

Lyndonville News

Information and Support for the ME/CFS/FM Community
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CEREBRAL ATROPHY

Introduction

I do not like to deliver discouraging news. But for many years the medical world has been dismissing CFS/ME because there has been no science to say that this illness is serious. Now that scientific information is pouring in abundantly. Is the medical world going to continue to maintain that ME/CFS is a trivial psychosomatic problem of neurotics and hypochondriacs?

In this issue of the Lyndonville News I would like to summarize several studies, two of which show the presence of cerebral atrophy. In lay terms, that means that the brain has decreased in size, presumably because of death of brain tissue. The other reviews outline a new study proving the cognitive symptoms and some older studies demonstrating decreased blood flow to the brain (cerebral hypoperfusion). In my opinion these issues are connected or linked.

Literature Review:

The Presence of Cerebral Atrophy in CFS

Reference: de Lange F, Kalkman J, Bleijenberg G, Hagoort P, van der Meer J, Toni I. Gray matter volume reduction in the chronic fatigue syndrome. *NeuroImage* 2005;26:777-781.

In this study, the authors studied 28 patients with CFS and 28 healthy controls using an automated, “user-independent” magnetic resonance imaging (MRI) voxel-based morphometry (VBM) technique for measuring brain volume and tissue concentration. They were also able to quantify the activity reduction of the CFS patients using a technique called actinometry. For better control they restricted the study, both patients

and controls, to women. They found that the volume of gray matter of the brain was significantly decreased in comparison to the healthy controls, ($p < 0.001$), and amounts to a reduction in brain tissue of 8% on average, and appears to be a global phenomenon rather than a local problem. The amount of brain tissue reduction was correlated to the severity of the activity limitation. Whether this is a cause or consequence of CFS is not known.

Reference: Okada T, Tanaka M, Kuratsune H, Watanabe Y, Sadato N. Mechanisms underlying fatigue: A voxel-based morphometric study of chronic fatigue syndrome. *BMC Neurol* 2004;4:14.

In this study MRI was used allowing “voxel-based morphometry” of 16 patients and 49 healthy age matched controls. CFS patients had reduced gray matter volume, primarily in the prefrontal cortex bilaterally. The authors state, “We observed a significant reduction in gray-matter volume in the bilateral prefrontal areas of CFS patients...In comparison to healthy controls, there was an average of 11.8% volume reduction in CFS patients.”

Literature Review: Cognitive Symptoms of CFS

Reference: Lange G, Streffner J, Cook D, Bly B, Christodoulou C, Liu W, et al. Objective evidence of cognitive complaints in chronic fatigue syndrome: A BOLD fMRI study of verbal working memory. *NeuroImage* 2005;26:513-524.

Many studies have been ambiguous about the cognitive difficulties in CFS. In this study, the authors, using blood oxygen level dependent (BOLD) functional MRI imaging show that CFS patients are able to process challenging information, but utilize more extensive cerebral networks and must exert greater effort to process auditory information. They state, “Our findings provide objective evidence for the subjective experience of cognitive difficulties in individuals with CFS.”

Comment: Many standard neuropsychological testing results have been considered “normal” or “consistent with depression”, primarily because the areas studied were not the areas of impairment in CFS. If neuropsychological testing were to be done, the focus should be on ability to maintain attention, verbal processing speed, reaction times, and the ability to acquire new information. For a review of the neurocognitive studies, see Jason L, Corradi K, Torres-Harding S, Taylor R, King C. Chronic fatigue syndrome: the need for subtypes. *Neuro-psychology Review* 2005;15(1):29-58. Hopefully this study by Lange et al will put to rest the controversy of the presence of cognitive deficits in CFS, because they can be seen on fMRI.

Literature Review: Abnormal Cerebral Perfusion in CFS

Reference: Schwartz R, Garada B, Komaroff A, Tice H, Gleit M, Jolesz F, et al. Detection of intracranial abnormalities in patients with chronic fatigue syndrome: comparison of MR imaging and SPECT. *American Journal of Roentgenology* 1994;162:935-941.

