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Measuring Adjustment to Illness in Persons with Multiple Chemical Sensitivity

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Abstract

This study examined adjustment to self-reported Multiple Chemical Sensitivity (hypersensitivity/illness relating to chemical odors) using the Psychosocial Adjustment to Illness Scale Self-Report (PAIS-SR). Respondents were a national sample of 305 volunteers who responded to requests for participants in newsletters, through support groups, and through physicians' offices. Respondents were 80% women, had a mean age of 46.8, and rated their level of chemical sensitivity on a Likert scale ranging from mild to totally disabled. The most disruption as measured by the PAIS-SR was evident on the social and vocational domains, and the least on extended family relations. Life disruption for this sample was associated with less education, no intimate relationship, lack of support from a partner, having a more severe physical condition, and working or living in an environment that continued to provoke symptoms. Age, gender, and length of illness did not significantly relate to total PAIS-SR scores. Some problems with the use of the PAIS-SR for this population may be the lack of an agreed upon medical treatment protocol for this population, and the lack of knowledgeable medical doctors to treat the condition.

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Introduction

The problem of self-reported illness from chemical odors has gained some attention in psychological and medical literatures recently [Ashford & Miller, 1991; Bell, Peterson, & Schwartz, 1995; Bell, Schwartz, Peterson, & Amend, 1993; Ziem & Davidoff, 1992], and some attention has been paid to possible causal mechanisms [Bell, 1992; Brodsky, 1983; Dudley, 1993; Heuser, Wojdani, & Heuser, 1992; Levin & Byers, 1992; Meggs, 1992; Meggs & Cleveland, 1993; Miller & Ashford, 1992; Randolph & Moss, 1982; Rea, 1992; Simon, Katon & Sparks, 1990].

Persons who self-report illness from chemicals to the extent that it interferes with their ability to carry out normal tasks or causes noticeable symptoms have been referred to as having Multiple Chemical Sensitivity (MCS), Environmental Illness (EI), Chemical Injury (CI), and other labels. Symptoms reported include headache, fatigue, difficulty concentrating, joint pain, irritability, and others, and reportedly occur to commonly encountered chemicals such as petrochemicals, pesticides, household cleaners, perfumes, and others [Ashford & Miller, 1991].

Persons who report these symptoms also report considerable life disruption as a result of having to avoid chemical exposures [Gibson, Cheavens, & Warren, in press]. This study was conducted to investigate adjustment to these reported difficulties.

Method

Participants

Participants are 305 persons with self-reported MCS recruited through a newsletter for MCS patients, support groups for persons with MCS, the Chemical Injury Information Network (CIIN) (an advocacy and education organization around chemical sensitivity issues), and physicians offices. Participants have a mean age of 46.8 years and are 80% women.

Measures

Adjustment was measured using the Psychosocial Adjustment to Illness Scale Self-Report (PAIS-SR) [Derogatis, 1986], a self-report scale tapping seven life domains including Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relations, Extended Family

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Relations, Social Environment, and Psychological Distress. The scale consists of 46 items and reliability varies depending upon illness group. Norms exist for lung cancer, renal dialysis, burn, hypertension, cardiac, and mixed cancer groups. Higher scores mean more life disruption.

Procedure

Volunteers responded to a total of 305 confidential mail questionnaires as part of an ongoing study of the life impacts of self-reported multiple chemical sensitivity. Participants were contacted through newsletters targeted toward persons with chemical sensitivity, support groups, and physicians offices. To preserve confidentiality, all identifying information was removed from surveys and each respondent was assigned a number.

Results

Overall PAIS-SR scores correlated significantly with level of education ($r = -.151$, $p = .008$), self-rating of severity of illness ($r = .356$, $p < .001$), and level of supportiveness of partner ($r = -.226$, $p = .001$), but not with gender ($r = .023$, $p = .692$), or length of illness ($r = -.013$, $p = .827$) (See table 1). Higher PAIS-SR overall scores were found in those who reported having to live in extremely unusual circumstances (such as tents or trailers) in order to avoid chemical exposures, $t = -3.46$ (263), $p = .001$, and in those not in romantic relationships $t(201) = 2.32$, $p = .021$ (See table 2).

Overall PAIS-SR scores were not significantly affected by having a physician educated about MCS, but Health Care Orientation Domain scores were (See table 3).

The life domains of Social Environment and Vocational Environment show the most disruption in this sample. Least disrupted is the Extended Family Relations subscale. Table 2

Analysis of variance indicated that PAIS-SR scores differed as a function of self-rated severity of illness, $F = 15.41$, $p < .001$ (See table 3). The Scheffe Multiple Range Test revealed that the severe and disabled groups had significantly higher PAIS-SR scores (indicating more disruption) than the mildly and moderately affected groups ($p < .05$).

The PAIS-SR has been used to measure adjustment in persons with illnesses that are better understood than MCS and for which there are established treatments, e.g., cancer,

diabetes. Most relevant to treatment and attitudes toward treatment is the Health Care Orientation subscale. Table 4 lists implied assumptions of the Health Care Orientation subscale, and, the possible problems that these assumptions may create in the case of MCS. Table 5 lists participants' responses to two items on this subscale. Table 6 illustrates sample items and responses from other subscales.

