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Life Satisfaction in Persons with Invisible Disabilities:
Chemical Sensitivity/Chemical Injury

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Abstract

Multiple Chemical Sensitivity (MCS), which involves illness reactions to low levels of chemicals in ambient air, can affect any organ system and cause varying levels of disability. Life satisfaction was explored in 209 persons with self-reported MCS using three measures, the Satisfaction with Life Scale, the Life Satisfaction Index Z, and the Congruity Life Scale. Participants had low mean scores on all three measures, and women had higher life satisfaction scores on two of the measures than did men. Reasons for low life satisfaction in this population are discussed in terms of the losses experienced by those who have MCS, and suggestions are made for service delivery and policymaking in order to protect those who have MCS and to prevent further spread of this condition.

Life Satisfaction in Persons with Invisible Disabilities: Chemical Sensitivity/Chemical Injury

The problem of multiple chemical sensitivity (MCS), also known as environmental illness (EI), and chemical injury (CI), has recently gained some attention and caused considerable controversy in the medical literature. This condition involves reports of illness reactions to low levels of chemicals in ambient air (Ashford & Miller, 1991). Symptoms reported vary in intensity from aggravating to life-threatening, and can affect any organ system including respiratory, cardiovascular, digestive, endocrine, or neurological. The most commonly reported incitants include perfume, pesticide, paint, new carpet, and auto exhaust (Bell, Schwartz, Peterson, & Amend, 1993). Bell et al. (1993) found that 66% of college students reported feeling ill from at least one of these chemicals, and 15% reported that four of these chemicals made them ill. In fact, Meggs, Dunn, Bloch, Goodman, & Davidoff (1996) found that 4% of a rural household population sample reported becoming ill from chemicals on a daily basis.

Despite the seeming widespread nature of this problem, there are more medical hypotheses than results concerning the mechanism or etiology of MCS. In preliminary studies MCS samples demonstrate immunological problems (Heuser, Wojdani, & Heuser, 1992), increased airway resistance (Meggs & Cleveland, 1993), neurological problems including reduced bloodflow to the brain during chemical exposure (Dudley, 1993; Heuser et al., 1992), damaged detoxification pathways (Rogers, 1990), and pesticides in the blood (Rea et al., 1992).

Though Gulf War veterans display symptoms of MCS (Miller, 1994), for reasons that are not understood most civilians with MCS appear to be women (Cullen, Pace, & Redlich, 1992; Gibson, Cheavens, & Warren, 1996; Heuser et al., 1992; Kipen et al., 1992; Meggs et al., 1996; Ross, 1992). Therefore, the patriarchal nature of the health care system complicates what is already a complex and poorly understood problem.

Research on life impacts/life indicators in MCS has been scater than medical research, but the few studies completed have found that persons with MCS report difficulties in relation to access, finances, social support, work, travel, hobbies, and family relations (Gibson et al., 1996; Gibson, Cheavens, & Warren, under review; Rippere, 1983). Because the research has been so limited, we know little about the psychosocial aspects of this poorly understood health condition for which there is no agreed upon treatment, and about which there is little public understanding.

Quality of life has been described as including the three components of positive and negative affect and life satisfaction, with life satisfaction understood as the cognitive component (Diener, 1984). Quality of life is predicted by both objective measures and psychological ones, with psychological variables often mediating the effects of the objective measures. For example, Burckhardt, Woods, Schultz, & Ziebarth (1989) found that self-esteem, perceived control over

illness, negative attitude toward the illness and perceived support were important mediating variables in women with arthritis. Stock and Okun (1982) found lower scores among handicapped elderly than nonhandicapped on a measure of life satisfaction. Burckhardt et al. (1989) found that severity of impairment was associated with quality of life in arthritis, while sex and SES were not.

Purpose

The purpose of this study is to examine life satisfaction, a component of quality of life, in persons with the invisible disability of MCS. The goal of this study is to examine life indicators using instruments validated in the study of other illnesses. Objectives are to contribute to the understanding of life impacts of MCS, and to educate researchers and health providers about psychosocial concomitants of this condition. In this study we were interested in the relationship of life satisfaction to environmental and health variables particular to MCS.

