

Social and Medical Implications of psychosomatic labelling of MCS individuals

By Dr Sharyn Martin 2011

Perpetuating the psychogenic view has created barriers between health care providers and patients with Medically Unexplained diseases such as CFS, FM and MCS and those with chronic pain. The common social outcomes in these instances are stigma, the experience of isolation and experience of emotional distress. The RACP 2002 Chronic Fatigue Syndrome (CFS) Clinical Practice Guidelines state that somatisation and somatoform are unhelpful diagnostic labels that are best avoided in patients with CFS. (RACP, 2002)

Unless there is direct evidence of malingering, speculative judgments about unconscious motivation should be avoided. *'The psychoanalytical concept of 'secondary gain' has been misused in medicolegal settings and does not rest on a solid empirical base'*. (RACP, 2002)

'It is all too easy for practitioners to collude with the insurance industry in unethical 'deny benefits' at all costs practices. These cases included 'expert' reports in which clinicians seemed oblivious to the fact that compensation neurosis is an outdated oversimplification of complex issues (Cantor, C and Neulinger, K. 2003)

Although the pathogenesis of MCS is not fully understood, this does not make it right to decide MCS is a psychological problem (Read. 2002 p. 25, para. 4). Such an approach cannot be justified medically or ethically. The New Zealand MCS report states *...It is important not to conclude that because a biological cause has yet to be determined then MCS should be considered a psychological disorder*. (Read, D. 2002)

Emotional, Behavioural Problems are not unique to MCS

There are psychological problems associated with living with chemical sensitivity, and similar pressures exist for other conditions and diseases that affect a person's whole life. Recent research with better defined patient populations concluded that psychiatric symptoms are more likely to stem from, rather than to cause, symptoms of environmental sensitivities.

Although emotional and behavioural problems, including depression, are more frequently found in people with sensitivities, fibromyalgia (*and other Medically Unexplained Diseases*) than in the general population, psychological symptoms cannot be accounted for by psychiatric illness alone (Sears E, 2007).

People dealing with a poorly recognized chronic illness that affects their brain, impairs their quality of life and earning potential, and has impacts on family and friends, would be under psychological distress. They could be expected to report anxiety and depression'. (Sears, M E 2007).

In fact psychological symptoms are a consequence of many disorders such hypothyroidism and UTIs, and are seen for what they are – an aspect of the disease and not the cause. 'Adding to the complexity for those with MCS are that findings that environmental factors such as pesticides and moulds have been shown to be associated with symptoms such as depression and anxiety'. (Sears, M E 2007)

In a study to assess the relationship between self reported chemical sensitivity, allergy and medical illnesses to anxiety and depression anxiety was positively associated with all three. Depression was comparable to anxiety in associations with chemical sensitivity and allergy, while it was more related to other illnesses. The relationship between chemical sensitivity, allergy and medical illnesses is not unique and does not support the contention that chemical sensitivity is somatised anxiety (Bloch, R M and Meggs, W J. 2007)

"The existing literature, although dispersed across many disciplines, suggests that many unexplained clinical conditions—for example, the chronic fatigue syndrome, fibromyalgia, and temporomandibular disorder—share demographic, clinical, and psychosocial features, as well as objective findings. In fact, it has been suggested that the diagnosis assigned to patients with one of these illnesses depends more on chief symptom and clinician specialty than on the actual illness " (Aaron and Buchwald, 2001).

“Comparative investigations in referral clinic populations have reported that up to

- 70% of patients with fibromyalgia meet the case definition for the chronic fatigue syndrome and, conversely, that
- 35% to 70% of patients with the chronic fatigue syndrome have fibromyalgia.
- Moreover, 13% to 18% of patients with temporomandibular disorder meet fibromyalgia criteria and
- 75% of patients with fibromyalgia satisfy the case definition for temporomandibular disorder.
- Other painful conditions, such as tension headache, also commonly co-occur with fibromyalgia.
- Furthermore, 32% to 80% of patients with fibromyalgia, 58% to 92% of patients with the chronic fatigue syndrome, and 64% of patients with temporomandibular disorder also have IBS.

- Conversely, 32% to 65% of those with IBS meet the criteria for fibromyalgia.
- Moreover, one study showed that the symptoms reported by patients with fibromyalgia and patients with interstitial cystitis were more similar to each other than to those reported by healthy controls.
- Finally, in 53% to 67% of persons with the chronic fatigue syndrome, illness worsens with exposure to various chemicals, and
- 55% of persons with fibromyalgia have symptoms consistent with multiple chemical sensitivity.
- In contrast, 30% of patients with multiple chemical sensitivity meet the criteria for the chronic fatigue syndrome.

