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Social Support and Attitude Toward Health Care Delivery as Predictors of Hope
in Multiple Chemical Sensitivity

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This research was supported in part by a James Madison University 1993 Faculty Summer Research Grant.

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Key words: Hope/Multiple Chemical Sensitivity/Chemical Injury

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Summary

• This paper examines hope as measured by the Herth Hope Scale, and its predictors in a sample of 305 persons self-identified with multiple chemical sensitivity. • The sample had relatively low levels of hope with scores unrelated to gender, severity or length of illness, income loss as a result of illness, or reported iatrogenic harm. • Hope scores were positively correlated with perceived social support, having found personal growth through illness, age, reported level of supportiveness from a partner, an improved course of illness, and level of reported safety of the home environment in regard to chemical exposures. • Negative correlations were found with attitude toward health care delivery, fatigue, and reported abuse/ostracism from family members other than partner. • Social support, Health Care Orientation, growth through illness, fatigue, and age predicted hope scores accounting for 55% of the variance. Implications and suggestions for future research are discussed.

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Introduction

Multiple chemical sensitivity (MCS), environmental illness (EI), chemical injury (CI) and other terms refer to conditions in which persons report negative symptoms in response to exposures to common chemicals. Symptoms reported differ in focus and intensity depending upon the type or duration of exposure, but share the characteristics of disabling and limiting the person's access to environments where such exposures might occur. Symptoms reported may affect any organ system including respiratory, digestive, cardiovascular, neurological, and musculoskeletal, and often include headaches, fatigue, joint pain, dizziness, depression, tension, increased or decreased heartrate, confusion, or muscle spasms (Ashford & Miller, 1991; Lewith & Kenyon, 1985; Randolph & Moss, 1982). Medical controversy surrounds the appropriate label for the condition, validity of complaints, causes of reported symptoms, indicated treatment, and concessions/benefits deserved by patients.

Hypotheses regarding causality involve immune system dysregulation (Levin & Byers, 1992; Meggs, 1992), damaged detoxification pathways (Rea, 1992; Rogers, 1990), "kindling" through the olfactory-lymbic system (Bascom, 1989; Bell, 1982, 1992; Miller & Ashford, 1992), vascular damage (Rea, 1992), and psychosomatic mechanisms (Black, Rathe, & Goldstein, 1990; Brodsky, 1983; Simon et al., 1990).

Biological substrates/markers of chemical sensitivity/chemical injury discovered to date include immunological abnormalities (Heuser et al., 1992); neurological abnormalities including abnormal EEG and abnormal MRI (Heuser et al., 1992), and abnormal evoked potentials in response to chemical challenge (Dudley, 1993); lack of viable detoxification pathways (Rogers, 1990); nasal abnormalities (Meggs & Cleveland, 1993); measurable blood levels of pesticides (Rea et al., 1992); low excretion of essential amino acids (Galland, 1987); and autoimmune disease (Heuser et al., 1992; Levin & Byers, 1992).

Research on physiological substrates is still in early stages, and controversy revolves around the tendency of some health providers to dismiss MCS as a psychosomatic disorder. Although MCS is recognized in the USA by the Social Security Administration, the department of Housing and Urban Development, the Americans with Disabilities Act, and many other state and local agencies, there is currently no official recognition or agreed-upon treatment protocol for this condition by the American Medical Association.

However, despite the unclear basis for the problem and lack of official recognition, this condition appears to be more widespread than previously thought. Many persons report suffering from low level chemical exposures. Meggs et al., (1996) found that one third of a rural household population sample reported becoming ill from chemicals, and 4% experienced this illness on a daily basis. Given this lack of recognition and the experience of unvalidated illness, one would expect to find some serious distress on the part of persons with MCS. In fact, the few studies that have addressed life indicators in MCS show that persons who self-report having MCS experience some accompanying serious life disruption (Gibson, Cheavens, & Warren, 1996; Miller & Mitzel, 1995; Rippere, 1983). Gibson et al. (1996) found that persons with MCS reported serious disruption in finances, social relationships, work, hobbies, access to public buildings, education and medical care. In addition, respondents cited disbelief and ostracism from others as particular stressors that engendered personal distress. Given these initial findings, it seems important to examine indicators of quality of life for this population, and to ask what variables enable some persons to continue to cope without despair with such a poorly understood condition.

