

Perceived Treatment Efficacy for Conventional and Alternative Therapies Reported by Persons with Multiple Chemical Sensitivity

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Multiple chemical sensitivity (MCS) is a condition in which persons experience negative health effects in multiple organ systems from exposure to low levels of common chemicals. Although symptoms experienced from particular chemicals vary across persons, they are generally stable within persons. The sensitivities often spread over time, first to related chemicals and then to other classes of chemicals. This study examined self-reported perceived treatment efficacy of 101 treatments used by 917 persons with self-reported MCS. Treatments examined included environmental medicine techniques, holistic therapies, individual nutritional supplements, detoxification techniques, body therapies, Eastern-origin techniques, newer therapies, prescription items, and others. The three most highly rated treatments were creating a chemical-free living space, chemical avoidance, and prayer. Both creating a chemical-free living space and chemical avoidance were rated by 95% of respondents as helpful. Results for most therapies were mixed. Participants had consulted a mean of 12 health care providers and spent over one-third of their annual income on health care costs. We discuss this drain on personal resources and describe respondents' attitudes toward the possibility of healing from MCS. *Key words:* chemical hypersensitivity, chemical injury, environmental allergy, environmental illness, environmental sensitivity, multiple chemical sensitivity. *Environ Health Perspect* 111:1498–1504 (2003). doi:10.1289/ehp.5936 available via <http://dx.doi.org/> [Online 9 April 2003]

Although some progress has been made in the development of a case definition for multiple chemical sensitivity (MCS) (Bartha et al. 1999) and in elucidating symptom profiles (Joffres et al. 2001), we still lack a widely accepted treatment protocol for the condition. Consequently, patients experiment with a wide variety of both conventional and holistic health treatments. Although practitioners of environmental medicine have a systematic approach for working with MCS, there is no common MCS treatment protocol accepted across medical disciplines. The field of environmental medicine espouses guidelines and techniques for addressing MCS, but critics maintain that the techniques have not been efficacious in double blind trials. Because research on treatments for MCS is sparse, people have few data on which to rely when choosing interventions. Physicians have described health findings from patient samples (Bell et al. 1995; Galland 1987; Heuser et al. 1992; Lieberman and Craven 1998; Ross 1992a) and suggested treatment strategies (Jewett 1992; Ross 1992b; Ziem 1992), but only a small number of published studies describe MCS treatment and follow-up (Lax and Henneberger 1995). In addition, only three studies to date have examined patients' assessments of a large number of health interventions for MCS (Gibson 2000; Johnson 1996, 1997a, 1997b, 1998; Leroy et al. 1996). All three studies found that chemical avoidance measures were rated as very highly effective, whereas prescription drugs were rated the least effective of all treatments.

Life impact research shows that people with MCS tend to spend a considerable amount of

their resources on health care, often pursuing a large number of therapies. Gibson et al. (1996) found that 305 persons with MCS reported spending almost \$6,000, or half of their personal income in the past year, and almost \$35,000 total on medical expenditures since developing MCS. Respondents saw a mean of 8.6 practitioners each, but perceived only a quarter of them to be helpful. Still, patients report having medical needs that remain unmet and experiencing considerable iatrogenic harm (Engel et al. 1996).

Our purpose in this study was to examine the types and numbers of treatments used by people with MCS and to investigate perceived efficacy of those treatments. The study was not limited to conventional techniques. Rather, we sought to gather data on any techniques that respondents had tried, in an effort to understand the experience of seeking medical treatment for a poorly understood condition. We chose to evaluate retrospective reports from patients to assess the large number of treatment methods tried by this population of considerable size. Results may be helpful to patients, providers, and advocates in making decisions about resource allocation.

Methods

Participants. Participants were 917 persons contacted through the Chemical Injury Information Network (CIIN, www.ciin.org) and through MCS support groups. People learn about and become members of CIIN and other support groups through other persons with MCS, physicians' offices, small media, and the

Internet. Most groups publish newsletters with resources and informational support for persons with MCS and other interested parties. Respondents were 82% women and 95% Caucasian. Participants' ages ranged from 20 to 82 years, with a mean age of 53 years. Respondents' characteristics are presented in detail in Table 1. When asked to identify the severity of their condition, 7% identified their MCS as mild, 32% as moderate, 45% as severe, and 13% as totally disabling.

Procedure. This research, including the survey materials, was reviewed by the James Madison University Institutional Review Board. All members of CIIN were invited to respond to a mail survey that gathered informed consent and asked about their use of 108 treatments to improve their MCS. In addition, other MCS support groups were contacted by CIIN and asked to distribute the survey to their members. More than 4,000 surveys were distributed.