Taken together, these direct comparisons of patient groups generally demonstrate high rates of diverse clinical conditions regardless of the condition examined.”

“In studies that assessed patients with a single unexplained clinical condition for the presence of at least one additional syndrome found that,

- among patients with fibromyalgia,
- 21% to 80% have coexisting chronic fatigue syndrome (39, 43, 61),
- 36% to 60% have IBS (8, 27, 32, 40, 43, 48, 51),
- 10% to 80% have headaches (27, 32, 43, 57),
- 75% have mandibular dysfunction (35), and
- 33% have multiple chemical sensitivity (54).
- Many patients with the chronic fatigue syndrome also have
- IBS (63%) (49),
- multiple chemical sensitivity (41%) (64), and

- other unexplained illnesses (67).
- Of interest, these studies suggest that sex may influence the co-occurrence of unexplained clinical conditions. For example,
 - IBS is more common among women (40%) than men (14%) with fibromyalgia (66), and
 - fibromyalgia occurs more often in women (36%) than men (12%) with the chronic fatigue syndrome (12)."

"The patients' symptoms and syndromes have been called "functional," "somatic," "medically unexplained," and "psychosomatic....A major limitation of all categories of explanatory models is their inability to account for the occurrence of unexplained clinical conditions in a large proportion of affected patients (for example, many patients do not have depression, have not been abused, or do not demonstrate neuroendocrine changes at the time of testing)." (Aaron and Buchwald, 2001)

Evidence against psychiatric/psychological mode

'Physicians seeking the most efficient and effective treatments have found that when people with environmental sensitivities were placed in an uncontaminated environment in which their physical symptoms resolved, their psychological symptoms also resolved. Successfully alleviating symptoms of sensitivities (with safe housing, workplaces, food, water, etc.) is necessary before other psychosocial interventions may be helpful.
(Sears, M E 2007)

Saito in 2005 found that MCS patients do not have either somatic or psychologic symptoms under chemical free conditions and symptoms may be provoked only when exposed to chemicals (Saito, M et al. 2005)

Development of sensitivities usually pre-dates symptoms of depression and anxiety in people with sensitivities, with 1.4% of patients identifying problems before the onset of sensitivities and 38% reporting the development of depression, anxiety and other symptoms after sensitivities

became apparent. (Sears, M E 2007)

Caress et al, 2002 found that only 1.4% of subjects reporting hypersensitivity to common chemical products had a prior history of emotional problems, whereas 27.7% developed problems after the emergence of hypersensitivity to chemicals.

Seeber et al, 2002, found that influences of trait anxiety and chemical sensitivity on reports of annoyance, bad odor or irritation are only weak. While there was a correlation between odor or bad smell and annoyance, reports of sensory irritation did not correlate to annoyance. In this study measures of self reported irritation were sufficiently reliable to show a dose-response relationship to various sensory irritants.

When abnormal psychological/psychiatric data are obtained on personality tests or from interviews administered to patients who report symptoms of MCS, investigators typically attribute these to either psychiatric traits or psychogenic origins of illness. A study by Davidoff et al, in 2000 evaluated the plausibility of non psychiatric explanations of psychologic/psychiatric symptom data. The study results show the strategy of administering psychometric tests to ill populations for the purposes of evaluating psychiatric illness or traits, and/or psychogenic origins of illness was shown to be potentially misleading (Davidoff, A L et al. 2000)

Psychogenic labelling has been found to be unhelpful and damaging.

“Psychiatric labelling is generally unhelpful. In most cases, there is little evidence that the disorder is “psychosomatic”, and inappropriate speculation about “school phobia” may be damaging and counterproductive. Early correction of such misunderstandings leads to fewer difficulties in the long-term.” (RACP, 2002)

In fact Joffres et al, 2001 state that ‘A priori labelling of these symptoms as psychogenic has done tremendous harm; It has hindered the ability of affected individuals to seek help, and also the amount of research conducted. It is time to recognise that we cannot separate the psyche

from the physical dimensions of the human being and that we must understand and support ES (environmental sensitivity) sufferers' (Joffres, M R et al. 2001)

While the debate continues into the causes of MCS, 'The controversy and confusion regarding the aetiology of MCS translates into poor medical diagnosis and treatment for patients with MCS (Gibson PR et al, 1998). Gibson reported in an earlier article that persons with MCS reported seeing a mean of 8.2 physicians each, waiting 7.5 years for a diagnosis spending a considerable amount of money on their health, receiving misdiagnoses, and suffering iatrogenic harm' (Gibson, P R et al. 1998).