Hope has often been used as an index of well-being among persons with chronic illness (Foote et al., 1990; Herth, 1991; Ralieggh, 1992). Staats (1989) has defined hope as "future referenced events that are wished for, have positive affect and have some cognitively perceived probability of occurrence" (p. 366). Miller & Powers (1988) characterized hope as an "anticipation for a continued good state, improved state, or relief from a feeling of perceived entrapment." Herth (1991) conceptualized hope as a multidimensional construct, containing

both global and specific dimensions (Dufault & Martocchio, 1985), and including experiential, spiritual/transcendent, rational and relational attributes. Farran, Herth, & Popovich (1995) have said:

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present. (p. 6)

Farran et al. (1995) distinguish between untested or unchallenged hope and a deeper hope that has survived trial and suffering, making the point that it is this deeper and tested hope that sustains persons in times of tremendous personal difficulties such as chronic illness.

Farran et al. (1995) believe that hope is an important coping strategy for those with chronic illnesses, and suggest that hope can be emotion-focused, problem-focused (i.e., the rational aspects of hope), or represent cognitive reappraisal as a coping strategy. The authors argue for better inclusion of hope as a variable in the stress and coping literature, citing clinical/biographical writings as indicators of hope's general importance, and a growing body of work suggesting that hope is associated with increased immune function when discussing its clinical outcomes.

Hope may be particularly important in conditions such as MCS, as sufferers report experiencing widespread impacts upon their personal resources, lifestyles, and social relationships (Gibson et al., 1996; Miller & Mitzel, 1995). The present study was conducted to determine levels of and predictors of hope in persons with a condition of uncertain cause and prognosis, and for which very little treatment is available. The study was designed to explore the relationship to and relative contribution of demographics (including age, gender, income, and income loss since illness), illness characteristics (length, severity, and course of condition), support from others (perceived social support, reported level of support from a romantic partner, and report of abuse or ostracism from family members other than partner), variables related to medical treatment (attitude toward health care and self-reported iatrogenic harm), an

attitudinal variable (having found personal growth through illness), an environmental variable (self-reported safety level of the home in regard to chemical exposures), and a fluctuating illness/situational variable (fatigue level at the time of data collection). It was hypothesized that persons with MCS would demonstrate low levels of hope and that predictors of hope may be subject to some unique characteristics of this condition. Given that social ostracism is reported by many with MCS (Gibson et al., 1996), and that the lack of caring others has been identified by the acutely ill as a threat to hope (Miller, 1989), it was hypothesized that social support would be an important predictor of level of hope. Illness characteristics were included as exploratory variables because they have often been excluded from previous research (Farran et al., 1995). Attitude toward medical delivery was included due to the lack of available medical care at this juncture for MCS, and it was hypothesized that the paucity of knowledge or help available would contribute to lower levels of hope. Safety level of the home is important in MCS, as those physicians who do specialize in and treat MCS recommend excluding chemicals from the home as a way of reducing chemical exposure (Ziem, 1992). Fatigue level was included due to its presence in many serious illnesses, and because it is a primary symptom in MCS (Bell et al., 1993; Lax & Henneberger, 1995).

Method

Participants

Participants were 305 self-identified persons with multiple chemical sensitivities contacted through newsletters, a national publication, support groups, physicians' offices, and the Chemical Injury Information Network (CIIN), an advocacy/educational organization working on the issue of chemical injury. Newsletter and publication advertisements asked volunteers to contact the author's laboratory to participate in the study. Leaders of MCS support groups gave out questionnaires at meetings. Members of CIIN were mailed questionnaires directly with requests to participate. Participants were 245 women and 60 men (92.8% Caucasians, 4.9% Native Americans, 1% Latina/Latino descent, and 0.7% Asian Americans), with a mean age of

46.8 years ($SD=10.67$; range = 23 to 79 years).

