Disability-Induced Identity Changes in Persons With Multiple Chemical Sensitivity

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In this qualitative study, the authors asked respondents with multiple chemical sensitivity (MCS) in an open-ended question how having the condition affected their identities. Authors then examined responses for themes, which they discuss within the framework of critical theory. Emergent themes included loss of a stable, familiar personality, loss of self-positioning, emotional suppression to meet others' expectations, redesigning the planned life, forced growth, struggling with support, discovering the spiritual self, and identity reconsolidation. The authors compare findings with published works on adjustment to chronic illness and other delegitimized illnesses, find them to be fairly congruent, and then discuss problems regarding cultural acceptance of MCS as a condition caused by chemical exposure.

Keywords: *multiple chemical sensitivity; environmental illness; identity; chronic illness; chemical injury*

Chronic illness poses major life difficulties for those affected. Individuals must not only endure the debilitating effects of disease but also must reconcile their illness and possible inability to work, parent, and maintain relationships in keeping with the values of our achievement-oriented society. Charmaz (l983) discussed the diminished sense of self that results from the life restrictions, isolation, and "discredited definition of self and becoming a burden" that are correlates of chronic illness (p. 170). Altschuler (1997) and Goodheart and Lansing (1996) expanded on the theme of identity change in response to chronic illness and the process by which people experience alterations in self to integrate changed health status. Altschuler suggested that individuals maintain two separate selves: an ill self that copes privately with the demands of the illness and a "well" self for presentational purposes. Goodheart and Lansing proposed a model wherein adaptation to illness is marked by the gradual experience of first disorganization and then reorganization of self.

These processes might be particularly problematic for those with illnesses that are unrecognized or poorly understood by most people, including health professionals. One such condition is multiple chemical sensitivity (MCS), also referred to as chemical injury (CI), environmental sensitivities (ES), chemical hypersensitivity, and environmental illness (EI). MCS has been discussed in the literature in terms of symptoms (Ashford & Miller, l998; Bell, l992; Bell, Peterson, & Schwartz, l995; Lax & Henneberger, l995), diagnostic markers (Heuser, Wojdani, & Heuser, l992), potential causation (Bell, l992; Davidoff & Fogarty, l994; Meggs, l995a, l995b; Miller, l996; Pall, 2003), incidence (Caress & Steinemann, 2003; Lax, l998; Meggs, Dunn, Bloch, Goodman, & Davidoff, l996), sociological significance (Ashford & Miller, l994; Kroll-Smith & Floyd, l997; Lipson, 2001), and accessibility to the built environment and public programs (Molloy, l992). It is thought to occur through the two-stage process of sensitization and triggering. Through sensitization, people become intolerant of common chemicals as a result of one massive exposure, such as a pesticide application or chemical spill, or following low-level chronic exposures to common toxicants, such as in sick or "tight" (enclosed) buildings. Symptoms are then triggered by exposure to a variety of chemicals, including those found in cleaners, perfumes, pesticides, paints, formaldehyde, and others (Ashford & Miller, l994; Randolph & Moss, l982). In addition, some people can react to foods, light, touch, sound, electromagnetic exposures (e.g., microwaves, wireless equipment, cell phones), and/or natural substances such as pollens and molds. Triggered symptoms might range from mild to life threatening and can affect any bodily system, including respiratory, digestive, neurological, endocrinological, musculoskeletal, or cardiovascular. People attempt to avoid symptoms through chemical avoidance, which, in turn, poses the problem of loss of access to public environments in which exposures might be encountered. People with MCS report losing access to work, education, others' homes, and, at times, even their own homes because of commonly used chemicals, such as pesticides, cleaners, smoke, fragrances, and paints, that provoke symptoms (Gibson, Cheavens, & Warren, l996). The condition seems to overlap considerably with both chronic fatigue syndrome and fibromyalgia (Buchwald & Garrity, l994), and some health providers believe the conditions to be related or to be one illness with different manifestations. The three conditions are poorly understood by the medical profession and share a delegitimized status. Caress and Steinemann (2003) found that MCS affects 12.6% of the population and cuts across gender, race, socioeconomic status, and age groups. A smaller group (3.1%) had been diagnosed medically. In addition Neutra, Kreutzer, and Lashuay (l999) found that 3% of the population report having electrical sensitivities (ES).

Despite considerable discussion and controversy regarding MCS, very little attention has been given to individuals' subjective experiences with this condition. Individuals with MCS experience difficulties with work, finances, medical care, housing, parenting, public access, and relationships, and they commonly report personal distress as a result. For example, two thirds of a sample of 305 people with MCS had lost or been forced to leave their jobs because they were no longer able to tolerate common chemical exposures such as perfumes, heating sources, and pesticides (Gibson, Cheavens, et al., l996). Work accommodations are difficult to acquire and inconsistently offered even when granted (Gibson, 2003). Gibson, Cheavens, et al.'s (l996) respondents reported that medical care was difficult to find, that they had endured considerable iatrogenic harm because medical providers would not take their sensitivities seriously, and that they avoided certain types of medical care

because they feared that some treatments would exacerbate their sensitivities. Finances had dwindled because of the inability to work, and a number of people had endured periods of homelessness. Those with housing were often homebound because of their need to avoid exposures to lawn chemicals, heating fuels, construction smells, and other toxins. In a later study, Gibson, Cheavens, and Warren (l998) found that people with MCS reported low levels of social support and considerable conflict with both family and friends regarding their requests that others help them avoid chemical exposures by making personal changes, such as giving up the use of fragrances.

The life hardships of those with MCS are shared by persons with other de-legitimized illnesses. Persons with chronic fatigue syndrome and fibromyalgia have described similar negative effects on employment, finances, social relations, family roles, and mental health (Anderson & Ferrans, l997; Kelly, Soderlund, Albert, & McGarrahan, l999; Tuck & Wallace, 2000); visit numerous physicians and often are psychologized (Green, Romei, & Natelson, 1999; Lehman, Lehman, Hemphill, Mandel, & Cooper, 2002); and demonstrate poor quality of life (Martinez et al., 2001; Price, Prince, & Edsall, 2000; Schweitzer, Kelly, Foran, Terry, & Whiting, 1995; Van Heck & De Vries, 2002; Wassen & Hendrix, 2003).

