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Perceptions of patients meeting the criteria for a diagnosis of "multiple chemical sensitivities": Exploration of social situation and need

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PERCEPTIONS OF PATIENTS MEETING THE CRITERIA FOR A DIAGNOSIS OF "MULTIPLE CHEMICAL SENSITIVITIES": EXPLORATION OF SOCIAL SITUATION AND NEED

by

Beth Miriam Lewis

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare.

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Abstract

PERCEPTIONS OF PATIENTS MEETING THE CRITERIA FOR A DIAGNOSIS OF "MULTIPLE CHEMICAL SENSITIVITIES": EXPLORATION OF SOCIAL SITUATION AND NEED

by

Beth Lewis

Adviser: Professor Mildred Mailick, DSW

While no one explanation as to the possible nature of "multiple chemical sensitivities" has gained unanimous acceptance within the medical/science community, similar controversy does not exist with regard to the recognition of social problems generated for people suffering from this condition. In an effort to identify areas of psychosocial need requiring social work intervention, a descriptive study was carried out with a group of patients seen in an out-patient occupational health clinic. Medical charts of a deliberate sample of 423 clinic patients, seen during the period 1980 - 1990, were reviewed, yielding a total of 83 patients meeting criteria specific to MCS. Of the 83 individuals invited to participate in the study, 52 completed a structured interview. The interview elicited subjects' perceptions regarding many aspects of their health and social situation, including their experience with health care providers, the effect of the health problem on work and family life, and the cause(s) of their health problem, among others.

Findings were notable for similarities among subjects in

their description of stages in the development and progression of a health problem felt to be chiefly physiological in nature. As described by a substantial portion of respondents, psychological and social components of the problem were felt to result from difficulties involved in coping with the effects of a chronic health problem which lacks formal recognition by the medical community and general public. Supportive relationships with family, professionals, and employers were perceived as helpful in subjects' efforts to cope with the problem. A majority of the sample were working; among the group of 17 respondents who were unemployed at the time of the interview, indoor air pollution was more often reported as the cause of their problem than were other exposures.

Implications of study findings for social policy, practice, research, and education are discussed.

ACKNOWLEDGEMENTS

The study of "multiple chemical sensitivities" represented a challenge in many different ways. The dispute among practitioners and policy analysts in the field with regard to a definition of "multiple chemical sensitivities" created difficulties in methodology. Further, the experience of delving into a problem, previous studies of which had drawn primarily on knowledge rooted in the physical sciences--admittedly well beyond the parameters of the author's comprehension--created the obstacle of self-doubt more than once along the way. Finally, the effort to carry out the study amidst the tasks of everyday life placed demands on friends and family, as well. Thus, the completion of this project was dependent on the professional guidance and support made available to me by several exceptional individuals, whose assistance I would like to acknowledge.

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INTRODUCTION

Overview

Clinicians in occupational medicine and community-based practices have reported an increase in the number of patients who are mildly- to totally-disabled by multi-system complaints which they attribute to exposures to a wide range of environmental irritants, intoxicants and allergens, with laboratory tests revealing no organic basis for symptomatology. The most commonly reported symptoms include: headaches, gastrointestinal difficulties, respiratory problems, skin disorders, muscle, joint and bone pain (18).

This set of presenting problems has been called "multiple chemical sensitivities" (MCS). It has been alternately referred to in the literature as "Environmental Illness" (EI), "Total Allergy Syndrome", "Chemical Hypersensitivity" and "20th Century Disease" (6,76).

A consensus among members of the medical community has not been reached as to the existence, let alone nature, of such a syndrome (MCS). Given the absence of laboratory data providing evidence of organic disease in most of the subjects, questions are raised as to whether MCS is primarily or fundamentally a psychiatric illness. This difference of opinion results in variability among practitioners in their approach to diagnosis and treatment of patients presenting with this constellation of symptoms.

The social dimension of the problem of occupational and

environmental health is broad in scope, yet exploration of the factors associated with the development of MCS has generally neglected the social context of workplace and environmental exposures as an area of study. Clinical research hypotheses, with regard to the existence of a syndrome and/or sub-sets among the population have been formulated without the benefit of exploratory social research yielding data which may serve as a basis for identifying areas of psychosocial deficits that require service and the types of social work interventions which may be useful in work with people who are suffering with these problems.

Background: Health and Safety Policy and Low-Level Exposures

According to experts in the field of health and safety policy, the passage of protective legislation has failed to keep pace with technological advances impacting on workplace and environmental health (15). The development of standards for recommended levels of exposure has historically lagged behind results of research indicative of associations between the development of disease and exposures to toxic substances (10). Further, it has been widely recognized by the field of occupational medicine that the budget for research of this type, during the 1980's, was cut to the point that meaningful study has been made impossible (69).

This incongruity in occupational and environmental health policy development has created dilemmas for occupational health practitioners providing care to workers and others

daily exposed to potentially harmful substances--in particular, exposures which are under the OSHA hazard limits. Portions of the workforce and community residents with such exposures may elect to utilize health services as a means of addressing these problematic conditions, seeking relief from physiological distress as well as opportunities for relocation in employment or residence, and financial compensation for losses incurred as a result of changes made necessary by the health problem. Health practitioners may increasingly be requested to provide such patients with documentation of "health risk" while necessary modifications to prevent or limit environmental and/or occupational exposures go unrealized due to a failure on the part of regulatory agencies to deem such modifications necessary for worker or community health. The absence of comprehensive standard-setting and enforcement of existing regulations of workplace and environmental toxins has also contributed to the growth of public interest groups concerned with environmental hazards, as well as increased interest in the field of clinical ecology--an approach to medicine that ascribes a wide range of symptoms to numerous common substances in the environment. With growing numbers of individuals seeking relief from health problems attributed to the environment, the clinical ecology movement has come under criticism from portions of the traditional medical community for carrying out exploitative and fraudulent practices (30). Added to the complexity of social forces is the changing nature of doctor-patient

relationships, with increasing emphasis on consumer advocacy, self-care and patient education models, accompanied by changes in funding and reimbursement of health care.

Social Work Intervention in Occupational Health & Safety

The role of social work in the occupational health setting thus involves addressing the psychosocial needs of patients who experience difficulties coping with health problems related to a range of occupational and environmental exposures, as well as addressing the social factors which generate the problems in the first place. In the case of MCS, several overriding issues create the need for psychosocial support and intervention: The lack of definitive diagnosis of work related illness, whether medical or psychiatric, creates difficulties in the use of the workers' compensation system as a means of addressing the financial loss accompanying work disability (45); work, social and family life may be disrupted by illness causing economic hardship and emotional upheaval; further, controversy among medical practitioners as to the nature of an illness may promote "doctor-shopping" - itself a problematic coping style in relation to adjustment to illness (48,61); finally, the organization of the workplace, as well as the presence of health hazards at work or in the environment, may impact on the individual's ability to cope with his or her health problem (36).

Research Project

Given the range of differing hypotheses with regard to the nature of this problem, patients' reports of their experiences might yield information necessary to further exploration of differing intervention modalities and the extent to which such modalities are dependent on specific approaches to, or explanations of the problem. The meaning of the basic practice principle, "starting where the client is," would be explored in the context of assessing unmet needs and investigating the efficacy of intervention aimed at enabling maximum client participation in the process of adjustment as well as advocacy in the workplace and environmental health arenas.

An exploratory/descriptive study was carried out with a sample of patients identified as meeting specific criteria suggestive of a "multiple chemical sensitivity 'syndrome'." Taped interviews were used for the purpose of gathering descriptions of subjects' perceptions of the problem, including connections drawn by subjects between events or circumstances and development of the problem. It was hoped that the results of descriptive data would point towards future evaluative study of the efficacy of various forms and techniques of social work intervention with the problem of multiple chemical sensitivity. Such intervention would include the variable use of advocacy-clarification, psychoeducational and self-help approaches, versus psychological supportive treatment, with individuals, families

and groups.

LITERATURE REVIEW

The field of Occupational Medicine has historically given recognition to the implications for social and economic policy inherent in the impact of technological advances on individuals' health. Policy setting in the occupational health arena has thus remained a shared domain of medicine and the allied health professions, along with the related social science disciplines. Currently, questions surrounding the possibility of short- and long-term health consequences of low-level and acute exposures to chemicals in the workplace and environment provide case studies for the clinical researcher and policy analyst alike.

The following literature review is an attempt to give shape to the multi-faceted nature of our present understanding of "multiple chemical sensitivities", including both the extent of our clinical knowledge of the problem, as well as the socioeconomic and political contexts of low-level occupational and environmental exposures.

MULTIPLE CHEMICAL SENSITIVITIES

The newly-emerging literature on "multiple chemical sensitivities" brings into focus the convergence of medical, social, psychological and ethical/legal perspectives on occupational and environmental disease prevention and

treatment.

According to a report issued by the Ad Hoc Committee on Environmental Hypersensitivity Disorders (1986), chemical sensitivity is:

> A chronic disorder that usually involves symptoms of the central nervous system and at least one other system that worsen upon exposure to suspect foods or chemicals and subside after withdrawal, and where there are no laboratory evidence of organic disease.
>
> The most commonly-reported symptoms include: tension, fatigue and headache, gastrointestinal difficulties, respiratory problems, skin disorders, muscle, joint and bone pain. Symptoms can range from being relatively mild and limited to incapacitating (30).

Cullen (1987) adds to this definition, presenting a multi-disciplinary approach to diagnosis and treatment of MCS (21). He clarifies that symptoms of MCS are elicited on contact with demonstrable (albeit low-level) exposures, differentiating the syndrome from frank delusional or paranoid states, and points to the need for further descriptive studies characterizing the clinical and demographic features of the problem.

Others (Cone et al, 1987; Hoffman, 1988) postulate the existence of "sub-sets" of asthmatics, and cases of acute and/or chronic (low-level) solvent intoxication among the chemically sensitive populations (18,35).

More recently, a work by Ashford and Miller (1991) introduces the notion of differing types of "sensitivities", as well as different groups of "chemically sensitive" populations (2). According to Ashford and Miller, these types

of sensitivities include:

1. A response to lower doses of toxic substances following repetitive exposures;
2. A classical "allergic" response to specific substances; and,
3. Responses following an acute or traumatic exposure.

Ashford & Miller's four population groups include:

1. Industrial workers (mostly male);
2. "Tight-building" occupants (mostly female);
3. Contaminated communities (all ages--middle-lower class) and;
4. Individuals (heterogeneous--middle-upper class).

PSYCHIATRY LITERATURE

Clinical case reviews and descriptive studies, both medical and psychiatric, have revealed a prevalence of psychiatric illness--notably, affective and somatoform disorders--among patients carrying the label of "total allergy syndrome" or "20th century disease" (9,75,77). Related studies have looked at the prevalence of allergic disorders among depressive patients, as well as the contribution of socio-psychological factors and personality styles to allergic symptom occurrence (1,3,14,27,49,58,62).

The social stigma accompanying a psychiatric diagnosis in our culture is considerable, and it is thus not surprising to find such explanations of MCS resisted by patients and family members, as well as by proponents of strengthened health and safety standard-setting. The latter group agrees with the notion that workers who are anxious about exposures may exhibit somatic symptoms, but maintains that the primary

diagnosis of psychiatric illness implies the existence of irrational and illogical fears, in turn lending credence to policies which support an emphasis on individual treatment models over models of primary and secondary prevention (54). Further, when social trends indicating a lack of trust in the regulatory process combine with the co-existence of hazardous materials and diseases of unknown etiology (e.g., cancer), the notion that claims of subjective symptomatology are psychological in origin is likely to be met with resistance which is rooted in the social dilemmas delineated above (8). On the other hand, those who speak to the psychiatric component of the illness tend to hold the field of clinical ecology--rather than weak or absent regulation of toxic hazards--partially or wholly responsible for the existence and increasing incidence of the problem (7,68,75,78).

Psychiatrists may be called upon to treat patients with MCS, generally in the face of patient resistance to and/or noncompliance with such referral and/or treatment (76,78). Brodsky (1983) describes the following set of characteristics common to patients carrying the label "total allergy syndrome":

1. Withdrawal from work;
2. A life-style engineered to avoid exposure to putative noxious substances and;
3. An identity as a disabled person.

Further, notes Brodsky, these patients' self-perception and (given) diagnosis of "allergy to most substances" has become "an organizing principle in their lives, central to their

identity and life-style" (5). Such observations, while accurately describing the patient's objective situation and coping mechanisms, do not constitute a set of diagnostic criteria, much as similar observations of patients who are in the process of litigating claims for illness fall short of constituting a diagnosis of "compensation neurosis", according to Mendelson (1985) (50). Others (Schottenfeld, 1987; Stewart, 1986) contend that patients with this problem usually fulfill the diagnostic criteria for atypical depression, conversion disorder, or other somatoform disorders, also stressing the role of "interpretive sets" (i.e., symptoms are believed to be indicative of disease) in determining the individual's response to symptoms and disease regardless of the etiology of symptoms (66,75).

The literature on the presentation to medical practitioners of patients with multiple somatic symptoms has relevance to the study of MCS and doctor-patient relationships in the diagnosis and treatment of this problem (47). "Doctor-shopping"--recognized as a common coping style among this population--is viewed as problematic for patient and physician, alike (47,61).

Mass Psychogenic Illness

Cohen (1978) defines mass psychogenic illness as:

> [M]ass hysteria, characterized by a group reaction in which employees who usually function normally experience various subjective, non-specific symptoms of sufficient severity to produce an inability to work, including:

> dizziness, nausea, headaches and weakness. Individuals involved typically share a belief that there are certain external causes for their physical symptoms, even though there is no identifiable pathogen or corresponding hazard.(16)

The authors report a prevalence of occurrence of mass psychogenic illness in work settings which are characterized by the performance of repetitive, perceptual-motor tasks at fixed positions and fixed work pace, with workers under considerable pressure to increase production, and general reports of poor labor-management relations.

The phenomenon of mass psychogenic illness (MPI) in the workplace setting is pertinent to the study of MCS largely because the "triggering agent", as it is referred to in the literature, is so often the smell of gas or solvent.

Social psychological analyses of "mass psychogenic illness" phenomena have revealed associations between the incidence of MPI and those job stressors typically found in lower-level positions (17), while, in contrast, the MCS literature usually emphasizes the relatively high socioeconomic status of patients with MCS. Both illnesses, however, are reported as more prevalent among women (17,51).

Cullen (21) proposes that some overlap exists in the population presenting with MCS and cases of MPI, particularly among individuals whose symptoms continue and/or exacerbate following the resolution of the MPI incident in the greater portion of the workforce.

OCCUPATIONAL STRESS

Stressful working conditions--including hazards--and their association with poor mental health and accidents among workers, cannot be disregarded in the study of the problem of multiple chemical sensitivities which may develop following a workplace and/or environmental exposure.

The definition of stress, in much of the literature, is derived from the measurement of functional disturbances (headache, low-back pain, pain in the neck and shoulders, gastrointestinal disturbances, trembling of hands, dizziness and heart palpitation), although there is much controversy about what constitutes "stress" and the ways to measure it. For example, one of the leading writers in the field of stress-related disease epidemiology, Kasl (1981), has described existing research on work stress and health as "fragmentary, difficult to replicate and subject to multiple etiological interpretation" (40).

Writing on the effects of new technology on the organization of work and its impact on the workforce, Fraser (1983) postulates that "stress" is the direct result of an "alien, restrictive, and socially-pressured environment", characteristic of most of today's workplaces, leading to "personal dissatisfaction, sickness, and social and economic disruption" (31).

The broad field of research on "occupational stress" has relevance to the study of MCS in the following areas:

1. Reported associations between psychosomatic complaints and workload, working conditions, job content, non-participation in decision-making, job uncertainty and social isolation; and, the reported higher incidence of psychosomatic diseases among occupational groups whose tasks are monotonous and whose performance failures are consequential (57).

2. Reported higher incidence of accidents among workers who have been moved from a job which they perceived to be good to a job which they consider to be poorer or less prestigious and among workers in areas where there is least possibility of advancement (31).

3. The reported negative impact of the presence of health hazards at work on individual workers' ability to adjust to a work-related health problem (36,46).

4. The reported failure of individual coping styles in relation to the reduction of work-related stress, (as compared with success of similar styles in relation to ameliorating stress outside of the workplace) and the suggestion that workplace problems require collective, rather than individual, solutions (28,56).

CLINICAL ECOLOGY

The clinical ecology literature places much emphasis on the concept of "total body load" as a contributory factor in chemical overexposure, with recommendations of avoidance of "offending substances" given as the primary mode of treatment (58). Allergists have generally refuted clinical ecologists' views of chemical hypersensitivity, positing that an objective evaluation of the diagnostic and therapeutic principles used to support such concepts indicate that it is an unproven and experimental methodology (30).

Bell (1982) traces the development of clinical ecology to the 1930's when a split within the field of allergy occurred over the methods for diagnosis and treatment of dysfunctions of the immune system (4). Theron Randolph, generally recognized as the founder of clinical ecology, originated the diagnostic procedure of hospitalization in an environmental unit in the 1950's. According to Bell, clinical ecologists propose that chronic exposure to common foods, environmental chemicals and natural inhalants--in addition to physical and psychosocial stressors--can trigger a wide range of mental, emotional and physical disorders in susceptible individuals. Bell attributes the lack of acceptance, among practitioners of medicine and psychiatry, of the work of clinical ecologists to the following factors:

1. The interdisciplinary nature of its work resulting "...in the absence of a single traditional field which could accommodate it and test its basic concepts";

2. The more clinical, narrow focus of classical allergists;
3. The disagreement of clinical ecologists with clinical toxicologists over the existence of safe thresholds for exposure to any given environmental agent and;
4. The timing of Randolph's original work which coincided with the expansion of modern psycho-pharmacology and growth of the widespread use of phenothiazine tranquilizers (4).