Measures. The survey included questions about demographics, the impact of MCS on finances, number of practitioners seen, application for any type of compensation for the illness, who identified the condition, and respondents' impressions regarding the cause of their MCS. The survey used a computer answer sheet to collect data about participants' perceived efficacy ratings of any of 108 different treatments they might have tried. The 108 treatments included were gathered from the three efficacy studies done to date (Gibson 2000; Johnson 1996, 1997a, 1997b, 1998; Leroy et al. 1996), elements of environmental medicine protocol, widely used nutritional supplements, well-known body therapies and other holistic therapies, and other current treatments described to us by persons with MCS. Treatments were grouped into the following nine categories: environmental medicine/oasis techniques, holistic

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therapies, individual nutritional supplements, detoxification techniques, body therapies, Eastern-origin techniques, newer therapies, prescription items, and others. Unless otherwise specified, respondents were asked to rate the efficacy of a treatment in terms of its usefulness in improving their MCS, rather than simply as an aid in coping with exposures. Exceptions were the use of air filters, oxygen, and charcoal masks, which were conceptualized not as treatments per se, but as aids in reducing exposures. For each treatment, participants were asked whether they had tried it and, if so, for how long. Those who had used a treatment were then asked to rate the efficacy of the treatment as “very harmful,” “somewhat harmful,” “no noticeable effect,” “somewhat helpful,” or “very helpful.” For therapies conceptualized as time-limited interventions (e.g., clinic sauna), we asked how long negative or positive effects had persisted after completion of the therapy.

Table 1. Respondent characteristics.

Characteristics	Number ^a	Percent
Sex		
Male	169	18.4
Female	748	81.6
Race		
African American	4	0.4
Latin American	6	0.7
Native American	18	2.0
Caucasian	867	94.5
Asian American	3	0.3
Other	19	2.1
Partner status		
Single	184	20.2
Married	490	53.8
Divorced	197	21.6
Separated	13	1.4
Widowed	26	2.9
Education		
< 12 years	16	1.8
12 years	76	8.3
12–15 years	285	31.2
16 years	273	29.9
Masters degree or beyond	264	28.9
Cause of MCS		
One large chemical exposure	185	20.2
Series of low-level exposures	536	58.5
Physical illness	48	5.2
Psychological stress	7	0.8
Unknown	80	8.7
Missing data	61	6.7
Level of disability		
Mild	65	7.2
Moderate	295	32.9
Severe	414	46.1
Totally disabled	123	13.7
Course of condition in last 2 years		
Considerable decline	181	19.8
Slight decline	152	16.6
Mixed course or no change	218	23.9
Slight improvement	225	24.6
Considerable improvement	137	15.0

^aTotal number of participants was 917.

Results

We received 967 surveys. Of these, 47 were incomplete and 3 were from children under age 18 years, yielding 917 usable surveys. Quantitative data were calculated using SPSS software (version 6.13; SPSS, Inc., Chicago, IL). Respondents' comments were read for content and themes regarding people's beliefs about recovering from MCS.

Quantitative data. When participants were asked what they believed to be the cause of their chemical sensitivity, 20.2% identified one large chemical exposure, 58.5% a series of low-level exposures, 5.2% a physical illness, 0.8% a psychological stressor, 8.7% did not know, and 6.7% did not answer the question. When asked who initially identified their MCS, 34% of participants reported identifying the problem themselves, 26% received diagnoses from health providers, 6% said the problem was identified by a friend or family member, 4% were helped by the media, and 29% said that it was some combination of the above. The course of their condition over the previous 2 years was described as evidencing a considerable decline by 20% of participants, a slight decline by 17%, mixed or no change by 24%, a slight improvement by 25%, and considerable improvement by 15%.

Only 23% of respondents were working outside of the home. Mean annual household income was \$46,000; mean personal income was \$20,000. For many, a substantial amount of this personal income was worker's compensation or disability income. Thirty-one percent of respondents (286 people) had been involved in a worker's compensation claim; 115 received compensation and 54 had cases pending. Fifty-five percent (505 people) had filed for Social Security disability; 376 received it and 38 had cases pending. Private disability was sought by 23% of respondents (or 206 people); 156 were granted and 13 had cases pending.

Participants had consulted a mean of 12 health care providers, but the mean number described as helpful was only 3. A considerable amount of income was spent on medical treatments. Participants had spent a mean total of \$51,000 on health care, \$7,000 in the past year. This means that 15% of their annual household income went to health care costs. In addition, respondents had spent a mean of \$57,000 in their attempts to create safe homes.