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Procedure

Volunteers returned a total of 305 questionnaires in time for analysis. To assure confidentiality, each participant was assigned a number, with names available only the investigator. The 288 respondents who volunteered to participate in further research were mailed an additional questionnaire six months later, and 268 returned information in time for analyses. Some variables (including the hope data) are therefore based on the initial N of 305, and others have an N of 268.

Measures

Questionnaires included measures of hope, social support, adjustment to illness, and various demographic and open-ended questions. Hope was measured with The Herth Hope Scale (HHS) (Herth, 1991), which measures affective, cognitive, behavioral, affiliative, temporal, and contextual dimensions of hope. The scale consists of 30 items scored on a 4-point Likert scale. Coefficient alpha in samples of cancer patients, well adults, well older adults, and older widows has ranged from .75 to .94. Test-retest reliability has ranged from .89 to .91 (Herth, 1991).

Social support was measured by part 2 of the Personal Resource Questionnaire 85 (PRQ85) which contains 25 items rated on a 7 point Likert scale (Weinert, 1987). Internal consistency (coefficient alpha) measured .90 with 333 white middle class adult participants (104 women, 229 men) with a mean age of 44.2 (Weinert & Tilden, 1990). Additional support measures were level of supportiveness of a romantic partner (if present), and reported level of ostracism or abuse from family members other than partner.

Attitude toward health care was measured by Health Care Orientation subscale of the 46-item Psychosocial Adjustment to Illness Scale Self Report (PAIS-SR) (Derogatis, 1986). While the PAIS-SR measures seven domains including Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relations, Extended Family Relations, Social Environment, and Psychological Distress, only the Health Care Orientation domain score will be discussed in this

paper. In addition, respondents were asked about perceived iatrogenic harm from either medical or psychological interventions.

Other variables measured were age, income, income loss since developing MCS (demographic variables), length, severity, and course of condition (illness characteristics), reported personal growth through illness (an attitudinal variable), self-reported safety level of the home in regard to chemical exposures (an environmental variable), and fatigue level at time of data collection. Fatigue, reported safety level of the home, and level of supportiveness of partner were all measured by single-items on 5-point Likert scales with high scores indicating greater fatigue, a safer home, and more support from partner respectively. Severity of condition was measured on a 4-point Likert scale. Participants were asked to read descriptions of progressively worse levels of chemical sensitivities (adapted from "E.I. Disability" 1987; see appendix), and to categorize themselves according to the best fit. For the purposes of this analysis, the variable measuring support from partner was dichotomized with those who rated their partners as either somewhat or very supportive coded as 1, and those who rated their partners as less supportive and those who did not have partners coded as 0. Abuse/ostracism from family was a dichotomous variable with those reporting abuse coded as 1 and those not reporting abuse coded as 0. Course of illness was coded into a dichotomous variable also. Those who reported an improvement in their condition were coded 1 and those who had become worse over time or stayed the same were coded 0. Income levels were reported in U.S. dollars. Perceived iatrogenic harm was asked about in open-ended questions and then coding schemes were devised to reflect the number and level of reported negative experiences with treatment. Examples of reported iatrogenic harm included having experienced negative reactions to drugs, being given inappropriate treatment as a result of misdiagnosis (including surgery), and having had symptoms of chemical sensitivity ignored by practitioners. Length of illness was reported in years.

Analyses

Variable relationships were first explored through correlation analysis. A stepwise multiple regression analysis was then conducted to explore the relative contribution of theoretically related variables that were statistically significantly correlated with hope. Four continuous variables and four dichotomous variables were thus subjected to a regression analysis with hope as measured by the Herth Hope Scale as the dependent variable.

