

Centers of Excellence for Systemic Exertion Intolerance Disease: A Call for Action

Tara Beck

Rowan University School of Osteopathic Medicine

Class of 2019

The Institute of Medicine recently released a report on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), a complex disease characterized by extreme fatigue, sleep abnormalities, cognitive dysfunction, pain and an array of autonomic symptoms that are exacerbated with exertion. The IOM's report highlights the prevalence of the disease, claiming that 836,000-2.5 million Americans are diagnosed¹. However, there is much criticism surrounding ME/CFS, including its actual prevalence, as this disease is not well known or researched within the medical community. The IOM claims that less than one-third of medical curricula discuss ME/CFS; consequently, physicians are not able to identify the symptoms of this disease and an estimated 84-91% of people suffering from ME/CFS go undiagnosed¹. While the pathogenesis of ME/CFS remains unclear, the medical community is finally recognizing the notion that this is a physical disease. In fact, the IOM recommends replacing the name Chronic Fatigue Syndrome with a less stigmatized title, Systemic Exertion Intolerance Disease (SEID), with hopes that an SEID diagnosis will be taken more seriously both in the eyes of the medical community and society, at large. Regardless of the diagnostic name, there is an urgent need for more research to discover the cause of SEID and understand the mechanisms associated with its development, progression and treatment.

While diagnosing Chronic Fatigue Syndrome is a difficult feat in itself, the real barrier stems from inadequate training that physicians receive to diagnose and treat patients with this disease. To date, there has been little emphasis on ME/CFS in medical school curricula, so physicians are simply not prepared to diagnose and treat the ME/CFS patient population¹. This calls for major reform within the health care system through the establishment of Centers of Excellence. Centers of Excellence are facilities designed to target specific diseases, such as ME/CFS, by providing specialized care by physicians solely trained to combat SEID. Dr. Ken Friedman, a strong advocate for the creation of ME/CFS Centers of Excellence describe these facilities as, "unique opportunit[ies] to create an integrative fabric in ME/CFS that unites clinical, laboratory and computational sciences...for discovery and deployment of effective treatment courses, while training the next generation of expert clinicians"⁶. Given the debilitating aspects that affect physical, cognitive, and mental components of a patient's life, it is logical to treat this disease using an interdisciplinary approach. These facilities offer a "one stop shop" for patients to, namely, receive a correct ME/CFS diagnosis and receive individualized care. In addition, these Centers of Excellence will provide the perfect opportunity for researchers to utilize the patient population to conduct studies and identify effective treatment for this disorder. Dr. Ken Friedman, a strong advocate for the development of Centers of Excellence, argues that research targeting this disease has grown very little; in 1995, there were less than 200 publications available, while 2013 had about 325⁶. The Centers of Excellence for ME/CFS can provide a

great opportunity to explore this disease and will certainly help further develop the fund of knowledge available for ME/CFS.

Poor physician training in ME/CFS has led to perhaps the biggest barrier: diagnosis. Physicians are often skeptical of a patient's symptoms, given the few diagnostic tools available to confirm the disease. The IOM describes the diagnostic requirements as an impaired ability to engage in occupational, educational or social activities for a period of more than 6 months; diagnostic requirements emphasize that this impaired activity is also accompanied by fatigue that is not the result of excessive exertion and does not go away upon rest. Additional symptoms include, "post-exertional malaise and unrefreshing sleep"¹. A patient must also experience a form of cognitive impairment or orthostatic intolerance in order to meet diagnostic criteria. While this criteria certainly seems like a simple checklist on paper, such symptoms certainly appear comorbid with many psychiatric conditions, making it difficult for an inexperienced physician to accurately diagnose ME/CFS. Centers of Excellence help expose young physicians and rotating medical students to patients with Chronic Fatigue Syndrome, allowing them to become proficient in making a diagnosis. For example, patient medical and social history must be thorough in order to make a conclusive diagnosis with ME/CFS. Information gathered must include "pre-illness functioning (education, job performance, social and family relationships) and current living circumstances (daily activities, stressors, major life changes and support sources)"⁴. By practicing conducting patient histories at Centers of Excellence, physicians will learn to identify significant lifestyle changes that warrant a ME/CFS diagnosis.

