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Access to Community Based Advocacy Services for Persons with Multiple Chemical Sensitivity

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Abstract

This paper describes results of an online survey of directors of Centers for Independent Living regarding customers with Multiple Chemical Sensitivities (MCS). Described are knowledge and perceptions regarding MCS, number of customers seen with MCS, accommodations and advocacy actions taken on their behalf, and resources needed to serve this population.

Keywords

multiple chemical sensitivity, chemical intolerance, chemical hypersensitivity

1. Introduction

Chemical Sensitivity (CS) is an invisible disability where people experience a variety of symptoms in response to everyday chemicals more easily tolerated by others. It is also referred to as multiple chemical sensitivity, chemical hypersensitivity, and chemical intolerance. Substances that commonly cause reactions in persons include formaldehyde, fresh paint, new carpet, diesel exhaust, perfume, and air fresheners, among others. Symptoms can affect respiratory, cardiovascular, digestive, neurological, and endocrine systems, and may include lethargy, difficulty concentrating, memory difficulties, nausea, headache, dizziness, irritability, and long-term fatigue (Ashford & Miller, 1998; Gibson & Vogel, 2007). CS has been shown to affect 12.6% of the U.S. population (Caress & Steinemann, 2003) with 4% developing symptoms from chemicals every single day (Meggs, Dunn, Bloch, Goodman, & Davidoff, 1996). CS has been researched in a number of countries other than the U.S. indicating that it is a global problem. In Sweden, 15.6% of teenagers (Andersson, Johansson, Millqvist, Nordin, & Bende, 2008) and 19% of adults (Johansson, Brämerson, Millqvist, Nordin, & Bende, 2005) report chemical sensitivity. In the Netherlands, 27% of adults reported experiencing multiple symptoms from chemicals (Berg, Linnegarg, Dirksen, & Elberling, 2008) and in Germany, 32% of adults blamed health problems on chemical exposure (Hausteiner, Bornschein, Hansen, Zilker, & Förstl, 2005). Japanese research has addressed characteristics of populations with MCS (Hojo, Ishikawa, Kumano, Miyata, & Sakabe, 2007;

Ishikawa & Miyata, 2000) and psychosocial factors in sick house syndrome (Imai, N., Imai, Y., & Kido, 2008).

Although individuals across age groups, socioeconomic status, race, and geographic locale are affected, MCS does appear to disproportionately affect women. Most persons report that the disability persists over time and large numbers of people are growing older with the problem. In addition, though this condition may begin at a young age, it may worsen over time due to the spreading phenomenon (Ashford & Miller, 1998). Once a person is on a downward spiral, she/he is likely to continue to decline (Gibson, 2014).

Life impacts of MCS may include unemployment, homelessness, lack of access to health care, and diminishing social support to the point of isolation (Chircop & Keddy, 2003; Gibson, Cheavens, & Warren, 1996; Larsson & Martensson, 2009). Workplace exclusion due to lack of accommodations is traumatic both economically and in terms of personal identity (Gibson & Lindberg, 2007). Many of these issues are addressed for individuals with visible disabilities through advocacy work by Centers for Independent Living and other similar disability advocacy services. Buildings can often be made handicap accessible and minimally invasive accommodations can be made to workplaces and homes. However, this is often not the case for the invisible disability MCS. Although chemical avoidance is the most effective treatment (Gibson, Elms, & Ruding, 2003), the required changes are often not made (Gibson & Lindberg, 2007).

Few health providers understand MCS and even fewer specialize in its treatment. Invisible disabilities in general tend to present not only difficulty in diagnosis and treatment, but considerable stigmatization (Dumit, 2006). Others' lack of knowledge and disbelief in MCS can lead to a lack of accommodation both in the work place (Vierstra, Rumrill, Koch, & McMahon, 2007) and in the community (Gibson, 2010), and to difficulty in acquiring services. Persons may request help from agencies mandated to work with persons with disabilities, including the Centers for Independent Living (CILs), nonprofit corporations established in the United States, Canada, and other countries to provide advocacy and tools for independent living to persons with disabilities.