Psychiatry has critiqued clinical ecology studies, as examples of "casual or vernacular science" (75), or as contributing to dysfunctional behavior by encouraging patients to adopt identities as disabled people (7), and/or to perceive themselves as being in opposition to a "medical establishment" (52). Such critics argue that reliance on the avoidance method has, in effect, formed a basis of truth to the notion that patients frequenting clinical ecology practices suffer from "20th Century Disease" (76). Recommendations of avoidance of "offending substances" as the primary mode of treatment can be difficult or nearly impossible for patients to follow, given the ubiquitous nature of such substances in the modern environment.

Other critiques of clinical ecology argue that patients with psychosomatic illness are being told by clinical ecologists that they have a disease caused by exposures to environmental chemicals, which supports their own notions about their illness and which does not succeed in leading to a cure for the majority of cases (77).

Clinical ecologists, in turn, claim that labeling patients as having a psychiatric disorder on the basis of

non-specific diagnostic criteria is also an example of "casual science" (43).

OCCUPATIONAL HEALTH AND SAFETY AND WORKERS' "RIGHT TO KNOW"

Literature dealing with workers' "right to know" what he/she is working with and the health consequences of exposures to those materials raises the following ethical/legal questions:

1. How much information is needed?
2. How should it be provided?
3. Does knowledge of potential hazards cause workers undue anxiety? (81).

A recent study of asbestos-exposed workers indicates that informing workers about their risks with regard to exposure to toxic substances presents little psychological risk, also revealing a strong desire on the part of workers to be informed (37). Brown (1979) has also discussed the social impact of the presence of carcinogens in the workplace, given the current lack of definitive knowledge about the exact mechanisms of carcinogenesis (10).

Ethical conflicts extend to occupational medicine practice as well. Nelkin--a sociologist who has written extensively in the area of occupational safety and health--cautions occupational health physicians about the wide gap between their self-perception and workers' attitudes toward them, which she feels is reflective of the latter's lack of

trust in the professional context of such work (53). Coye, an occupational health physician, writes on ethical issues as they impact on occupational medicine research. She points out that most workers have good reason to question the usefulness of research conducted for the purpose of learning more about the effects of exposures to chemical in the workplace, if results are rarely shared with them and they continue to be exposed to the hazards which have been studied (19).

The notion of "risk" has been related to social status, professional commitments and feelings of personal control (54). Sociologists Nelkin (1985) and Elling (1986) discuss the interdependence of socioeconomic conditions and technological advancement as it impacts on workers' concerns about health and safety (53,29). Nelkin & Brown (1984) assert that differences in exposures to hazards reinforce the distance between upper management and production workers, with health and safety issues becoming a "metaphor for social injustice or repression and a symbol for broader concerns about the nature of [their] work" (54). Convincing others of the validity of complaints that are not fully supported by the scientific literature, according to Nelkin, becomes a mammoth task for workers who are unable to gain access to the data necessary to evaluate hazards, with the result that, "establishing cause is a comment on the social system [and] a way to define responsibility and assert control" (53).

Elling maintains that these issues are actually embedded in the larger "social context" of occupational safety and

health information, or, as he puts it, "the social psychology of occupational health and safety information." According to Elling, such information exists in the context of the conflict between private property rights and OSHA regulation. In this view, dominant class interests, sponsorship of research and the role of "ambiguity" with regard to health hazards are inherent in the formation of individuals' notions of "risk", how it is perceived, and the impact of such perceptions on individuals' health and use of the medical profession to address health risks (29).

RESEARCH QUESTIONS

Descriptive research exploring patterns of patient interaction with social systems is a necessary first step in better defining the social aspects of multi-system symptoms attributed to environmental exposures, alluded to in the foregoing literature review.

The following questions emerged with respect to exploratory study of individuals' illness behavior and modes of coping with the problem of MCS:

1. How do people who have been told that they suffer from this illness describe their problem?
2. For those who attribute their problem to exposure in the workplace, how do they describe relationships and existing channels of communication among workers, supervisors and management, relevant to their

attempts to modify exposures?

3. Do sub-groups exist within this population? For example, do some patients describe the problem mainly in terms of the failure of outside groups--e.g., regulatory agencies, health care institutions, places of employment, and their representatives--while others focus on subjective complaints and individual restrictions in life-style as the overriding factor in the development and continuation of the problem? Are practitioners likely to adopt different approaches to intervention with these subgroups?
4. Conversely, are these aspects of the problem representative of chronological stages in the development of the illness, such as: Awareness of changes in one's health; initial attempts to do something about the problem; continuing efforts to cope with the problem in all social spheres; acceptance and/or understanding of the problem; and, finally, development of effective coping techniques. What does the concept of "regularities in response" to the problem of MCS imply in terms of intervention?
5. How does the "system" respond to patients who are believed to be suffering from a psychiatric disorder, and how is treatment conceptualized for these patients, as compared to all other patients? What is the impact on patients who are treated as having primarily a psychiatric problem?

6. To what extent are social and demographic features--such as gender, socioeconomic class distinctions, and access to resources--definitive of both the nature of the presenting problem and patient attitudes toward the problem, as well as system responses to the problem?
7. What is the role of the non-medical practitioner in the provision of advocacy and linkage to social systems--such as the workplace, family and community--in which patients have experienced disruption due to the development of multiple chemical sensitivities?

METHODOLOGY

This chapter describes the procedures followed in order to obtain a cohort of clinic patients meeting the criteria for inclusion in the study. At the time of the project undertaking, the total clinic population was over 4000.

Given the controversial history surrounding the identification of this illness, it is essential to designate the diagnostic criteria which must be met in order for a patient to be included in the study. For this reason the initial discussion of the procedure will describe how diagnostic criteria were arrived at and served to define this medical condition. Having defined the condition, we describe the procedure whereby the deliberate time sample of clinic cases was identified, how patients included in this clinic population who met the diagnostic criteria were selected, and the limitations of the study sample. Finally, we describe how the procedures for data collection from existing clinic records, and the interview process, were implemented.

Description of the Setting

The study was carried out in the Yale University Occupational Medicine Program. The Program was initiated in 1979 by medical residents at the Yale University School of Medicine, with support from medical school faculty. Federal funding, earmarked for the training of medical students, interns and residents in occupational medicine was initially

made available to the Program, however these monies were subsequently rescinded in the early 1980's, under the Reagan administration. The Program was then able to secure financial support through a special fund for patient care, administered through Yale-New Haven Hospital, the University's teaching hospital.

From its inception, the Occupational Medicine Program has involved three major components: First, the occupational health clinic offers diagnostic services and treatment to patients in need of an occupational evaluation of their medical symptoms. The clinical program also provides advanced clinical and research training for physicians specializing in occupational medicine. Second, consultation with regard to occupational and environmental hazards--including on-site evaluation and recommendations--is provided by the program to industrial, labor and community organizations. Finally, the program conducts clinical and epidemiological research, informing occupational health and safety policy on local, state and national levels.

The staff consists of a multi-disciplinary team, composed of physicians, epidemiologist, industrial hygienists, a public health educator/administrator, social worker, and psychiatric consultant. Patients are referred from a variety of sources, including employers, labor organizations, lawyers, other physicians, and through media promotion and word-of-mouth. The largest portion of patients seen are those with concerns about potentially hazardous exposures, and without

occupational disease. Such patients are offered information, and, where appropriate, reassurance. Diseases of the lung (asbestosis, asthma and others) are among the most frequent occupational diseases seen in the clinic. Symptoms due to exposures to lead, organic solvents and heavy metals are a second common category of problems. Psychiatric sequelae of workplace exposures and injuries are evaluated and referred for treatment.

Depending on the nature of the problem, and willingness on the part of an employer, investigation of the workplace or community may be carried out by the team, with input from the industrial hygienist. The team also counsels patients with regard to use of public regulatory agencies, such as OSHA and the State Department of Environmental Protection, as well as referral and follow through with such benefit programs as the workers' compensation system.

Overview

In the Summer, 1988, the author submitted a proposal to study occupational health clinic patients' perception of their psychosocial situation, through the Yale University Occupational Medicine Program. These patients would be those who met certain criteria, which had been developed by Mark Cullen, M.D., the Program's medical director, for a clinical disorder of unknown cause, known as Multiple Chemical Sensitivities (MCS). According to Dr. Cullen, this set of criteria:

.....includes the following cardinal features:

1. Onset of symptoms in a previously healthy person after the occurrence of a typical occupational or environmental illness such as an intoxication or injury due to high level exposure(s) to an established toxin. This 'precipitating' illness may be single or recurrent and of any degree of severity; often it is mild and apparently self-limited.

2. Development of symptomatic responses, usually resembling those of the precipitating illness, after re-exposure to increasingly smaller amounts of the same or similar toxin.

3. Generalization of responses to include symptoms referable to additional organ systems, almost invariably including central nervous system symptoms, among others.

4. Generalization of responses to occurrence after exposures to increasingly diverse and chemically unrelated classes of substances at decreasing levels of concentration. Responses typically occur at doses at least two orders of magnitude below accepted TLVs. ["Threshold Limit Values", as set forth by OSHA. See Glossary.]

5. Inability of any widely available test of organ function to explain the constellation of symptoms.

6. Absence of psychosis or major medical condition.(20)

Sampling Methods

The current status of the diagnosis of this illness affected the selection process. It involved consideration of the doubts and difficulties represented in the following discussion.

Much recognition has been given to the wide spectrum of

differing opinions and general lack of consensus among physicians--both within and outside of the field of occupational medicine--with regard to the nature and, for that matter, the existence of "Multiple Chemical Sensitivities."

Within the field of Occupational Medicine, the range of differing viewpoints include explanations based on:

> ...immune dysfunction, excessive free radical generation, behavioral conditioning, olfactory-limbic dysfunction and psychological disorders.(24)

A study conducted Dr. Benjamin Hoffman, M.D. in Spring, 1988, utilizing a group of 40 patients selected from the clinic population concluded that:

> ...patients with [MCS] comprise a heterogeneous population. It is likely to be a diverse group that contains multiple sub-groups, including asthmatics, depressed or anxious individuals, atopics, and perhaps a group that truly represents the low end of the dose response relationship curve for effects to toxic substances.(35)

Further illustrative of the range of opinion and lack of clarity among health care professionals with regard to the nature of the illness, were the results of an informal survey conducted by the author in the early part of 1989 among a group of seven attendees at Dr. Cullen's lecture on MCS. Directly prior to the lecture, attendees were given a brief questionnaire to complete (Appendix A). Among the group were 4 physicians, 2 doctoral students in the allied health sciences, and 1 registered nurse. In response to a question

with fixed alternative responses regarding their opinions about the disorder, 4 of the 7 felt that "not enough was known" about the disorder (i.e., to either characterize it as a syndrome or to fashion appropriate strategies for intervention); the remaining 3 felt that there were "sub-groups" among the population labeled as having "MCS", each requiring separate diagnoses, and each requiring different treatment.

This finding has been further supported by other studies indicating that most occupational health physicians believe that MCS is more psychological than organic in nature (60).

Finally, as explicated in the preceding chapter, many in the fields of psychiatry and allergy have argued for the need to carry out psychiatric evaluations of patients with "supposed" allergies (7,62,76), while the predominant view among clinical ecologists is one characterizing the disorder as primarily physiological--the body's reaction to an "overload" of low-level chemical exposures in the environment (58).

Given the wide variability of opinion about the disorder among health professionals, the author, along with the program's medical director, assumed that many patients who met the criteria for MCS might have been given an alternative diagnosis, possibly representative of those "subsets" of diagnostic groupings, mentioned above, thought to comprise the MCS population. In particular, certain diagnoses were believed by Dr. Cullen to be more commonly utilized than

others in evaluating problems which shared many, or all, of the features of MCS. These diagnoses included:

-Upper Airway Irritation Due to Fumes
-Acute Solvent Intoxication
-Pesticide Poisoning
-Any diagnosis (including all mentioned above) accompanying an "Ambient" (i.e., environmental, rather than occupational) exposure.

With limitations on time and staff availability, a review of over 4000 medical charts was felt to be impractical. In order to identify the largest possible number of cases with the potential of meeting criteria for study inclusion, a deliberate sampling method was utilized involving selection of four subsets of patients from the total population and allowing for overlap between the groups. The four groups, chosen in the following sequential order, included:

1. Patients with one of the four diagnoses (either primary, secondary or tertiary) as specified by Dr. Cullen to be most likely to yield cases appropriate for inclusion, (MCS, Upper airway irritation due to fumes, Acute solvent intoxication, and Pesticide poisoning.)

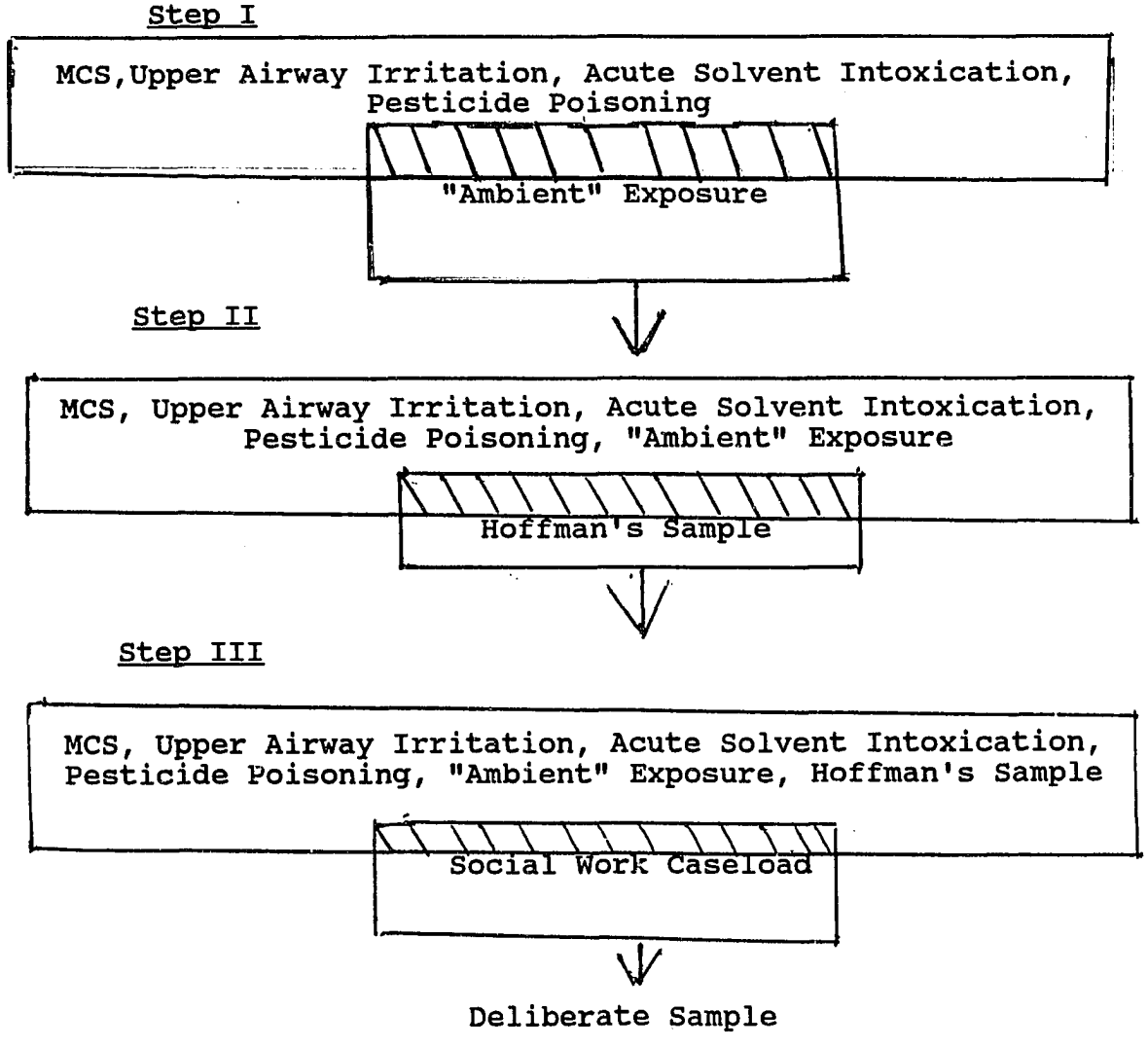
2. All patients with "ambient" exposures (See Appendix B for a partial listing of diagnoses appearing in this group.)

3. Patients who had previously been identified as meeting the criteria for MCS in Hoffman's study, completed earlier in 1988. Dr. Hoffman had made use of criteria similar to the author's (also derived from the work of Dr. Cullen) as a basis for selecting 40 cases from among the total clinic population (Appendix C).

4. Patients from the author's clinic caseload selected on the basis of presenting complaint and/or problem. The total caseload included all patients (N=470) referred by physicians for social work services, or identified by the social worker as being able to

benefit from services through case finding at weekly interdisciplinary case conferences, during the period 1980 to 1988. Cases with presenting complaints such as "unknown chemical exposure," "chronic headaches," and "stress-related problems" were selected by the author as worthy of chart review for the purposes of this study. (See Appendix D for a listing of diagnoses of those selected.)

The following chart illustrates the steps taken in order to arrive at the deliberate sample. (Shaded areas indicate the overlap between subsets of the total population):



This effort yielded a total of 410 cases for chart review, 109 of whom had appeared in more than one of the groups. Demographic characteristics of this group, as well as those of the sampling frame (N=4000+) from which it was derived, will be considered later on, in the chapter on study findings.