Treatments used by fewer than 25 respondents were excluded because of small sample sizes, leaving 101 treatments for analysis. Respondents had used a mean of 31.4 of these treatments, including 9.6 nutritional supplements, 5.6 environmental medicine techniques, 3.2 holistic therapies, 3.4 body therapies, 2.5 prescription items, 1.6 detoxification processes, 1 Eastern-origin technique, 0.3 newer therapies, and 4 therapies categorized as “other therapies.” Table 2 reports the number of respondents

who tried each treatment and their perceived efficacy ratings. We also computed a ratio for each treatment of the number of persons reporting help to the number reporting harm. Ratings of “no noticeable effect” were not included in this ratio. Treatments with the highest help:harm ratios have more positive and fewer negative effects, according to respondents' perceived efficacy ratings. For example, a ratio of 2 means that the treatment was rated as helpful by twice as many people as rated it harmful. Those with help:harm ratios < 1 were rated more likely to harm than help. Therefore, a ratio of only 0.25 would mean that the treatment was rated as helpful by only one-quarter of the number, or 25% of the number who rated it as harmful.

The three most highly rated treatments were creating a chemical-free living space, chemical avoidance, and prayer. Both creating a chemical-free living space and chemical avoidance were rated by 95% of people as helpful. The chemical-free living space was 155 times more likely to be rated as helpful than as harmful, and chemical avoidance was 119 times more likely to be rated as helpful than harmful. Prayer was 48 times more likely to be rated as helpful than harmful, with 94% of people rating it as helpful. Other therapies rated as highly effective and with help:harm ratios above 10 included rotation diet, air filters to prevent exposures, personal oxygen to cope with exposures, acidophilus, acupuncture, touch for health, reflexology, moving to a safer location, and meditation. Table 3 shows the 35 therapies with help:harm ratios \geq 5.

Therapies rated as more harmful than helpful with help:harm ratios of < 1 included provocation–neutralization (P-N) testing for chemicals with preservative, UltraClear, hydrogen peroxide, Microhydrin, all the antidepressants, antiseizure medications other than Neurontin, acyclovir, Valium, Xanax, and glutathione in a nasal spray (as opposed to a nebulizer). These therapies are listed in Table 4.

When we examined responses of participants who had used treatments long-term (5–11 months or more), most of the treatments ($n = 82$) fit a pattern of a decrease in harmful effects and an increase in helpful effects (although the amount of change varied). “No noticeable effect” ratings varied considerably. Chemical avoidance and a chemical-free living space shifted only slightly in ratings because these interventions were rated so highly that there was almost no room to improve.

Only four treatments did not fit the above pattern. One exception was P-N testing for chemicals with preservative, which increased in both harmful and helpful ratings with long-term use. The harmful effects of best chiropractic technique were eliminated; however, there was a 17.5% increase in “no noticeable effects,” bringing the total to 55.6%. Antibiotic therapy

for *Mycoplasma fermentans* showed an increase in “very harmful” ratings (an increase of 4% brought “very harmful” effects to 25.4%). “Somewhat harmful” ratings declined, however, and “very helpful” increased by 2.5%. Alexander technique ratings for “very harmful” increased by 1.8%, but “somewhat harmful” ratings decreased from 4.9 to 0%. Data from this analysis are available from the first author.

Interventions that were time-limited by nature, such as sauna therapy at a clinic and

relocating, were reassessed separately to examine how long both helpful and harmful effects endured. These results are presented in Table 5.

Mean number of treatments tried increased with level of self-reported severity of MCS. People with mild MCS reported using a mean of 24.8 (SD = 14.6) different treatments; moderate, 29.0 (SD = 14.2) treatments; severe, 32.6 (SD = 13.7) treatments; and those totally disabled, 37.0 (SD = 13.2) treatments.

A correlational analysis was conducted using total number of treatments tried, total number from each category, income, number of practitioners seen, number of practitioners helpful, and amount of money spent on health care as continuous variables. Course of illness was coded as a dichotomous variable for this analysis, with either a slight or considerable improvement over the past 2 years coded as 1, and a slight or considerable decline or mixed course as 0. An improved course of condition

Table 2. Perceived efficacy of 101 treatments tried by 917 persons with MCS.