The independent living movement supports community integration for people with disabilities and though initially praised as grassroots organizations engendered by disabled people themselves, the CILs operate in a cultural context that can limit their efficacy. Hasler (2005) has criticized the CILs in the UK, "Although independent living covers the full range of activities of a disabled person's life, CILs in the UK have tended to focus on a few core subjects, such as accessible housing and the use of personal assistants" (p. 228).

A 2009 study of the use of CILs by consumers with MCS showed uneven treatment and dissatisfaction from the point of view of the consumers (Gibson, Suwal, & Sledd, 2009). Of 68 respondents, 41 had applied to a CIL but only 17 reported receiving any services. Of the 41 who applied, 25 reported that the centers were not accessible or safe. Nineteen participants requested accommodations for their initial visit and 11 were not met. Fifteen of the respondents believed the staff member they worked with was “not at all familiar with MCS”, 20 said they were “somewhat familiar”, and 4 said “very familiar”. The current study examines perceptions regarding MCS and services provided to consumers with MCS from the perspective of CIL directors. Monitoring access and services available to an excluded population will help us to understand how persons with this invisible disability are treated by community disability services.

2. Method

2.1 Participants

Participants were 74 persons (60 women and 14 men), 47 of whom referred to themselves as CIL directors, 4 as coordinators, 6 as managers, and 17 as other, including advocates, specialists, and organizers. The majority was Caucasian (n = 62), with 2 each identifying as African American, Asian American, Native American, and Pacific Islander. One person self-described as Latin American and 2 did not identify race.

2.2 Materials

A 71-item questionnaire was created to assess knowledge and experience of Directors of Centers for Independent Living regarding people with Multiple Chemical Sensitivities. We asked how knowledgeable respondents were about MCS, what sources they had used to obtain this knowledge, and what their views were regarding etiology. We then asked how many consumers with MCS had been seen at their center, what services and accommodations had been provided, and what policies, protocols, and staff education regarding MCS were implemented at their center. Last, we inquired about what would help the centers to better serve those with MCS.

2.3 Procedure

After receiving approval from our university Institutional Review Board, we placed the survey on Qualtrics, an online survey maker, and sent the link via e-mail to all directors of CILs in the continental United States, Hawaii, and Alaska. We contacted 646 CIL directors through e-mail addresses retrieved from the Independent Living Research Utilization website. We placed 80 phone calls to CILs whose e-mail addresses were invalid. This resulted in an additional 27 e-mail addresses, six of which bounced back. To boost participation, we sent three e-mail reminders thanking those who had participated and requesting input from those who had not yet responded. In addition, participants were offered an incentive of having their name entered into a raffle for a $50 gift certificate to Amazon.com. Once the survey was closed, we eliminated surveys that were more than half blank and multiple surveys that had come from the same IP address (and hence the same computer). When multiple responses came from the same location, we retained the first or most complete response or the response from the person with the most responsibility in the organization. This resulted in 74 completed surveys.

3. Results

The majority (69%; n = 51) of respondents had been employed with their CIL for four or more years and 89% (n = 66) of respondents categorized themselves as having disabilities. Mean age for respondents was 51 years. When describing their familiarity with MCS, 52.7% (n = 39) responded that they were "somewhat familiar", 40.5% (n = 30) "very familiar", and 6.7% (n = 5) said that they were either "somewhat" or "very unfamiliar" with MCS. When asked how satisfied they were with their knowledge of MCS, 19% (n = 14) described being "very satisfied", 61% (n = 45) "somewhat satisfied", and 20% (n = 15) "not at all satisfied". Respondents had learned about MCS through the internet (64%; n = 47), by reading journal articles on chemical sensitivities (64%; n = 47), through reading materials from consumers (62%; n = 46), through the media (i.e., television or radio) (35%; n = 26), by reading the 2002 ILRU booklet on "Understanding and Accommodating Multiple Chemical Sensitivity" (27%; n = 20), through reading one or more books focused on MCS (22%; n = 16), or by attending an MCS conference (12%; n = 9). When asked about the etiology of MCS, 11% (n = 8) saw MCS as being all physiological, 42% (n = 31) said mostly physiological, 43% (n = 32) said that it was combined psychological and physiological, 1% (n = 1) said mostly psychological, and no one saw it as all psychological. See Table 1 for more detail regarding respondents' views of MCS etiology. Eighty-four percent of respondents reported that their center had *ever* seen a consumer with MCS (n = 62). In the *past year*, 36% (n = 27) had seen 1-2 consumers with MCS, 24% (n = 18) 3-4, 7% (n = 5) 5-8, 1% (n = 1) had seen over 8 consumers, and 28% (n = 21) had not seen any.