While the development of Centers of Excellence benefit physicians, they also greatly help the patients suffering from ME/CFS. An editorial completed by Lori Chapo-Kroger, RN, a nurse and patient who suffers from Myalgic Encephalomyelitis, implores the benefits that these Centers of Excellence could provide through individualized, explicit care. In order to maximize the benefits that these Centers can provide, facilities should be placed in an urban setting located near Medical Schools and teaching hospitals. Such bustling areas will ensure that a maximum number of patients can benefit. Additionally, strategically placing these centers near medical schools and teaching hospitals will ensure that healthcare professionals receive training in dealing with ME/CFS patients. As rotations through these Centers of Excellence become a standard in Medical Education, physicians will be able to recognize and diagnose ME/CFS, a crucial step toward healing. Even if physicians are not comfortable treating patients with CFS, they will at least be knowledgeable enough to diagnose and refer a patient to the nearest Center of Excellence.

Within her report, Chapo-Kroger explains that many patients visit an average of 4 different physicians before receiving a ME/CFS diagnosis. Using data collected from Horizon Blue Cross Insurance of Massachusetts, the cost per visit to a primary care doctor averages between \$150-180; compounded with added costs of lab work and other diagnostic tests, one could predict that nearly \$200 is spent per visit. That means that an average of \$800 is spent per patient in order to receive a ME/CFS diagnosis¹². This current method of practice not only burdens the patient, forced to waste time visiting a number of doctors before correctly being diagnosed with CFS, but is also a major economic burden in the health care system. Even after a diagnosis is made, the

current fund of knowledge for ME/CFS is so limited, that physicians do not know how to properly treat this patient population. Instead of targeting funds toward research on ways to improve treatment, the medical system writes down a prescription and sends patients on their way, simply because there is not enough known about proper care management. Quality of life certainly declines for ME/CFS patients, leaving approximately 25% bed- or house-bound—of course, this is an entirely different economic burden in itself. The IOM reports that “ME/CFS patients experience loss of productivity and high medical costs that contribute to a total economic burden of \$17 to \$24 billion annually”¹. Given the enormous economic burden that ME/CFS currently places on the Health Care field, not to mention the suffering that patients endure, action must be taken to combat this disease. A budget to develop Centers for Excellence for ME/CFS is a streamlined, effective way to improve research, diagnostic and training skills to accomplish the task.

To date, there are 45 states that have at least one medical school program. In order to increase the number of patients reached by these centers, as well as ensure that all future physicians are receiving adequate training on identifying symptoms of ME/CFS, it makes most sense to place a Center of Excellence near at least one medical school per state; the 5 states that do not have medical schools, including Alaska, Delaware, Idaho, Montana and Wyoming, can have a center placed near a teaching hospital for a total of 50 Centers of Excellence. Using the IOM’s estimate of \$17 billion economic burden of ME/CFS in the current system, these funds can be instead utilized toward providing effective treatment and diagnostic criteria for ME/CFS so physicians will not need to waste money on diagnostic tools or spend excess money experimenting with treatment options for patients, but instead have a concrete treatment plan available at the Centers for Excellence¹. Dividing these funds, along with any additional funds that the government allocates, can allow each center to receive \$340 million per year. This money can be used to, not only construct actual Centers of Excellence, but also hire an interdisciplinary team, including a doctor, particularly an Osteopathic Physician capable of using Osteopathic Manipulative Therapy as treatment for CFS patients, nurses who can work both within these centers as well as conduct home visits with house-bound patients, a Mental Health Specialist to help the patients cope with the mental aspects of this disease, Physical Therapists to help patients develop exercise routines to improve quality of life, fitness instructors, particularly a yoga instructor who receives additional training in ME/CFS patients, a nutritionist to help maintain balanced, “feel good” meal plans for patients and a social worker to help the patient cope with any societal barriers that an SEID diagnosis brings along. Of course, these centers will also serve to increase research on treatment and diagnostic aspects of ME/CFS and improve medical education. The interdisciplinary dream teams that these Centers of Excellence produce can ensure that patients will not only receive the best care possible, but also provide a community of support and awareness.