Method of Case Selection from Deliberate Sample

In order to facilitate the process of case selection, a "scoring sheet" was developed by the author, operationalizing the major concepts presented in Dr. Cullen's description of the disorder's features. The determination of inclusion for each case was based on the application of the scoring sheet to the case material in the chart. Inclusion in the study required that each set of criteria be checked appropriately, as follows:

		Yes	No
1.	Prior illness (i.e., somatoform or other confounding illness)	____	x
2.	Believable single or multiple precipitant: a. Coherent story	x	____
	b. Availability of outside data	x	____
3.	Generalizing: a. Multiple organ systems	____	____
	b. Multiple chemicals	x	____
	c. Low levels	x	____
4.	Major psychiatric illness or any other that may explain problem.	____	x

Each of the 410 charts was reviewed by either the author or a research associate, using the following method of review: If a letter from the primary physician, explaining the patient's problem, appeared in the chart, the scoring instrument was administered directly to the material contained in the letter; if no such letter appeared, the instrument was applied to the initial chart note. Those cases for which a question remained as to its inclusion in the study were given to the program's Medical Director for final review. This process of selection yielded 70 cases meeting the criteria for inclusion, as follows:

	Cases Reviewed	Cases Chosen
Upper Airway Irritation (1°, 2°, 3° diagnosis)	141	17
Acute Solvent Intoxication	5	0
MCS (1o,2o diagnosis)	34	31
Pesticide Poisoning	9	1
Ambient Exposures	159	9
Hoffman Study	12	11
Social Work Caseload	50	1
Total	410	70

Following the selection of these 70 cases, 13 more patients (12 of whom were given a diagnosis of MCS) were seen in clinic who met study criteria. These cases were added to the 70 already chosen for inclusion, bringing the final total to 83. (See Appendix E--Chart illustrating the method of case selection from the total clinic database.)

Limitations of the Sample

1. Sampling Frame

By the time this project was undertaken, the Occupational Health Clinic had been in operation some nine years (1979-1988). Over 4000 patients had been seen at the program's two clinic sites.

Several years prior to the study undertaking, a data collection tool had been developed by program staff for the purpose of entering into a clinic data base patient information gathered at the time of intake. Thousands of records of patients who had been seen prior to the development of this tool were coded retrospectively, leaving room for error in interpretation of file material, as well as gaps in pertinent information. In some cases, for example, information on key variables, such as race/ethnicity, was not available in the old records.

It is important to note, as well, that a lag existed (in some cases, months) between the date of patient intake and the coding and entering of new patient data. Thus the aggregate data, available in the database, was not necessarily an accurate reflection of the actual caseload at any given point in time. This was particularly problematic with data on MCS, as there was a rapid increase in the rate of both new presentation and diagnosis of this problem at the time of the study undertaking. For example, a current listing (obtained in 12/92) of patients with a primary diagnosis of MCS initially seen in clinic prior to 1989, includes 41 cases--10

more than the list of the same population obtained in October 1988. Nine of these additional 10 patients were seen in 1988, and one was seen in 1987.

Finally, it is not known what, if any, steps were taken to check the accuracy of either the coding or the data entry process, nor is it known what percentage of error is contained in the data base as a whole.

2. Problems in Data Retrieval

Added to the problem of accuracy within the data set was the equally limiting problem of data retrieval. The author was dependent on the activity of other clinic staff for this process. Therefore, major errors in data retrieval were not observed until after the completion of the study, when a new list of patients was requested. In particular, it was discovered that the number of patients in the sampling frame with a primary diagnosis of acute solvent intoxication at the time of the study undertaking was actually 80, rather than 5.

Below are comparative tables of data retrieved in October, 1988 and December, 1992, illustrative of the problem of data retrieval as a contributing factor in the limitation of the sample. (The numbers in parentheses represent those patients, out of the additional number retrieved in 1992, who were seen prior to 1988. The remainder of the additional cases retrieved were seen in 1988, and were thus more likely to have been added to the data set after October, 1988, when the initial deliberate sample was drawn):

	"Up to present" 10/88	"Prior to 1989" 12/92	
Upper Airway Irritation			
Primary diagnosis	130	146	(7)
Secondary diagnosis	10	10	
Tertiary diagnosis	1	2	(1)
Acute Solvent Intoxication			
Primary diagnosis	5*	80	(68)
Secondary diagnosis	0	12	(11)
MCS			
Primary Diagnosis	31	41	(1)
Secondary Diagnosis	3	3	
Pesticide Poisoning			
Primary diagnosis	9	12	
Total	189	306	(88)

*Only primary acute solvent intoxication patients with secondary or tertiary diagnoses of either upper airway irritation or MCS were retrieved, presumably in error.

3. Variability of Diagnosis

As we have discussed earlier, the decision to diagnose a problem as "MCS" is likely to be dependent on numerous factors, including, among other factors:

1. The opinion of the clinician rendering the diagnosis with regard to the nature or existence of MCS and;
2. The date the patient was seen, relative to the advent of the term "MCS".

The term "Multiple Chemical Sensitivity" came into use as a diagnostic entity in approximately 1986, in the course of discussions about the nature of the problem, which were held

among the staff with the clinic director. This series of discussions ultimately led to a decision to publish a collection of articles on the subject (21) which served to popularize the use of the term "Multiple Chemical Sensitivities" to describe the problem. Prior to this time, patients with presenting complaints, similar to those which were later described as "MCS", presumably were given a variety of diagnoses--hence the author's decision to utilize a deliberate sampling technique to uncover cases appropriate for study inclusion, other than those with a formal diagnosis of MCS. However, a recent analysis of the data set reveals that 15 (over 30%) of the 41 patients seen prior to 1989, who currently appear in the database (12/92) listed as having a primary diagnosis of MCS, were initially seen in the clinic prior to 1986. This finding is indicative of the practice of "retrospective" coding of MCS in certain cases. It is not known on what basis certain patients were coded retrospectively as MCS, while others, perhaps with similar complaints, were not. Further, one patient with a diagnosis of allergic rhinitis included in the original deliberate sample, drawn in 1988, has since been "re-coded" as having MCS. This patient, initially seen in the clinic in 1988, appeared in the database, in 10/88, as having a primary diagnosis of allergic rhinitis and a tertiary diagnosis of upper airway irritation. However, in the most recent (12/92) retrieval of the data, he appeared among the group with a primary diagnosis of MCS. Interestingly, when his chart had

been reviewed for possible study inclusion in 1988, it was not considered to have met study criteria.

Thus, similar problems of variability in the opinions of the author, director, and research assistant, as to whether patients met study criteria, entered the case selection process, as well. This resulted in the probable failure to include patients appropriate for study, as well as in the erroneous inclusion of patients with alternative diagnoses, as noted below.

Further discussion of the range of diagnoses among patients chosen for inclusion in the study, and possible association with such factors as date seen and patient gender, will be taken up at greater length in the following chapter.

Interview Procedures

Letters were sent to each of the 83 patients inviting their participation in the study. If patients were interested in participating, they would indicate, on an enclosed form, the best time to contact them in order to schedule a telephone interview (Appendix F).

Twenty-eight of the 83 who were sent a letter did not participate for the following reasons:

- 15 were not able to be contacted or did not respond. One patient was deceased. (A family member responded.)
- 5 refused to participate.

8 who had responded positively to the initial invitation, were either unavailable at the scheduled time of the interview and could not be reached for rescheduling, or gave incomplete interviews and were thus excluded from the study.

Three of the remaining 55 respondents interviewed were later removed from the study as, on further review of these cases with the medical director, it was felt that they had been judged erroneously to have met study criteria. This brought the final sample total to 52. (A cross-classification of the characteristics of the 31 non-participants and the 52 participants will be presented and discussed further in the chapter on "Findings").

A 75-question, structured interview (Appendix G) was administered by telephone to 45 of the subjects by a research assistant with a doctorate in Human Development and Family Relations, hired especially for this purpose. The author conducted the remaining 7 interviews. All completed interviews were checked by the author. Closed-ended questions were tabulated by the interviewer, and open-ended questions were taped, with permission of the respondent, and then transcribed for the purpose of further analysis. Most interviews averaged from one to one and 1/2 hours in length, with two interviews lasting approximately 3 hours.

Open-ended questions, scattered throughout the interview, were designed to gather data on respondents' subjective experience with a range of aspects of their health problem. Open-ended questions included the following:

1. (Now I'd like you to) Describe your health problems to me.

2. What does your doctor, or do your doctors think is your health problem?

3. When did your health problems begin?

4. When did you first talk about your health problems with others, either at work or elsewhere? Tell me about that time.

5. When was the next time you talked about your health problem with others? Tell be about that time.

6. Tell me about the first time you went to a health care provider about the problem. (second, third, fourth, etc., up to eight)

7. What kinds of support services would be most useful for a person in your situation, with your kinds of health problems?

Demographic data, as well as information about patients' workplace and social support system, were gathered through use of fixed alternative questions.

In addition, given the tendency in the literature to characterize MCS as a somatoform illness, and/or lifestyle involving an identity as a disabled person, two questionnaires, validated in previous studies, were used to measure interpersonal dependency and illness behavior (34,79). It was hoped that further descriptive material in these areas would shed light on the extent to which low self-esteem and dependency, in the interpersonal sphere, and preoccupation with one's illness, in the illness behavior sphere--both of which have been linked with somatization (48)--were characteristic of the study population.

Data derived from the questionnaire were compiled into

frequency-percentage tables for univariate analysis. T-tests were used to test the significance of mean differences between sub-groups. Chi-square was used to test significance of associations between nominal variables. Correlation analysis (Pearson's r) was used in determining the significance of associations between selected ordinal and interval variables.

Following the completion of all interviews, subjects were invited to a group discussion (Appendix H) to hear more about the project goals, and to provide feedback with regard to preliminary findings, based on an informal review by the author of study results. A summary of the results of this meeting, attended by approximately 17 of the subjects, appear in the following chapter.

FINDINGS

In this chapter are included the major findings of the study. Initially, the study sample and total clinic population from which it was derived, are compared in order to identify the ways they differ on such attributes as gender, age, and race/ethnicity. Note that the study sample includes all patients meeting the criteria for inclusion in the study.

Given the limited size of the sample, percentages and actual numbers will be utilized throughout the discussion of findings. Cross classifications will then be analyzed to determine the relationships between attributes. Finally, significant differences will be noted and discussed, and a summary of findings will conclude this chapter.

A. Characteristics of Total Clinic Population & Deliberate Sample

At the time of the study undertaking (1988-89), the total clinic patient population numbered over 4000. Approximately 70% of the total group of patients were actively working at their regular job at the time of their visit to the clinic. Only 31 out of the total group, or less than 1% of the patients, had a primary diagnosis of MCS.

Table 1 compares demographic characteristics (age, gender, race/ethnicity) of the total database with those of each of the four subsets, comprising the final deliberate sample selected for chart review. A key describing each subset population is located at the bottom of the table.

Table 1: Demographic Characteristics: Database & Deliberate Sample

	Database		Subset1		Subset2		Subset3		Subset4		Del.Samp	
Age	N=4080		N=189 *		N=159 **		N=12 ***		N=50 ****		N=410 !	
Mean	52		42		46		40		41		42	
Range	(18-85)		(19-80)		(1-71)		(28-59)		(28-63)		(1-80)	
Gender	N	%	N	%	N	%	N	%	N	%	N	%
Male	3565	87	93	49	60	38	7	58	21	42	183	45
Female	515	13	96	51	99	62	5	42	29	58	227	54
Race/ Ethn.	N	%	N	%	N	%	N	%	N	%	N	%
Cauc.	3345	82	160	85	147	92	12	100	46	94	365	89
Afri-Amer	299	7	13	7	8	5			3	5.5	24	6
Latino	145	3.5	10	5	2	1.5			1	.5	13	3
Asian	5	.5										
Uncode	286	7	6	3	2	1.5					8	2
TOTAL	4080	100	189	100	159	100	12	100	50	100	410	100

* **Subset 1** - Patients with 1o, 2o, or 3o diagnoses of upper airway irritation, acute solvent intoxication, multiple chemical sensitivities, pesticide poisoning. Missing are approximately 75 cases of 1o diagnosis of acute solvent intoxication.

Subset 2 - Patients with coded ambient exposure and having a variety of diagnoses, exclusive of those listed in Subset 1, except for acute solvent intoxication.

***Subset 3** - Cases selected from a group of 40 patients who were subjects in previous study. The remainder (28) of study subjects appeared in either the Subset 1 or Subset 2 listings.

****Subset 4** - Purposive selection of cases from the total social work caseload (N=470). Of the 108 cases selected, 58 were already included among the previous 3 Subset lists.

!**Deliberate Sample** - Combined group of Subsets 1, 2, 3 and 4, subjected to chart review.

Thirty-four diagnostic categories accounted for approximately 84% of the total population. The following 4 diagnostic groups, accounting for 56% of the total, were the largest among the diagnostic groups represented in the database, as follows:

1. "No disease" (N=1030, 25% of total population)
2. Pleural plaques (evidence of asbestos disease) (N=600, 15% of total population)
3. Asbestosis (N= 500, 12% of total population)
4. Non-occupational Chronic Obstructive Pulmonary Disease (COPD) (N=152, 4% of total population).

In comparison, the 4 diagnostic groups chosen for the deliberate sample were representative of the following percentage(s) of the total population from which they were selected:

1. Upper Airway Irritation due to fumes (N=140, 3% of total population)
2. Acute Solvent Intoxication (N=76, 2% of total population)
3. **Multiple Chemical Sensitivities (N=31, .8% of total population)**
4. Pesticide Poisoning (N=9, .2% of total population).

B. Characteristics of non-participants

Of the 423 cases subjected to chart review, 70 were selected as meeting study criteria. Thirteen more newly-seen patients were added following the initially case selection, to bring the total to 83. Of these, 31 were non-participants--23 women and 8 men--leaving a total of 52 subjects in the final study sample. Table 2 illustrates the reasons for non-participation among this group.

Table 2: Reasons for Non-participation

	N
Initially included, later removed from study	3
Unable to contact or failed to respond to two consecutive requests for participation	15
Refused to participate	5
Unavailable for scheduled interview; or giving incomplete interview	8
Total	31

In order to address the possibility that willingness to participate in the study might be associated with certain attributes, we looked for differences between the group of non-participants and participants, in age, gender and diagnosis. Information on other variables, such as current work status, income level and source of income, while also of potential interest as a differentiating factor between participants and non-participants, was not available.

The difference in average age between non-participants (mean age=46; range=23-69) and participants (mean age=45; range=27-64) was not statistically significant. While only 60% (N=33) of the 55 female invitees actually participated in the study, compared to 68% (N=19) of the 28 male invitees, the difference in rates of participation for males and females was not statistically significant.

Different rates of participation among the various diagnostic groupings in the original sample of 83 invitees

were also noted, although tests of statistical significance were not applied. Generally, the diagnoses which were singly represented in the original group of invitees were unlikely to appear in the final sample, while a majority of the diagnostic groups in which two or more patients were represented appeared, in varying proportions, among the final group of participants.

As noted in Table 3, below, the diagnostic groups with 2 to 3 patients each (Group B) were more likely than those which were singly represented (Group A), to appear in the final sample, along with the three largest diagnostic categories (Group C). This finding argues for the consideration of other diagnostic categories--in addition to the four, as noted by Dr. Cullen (p.26)--as potentially including patients who may meet the criteria for MCS.

Table 3: Diagnoses of Non-participants & Participants

# Diagnostic Groups, Invitees	Diagnoses	# Dx, final sample
GROUP A: Diagnoses -- one pt. (N=7)	Amenorrhea, Anxiety d/o, Headache, NOS, Panic d/o, Phobic d/o,Pesticide Poisoning, Toxic poisoning	1
GROUP B: Diagnoses -- two - three pts. (N=7)	Asthma,(non-occup), Asthma, (occup), Pharyngitis, PTSD, Somatization d/o, Urticaria, NOS, "No diagnosis"	6
GROUP C: Diagnoses -- four or more pts. (N=3)	**Acute Solvent Intoxication, MCS, Upper Airway Irritation**	3
TOTAL (N=17)	TOTAL # Dx Grps., Final Sample:	10

C. Study results

There were 19 men and 33 women in the final sample (N=52). Mean age was 45 (range, 27 to 64), with no significant difference in average age between female (age=45) and male (age=43) respondents. The mean age of onset was 42 (range, 34 to 44). The group was Caucasian, and either Protestant or Catholic in reported religious affiliation.

Most subjects (N=30) were married; 2 subjects reported living (unmarried) with their partner; 10 were never married; 9 were separated or divorced and 1 was widowed. No significant differences in marital status were noted between men and women. Most respondents (N=33) had children, with the majority of this group having between 2 and 4 children each; however, only 17 respondents had a child, or children, living with them at the time of the interview.

Educational level among the sample was high, on an average, with the majority (N=39, or 75%) having either college education (N=28, or 54%) or graduate degrees (11, or 21%). The remaining 13 subjects, or 25% of the sample, had a high school education or less. Level of education was statistically associated with gender with use of the t-test, with women averaging a significantly higher educational level than men (t=-2.3, DF=50, P=.025). Table 4 is a comparison of male and female reported educational levels.

Table 4: Education by Gender

Education	Male N	Male %	Female N	Female %	Total N	Total %
Some College ed and/or beyond	11	58%	28	85%	39	75%
H.S. Degree or less	8	42%	5	15%	13	25%
Total	19	100%	33	100%	52	100%

Income

Six subjects, (only one of whom was unemployed at the time of the interview), did not report individual income, and 11 subjects (4 of whom were single or divorced) did not report family income. As illustrated in Table 5, below, income levels varied widely, with a range of less than $7,000/year (27%, N=14) to $35,000 or more/year (25%, N=13). Family incomes, however, ranged higher, with 50% (N=26) reporting family incomes of $35,000 or more/year.

Table 5: Distribution of Individual & Family Income

Income	Indiv. Income N	%*	Cum. %	Family Income N	%	Cum. %
<$7,000/year	14	26.9	30.4	4	7.7	9.8
$7,000-$12,999	4	7.7	39.1	0	0.0	9.8
$13,000-$20,999	6	11.5	52.2	2	3.8	14.6
$21,000-$34,999	9	17.3	71.7	9	17.3	36.6
$35,000 & over	13	25.0	100.0	26	50.0	100.0
Non-report	6	11.5		11	21.2	
TOTAL	52	100.0		52	100.0	

* Rounded to the nearest .1%

Neither reported individual income nor family income were statistically associated with gender, with use of the T-test. Both individual and family income were positively associated, at the statistically significant level, with age ($P<.05$ and $P<.03$, respectively), and current occupation ($P<.01$ and $P<.02$, respectively.)

Diagnosis

Subjects' diagnoses were obtained from the clinic data base. There were a total of ten diagnoses among the sample, including the category "No diagnosis." The majority of respondents had been diagnosed as having "Multiple Chemical Sensitivities" (MCS), (54%, N=28). The second largest diagnostic grouping was "Upper Airway Irritation due to Fumes" (17%, N=9). A cross classification of diagnosis and gender appears in Table 6.