	Number tried	Very harmful (%)	Somewhat harmful (%)	No noticeable effect (%)	Somewhat helpful (%)	Very helpful (%)	Help:harm ratio ^a
Environmental medicine and oasis techniques							
Chemical avoidance	875	0.5	0.3	4.7	38.0	56.5	118.6
Chemical-free living space	820	0.1	0.5	4.5	38.6	56.2	155.2
P-N for chemicals with preservative	159	22.0	18.1	25.4	27.1	7.3	0.9
P-N for chemicals without preservative	218	11.9	12.8	28.3	31.4	15.5	1.9
P-N without glycerin or preservative	178	12.5	8.3	25.0	30.2	24.0	2.6
Sauna at clinic	151	7.1	7.7	20.6	30.3	34.2	4.4
Sauna at home	245	7.1	11.4	19.6	38.8	23.1	3.4
Rotation diet	560	1.6	4.1	22.1	44.0	28.2	12.7
Air filter (to prevent exposure)	786	1.8	4.2	11.8	47.5	34.6	13.7
Charcoal mask	598	4.5	8.3	9.8	55.1	22.3	6.0
Aluminum foil to seal off-gassing	253	5.6	5.3	14.7	35.7	38.7	6.8
Personal oxygen to cope with exposures	326	2.9	4.4	14.2	39.8	38.6	10.6
Individual nutritional supplements							
Intravenous magnesium	175	4.2	6.8	25.5	40.6	22.9	5.8
Buffered vitamin C powder	516	4.0	8.8	29.4	37.3	20.5	4.5
Other vitamin C	683	2.8	6.7	38.8	35.3	16.4	5.5
Vitamin E supplements	709	2.1	5.1	53.1	29.3	10.3	5.4
Coenzyme Q10	517	2.5	5.8	51.4	28.8	11.5	4.9
Magnesium supplements	644	2.3	3.8	41.4	34.4	18.0	8.6
Calcium supplements	663	2.6	5.2	56.6	25.0	10.6	4.6
Chromium supplements	399	3.8	4.5	57.8	22.2	11.8	4.1
Other mineral supplements	666	2.0	5.7	43.4	35.0	13.9	6.4
Grapefruit seed extract	325	7.7	11.6	43.3	27.6	9.8	1.9
Echinacea	515	5.6	11.8	48.6	23.0	11.0	2.0
Goldenseal	299	5.8	13.5	48.4	21.5	10.9	1.7
Siberian ginseng	283	5.9	15.0	48.3	26.2	4.5	1.5
Milk thistle seed	458	3.2	6.5	41.6	33.6	15.1	5.0
Garlic	555	5.2	10.2	46.5	25.9	12.2	2.5
Acidophilus	661	0.9	3.2	44.0	32.8	19.2	12.7
DHEA	352	8.2	15.1	46.4	20.7	9.5	1.3
Thyroid supplements	406	3.8	8.4	39.8	28.1	19.9	3.9
Holistic therapies							
Homeopathy with homeopathic doctor	401	4.9	9.1	32.6	33.8	19.5	3.8
Over-the-counter homeopathy	425	4.0	6.8	36.6	40.1	12.6	4.9
Bach flower remedies	236	2.5	6.6	50.2	29.6	11.1	4.5
Acupuncture	422	3.9	6.3	36.0	32.5	21.3	5.3
Herbal medicines	650	4.2	7.6	24.5	41.8	22.0	5.5
Macrobiotic diet	182	13.5	15.1	24.0	33.3	14.1	1.7
Juicing	315	4.4	8.8	42.0	31.2	13.6	3.4
Aromatherapy	127	19.8	20.6	19.1	30.5	9.9	1.0
Chelation	131	11.0	13.2	27.2	31.6	16.9	2.0
Neural therapy	56	10.7	10.7	28.0	36.0	14.7	2.4
Detoxification							
Remove mercury dental fillings	425	3.1	6.1	47.1	27.3	16.5	4.8
Hulda Regehr Clark's parasite program	87	18.7	9.3	36.4	27.1	8.4	1.3
Coffee enemas	146	5.4	14.3	32.0	32.7	15.6	2.5
Colonics	222	4.8	8.4	28.2	38.3	20.3	4.4
Liver flushes	148	9.6	9.6	25.5	35.7	19.7	2.9
Gallbladder flushes	95	3.8	9.5	33.3	36.2	17.1	4.0
UltraClear	232	8.7	27.0	30.3	22.8	11.2	1.0
Hydrogen peroxide therapy	123	17.4	13.2	40.3	15.3	13.9	1.0
Eastern origin techniques							
Meditation	423	0.7	2.1	43.3	41.2	12.6	19.2
Yoga asans (postures)	260	3.0	5.9	41.9	37.4	11.9	5.5
Tai chi	154	3.2	9.0	54.5	21.8	11.5	2.7
Qi gong	109	3.3	6.5	40.7	36.6	13.0	5.1

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had a small positive correlation with number of treatments tried and strong positive correlations with all categories of treatments; the highest correlations were with nutritional supplements ($r = 0.112$, $p = 0.001$), holistic treatments ($r = 0.089$, $p = 0.007$), body therapies ($r = 0.069$, $p = 0.037$), detoxification techniques ($r = 0.066$, $p = 0.046$), and other treatments ($r = 0.041$, $p = 0.221$).

