Reflections on FMS Treatment, Research, and Neurotherapy: Cautionary Tales

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SUMMARY. Treatment planning for a patient diagnosed with fibromyalgia (FMS) requires neurotherapists to consider a wide range of potential causes during history taking. Effective treatment planning often involves interventions from multiple specialists coordinating treatments. Creation of a treatment team may involve, in addition to neurotherapy, medical specialties such as infectious disease, physical medicine, neurology, nutrition, and rheumatology, as well as cranial sacral and myofascial treatments, and surface electromyography (sEMG). Understanding the signs of common complications in those diagnosed with FMS is vital to effective treatment. doi:10.1300/J184v10n02_05 *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com>*

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Lessons learned from the experiences of subjects in the Rush-Presbyterian-St. Luke's Medical Center and Neurotherapy Center of Washington fibromyalgia study (Kravitz, Esty, Katz & Fawcett, 2006) provide a rich and evolving store of information for neurotherapists treating anyone diagnosed with fibromyalgia (FMS). The coexisting conditions described below are not proven causes of FMS, even though it is often tempting to make that assumption. However, making such a link is a task that will require more research. Nonetheless, an appreciation of common complications often accompanying the FMS diagnostic label is essential to good treatment planning. This note is offered as supplementary information that may be helpful to therapist and patient alike.

Getting clear and reliable research results with people diagnosed with FMS is very difficult. The official criteria for this diagnosis were established for research purposes in 1990 as a result of a consensus conference (Wolfe et al., 1990). Two groups of doctors evaluated patients who had been diagnosed by physicians considered experts on the condition. The resulting consensus opinion, arrived at independently between the two groups, was that all of the patients expertly diagnosed with FMS exhibited 11 of 18 tender points in selected sites on

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the body. This work, which was originally intended only for use in a single study, became the standard for diagnosing FMS.

Full discussion of the difficulties with these criteria would be lengthy and inconclusive. The important point here is that diagnosis of FMS is complicated. FMS is a condition that appears to have multiple causations, a complex interplay and mix of psychophysiological dysfunctions, soft tissue damage, physical and emotional trauma, infectious agents, toxic exposure, and genetic syndromes. Some of the Rush study participants (Kravitz et al., 2006) had a combination of these problems. The resulting variety of symptoms that can be present in one person makes treatment planning a challenge. The remainder of this paper discusses different etiologic factors that may be involved with the various subtypes of FMS and their implications for treatment.

CENTRAL NERVOUS SYSTEM FACTORS

As a result of following some of the subjects in the Rush study even after the study ended, the Neurotherapy Center of Washington therapists came to a deeper understanding of the frustrations of patients and clinicians alike. Despite current research establishing that people diagnosed with FMS are suffering from a central nervous system (CNS) problem, there is still a perception among some health care providers that it is a psychosomatic problem and that psychotherapy is the treatment of choice. One leading FMS researcher states that FMS is a distinct clinical syndrome deserving of informed medical care and continued research to better understand chronic widespread pain (Russell, 1999). Staud, Price et al. (2001) report that pain ratings in response to a heat stimulus are greater in fibromyalgia subjects as compared to controls, providing evidence for central abnormal pain modulation controls. Staud, Caril et al. (2001) write that "FMS subjects required much lower mechanical pressures than controls to elicit wind-up, indicating abnormal pain mechanisms. These same mechanisms may also play an important role in FMS pain" (p. 79). Wittrup et al. (2001) looked at markers of CNS injury through measures of inflammatory markers in cerebrospinal fluid and serum. They found an immuno-inflammatory process in the CNS that supports "a model of immune-mediated brain injury leading to abnormal sensory processing and widespread allodynia in FMS" (Wittrup et al., 2001; p. 81). They also suggest that their findings support subgrouping FMS patients by etiology.