Table 6: Diagnosis by Gender

Diagnosis	F	M	Total
Multiple Chemical Sensitivities MCS	16	12	28
Upper airway irritation	8	1	9
Acute Solvent Intoxication	2	1	3
Occupational Asthma	2		2
PTSD		2	2
Urticaria, NOS	1	1	2
Somatization disorder	1	1	2
Pharyngitis		1	1
Pesticide Poisoning	1		1
"No Diagnosis"	2		2
TOTAL	33	19	52

The variability in diagnoses of patients presenting with this pattern of complaints may be dependent on numerous factors, including, among others, physician orientation to the problem of MCS (55) and the timing of the advent of the term "multiple chemical sensitivities", along with its use as a diagnostic entity (circa 1986) (21, 74). Physicians making a diagnosis of MCS may be influenced by multiple social factors, including patient gender and personality style (65); patient socioeconomic background (13); and, the sociopolitical climate surrounding the evaluation of health problems attributed to occupational and environmental toxins (73). Further, along with "sick building syndrome" (39), somatization disorder has been viewed as mainly affecting women (33,70); therefore, the steady increase, in the early years of clinic operation (1980-1985), in the number of male patients diagnosed with somatization disorder, along with other psychiatric illness--e.g.,PTSD (67)--may have been a factor in the decision to create a new diagnostic category to describe the presentation (i.e., particularly in male patients) of symptomatology continuing long after the occurrence of acute toxic exposure.

Table 7 illustrates the changing patterns, over time, in clinic physicians' diagnosis of patients meeting criteria for inclusion in the study (N=83). Note the number of patients, seen prior to 1986, (N=13), retrospectively coded as having MCS. Also note that female patients, seen prior to 1986, were more likely than male patients to be given either a diagnosis with physiologic basis (e.g., upper airway irritation) or no

diagnosis, while conversely, male patients seen during this period were more likely to be given a psychiatric diagnosis (e.g., phobic disorder, somatization disorder and post traumatic stress disorder [PTSD]).

Table 7 further illustrates similar proportions of the male (46%, N=13) and female (43%, N=24) patients initially seen prior to the advent of the diagnosis of MCS.

Table 7: Diagnosis by Gender and Year-of-Visit

0=Men (N=28) +=Women (N=55)

Diagnosis	Year of Visit to Occupational Health Clinic
Acute Solvent Intoxication	0 0 + +
Amennorhea	+
Anxiety d/o	+
Asthma,non-occupational	0 +
Asthma, occupational	+ + +
Headache, NOS	+
MCS	0 0 0 0 00 0000 0 0 0 0000 ++ + + + ++ ++ ++++ ++ ++ ++ ++ ++ +++
Panic d/o	+
Pesticide Poisoning	+
Pharyngitis	0 +
Phobic d/o	0
PTSD	0 0 0
Somatization d/o	0 +
Toxic poisoning	+
Upper airway irritation	+ 0 0 +++ ++ + +++ +
Urticaria, NOS	+ 0
No diagnosis	+ ++
YEAR:	'80 '81 '82 '83 '84 '85 '86 '87 '88 '89 '90

Types of Exposures/Where exposures took place

A range of environmental exposures--including, but not limited to, solvents, pesticides, metal dusts, fumes, and indoor air pollutants--have been associated with the development of MCS. (According to Nethercott [1993], Terr [1989] has added "stress at work" to this list of exposures [52]). We were interested in knowing whether subjects reported having had exposures similar to those listed above, and whether certain exposures were predominant among this sample.

Subjects were asked to describe what they felt had caused their problem. Responses were then grouped into the following categories, illustrated in Table 8, below. Note that four of the responses were grouped under the category "other", as they did not easily fit into the other categories listed. Results indicate a predominance of reported exposures to solvents and indoor air pollution, compared with other categories of exposure reported by subjects.

Table 8: Reported "Cause"/Exposure Leading To Health Problem

Reported exposure	N	%
Acids	9	17
Formaldehyde	9	17
Indoor Air Pollution	12	23
Pesticides	4	8
Solvents	14	27
Other*	4	8
TOTAL	52	100

* "Cyanide", "Don't know", "Mind", "Pain medication"

Etiologic Agent/Toxin

Each subject's coded etiologic agent (or "toxin", as it is coded in the clinic data base) was then obtained in an effort to compare physicians' assessment of subjects' exposure(s) with subjects' report of the exposure leading to development of the health problem.

Table 9 lists the etiologic agents represented in the sample. Note the large (combined) portion of subjects (N=27, 52%) with either the etiologic agent "indoor air pollution" (N=10; 8 female, 2 male), or for whom no etiologic agent was coded (N=17; 12 female, 5 male):

Table 9: Etiologic Agent as Recorded by Occupational Health Clinician

Toxin	N	Toxin	N
Coal Tar Pitch	1	Solvents	2
Aromatic Solvents, NOS	1	Epoxy resins	1
Toluene	1	HDI	1
Diesel Fumes	1	Plasticizers	1
Ethylene Oxide	1	Pesticide	3
Trichloroethane	2	Chlorine	1
Formaldehyde	4	**Indoor Air Pollution**	**10**
Oils, NOS	1	Stress	1
Chemical dust	2	Stainless steel weld	1
4 PC carpets	1	**Uncoded**	**17**
		TOTAL	52

The majority of coded etiologic agents (58%, N=11), (including 7 out of the 10 cases of "indoor air pollution", and 3 of the 4 cases of formaldehyde) were matched with the "cause"/exposure by subject report.

The large number of subjects for whom no etiologic agent was coded was of particular interest, as the diagnosis of MCS

is dependent on the documentation of exposure, according to the cardinal features of the problem as set forth by Dr. Cullen (19, 20). We were therefore interested in learning about the reported exposures of the group of 17 subjects for whom no etiologic agent was coded. As noted in Table 10, below, the largest reported-exposure category for this group of 17 subjects was "formaldehyde" (30%, N=5).

Table 10: Reported "Cause"/Exposure: Subjects with "Uncoded" etiologic agent

Acids	4
Solvents	1
Pesticide	1
Indoor Air Poll.	3
Formaldehyde	5
"Other"	3
TOTAL	17

Where reported exposure took place

Most subjects (N=44) reported that they were first exposed to the cause of their problem at the workplace. The remaining 7 subjects reported that the problem developed as a result of exposures both in- and outside of the workplace. (One subject did not answer this question.)

Changes preceding the development of the health problem

Although used in the present study as a criteria for case inclusion, the description of the onset of the health problem as developing after the occurrence of illness following an identifiable toxic exposure is not one of the more widely-accepted among the criteria which have been posited as

constituting the case definintion of MCS (52). In the author's experience, however, such exposure is typically reported to have occurred following, or in conjunction with, a change in work assignment or a move to a new home. Both "changes" frequently involve the introduction of new toxic exposures from which the patient reports having felt unprotected. We were therefore interested in learning more about reported changes of this type among the sample.

Subjects were asked whether any changes had occured, either in the workplace or non-work environment, which they felt might have contributed, either directly or indirectly, to the development of the health problem. Most subjects (94%, N=49) reported a change to have taken place which they felt was related to the problem. Note, in Table 11, below, the large portion of subjects (58%, N=30) who reported (combined) changes in job, home or car, and exposures to new substances as preceding the development of the health problem:

Table 11: Reported Changes Contributing to Development of problem

Reported Change:	N	%
New job, home or car	19	37
Exposure to new substance	11	21
Renovation (work or home)	9	17
Underventilation	8	15
Accident on job	2	4
"No change(s)"	3	6
TOTAL	52	100

Length of time between exposure and onset of illness

The author was interested in learning about the range in the length of time reported by subjects to have occurred between the time of the exposure and the onset of health problems. Results, illustrated in Table 12, below, indicate the majority of subjects (65%, N=34) reporting that the development of health problems began soon (within 3 months) after the toxic exposure. A sizeable portion of the sample, however, (25%, N=13) reported a delay of greater than one year in the onset of health problems following the exposure.

Table 12: Length of Time between Exposure and Onset of Health Problem

Length of time	N	%
Same month	24	46
Between 1 and 3 mos.	10	19
Between 3 mos. and 1 yr.	5	10
Over 1 yr.	13	25
TOTAL	52	100

Occupational Status

The Hollingshead Occupational Status Index (Appendix H) was used to measure the reported occupational status of subjects both at the time of their exposure ("old" occupation) and at the time of the interview ("current" occupation). Table 13 illustrates the frequencies and percentages of subjects' reported "old" and "current" levels of employment.

Table 13: Comparison of "Old" and "Current" Occupational Levels

OCCUPATIONAL LEVEL	"Old" occupation		"Current" occupation	
	N	%	N	%
Level 0 Unemployed	1	1.9	17	32.6
Level 1 Farm Laborers/Menial Service	0	0.0	1	1.9
Level 2 Unskilled	2	3.8	0	0.0
Level 3 Machine operators/Semiskilled	11	21.2	4	7.7
Level 4 Smaller business owner/Skilled	3	5.8	7	13.5
Level 5 Clerical/Sales/Small business own.	8	15.4	3	5.8
Level 6 Technicians/Semiprofessionals	8	15.4	5	9.6
Level 7 Managers/Minor professionals	4	7.7	3	5.8
Level 8 Administrators/Lesser professional	10	19.2	8	15.4
Level 9 Higher Executives/Major Profess.	5	9.6	4	7.7
TOTAL	52	100.0	52	100.0

Most subjects (67%, N=35) were working at the time of the interview, although this proportion was greatly reduced from the proportion (98%, N=51) who reported having been employed at the time their health problems began. Thus, although the average "Old" occupational level, for both men and women, was greater than one level higher than the "Current" occupational level, this difference was due almost entirely to an increase in unemployment (32% increase), which was greater among women

(33% increase) than among men (26% increase). For those subjects (N=35) who were working at the time of the interview, occupational level at the time that health problems began was predictive of their current occupational level at the statistically significant level (r=.37, P<.01), with a majority (68%) working at jobs in the same occupational level as they had been when the reported exposure had occurred. "Current" occupational status was also positively correlated with educational level (r=.41, P<.01).

Neither "old" nor "current" occupational status was statistically associated with gender, although, when controlling for unemployment, group differences in mean "Current" occupational level, between men and women, approached statistical significance, (T=-1.75, df=33, P=.089), with employed women working at moderately higher occupational levels than men.

Table 14 illustrates gender differences in mean "old" and "current" occupational levels; note that for employed women, occupational level is higher at the time of the interview than at the time of exposure(s), with the opposite holding true for employed men.

Table 14: Mean Occupational Level by Gender

"Old" occupation	Mean occupational level	Standard deviation
Males (N=19)	5.3	2.2
Females (N=33)	5.7	2.3
Total (N=52)	**5.6**	**2.3**
"Current" occupation (including unemployed)		
Males (N=19)	3.8	3.1
Females (N=33)	4.1	3.5
Total (N=52)	**4.0**	**3.3**
"Current" occupation (excluding unemployed)		
Males (N=14)	5.1	2.4
Females (N=21)	6.4	1.9
Total (N=35)	**5.7**	**2.1**

Unemployment

Given the relatively young average age of onset of health problems in this group (age 42), the alarming increase in unemployment at the time of the interview (32%) is indicative of a major area of psychosocial need in the population meeting the criteria for MCS. As noted in Table 12, above, only 2% (N=1) of the population reported having been unemployed at the time of the exposure believed to have caused their health problem. In contrast, 33% (N=17) reported being unemployed at the time of the interview--some 6 years, on an average, (range = 1 month to 9 years) following the onset of health problems. We were therefore interested in factors which might be associated with unemployment for this large segment of the

study population.

While a larger proportion of women were unemployed at the time of the interview (36%), compared to men (26%), this difference was not statistically significant. The average age of the group of unemployed subjects was slightly older (age 47), although not significantly, than the total sample (age 45). A greater proportion of the unemployed were married (65%) than was true for the entire sample (58%), however, this difference was not statistically significant. Most of the unemployed subjects had a diagnosis of MCS (59%, N=10), however, this closely reflected the proportion of MCS-diagnosed subjects in the entire sample (54%); 3 subjects had a diagnosis of Upper airway irritation, and the remaining 4 unemployed subjects had the following diagnoses: Somatization disorder, Occupational asthma, Acute solvent intoxication, and Pesticide poisoning.

All classes of previous employment, ranging from unskilled to executive/administrative positions, were represented among the unemployed, with no significant differences noted.

Further analysis of the exposures reported by unemployed subjects to be the cause of their health problem revealed a large proportion reporting "indoor air pollution" as the cause of their problem (N=7, 41%), as compared to the proportion for the total sample (23%). Significant differences were noted in the number of unemployed (N=7, 41%) and employed (N=5, 14%) subjects reporting "indoor air pollution" as the cause of their health problem ($X2=4.6, df=1, P=.03$).

Table 15 illustrates a comparison between reported exposures of the unemployed group and the total sample.

Table 15: Reported "Cause"/Exposure Leading to Development of Health Problem: Comparison of Unemployed with Total Sample

"Cause"/Exposure	Unemployed		Total Sample	
	N	%	N	%
Acids	2	11.8	9	17
Formaldehyde	3	17.6	9	17
Indoor Air Pollution	7	41.2	12	23
Pesticides	1	5.9	4	8
Solvents	3	17.6	14	27
Other*	1	5.9	4	8
TOTAL	17	100.0	52	100

* "Cyanide", "Don't know", "Mind", "Pain medication"

As illustrated in Table 16, below, however, no significant differences between unemployed and employed subjects were noted with regard to physician-coded etiologic agents including both of the largest subsets, "indoor air pollution", and "uncoded".

Table 16: Physican-Coded Toxin -- Unemployed/Total Sample

Toxin	Unemployed		Total Sample	
	N	%	N	%
Coal tar pitch	1	6	1	2
Formaldehyde	1	6	4	8
Oils, NOS	1	6	1	2
Epoxy resins	1	6	1	2
Pesticides	1	6	3	6
Chlorine	1	6	1	2
Stain.Steel welding	1	6	1	2
Chemical dust	1	6	2	3
Indoor air pollution	**4**	**23**	**10**	**20**
No coded toxin	**5**	**29**	**17**	**33**
Aromatic solvents,NOS			1	2
Toluene			1	2
Diesel fumes			1	2
Ethylene oxide			1	2
Trichloroethane			2	3
Solvents			2	3
HDI			1	2
Stress			1	2
4 PC Carpet			1	2
TOTAL	17	100	52	100

Effects on Salary and/or Promotions, Attributed to the Health Problem

Disruption in employment and subsequent financial need has been described in the literature as a predominant stressor in the lives of people with the problem of MCS (2,9). We were interested in learning what proportion of the sample reported actual changes in their salary level, or chances for

promotion, which they felt were a direct result of the health problem. Subjects were asked to describe their perception of the impact of their health problem on salary increases and/or promotions at work in response to the closed-ended question, "How has your health affected your salary or your getting promoted?"

Results indicate that if problems were experienced in this area at all, they tended to be severe, rather than mild; a sizeable group, however, reported no effects on salary or opportunities for promotion. Responses did not differ significantly between men and women. A negative correlation ($r = -.17$) between impact on salary/promotions and "Old" occupational level also did not approach statistical significance.

Results of male and female responses to this question are illustrated in Table 17, below: (One male subject did not answer this question.)

Table 17: Effect of Health Problem on Salary & Promotion

Q:"How has your health affected your salary or your getting promoted?"

A:	Male		Female		Total	
	N	%	N	%	N	%
"No effect"	7	39	12	37	19	37
"Prevented promotions - or - pay cut of <20%"	3	17	6	18	9	18
"Pay cut of 20-50%"	0	0	2	6	2	4
"Pay cut of >50%"	8	44	13	39	21	41
TOTAL	18	100	33	100	51	100

Number of Employees

We were interested in the size of the workplace in which subjects were working at the time of the exposure, and whether workplace size was a factor in adjustment to illness. In this regard, we suspected that smaller employers might have access to fewer resources at their disposal to make needed changes, and potentially less flexibility in terms of the ability to offer subjects reemployment in alternative work settings within the organization. On the other hand, we reasoned, larger employers might, by necessity, adopt a more impersonal outlook on the problem, with the possibility that subjects would experience a greater degree of isolation.

Results, illustrated in Table 18, below, indicate that the size of the workplace varied greatly among the sample, with no significant associations found between this and other variables of interest.

Table 18: Number of Employees at Workplace Where Exposure Occurred

Number of employees:	N	%
One other	3	6
3 to 25	16	32
26 to 100	12	23
Over 100	20	39
TOTAL	51	100

Input

We were interested in learning whether formal opportunities for employee input in the work organization

would effect development and/or adjustment to the health problem. Information in this area was obtained by asking subjects the following question: "Are/were there formal opportunities for employee input at the workplace, e.g., committees, suggestions box, etc.?" The majority (60%, N=31) answered "no". The majority (N=13) of the remaining 20 subjects who answered "yes" worked in organizations employing over 100 employees. Fewer women than men reported having formal opportuntities for input at the workplace; gender difference among those answering "yes" to this question approached statistical significance, with use of the chi-square, (X2 5.05, DF2, P=.07). Frequencies of male and female response are illustrated in Table 19, below:

Table 19: Opportunities for Input at the Workplace where Exposure Occurred

Q: "Were/are there formal opportunities for employee input at your workplace?"

	Male(Total=19)		Female(Total=32)	
	N	%	N	%
Number answering "yes"	11	58%	9	28%

Communication with Co-workers, Supervisors, Management

The effect of workplace communication patterns, either among workers, or between workers and supervisors/management--particularly with regard to the transmittal of information about health hazards and discussion of occupational health problems, in general--was felt to be an area worthy of further exploration in the study of patients' perceptions of the

health problem. As the exposure reported to have led to the health problem had taken place at work for the majority of subjects, it was assumed that the perception of open lines of communication among employees--supportive of discussion of problematic exposures, health concerns, and the reduction of health hazards--would potentially play a positive role in overall adjustment to the health problem, as well as in prevention. We therefore expected that the majority of subjects would report difficulty in all levels of communication at the workplace.

