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Unmet Medical Needs in Persons with Self-Reported Multiple Chemical Sensitivity

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## Abstract

We studied unmet medical needs in persons self-identified with Multiple Chemical Sensitivities (MCS). Respondents are 187 persons who are part of an ongoing study that examines life impacts of living with MCS. The present study had participants complete a two-year follow-up questionnaire assessing unmet medical needs. We inquired about their ability to locate safe medical facilities, sufficiently educated medical practitioners, specific procedures that respondents considered threatening to their health, and procedures obtained without the use of anaesthesia. We found the most common obstacles to obtaining treatment to be the presence of harmful substances in medical offices including fragrances worn by medical personnel, and the inability to find medical practitioners trained to provide proper care for MCS patients. In addition, due to respondents' inability to tolerate anaesthesia, many reported avoiding needed procedures altogether or actually enduring procedures (commonly performed with anaesthesia) unanaesthetized. Responses to our inquiries are presented in tables and graphs, procedures endured without anaesthesia are itemized, and the implications for access to health care facilities and practitioners are discussed.

## Introduction

Multiple Chemical Sensitivity (MCS), also known as Environmental Illness (EI) and Chemical Injury (CI), is a condition in which persons report being adversely affected by substances in the environment. Substances such as pesticides, fragrances, petrochemicals, medications, anaesthetics, dust, pollen, and foods are examples of the incitants reported to cause disruption in a variety of bodily systems including respiratory, neurological, circulatory and muscular (Ashford & Miller, 1991; Bascom, 1989; Bell, 1982; Lewith & Kenyon, 1985; Randolph & Moss, 1982; Rea, 1992; Ziem & Davidoff, 1992).

Persons who experience MCS/CI report disruption in many life domains, including the acquisition of adequate medical care due to their need to avoid chemical exposures (Gibson, Cheavens, & Warren, 1996). For example, some report difficulty in locating practitioners who are both sensitive to patients' needs and educated about the condition/illness. Medical offices are often inaccessible to this population due to the presence of chemicals that may provoke reactions.

## Method

### Participants

This study is part of an ongoing study of 305 persons (80% women; mean age = 46) self-identified with MCS who were recruited through newsletters, support groups, and physicians' offices. Of these participants, 187 completed a two-year follow-up survey designed to assess unmet medical needs.

### Procedure

We inquired in open-ended questions about unmet medical needs of participants. Specifically we asked about needing but not obtaining medical help because of inaccessibility to medical facilities due to chemical barriers, needing but not obtaining medical help because of the inability to find a practitioner who would consider the chemical sensitivity in provision of care, and needing but not obtaining medical treatment because the participant considered the medical procedure to be a danger to her/his health because of the sensitivities. We also asked about difficulties with or avoidance of anaesthesia.

## Results

Respondents reported having considerable difficulty obtaining a variety of medical interventions. Responses are summarized in Figures and accompanying Tables 1 through 4. Persons described difficulty with locating accessible facilities due to the presence of

indoor chemicals such as pesticides, heating systems, carpets, cleaners, and perfumes on medical personnel. Additionally, respondents reported difficulty in finding practitioners with training in chemical sensitivity or willingness to consider patients' sensitivities. Physicians often attributed reactions to psychological causes.

Some persons feared that they would inadvertently become ill as a result of medical interventions and medications. Consequently they delayed or avoided obtaining treatment. Respondents avoided general dental work ( $n = 28$ ), medications ( $n = 25$ ), surgeries ( $n = 18$ ), and diagnostics ( $n = 15$ ). e.g., One woman described being so sensitive to dental anaesthetics (even locals) that she suffered from an abscessed tooth for two years. Many respondents dreaded medical emergencies because they feared that treatments would be administered without consideration for their sensitivities.

Some participants reported enduring painful medical procedures without the use of anaesthetics. Again, dental work emerged as a problem with 50 persons reporting having general work, 7 reporting having had root canals, and 6 having teeth pulled without the use of anaesthesia. Other procedures reportedly obtained without anaesthesia included exploratory procedures such as bronchoscopy, cystoscopy, and colonoscopy. Some participants reported having procedures which usually are done with general anaesthesia using only local anaesthesia, ie., removal of breast implants and surface tumors, and surgeries for bladder repair and hernia.

### Discussion

Responses indicate that persons in this sample have considerable difficulty obtaining a variety of needed medical interventions. Persons described difficulty with locating accessible facilities due to the presence of indoor chemicals, and because physicians attributed their health problems to psychological causes.

Participants' responses in this study indicate that much of the health care system is perceived to be inaccessible to persons self-identified with MCS. Reported obstacles to obtaining medical care include chemical barriers, the perceived lack of training for medical personnel in regard to MCS, the presence of perfumes in medical offices, and the frequent need for anaesthesia. As a consequence, a subset of the population appear to have serious medical needs that remain unmet. Respondents in this study have coped by seeking alternative practitioners, attempting to educate their own doctors, or avoiding medical treatment altogether. Alternative practitioners were sometimes able to provide safe care, and some persons even reported using alternative anaesthetics such as acupuncture or hypnosis for surgeries. Those who shared information and collaborated with their own doctors often were able to find solutions to the obstacles presented by their sensitivities. In fact, educating doctors about MCS is cited as one of the most

crucial elements in improving access and services for those with chemical sensitivity (Cheavens, Gibson, Warren & Pasquantino, 1993). Some who avoided treatment experienced symptom exacerbation or even endangered their lives if problems escalated into emergencies, indicating that this is a crucial problem for further study if health care is to be accessible to all portions of the population. It is crucial that medical providers consider sensitivities when providing care, and obtain education in regard to treating those with MCS.

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