Of particular interest to neurotherapists is research from brain scans. Using SPECT scanning, Mountz (2002) identified decreased blood flow in the thalamus and caudate nucleus. These are areas that generally modulate pain signals. The research group concluded that "... specific parts of the brain's limbic system, the thalamus and caudate nucleus, have decreased blood flow. These areas seem to modulate pain by inhibiting incoming pain signals. If they are not functioning normally, they will not be able to inhibit pain signals. Fibromyalgia seems to 'turn off' these areas, which allows pain signals to continue uninhibited through the brain" (p. 38).

Based on my clinical experience over the last decade with many FMS patients, it is difficult to agree with the suggestion that fibromyalgia is the cause of a change in brain function. Given what is now known from QEEG, imaging data, and patient histories, trauma of some type has changed the brain's functioning and *this is the biomechemical contribution to the onset* of fibromyalgia symptoms. The thalamic area of the brain is especially vulnerable to physical damage from blunt and whiplash trauma. The sella turcica (Turkish saddle) is the bony cavity in which the pituitary gland is encased. The pituitary stalk passes through a small opening leading to the hypothalamus. This cozy little dwelling is highly protective of the master gland, but the design has a significant drawback to overall functioning following any head trauma involving acceleration or deceleration. When any momentum causes the head to be accelerated or decelerated, the brain, suspended in fluid, bounces in relation to the forces involved, or is twisted in any rotational event such as a car spinning. The result is a stretching of the pituitary stalk and interference with hormone functions in which the pituitary is a key player (Silverman, 2002). The pituitary is responsible for regulating hormones that affect many organ systems. Thyroid, sex and adrenal hormone

problems are only a few issues that can follow trauma to this part of the brain.

Donaldson, Donaldson, Mueller, and Sella (2003) identified sub-groups in fibromyalgia based upon quantitative EEG (QEEG) brainwave patterns. This research points to a significant CNS component in FMS. Perhaps, as they suggest, there is an EEG signature in people with fibromyalgia. Schwartz and Begley (2002) provide a lively and well-documented history of research on the mechanisms and applications for treatments based on neuroplasticity and give hopeful news about the ability of the brain to change in response to stimulation.

An increased understanding of the role of brain function on pain and on chronic illnesses is appearing more frequently in pain research literature. Researchers (Tennant, 2003) presenting at the American Pain Society and the American Academy of Pain Medicine reported, ". . . clear evidence that chronic pain produces cardiovascular and immunologic complications. Even more compelling was a study by Sora and Associates from Northwestern University that compared brain mass in chronic pain patients with normal controls. The chronic pain patients' gray matter had significantly less density . . . Although nervous system-type pain, per se, is in early stages of research, practitioners and patients need to be keenly aware that there is growing evidence that uncontrolled pain may produce pathologic, neurologic, immunologic, cardiovascular and endocrine changes" (p. 8).

Neurotherapy

Even if the CNS dysfunction factor of FMS etiology is accepted, does it follow that treatment to correct only the CNS contribution to the syndrome is sufficient for recovery? It is my belief that treatment of CNS dysfunction is an essential component of any treatment plan for recovery from the symptoms of FMS, but in most cases it is not sufficient. Neurotherapy will be most successful in those who were functioning well prior to a physically traumatic onset. It will not produce significant change in those with ongoing infection, significant toxic exposure, or structural damage. Complicated psychological trauma is another complication, as are genetic syndromes.

As neurotherapists accept the challenge to improve the CNS functioning of people diagnosed with FMS, the body must not be forgotten. Soft tissue and structural problems, as well as endocrinological issues caused by biomechanical forces of head trauma, must be addressed directly. Infectious agents are often a constant drain on energy and nutrition, and they may have entered the CNS. All of these problems must be detected and properly treated to maximize clinical benefits. Some case examples illustrate common problems presented by FMS patients.

INFECTION

D is a 51-year-old woman who entered the Rush study at age 46. She was in the placebo group first, and had no positive response, but had some significant, but not complete, relief from the active treatment. There was improvement, but she still had some symptoms even after some post-study FNS treatment. She returned for more treatment in late 2005 with pain all-over, aching, and cognitive fogginess. Surface EMG (sEMG) evaluation revealed 8 imbalances of 13 muscles tested, many of them extreme imbalances. Response to the EEG stimulation treatment led to rapid improvement in cognitive functioning. Three sEMG treatment sessions gave her some tools that diminished pain a bit, but nothing helped with the aching. She was recently diagnosed with Lyme disease and has just begun treatment. Her partial response to treatments is typical of those who have a chronic infection.