In an effort to learn more about communication patterns at subjects' "old" (and "current", if the same) workplace, and whether significant associations between this and other variables might emerge, subjects were asked the question, "How easy is/was it to talk with other coworkers (supervisors, management), in general, in your workplace?".

The majority of subjects (71%) reported that it was "very easy" to talk with other employees; on the other hand, most (53%) reported some difficulty talking with supervisors, and the majority (72%) reported moderate to severe difficulty talking with management. Further analysis of those reporting greatest difficulty in communication at all levels (N=6) revealed that all of these subjects were working at the time of the interview, their "current" occupational levels ranging from skilled trades to professional.

Rather than shedding further light on communication patterns particular to workplaces of patients diagnosed with MCS, this finding is perhaps reflective of a more universal

experience of workers who, due to nature of most work organizations, are likely to have a greater access to direct communication with co-workers than with supervisors and/or management.

Rate of response to this question ranged from 92% (N=48) to 73% (N=38). There were no significant differences between male and female subjects' responses to this question. No significant associations were found between this and other variables. Results are illustrated in Table 20, below:

Table 20: Ease of Communication with Coworkers/Supervisor/Management

How easy to talk with:	Very easy		Somewhat easy to somewhat hard		Very hard		TOTAL	
	N	(%)	N	(%)	N	(%)	N	(%)
Coworkers	34	(71)	13	(27)	1	(2)	48	(100)
Supervisor(s)	18	(47)	18	(47)	2	(6)	38	(100)
Management	12	(28)	26	(60)	5	(12)	43	(100)

Referral Source ("Who was influential in your decision to seek help for this problem?")

Sources of influence for patients meeting the criteria for MCS has been examined in the literature, in particular with respect to the extent to which the media may be responsible for an increase in concern among the general population with regard to health effects of low-level environmental and occupational exposures (6,71). In this regard, we were interested in learning what sources of

influence were identified by this sample as being either wholly or partially responsible for their decision to seek help for their problem. Most subjects listed more than one source; however, the overwhelming majority (N=32) reported that they, themselves, were most influential in their own decision to seek help. There was no significant difference in responses of men and women to this question.

Overall, sources of influence for this group were informal in nature, including the effect of the media. Note, in Table 21, below, the relative lack of importance placed by subjects on the influence exerted by formal social systems--employers, legal system, and unions.

Table 21: Referral Source

Q: Who was influential in your decision to seek help?

	N
Oneself	32
Spouse	18
Coworker(s)	14
Media	13
Parents	10
Lawyer	7
Employer	6
Children	4
Union	3

Physician Seen

A recent study (52) points to differences among physicians in the use of diagnostic criteria to categorize

patients as having MCS, based, in part, on the number of patients (i.e., with this problem) evaluated. In this regard, there was a range of differences in views of the problem of MCS, orientation to clinical ecology, and experience with this population among the group of clinician (14 physicians, 1 nurse clinican) who had evaluated the patients chosen for this study. We were thus interested in learning to what extent individual diagnosis was dependent on the clinician seen at the time of the visit to the clinic.

In order to look more closely at characteristics felt to effect the physician's categorization of patients as having MCS, a crosstabulation of subject age, gender, and occupational status with the dependent variable "physican seen" was performed. No significant associations were revealed, however small cell size (<5) was a limiting factor in the analysis. (Two physicians saw 24 of the subjects. These physicians were the only full-time junior or senior faculty in the program, with the other clinicians being either residents or fellows, or part-time clinical faculty.)

Table 22 illustrates the number patients evaluated by each clinician who saw the subjects in the study:

Table 22: Number of Patients Evaluated by Occupational Health Clinician

Number of patients seen	Number of clinicans who saw this many patients		Cumulative total of patients seen
	#	Cum. #	
1	3	3	3
2	6	9	15
3	3	12	24
4	1	13	28
9	1	14	37
15	1	15	52

Number of Health Care Providers Seen

The literature has described a pattern of seeking multiple opinions from medical professionals common among patients with a diagnosis of MCS. One author points to many doctors' unwillingness to treat these patients (8) as a contributing factor in "doctor-shopping" among patients with MCS. We were interested in learning about various aspects of subjects' experience seeking professional help for this problem, including such variables as: Number and types of health care providers consulted for the problem, and over what period of time these opinions were sought; how long after the problem began professional advice was sought and; what type of advice was provided by health professionals, and whether subjects followed such advice.

Subjects were asked to report the number (up to eight) of physicians, or other health care providers consulted for

the problem and how long after the onset of the health problem each consultation took place. The majority of subjects (N=30) reported having consulted at least 5 different physicians, or medical providers, within the first year following the onset of the health problem.

Table 23 illustrates the number of respondents who saw a successive number of health care providers regarding their health problem: (One respondent did not answer this question.)

Table 23: Number of Health Care Providers Seen

Number of providers seen:	Number of subjects who saw this number of providers:
1	51
2	50
3	45
4	41
5	30
6	25
7	21
8 (or more)	19

MD/Date

We were interested in the amount of delay, if any, between the time that health problems began, and the subjects' first visit to a physician. Subjects reported seeing a health professional for the first time between up to one month to over three years following the onset of the problem, with an average time lapse, for the entire sample, of approximately two to three months. Most subjects saw physicians about the

health problem very soon (within a month) after the onset of symptoms. Results are illustrated in Table 24 below.

Table 24: Length of Time between Onset of Problem and First Visit to Doctor

Q: Once you began having a health problem, how long was it before you saw a doctor for this problem?

A:	N
"Within the first month"	28
"Up to three months"	8
"Between 3 mos. and 1 year"	8
"Between 1 and 3 years"	6
"Over 3 years"	2
TOTAL	52

Time Between Onset of Health Problem and Clinic Visit

The author was interested in the range in length of time between the onset of subjects' health problem and the date of their initial visit to the clinic and whether significant differences occurred among the sample in this regard. In particular, there was an interest in differences between men and women in their patterns of usage of occupational health clinic services to address this problem, as well as an interest in whether differences among the sample were statistically associated with such outcome measures as employment status and restriction in activity.

Findings indicate no significant difference between male and female patterns of usage of occupational health services in terms of the length of time between the onset of health problems and the visit to the clinic; no other significant

associations were noted with the variables mentioned above. The majority of both males and females were seen between one and three years following the onset of their health problem.

Table 25 illustrates the range in length of time (in years) between the onset of health problems and the visit to the clinic. The mean length of time for the sample was 3.3 years:

Table 25: Years between Onset of Health Problem and Occupational Health Clinic Visit

	N	%*	Cum. %
Under one yr.	7	13.5	13.5
One to three yrs.	25	48.1	61.5
Betw. three and eight yrs.	13	25.0	86.5
Over eight years	7	13.5	100.0
TOTAL	52	100.0	100.0

*Rounded to the nearest .1%

Experience with Health Care Provider: Advice & Referral

Subjects were asked the following questions about their experience with health care providers seen for the problem:

1-"Was any advice given?"

2-"(If yes) Did you follow the advice? (Partly, completely, or not at all).

3-"Was a referral made to another health provider?"

Respondents' experience with the first health care provider consulted was analyzed with the following results, illustrated in Table 26, below: (One respondent did not answer this question.)

Table 26: Advice/Referral Provided by Physician

	N	%
Followed advice, either partially or fully	18	35
No advice given	17	33
Referred to another specialist	16	32
TOTAL	51	100

An analysis of subjects' experience with all health care providers consulted (first through eighth), revealed that providers' advice was followed, either partially or completely, an average of 39% of the time (range = 19% to 69%). Health care providers failed to offer any advice to respondents an average of 20% of the time (range = 8% to 33%). Respondents' reports of referral to another specialist dropped steadily from 32% (N=16), with the first provider, to 5% (N=1) by the 7th provider, and 0% among the 19 subjects who reported having seen 8 or more M.D.'s.

Type of Health Care Provider Seen

Table 27 illustrates the number of different types of health care providers seen by subjects for this problem. Note that the "Specialist" category--by far the most common type of provider seen for this problem--refers to physicians other than general practitioners, internists, and psychiatrists; among this sample, specialists included occupational health physicians, dermatologists, allergists, neurologists, and pulmonologists. Non-traditional health care was not as commonly utilized as might have been expected.

Table 27: Number of Different Providers Seen By Individual Subjects

Type of Provider:	Mean	Mode	SD	Minimum	Maximum
General Pract.	1.5	1	2.1	0	14
Specialist	4.6	2	3.4	1	18
Company MD	.2	0	.6	0	3
Other*	.5	0	.9	0	4
Psychiatrist	.4	0	.9	0	4
Social Worker	.1	0	.3	0	1

* (Non-traditional medical care, including naturopath, chiropractor.)

Further analysis of subjects' use of health professionals revealed that seeking help from psychiatrists was positively correlated with seeking help from other medical specialists ($r=.41$, $P<.01$).

Social Support

The author was interested in learning about the avenues of support available to people with this problem, and at what point, and in what settings, following the onset of health problems, these avenues of support were utilized. Subjects were asked the open-ended question: "With whom did you first talk about this problem?" Significant associations with other variables of interest, such as gender of respondent, "current" occupational status, and the number of health care providers consulted for help with the problem, were sought in the analysis.

To obtain data in this area, subjects were asked to whom

they spoke first about the problem, when, and in what setting. They were then asked the same questions about the second time they spoke with someone. Crosstabulation analysis revealed no significant differences in the sample in relation to the three variables (gender, occupation, and number of providers seen) mentioned above.

Table 28 illustrates the range of response to this question:

Table 28: First Person Talked With About Problem

Person talked with:	Male	Female	Total	
			N	%
Spouse/relative /friend	9	7	16	31
Workplace/ management	3	11	14	27
Coworkers/union	4	8	12	23
Health professional	3	7	10	19
TOTAL	19	33	52	100

A higher percentage of the men (approximately 50%) spoke first with spouses, friends or relatives, outside the workplace, compared with women (less than 25%), while a higher percentage of the women (30%) spoke first with someone at the workplace about the problem, compared with men (approximately 12%). The interview did not attempt to elicit subjects' use of clergy members, in this regard, however further exploration of this area of support--not carried out within the confines of this study--is indicated.

The physician was more likely (19%, N=10) to be the second

person spoken to, rather than the first (25%, N=13).

Most subjects reported speaking with someone on the same day as the onset of illness. Table 29 illustrates the time lapse reported to have occurred between the onset of health problems and the time respondents first spoke with someone about the problem:

Table 29: Length of Time between Onset of Problem and First Time Talked

Q: How long after the onset of health problems did you wait before speaking with someone?

A:	N	%
Same day	32	62%
Up to one month	7	13%
One month to one year	8	15%
Between one and five years	5	10%
TOTAL	52	100%

Confidants

The majority of subjects (N=47) responded "Yes" to the question "Do you have one or more persons to whom you can confide your feelings?" Twenty-eight of these said it was very helpful to talk with them; 16 said it was somewhat helpful; and 3 said it was not helpful.

Measurement Scales: Illness Behavior Inventory
Interpersonal Dependency Inventory

Subjects were administered two questionnaires validated in previous study: the Illness Behavior Inventory (IBI) (Turkat & Pettegrew, 1983), and the Interpersonal Dependency Inventory (Hirschfield, et al, 1977).

A. Illness Behavior Inventory

The literature reports a high degree of what has been termed "illness behavior" (e.g., the carrying out of activities when feeling ill; speaking about one's illness with others; or, the decision to seek medical attention [80]) among patients with multiple chemical sensitivities (7). In an effort to obtain reliable data on subjects' attitudes toward illness and its impact on their ability to carry on social and workplace activities, the IBI--a 20-item, self-report measure of illness-related behaviors--was utilized. The IBI is concerned with measurement of two dimension of illness behavior: work-related illness behavior, and social illness behavior. In the work sphere questions relate to curtailment of work behavior and activity when feeling ill. In the social sphere, questions relate to illness behavior as evidenced in social situations and settings such as "acting more ill than one actually feels", complaining about feeling ill, and frequently bringing one's illness up in social conversations. Of interest is the fact that, in developing the IBI, authors Turkat & Pettegrew found statistically significant relationships between reported illness behavior and treatment outcome measures in a chronic pain population. According to these authors, a moderately strong correlation was found between the IBI and amount of medical expenditures, frequency of physician visits, days of hospitalization, frequency of work days lost, and percentage reduction in daily work activities. The tool differentiates between high and low illness behavior patients among several ill and healthy

populations. Turkat & Pettegrew argue for its usefulness as "a dependent measure for behavioral treatment studies with patients who exhibit excessive or inappropriate illness behavior" (79), as well as being useful as "an important independent variable identifying and predicting parameters of illness behavior in various populations."

Table 30 illustrates the comparison between mean scores achieved by MCS study subjects and those reported in Turkat & Pettegrew's study population diagnosed with diabetic neuropathy. Turkat & Pettegrew divided their sample into two groups: The High-IBI (HIB), or those with greater levels of illness behavior, and the Low-IBI (LIB), or those with lower levels of illness behavior. The MCS study sample averages in the mid-range in scores. Application of this instrument with patients meeting the criteria for MCS, in contrast with the population utilized in previous study for which there exist laboratory tests to aid in their diagnosis, is limited in its value; however, it is interesting to note that while MCS patients do not fall within the low IBI score range, on the average, they also are not among those with the highest measured levels of illness behavior, as might previously have been assumed.

Use of the T-test, chi-square and Pearson correlation coefficient revealed no statistically significant associations between IBI score and subject age, gender or diagnostic group.

Table 30: Comparison of IBI scores: MCS Sample/Other populations

	Mean IBI scores for MCS study sample (N=50)	Mean IBI scores for High-IBI Groups (HIB) (Turkat & Pettegrew)	Mean IBI scores for Low-IBI Groups (LIB) (Turkat & Pettegrew)
Social dimension	30.78 (range=16-55)	37.54	27.82
Work dimension	33.16 (range=11-50)	36.18	25.91
Total IBI	63.90 (range=52-88)	72.55	53.73

B. Interpersonal Dependency Inventory (IDI)

The Interpersonal Dependency Inventory (IDI) measures three components of interpersonal dependency: Emotional reliance on another person, lack of self-confidence, and assertion of autonomy. In their discussion of the development and use of this tool, the authors (Hirschfield et al) point to the implications of excess interpersonal dependency in the genesis of depression, alcoholism and other emotional disorders. In carrying out the study with the MCS sample, there was an interest in measuring levels of interpersonal dependency, given the literature linking dependency with somatization (48).

Contrary to expectations, low levels of interpersonal dependency among the MCS study sample population, as measured by the IDI, were noted, illustrated in Table 31, below.

Table 31: Comparison of IDI scores: MCS Sample/Other Populations

IDI	MCS Study Sample		Normals (Hirschfield et al)		Psychiatric patients (Hirschfield et al)	
Emotional reliance	Mean 35.1	S.D. 7.2	Mean 39.2	S.D. 7.8	Mean 48.7	S.D. 10.2
Lack of self-confidence	25.3	5.4	29.8	6.4	34.3	7.5
Assertion of autonomy	28.6	5.5	30.2	6.1	29.6	6.3

A major source of controversy among the traditional medical community--including occupational medicine--with regard to the problem of MCS is the extent to which this problem can be characterized as predominantly psychological, versus physiological, in nature and/or origin. The literature also points to a disparity in views between traditional medical providers and patients with the problem of MCS, with the latter viewing the problem as essentially physiologic in nature. The author was therefore interested in learning whether, given an opportunity to comment on the overall nature of their problem, differences might emerge within the group with respect to the extent to which subjects characterize the health problem as being essentially physical, versus psychological or social, in nature. Alternatively, the author was interested in the extent to which subjects identified the health problem as having psychological or social components.

Subjects were asked the question: "Would you describe your health problem as physical, psychological, social or some combination of the three?" Although a surprisingly large number of subjects (N=20, 39%) felt that their health problem had psychological and/or social components, none felt that their health problem could be described as "psychological" or "social" alone. In keeping with reports in the literature, the vast majority of subjects felt their health problem to be strictly "physical", as illustrated in Table 32. (One subject did not answer this question).

Table 32: Description of Health Problem

Description	N	%
"Physical only"	31	61
"Psychological component"	6	12
"Both psychological & social component"	14	27
TOTAL	51	100

Analysis of the relationship between this and other variables, including gender, "current" occupational status, and reported levels of restriction placed on activities, either at work or at home revealed no significant associations.

Restrictions in Work and Activities in the Home

Restrictions in activities due to an ever-widening set of problematic exposures -- both at work and at home -- have been noted in the literature to be common to the population

diagnosed with MCS. We were interested in learning to what extent this group reported restrictions in each of these areas, and whether restriction in one area was predictive of restriction in the other area.

Responses to the two questions, "How much does your health restrict your daily activities at work? At home?" were highly correlated ($r=.7025$, $P<.001$). No significant associations were found between reported degree of restriction (in either area) and gender, or age. A negative correlation at the $P< .001$ significance level, ($r=-.62$), between "current" occupational status and degree of reported restriction in one's work is most likely a function of the large number of currently unemployed subjects in the sample; a negative correlation at the $P< .01$ significance level, ($r=-.36$), was also noted between current occupational status and restriction at home, suggesting that lower-occupational level and/or unemployed subjects were more likely to experience overall restriction in daily activities outside of work as a result of their health problem than higher-occupational level and/or employed subjects.

Between 15% and 20% of the group reported experiencing no restrictions at all, either at work or at home. The remainder reported mild to total restrictions at home and at work, as noted in Table 33, below. (One subject did not answer this question.)

Table 33: Restriction in Work/Non-work Activity

Q: "How much does your health restrict your daily activities:

	"At work?"		"At home?"	
Responses:	N	%	N	%
"Not at all"	10	20	8	15
"A little"	10	20	10	20
"Some to alot"	17	33	28	55
"Completely"	14	27	5	10
TOTAL	51	100	51	100

Complaints

Responses to the statement, "Now I'd like you to describe your health problems to me," were analyzed for the types and numbers of complaints reported.