Course of illness had a small nonsignificant negative correlation with number of

practitioners seen ($r = -0.040$, $p = 0.236$), but a significant positive correlation with number of practitioners rated as helpful ($r = 0.101$, $p = 0.003$). Total money spent on care had an insignificant negative correlation with course of illness ($r = -0.042$, $p = 0.279$)

Qualitative data. Respondents wrote long descriptions of their efforts to cope with and recover from MCS. Several themes emerged repeatedly in respondents' descriptions of their views of the possibility of and requirements for

recovery. One fairly widely held view was that there is no treatment for MCS save for chemical avoidance. Persons commented on spending large amounts of money with no effect from any of the treatments tried and noted specifically that only avoidance was useful. These respondents seemed also to feel that it was a waste of resources to pursue numerous questionable treatments. Some of these respondents had actually tried very few treatments. Others may have developed this view after

Table 2. Continued.

	Number tried	Very harmful (%)	Somewhat harmful (%)	No noticeable effect (%)	Somewhat helpful (%)	Very helpful (%)	Help:harm ratio ^a
Body therapies							
Traditional chiropractic	498	2.2	6.1	47.4	31.8	12.5	5.3
Chiropractic with applied kinesiology	278	3.2	3.6	41.7	35.6	15.8	7.5
Network chiropractic	63	11.6	15.1	36.0	23.3	14.0	1.4
Chiropractic with contact reflex analysis	57	18.6	5.7	32.9	28.6	14.3	1.8
Best chiropractic	29	7.1	14.3	38.1	23.8	16.7	1.9
Applied kinesiology without chiropractic	191	7.1	5.6	32.0	34.0	21.3	4.4
Alexander technique	38	4.9	4.9	68.3	19.5	2.4	2.3
Trager	31	7.1	14.3	50.0	23.8	4.8	1.3
Reiki	170	2.7	4.8	44.6	34.4	13.4	6.4
Acupressure	308	1.0	3.5	28.3	46.0	21.2	14.9
Massage	501	0.8	7.9	32.5	39.4	19.4	6.8
Touch for health	75	2.5	1.3	41.8	35.4	19.0	14.3
Polarity balancing	117	3.3	4.9	45.9	29.5	16.4	5.6
Reflexology	204	2.4	2.4	38.5	43.4	13.2	11.6
Rolfing	60	7.8	14.1	35.9	26.6	15.6	1.9
Osteopathic adjustment	171	5.0	5.5	44.2	30.4	14.9	4.3
Craniosacral work	270	4.0	2.6	36.6	36.6	20.1	8.6
Total body modification	42	8.6	6.9	29.3	36.2	19.0	3.6
Newer therapies							
Mycrohydrin	57	10.8	15.4	53.8	10.8	9.2	0.8
Oxygen therapy	162	5.6	5.1	20.3	44.1	24.9	6.4
Eye movement desensitization and reprocessing	64	15.8	7.9	51.3	17.1	7.9	1.1
Neurolinguistic programming	37	8.8	2.9	64.7	17.6	5.9	2.0
Prescription items							
Nizoral	153	16	17.8	25.2	31.3	9.8	1.2
Nystatin	402	7.9	14.5	33.2	31.9	12.5	2.0
Diflucan	249	9.9	14.5	28.9	31.4	15.3	1.9
Prozac	183	37.6	21.5	25.8	9.7	5.4	0.3
Zoloft	148	45.5	22.7	23.4	5.8	2.6	0.1
Elavil	149	33.9	23.6	27.3	9.7	5.5	0.3
Other antidepressants	306	32.4	17.6	27.2	17.6	5.1	0.5
Neurontin	100	19.6	15.7	24.5	24.5	15.7	1.1
Other antiseizure medicine	76	37.6	12.9	24.7	16.5	8.2	0.5
Antibiotic therapy for <i>Mycoplasma fermentans</i>	38	17.4	13.0	21.7	21.7	26.1	1.6
Acyclovir (Zovirax)	68	19.8	13.6	40.7	18.5	7.4	0.8
Transfer factor	64	13.2	13.2	26.5	30.9	16.2	1.8
Valium	125	23.1	21.6	34.3	17.2	3.7	0.5
Xanax	134	25.0	20.8	27.8	19.4	6.9	0.6
Glutathione in nasal spray	54	16.2	17.6	35.3	25.0	5.9	0.9
Glutathione in nebulizer	33	18.0	10.0	22.0	26.0	24.0	1.8
Other							
Changed residence	513	2.9	4.5	6.0	42.3	44.3	11.7
Enzyme potentiated desensitization	61	19.1	10.3	17.6	20.6	32.4	1.8
Nambudripad desensitization	207	3.8	3.8	38.6	31.0	22.9	7.1
Magnets	265	11.1	9.0	48.4	20.4	11.1	1.6
Prayer	609	0.7	0.7	34.4	35.6	28.6	48.3
Faith healer	127	3.1	1.6	51.6	25.8	18.0	9.3
Exercise	763	4.3	10.4	23.7	40.3	21.3	4.2
Hypnosis	111	7.1	6.3	60.3	16.7	9.5	1.9
Psychotherapy to cure MCS	200	6.6	8.0	65.3	15.5	4.7	1.4
Psychotherapy to cope with MCS	362	3.8	7.0	24.1	47.7	17.3	6.0
Support group	520	1.5	7.2	15.5	42.3	33.6	8.7