Gibson and Vogel's study in 2009 found that people with MCS have an overall mean Sickness Impact Profile score of 25.25%, showing serious impairment, with the most serious dysfunction in the categories of work (55.36%), alertness behaviour (53.45%) and recreation and pastimes (45.20%). They found that chemical sensitivity is poorly understood by providers and results in extensive financial and treatment obstacles for those who experience it. Understanding the impact of the health condition is crucial to communicate with and treat persons who experience the sensitivities (Gibson and Vogel, 2009)

Graveling et al in their literature review found that for a small number of people MCS does exist and the available evidence seemed to strongly support a physical mechanism rather than a psychological basis. (Graveling, R A et al. 1998)

'Research shows that psychological interventions are not entirely effective. For example, cognitive-behavioural therapy, used to desensitize one to the fear of sensitivity to substances, only partially reduced symptoms in a single case. Medication and psychological interventions may be used to treat phobia or panic disorder, but for individuals with environmental sensitivities, lasting benefits have been achieved only by avoiding incitants.

In a survey of 917 people with multiple chemical sensitivities, tranquilizers and antidepressants were the least effective therapy and caused harm (possibly because of a genetically-determined inability to metabolize them). In another study, psychological treatment of medically unexplained physical symptoms provided no additional benefit compared to care by a general practitioner'. (Sears, M E 2007)

Some problems found in the 2000 Gibson study associated with psychotherapists were:

- Inadequate medical screening
- Not listening to what patients say
- Fitting new problems into old categories
- Psychological intervention for individuals with MCS has been anything but supportive
- People reported having felt harmed by mental health providers e.g. prescribed psychoactive drugs
- Gender bias in mental health especially affects women
- Inappropriate psychological labelling was distressing e.g. depression, schizophrenia, post traumatic stress disorder ... because individuals were affected by chemicals
- Contamination of depression inventories with somatic items
- Inappropriate test methods
- Ignoring studies that support physical explanations(Gibson, PR 2000)

Lack of education about the dangers of chemicals and MCS can also add to the distress of individuals with MCS. Their self-management efforts can be misunderstood by the general public and police, who may then involve local mental health services. Some individuals with MCS have been detained in a mental health facility which is basically dangerous for them (Sears, M E 2007). Once detained they are in an unsafe environment in which they can be exposed to triggering substances that can cause them more harm, and if medicated can suffer dangerous reactions – individuals with MCS can die as a result of chemical exposure.

Social and Medical Consequences

Using a psychosomatic basis is not helpful and dismissive of the needs of those with MCS.

For those with MCS, if the psychogenic approach is not changed, individuals with MCS will continue to experience prejudice in their efforts to get safe and appropriate health care. They will not be believed and will continue to be trivialised by clinicians in their efforts to have their needs safely and properly addressed.

Individuals with MCS usually have other diseases, some of which are chronic, painful and disabling conditions. These are not necessarily related to MCS, and can be diseases requiring health interventions. Such conditions can be missed or left untreated if an individual is thought to have a psychological problem and individuals with MCS will simply go on suffering the most

appalling physical distress, compounded by insults and inhumanity

Disability status and eligibility for support is mediated by the medical profession. It can be 'hit and miss' as whether or not a medical professional understands about MCS and is sympathetic. Health care providers are also aware of the 'stigma' of being seen as pro MCS and the marginalised by mainstream medicine. It becomes difficult to impossible to be included in medical, social and disability services.

Insurers, industry and states have a vested interest in denying and dismissing claims. There is a long process of claims and counter claims, defendants employing defer and delay tactics. For those with MCS the process of exclusion from services because of suggestions of a mental illness it is insulting and humiliating.

The lack of acceptance and integration into the medical institutions leaves health care inaccessible to those with chemical sensitivities.

A psychosomatic view ignores:

- The existence of massive information on the effects of chemicals on health in the general population for example air pollution and heart conditions, asthma;
- Existence of documentation on physiological stressors and physiological changes in MCS

Maintaining and perpetuating this view:

- Means that disability advocates will continue to be unfamiliar with the chemical barriers and may view access as low priority and competing for limited resources. Disability services will continue to be ill equipped to accommodate the needs of those with MCS
 - Removes motivation for advocates and others who interact with people with MCS to attempt to understand the complexity of how chemical sensitivities develop and impact on people's lives.
 - Long term damage to prospects of research projects, clinical guidelines and chance of quality of care

- Short (and long) term damage to sufferers and their families

As well as denied treatment/acknowledgement of MCS, denied medical treatment for non-MCS related disorders.