Results

Mean level of hope in 305 respondents as measured by the Herth Hope Scale was 65.8 ($SD = 14$). Herth has reported means of 80 ($SD = 7.1$), 72 ($SD = 6.3$), and 54 ($SD = 5.6$) in adult well, older adult, and elderly widowed populations respectively. Respondents in this study showed more variability overall, but as a group had low levels of hope that surpassed only the hope level of elderly widowed people. Thus the hypothesis that respondents would demonstrate low levels of hope was supported. There were no significant differences in hope as a function of gender. Women reported a mean of 66.45 ($SD = 13.98$); men reported a mean of 63.42 ($SD = 15.53$) $t=1.47$, $p = .141$. Hope scores correlated significantly positively with social support as measured on the PRQ85, reported level of support from a romantic partner, finding personal growth through the illness, age, an improved course of illness, and level of reported safety of the home environment in regard to chemical exposures. Interestingly, an improved course of illness was also positively correlated with a safer perceived home environment ($r = .18$, $p = .001$). Negative correlations emerged between hope levels and the Health Care Orientation subscale of the PAIS-SR that addresses attitude toward medical treatment (where a higher score means poorer adjustment), fatigue level at the time of data collection, and reported abuse/ostracism from family members other than partner (See table 1.) Variables that did not correlate significantly with hope included perceived severity of illness, number of years ill, level of reported iatrogenic harm from medical or psychological providers, income levels, or amount of income loss since becoming ill. Strongly correlated variables were included in a stepwise multiple regression, and accounted for 55% of the variance. Entering the equation were PRQ85

score (accounting for the largest amount of variance), Health Care Orientation Score on the PAIS-SR, fatigue level at time of data collection, perceiving growth through illness, and age (see table 2). Safety level of the home did not enter the equation, but is listed on table 2 because it contributed some marginal variance. Course of illness, abuse from family, and having a supportive partner did not contribute additional significant variance.

Discussion

One support variable (perceived social support), one medical variable (Health Care Orientation subscale score), one illness/situational variable (fatigue level), one attitudinal variable (having found personal growth in illness), and one demographic variable (age) contributed significantly to the construct of hope. Safety level of the home was marginal.

Perceived social support contributed most of the variance. This is consistent with the findings of Foote et al. (1990) who found that social support correlated 0.6846 with hope ($p < .001$).

The direction of the relationship between social support and hope in MCS is not clear. Social support may be instrumental in inspiring hope, persons with high levels of hope may have more "drawing power" in terms of social interaction (Foote et al., 1990), or it is possible that both social support and hope are accounted for by other attitudinal variables.

Relevant to these variables is work by Ralieggh (1992) with cancer patients which found that the majority of patients reported thinking positively about their illness, but did report transient periods of losing hope. They coped with these periods by using family, religion and friends, supports often reported to be denied those with MCS. Although many respondents in this study reported relying heavily on their spirituality as a coping mechanism, they were likely to report that actual access to church and the church community was denied to them because of the accompanying perfumes and other chemicals in the church environment. Respondents reported that family and friends became unavailable to them as well because they either did not believe that chemicals were causing the person's symptoms, or they were unwilling to make the requested accommodations (e.g. refraining from wearing perfume).

Greene et al. (1982) have said that a patient's ability to "sustain a hopeful outlook in the face of illness implies that they ignore or suppress certain aspects of reality" (p. 592-593). This may be exceedingly difficult in MCS, as chemical exposures, limitations in access, and skepticism of others are commonplace experiences. Attitude toward health care is complicated in a condition that is misunderstood, currently the subject of controversy, and treated only by subgroups of physicians. Respondents in this sample had fairly high scores on this portion of the PAIS-SR, reflecting high disruption in their confidence in the medical establishment and in their own treatment. This is not surprising given the current state of knowledge regarding chemical sensitivity, and given the fact that respondents reported being sick for a mean of seven and a half years before their condition was identified. Many respondents expressed considerable anger at having spent large sums of money, endured expensive and intrusive medical tests, and seen a large number of practitioners before receiving a diagnosis. Others felt that in spite of the fact that little is currently understood about MCS, they at least had the best help available. The fact that attitude toward health care was second only to social support in the regression equation argues for the importance of the availability of improved medical care for this population.

It is not surprising that fatigue entered the equation, given the struggles reported by respondents in relation to managing their energy levels, and the overlap of MCS with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) reported in the recent literature (DeLuca, Johnson, & Natelson, 1994).