In a report addressing the desperate need for Centers of Excellence, Ken Friedman posed several arguments to increase funding for these centers from the Federal Government. A 2010-2013 report on NIH Spending on Chronic Illness shows that Chronic Fatigue Syndrome affects the greatest number of patients, yet receives the least amount of funding compared to less prevalent disorders; a prime example of this is Multiple Sclerosis. MS prevalence is 250,000-350,000

people in the US; CFS is nearly double, yet only receives \$5 million in funding compared to MS \$98 million, according to the NIH Spending Report³. This negative correlation between prevalence of CFS and money spent on the disorder calls for a redirection of funds within the Federal Government's budget—the money spent should at least be comparable to the budget for other neurological disorders, such as MS. The U.S. Department of Health and Human Services would like to invest \$5.25 billion over 10 years to “enhance training of both primary care practitioners and other physicians in high-need specialties”¹¹. The increasing prevalence and mystery of Chronic Fatigue Syndrome certainly characterizes this disease as an area of high-need. By allocating a portion of these funds to create Centers of Excellence for SEID, the government will not only fulfill the mission of improving quality health care to those who suffer from ME/CFS, but also limit the money spent on patients who need a confirmed ME/CFS diagnosis.

While there are many economic advantages of developing Centers of Excellence, perhaps the greatest benefit these facilities provide is the ability to heal patients from the debilitating symptoms of CFS, including fatigue and activity limitations, sleep disturbances, pain, cognitive and emotional problems as well as orthostatic intolerance. The clinical management plan presented by Dr. Friedberg's *CFS/ME: Primer for Clinical Practitioners* offers a plan of action to target each symptom: the non-restorative sleep in ME/CFS indicates waking up feeling tired, sore and mentally “foggy” despite adequate sleep the night before. Treatment includes an hour of relaxation prior to bedtime, regular sleep and wake times, avoid naps after 3pm and avoid attempts to force sleep—if unable to sleep, move to another room and do a quiet activity, such as reading or listening to soft music; it is important to avoid light from the TV or computer.

ME/CFS is also associated with fatigue on exertion. A patient's initial degree of activity limitation can be measured using the Functional Capacity Scale, a 10 point scale of how well a person can perform activities of daily living⁴. Based on these results, an interdisciplinary team can outline a plan of action for the patient that will help improve this score without exacerbating symptoms. These exercise programs should focus on training patients to deal with daily activities.

A review published in Cochrane's Medical Journal explores exercise therapy as a promising treatment for CFS patients. This review included analysis of eight studies of 1518 patients who had a clear diagnosis of CFS. Most of these studies asked participants to exercise three to five times per week, using 5-15 minute increments. Results show that exercise therapy had a positive effect on improving patient's overall health, including physical functioning, sleep, and self-perceived general health⁷.

While gradual exercise is an important aspect of CFS care, another major component to treating ME/CFS is stress relief. Additional treatments made available to patients at these Centers of Excellence can include Stress Management and Reduction courses, tailored to dealing with the debilities that a CFS diagnosis entails. One study investigated the benefit of isometric yoga on patients with Chronic Fatigue Syndrome. This randomized trial compared patients receiving traditional pharmacotherapy or pharmacotherapy plus 20 minute daily yoga for approximately two months. Patients' moods were assessed using the Profile of Mood Status before and after

each 20-minute yoga session. Additionally, patients were given Chalder's Fatigue Scale questionnaire before and after intervention in order to assess overall improvement of fatigue. Results found a significant decrease in fatigue scores immediately after each yoga session and an additional significant decrease in Chalder's Fatigue Score for the experimental group that received both pharmacotherapy and yoga, but no significant decrease in the control group that received pharmacotherapy, only⁹.

Surely, the chronic, complex symptoms associated with CFS make it very difficult to rely solely on pharmacologic treatments for pain relief. Osteopathic Medicine recognizes the relationship between the neuromusculoskeletal system and autonomic nervous system¹⁰. Osteopathic Manipulative Treatment certainly seems like an effective method for treating SEID. While there is little research available to determine Osteopathic Manipulative Treatment available for CFS patients, a study in the Journal of the American Osteopathic Association describes Osteopathic Manipulative Treatment used to relieve symptoms in patients suffering from Postural Orthostatic Tachycardia Syndrome (POTS). POTS is associated with orthostatic intolerance, fatigue exercise intolerance, palpitations and cognitive dysfunction-these symptoms are nearly identical to CFS. In fact, many patients with CFS are diagnosed with POTS. This particular study sites a case of a patient diagnosed with POTS whose symptoms did not subside with traditional medical treatment. Instead, this patient was referred to an Osteopathic Physician who was able to conduct Osteopathic Manipulative Treatment over a series of visits; at this patient's 18-month follow up, her symptoms dramatically improved⁵.