Despite these reported hardships, the voices of those with MCS are rarely heard in the debate. Kroll-Smith and Floyd (l997) interviewed 121 persons with MCS and, in a book based on qualitative method, situated the MCS body as overtly challenging the content, structure, and ownership of medical expertise in late capitalism. Persons with MCS are seen as adopting the rational language of science to describe and explain what conventional medicine cannot: their bodies' reduced ability to function in the face of chemical exposures.

Two other published qualitative studies to date address this population. Lipson (2001) addressed self-care in an ethnographic study based on personal interviews and found that persons with MCS relied on systems of self-care that included management/limitation of chemical exposures, active and passive detoxification, and emotional care via finding meaning in the experience. Chircop and Keddy (2003) interviewed women with MCS using a life history approach within an ecofeminist framework and identified four relevant general themes. Interviewees discussed the problem of indirect exposure (through others including family members), burden of proof (having to provide proof of real illness), seeking refuge, and experiencing a change in value system. Lipson underscored the importance of listening to the voices of those with MCS, particularly in our current context that lacks validation and includes "frank disbelief" (p. 114) regarding this condition.

In this article, we describe a study we undertook to investigate changes in identity that might occur as a result of coping with a poorly understood and largely dismissed condition. In addition, we sought to illuminate the personal phenomenology of coping with MCS for helping professionals and others who interact with this population in the hope of igniting interest in the sociological, political, and medical aspects of the condition.

CRITICAL THEORY APPROACH

We were specifically interested in the effect of MCS on the self-structure and identity of those who experience it. We used the critical theory paradigm to answer the

question of how having MCS would cause changes in one's sense of identity and/or conceptualization of self. We define *identity* as one's understanding of self, including one's skills, values, social positioning, purpose in life, and impact on others. Critical theory is based on the assumption that a particular society's knowledge and institutions are constructed by the members of the society and are, therefore, not objective or tangible but influenced by dominant cultural pressures (Comstock, l994; Kincheloe & McLaren, 1994). It aims to pursue transformations of oppressive, subordinating, or misconceived information through the use of current structural and historical contexts (Guba & Lincoln, 1994). Social understanding is a prerequisite for social change. Critical theory strives for social change through a process of enlightenment, which takes the form of a dialogue between researcher and research participant (Comstock, 1994). Thus, we used the critical theory paradigm to shed light on the unacknowledged, misconceived, and delegitimized identity changes in individuals with MCS. We used written questionnaires in an attempt to understand this marginalized group's social positioning by providing a forum for the expression of voices unheard in mainstream medical discourse.

Based on the wide geographic distribution and severe health difficulties experienced by many potential participants for the study, we determined that the questionnaire format was the most effective method for gathering the widest possible range of responses. Severely injured individuals would find participation in face-to-face meetings impossible because of the presence of fragrances and other chemicals outside of their homebound environment. In addition, given the geographical distribution of informants, travel costs would have been prohibitive. Although phone interviews would have allowed for direct dialogue between participants and researchers, the written format allowed for a large outreach that might have been prohibitively expensive given the number of participants. In addition, some persons with MCS have difficulty with telephones due to plastic, mold-inhibiting chemicals in the mouthpieces, and electrical, radio, or magnetic fields. They also might have difficulty maintaining enough physical energy for an extended conversation.

METHOD

Participants

As part of a longitudinal study of the life impacts of MCS, 203 adults (178 women and 25 men) responded to an open-ended question on how their sense of identity or self had changed as a result of having MCS. Studies published to date from the larger project have examined life disruption (Gibson, Cheavens, et al., 1996), social support (Gibson, Cheavens, et al., 1998), and hope (Gibson, 1999). Initially, we recruited 305 persons through newsletters targeted to this population, support groups, and physicians' offices, and from a random sample of one third of the membership of the Chemical Injury Information Network (CIIN), a nonprofit educational and advocacy organization. The 268 persons willing to participate in future studies received a 2-year follow-up survey that included the essay question on identity. Of these, 203 returned the survey. Much of the attrition was due to relocation, as persons with MCS have difficulty finding and maintaining safe housing.

Despite our attempt to keep contact with participants via change-of-address forms, a substantial number of persons had moved without contact. In the present work, 88% of the participants are women. Participants responded from sources as follows: 26.9% from CIIN; 20.4% from the National Ecological and Environmental Delivery System (NEEDS), a large mail order business supplying goods to those with allergies and sensitivities; 17.4% from the Human Ecology Action League (HEAL), a national support organization for those with MCS; 7.5% from the National Center for Environmental Health Strategies (NCEHS), a national advocacy group; 8% from other smaller support groups; 2% from physicians' practices; and 16.9% from "other" (likely recruited by individuals who had participated in the study). Of the informants, 23 described the level of the severity of their condition as mild, 67 as moderate, 77 as severe, and 34 as disabling. Two informants did not rate their level of severity. At the time of data collection, only 23% were still employed. The mean age of the informants was 47 ($SD = 10.32$), and the mean age at which they began to have symptoms was 32 ($SD = 12.92$). Informants had been ill a mean of 15 years ($SD = 13.32$), and it took them an average of 8 years to identify the cause of their condition. A majority of the respondents (92%) were European Americans. Five percent were Native American, and 3% were Latino or Latina, Asian, or other. Fifty-four percent of the informants were currently married, 17% were single, 21% were divorced or separated, and 5% lived with a partner. Forty-nine percent attributed their illness to one identifiable chemical exposure, and of these, 60% said it had occurred in the workplace. Seventy-five percent lost or had to change employment because of their MCS.

Procedure

As a component of the larger follow-up questionnaire, informants responded to a four-part, open-ended question regarding their sense of self. After receiving ethics approval from the university institutional review board, we distributed initial mail surveys to those who responded to our request for participants. All initial participants provided informed consent; those willing to participate in future research signed an additional statement of their willingness to contribute to future studies and provided contact information including address and phone number. Two years later, we sent those agreeing to participate in further studies a questionnaire that included measures of hope, social support, life satisfaction, involvement in advocacy work, and short answer questions about medical and dental needs. The open-ended identity question specifically asked

> How has having MCS/CI affected your sense of identity or sense of self? How are you different as a person because of this condition? Are there parts of yourself that do not get expression? How do you deal with this?