In all, 42 different complaints were reported, with a range, per individual, of 1 (N=9) to 10 (N=2) complaints, for both men and women. The mean and median number of complaints reported for both genders, per individual, was 4.

Table 34, below, is a listing of the 42 complaints, in order of prevalence reported. Note the prevalence of complaints such as fatigue, headache, dizziness, concentration problems and memory loss, reported elsewhere as predominant among this population (33,38,52,75).

Table 34: Complaints in Order of Prevalence

C/O	# reporting c/o	C/O	# reporting c/o
Fatigue	16	Choking	3
Upper Respiratory Irritation	16	Blurred vision	3
Headache	15	Yeast	2
Dizziness	14	Sweats	2
Concentration/Memory Problem	14	Voice loss	2
Skin Burning	10	Hair loss	2
Sinus Infection	8	Weight gain	2
Nausea	8	Nerve damage	2
Behavioral Changes	8	Heart palpitation	2
Rash	8	Immune system	2
Chest pain	7	Bad taste in mouth	1
Gastrointestinal complaints	7	Urinary frequency	1
Depression	5	Numbness	1
Allergies	5	Insomnia	1
Joint pain	5	Loss of coordination	1
Lung pain	5	Loss of libido	1
Convulsions	4	Change in body temp.	1
Eye irritation	4	Nervousness	1
Swelling	4	Fear of heart attack	1
Shortness of breath	4	Asthma	1
Sores	3	Fever/weight loss	1

Recommendations

In response to the open-ended question: "What kinds of supportive services do you think there should be or should have been for yourself or for others with your problem?", most subjects offered more than one recommendation. The recommendations most frequently given were "More education for health professionals", (including the possibility of receiving better medical treatment for the problem) (N=33), and "More public awareness" (N=23). "Group and individual therapy" came next in order of prevalence (N=20), followed by "Disability recognition and compensation" (N=16). Only 8 subjects recommended "Strengthened OSHA regulations" and 7 recommended "Further research."

Description of the Health problem

In an effort to address the commonly identified areas of patient-physician communication, and patient perception of health/illness, respondents were asked several open-ended questions, beginning with the following: "In your own words, I'd like you to describe your health problems to me."

Differing modes of presentation of the health problem among this population may elicit different forms of intervention on the part of the physician (65). Analysis of responses was based on the author's interest in subjects' perceptions of their health problem, and the relationship, if any, of variability in their description of the problem to differences in individual adjustment to illness.

In general, subjects' descriptions of the health problem appear to consistently link their symptoms with exposures to a variety of environmental stimuli. An example of the more prevalent form of description of the problem--the linking of symptoms with exposures--is the following description given by a woman who believed her health problem was due to exposure to shampoo:

> "I know I have nerve damage from shampoo. I have to wear a hairpiece all the time to shield my head from the light. If I get any light on my scalp, it becomes instantly worse and I get more and more sensitive to light. If I get into any type of formaldehyde or chemicals, I start to get lung reactions. I can't breathe, I get confused, I get dizzy, I get disoriented sometimes."

Another example of this type of description is given by a male respondent, as follows:

> "I just can't be around any chemicals, paints, hair sprays, anything that is a petrochemical. You want to know the effects it has on me? Weakness, dizziness, I can't think straight, nausea, stomach cramps, fatigue, disoriented..that's about it."

Variability in the description of the health problem appears to occur in the extent to which subjects give emphasis to either the problematic exposures, or the symptoms experienced. Descriptions of the health problem thus appear to fall into one of three categories: The first, called "exposures primary", is characterized by an emphasis on the environmental agents that cause the health problem, rather than one's reactions to the exposure. For example, one man described his health problem as follows:

> "Well, I am suffering from an environmental illness due to working in a laboratory, a research laboratory, which involved coming into contact, and therefore I am supersensitized to these chemicals. And these chemicals I have found to be in the environment, outside the laboratory. And therefore I am environmentally ill from these chemicals. Anything that contains some chemicals, which I still question as to what they are."

More men than women tended to describe their health problems in this way.

The second category, called "symptoms primary", is characterized by the emphasis given to one's symptoms, rather than, or separate from, the environmental agents that are felt

to cause the problem. More women than men described their health problem in this way, such as the following statement of a female subject:

> "MCS. I get congested. I get infected very easily. The more I'm on to what's going on - it doesn't happen as much any more. I used to have it worse. I get congested, dizzy, confused. Like, my lungs are tight. I have back problems - also with P.T. and structural stuff - it's nowhere near as annoying as it used to be."

Or, as another female subject described:

> "Well, I started with allergies that I had. That was nothing new. They just got worse. Then I went into occasional sinus problems where they would block and clear. Then it became so frequent that they became infected and I am still struggling with a chronic sinus infection. At the present time, I seem to be - other than chronic sinus infection, I seem to be holding my own. Trying to,anyway."

And, another woman stated:

> "Primarily, the weight gain. I have put on fifty pounds in one and a half years. I develop all these cold night sweats. I had a lot of throat infections, sinus infections...quite often I had chest pain on the left side. The left side of my face would become numb. I was in the ER eight times thinking that I had a heart attack."

Finally, a male subject described the problem in the following way:

> "When I first started out with my problem I was feeling alot of nausea. I was sometimes vomiting, very tired and run down. I was getting light headaches and chest pains and just depression. Now I find myself frequently tired, not necessarily doing alot of work like that but I just get tired pretty easy. And my chest pains are still with me.

> Outside of that, my sensitivity to odors and stuff like that bothers me. Outside of that, it is about it."

The third category - by far the most prevalent - is "mixed", in which the problem is described in terms of symptoms which occur with specific exposures, as we have discussed above. The following is an example of a female respondent's "mixed" description:

> "It seems to be toxic stuff leaching out of the vinyl interiors of cars and it causes some real severe neurological symptoms for a period of time and then it seems to...when I get into other new cars, then I start to get these symptoms back again and I avoid other new cars."

Finally, another man said:

> "I haven't had too many over the years. The most serious thing I had was a bout with pleurisy about 1979. It was only after the pleurisy that I developed a sensitivity to gasoline and paint, turpentine, petroleum-based products, perfumes, powders, things of that nature. I would get a headache. I get a pain in the center of my forehead, sort of a dull headache. It depended what the aroma was, the smell."

Perception of physician's opinion of the health problem

Given the extent of the controversy among physicians regarding the existence of this problem, the author was interested not only in subjects' understanding of the diagnosis 'MCS' as conveyed by the physician, but, also, in perceived differences between their own and the physician's

opinion as to the nature of their problem. A summary of the literature points to this area as being the source and stimulus for difficulty in communication (12,32,38,47,61). As perceived in the literature, the sample in this study is seen to deviate from other study findings of similar patient-physician communication patterns.

Subjects were asked the question: "What does your doctor, or do your doctors, think is your health problem?" Responses were analyzed with regard to the degree of congruence perceived by the subject to exist between their own and their physician's opinion of their health problem, and generally fell into one of three categories.

In the first category of response, which we call "concur", subjects characteristically state their perception of the physician's opinion as concurring with their own. The following are examples of responses in this category:

> "What I have been telling you. You know, that [it was] the formaldehyde poisoning." (female respondent)

> "Well, they just think that I've developed chemical sensitivities, very strong allergies to certain chemicals, as well as other things. They just feel that I will always be a chemically sensitive person. I need to avoid as much as I possibly can in the chemical area." (female respondent)

The second category, which we call "different", includes responses indicating subjects' perception of their physician's opinion as being different from their own. This category also

included responses in which subjects described the physician as having "no opinion" about what their problem might be. The following are examples of responses in this category:

> "The medical doctors tend to think it is mental so I avoid traditional [doctors]. They give you shots and I don't want shots. I feel like maybe doctors think they can alter me to fit the environment and I would rather alter the environment to fit me." (female respondent)

> "I don't go to doctors very much. I try not to go to doctors frequently because I have my own ideas about health and nutrition and I don't think that doctors are very knowledgeable so far as general practitioners." (female respondent)

> "I don't have any doctors. I don't believe in doctors. Doctors are not taught nutrition. Maybe they changed a little now, but I would say 85% of the doctors today are drug pushers. It is hard to get a doctor that really knows anything about nutrition or vitamin therapy or backgrounds like in environment and this is the whole thing." (male respondent)

> "They would try putting me down. .... as soon as I would mention where the exposure took place of course the door would shut, and you could just see instant closing of the door." (female respondent)

The third and final category of response, called "combined", includes those in which the subject describes his/her perception of the physician's opinion as either uncertain or somewhat like their own, with slight differences. For example, subjects might qualify their agreement with the doctor's opinion - which may be essentially supportive of their own - on the basis of what they perceive as a major limitation in the doctor's view in some important aspect, as

follows:

> "The occupational health doctor, of course he took a pretty strong stance, but I still don't believe that he truly understands the ramifications of this illness, or if he does, he is afraid to say because of being ostracized." (female respondent)

> "Doctors in the area had no idea what was going on. Your clinic diagnosed it 'suffering from effect of tight building syndrome' or something - closest they could come to it." (male respondent)

> "I think [the doctor] said...this multiple chemical sensitivities was my problem - its a new class of illnesses or whatever. It basically doesn't get better like an allergy where you build up an immunity, but more each time you have some exposure.....Basically I think that he thought, or at least his attitude was ...that he thought I was not physically ill but [it] was more a psychological thing because they kept urging me to go see a social worker at that time, and I didn't want to...because I am very attuned to those kinds of things." (female respondent)

> "They say its the chemical and that was it. They couldn't pinpoint anything further than that...and they said there was no type of chemical testing that would actually prove, you know if they would be able to find out exactly what the problem was." (male respondent)

The interest in communication patterns prompted an analysis of correspondence with other study variables. It was found that in none of the other variables, except for gender, do any of the categories differ.

Stages of Illness:

Comments elicited during the interview in which subjects relate the "story" of their illness (42) point to successive

"stages" in the illness, common to many respondents. Following are the results of qualitative analysis of subjects' responses to open-ended questions which sought to uncover explanations and descriptions of a range of feelings throughout the development of the illness and ways of coping with the problem at each stage.

The first stage involves the recognition of the problem, including perception of a change in one's health. It is accompanied by feelings of isolation from others--particularly at one's place of work--who do not have or do not understand the problem.

Descriptions of the initial stage of illness typically involve expression of fears of psychological dysfunction, as follows:

> "Sometimes I thought I was losing my mind."
>
> "I was having a reaction to something, but nobody knew what it was."
>
> "I had the feeling at the time that everybody thought I was nuts."
>
> "It can drive you crazy to try to prove your point."
>
> "Although people might be sympathetic, still I felt that maybe it was in my head."

Early intervention would involve exploration and identification of supportive social network ties, including co-workers, supervisors, employers, union representatives, physicians, family and/or friends. (In one case, early intervention involved meeting with the patient and spouse

along with the union president, at the union headquarters, rather than at the clinic.)

The second stage involves attempts on the part of the respondent to address what is perceived to be the cause of the problem. Comments of subjects regarding this stage typically refer to their efforts to cope with others' responses, ranging from supportive (e.g., putting recommended job modifications into effect), to non-supportive (e.g., failure on the part of employers to recognize or accommodate the problem.) Several subjects also stated that they felt unable to take action due to fears of reprisal. Descriptive comments typical of this stage include the following:

> "I was very fortunate in that I was always able to have a place [i.e.,at work] where there was a door nearby which could be left open."
>
> "My boss was very concerned because I was one of his better workers and he didn't want me to quit."
>
> "I tried not to say anything as long as I possibly could. I was really worried about losing my job, so I wasn't going to say anything to anybody."
>
> "I was treated as a liar. After a while, you're on the defensive. You need someone to back you up and say, 'Now just a minute - there <u>is</u> a problem here.'".

The variation in employees' ability to effect health and safety changes in their work environment is a worthwhile area for further study (64). Subjects report a broad range of experiences regarding changes in the workplace relative to the problem of MCS; whether changes made early on result in improved health outcome in the short- or long-run is still not

known. For example, some report enjoying their jobs immensely, being regarded as highly valued employees, and having accommodations readily made by their employer in an effort to retain them as employees. However, these same respondents report having gone on to develop a worsening of their health problem, including an increase in the disabling nature of their complaints. On the other hand, some subjects report that their employers refuse to acknowledge any aspect of work-relatedness of the problem--including recognition of the need to make accommodating changes in the work environment. Such subjects report being told that if they cannot work in the environment as it is, they should not come to work. In these cases, subjects may or may not take individual action on their own, depending, in part, on the availability of supportive mechanisms within the workplace. (In one case, for example, a subject who was a member of a union, came to work with a gas mask, when her employer refused to acknowledge a problem with indoor air pollution in the workplace.) While the nature of subjects' experience effecting changes and accommodation by the employer does not appear to be related to the severity or chronicity of the health problem, it may be related to the ability of people with this problem to continue working.

The third stage involves subjects' sense of being overwhelmed by the restrictions imposed on them by the problem, and discovery of additional problematic exposures on a daily basis. During this stage, the use of group treatment

can be especially supportive, with subjects reporting that such treatment provides acceptance and validation of their feelings. The group provides a supportive environment for patients to evaluate their reactions to exposures and capacities to cope with the problem. For example, one subject who had been a member of a six-week group expressed her feeling that the group had helped her to gain a better appreciation of her ability to cope, as she was able to see others in the group who were having greater difficulty. Another subject related that she had used the group to exchange information with others about alternatives that had been useful in ameliorating her problem, and to discuss efforts to collect signatures for a petition aimed at having the employer make repairs on the ventilation system. Comments elicited regarding feelings during this stage typically focus on perceived difficulties maintaining control over both symptoms and exposures, as follows:

> "I can't breathe. I get confused, I get dizzy. I get disoriented sometimes. If it is bad depending on the severity...I know I have to get out of the situation."
>
> "There are times when I wonder if I am going to make it through the day."
>
> "You can tell by listening to me that I am ill."
>
> "I can be sitting here and be fine and all of a sudden someone will walk by me that might have some perfume on and my eyes begin to itch and I begin to choke and I have to go out and get air."

The fourth stage involves the search for cure, and visits

to multiple physicians, naturopaths, and clinical ecologists. Psychiatrists may be avoided during this stage, although a psychiatric evaluation may be ordered by the treating physician, workers' compensation commission, or patient's attorney. Psychotropic medication may be felt by the patient to be "toxic", and therefore to evoke an exacerbation of their symptoms, although not in all cases. Generally, doctors are perceived to be helpful--whether or not subjects perceive them as characterizing the problem as chiefly psychological--if they offer patients psychological support, acceptance, and a non-judgmental approach. Subjects perceived an adversarial relationship more likely to have developed with doctors who had not initially validated their illness. Lengthy correspondence with physicians and other caregivers (one patient sent a tape) occurs in many cases.

The final stage is one of acceptance and development of viable coping strategies. This stage involves the recognition that exposures are omnipresent and on-going and that the medical profession may not have a "cure" for the problem. For the most part, however, solutions are viewed as individual, and are achieved only after a lengthy struggle to control one's environment has yielded limited results. Following are subjects' reports of feelings during this stage:

> "Even though the symptoms come and go, I have learned to live with them."
>
> "The situation and my reaction is no where near as bad if I am calm and if I am not under any stress."
>
> "I just walk[ed] outside and I felt quite a good

> deal better after just walking around outside in the fresh air, maybe a 1/2 hour or so."
>
> "I went through a transition where I developed an acceptance of the problem and moved into creating a more normal life and not always dwelling on what is going on."

Focus Group Discussion: March, 1991

A total of approximately 17 subjects attended a focus group meeting in March, 1991, in response to a letter inviting their feedback to preliminary results of the study (Appendix H). Twenty-three of the remaining 37 subjects who did not attend the meeting indicated that they would like to receive a written summary of results of the study, once available.

Following is a summary of subjects' thoughts on the five major discussion topics which emerged in the course of the 1 and 1/2 hour meeting.

Topic #1: What does the notion that there is a "psychological component" to the illness mean to people with this problem?"

> One attendee stated, "I think [they] get this 'psychological component' from the inability to classify what this disease is."
>
> One person suggested that people who are susceptible to this problem had been psychologically traumatized earlier in life. Many attendees disagreed with this notion.
>
> Most attendees felt that psychological problems would necessarily follow on the changes that had occurred in one's life, due to the problem. Many others pointed out that psychological problems stem from the fact that "no one understands it."

One attendee said that they felt that others perceive them as being "troublemakers"-- i.e., due to the fact that they "can't work around this or that." This, in turn, leads others to think of the problem as essentially psychological. Further, this attendee pointed out, since certain exposures may be tolerated for short periods of time, and other times not at all, others may be encouraged to doubt whether the problem was "real."

One subject urged the author to reconsider the notion of psychological component, as it should be seen as part of the aftermath of the health problem, not its cause. This attendee stated, "This disease has a psychological component similar to that of other people with chronic illness. I don't think the level of psychosomatic illness in this population ... will exceed that found in the general population."

Topic # 2: Is there a consistent approach to intervention on the part of the medical profession? What might be the reasons for different forms of intervention, and what impact does lack of consistency in intervention have on those with the problem?

One person expressed strong negative feelings about their visit to the clinic, as they had expected to be told to avoid certain exposures and were not. Others, they felt, had been told to avoid certain things. This person found the lack of consistency in approaches to intervention confusing and troubling.

Another attendee said that they couldn't remember the physician having taken an extensive occupational/exposure history.

Another attendee pointed out that OSHA had been in to the shop where they worked, and that perhaps this was a factor in the physician's decision to advocate on her behalf with regard to making changes in the workplace.

Topic # 3: What are some obstacles to further progress in research efforts with regard to the problem of MCS?

Several attendees agreed with the comment that "political" forces were keeping further research from going on.

Many agreed that the sensationalism of the media (i.e., portraying patients as living on mountain tops, and other extreme forms of behavior) has caused the general population to view the problem in a distorted way, and has kept the public from recognizing how widespread the actual problem really is.

Topic # 4: Have people with this problem experienced any improvement in their health over time? To what do they attribute this improvement?

Several attendees discussed the issue of avoidance and whether this helps or not; some felt avoidance had not appeared to be helpful in the long run.