Growth included having been able to find some kind of personal growth or development as a result of coping with MCS, and may also be part of a general attitudinal disposition that includes positive expectations, the feeling of being cared for, and the ability to grow from adversity.

Age is an interesting variable in this study, as it was negatively related to hope. Although hope scores have been found to decrease with age (Staats & Stassen, 1986), or be unrelated to age (Foote et al., 1990), in this study, persons who were younger had lower levels of hope. This may be because participants who reported becoming sensitive to chemicals later in life reported

on open-ended questions having to sacrifice retirement plans, while persons who sensitized at a younger age reported losing a lifetime of ability to work, with its ensuing long-term economic and social consequences.

Reported safety level of the home did not enter the equation, but did contribute some marginal variance. Fatigue level was significantly negatively related to safety level of the home ($r = -.1912$, $p = .001$), meaning that a safer home was associated with a lower level of fatigue. Chemical avoidance is prescribed for this population by a number of physicians, and the importance of constructing a safe environment for those who have serious sensitivities to chemicals has been discussed in the literature (Ashford & Miller, 1991; Randolph & Moss, 1982; Rogers, 1986, 1990; Ziem, 1992). The discussion of this variable is necessarily speculative given the paucity of research on this topic. Nevertheless, it may be an important variable for respondents. Perhaps a chemically less contaminated environment, by providing the prescribed chemical avoidance, provides a base from which persons can begin to take control of their lives by reducing symptoms. This in turn may lower anxiety, improve well-being, and thus provide some hope for recovery.

Social support, attitude toward health care, and personal growth attitudes might be expected to be related to hope in any condition of ill-health in a manner similar to that in this sample. Age and safety level of the home, however, are probably more unique to the condition of MCS, with age operating in an unexpected direction and safety level of the home being unique to this health condition. Environmental medicine specialists heavily emphasize the need for a chemical-free home environment (Ashford & Miller, 1991; Randolph & Moss, 1982; Rogers, 1990; Ziem, 1992), and the present study (which found a positive correlation between a safe home and an improved course of illness, and some contribution of a safe home to hope) suggests that this practice is helpful.

The low levels of hope and negative attitudes toward medical services in this sample may reflect the frustration of persons who report experiencing a condition for which there is

currently no agreed upon definition, no accepted cause, and wide controversy regarding treatment. Both medical and psychological research should address the needs of this population. 13

In addition, health care providers can use these findings to begin to understand the support needs of this population. These persons often find their way to mental health practitioners either through self or physician referral, and present with a unique constellation of needs. For a more detailed discussion of these needs and counselling suggestions, see Gibson et al. (1996). Although this work is preliminary, it suggests that until more is known about this condition, practitioners may help foster a sense of hope in clients through bolstering social support, helping them find what appropriate medical help may be available, encouraging them to learn from and grow through a difficult experience, and supporting the client's creation of a safe home. Clinicians can also be aware that this condition may be more disruptive for younger persons who have not yet established careers or acquired advanced training because of the limitations present when one is attempting to avoid chemicals. Adjusting to a loss of lifetime ambitions and the inability to become financially secure may be more difficult than perceiving oneself as having a disability later in life.

This study should be seen as exploratory work aimed at examining variables associated with hope in self-identified persons with MCS. No claim of representativeness of sample can be made, as respondents were volunteers and self-identified, and there is currently no widely accepted definition of this condition. Variables were measured as self-perceived by respondents, which is both a strength and a weakness of this research. In addition, not all variables possibly related to hope were examined. For example, no spiritual variables were included. Future studies should examine philosophical and spiritual variables, use more clearly defined populations, and attempt to examine in more detail the questionable directionality of the relationship between social support and hope. This is cross-sectional work, and statistical relationships that emerged should be viewed with caution and verified through longitudinal research.

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Workshop on Multiple Chemical Sensitivity.

Acknowledgement

I thank Arnold Kahn for his helpful comments on an earlier version of this manuscript.