Method

Participants

Respondents are 209 persons with self-reported multiple chemical sensitivity, 82% women, primarily Caucasian (91.9%), and including 10 Native Americans, 2 Latinas, and 2 Asians. Persons were contacted through advertisements placed in publications written for persons with MCS, through support groups and physicians offices, and through national advocacy and educational groups geared toward chemical-related illness.

Measures

Respondents completed questions about demographics, the illness characteristics of severity, length, and course of illness, one question designed to explore leisure satisfaction, and three measures of life satisfaction — the Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985), the Life Satisfaction Index Z (LSIZ) (adapted from Neugarten, Havighurst, & Tobin's 1961 Life Satisfaction Index A by Wood, Wylie, & Sheafor, 1969), and the Congruity Life Satisfaction Measure (CLS) (Meadow, Mentzer, Rahtz & Sirgy, 1992) .

Satisfaction With Life Scale. Diener (1984) believes that life satisfaction measures should be global and not include comparison standards, as persons should base their judgements of satisfaction upon their own internal standards. The SWLS is therefore not domain specific, and consists of five general items scored on a 7-point Likert scale with possible total scores ranging from 5 to 35 (Diener, Emmons, Larsen, & Griffin, 1985). Arrindell, Meevvesen, & Huyse (1991) found an internal consistency of .87. Test-retest reliability was measured at .82 for a two month interval in 176 undergraduate students (Diener et al., 1985).

The SWLS correlated only .02 with the Marlowe-Crowne, suggesting that it is not tapping social desirability (Diener et al., 1985), .50 with Bradburn's Positive Affect Scale (PAS), -.37 with Bradburn's Negative Affect Scale (NAS), and .68 with Andrews and Withey's Delighted-Terrible scale (Diener et al., 1985). It showed a moderately strong positive correlation of .54 with

Rosenburg's Self-Esteem Scale (Diener et al., 1985). Arrindell et al. (1991) found no significant correlation with sex, age, or educational level, but did find a significant correlation with marital status such that those in marriages or intimate relationships had higher scores than unmarried or widowed/divorced.

Life Satisfaction Index Z. The LSIZ measures life satisfaction, is not domain specific, and includes some affective content. The form used is adapted from Neugarten, Havighurst, and Tobin's (1961) Life Satisfaction Index A by Wood, Wylie, and Sheafor (1969) who dropped 7 items from the original 20, thereby improving internal reliability. The initial item scoring of agree, disagree, or don't know has been modified to a 5-point Likert scale yielding scores from 5-65.

Internal reliability for the LSIZ has ranged from .74 to .83 (Himmelfarb & Murrell, 1983; Stock & Okun, 1982, Wood et al., 1969). Burckhardt et al. (1989) found test-retest reliability at a three week interval to range from .80 to .90 over three testing periods.

The LSIZ correlated .67, .75 and .72 with the Quality of Life Scale (QOLS) over three time periods (Burckhardt et al., 1989), .33 with the Positive Affect Scale, -.39 with the Negative Affect Scale, and .46 with a single quality of life item (Stock & Okun, 1982). In addition, Lohmann (1977) found the LSIZ to correlate significantly with several measures of adjustment and morale. Downe-Wamboldt (1991) found that LSIZ scores were significantly negatively correlated ($r = -.34$) with illness-related stress, but not with SES ($r = -.04$).

Congruity Life Scale. The CLS is based on judgment theory that says that "the degree of life satisfaction experienced by a person at any given moment in time is a direct comparison between some standard and actual conditions" (Meadow et al., 1992, p. 25). Each of the ten questions considers a different social comparison which is rated on a 6-point Likert scale, e.g., "Compared to the accomplishments of your friends and associates, how satisfied are you?" Scores are summed and divided by the number of questions. Authors found means of 4.762 (SD=1.002) and 4.854 (SD=.850) for two samples of community residents aged 55 and older. Internal consistency as measured by Cronbach's Alpha was .95 for both samples. Scores correlated with the Delighted-Terrible scale .47 for sample one and .394 for sample two.