Another said that after ten years the problem seemed worse than it had in the beginning: "Every day it seems like there is something new that bothers me."

Some said the problem was cyclical --it would get better, then it would reappear. Others said they had improved over the years.

Many stated that they felt better after physical exercise. One person suggested scuba diving as a remedy.

One person noted: "We are living in a chemical age--everything is synthetic." Another person pointed out that this statement could be used as an argument against a workers' compensation claim, in that the problem is seen as being caused by the environment, rather than the workplace.

Others stated they felt fortunate that at least they were aware of the potential problems in the environment, and therefore made a point of avoiding them; the general population, not suffering from MCS, were "desensitized" to toxic exposures, and thus did not feel ill on exposure. One person felt that a failure to understand the dangers of toxic exposures--and, thus, to protect

oneself from exposures of this kind--can ultimately lead to the development of cancer.

Topic #5: Where should efforts be placed in helping the population with MCS?

Subjects felt that help knowing how to live with this problem took precedence over retraining, and vocational rehabilitation efforts. They also felt that rehabilitation efforts were difficult--if not impossible--due to the nature of the problem, which involved problems with memory and concentration. Further, the group acknowledged that it was difficult for many people with MCS to continue to work indoors in any capacity.

The biggest problem, for some, was the feeling of being socially isolated and unable to continue doing the things which used to provide opportunities for socialization, and relaxation (e.g., going to the library, having friends over, etc.) One person spoke of the need to develop "safe" places in which to socialize.

Several attendees exchanged names, addresses and telephone numbers in an effort to form an informal support group for the future.

DISCUSSION

This study describes the perceptions of patients who have been diagnosed and/or meet the criteria for "multiple chemical sensitivities." It does not directly address questions regarding the nature or etiology of a health problem which continues to require further scientific study. Rather, it represents an attempt to provide further information regarding patients' experience with the problem, toward the goal of designing helpful interventions with this population.

Description of the Health Problem

All subjects except one felt that the health problem was chiefly physiological in nature. Although almost 1/2 of the subjects characterized their problem as having a psychological and/or social component, this component was almost universally described as resulting from difficulties faced in coping with the problem, rather than the nature of the problem, itself. In this regard, many subjects felt that psychological support--either through individual or group counseling--was helpful in their efforts to cope with a difficult, chronic illness.

Subjects' descriptions of the health problem differed with regard to the extent to which exposures (and avoidance of same), versus symptoms, were emphasized as the major difficulty involved. As well, there was a range in the degree of concurrence they perceived between their own and the

physician's outlook on the problem. However, despite such differences, most of the subjects expressed similar perceptions with regard to the progression of the problem, as well as the feeling that others--including health care providers--often located the problem within the individual, as primarily psychological in origin, rather than within the environment. This was commonly perceived by respondents as a barrier to communication with others about the problem, ultimately affecting their ability and capacity to cope with changes in their overall health. The task involved in overcoming such views, in order to either effect changes in their environment or to obtain help--even if primarily supportive in nature--was identified as paramount among the difficulties respondents faced in coping at every stage of the problem.

The Workplace as a Factor in the Development of the Problem

Subjects' description of their work setting--with regard to size, communication patterns, and opportunities for input--appears to vary widely among this population, with no significant associations found between such attributes of the workplace and other variables of interest. Male and female subjects differed, however, in their perception of the availability of formal opportunities for input at the workplace, with male subjects describing greater opportunities

for such input.

Most subjects described ease in communication at the coworker level, and progressive difficulty in communication with superiors, on up to management. Female subjects, however, appeared to utilize the informal support system at the workplace to a greater extent than male subjects to discuss the problem, early in its development, with coworkers or supervisors.

Although the majority of respondents continued working at essentially the same level of employment following their exposure and/or onset of illness, approximately 1/3 (N=17) of the sample were unable to continue working after the onset of the problem. Among the group of unemployed, a majority (71%, N=12) were female. Significant differences were noted between the group of employed and unemployed subjects with regard to exposure to indoor air pollution: indoor air pollution was more often the physician-coded etiologic agent, as well as subject-reported exposure, among the group of unemployed subjects, than it was for subjects who were employed at the time of the interview.

Most subjects reported a change having occurred (typically, job reassignment or move to a new home) which ultimately led to the development of the health problem. Such changes, usually involving the introduction of new exposures, were far more likely to be described as preceding the development of the

health problem than was the report of an "accident" at work.

Demographics of the Population

The average age of the sample (mean age = 45; mean age of onset = 42) was younger than the average age of the sampling frame from which it was derived (mean age = 52). Other studies of MCS have confirmed this average age of onset (2), as well as the relative youth of the MCS population in comparison with the general population seen in occupational health clinics (22).

The absence of racial/ethnic diversity among the group meeting the criteria for MCS has been noted in this and in previous studies of this population. As well, the underrepresentation of racial/ethnic minorities (i.e., relative to their added risk of occupational disease and injury) among the general population utilizing occupational health services, of which the MCS population is a subset, has been noted elsewhere (26,63). However, the absence of racial and ethnic heterogeneity among the MCS population, while described, remains, as yet, unexplained. The absence of diversity in samples meeting the criteria for MCS may be reflective of a host of factors beyond the possible--though questionable--likelihood that little or no incidence of this illness exists among racial and ethnic minority groups. Such factors might include, among others, a low rate of presentation to preventive health care settings among groups having poor

access to health care in general, and a tendency among some practitioners to view more narrowly the presenting complaints of racial or ethnic minority patients, and therefore to diagnose their problem as something other than MCS.

The range in individual incomes - from near poverty to upper-middle income level - reflects a broad range of socioeconomic status among the sample. Reported individual earnings averaged somewhere between $15,000 and $20,000/year, while 50% of the sample reported family earnings of $35,000 and over/year. This disparity in income levels is in keeping with other results indicating wide-ranging variations in occupational categories for the population considered to be at risk for developing MCS.

Overall, differences in attributes between the male and female subjects were noted in the area of educational level, with women having a significantly higher educational level than men. An association between gender and occupational status was also noted, with female subjects averaging a higher occupational status than male subjects despite higher rates of unemployment among women, however this association did not reach statistical significance. These gender differences are consistent with those noted elsewhere in the literature (2).

Experience with Health Care Providers

Subjects generally experienced symptoms within the first three months following the reported exposure, although several reported a delay in the development of a health problem of over

one year following the exposure. Professional health care is usually sought within the first 3 months following the onset of symptoms, however the visit to the occupational health clinic was usually delayed: Thirty-six subjects (69% of the sample) visited a doctor within three months of the onset of their health problem, while an average of 3.3 years lapsed, among the sample, between the onset of health problems and their visit to the Occupational Health Clinic.

The majority of subjects reported seeing at least five physicians (or other health care provider) for this problem, and over 30% of the sample saw 8 or more health care providers. Subjects' encounters with health care providers were described, in the main, as consisting either of referral to other physicians, or failure to provide any advice.

Social Support

Subjects utilized a variety of different support systems with regard to their health problem, with some gender differences noted. Men more often reported initially having sought the support of friends or relatives outside the workplace while women more often reported having sought this support at the workplace, from either coworkers or employers, although this difference was not significant. Most subjects spoke with others about the problem before speaking with a health care provider, and this discussion most often took place immediately after the problem began.

Although many subjects discussed the problem of social isolation resulting from the practice of avoidance, most subjects reported having more than 1 person to whom they can confide their feelings and having made use of this support with regard to their health problem. In this regard, all areas of social support would be seen as benefitting from further education with regard to the problem of MCS.

Results indicating a high degree of correlation between reported restrictions at home and restrictions in the workplace generally support the notion that those who report a high degree of restrictions in activities are similarly affected at home as well as at work. Those who were unemployed at the time of the study interview reported higher levels of restrictions in both areas than did those who were working.

Subjects' illness behavior (IBI) and interpersonal dependency (IDI) test scores were within average ranges. Higher mean scores were obtained from those who reported being unemployed, on both the social and work-related illness behavior aspects of the Illness Behavior Inventory, however, average scores were achieved by this subset of the sample on the Interpersonal Dependency Inventory. These results indicate that higher levels of "illness behavior", rather than "interpersonal dependence", may characterize the group who become totally disabled following the onset of problems related to MCS.

Implications

Psychosocial need among the population meeting the criteria for "multiple chemical sensitivities" has implications for the profession in several areas, including policy, practice, education, and research.

Study findings point to a range of difficulties experienced by individuals with a chronic health condition which has neither public acceptance nor expression. Lack of consensus as to a definition of this problem has created dilemmas among practitioners as well as policy makers with regard to direction for further activity. The resulting inconsistency in practitioners' approach to diagnosis and intervention, has contributed to continued--often futile--searches for effective treatment among those suffering from this problem. Public agencies on both the local and national levels lack the availability of sound data on which to base policies which would address the need for prevention and/or amelioration of the social impact of this problem.

In the area of health and safety policy, the findings speak to an increased need for educational programs aimed at informing the workforce and community residents about the health effects of exposures (including indoor air pollution) specific to their workplaces and communities. This effort would assist in providing the lay public with the ability to make accurate assessments of potential hazards. Education and

information about workplace exposures should be provided to every employee, at the time of hire and regularly throughout their employment, particularly at points of change in assignment. OSHA's role in fostering the existence of health and safety committees in the workplace whose charge would include the overseeing and implementation of such educational programs is supported by findings in this study. In addition, findings point to the need for strengthened regulatory policy in the area of provision of appropriate protection from hazardous exposures for workers and community residents. Based on study findings, the failure to develop adequate policy in both of these areas has contributed to the occurrence of exposures of a hazardous nature among workers and community residents which are both preventable and unnecessary. Lack of appropriate education and information has also contributed to the development of adjustmental problems associated with hazardous exposures, as well as fears based on unfounded notions of risk. Finally, in view of the continuing need to adequately fund OSHA's efforts in the regulation of workplace health hazards, policy supporting the employee's right to refuse, without penalty, work that is felt to be potentially hazardous, or for which adequate training, education and protection has not been provided, is also indicated based on study findings.

In summary, in the area of health and safety policy, the

provision of adequate health and safety education, personal protection, and job security in hazardous workplaces are all supported by study findings illustrating subjects' reports of gaps in these areas.

Implications of study findings for social welfare policy abound, with issues of access to adequate and appropriate health care, income replacement, and employment figuring in the forefront of policy recommendations. The availability of housing and recreational facilities, capable of accommodating people with these restrictions is also raised as an important, though secondary, consideration.

The provision of health care benefits to cover the cost of long-term medical care is critical among social policy recommendations. Treatment, which has generally been recognized to be of a long-term, supportive nature, must be made accessible for individuals in their efforts to cope with the health effects of this problem. Provision of income replacement, either through the workers' compensation programs, or through social security benefits, for individuals who are either temporarily or permanently unable to secure appropriate employment due to the effects of this condition, are also necessary. Finally, public agencies must recognize the existence--if not the nature and etiology--of this problem, and accordingly offer support to individuals in the form of training in, and opportunities for, the transfer of job skills

to alternative work settings.

To summarize, in the area of social welfare policy, study findings point to the importance of job training, disability and workers' compensation, access to health care, and availability of accessible public and recreational facilities in the prevention and amelioration of social problems associated with the development of "multiple chemical sensitivities."

Direct practice with this population is essentially supportive, with the need for such intervention beginning early on, and extending well into the progression of the health problem. The problem of multiple chemical sensitivities, characterized by increasing sensitivities to environmental stimuli ubiquitous to a variety of work and community settings, causes its sufferers to become restricted in many areas of activities, with a sizeable portion of the population becoming totally disabled and consequently lacking in adequate means of income support.

Though many--perhaps the majority--of those afflicted with the problem continue to carry on with their activities, they do so with great difficulty, and are understandably in need of the benefits afforded by a variety of supportive relationships. Thus, findings speak clearly to the need for interdisciplinary practice in the provision of a range of services. Due to the combined impact of medical as well as psychosocial difficulties

generated by this problem, the population with multiple chemical sensitivities currently utilizes services provided in medical, mental health, social welfare and legal service agencies, and labor organizations, where social workers are likely to work along with other disciplines in the provision of service. Social work practice with patients and their families in these settings must be carried out in close collaboration with physicians, industrial hygienists, other mental health professionals, lawyers, and others with whom the patient comes into contact in their efforts to obtain needed services.

The findings also speak to the need for further development in the area of education for professionals who are likely to come into contact with this population. Professional assistance must be based on knowledge of the complexity of this problem, rather than on a set of assumptions which result in the practice of "labeling" such individuals. With regard to professional social work education, a rudimentary familiarity with the problem of industrial and environmental hazards and their impact on populations could be achieved on the graduate social work level by introducing the following information into the curriculum: Basic knowledge of national rates of occupational-related injury, disease and fatalities and demographic characteristics of those at greatest risk; an introduction to the area of environmental health hazards; knowledge of OSHA, its history and regulatory policy mandate,

and the shortcomings of this agency due to inadequate funding; knowledge of the workers' compensation system, the parameters of its income replacement and vocational retraining function, and difficulties in the compensation of disease as compared with injury; and an introduction to the range and roles of different disciplines working in the field of occupational health and safety, with regard to their availability as resources for populations at risk. In this way, the approach to intervention with persons who complain of symptomatology related to industrial or environmental exposures will be based on a sound knowledge of the general concepts underlying health and safety policy. Professional social workers should also have some familiarity with the kinds of problems individuals and communities face with regard to adjustment to occupational-related illness or disability, as well as knowledge of the range of individual and community response to the presence of hazards in workplaces or communities. Preparation for professional practice in this area should include content in the following areas: intervention with individuals, families and groups, linkage with workplace, labor groups and community resources, and advocacy for the strengthening of health and safety policy on the legislative level. Such information should be included in the core curriculum, particularly for those students with interest in the "World of Work."

In the area of research, findings support the need for

further research on the health effects of low-level exposures--particularly in the area of indoor air pollution--carried out with federal support by agencies such as NIOSH (National Institute for Occupational Safety & Health) and NIEHS (National Institute of Environmental Health Sciences) toward the goal of establishing standards for exposures which heretofore have been outside the realm of OSHA regulation.

In the area of social work research, findings point to the need for further study of the factors associated with positive outcome in the health and social functioning of people with this problem. This would include further descriptive study of the role of familial support, as well as professional intervention --including the role of mutual aid and self-help models--in the enhancement of the affected individuals' coping capacities.

In final summary, social workers can and should play a major role in designing interventions aimed at addressing the problem of personal and social adjustment to occupational and environmental illness which is not yet understood or well-defined by the medical profession. Educational efforts aimed at ameliorating fears based on inadequate understanding of environmental and occupational exposures, as well as advocacy for the prevention of unnecessary exposure to known hazards, continue to be important areas for social work practice.

APPENDIX A: **QUESTIONNAIRE ADMINISTERED TO ATTENDEES, "MCS LECTURE" BY M. CULLEN, 1989**

Thanks in advance for your time in filling out this brief questionnaire. This will assist with current efforts to conduct exploratory social research with a segment of the Occupational Health Clinic patient population.

1. What is your occupation?_____

2. Gender: ___M ___F

3. Age: _____

4. When and in what context were you first made aware of the existence of Multiple Chemical Sensitivities?

5. What is your present understanding of Multiple Chemical Sensitivities? (Brief diagnostic or descriptive statement):

6. What is the nature of your current contact with individuals having this problem?

   ____Treating physician (how many patients?_____)

   ____Other (Explain:_____

   ____I have no current or previous contact with this population.

7. Which do you think is the most appropriate treatment for patients with this problem? (check one)

   ____Medical doctor

   ____Psychiatrist

   ____Both of the above

   ____Either of the above, depending on the patient

   ____Neither one of the above, (Other:_____)

   ____Unsure

8. Please check the statement which most closely reflects your thinking with regard to Multiple Chemical Sensitivities:

____ This is primarily a presentation of somatization disorder and should be treated accordingly.

____ There are several subgroups of patients within the larger set of those labeled as having this syndrome. Each of these subgroups requires a different form of intervention.

____ Not enough is known about this syndrome and further descriptive research is needed in order to design appropriate methods of intervention.

____ I disagree with the concept that this problem can be characterized as a syndrome.

APPENDIX B: **PARTIAL LISTING OF DIAGNOSES OF 159 PATIENTS WITH "AMBIENT EXPOSURES" CHOSEN FOR CHART REVIEW**

no diagnosis	49	irritable bowel syndrome	1
pleural plaques without asbestosis	7	industrial bronchitis	1
asthma, non-occupational	6	occupational asthma	1
COPD, non-occupational	4	sarcoidosis	1
asbestosis, with or without plaques	4	amenorrhea	1
headaches, NOS	4		
diarrhea nos	2	carbon monoxide poisoning	1
laryngitis,	2	freon intoxication	1
panic disorder due to stress	2	neurofibromatosis	1
contact dermatitis, non occupational	2	rheumatism	1
mercury poisoning,	2	phobic disorder	1
lead poisoning,	2	dermatitis	1
schizophrenia	2	itch, NOS	1
multiple sclerosis	2	skin burning	1
migraine headaches	2	toxic poisoning	1
lung cancer,	1	congestive heart failure	1
Cushing's syndrome,	1	hypersensitivity pneumonitis	1
Maternal exposure potentially affecting newborn	1		

APPENDIX C: CRITERIA UTILIZED IN BENJAMIN HOFFMAN'S STUDY[1]

Criteria for the diagnosis of "MCS" were developed for the purpose of establishing diagnostic conformity based on clinical experience and, in part, upon criteria developed by others. These criteria are:

1. No concurrent illnesses are present.

2. The syndrome is acquired after "environmental exposure" of excessive (such as an accident or spill) or continuous high level exposure (such as in industrial settings) to a specific, well characterized toxin. Can be viewed as the "inciting lesion" or "environmental event."

3. The illness phase of MCS occurs with the following criteria, all based on the concept of "generalization."

    a. Symptoms are elicited on exposure to more than one class of substances (more than one mode of toxicologic actions is involved) and are self-limited upon cessation of exposure.

    b. Symptoms involve more than one organ system.

    c. Exposure is defined as ambient dose levels and would be at least two orders of magnitude below assumed NOEL's and/or TLV's.

    d. Exposures are demonstrable and tolerable to other individuals so exposed.

    e. The exposure-symptoms complex has occurred more than once.