In congruence with critical theory tradition, the written questionnaire format as well as the content of the questionnaire itself allowed for the active participation of the research participants. The open-ended questionnaire incorporated some flexibility into the format, in that respondents could complete the questions in their own time. We did not bring a preplanned hypothesis to the study to test during the course of the research.

We numbered surveys and separated them from consent forms when received, keeping both in a locked closet to which only the first author has a key. Research assistants saw only the numbers when accessing and coding the surveys. Thus, the study had both confidentiality and anonymity.

Responses varied in length. One respondent answered with a question mark, 1 with the words "I don't know," and 3 asserted in one sentence that MCS had not changed their identities. The remaining responses varied from a half-page to four pages in length, with 35 answers being longer than one page. We used theme analysis as a guide for identifying common themes in the respondents' essays. We read and reread responses, classified emergent themes, and resolved disagreements among researchers through discussion.

Once categories were saturated, we compared our findings to those in other studies of chronic illness, research descriptions of other marginalized conditions such as FM and CFS, personal biographies and autobiographies of persons with MCS (e.g., Berkson, 1996), stories that highlight coping in MCS newsletters, and other personal accounts given to the first author in 10 years of researching MCS. We also asked several respondents and advocates in the field who communicate with large numbers of persons with sensitivities to evaluate and respond to our descriptions of themes in the article. Two advocates provided very detailed editing of the entire manuscript in addition to feedback regarding the themes. All who provided feedback felt that the themes appropriately captured the experiences of those with MCS. One participant, who is also a researcher, said,

> I read through the document and felt that I could totally identify with everything that was said—It felt wonderful to read, I felt validated and legitimized—how amazing! All of these same things that I feel about my loss of work, loss of relationships, loss of health, loss of so many things, are reflected in this paper.

Two advocates had the concern that the article might overrepresent the positive adjustment to MCS to the exclusion of those who are not able to find growth in the condition. In addition, they pointed out that we had not heard from or represented those who had died from the condition through suicide, fatal reactions, or secondary complications, such as not being able to use traditional medical interventions such as chemotherapy. One advocate wanted it known that although there are no official tallies, she is aware of 39 people who have died because of MCS.

The researchers are an academic psychologist who has studied the life impacts of MCS for several years from a disability perspective (and is thus trusted by the MCS community not to impute psychological causation) and four students with an interest in health and disabilities. These students have graduated. One is now a resident in osteopathy, one is an occupational therapist, one has a master's degree in American studies and museum studies with a special interest in disabilities, and one is a mental health counselor.

THEMES

Respondents' essays embodied eight major themes, which we categorized into the two major categories of loss and response to loss. Loss included the themes of the loss of a stable personality and a disruption in the roles that connect self with others

(loss of self-positioning). Response to loss comprised six themes: the suppression of emotions regarding MCS in an attempt to appear "normal" and thus meet others' expectations, the necessity to replan a life around the disability, mandatory personal growth in response to dealing with the illness, interpersonal support, spiritual support, and the reconsolidation of self that includes but is not overwhelmed by the illness.

Loss

Loss of a Stable, Familiar Personality

The informants' former stable self-perceptions were disrupted by unwanted and intrusive changes in personality and behavior. "I went from a strong independent woman into a fearful dependent one. I hate this" was the response of a woman who experienced a weakened sense of self as a result of MCS. Similarly, a loss of independence was expressed in the statements "I feel very 'needy' and I was never that way before." One informant described herself as "more inner oriented" as a result of MCS. Others described feeling selfish as a result of having to focus on self-care:

> I never thought of myself before. It was always my family or some friends who needed some special attention. Now I must always consider "How would this affect me?" I feel that I have become self-centered, but it is necessary to survive in any happiness.

Another informant stated, "I feel worthless and have a great loss of self-esteem . . . I feel no sense of accomplishment or pride in a job well done." Many described becoming fearful of public exposures and resented the need to research numerous details about environments before leaving home. Life now required extensive planning to avoid exposures. As part of this exposure avoidance, informants were repeatedly forced to explain the restraints of their condition to others in the course of their social interactions. One informant related, "I hate explaining why I can't do something. I don't like being different." In many cases, respondents expressed anxiety about possible exposures to chemicals such as perfume and smoke at social events. This need to avoid such exposures made some people feel that they had become intolerant of others' habits.

One woman who described her condition as severe explained her inability to define clearly a sense of identity because of the direct interaction and constant effect of chemicals on her self-perception:

> How does one cope with an illness that is mind-altering? An illness that is frequently influencing and controlling your mind and actions. You get to the point of not knowing what your personality is anymore. You know how you used to be but since growth and change is a continuing process throughout life how do you know if it is you or the chemical influence? When I'm happy or sad I have to double check, am I happy or sad or is there a chemical near that is causing me to be happy or sad? Do I have to leave the situation or can I stay? I am no longer a separate entity. I am what I am with the influence of the chemicals now. I don't like it at all. I do things that I would consider to be out of my usual character. It exaggerates my tendencies. People set different parameters of behavior for themselves which depend on what situation they are in. Some characteristics of a person's behavior are inappropriate

in certain circumstances. With MCS you sometimes lose the ability to regulate your behavior to the situation you are in. Does that make sense? The mind is the most important part of a person and MCS keeps messing with that.

Many expressed frustration and anger over the sense of being robbed of their familiar and customary affect. One informant said, "MCS has deeply affected my ability to enjoy life. It has strangled my fun loving/kind/true self." Some saw themselves as having become more self-centered or even jealous and mean spirited. For example, some described being envious of people who could travel or go out in public without worrying about exposures. In extreme situations informants described the desperation of having nothing left to live for. One informant described that she initially

planned on dealing with it (MCS) by suicide [but] changed my mind about that course of action, but if a life threatening illness comes along, I definitely will not agree to treatment. I no longer get pap tests or mammograms.

Loss of Self-Positioning

Numerous informants described a loss of self-positioning or definition in relation to the external environment. Persons with severe sensitivities cannot work or use their skills in their field of choice or enter places of worship because of chemical exposures. Many described losing their independence and relying on others, mostly family and close friends, to grocery shop, cook, or clean for them. The narratives embodied descriptions of restricted living that precluded work, family interaction, and recreational activities.