Another core diagnostic feature of ME/CFS is post-exertional malaise, a feeling of extreme fatigue following minimal physical or mental activity. In order to relieve this fatigue, physicians have advised patients to practice the pace method, which involves spreading out activities to prevent post-exertional flare ups. For example, instead of completing housework in one uninterrupted time period, tasks may be divided into smaller timeframes with adequate resting intervals. Patients are advised to keep an activity log in order to monitor daily activities and identify those that cause an exacerbation of symptoms. Using this log, patients are able to identify their "energy envelopes" which help determine their optimal levels of physical activity⁴. It is important for healthcare providers to work with patients to identify these energy envelopes in order to avoid post-exertional symptoms, while identifying exercise and daily activity that are optimal for that particular patient. Centers of Excellence can provide an opportunity for health care workers to closely monitor these energy envelopes through the use of Social Workers. These case workers are a key resource to help patients overcome many barriers of this debilitating disease, including economical and occupational. In addition to helping patients identify their energy envelopes, Social Workers can also benefit by helping house-bound CFS patients receive basic living necessities, whether that be transportation or grocery shopping and cleaning.

It is apparent that SEID has a number of debilitating physical symptoms, but these disabilities can certainly trigger a number of mental health issues, including anxiety and depression. The prevalence of clinical depression in patients with ME/CFS is roughly 40%⁴. One of the tenants of Osteopathic Medicine is to treat mind and body as a single unit; comprehensive treatment for ME/CFS includes not on the physical components of the disease, but mental, as well. Such

treatment includes developing coping skills for the patient to deal with the debilitating lifestyle that can come from this disease. These skills include low effort activities, like music, relaxation and art therapy that can generate well-being without exacerbating symptoms. Formal Cognitive Behavioral Therapy is also advised for both patients and their families in order to further help a patient cope with the disease and generate understanding and support from loved ones. Centers of Excellence in ME/CFS can train Mental Health Specialists to deal with the mental adversities that SEID patients endure. Given the team-based approach to care, it will be simple for the patients to transition from one physical doctor appointment to a mental health one, without having to worry about finding a specialist experienced with ME/CFS.

Of course, mental and physical health represent the dynamic duo in interdisciplinary care. However, nutrition is a key element in overall well-being. Although little statistical data has been collected, it is suggested that a healthy diet may alleviate some of the symptoms of ME/CFS. Foods rich in antioxidants, such as fresh, dark-colored fruits and vegetables, fiber rich foods and foods that contain essential fatty acids, like fish, can help improve one's overall well-being⁴. Working with patients to develop a nutrition plan that provides optimal balance and nourishment certainly can improve one's well-being. It is also important to make sure that patients are getting adequate Calcium and Vitamin D, as limited mobility from fatigue makes them particularly susceptible for osteoporosis. Centers of Excellence can contain a nutritional team member to ensure that all areas of patient health can be addressed.

A shining example of the success that Centers of Excellence can provide is the Stanford Center for Chronic Fatigue Syndrome. This organization identifies a long-term goal of establishing inpatient care, separate from a hospital environment, to allow patients with CFS to benefit from a holistic approach to their treatment. Stanford's ME/CFS Initiative funds an array of research projects and clinical trials, all geared toward unveiling the mystery behind Chronic Fatigue Syndrome. This particular site has garnered a community of patients who suffer from ME/CFS; many of them share stories that explain the benefit that Stanford's Center has provided. Mia Anderson, a patient at the Center, describes her first exacerbation with Chronic Fatigue Syndrome: she arrived home after finishing final exams at school and collapsed by the front door. Anderson describes the successful and personalized care that she received which, not only helped her regain her life physically, but also allowed her to connect with other patients fighting the same disease. Mia explains that Stanford's Initiative center allows patients to "support one another and...helps with the feelings of isolation"⁸. The development of Centers of Excellence can ensure that all patients receive the same level of quality care and successful treatment as Mia Anderson.