^aRatio of number reporting help to persons reporting harm.

investing resources in numerous unsuccessful attempts to heal. This view was exemplified in the response from one woman who responded to the question “Are there treatments other than those listed above that you have tried?” with “There are others? God help us!” A considerable number of participants reported having no money to invest in treatment. Some who did have resources felt that to improve it was necessary to “do everything,” meaning that they combined chemical avoidance with a strict nutritional program and select holistic and/or conventional medicine techniques.

Some were critical of the view that there is no cure. One respondent said

For those who say “there is no cure,” I think of it in terms of someone who has an amputated leg, being offered a prosthetic, and saying well it’s not a real leg, no cure. I may not be “cured” but I am at a much better place than at my worst, and it shows me that the body can heal substantially, if given support.

A few gave very esoteric descriptions of using a series of little-known therapies and having perhaps not complete remission, but substantial improvement. Well-known MCS

doctors were mentioned and credited with improving respondents’ health, even to the extent of saving their lives. A small number of respondents had tried a great number of treatments to no avail, but still believed that their current therapy would be the one that made the difference. A few reported being healed in a religious manner.

One respondent’s description of MCS suggests Miller’s (1996) conceptualization of chemical sensitivity as a broad mechanism for disease rather than a discrete illness. The quotation seems to capture both the complexity and the seriousness of the impact of MCS upon the body:

I think MCS, like most health breakdowns, is probably best conceptualized not as a discrete “illness” or “disease” which can be mastered to X degree by particular “treatments”; rather it is a complex set of ways in which a person may break down if his [sic] life patterns are unhealthy in major ways. Noxious chemical exposures and other external stressors interact with one’s particular physical, mental, emotional, and spiritual habits and vulnerabilities to produce symptoms (discomfort; impaired functions). Getting healthier is much more global than just getting so-called treatments (usually mostly physical)—and of course physical healing may be severely restricted even with good new health habits if enough bodily damage has occurred.

These views correspond roughly with those held by various practitioners and members of the MCS community and represent different constructions of the problem of MCS.

Discussion

This research found that people are trying a large number of interventions for MCS and spending a large portion of their limited income on these treatments. Although number of treatments tried was positively related to an improved course of illness, total money spent and number of practitioners seen were not. The highest-rated therapies were fairly noninvasive and low risk. Consistent with earlier studies, creating a safe living space and chemical avoidance were rated as the most effective treatments for MCS. Lowest perceived efficacy ratings were given to prescription drugs and other higher-risk interventions. Although chemical avoidance at home through creation of a safe living space was low risk and rated effective, it did require a considerable financial investment (\$57,000 was the average investment).

When longer-term use of the treatments was examined, most treatments decreased in harmful ratings and increased in helpful ratings. This may have occurred because respondents may have discontinued the use of treatments not perceived as helpful. However, for some treatments, longer-term experimentation tended to reduce the “no noticeable effect” category; perhaps extended time is needed to decipher actual effects.

Table 3. The highest rated of 101 treatments.