Arguably, the most pervasive and influential loss was related to work and/or profession. People whose disabilities were not accommodated at work lost their livelihoods and experienced, along with the material losses, substantial repositioning as "one who does not contribute." One woman wrote, "Because I am unable to work, I feel like an outsider who is not contributing to the welfare of my city, state, country, and world." In a society in which work roles define a substantial portion of self, people struggled to retain a coherent sense as separate persons.

Before MCS a great part of my identity was my occupation. Because of my illness my employer let me go. I went from being a healthy, working mother and wife to an ill, unemployed, separated person. I am still a mother and I often feel that if I lost that part of my identity I would have no reason to exist.

In some cases in which the disability intruded early in a career, people had no substantial vision of themselves as contributing workers but had to project/imagine how that might have evolved had they had the opportunity.

I am an RN but had to give up that career in my early 30s because of migraines. The sensory (disturbance?) would start a few hours after on duty [sic] and the vomiting and severe pain a half-hour later. Nursing would have been a great career for me. I love people and I am empathetic.

People discussed the lack of outlets for intelligence, creativity, and training, and named a "sense of waste professionally" or the inability to "fulfill potential as a

scholar." One woman said, "I feel sad [that] my 3.8 GPA and effort has led me to social security not employment." Another, also unemployed stated,

> I feel that my intelligence is not being utilized by not working. I still have much to contribute and this part of me is not being expressed. I would like to work at home but the computer bothers me for long periods of time.

One woman with severe MCS described cumulative work-related loss:

> I feel invisible and not in control of my life. I ignore all this the best I can. I have experienced homelessness and loss of my life's savings, loss of personal belongings, ability to earn an income in which to support myself and hope for the future. My quality of life is poor and limiting.

Family roles were threatened by people's inability to provide for or interact with significant others as they once did. Sometimes, relationship break-ups resulted from the stresses of illness and restricted lives:

> My marriage is ending. The main reason is communication problems/inability to discuss and resolve problems. The MCS was a big problem that my husband resented and he wasn't supportive of the treatments I sought. He thought the whole thing was "weird" and I needed a mental health counselor.

Children and siblings, likewise, had difficulty understanding the disability. When this occurred, women with MCS were extruded from family roles:

> I don't see my children, identical twin sister, brother, because of chemicals—perfume, cigarette smoke, and fabric softeners to be specific! This just leaves me sad, lonely and frustrated—and well as unloved—Wouldn't they STOP using things that make me sick if they loved me? I would for them!

Isolation was cited as a hindrance to making new contacts. One divorced woman stated,

> I really miss having male companionship. The one I cared about very much and who really made every effort to understand what was happening to me died in May '92. There won't be anyone else. No way to meet anyone.

Relationships were often not replaced; potential romantic, attractive, and sexual selves were hampered by lack of energy, limitations in access, and changes in personal appearance. People related that others would not be able to understand their needs. A woman with mild MCS, who was still working, explained,

> I've stayed out of relationships (romantic) because I didn't think anyone would understand my needs. I've not had children because of this illness. These have been hard to deal with. Sometimes I grieve for the many losses I have had; it never seems to end.

Women were often prevented from presenting themselves as attractive according to Western beauty standards due to illness-related appearance changes. "I no longer had the energy to make sure my clothes looked nice and get stains removed;

the beautiful bleached blonde hair was no longer sensible because of the chemicals involved." Thus, women devalued themselves for failing to meet culturally imposed standards and imposed greater stresses on themselves in the process. Feminists have been critical of appearance-related cultural requirements for all women regardless of body type or comfort, yet very little attention has been given to appearance stressors for women with chronic illnesses. In the case of MCS, it appears that women will endanger their health in an attempt to maintain cultural appearance ideals. For example, many respondents discussed engaging in activities such as wearing makeup and getting permanent waves despite the fact that the chemicals involved caused them illness reactions.

Sometimes, an outgrowth of the inability to meet standards of appearance for women was difficulty entering romantic roles due to feelings of inadequacy. Some felt particularly damaged by having a "deviant" appearance:

> Recently I had my face cut open in an accident, it left an ugly scar. Very prominent, very ugly. Since I can't tolerate cosmetics, even the natural ones supposedly "safe" in most MCS patients, I can't even cover it up. For MCS patients even simple things become monumental. I can't even benefit from a plastic surgeon.

Even if women did make contacts with others, physical illness interfered with "normal" sexual functioning for some: "The hardest is the sexual stuff. My sexual abilities have been very much impaired by damage to endocrine system as well as fatigue. But I express my sexuality through watercolor painting and a passionately beautiful flower garden."

In addition, the material self or identification with material possessions was disrupted as people were unable to tolerate off-gassing fumes from many items such as new clothing, plastics, print material, and furniture. Women wore tattered old clothing because they could not tolerate new clothes. Household items were sacrificed and not replaced. Favorite items such as antiques, paintings, and floor coverings were removed and replaced with less toxic (and, in some cases, less attractive) items or with nothing at all.

Respondents described cumulative losses with regard to self-positioning that left them to cope without job, money, family, or items of personal comfort. People described being a liability to others, having no sense of accomplishment, and making no contribution to society. In sum, they talked not about who they were but about who they no longer were.

Responses to Loss

Emotional Suppression to Meet Others' Expectations

A recurring theme for respondents was their struggle to remain a part of mainstream society, even at the risk of their own health. Informants reported enduring harmful chemical exposures in an attempt to remain "normal." One person claimed, "One thing that helps me cope is denial, I pretend that I'm not any different from other people." Fear of alienation dictated the actions of some people as illustrated in the following quote: "I'm always angry and frustrated with myself and

others. If I expressed this to people regularly I'd be totally friendless. I have to stuff most of my feelings in order not to totally alienate others."

MCS lacks cultural validation or understanding, and respondents endured social pressures to maintain a particular presentation: "I think it has affected my self-esteem as I have trouble dealing with other people's spoken and unspoken skepticism about the reality of MCS. I find myself questioning my reactions and feeling embarrassed." One woman described being perceived "as a malingerer or hypochondriac or someone with neurosis" when attempting to explain her condition to others:

> People have a hard time understanding that fumes can actually make one ill, and why not? It is hard for ME to understand at times. I would much rather go with the flow and not have to pay attention to such details.