When asked if the center had a policy or protocol for working with MCS consumers, 42% (n = 31) did and 55% (n = 41) did not. Although only 42% (n = 31) of centers had *official* MCS policies or protocols, 62% (n = 46) actually described some policy or practice in place to address the needs of MCS consumers (Table 2) and 77% (n = 57) did have a policy regarding the use of fragrances in their centers (Table 3). Fragrance-free policies can be difficult to implement and Table 4 describes methods used by centers to communicate/enforce these policies. When asked if the center had a designated staff member advocating for consumers with MCS, only 9% (n = 7) did and 89% (n = 66) did not.

Centers had provided a variety of accommodations and services to consumers with MCS in order for them to access both the centers and the outside community. Centers limited fragrance and chemical cleaners, met consumers outdoors or at alternate locations, and advocated in the community for workplace, community, and housing accommodations. Table 5 lists accommodations and services offered.

When asked to specify any additional services provided to consumers with MCS, two CILs reported having a peer support program, one offered a support group specifically for MCS consumers, and one offered phone support to an MCS consumer who phoned the center regularly during her relocation to a safer geographic area. In addition, two CILs used air purifiers, one moved offices to escape harmful cleaning products, one helped a consumer remove a "smart meter" (known to emit higher EMFs than standard meters) from his/her home, one assisted a consumer in getting home care, one provided referrals and information, and one provided independent living training for MCS consumers.

Difficulties reported by CILs when serving consumers with MCS included mounting the necessary advocacy to secure external resources and accommodations; assisting consumers in finding employment suited to their needs (such as jobs that require no exposure to ink); finding safe housing, education, and health care; and providing support groups. Furthermore, centers listed other problems hindering their ability to help MCS consumers. For example, one center listed problems with accommodating their own staff with MCS; another had difficulties with chemical emissions from neighboring businesses. In addition one center commented that consumers sometimes lacked awareness that they experienced MCS. Because MCS is a "contested" illness, centers reported problems with doctors, landlords, business owners, and CIL staff that were unfamiliar with the condition. Problems with arranging meetings for consumers with MCS were also identified. Centers reported problems with meeting off site, meeting outside, consumers who were too sensitive to meet at all, and with phone meetings. Some CILs experienced problems controlling exposures within the center including exposures to fabric softeners, cleaning chemicals, perfumes, and fragrances on walk-ins and those who disregard the fragrance policy. In addition, centers reported remodeling issues, problems with EMFs in the center and staff failing to make appropriate adjustments. Finally, CILs identified problems serving consumers with MCS because of characteristics and behaviors of some MCS consumers. For example, some had multiple disabilities, were unable to focus, refused to give any information or sign up for services, and cancelled appointments because of illness episodes.

4. Discussion

Most centers had seen consumers with MCS, though over half did not have any formal policy for serving this population. Only 9% reported having a designated staff member to serve people with MCS. Despite this, many centers had made accommodations for MCS consumers such as moving offices, removing harmful carpeting, using air purifiers, etc. Almost half had assisted consumers with MCS in making their services more accessible through alternative types of meetings. These changes are very helpful to and can help gain access for those with MCS. The community assistance most often given by CILs to MCS consumers included advocacy for housing and for workplace accommodations. CILs identified a need for more information on MCS. Most CILs in the study were open or enthusiastic about the possibility of education and/or training regarding MCS.

Problematic for those who experience MCS is the fact that some respondents identified psychological factors as components of MCS etiology. These beliefs can interfere with viewing MCS as a true disability and stigmatize consumers who request advocacy.