Sirgy et al. (1995) further validated the scale with six different samples in five different countries for a total N of 1226 (mean age for all samples was 34.8). Sirgy et al. found the CLS correlated significantly with cognitive age, income, employment, education, marital status, social contact, activity, religiosity, morale, tv viewership, and self-rated health. Correlations with age, gender, and parenthood were not significant. Meadow et al. (1992) found significant correlations with income, education, activity, religiosity, morale, self-rated health, and tv viewership (negative), but not with parenthood, gender (although men in sample one were more satisfied than women), or employment.

In the present study, use of the SWLS, LSIZ and the CLS yielded a global cognitive life satisfaction measure without comparison standards (the SWLS), a global measure with some affective material included (the LSIZ), and a measure based on judgment theory with suggested comparisons built into the measure (CLS). The measures were chosen for their appropriateness as measures of quality of life because they have been used broadly, and have good internal consistency and test-retest reliability. The LSIZ has the added benefit of having been used with persons with chronic illnesses and with disabilities.

Procedure

Participants returned confidential mail questionnaires from which all identifying information was removed and placed in a locked closet accessible only to the researchers. All APA ethical guidelines were observed, and respect was given to disability issues by accommodating procedures to respondents' requests, e.g., all paper was aired out prior to mailing, as some respondents reported becoming ill from the solvents in freshly photocopied paper.

Results

Results indicated high positive correlations among the three life satisfaction measures [See Table 1].

The mean score of the participants on the CLS was 3.86, $SD = 1.89$. Although not conducted with ill populations, comparison studies were found which utilized the CLS with community samples. These comparisons revealed that the participants in the current study scored a great deal lower than did community respondents in all countries except for China (Sirgy et al., 1995) [see Figure 1]. Correlations among all three measures of life satisfaction and with other variables are shown in Table 1.

Participants in the current study reported SWLS scores with a mean of 14.86, $SD = 7.64$ [see Figure 2]. Previous researchers using the SWLS reported scores ranging from 23.5 to 25.8 for medical outpatient and elderly samples respectively (Arrindell et al., 1991; Diener et al., 1985; Lewis & Borders, 1995). Again, participants with MCS scored considerably lower than did previous samples.

Similar results were found regarding the LSIZ. Compared to the results obtained from studies involving individuals with other chronic illnesses and handicaps (Burckhardt et al., 1989; Stock & Okun, 1982), individuals with MCS reported much lower life satisfaction ($M = 39.71$, $SD = 9.93$) [see Figure 3].

Significant gender differences were found on two of the three life satisfaction measures. On the SWLS women scored 15.58 ($SD = 7.70$) and men scored 11.54 ($SD = 6.52$), $t(df = 206) = 2.97$, $p = .003$. Women also scored higher on the LSIZ with a mean of 40.61 ($SD = 9.28$) while men had a mean of 35.39 ($SD = 11.81$), $t(df = 44.48) = 2.50$, $p = .016$. There were no gender differences on CLS scores.

Discussion

The results of this study show that life satisfaction in MCS is significantly related to two of three illness variables (course of illness and fatigue, but not length of illness), leisure satisfaction, income, and being in a romantic relationship. Taken together these findings suggest the importance of resources such as finances, personal relationships and health care for the person with MCS.

Gender was related to life satisfaction as measured on two of three instruments. The reasons for higher life satisfaction among women in this sample are unclear. However, future research could explore possibilities related to resource loss for persons with MCS. For example, men more so than women may be accustomed to having and providing material resources. The attendant loss of income in MCS may jeopardize a man's ability to engage in breadwinner roles or other behavior stereotypically associated with the male role. Alternatively, although women's health conditions are often delegitimized and psychologized, weakness is not necessarily seen as incompatible with the female role. Others' perceptions of those with MCS may be more negative toward men. Cheavens and Winstead (1996) found that college students were less likely to perceive men's complaints about fragrance (as presented in a vignette) as physically-based than those of women. The lack of gender differences on the CLS may relate to comparison standards included in the instrument. Although this is speculative, it is possible that the achievement-related comparison standards built into the CLS enabled men (who often have more resources than women in regard to finances, career, etc.) to report more satisfaction than they did on the two measures without built-in comparisons.