Having experienced such reactions from others, many sufferers felt constrained in regard to communicating about their condition. "MCS/CI does not get expression to those around me. They've set boundaries not to talk about it." Often, affected individuals were unable to discuss their illness with others, even family members. One women who described her condition as severe stated, "Immediate family except husband will not let me speak about my illness."

The fear of psychiatric labeling inhibited the behavior of some: "I had to forego personal help with emotional (PTSD-related?) problems for about a decade due to the critical political necessity of not seeming like a 'crazy' EI."

Thus, many felt forced to hide both their sensitivities and their emotional responses, instead pretending to feel well to avoid the alienation and isolation that can come with being disabled. One woman who was severely affected said, "Through it all I always wear a smile and am cheerful around others while on the inside I have a great big ache."

Redesigning the Planned Life

Chronic illness demands that an afflicted individual undergo incessant, unforeseen life changes that require adjustment. MCS poses a threat to one's dreams, planned goals, and overall longevity. The unexpected nature and sometimes sudden onset of MCS requires drastic modification of an individual's professional aspirations, intellectual pursuits, and the evolution of one's personal life. One woman, who is disabled from MCS said,

> I was no longer in control in my old world. I had to develop a new world I could control. No longer could I improve the world by working with the young in a school setting—so I have become an activist with my husband—for MCS.

The struggle to incorporate a chronic illness into one's sense of self is depicted in the following quote:

> I suppose I need to redefine my definition of work to be more than just employment. Work redefined as being any task that I undertake. I do take pride in anything that I do, whatever you do should be done to the best of your ability. With MCS sometimes ability is nil. What good is work if it doesn't have monetary value? How do I get over my desire to be a proprietor or to at least be employed? If my way of thinking

(what society has taught me) is to judge worth on employment and I am unemploy-able, then what does that make me? I am not a contributing member of society. Occa-sionally I have anger towards a person just for the fact that they are employed. Although I find it quite difficult to deal with the MCS symptoms, I sometimes feel that I have a harder time dealing with the fact that I am unemployable.

The loss of ability to travel comfortably and safely can make it inconvenient, if not impossible, to visit friends and family, maintain professional positions, or to be a helper to others. Often, the financial burden of accumulated medical bills necessi-tates a reconsideration of one's previous retirement plans. In most cases, retirement dreams had to be altered dramatically because of respondents' inability to travel or live in certain locations. MCS is also physically challenging. A sick, weakened body is unable to keep up with the physical exertion that many sports activities demand; thus, something as ordinary as athletic participation becomes impossible for those who experience MCS. Deprived of choices and limited to a solitary way of life, per-sons with MCS often experience drastic changes in every aspect of life.

Forced Growth

Informants described forms of personal growth that seemed forced on them by their health condition. Some described having learned to accept help from others and having had to become more assertive in asking for such help or for accommoda-tions. Informants had to live more careful and balanced lives in terms of self-care, exercise, and diet because of new vulnerabilities. Setting firm personal boundaries became necessary to avoid exposures or fatigue from overexertion. One woman with severe MCS and no longer able to work said, "Having MCS/CI has certainly forced me to acknowledge and defend my personal boundaries." Another, with a moderate condition, said,

> Today I take better care of myself—I lead a more balanced life by working less, by exercising regularly (not compulsively or excessively), eating balanced, slowing down my activities, my own movement. My whole existence is based upon balance and recognizing my boundaries (neither of which I understand, let alone observe during the exposure).

Part of responding to MCS in this way involved struggling with the political and economic issues regarding environmental contamination for persons who might not otherwise have paid attention to this type of discourse. One woman said, "It has been ruinous in terms of normal career and income development. It's forced me into expressing political and economic and social status values that I'd have likely left unexplored." Another described, "I have become a political person . . . I contact legislators and as I get worse due to pollution I get no help, express my ideas more radically." This forced movement led many to adopt a new self-definition of "activist," a role that does not adequately express the work ethic or satisfy the West-ern cultural definition of success.

Interpersonal Support

Informants' statements reflected the important role of social support in negotiating identity under difficult conditions. Some received and appreciated positive input from family and friends who offered them understanding.

> I have a very loving and understanding husband who allows me to let out my angers and emotions and listens to me and trys [sic] to understand what I'm going through. This is my way of dealing with things, and I am determined I am going to get better.

Similarly, another woman stated, "I have been in therapy and had a chance to express grief, etc. due to acquiring a chronic illness. I can express myself well and have friends who understand." Unfortunately, not all the informants reported having such successful supportive interactions:

> I no longer have to go to family gatherings where they wore perfume—it was their right, same as for aftershave. My presence was only tolerated, now I just don't go and I'm much better. I wasn't getting family support from kids or husband during the entire time. I learned that I had to take care of and watch out for myself. At that time I was wife and mother. I lost my sense of identity. NOW I am a person trying to find out what I want and what is truly important.

In addition, many came to see others in a more negative light than previously:

> I've become more aware of most people being self-centered. I'm a very giving person, always doing for, being there, physically helping "friends and relatives" When I became disabled (over a 3 year period in a sick building) almost no one was there for me.

Other people suffered loss of friendships but coped by making new friends and moving on. As one respondent stated, "Often we see ourselves in those around us. When they leave, we feel sorrow, a loss. We make new friends . . . and go on." Others described finding acceptance in spite of a limiting condition, and they subsequently deepened relationships with those who provided such acceptance.

Many informants helped or advocated on behalf of others, as they were able to relate to others' hardships. One woman explained, "I have 21 years experience with MCS and I believe this is an inspiration to others and I believe I give them hope." A number of individuals felt stronger connections with other people with MCS or similar illnesses due to mutual understanding. One informant stated, "Although the threat of abandonment [from significant others] looms overhead, I have developed supportive, loving relationships with other EIs all over the country largely due to my activism." Because of the restricted life informants were forced to lead, many expressed compassion for and encouragement of others. One woman claimed, "I have found my life work in helping other MCS/EI people." A few started "pen pal" relationships to feel a connection with other people with MCS. These relationships seemed to help many informants mitigate the effects of isolation from illness-imposed restrictions and provided a venue for helping others.