The future of medicine is certainly changing; there is a greater emphasis being placed on a holistic approach to care, one that considers the mind and body of patients and focuses on improving quality of life. There is no doubt that the current practice of medicine has its flaws. The United States health care costs soar above other nations, but do not correlate with the health of patients. The current medical model is setup so patients visit a doctor, perhaps get a diagnosis within the first visit-if lucky-then must go out a search for a network of support for treatment, such as mental health, nutrition and fitness. For a complex diagnosis such as ME/CFS, that

coordination is daunting and can certainly exacerbate exhaustion in even the healthiest of patients! These Centers of Excellence for ME/CFS provide a seamless solution to ease the coordination of care and help heal patients. As an Osteopathic Medical Student, I value the healing aspect of medicine and recognize that physicians cannot treat patients alone; the health and well-being of patients relies on an interdisciplinary approach that Centers of Excellence can provide. I cannot think of a more complex disease, particularly one that has such prevalent physical and mental components, as ME/CFS. I yearn for the day that all physicians recognize the holistic, interdisciplinary nature of medicine and feel that the creation of 50 Centers of Excellence targeted at diagnosing and healing patients with SEID is a great place to start.

References

- ¹ "Beyond ME/CFS: Redefining an Illness." *Institute of Medicine*. Institute of Medicine of the National Academies, 2015. Web.
- ² Chapo-Krogger, Lori, RN. "Center of Excellence Myalgic Encephalomyelitis." *PsycEXTRA Dataset* (n.d.): n. pag. CFSAC, Dec. 2014. Web. 20 July 2016.
- ³ "Estimates of Funding for Various Research, Condition and Disease Categories." *NIH Categorical Spending -NIH Research Portfolio Online Reporting Tools (RePORT)*. N.p., 10 Feb. 2016. Web. 22 July 2016.
- ⁴ Friedberg, Fred. "ME/CFS: A Primer for Clinical Practicioners." *IACFS/ME*. IACFS/ME, 2012. Web. 23 July 2016.
- ⁵ Goodkin, Michael B. MD; Lawrence J. Bellew, DO. "Osteopathic Manipulative Treatment for Postural Orthostatic Tachycardia Syndrome." *The Journal of the American Osteopathic Association*, November 2014, Vol. 114, 874-877.
- ⁶ Johnson, Cort. "The Case for Centers of Excellence in Chronic Fatigue Syndrom." *Health Rising*. Health Rising, 1 Feb. 2015. Web. 20 July 2016
- ⁷ Larun, L., K. Brurberg, J. Odgaard-Jensen, and JR Price. "Exercise as Treatment for Patients with Chronic Fatigue Syndrome." *Cochrane Review* (2016): n. pag. Common Mental Disorders Group, 24 June 2016. Web.
- ⁸ "ME/CFS Initiative." *Stanford ME/CFS Initiative*. Stanford Medicine, 2016. Web. 25 July 2016.
- ⁹ Oka, T., T. Tanahashi, T. Chijiwa, B. Lkhagvasuren, and N. Sudo. "Isometric Yoga Improves the Fatigue and Pain of Patients with Chronic Fatigue Syndrome Who Are Resistant to Conventional Therapy: A Randomized Controlled Trial." *Biopsychosoc Med* 27th ser. 8.1 (2014): n. pag. *Medline*. Web.
- ¹⁰ Patterson MM, Wurster ED. Neurophysiologic system: integration and disintegration. In: Ward RC, executive ed. *Foundations for Osteopathic Medicine*. Baltimore, MD: Lippincott Williams & Wilkins; 1997:141-144.
- ¹¹ Secretary, HHS Office of the. "Highlights of the President's HHS FY 2016 Budget." *HHS.gov*. N.p., n.d. Web. 25 July 2016.
- ¹² "Typical Costs for Common Medical Services." (n.d.): n. pag. *Horizon Blue Cross Blue Shield Massachusetts*. Web. 20 July 2016.