Limitations of the study include some inactivated e-mails, the necessity of making phone calls to acquire current e-mails, and centers that were uncooperative on the telephone. The e-mails gathered from the ILRU website had not been updated for two years; as a result some of the e-mails listed were inactivated, went to the wrong recipient, or bounced back. To compensate for the bounced back emails, we called the specific center when an e-mail bounced back to acquire their most current director's e-mail. Of those that we called, some refused to even talk to the student researchers. For example, one center refused to give us their e-mail address multiple times when we attempted to get in contact with their director.

Furthermore, the response rate was very low in comparison to the number of e-mails we sent. Although they had an incentive of qualifying for a drawing to receive a $50.00 gift certificate from Amazon.com, complete protocols were gathered from only 74 centers. Some centers completed the survey more than once, causing us to have to delete duplicate responses. Because of the low response rate it is uncertain whether these results are representative of the attitudes and experiences of CIL directors. It is likely, however, that these centers are the *most* amenable to discussing the issue, and it may be that results would be more negative had we been able to get a higher response rate.

Because the experiences of consumers have varied so greatly and some have been very negative (Gibson et al., 2009), it is important to find ways to make services at CILs inclusive for persons with MCS. The life impacts of MCS are potentially so severe that community response is mandatory. Access is often poor (Gibson, 2010) making it difficult for persons to use the services of physicians, libraries, parks, and even education. Healthcare needs are often unmet (Gibson, Leaf, & Komisarcik, 2016; Gibson, Kovach, & Lupfer, 2015), and even social workers who regularly work with this population have been shown to be unaware of the needs of these clients (Doiron, 2007). Though CILs do not have unlimited resources, materials and resources to work with consumers with MCS are available. For example, in 2002, a guide to understanding and accommodating persons with MCS was distributed to every CIL and Vocational Rehabilitation Center in the US, Canada, and US territories (Gibson, 2002).

The lack of formal policies, scarcity of designated staff, and problems with serving MCS consumers may explain some of the obstacles experienced by CILs in serving consumers who experience this disability. The wide variability in the availability of services and protocols makes for uneven services between CILs for persons with MCS. Directors identified education, information, and training as their largest needs in relation to serving consumers with MCS. Updated information targeted to CIL advocates and encouragement from directors to self-educate could improve knowledge amongst staff and thereby improve potential MCS services. Future research could include surveying MCS consumers on their experiences since 2009 with CIL staff.

In addition, understanding that everyday toxics are risk factors for sensitive populations, and, by many accounts, for all populations, would take us in safer directions regarding building, maintenance, and stewardship of public spaces. For example, in the Hojo et al. (2007) study, over a quarter or respondents (27.4%) reported that pesticides/agricultural chemicals initiated their MCS. Fox and Kim (2004) said, "Understanding predisposing and sustaining risk factors of persons with emerging disabilities is necessary before system-wide independent living interventions can be developed through centers for independent living, public health departments or other state-wide agencies involved in implementing disability policy" (p. 325).

Once these environmental risk factors are understood, the person with MCS will no longer be a de-contextualized entity and, as such, a target for within-person attributions that place personal blame or invoke psychological etiologies for chemical intolerance (Gibson, 1997). When disabilities in general are understood to be "produced and perpetuated" (Davidson, 2005) by environmental factors, understanding of environmental sensitivities will follow. Davidson has eloquently explained the need for viewing disabilities in a global perspective:

If we imagine that disability is something that bodies "have" or display, then we restrict the meaning of the term to a medical definition of that impairment. But if we imagine that disability as defined within regimes of pharmaceutical exchange, labor migration, ethnic displacement, epidemiology, genomic research, and trade wars, then the question must be asked differently: does disability exist in a cell, a body, a building, a race, a DNA molecule, a set of residential schools, a special education curriculum, a sweatshop, a rural clinic? The implications of seeing disability spatially force us to re-think the embodied character of impairment and disease (p. 119).