Spiritual Support

Some individuals also experienced growth by turning to a higher being or discovering their spirituality. One person wrote that being forced to give up so many of her activities brought her closer to God. Another said,

> I know that God wants me to recognize and grasp, retain my sense of self worth. He himself has very vividly shown me that. At times I'm okay with it. He has shown me He wants me to walk straight and tall, with my head up!

This woman went on to explain how this came during an experience that helped her to begin to heal. The lack of available medical care and isolation pushed another woman with severe MCS toward a spiritual orientation: "This has made me depend on me and turn my life completely over to God. When I have a bad attack instead of rushing to the hospital or doctor I leave it in the Lord's hands."

Some participants expressed thankfulness for what they did have and a greater appreciation of the "little things" in life. Many described taking "nothing for granted." Some described a closer spiritual connection to nature. Many informants believed that their deepening spirituality gave them direction and new means of self-expression. Those who had experienced life-threatening symptoms faced their mortality.

Identity Reconsolidation

Some informants described a positive experience of identity reconsolidation, that is, finding strength through facing adversity and becoming emotionally stronger. They withstood the pressures of confronting illness in a society that mandates wellness and found a new strength to survive. Sometimes, these pressures were extreme, as described by one participant. "Not even the dehumanizing effects of 11 months of homelessness have broken my spirit." Another stated, "I may not be able to be as physical as before, but 'it' can't rob my spirit."

Through identity reconsolidation, some began to rely more on themselves than they previously had and became more powerful and confident. A number of respondents thought that they had a better understanding of their personal priorities. Some discovered or developed new talents, focusing on their present abilities. One participant stated, "I focus on what [I] can do and not what [I] can't. [I] try to find ways to participate. I talk to animals even when I can't pet them." Many searched for outlets for remaining abilities. As one participant stated, "I've lost much of my old life due to EI, but have searched and succeeded in finding new areas to give my life some meaning and challenge."

With reconsolidation, women described themselves as someone disabled but not delegitimized. By granting themselves legitimacy, they had given themselves permission to develop in spite of, or even because of, the illness. One woman with severe MCS described transforming losses into usefulness and growth:

> I feel I've always been a strong person mentally, and now I've become an even stronger person mentally and emotionally. I no longer teach in a classroom, but now I teach about EI/MCS. I am much more in touch—in tune with myself now than even before. I am much more confident about my convictions in life/I am much less

materialistic because of my EI. I have learned how little I need to live/survive. I appreciate nature more. Most days I love life more then I did before.

In many cases, people went beyond reconsolidation to a level of personal integration and growth that they believed would not have occurred without the illness. People grew beyond "adjustment" or coping to a kind of personal transformation. One woman said, "I am more now than I was before the illness. It has taught me much." Another explained, "If I had to get sick to get 'better,' then I can be grateful for that." A woman now disabled by MCS said,

> I am a stronger person. I have changed from being a people pleaser and relying on others' opinions of me to seeing who I am, forming my own opinion and liking who I've become in the process. Although parts of me do not have opportunity for expression, I concentrate on those that do.

Another woman with severe MCS described a complete self-transformation:

> I feel that having MCS/CI has forced me to look deeply into myself and grow tremendously in terms of my sense of identity. In this sense it has been a fantastic blessing. Because of the spiritual, emotional and psychological work I have done in response to my illness. I feel a strong sense of self worth and achievement about how I have responded to illness. I no longer feel dependent on work or status for my identity. I feel this is the greatest achievement of my life.

Yet another described emerging through both forced growth and reconsolidation to something greater then the sum of her successes with the challenges of illness:

> I have been damaged physically but I have rebuilt myself as a result. I am more conscious of what I eat and drink, and how the body is a wonderful entity. I have greater respect for the human species to overcome illness. I also have more respect for the beauty that is still in the world. I appreciate so much more the wonder of life and this planet. I am wiser and stronger in my soul. I'm connected to the thread of humanity more now then I was before my illness. I have expanded my knowledge of medicine, environment, human emotions. I am more now than I was before the illness, it has taught me much.

Gratitude for difficulty was implied in some responses, such as this one: "On the other hand, the difficulties I've experienced with MCS have opened the door to a richer, spiritual life, a faith I never had before. If everything had been easy, I might never have found this path."

Although this data collection was cross-sectional, many respondents' descriptions of an extended struggle that began with loss and eventuated in growth and acceptance implied that the categories are connected in a temporal fashion, with stages of adjusting to MCS:

> It's 6 years now since I've been ill and essentially housebound. I've been through different stages of adjustment along the way and identity issues varied according to what stage I was at. At this point there are both pros and cons in terms of my illness. I have a much stronger sense of self because of all I've had to deal with. I know more who I am, my strengths and weaknesses. I've had to go deep inside for strength time after time and though I've felt acute anguish and desperation at times I am a more complete person as a result of meeting these challenges and going through difficult periods.

This woman with moderate MCS clearly described experiencing loss of self-positioning before redesigning the planned life in her life trajectory:

> MCS loss of career (education and art), loss of mobility, future plans, our financial security . . . physical strength and endurance, personal looks and loss of style. I was no longer in control in my old world. I had to develop a new world I could control.

The respondent continued, describing a new health care regimen, relocation, and newly acquired activism. In another example of the process in time, a woman moderately affected with MCS described loss of occupation, disabling health problems, financial bankruptcy, and divorce:

> All this has served to break down so much of my life. My sense of self as it related to my previous yuppie profession is of course no more. My sense of self from who I am in the true sense of the word (character, motivation, strength, love, compassion) has emerged stronger than ever.

CONCLUSION

Most participants described identity changes in some form. Emergent themes in informants' descriptions of identity changes included loss of a stable familiar personality and loss of self-positioning. In response to these losses, respondents described suppressing their true feelings to meet others' expectations, experiencing forced growth, redesigning the planned life, examining their social support, discovering the spiritual self, and reconsolidating their identities. Emergent themes were examined for congruence with patient processes described in recent literature on adjustment to chronic illness and in literature relating to other delegitimized conditions, that is, chronic fatigue syndrome and fibromyalgia.