This paper was one of the first to look at the incidence of both the “high intensity” (bright) spots on the MRI scan and the brain blood flow abnormalities in patients with CFS. The MRI abnormalities were present in 50% of patients compared with 20% of controls. The SPECT abnormalities were common in CFS at 81% vs 21% in controls. The authors implied that the SPECT seemed to correlate with the clinical picture.

There are now many papers on SPECT scans and cerebral perfusion studies. For a review I would suggest: Jason L, Corradi K, Torres-Harding S, Taylor R, King C. Chronic fatigue syndrome: the need for subtypes. *Neuropsychology Review* 2005;15(1):29-58

Comment: For many years patients with CFS have said that their cognitive symptoms are among the most disabling symptoms they experience. In the early 1990’s Dr. Sandman used the term “CFS dementia” and everyone was horrified, including me. But it is now clear that he was correct, depending upon how you define dementia.

Usually, we associate the term dementia with Alzheimer’s disease, which over a period of a few years converts a vital, intelligent person into one unable to recognize family members. This does not occur in CFS. Over the past twenty years I have heard patients say that their abilities are more and more limited. I am sure this is true, but their speech was normal, they were still able to take care of themselves reasonably well. Because they had adjusted to the ravages of the illness, some were even doing reasonably well. These observations are not changed by the recent publications. What we are now seeing in the medical literature is evidence that CFS is a neurological disease and some patients have reduction in brain gray matter (cerebral atrophy).

I would feel that the results mentioned above are linked to the poor prognosis seen in many of the CFS long term studies. For those persons with severe CFS persisting for more than five years, the likelihood of recovery is slim. I would assume that the neurological damage that causes the symptoms is also causing the cerebral atrophy, and that is not likely to be reversed.

What is causing this cerebral atrophy? We do not know is the simple answer. But for years we have seen abnormalities in the MRI scans, then SPECT scans showing reduced blood flow to the brain. Sometimes I hear neurologists say that the small “hyperintense” MRI lesions can be due to vascular or embolic phenomena (tiny blood clots or strokes), and this explanation is consistent with the reduced blood flow seen on studies. Like CFS, multiple strokes will cause cerebral atrophy.

Could it be that the reduced blood flow to the brain is the cause of the neurologic injury? Is there a hypercoagulable state causing these problems? Is there “sludging” of the blood flow in the brain because of reduced circulating blood volume? We don’t know and it is

time that serious research is initiated on scale that occurred in multiple sclerosis years ago.

If the cerebral atrophy is due to reduced cerebral blood flow, it is theoretically preventable by opening the cerebral vessels and increasing the circulating blood volume. I can be criticized for speculating here, but I freely say that I do not know. But we need the studies to find out.

ME/CFS is a debilitating disease of the central nervous system that causes widespread disability. Unlike Alzheimer's disease, ME/CFS affects young people in the prime of their life and affects children as well. It should no longer be considered a trivial problem. I am unhappy with these new research developments, but I find them hard to refute. But it is even harder to witness a medical world that continues to speculate whether CFS is "real" or not.

Disability Study

A person I have known for several years is seeking information about ME/CFSers disability experience. I am wholly in support of her project.

She writes, "I am a writer seeking contact with CFIDS patients for an account of CFIDS disability issues. I would like to interview people willing to share their thoughts and stories concerning any or all of the following: 1) how your illness has impacted your ability to work; 2) how having CFIDS has affected your sense of identity and your capacity to live a normal life; 3) what kinds of experiences you've had negotiating disability issues with the medical community and with government and private insurance carriers; and 4) what kind of reception you've met in publicly disclosing your illness and in handling its impact upon friendships and family. I can promise neither fame nor remuneration for your generosity, only my earnest effort to respect your words, experience, and ideas.

I taught college English for 27 years and have had CFIDS for over 20 years. I now live on SS disability and the income from a very small writing business. I will be as timely as possible in my replies to you. Thanks to all who write: *SCRIBE/P.O. Box 4/Slaterville Springs, New York/14881."

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