Reasons for Low Satisfaction

Persons with MCS are considerably less satisfied with their quality of life when compared to other individuals with chronic illnesses or handicaps. Life disruption, especially involving losses, is one possible reason for low life satisfaction among these participants. Gibson et al. (1996) found that job loss, unsafe housing, and diminished contact with family members and friends is not uncommon for persons once they are diagnosed with MCS. In more severe cases of MCS, avoiding public places is a necessity in order to prevent exposure to chemicals. Everyday tasks such as grocery shopping, attending church, seeing movies, or going to restaurants become difficult ordeals. Medical attention also declines in quality due to inaccessible offices, misdiagnoses, or uninformed practitioners who do not take their clients seriously.

Implications for Service

Acknowledging the condition of MCS suggests profound implications for service delivery. Self-identified MCS patients have reported the need for improved medical service delivery, with 61% of the respondents citing physician education as a priority (Cheavens, Gibson, Warren, & Pasquantino, 1993). This finding underscores the need for radical modifications of the health care system in order to effectively treat MCS sufferers. Of primary importance is the training of medical service providers to identify and treat chemical injuries, and the modification of the very physical environments of health care facilities to reduce chemical barriers. Helping professionals, such as rehabilitation counselors, social workers, and psychologists, also need direction and education regarding service delivery for those with MCS.

Policymaking in a Patriarchal Industrial Culture

Policymaking in relation to chemicals and health should address the goals of protecting and accommodating those with chemical sensitivities, and preventing the occurrence of further injuries. Although persons whose sensitivities to chemicals serious enough to interfere with their daily functioning are included in the Americans with Disabilities Act, in practice, appropriate accommodations are seldom made. This results in further exposures and deepening injury. Accommodations made early after diagnosis may prevent a worsening of the condition, thus maintaining life quality and the ability to work. Prevention of further cases of chemical injury necessarily involves safety in the home, the workplace, and in public, and is subject to regulatory policy. However, the political power of corporations often weakens regulations, thus placing persons more at risk for chemical exposures. Sufficient knowledge exists to prevent most home and workplace overexposures, as well as industrial accidents, yet, problems and persons' complaints are often ignored until they become emergencies.

The patriarchal nature of our health care system places obstacles in the way of appropriate diagnosis and treatment should a serious exposure occur. Since allopathic medicine became the ascendent system of health, Western medicine has been controlled and administered primarily by men. The woman with chemical injury is asking for help within the context of a system that has historically ascribed women's ailments to the misbehaving uterus or ovaries, or to psychosomatic problems (Ehrenreich & English, 1973). Chemical injury adds to the illness process the invisible nature of the disability, and the suggestion that the industrialized nature of Western culture is the nature of the problem. There is therefore a tremendous resistance to recognition or accommodation because of the implications for accountability. The suggestion that chemicals cause illness is probably the greatest cause for resistance. Gulf War Veterans, who share many symptoms and illness indicators with civilians with MCS (Miller, 1994), have met with the same resistance from governmental agencies as have civilians with chemical injuries. In the case of the Gulf Vets, the injury is often not invisible, as when their children manifest birth defects resulting

in physical disabilities. Yet the complaints of both vets and civilians with chemical injuries have been systematically ignored. In Congressional hearings, Sylvia Copeland, Chief of the CIA Task Force on Persian Gulf War Veterans' Illnesses, reported that the CIA had not spoken to veterans as part of the investigation into the Gulf War Illness, as it was not the CIA's job to do so. Similarly, reports that the sperm of some Gulf War Vets is caustic have not been investigated as "There is no reason to test the sperm" (Hudson, Miller, & Briggs, 1995). Thus reports of widespread health problems among both vets and their families are met with denial that is characteristic of dominants in a hierarchically stratified culture when they are called to task by subordinates for their harmful behavior.

The person with chemical injury is made ill, ignored, and delegitimized by a technological culture. Life satisfaction measures reflect the great losses and consequent decline in quality of life that follow. That persons with chemical injuries score lower on life satisfaction than almost any other group measured with these instruments speaks to the serious life disruption being created by toxic exposures in a contaminated environment. In order to prevent the spread of these devastating experiences, it is necessary to seriously address that contamination.

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