Goodheart and Lansing (1996) proposed a response pattern that develops in a characteristic sequence in individuals with chronic illness. Stages involving "disorganization" of self and eventual "adaptation to illness" seem applicable to many informants in this study. Uncertain about the future, many were forced to redefine their life plans as a result of MCS. Similarly, Goodheart and Lansing described a psychological disorientation that many chronically ill individuals experience brought about by forced changes and disruptions in their life functions and normal routines. A number of our informants also reported growth patterns that included developing new coping strategies and restructuring their lives in positive ways. Overall, the qualitative findings of this study parallel Goodheart and Lansing's theory of disintegration and reintegration of self in the face of chronic illness (although we cannot be certain that an order exists, because this was cross-sectional research) and share some overlap with themes identified by Chircop and Keddy (2003).

Informants in our study encountered difficulties in integrating the impact of MCS into their daily lives. Altschuler (l997) described the impact of chronic illness similarly to Goodheart and Lansing (1996) when she examined the onset of illness and its subsequent effect on the "social" and "ill" aspects of identity. Individuals are able to grow only when they are able to integrate these two aspects. The balance of these two aspects directly affects the individual's relationship with the external world. Reconciliation of these two aspects of self is necessary for a balanced relationship between one's internal and the social world. Societal denial of illness

makes it more difficult for persons to integrate the ill self, which, in turn, poses stress to personal health.

Many individuals in our study reported pervasive MCS-imposed life limitations that strongly affected social and professional arenas and robbed individuals of their previous definitions of self. Charmaz (l983) stressed the restricted life, the social isolation, and the discrediting definitions of self as elements that lead to a loss of self in the chronically ill. What we refer to as loss of self-positioning is congruent with Charmaz's discussion of becoming a burden, in that "the person can no longer claim identities based on prior external activities, interests, and pursuits" (p. 189). Similarly, "being alone in illness" was one of three themes in the lives of persons with chronic illness described by Öhman, Söderberg, and Lundman (2003). Their respondents' reports of reduced contact with loved ones, difficulty in finding persons to relate to, and feeling like outsiders, bear similarity to our respondents' loss of self-positioning.

The stigma and delegitimization experienced by those with MCS is shared with the emerging conditions chronic fatigue syndrome (CFS) and fibromyalgia (FM), and permeates much of the interface that persons with these conditions have with their communities. Åsbring and Närvanen (2002) analyzed four themes from interviews with women experiencing either CFS or FM. Three of the four had elements of hiding the illness/avoiding others' demands/avoiding an illness identity, thus coinciding with our found theme of hiding the disability/succumbing to others' expectations. The authors see the women as hiding their illness to maintain their preillness identity. Paulson, Danielson, and Söderberg's (2002) themes of being a different man than before fibromyalgia and not being understood seem similar to our theme of the loss of a stable, familiar personality.

Bury (l982) noted three important aspects of the illness-induced disruption: the "disruption of taken-for-granted assumptions and behaviors" (p. 169), the "rethinking of the person's biography and self-concept" (p. 169), and the response of facing the altered situation by mobilizing resources. Yet, some of the resources discussed by Bury are not available to those with delegitimized illnesses. For example, he wrote, "Access to medical knowledge, at least in the case of physical illness, offers an opportunity to conceptualize the disease as separate from the individual's self" (p. 172). Later, he noted, "To be able to hold the disease 'at a distance' as it were, assists the claim that one is a victim of external forces. To do anything less is to accept fully the burden of responsibility" (p. 173). Conceptualization of illness as separate from the individual, as Bury described, aids in legitimization, which was defined by Bury as "the process of attempting to repair disruption, and establish an acceptable and legitimate place for the condition within the person's life" (p. 456). Persons with MCS, chronic fatigue, and fibromyalgia cannot participate in this medical legitimization of their condition. Care rendered is misdirected, often ineffective, and, in MCS, even harmful (Gibson, Elms, & Ruding, 2003). Discordance in the relationship with one's physician is a common theme in the literature on chronic fatigue syndrome and fibromyalgia (Åsbring & Närvanen, 2002; Dobkin et al., 2003 Green et al., l999). The lack of recognition of these conditions seriously impedes this process of contextualizing the illness and affects individuals' ability to integrate it into personal identity.

Similarly, Charmaz (l983) noted that ill persons are often discredited for failing to meet expectations normed on healthy people. Supportive others, by contrast, "usually bolster the ill person's self, thereby maintaining continuity with the past

pre-illness self" (p. 183). Yet, persons with delegitimized conditions often report a lack of support and disbelief from laypersons and physicians alike, leaving them to integrate and cope with the condition on their own. For example, women with chronic fatigue syndrome and fibromyalgia reported not only psychologizing of their symptoms but questioning of their moral character as well by caregivers, coworkers, and health care providers (Åsbring & Närvanen, 2002).

Although people in this study experienced physical suffering and a lack of access to community resources, many of the negative identity themes were related to the cultural treatment of persons with poorly understood illnesses (e.g., loss of self-positioning, hiding true feelings, lack of interpersonal support) and the lack of a paradigm for chemicals as causes of illness. The negative themes in this study share some overlap with Chircop and Keddy's (2003) taking refuge and burden of proof. Like those with other conditions that are either psychologized (Ballweg, 1995) or delegitimized (Ware, 1992), people with MCS are situated in an experience constructed as "not real" by dominant social and economic forces. This construction frees others from learning about the problems, making accommodations, or even communicating in meaningful ways with those who are affected. Lack of workplace accommodation contributes to poverty, marginalization, and homelessness for this population. Zwillinger (1997) has published her collection of photo essays of people who are homeless or live in unusual circumstances because of MCS. Homelessness is a natural sequitur to income loss and delegitimization. Women's independence is threatened without livelihood; women's voices are silenced in mainstream discourse without professional outlets. Health care coverage disappears with the job, as does most personal interaction.