Discussion

Persons with self-reported MCS report considerable disruption in their Social and Vocational Environments. This is consistent with other studies of life impacts for those reporting this condition [Gibson, Cheavens, & Warren, in press]. The lesser disruption on the Extended Family Relations scale is consistent with findings of White, Richter, and Fry [1992] in a sample of 158 women diabetics.

Better adjustment on the PAIS-SR for this sample was associated with a higher level of education, more support from a partner, a less severe physical condition, a higher income, an improved course of illness, and having chemical-free environments both at home and at work. Age, gender, and length of illness did not correlate significantly with total PAIS-SR scores.

Even though this instrument has been used with persons reporting MCS [Fiedler, Maccia, & Kippen, 1992], some methodological problems were evident due to the assumptions underlying the PAIS-SR. For example, questions about medical treatment showed some missing data on questions that assume that adequate medical treatment exists for the condition measured. These results must be interpreted with caution given these assumptions, the lack of a precise definition of MCS, and the possible selection biases inherent in the use of a self-identified volunteer sample.

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Table 2
T-tests

Total PAIS-SR scores by relationship status

Mean score in intimate relationships	63.77
Mean score not in intimate relationships	69.25*

* A higher score indicates poorer adjustment.

t-value = 2.32 (df=300) p=.021

Those in relationships had better adjustment.

Total PAIS-SR scores by having lived in unusual circumstances or not

Mean score lived in unusual circumstances*	69.11
Mean score did not live in unusual circumstances	60.37

*Some persons reported having to live in highly unusual circumstances such as tents, cars, etc. due to inability to tolerate the chemicals in traditional housing, or having become homeless because of lack of resources.

t-value = -3.46 (df=263) p = .001

Those who had not had to live in unusual circumstances had better adjustment.

Health Care Orientation Domain Scores by having a doctor educated about MCS or not

Mean score had educated doctors	10.52
Mean score did not have educated doctors	13.67

t-value = 6.51 (df=299) p _ .001

Those with doctors educated about MCS had better health care adjustment.

Table 3
ANALYSIS OF VARIANCE FOR TOTAL PAIS–SR SCORES BY SELF–RATED LEVEL OF SEVERITY OF ILLNESS

<u>Level of Severity</u>	<u>Mean</u>	<u>SD</u>
Mild	54.44	21.73
Moderate	60.09	18.15
Severe	71.38	19.17
Disabled	75.27	15.40

Omnibus F = 15.41 p = .001

Scheffe Multiple Range Test

* denotes pairs significantly different at .05 level

	<u>mild</u>	<u>moderate</u>	<u>severe</u>	<u>disabled</u>
mild				
moderate				
severe	*	*		
disabled	*	*		

Table 4
PROBLEMS WITH HEALTH CARE ORIENTATION DOMAIN FOR MCS PATIENTS

<u>Assumption Made</u>	<u>Problem for MCS</u>
1) That adequate health care exists for the condition in question.	Most physicians are untrained in the area. There is no generally agreed upon treatment.
2) That a high score reflects a cynical attitude toward providers.	Recognition that one is being poorly cared for may be a sign of health for those with MCS.
3) That the patient has been given appropriate medical information about their condition by providers.	Since providers are untrained in this area, patients often must educate themselves.

note: 20% of this sample had no physician educated about chemical sensitivity.

Table 5
HEALTH CARE ORIENTATION INDIVIDUAL ITEMS

Question: In general, how do you feel about the quality of medical care available today and the doctors who provide it?

<u>Response</u>	<u>% answering</u>
a) Medical care has never been better, and the doctors who give it are doing an excellent job.	1.0
b) The quality of medical care available is very good, but there are some areas that could stand improvement.	40.9
c) Medical care and doctors are just not of the same quality they once were.	5.0
d) I don't have much faith in doctors and medical care today.	53.1

Question: During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?

<u>Response</u>	<u>% answering</u>
a) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.	18.8
b) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.	39.3
c) The treatment has been pretty good on the whole, although there have been a few problems.	34.2
d) The treatment and the treatment staff have been excellent.	7.7

Table 6
SINGLE ITEMS – OTHER DOMAINS

<u>Domain</u>	<u>Item</u>	<u>Responses</u>	
Vocational	Has your illness interfered with your ability to do your job?	a) no problems	1.7%
		b) some mild problems	15.9%
		c) serious problems	44.9%
		d) totally prevented from doing job	37.5%
Domestic	Have you experienced any physical disability with your illness?	a) no physical disability	6.6%
		b) slight physical disability	18.2%
		c) moderate disability	35.8%
		d) severe disability	39.4%
Social	Do you still participate in social activities (social clubs, church groups, movies, etc)?	a) little or none	51.6%
		b) reduced significantly	30.6%
		c) reduced slightly	12.8%
		d) remains unchanged	4.9%

Table 7

DOMAIN ITEM MEANS FOR PAIS-SR

range 0–3 with higher score = more disruption

<u>Domain</u>	<u>Item Mean</u>	<u>SD</u>
Health Care Orientation	1.43	.50
Vocational Environment	1.84	.77
Domestic Environment	1.55	.59
Sexual Relationships	1.26	.75
Extended Family Relationships	1.06	.71
Social Environment	1.72	.69
Psychological Distress	1.32	.66