Table 1

Statistically significant correlations between predictor variables and hope scores

<u>Variable</u>	<u>Correlation</u>	<u>n based on</u>
PRQ85	.71***	305
PAISMED	-.35***	305
Age	.12*	304
Fatigue	-.26***	305
Growth	.20***	297
Homesafe	.27***	303
Course	.17**	305
Abusefam	-.14*	257
Partsup	.31***	203

* $p < .05$; ** $p < .01$; *** $p < .001$

Note. PRQ85=Score on Personal Resource Questionnaire measuring perceived social support.

PAISMED=score on Health Care Orientation subscale of the PAIS-SR measuring attitude toward medical services. Growth=finding personal growth in illness. Age=age in years.

Homesafe=reported level of safety of home environment. Fatigue=fatigue level at time of data collection. Course= reporting improvement in course of illness. Abusefam=reported abuse/ostracism by family other than partners. Partsup=reported level of supportiveness of romantic partner.

Table 2

Summary of Stepwise Regression Analysis for Variables Predicting Hope as Measured by the Herth Hope Scale for Self-Identified Persons with MCS (n=305)

Variable	Multiple R	R ²	R ² change	beta	F	Sig F
PRQ85	.71	.50	.50	.63	193.38	.00
PAISMED	.72	.52	.02	-.11	7.08	.01
Fatigue	.73	.53	.01	-.11	6.72	.01
Growth	.74	.54	.01	.10	5.75	.02
Age	.74	.55	.01	.10	5.21	.02
Homesafe				.08	3.18	.08

Note. PRQ85 = Social Support as measured by the Personal Resource Questionnaire 85.

PAISMED = Health Care Orientation score from the Psychosocial Adjustment to Illness Scale.

Growth = reported personal growth from the experience of coping with MCS. Fatigue = level of fatigue at time of data collection. Age = age in years. Homesafe = level of perceived safety of home environment in regard to chemicals.

Severity of Condition Measure for MCS*

Class I: Able to work. Frequently has many symptoms, some of vague nature. May find petrochemicals and other environmental exposures such as auto exhausts, cigarette smoke, and cleaning materials to be unpleasant or produce uncomfortable feelings but able to work effectively.

Class II: Able to work at home or with controlled environment at work place. May have to use gas mask or charcoal mask and air purifier filter system. Exposure to inciting agents causes acute symptoms which may alter functional capacity (severe headache, muscle pain, poor concentration, memory loss, etc.). May have to change job or work conditions if environmental pollution is severe enough.

Class III: Unable to work effectively, even with environmental control, using avoidance, masks or filters. On some days, may be able to work 30 to 60 minute shifts several times a day if in a very controlled environment. Reacts to chemicals such as insecticide, phenols, chlorine, formaldehyde, perfume, petro-chemicals, etc. Has severe mental and physical symptoms which may or may not clear. Public exposures such as church, post office, movie or shopping are not tolerated. Visitors to home must clean up significantly. Can usually care for self in a home situation. May be able to drive if automobile made free of inciting agents, sealed, and has charcoal air filters. Has difficulty with other family members or guests in home who bring in aggravating exposures on clothing, printed material, hair, etc. Adversely reacts to any medication. May have to move if existing home has uncontrollable outdoor pollution, is new and has not outgassed, or has other significant problems of mold, flooring, or other incitants. Requires a clean room, carpet-free, cleared of inciting agents, special heating and air filtering.

Class IV: Totally disabled. Requires assistance to function in rigidly controlled home environment. Reactive symptoms have spread to virtually all environmental agents including chemicals, foods, pollens, and molds. Has mental and physical symptoms that are incapacitating, although frequently not structurally described. Total and very restrictive environmental control required in home and vehicle. Cannot tolerate family or help who have outside exposures with even small contamination of clothing or hair with odors. Visitors usually are too toxic to be tolerated indoors. Usually requires several moves to different areas of the country to find tolerable climate which is also chemical free. May require unusual and extensive measures to make a tolerable clean refuge area to sleep in. Has difficulties with virtually everything in environment.

* Adapted from "E.I. Disability Classification" (The Human Ecologist, 1987, No. 35, P. 13.).

Material relating to food sensitivities was deleted.