

Dear Sir or Madam,

I am writing with respect to the redraft of the report entitled "A SCIENTIFIC REVIEW OF MULTIPLE CHEMICAL SENSITIVITY: IDENTIFYING KEY RESEARCH NEEDS".

I have a Masters in Statistics and I am also a sufferer of chemical sensitivity. I wish to make a few comments on statistical issues in this report. I hope to be able to explain these issues in a simple enough manner so that someone with no statistical or scientific background may be able to understand.

Comments on Section 3.1.8 Psychological Factors

The major flaw of the studies in this section is that psychological studies are likely to attract people with psychological problems who feel that the study may be in some way beneficial to them and discourage some sufferers without psychological problems who feel that a psychological study is pointless for MCS sufferers. Hence such a study would not be representative of the average MCS sufferer. This is called **SELECTION BIAS**. Selection bias occurs when study subjects are not chosen in a manner which is representative of the group of interest as a whole. One study in this report, (Witthöft et al., 2008), noted that its subjects had an "enhanced trait of absorption (related to suggestibility, openness to experience, and fantasy proneness)" and this was used to suggest that MCS symptoms are psychological in origin. However, this is just the sort of patient profile you would expect in patients willing to participate in a psychological study for a non psychological illness. This is because a study focusing on a psychological explanation for a non psychological illness is likely to attract two types of participants:

- 1) MCS sufferers who have psychological conditions
- 2) MCS sufferers who don't have psychological conditions but are suggestible and open to experience and therefore willing to participate in a study that most MCS sufferers would see as pointless.

The obvious exclusions from the study are MCS sufferers that are not suggestible and have a strong belief that their illness is not psychological in origin. The high rate of absorption noted in the aforementioned study is likely to do nothing more than illustrate the above error in selection bias and the exclusion of the third group. I believe that selection bias may be a problem for many of the studies in this section and may explain why some studies in this section record such high rates of psychological symptoms while others do not (Caress and Steinemann (2003)). Selection bias is a major concern. If selection bias occurs it will invalidate a study.

Another concern in this section is how reliable the scales that have been used to measure various psychological/psychiatric traits may be. From the report I quote:
"The prevalence of psychiatric morbidity in MCS has been studied. Black (2000) reported that depending on the assessment procedure used, the prevalence of psychiatric disorders in MCS subjects ranges between 42%-100% ".
Why is this statistic so vague? There is a massive 58% region of uncertainty in this statistic. It is not acceptable to put a difference of 58% down to different assessment procedures – this just implies that the assessment procedures are not reliable. Either a

person has a psychiatric disorder or they don't and if different assessment procedures give different results then one of them is clearly wrong. So this leaves us with the question: Is the determination of psychiatric disorder reliable? Obviously, the implications are very different if the true prevalence is 42% rather than 100%. If the true prevalence is merely 42% then this tends to suggest that psychiatric disorder is not the cause of MCS.

This section also talks about two studies on psychological factors in MCS and somatoform disorders, (Witthöft et al., 2008) and (Skovbjerg et al., 2009), that differ on the variable of absorption. This difference is attributed to "different questionnaire formats and also to different control groups, in this latter case a population control group not of healthy individuals but of individuals sensitive to odorous chemicals but who had not pursued medical care." I find it very worrying that this study seems to find it acceptable that different questionnaire formats can produce different results.

Comments on Section 4.1.2 Studies on the prevalence MCS in other countries

In this section a study, (Bell et al., 1996), on MCS symptoms in a university reports a rate of prevalence of 0.2% for physician-diagnosed MCS. It should be noted that this can in no way be used as a prevalence estimate for MCS in the general population because people who are unwell are more likely to stay at home hence any prevalence rate taken at a university would be a gross underestimate of the true prevalence rate in the general population. I find it very misleading that this prevalence rate is included in this report as the way the report is worded at the moment most readers will not realise that this is not the same as a prevalence rate in the general population. Some comment needs to be added that this rate should be expected to be much less than the prevalence rate in the general population. Furthermore, in the last paragraph, I think that the observation that "the prevalence of MCS ranges from 0.2% to 4% for populations or selected population subgroups" is just not meaningful when the lowest percentage comes from a subgroup that is biased in favour of healthy subjects. Perhaps it would be less misleading to just quote the prevalence estimates for general populations rather than subgroups in this summary fashion.

Comments on Section 5.3.3 Prognosis and Treatment

While I think that the ideas in this section are a good start I do not feel that they will be enough to even maintain a stable level of health for most patients. For instance this section states:

"Self-management involves providing the patient with information about the nature of the problems being experienced and guidelines regarding symptom management"

While I think that providing patients with information for a self management approach is a good idea it will take a lot more than this to make self management possible. It is possible to be very informed about chemicals in our society but still be unable to reduce exposure to a tolerable level because there are often no consumer options that are suitably low in chemicals available. I will use myself as an example here to try and give a clear example of the problems people with chemical sensitivity face. Lately, I find myself becoming increasingly sensitive to the fabric softeners added to new garments, especially perfumed fabric softeners. This has left me unable to find clothing suitable to wear in

winter (I have only one set of clothes I can tolerate at the moment and it is not warm enough for winter). Organic clothing is not an option because synthetic fabric softeners (such as teflon) are even used in organic clothing. It would help enormously if there was a ratings system especially designed for people with chemical sensitivity so that they could know when they are buying a product if it will be tolerable for use. I would also like to see the use of perfumed fabric softeners in new garments restricted as they are unnecessary and if a group of people cannot meet basic human needs such as finding suitable clothing this becomes a human rights issue.

Thanks for your consideration.