Treatment	Number tried	Harmed (%)	No effect (%)	Helped (%)	Help:harm ratio
Chemical-free living space	820	0.6	4.5	94.8	155.2
Chemical avoidance	875	0.8	4.7	94.5	118.6
Prayer	609	1.4	34.4	64.2	48.3
Meditation	423	2.8	43.3	53.8	19.2
Acupressure	308	4.5	28.3	67.2	14.9
Touch for health	75	3.8	41.8	54.4	14.3
Air filter (to prevent exposure)	786	6.0	11.8	82.1	13.7
Rotation diet	560	5.7	22.1	72.2	12.7
Acidophilus	661	4.1	44.0	52.0	12.7
Relocation	513	7.4	6.0	86.6	11.7
Reflexology	204	4.8	38.5	56.6	11.6
Personal oxygen to cope with exposures	326	7.3	14.2	78.4	10.6
Faith healing	127	4.7	51.6	43.8	9.3
Support group	520	8.7	15.5	75.9	8.7
Craniosacral work	270	6.6	36.6	56.7	8.6
Magnesium supplements	644	6.1	41.4	52.4	8.6
Chiropractic with applied kinesiology	278	6.8	41.7	51.4	7.5
Nambudripad desensitization (NAET)	207	7.6	38.6	53.9	7.1
Aluminum foil to seal offgassing	253	10.9	14.7	74.4	6.8
Massage	501	8.7	32.5	58.8	6.8
Oxygen therapy	162	10.7	20.3	69.0	6.4
Reiki	170	7.5	44.6	47.8	6.4
Other mineral supplements	666	7.7	43.4	48.9	6.4
Charcoal mask	598	12.8	9.8	77.4	6.0
Psychotherapy to cope with MCS	362	4.5	24.1	65.0	6.0
Intravenous magnesium	175	11.0	25.5	63.5	5.8
Polarity balancing	117	8.2	45.9	45.9	5.6
Herbal medicines	650	11.8	24.5	63.8	5.5
Other vitamin C	683	9.5	38.8	51.7	5.5
Vitamin E supplements	709	7.2	53.1	39.6	5.4
Yoga asans (postures)	260	8.9	41.9	49.3	5.5
Traditional chiropractic	498	8.3	47.4	44.3	5.3
Acupuncture	422	10.2	36.0	53.8	5.3
Qi gong	109	9.8	40.7	49.6	5.1
Milk thistle seed	458	9.7	41.6	48.7	5.0

Table 4. Treatments rated more likely to harm than help.

Treatment	Number tried	Harmed (%)	No effect (%)	Helped (%)	Help:harm ratio
Zoloft	148	68.2	23.4	8.4	0.1
Prozac	183	59.1	25.8	15.1	0.3
Elavil	149	57.5	27.3	15.2	0.3
Other antidepressants	306	50.0	27.2	22.7	0.5
Valium	125	44.7	34.3	20.9	0.5
Antiseizure medications (other than Neurontin)	76	50.5	24.7	24.7	0.5
Xanax	134	45.8	27.8	26.3	0.6
Microhydrin	57	26.2	53.8	20.0	0.8
Acyclovir (Zovirax)	68	33.4	40.7	25.9	0.8
P-N for chemicals with preservative	159	40.1	25.4	34.4	0.9
Glutathione in nasal spray	54	33.8	35.3	30.9	0.9
UltraClear	232	35.7	30.3	34.0	1.0
Hydrogen peroxide	123	30.6	40.3	29.2	1.0

It is important to qualify that we asked specifically about whether a treatment actually improved or cured MCS. The fact that a treatment does not cure MCS does not mean that it does not provide symptomatic relief or support the patient's general physical state. In fact, many people noted in the qualitative comments that it was only the combination of treatments that helped them improve. Many reported that it was necessary to do environmental controls, a correctly tailored program of nutritional supplements, and a number of other interventions that addressed their own unique constellation of symptoms. Therefore, we do not advocate discontinuing treatments perceived to be helpful simply because they are not reported here to actually cure MCS. On the other hand, we did want to identify interventions with high harm rates, so patients can take that information into consideration when deciding where to allocate their time, energy, and financial resources.

The nonsignificant correlation between course of illness and number of practitioners seen may support the view that simply going from practitioner to practitioner is not curative. However, because correlation does not imply causation, those in downward health spirals may have felt a need to contact more providers. The significant positive correlation between number of practitioners rated as helpful and course of illness makes intuitive sense, though patients who are not currently in a downward slide may be easier to help and therefore more likely to rate their providers as helpful.

