 1999)* is available from Claudia S. Miller, M.D at 210-567-7407 or (e-mail).

*Internet Support Groups, Bulletin Boards, and Chat Rooms:*

- \_ Groups designed for people with MCS to share educational resources and moral support are available through [www.yahogroups.com](http://www.yahogroups.com). To search for groups, use the terms *environmental illness*, *chemical sensitivity*, or *Multiple Chemical Sensitivity*.