Those with MCS represent a hidden population of persons without resources, who no longer benefit from most of Western social institutions. Their stories are sometimes told by others, and their problems are often attributed to mental or emotional factors. Their own voices challenge the economic status quo in their suggestion that common chemicals are able to sensitize and permanently injure people. It is easier for those in the dominant culture to disbelieve than to address the issue of pervasive toxins in everyday life, in large part because of the enormous financial investment in the chemical materials that are ubiquitous in industrial culture. In fact, the Interagency Work Group on MCS (1998) stated before even citing the literature that MCS will be dealt with in terms of risk assessment. If confronting MCS is too expensive, those who have become ill will be seen as necessary sacrifices for the convenience of "better living thorough chemistry."

Health care providers generally pay little attention to toxicants as causes of physical or neurological dysfunction, yet there is a growing body of research that links environmental toxins to many forms of illness. Dioxin residues from PCBs and pesticides are associated with breast cancer (Thornton, 1993) and endometriosis (Gibbons, 1993). Pesticides have been associated with birth defects, Parkinson's disease (Semchuk, Love, & Lee, 1992), neurological dysfunction (Sherman, 1995), and childhood brain tumors (Davis, Brownson, Garcia, Bentz, & Turner, 1993; Gold, Gordis, Tonascia, & Szklo, 1979). Solvent exposures can engender neuropsychiatric dysfunction that persists long term (Baker, 1994; Morrow, Ryan, Hodgson, & Robin, 1991; White, Proctor, Echeverria, Schweikert, & Feldman, 1995) and includes decreased activity on a PET scan; EEG asymmetries; impairments in learning, memory, attention, and psychomotor speed; and elevations on every clinical scale on the MMPI (Morrow et al., 1991). Also associated with solvent exposure are mood distur-

bance, absentmindedness, sensorimotor disturbances, sleep problems, fatigue, and somatic complaints (Hooisma, Hanninen, Emmen, & Kulig, l994). Yet, these chemicals are pervasive in the environment and are found in high levels in some work or even home environments.

Social Action and Political Action

As some of the personal statements indicate, persons with MCS have responded by becoming involved in advocacy and political action. Women with MCS have begun support groups that educate and guide others in taking political action on environmental issues that relate to toxins and health. Some have taken a disability rights approach and demanded reasonable accommodation in the workplace, safe housing, and appropriate medical care for those already affected by MCS. Because many with MCS report that their health deteriorated following a large chemical exposure, others work on the larger issue of environmental pollutants in hope of preventing additional cases of MCS. Other educational and advocacy work has concerned the public's right to know about toxins to which people are exposed. Ingredients in fragrances are trade secrets and do not have to be revealed by manufacturers. Fragrances do, however, contain ingredients that are central nervous system (CNS) depressants (acetone, linalool, and a-terpineol) and/or lung irritants (benzaldehyde, benzyl alcohol, camphor, ethanol, and ethlacetate). Persons who took social and political action demonstrated Chircop and Keddy's (2003) change in value system, in that their reconsolidation process involved an awakening to environmental issues in the broad sense.

The actions of our industrialized society in the 20th century have endangered the health of many, and perhaps even the reproductive integrity of the human race (Colborn, Dumanoski, & Myers, l997). As Lax (l998) has pointed out, MCS must be understood within the context of industrial capitalism. Kroll-Smith and Floyd (l997) have called MCS "an indictment of modernity" (p. xi).

Making accommodations for those who are already sensitive is a necessary but not a sufficient response to the challenge of MCS and ES. People with these conditions certainly need safe housing, appropriate medical care, access to fragrance-free and, sometimes, cell phone–free opportunities for social interaction and accommodations in the workplace. All are important steps in responding to this sometimes-invisible disability connected with chemical and electromagnetic exposures. Often, work accommodations can be as simple as limiting smoking and fragrance and improving air flow (Labor Institute, l993). Informed medical care requires understanding and acceptance of the condition by practitioners rather than the delegitimization and denial that people with MCS currently face when they seek medical attention. The availability of fragrance- and smoke-free activities without cell phones or fluorescent lights in use depends on the compassion and vision of those who construct the interactions. For example, organizations such as the U.S. Architectural and Transportation Barriers Compliance Board (establishes guidelines for compliance with the American With Disabilities Act), the National Council on Independent Living, the Association for Women in Psychology (AWP), the National Women's Studies Association (NWSA), and Division 35 (Psychology of Women) of the American Psychological Association have all had fragrance-free national meetings.

Even these accommodations, however, are not a sufficient response to a condition that appears to have robbed 2% of the population of their livelihoods (Caress & Steinemann, 2003; Neutra et al., l999). A responsible MCS strategy requires helping those who are ill find housing, medical care, and accommodations, as well as preventing the spread of the condition. The approach must be holistic and systemic. Although individual accommodations can improve quality of life for those with MCS and should be provided, they are mere Band-Aids if we continue to sensitize greater portions of the population through further environmental degradation.

There is no known technological fix for MCS, although people search for one by using newer and larger air purifiers and experimental treatments. The only treatment that helps a majority of those with MCS is chemical avoidance (Gibson, Elms, et al., 2003; LeRoy, Davis, & Jason, l996).[1] We must understand the lesson in this and rethink our Western model of progress. Chircop and Keddy (2003) have encouraged us to "help investigate and hold accountable the sociopolitical forces that are responsible for the sanctioning and execution of environmentally hazardous enterprises" (p. 381). True progress is not single-mindedly linear and technological. It is, rather, based on more than just economic development, in that it is holistic and engenders quality of life for all people.

This study has several limitations. The use of a mail survey excluded those who are not literate, are not English speaking, were homeless or institutionalized at the time of the study, or who are so sensitive that they are made sick by any paper or ink. The distribution of our request for participants selected for persons involved in support groups. Members of CIIN in particular might be better educated and more politically involved than nonmembers. The static written questionnaire excluded any iterative element from data collection. The retrospective nature of the data collection allows for response bias. In addition, it is not clear how participants' responses to the identity question were influenced by other content in the larger questionnaire. It is possible that answering earlier questions influenced responses to the questions about identity. Some people spontaneously wrote comments such as "Wow. I really learned a lot about myself completing this."

Despite these limitations, we hope that this study can shed some light on the experience of having sensitivities and contribute to progress toward a truly inclusive society.

NOTES:

1. See the *MCS Information Exchange Newsletter*, 1996 to 1998, by A. Johnson, available from MCS Information Exchange, 2 Oakland Street, Brunswick, ME 04011.

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