The results show primarily that a safe living space and chemical avoidance are reported by patients to be the most efficacious treatments for chemical sensitivity. Two relevant issues here are the difficulty of chemical avoidance and the lack of availability of safe housing. Because of the presence of toxic substances in virtually every environment, chemical avoidance requires substantial isolation. Persons wanting to preserve employment, social interaction, or any community involvement face the almost impossible nature of avoiding debilitating exposures. The understanding of chemical barriers is in its infancy, as is general

MCS research, so safe public spaces for the chemically sensitive are rare. Chemical barriers in the home are ever present as well. The use of toxic materials in buildings and the ubiquitous nature of chemical exposures render most living situations unsuitable for those with MCS. Gibson et al. (1996) found that 66% of their sample of 305 persons with MCS had lived in unusual conditions such as in their cars, in RVs, on porches, or in tents at some time during their illness. A housing survey done by the housing committee of the Environmental Health Coalition of Western Massachusetts found similarly that 10% of their sample of 49 persons with MCS were homeless at the time of the survey, and another 10% lived in situations such as campers, trailers, and cabins (Wachsler 2001). The housing problem afflicts those at lower income levels inequitably; the survey found that 47% of those with annual incomes of under \$12,000 had substandard or no housing. The housing committee also found that almost three-quarters of respondents had had to live in places that made them sick, and almost half had to spend beyond their means to remain in safe housing. A little over half (55%) considered their current housing to be safe. Gibson et al. (1996) found that only 41% of MCS respondents reported living in safe housing, whereas 44% said it should be better, 11% said it was mostly unsafe, and 5% said it was not at all safe. CIIN is currently investigating why people with MCS stay in unsafe housing. One theme that has emerged in the inquiry by CIIN is that some people attempt to compensate for unsafe homes with filters, supplements, and treatments (Wilson 2001). However, the ratings in this study clearly suggest that supplements and treatments do not compare in perceived efficacy to safe housing and chemical avoidance. Safe housing and chemical avoidance may therefore be more pertinent to MCS patients than treatment: The rated efficacy of even the most highly rated treatments was only a fraction of that of safe housing and chemical avoidance.

Limitations. Limitations of this study involved the use of computerized answer

sheets, the use of retrospective self-report surveys, the use of an unscreened convenience sample, a low response rate, respondents' concurrent use of multiple treatments, and the inclusion of persons who had tried the treatments for varying lengths of time. In addition, although we stored the surveys in baking soda before distribution, the answer sheets did not receive this treatment and were problematic for some people. This problem may not only have eliminated possible respondents, but interfered with participants' ability to answer questions clearly. As one respondent said "Do you know how hard it is to answer this survey with brain fog?"

Some data also were lost because of respondents' lack of familiarity with computerized forms and their choice of two or more answers for one question. For example, some people checked that a treatment was both helpful and harmful. These respondents may have been trying to report on multiple attempts of a treatment, multiple effects from a treatment, or treatment from more than one practitioner. However, multiple answers were unreadable by the computer and ultimately contributed to missing data.

In addition, respondents noted having difficulty separating effects of specific therapies when a combination of treatments was being used. Respondents may have also had other comorbid conditions, treatment of which could either hamper or augment treatments taken for the MCS.

The response rate for the study was low, with 917 persons out of about 4,000 responding. We do not know all of the self-selection factors that might have operated. Some nonrespondents reported that they had been away from their homes (and missed their mail) because their homes or neighborhoods had become unsafe for them during the window of time allotted for completion of the survey. For example, one person had left her home because of road construction and paving and had been living in a tent for several weeks. Therefore, persons unable to access their homes because of toxics would have been screened out of the survey. A number of other variables might have operated to screen persons either into or out of the study. In addition, it is not known whether persons not associated with support groups would respond similarly to the studied sample.

Statistical associations found through correlational analyses in this study need to be confirmed through further research. Some statistically significant associations may be due to a large number of participants and not meaningful.

Conclusion

Nonetheless, this work provides some information about the perceptions of MCS patients

Table 5. Length of helpful and harmful effects of time-limited therapies.

	No.	< 1 month (%)	1–3 months (%)	4–6 months (%)	7–12 months (%)	> 1 year (%)
Sauna						
Helped	74	20.3	17.6	13.5	14.9	33.8
Harmed	13	23.1	23.1	7.7	7.7	38.5
Nambudripad desensitization						
Helped	40	2.5	10.0	10.0	20.0	57.5
Harmed	4	0.0	50.0	0.0	25.0	25.0
Craniosacral						
Helped	75	45.3	21.3	6.7	4.0	22.7
Harmed	2	0.0	0.0	0.0	50	50
Changed residence						
Helped	170	4.7	6.5	8.2	12.4	68.2
Harmed	3	66.7	33.3	0.0	0.0	0.0

regarding a large number of interventions. Future research should attempt to address some of the limitations of this study while still making use of patient input. In addition, future research samples need to be more racially diverse. Despite the wide prevalence of MCS (Kreutzer and Neutra 1996; Meggs et al. 1996; Voorhees 1999) and its conceptualization as an emerging public health problem (Ashford and Miller 1994), progress in prevention and treatment of the condition has been minimal. It is important to find efficacious treatments that minimize the financial depletion of a population that has difficulty remaining in gainful employment.

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