Irritable bowel syndrome, ulcerative colitis, and infections such as mycoplasmas, herpes, chlamydia and Lyme disease are common in those with FMS diagnoses. These conditions will make treatment response guarded at best. As an example, Dennis and Bright (2003) wrote a paper on treating fungal sinusitis. They had collected data on 624 patients treated over 14 years with diagnoses of fibromyalgia, chronic fatigue syndrome (CFS), arthritis, and other immune diseases. These patients were treated with medications, surgery where indicated, and environmental cleanup to specific standards of fungal presence. "Neurofeedback was at-

tempted without success before environmental cleanup was accomplished" (p. 89). The conclusion was that wellness and effective neurotherapy can be achieved only *after* appropriate interventions targeting the infectious process are completed.

Nicolson et al. (2000) has done extensive research on the nature of Gulf War Illness, documenting the difficulty of differentiating FMS from CFS and rheumatoid arthritis. They concluded:

> Bacterial and viral infections are associated with many chronic illnesses as causative agents, cofactors or more likely as opportunistic infections in immune suppressed individuals. The prevalence of invasive pathogenic *Mycoplasma* species infections (and possibly other bacterial infections, such as *Chlamydia, Borrelia*, etc.) in patients with Chronic Fatigue Syndrome, Fibromyalgia Syndrome, Gulf War Illness, Rheumatoid Arthritis and other chronic illnesses was significantly higher than in healthy controls. When we examined chronic illness patients for multiple *Mycoplasma* species infections, we found that almost all patients had multiple intracellular infections, suggesting that multiple bacterial infections commonly occur in certain chronic illness patients. These patients generally respond to particular antibiotics if administered long-term, but an important part of their recovery involves nutritional supplementation with appropriate vitamins, minerals, immune enhancement and other supplements. Nutraceuticals appear to be necessary for recovery and maintenance of a strong immune system. In addition, patients should be removed from potentially immune-depressing drugs, such as some antidepressants, to allow recovery of their immune systems. Other chronic infections (viral) may also be involved in various chronic fatigue illnesses with or without mycoplasmal and other bacterial infections, and these multiple infections could be important in causing patient morbidity and resulting difficulties in treating these illnesses. (p. 89)

Viral infection can even exist inside muscles. One recent report (Douche-Aourik et al., 2003) concluded that, "Enterovirus RNA has been found previously in specimens of muscle biopsy from patients with idiopathic dilated cardiomyopathy, chronic inflammatory muscle diseases, and fibromyalgia or chronic fatigue syndrome (fibromyalgia/chronic fatigue syndrome). These results suggest that skeletal muscle may host enteroviral persistent infection" (p. 47).

PARASITES AND CHRONIC PAIN

A parasitic gastrointestinal infection can cause extreme soft tissue pain. A clinical example was found in one 23-year-old patient who had a parasitic infection that caused inflammation of the descending colon that lead to inflammation of the tissues around the left hip with swelling and intense pain. Inflammation of the transverse colon leads to inflammation of surrounding soft tissues such as the genitofemoral, lateral femoral cutaneous and femoral nerves, and the fascia connecting the diaphragm to the T12 area of the spine. Inflammation of these structures sets up a cycle of nerve irritation, swelling, compression, reduced range of motion, and increased nerve irritation. The effects are widespread causing pain even with proper breathing and normal movement, resulting in more bracing against pain, leading to more constriction of movement, increased irritation and inflammation. Breaking this cycle requires elimination of the infection followed by myofascial release and re-education of body mechanics. Detection and diagnosis of some of these infections can be a complicated process but is the necessary first step of a treatment plan.

