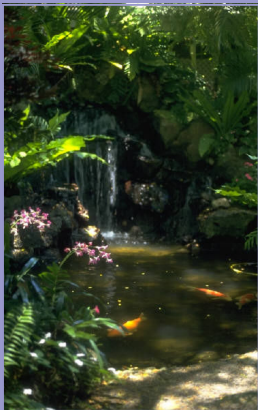


Sal's Place

“Was there ever a condition that went by so many names?”



The Name Game

A distinct controversy is currently raging in the MCS community. Or, is it MCS? Some call it TI, some call it CS, and some call it CI, TILT, TE, IEI, or other names. There are legal, ethical, scientific, and other complications to each name choice. Was there ever a condition that went by so many names?

I originally thought that this was strictly an MCS patient issue. However, I now realize that the doctors fight over the name just as hard. I use the term MCS loosely to represent all of us who have EI. I mean MCS et al, without typing it out long form each time. I am open to the possibility that all these conditions have the same etiology and will one day be labeled as such. It is not my job, but that of those conducting studies in the scientific community to select a final name.

A good friend told me, "If it looks like a duck, walks like a duck, and quacks like a duck, it IS a duck. Another good friend often told me "We can accomplish anything, if we don't care who gets the credit." I don't care who gets the credit. It does not matter who gains recognition as long as it happens. It does not matter what it is eventually called either and I will continue to refer to it in brochures and other material as MCS, also known as TI, TILT, CI, CS, EI etc. until an etiology is discovered and the condition is clearly named.

There are a few things about the name that require mention. It's not as easy as jumping on board with a name. There are many legal, social, medical, and psychological sides to the issue and the condition that at some point need to be agreed upon.

MCS is not currently recognized in the courts; therefore a court case where there is mention of MCS is usually not heard due

to Daubert. Daubert disallows MCS from going to trial due to the lack of a clinical definition or tests that can prove an individual has the condition. While changing the name helps in the courts for a few who have legal cases, it leaves the rest of the community without recognition for a longer time, as those patients are no longer part of the MCS statistics because they are labeled under another name. When patients are not labeled with MCS, the chemical companies and others can downplay the significance of the condition because it appears that the prevalence is lower.

When patients are not labeled with MCS, they cannot be used to replicate prior MCS studies. In order for science to recognize a paradigm or condition, tests must be replicated and show reliable and valid results. Science will not accept anything based on one study. All the studies on MCS in the past have been for naught if the name changes. Time and money is now being divided into other names, which reduces funding used for a common cause and delays overall progress. Since science requires replication, it will be more difficult to reach any consensus on the etiology of this condition.

As far as I know, the US is the only country battling over the name. All the other countries, to my knowledge, use the term MCS. From that standpoint, we stand to get recognition faster with the MCS name because progress made by other countries will serve to assist us in making faster gains. My current view is to support all efforts, on behalf of the condition, regardless of name, as long as none try to hurt another's effort. In the long run, the names will likely merge into one when the etiology is uncovered.

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