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[1]From, Hoffman, B., M.D., Multiple Chemical Sensitivity, MPH Thesis. Yale University 1988. p. 17-18.

APPENDIX D: DIAGNOSES OF 50 CASES CHOSEN FOR CHART REVIEW FROM SOCIAL WORK CASELOAD (1980-1988)

no diagnosis	9	low back strain	1
anxiety	4	sinusitis	1
depression	4	threatened abortion	1
PTSD	3	thymus disorders	1
reactive airway disease	3	schizoid personality disorder	1
asthma, occupational	3	pharyngitis	1
asthma, non-occupational	2	nerve injury	1
stress reaction	2	lymphadenopathy	1
conjunctivitis	2	maternal exposures potentially affecting newborn	1
bronchiolitis	2	gastroenteritis	1
toxic effects of solvents	1	dizziness	1
organic brain syndrome non-occupational	1	encephalitis, unspecified cause	1
sarcoidosis	1		

APPENDIX E

YALE OCCUPATIONAL MEDICINE DATABASE
N=4000+

Subset 1		Subset 2		Subset 3		Subset 4	
MCS *Acute Solv. Int Upper Airway Irrit Pesticide Poisoning		Ambient Exposure		Hoffman Study		Social Work Caseload	
N=189	+	N=159	+	N=12	+	N=50	=

N=410 + 13 (Newly seen cases) =

N=423
CHART REVIEW

+

APPLICATION OF SCORING INSTRUMENT =

SAMPLE MEETING CRITERIA FOR INCLUSION

(N=83)

APPENDIX F: LETTER OF INVITATION

As a previous or current patient of the Occupational Health Clinic, you are invited to participate in a study of patients with chemical exposures in the workplace or environment. We are hoping that the information that is gathered in the study will assist practitioners and others who share a concern about the consequences of such exposures for workers and/or community residents. All information gathered will be kept confidential.

If you agree to participate, we will contact you soon to set up an appointment for an interview at a mutually convenient time and which may be conducted either by telephone or in person, depending on what is best for you. The interview will last approximately one to one and a half hours. In no case shall your participation result in any financial cost to you; all related costs will be borne by researcher(s).

You are free to decide whether or not to participate in this study and if at any time during the course of the study you wish to withdraw, this would in no way interfere with your relationship with the Occupational Health Clinic in the future. As stated above, any information you give will be kept confidential. You may also refuse to answer any specific questions.

Please indicate whether you choose to participate in the study by filling out the attached form and returning it in the self-addressed enclosed envelope. If you have any questions about the study, please don't hesitate to contact Ms. Lewis at 785-4197 or 785-5885.

Thank you for your time and interest.

Sincerely yours,

Beth M. Lewis, MSW

Mark R. Cullen, M.D.

TO: Beth Lewis, MSW

FROM:

_____ I am interested in participating in the study.

_____ I am not interested in participating in the study.

_____ I would prefer a telephone interview. The best time of day for me would be:

____a.m. (between 9:00 - 12:00)

____p.m. (between 2:00 - 5:00)

____evening (after 7:30)

_____ I would prefer a face-to-face interview.

Please indicate your current address and telephone number:

Address_____

_____

Telephone: Work _____

Home _____

APPENDIX G: MULTIPLE CHEMICAL SENSITIVITIES QUESTIONNAIRE

Identifying Information (From Database)

1. __ __/__ __/__ __ date of birth
   month day year

7. sex: (1) male (2) female

8. physician: (01) JA (04) MC (07) BH (10) CM
   (13) CR (02) JB (05) LF (08) JH (11) MM
   (14) JR (03) WB (06) JG (09) CK (12) RM
   (15) LW

10. __ __ __ __ primary diagnosis

14. __ __/__ __/__ __ date of first visit

20. __ __/__ __/__ __ date of MCS interview

Demographic Data/Socioeconomic Status

26. How do you describe your racial or ethnic background?
   (1) Caucasian (2) African American (3) Hispanic
   (4) Asian/Amerasian (5) Other

27. What is the religion in which you grew up as a child?
   (1) Catholic (2) Protestant (3) Jewish (4) Other

Have you ever been married?
IF EVER MARRIED: When were you first married?
Are you still married to this person?
IF NOT STILL MARRIED: When were you separated or widowed?

Have you ever married again?
REPEAT QUESTIONS THROUGH CURRENT MARRIAGE.
IF NOT CURRENTLY MARRIED: Are you now living with someone?

28. currently: (1) never married (3) separated/divorced
(2) married (4) widowed
(5) with posslq

	first married/living with	separated/widowed
29.	__ __/__ __	__ __/__ __
37.	__ __/__ __	__ __/__ __
45.	__ __/__ __	__ __/__ __
53.	__ __/__ __	__ __/__ __

61. __ __ How many children have you had?

63. __ __ How many of these are dependent children living with you now?

65. __ __ Are there any other dependent children living with you now?

67. How many years of school have you completed?
(1) less than seventh grade
(2) seventh through ninth grade
(3) tenth or eleventh grade
(4) high school graduate/GED
(5) some college or specialized training
(6) four years of college
(7) graduate or professional training

68. What is your present family income before taxes? This means the income earned by all adults in your home. It includes social security or other benefits, as well as welfare or AFDC payments.

(01) < $7,000
(02) $7,000-$9,999
(03) $10,000-$12,999
(04) $13,000-$16,999
(05) $17,000-$20,999
(06) $21,000-$24,999
(07) $25,000-$29,999
(08) $30,000-$34,999
(09) $35,000 or more

70. What is your income before taxes?
(01) < $7,000
(02) $7,000-$9,999
(03) $10,000-$12,999
(04) $13,000-$16,999
(05) $17,000-$20,999
(06) $21,000-$24,999
(07) $25,000-$29,999
(08) $30,000-$34,999
(09) $35,000 or more

Health Problems

Describe your health problems to me.

What does your doctor (do your doctors) think is your health problem?

When did your health problems begin? What were your symptoms at that time? Did your symptoms ever go away for a month or more? IF YES: Did they ever come back again after that? REPEAT QUESTIONS UNTIL RECORDING CURRENT STATUS.

31. __ __/__ __ month/year of onset of problems

43. So far as you can say, what caused your health problems?

(01) acids	(05) pesticides
(02) chlorine	(06) petrochemicals
(03) degreasers	(07) plasticizers
(04) herbicides	(08) sick office
	(09) other

45. __ __/__ __ When were you first exposed to CAUSE?

49. Where did this first exposure take place?
(1) home (2) office (3) neighborhood (4) car (5) other

50. Had there been any changes in that environment?
(01) move or new car
(02) renovation
(03) overcrowding/underventilation
(04) exterior construction work
(05) new cleaning fluids
(06) new herbicides
(07) new pesticides
(08) accident/spill/leak
(09) other:

52. How long did it take from that first exposure to the first time you started to have symptoms?
(1) same day
(2) same week
(3) same month
(4) within three months
(5) within six months
(6) within a year
(7) a year or more

61. What is your current occupation? _____

(00) unemployed
(01) farm laborers and menial service workers
(02) unskilled workers
(03) machine operators and semiskilled workers
(04) small business owners, skilled manual works, craftsmen, tenant farmers
(05) clerical & sales workers, small farm and business owners ($25-50,000)
(06) technicians, semiprofessionals, small business owners ($50-75,000)
(07) small business & farm owners ($75-100,000), managers, minor professionals
(08) administrators, lesser professionals, medium business owners ($100-250,000)
(09) higher executives, major professional, large business owners ($250,000+)

63. How much does your health restrict your daily activities at work?

(1) not at all (2) a little (3) some (4) a lot
(5) completely

64. How much does your health restrict your daily activities at home or with friends?
(1) not at all (2) a little (3) some (4) a lot
(5) completely

65. Has your health affected your salary or your getting promoted? How?
(1) no effect
(2) prevented promotions/raises
(3) pay cut of up to 20%
(4) pay cut of 20-50%
(5) pay cut of more than 50%

66. Did this problem develop at the workplace, outside the workplace, or both?
(1) at work (2) outside work (3) both

67. Do you describe your problem as physical, psychological, social, or some combination of the three? (If asked: how would you describe the nature of your problem?)
(1) physical
(2) psychological
(3) social
(4) physical/psychological
(5) physical/social
(6) psychological/social
(7) all three

68. What was your occupation at the time you were first exposed?_____

(00) unemployed
(01) farm laborers and menial service workers
(02) unskilled workers
(03) Machine operators and semiskilled workers
(04) small business owners, skilled manual works, craftsmen, tenant farmers
(05) clerical & sales workers, small farm and business owners ($25-50,000)
(06) technicians, semiprofessionals, small business owners ($50-75,000)
(07) small business & farm owners ($75-100,000), managers, minor professionals
(08) administrators, lesser professionals, medium business owners ($100-250,000)
(09) higher executives, major professional, large business owners ($250,000+)

Social Support System

11. How many employees are/were at the workplace (in the same building) when you first developed problems?
(1) self only
(2) self and one other person
(3) 3-10 people
(4) 11-25 people
(5) 26-50 people
(6) 51-100 people
(7) over 100 people

How easy is/was it for most people to talk with the following people at that workplace?

12. Among co-workers?
(1) very easy (2) somewhat easy (3) half & half
(4) somewhat hard (5) very hard

13. Among workers in different departments?
(1) very easy (2) somewhat easy (3) half & half
(4) somewhat hard (5) very hard

14. Among supervisors in different departments?
(1) very easy (2) somewhat easy (3) half & half
(4) somewhat hard (5) very hard

15. Between supervisor and supervisee?
(1) very easy (2) somewhat easy (3) half & half
(4) somewhat hard (5) very hard

16. Between management and employees?
(1) very easy (2) somewhat easy (3) half & half
(4) somewhat hard (5) very hard

17. Are/were there formal opportunities (i.e., like committees, suggestion box, etc.) for employee input at the workplace? (1) no (2) yes

18. If yes, how do/did they work?
(1) no opportunity (2) poorly (3) moderately well
(4) very well

With whom did you first talk about your health problem, either at work or elsewhere? Tell me about that time.

19. (01) co-worker (06) spouse/posslq (10) other relative
(02) management (07) parent (11) friend
(03) supervisor (08) sibling (12) health profess
(04) union rep (09) child (13) legal profess
(05) worker in different department (14) other

21. (1) at work (3) with friends (5) legal office
(2) at home (4) medical office (6) other

22. __ __/__ __ month/year

Interpersonal Dependency

bottom of page 128
129
top of page 130

When was the next time you talked about your health problem with others? Tell me about that time.

26. (01) co-worker (06) spouse/posslq (10) other relative
(02) management (07) parent (11) friend
(03) supervisor (08) sibling (12) health profess
(04) union rep (09) child (13) legal profess
(05) worker in different department (14) other

28. (1) at work (3) with friends (5) legal office
(2) at home (4) medical office (6) other

29. __ __/__ __ month/year

Do you have someone, or more than one person, to whom you can confide your feelings? Who?

33. (1) no one (2) one person (3) more than one person

34. (1) no one (2) family (3) friends (4) both

35. Have you talked with this person (these people) about your health problems?
(1) no (2) yes

36. How helpful was it for you to talk with this person?
(1) not helpful (2) somewhat helpful (3) very helpful

Health-Care Delivery System

11. In general, has your experience with health care providers over the years been:
(4) excellent (3) good (2) fair (1) poor

12. With respect to the problem you have now, has your experience with health care providers been:
(4) excellent (3) good (2) fair (1) poor

What kinds of health care provider have you seen? (Give number of each.)

13. ___own GP/internist/family practitioner
14. ___own physiological specialist
15. ___company physician
16. ___social worker/counselor
17. ___psychiatrist
18. ___nurse
19. ___other

Tell me about the first time you went to a health care provider about the problem. Whom did you see? When was this? What advice were you given? Did you follow this advice? Did your problems get better, worse, or stay the same after seeing this provider? Did you see anyone else after this? (REPEAT QUESTIONS UNTIL ASKING ABOUT CURRENT PROVIDER.)

20. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician
(4) social worker/counselor
(5) psychiatrist
(6) nurse
(7) other

21. __ __/__ __ date of first contact with health care provider

25. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

27. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician
(4) social worker/counselor
(5) psychiatrist
(6) nurse
(7) other

28. __ __/__ __ date of first contact with health care provider

32. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

34. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician
(4) social worker/counselor
(5) psychiatrist
(6) nurse
(7) other

35. __ __/__ __ date of first contact with health care provider

39. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

41. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician (6) nurse
(4) social worker/counselor (7) other
(5) psychiatrist

42. __ __/___ ___ date of first contact with health care provider

46. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

48. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician (6) nurse
(4) social worker/counselor (7) other
(5) psychiatrist

49. __ __/___ ___ date of first contact with health care provider

53. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

55. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician (6) nurse
(4) social worker/counselor (7) other
(5) psychiatrist

56. __ __/___ ___ date of first contact with health care provider

60. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

62. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician (6) nurse
(4) social worker/counselor (7) other
(5) psychiatrist

63. __ __/___ ___ date of first contact with health care provider

67. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

69. (1) own GP/internist/family practitioner
(2) own physiological specialist
(3) company physician (6) nurse
(4) social worker/counselor (7) other
(5) psychiatrist

70. __ __/___ ___ date of first contact with health care provider

74. (1) did not follow advice (2) followed partly
(3) followed completely (4) no advice given
(5) referral made

Which of these were influential in your decision to seek professional help?

		no	yes			no	yes
11.	spouse/posslq	(1)	(2)	17.	co-worker	(1)	(2)
12.	parent	(1)	(2)	18.	union	(1)	(2)
13.	sibling	(1)	(2)	19.	employer	(1)	(2)
14.	child	(1)	(2)	20.	media	(1)	(2)
15.	other relative	(1)	(2)	21.	lawyer	(1)	(2)
16.	friend	(1)	(2)	22.	other	(1)	(2)
17.	co-worker	(1)	(2)	23.	no one/self	(1)	(2)

What kinds of support services would be most useful for you or for a person in your situation, with your kinds of health problems?

24. (1) no (2) yes more education for health professionals
25. (1) no (2) yes more public awareness
26. (1) no (2) yes disability recognition & compensation
27. (1) no (2) yes work rehabilitation
28. (1) no (2) yes safe house
29. (1) no (2) yes group therapy
30. (1) no (2) yes research
31. (1) no (2) yes strengthened OSHA

Appendix H

Dear:

As a respondent, you are invited to participate in a group discussion to review preliminary results of our study of patients with chemical exposures in the workplace or environment. Participants in the group discussion will include researchers and other study respondents. The purpose of the discussion is to invite comments from group participants, toward the goal of furthering the usefulness of final study results. Preliminary study results will be shared in a manner in keeping with the maintenance of confidentiality of individual respondents.

The meeting will be held on (date) from 7:00 to 9:00 P.M. in the (room) on the first floor of the Hospital. Free parking is available in (parking lot # and directions).

Please complete the bottom portion of this letter indicating whether you plan to attend, and return it in the enclosed, self-addressed, stamped envelope.

Thank you for your continued interest and participation.

Sincerely yours,

Beth M. Lewis, MSW

Mark R. Cullen, M.D.

- -

____ I plan to attend the (date) meeting.

____ I am unable to attend the meeting on (date) but would like to receive a printed copy of the study results when available.

____ I will not be attending the meeting on (date).

Name _____

Appendix I

Four Factor Index of Social Status. Hollingshead, AB (1976). A Working Paper.Department of Sociology, Yale University.

Level 0	Unemployed
Level 1	Farm Laborers/Menial Service Workers
Level 2	Unskilled workers
Level 3	Machine Operators & Semiskill Workers
Level 4	Smaller Business Owners, Skill Manual Workers, Craftsmen, & Tenant Farmers
Level 5	Clerical, Sales Workers, Small Farm & Business Owners
Level 6	Technicians, Semiprofessionals, Small Business Owners
Level 7	Smaller Business Owners, Farm Owners, Managers, Minor Professionals
Level 8	Administrators, Lesser Professionals, Proprietors of Medium-Sized Businesses
Level 9	Higher Executives, Proprietors Large Businesses and Major Professionals

Glossary

ambient air That portion of the air external to buildings to which the general public has access.

carcinogenic Producing cancer.

contaminant A substance not normally present in the atmosphere.

formaldehyde An odorous gas (HCHO) emitted from many building materials that is an irritant to the eyes and respiratory system.

OSHA (Occupational Health & Safety Administration) Primary regulatory agency for occupational safety and health. Its standards are law throughout the U.S. and its compliance officers can inspect the workplace at any time to determine the status of health and safety and to cite employers for violations of the law.

pollutant A substance not normally found in air or water that may be harmful to living organisms.

respiratory irritants A diverse spectrum of compounds, gases, and chemicals that when inhaled result in irritation to mucous membranes manifested as nonspecific inflammation.

solvent (exposure to) Exposure to solvents may affect the nervous system, kidneys, liver, skin, and mucous membranes. Areas of controversy with regard to the health effects of solvent exposure include: effects on the central nervous system, the relationship between solvents and chronic renal disease, and the hepatoxicity and human carcinogenicity of certain solvents.

threshold limit values Guidelines for control of workplace atmospheres by personnel with adequate training and experience in industrial hygiene. Published annually by the TLV Committee of the American Conference of Governmental Industrial Hygienists (ACGIH) since the 1940's, the 1969 listing was adopted in its entirety in 1970 with the passage of the OSHA and given the status of law. Although many people improperly consider TLV's to be "safe levels" of exposures to toxic substances, in fact, where exposure to toxic materials cannot be kept at zero levels, the TLV's are recommended to be used as a guide to the maximum tolerable exposure levels.

tight building/tight building syndrome A characteristic set of symptoms, typically headache and mucous membrane irritation, recognized recently among occupants of buildings tightly sealed to prevent the infiltration of outside air. Outbreaks have occurred chiefly in government offices, business offices, and schools or colleges.

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