GENETIC SYNDROMES

Ehlers-Danlos Syndrome (EDS), a genetic condition, is sometimes found in patients diagnosed with fibromyalgia. EDS is a rare hereditary connective tissue disorder characterized by unusually flexible joints, very elastic skin and fragile soft tissue. The skin can be stretched several inches and yet retain its original shape on release. People with this syndrome bruise

easily, have a lot of sprains and dislocation of joints, bleed easily, and may have hernias. There is no fully effective treatment, but some physical therapy can strengthen tendons around the joints. A mistaken diagnosis of FMS is understandable for people with EDS because the nature of the tissues creates a vulnerability to injuries from many of life's ordinary activities.

Another genetic condition that can complicate treatment of FMS is von Willebrand's Disease (vWD). It involves a deficiency of a protein that affects platelet function, resulting in slowed cessation of bleeding. Platelets that should form the first step in repairing a cut are not active, so bleeding does not stop quickly. People with vWD bruise easily, and bleed excessively after a cut or from dental work. Recovery from any invasive procedure is prolonged, and even a colonoscopy can be physically traumatic. Fatigue from iron deficiency becomes a problem.

STRUCTURAL INJURIES

Acceleration and deceleration forces wreak exquisite damage on the brain's internal structures leading to cognitive dysfunctions of memory and attention as well as to the inability of the brain to properly handle noxious stimuli, including vestibular problems. Structural damage resulting from physical trauma is often involved in the onset of FMS. Severe coccyx injury from a fall onto the tailbone often occurs during stairway accidents, or from sports activities. This can be a cause of chronic headache. Whiplash can cause a reversal of normal curvature of the spine (cervical lordosis). This causes extreme pain and requires skilled physical therapy.

Motor vehicle accidents are the most common cause of traumatic brain injury, and whiplash is a commonly reported as a precipitating cause of FMS. The effects of whiplash extend far beyond the muscle damage that causes headache and the neck/back spasms that can lead to chronic pain. Damage to the central nervous system results from physical forces on the brain inside the skull. "Wherever there is momentum, there is a potential for tissue injury. Whenever a whiplash injury occurs, there is a risk for chronic painful complications such as fibromyalgia" (Pellegrino, 2002; p. 14).

Brown (2001) documented G forces to the brain resulting from low-speed rear-end collisions. In the first 100 milliseconds after collision, the car moves from under the body and the torso rises. The forces involved are compression, torsion, and shear. It is the compression and shear that cause big problems. In 200 milliseconds the head starts back and rises. Between 200 to 300 milliseconds later, the body starts forward–even faster than it went backward–but the head always lags behind, and then whips forward. One hundred milliseconds after a 20 mph impact, the acceleration inside the skull reaches 18Gs. "The most important factor regarding motor vehicle collisions and injuries is how much (or how little) of the collision force is absorbed by the occupants" (Pellegrino, 2002; p. 3).

VESTIBULAR DAMAGE

Serious vestibular problems can result from head trauma and be coexistent with the FMS diagnosis. These must be taken very seriously because the condition affects all treatment of these patients, neurotherapy as well as sEMG. A clinical example illustrates the need for careful treatment planning to avoid undue use of resources.

One patient responded well to FNS with improvement in the cognitive area. Treatment of the muscle imbalances was temporarily helpful, but would not hold. She had inner ear damage that interpreted an off-center posture as being balanced. This kept the muscles in chronically stressful positions that reinforced muscle imbalances and pain. This condition must be repaired. Many of these people require treatment for benign paroxysmal positional vertigo.

Another dysfunction that can result from biomechanical trauma is a perilymphatic fistula, an opening in the inner ear that causes severe dizziness. It can sometimes be repaired surgically. Another patient responded with improvement in cognitive functioning, but the pain persisted. She had a serious fall on the tailbone that was responsible for continuing pain. Appropriate myofascial treatment has

been helpful in reducing pain. Such falls are often a factor in chronic headache.

CONCLUSION

In summary, taking the history of people diagnosed with FMS should delve into great detail about head trauma and past illnesses that were not usually considered significant at the time. This meticulous investigation is important even though thorough attention to the details of their history and symptoms can seem somewhat tangential to their main concerns. Involvement of proper specialists is then required. Neurotherapy alone will often not help these people.

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