Table 1. Views of Seventy-Four CIL Directors Regarding the Etiology of MCS

In your view, how often is MCS the result of:	Never	Sometimes	Often	Always
One large chemical exposure	4	59	9	0
Ongoing low chemical exposure	0	36	34	2
Result of genetics	15	45	10	1
Psychological factors or disorders	19	45	6	0
Result of stress	16	43	13	0
Elevated risk perception	16	50	3	1
Personal belief or expectation	29	35	7	0
Exaggerated fear of chemicals (chemophobia)	21	44	4	0

Table 2. Components of MCS Protocols at 74 CILs

MCS Protocol	Frequency
Center is scent free	13
Accommodations are made for meeting with MCS consumers	12
Scent free policy is posted	10
Natural cleaning products are used	6
Minor adjustments are made	6
Scent free events and classes are held	4

Environment is chemical-free	3
Staff restrictions	3
No smoking	3
Meetings are held by phone	2
Home visits are made	2
No air fresheners/deodorizers are used	2
No scented candles are used	2
Air filters are used in facilities	2
Nontoxic material used for remodeling	2
Removal of carpeting for support groups	2
Currently developing a protocol	2
Staff ask for input prior to first meeting	1
Unwritten but enforced policy	1
Accommodations are made for interviews	1
Consumers are met in private room	1
Consumers are met in “safe room” with minimal exposure	1
Consumers are met outside	1
Posted “cleaner air” sign (indicative of comprehensive clean air policy)	1
Those with strong fragrances are asked to reschedule	1
Air filters are used in vehicles	1
Flexible work arrangements are made for MCS staff	1

Table 3. Fragrance Policies at 74 CILs

Fragrance policy	Frequency
No Fragrances	20
No perfumes/colognes	16
No scented cleaning materials	12
No room sprays/air fresheners	9
No candle/potpourri	5
No Aftershave	4
No smoking	4
No hair spray	2
Clean when people are not in office	2
Avoid nail polish	1
Avoid nail polish remover	1
Avoid marking pens	1

Avoid diesel fuel and exhaust	1
No alcohol	1
Scent-free office supplies	1
No scented deodorant	1
No Volatile Organic Compound (VOC) paint	1

Table 4. Implementation of Fragrance-Free Policies at 74 CILs

Policy implementation	Frequency
Posted notice of fragrance-free policy	8
Off-site events are fragrance-free	6
Fragrance-free policy for staff	4
Employee handbook instructions regarding fragrance-free policy	2
Fragrances banned in and out of office	2
Publications informing of fragrance free policy	2
Fragrance-free policy given to consumers during intake	1
All those involved in center refrain from using chemical substances (staff, volunteers, visitors, board members, and consumers)	1
Employees with MCS must contact director/supervisor to set up a plan	1
Only approved supplies and equipment used	1
Staff training on fragrance-free policy	1

Table 5. Number of CILs (out of 74) Providing Particular Accommodations and Services to MCS Consumers

Has a representative from your center ever:	Frequency
Refrained from using fragrance and other scented products when meeting with an MCS consumer?	63
Alerted consumers to any chemical changes in the office environment (such as painting or new carpet)?	48
Lessened the use of chemical cleaners or products for a consumer with MCS?	47
Refrained from using chemical pesticides in order to accommodate persons with MCS?	43
Advocated for accommodations in the workplace for a consumer with chemical sensitivities?	37
Made a home visit to accommodate a consumer with MCS?	35
Helped a consumer with MCS search for safe low-income housing.	34
Met with a consumer at an alternative location to accommodate chemical sensitivity?	34

Helped a consumer with MCS find counseling or a support group?	24
Helped a consumer with MCS make his/her home free of chemical incitants?	23
Assisted a consumer with MCS with transportation to the community center.	19
Helped a consumer with MCS to receive community accommodations such as fragrance-free hours in a library or other public setting?	17
Helped a consumer with mcs set up self-employment?	11
Helped a consumer pay for medical care?	10
Helped a consumer with MCS pay for oxygen?	5
Helped a consumer with MCS apply for workers compensation?	4

Table 6. Resources Needed by 74 CIL Directors to Better Serve Consumers with MCS Frequency

Education and Information	14
Training	7
Training from an expert	4
Advocacy tips/hints for serving those with mcs	4
In-service	2
Experience working with MCS consumers	2
Internet links to resources	2
Scent-free society	2
Educational videos	1
Simple reading materials/poster	1
Resource guides to local community for MCS consumer	1
MCS listed under ADA	1
Copies of ILRU Booklet	1
Newsletter updates	1
A webinar	1
People with MCS to come and talk	1
Consumer oriented information	1
Information to give to public (non-MCS people)	1

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