Impact on families and family dynamics.

Alternative 1. Family/partner do not support sufferer.

- The medical stigma of psychogenic origin reinforces social and cultural ideals and provides a basis on which MCS can be denied.
 - Family, friends may experience and display anger and frustration at the sufferer not being able to function 'normally'.
 - Families may be unwilling or unable to accommodate MCS
 - Sufferer may try to fit into a 'contaminated' environment, which leads to worsening of the condition.
 - Leads to family breakdowns
 - Sufferer even more isolated with less support and human contact

Alternative 2. Family/partner does support sufferer and takes measures to protect the sufferer

- May be accused of encouraging the illness behaviour
- Where child a child suffers from MCS may be removed from the family 'in the child's best interests'
 - Where a partner/spouse involved, they may be accused of denying treatment, eg by not taking sufferer to hospital or medical facility that the partner/family knows will exacerbate the condition

- Family members and partners may also experience some degree of isolation (from friends, family, social contacts).
- They need to take on extra responsibilities and activities such as the shopping, , appointments for general services (such as dealing with banks, car registration etc)

As well as being denied treatment/acknowledgement of MCS, people with MCS are denied medical treatment for non-MCS related disorders. The implications for the family is - How are they to deal with major medical events when they may need to deal with an emergency and take them to a hospital?

Life Impacts for people with MCS (Gibson et al, 2007)

Work and Finance.

- Up to 75% of people with MCS are unable to work, of those only 7% considered their environment safe
- Many of those unable to work were forced from the workplace
- Many have difficulties with obtaining WCB, insurance claims and disability pensions

An ASEHA 2011 survey found that 84.8% of respondents with MCS reported being unable to work.

Medical and Social Services Care

- Inaccessible for the majority of those with MCS.
- Barriers include chemical pollution, expensive medical costs, treatments ineffective with many doing more harm than good

A 2011 ASEHA survey of MCS sufferers found that 59.5% were unable to access Health Services, and 83.3% to Allied Health and Respite Care Services. Only 39.5% considered that their GP to be helpful, 30.2% sympathetic and 30.2% neither. Sixty-six percent reported that

they were unable to access Disability and Social Services. The reasons given for the inability to access services were poor indoor air quality, perfumes, pesticides, finances and inability to qualify.

Housing

- Low to no income means unable to find appropriate housing
- No appropriate housing available
- Increased expenditure in an attempt to make home safe
- High relocation costs often out of reach
- Relocation can increase isolation

The combined negative impact from issues with Work & Finance; Medical & Social Services care and Housing has a compounding negative on personal distress and identity changes.

Personal distress

- Loss of work
- Lack of medical care
- Limited housing opportunities
- Limited public access
- General disbelief from layperson and professionals

People with MCS experience unwelcome identity/personality changes due to

- Chemical exposures and isolation
- Loss of sense of 'role in society'
- Exclusion/inability to perform in 'family role'
- Having to completely re-plan and re-design their lives and future.

All of these compounding factors leads to

- Further isolation (physical and social) and trauma
- 1/5 MCS sufferers have seriously considered suicide with 3.3% having made suicide attempts in the Gibson 2007 study.
- Low social support with families and friends unwilling or unable to understand or accommodate their sensitivities
- Lack of acceptance and integration into medical institutions leaving health care inaccessible Gibson, 2007

An ASEHA 2011 survey found that

The degree of isolation (*from community, friends, family, distance*) amongst people with MCS was 37% high, 50% medium and 13% low isolation.

The degree of disability amongst people with MCS was 52.2% total, 43.5% partial with only 4.3% not disabled.

People with MCS suffer a loss of a stable family life, 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 and are in line with that in people with chronic illness and other delegitimized illnesses (Gibson et al, 2005).

Rather than physicians not be able to help people with MCS there are a number of areas where GPs can assist such as Letters or paperwork required for social welfare services.

- In-home support
- Carers
- Unemployment benefits
- Sickness benefits
- Disability support
- Compensation payments for workplace injury
- Referral to specialists, physiotherapists and OTs etc – MCS patients are likely to have other chronic health issues that require specialist care or other type of intervention.
- Government Housing suitable for allergy/MCS patients

- Home schooling
- Disability parking
- Assistance with medical aids e.g. wheel chair, oxygen at home
- Aged care or respite services
- Pain management services
- Chronic illness/loss/grief counseling
- Social workers
- Rehabilitation
- Ambulance transport services

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