ME/CFS and Societal Issues

According to government estimates, about 1 million people in the U.S. currently suffer from the disease that it calls “chronic fatigue syndrome.” About half of these are disabled and a substantial percentage are bedridden. People with ME/CFS get usually get sick in their prime of life -- often in their 30’s or 40’s, sometimes in their teens or 20’s. Few recover from the illness.

ME/CFS thus is an extremely expensive illness for society. A 2008 study estimated the total annual cost burden in the U.S. as between $18.7 billion to $24 billion.

For people who suffer from ME/CFS, the challenges of the disease itself tend to be vastly compounded by the lack of societal recognition for its characteristics. To the extent that many people are aware of the illness at all, they often think of it as something trivial, consisting of mild tiredness of the sort that everyone gets from time to time.

Clinicians and researchers focusing on the illness, on the other hand, describe a disease rivals the debilitation experienced by cancer or AIDS patients in their final months of life. “My HIV patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested,” said Nancy Klimas, a physician and researcher. “Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have HIV. But CFS, which has a million people in the United States alone, has had a small fraction of the research dollars directed towards it.”

Although ME/CFS is defined by the CDC as a chronic rather than a deadly illness, this obscures the fact that specific types of deaths tend to be associated with ME/CFS. Deaths from non-Hodgkins lymphoma and heart disease are particularly common in severe sufferers, for example. One study suggested that although CFS patients have the same top two causes of death -- heart attacks and cancer -- as people in the general population, they die of those causes on average 20 years earlier than the average. The third leading cause of death in the study was suicide.
Compared to other similarly severe chronic illnesses, government funding for ME/CFS is miniscule. For instance, the NIH budget for 2012 allotted $6 million for CFS. This contrasts to $135 million for Multiple Sclerosis (a disease affecting half as many Americans as CFS); $115 million for Lupus (1.5 million sufferers); $46 million for West Nile Virus (less than 4,000 sufferers and 30 deaths); and $25 million for Lyme Disease (150,000 sufferers).

Appropriate medical care is similarly lacking for sufferers of the disease. For years, medical school students were taught that CFS was likely a psychological illness, and many practicing doctors still harbor that belief. While most doctors have heard of the disease and some can cite the CDC criteria for it, few have substantial knowledge about the medical literature related to it or about the aspects of the immune system (such as natural killer cell dysfunction) that seem particularly associated with it.

ME/CFS is a complex disease with a wide variety of symptoms, and it thus can be difficult for doctors to get a comprehensive understanding of their patients’ conditions within the context of a typical office visit. Many patients remain undiagnosed or misdiagnosed. Most doctors are unaware that commonly used medical treatments (including certain antibiotics, antidepressants, anesthesia and exercise) can have negative effects on ME/CFS patients, and also have little knowledge about what treatments actually might be helpful for them. Frequently doctors become overwhelmed with the wide variety of symptoms that ME/CFS sufferers report, and thus fail to appropriately diagnose additional illnesses that might be effectively treated.

Many ME/CFS patients report that interactions with the medical community are particularly stressful for them. Doctors’ offices and hospitals tend to be high-stimuli environments, meaning that patients with sensitivities to noise, light or chemicals can find them to be intolerable or unpleasant. Bedridden or housebound patients have a hard time getting to the doctor and can take a long time to recover from the exertion. Many ME/CFS patients have cognitive difficulties that make it difficult for them to persuade skeptical physicians that they are suffering from physiological rather than psychological illnesses. ME/CFS patients often are particularly heavy users of dietary supplements but do not always feel comfortable discussing what they’re taking with their physicians. Many severely ill ME/CFS patients report that subsequent to presenting at emergency rooms with severe symptoms, they have been committed to psychiatric facilities.

Insurance companies often deny benefits or coverage to people with ME/CFS patients, thus leading many doctors familiar with the disease to diagnose it as something else.
Because of lack of insurance coverage or frustration with quality of care, many ME/CFS patients -- including those who are bedridden and desperately sick -- drop out of the medical care system entirely. The right to die also has become an issue for some severely ill ME/CFS patients wanting to put an end to their suffering.

Regardless of how sick they are or how many medical test abnormalities they display, most ME/CFS patients have a difficult time getting approval for government or workplace disability. Although severely ill ME/CFS patients almost invariably display a variety of specific test results, the fact that none has been accepted as a universal biomarker for all cases of the disease generally makes those abnormalities not be taken into consideration in hearings. The cognitive difficulties, fatigue and pain that are most problematic for ME/CFS sufferers tend to be viewed as difficult to prove by those granting disability requests. Some ME/CFS patients resort to exercise challenge tests in order to prove the extent of their disability, with some taking months to recover from the exertion.

Whether or not ME/CFS patients get approved for disability benefits, a high percentage fall into poverty due to the inability to work during the years that for other people are the ones of prime earning potential.

Budgetary constraints and sensitivities to toxic mold, chemicals and noise can make finding appropriate housing a challenge for ME/CFS patients. Patients who are mostly or fully bedridden face additional difficulties. Few medical practitioners know how to properly treat severely ill ME/CFS sufferers who are hypersensitive to a wide variety of stimuli. Just finding someone to help with chores or errands can be a challenge for many patients. Almost all assisted living facilities have minimum age requirements and are designed for residents with much different health issues than ME/CFS patients. Some patients receive shelter and support from their families, but this often dwindles as the years and decades pass.

Many ME/CFS patients become isolated, due to difficulties navigating the outside world. Orthostatic intolerance prevents some from standing or even sitting up, and most public places are not designed for horizontal people. Some patients stop driving because of issues with disorientation or seizures. Environmental sensitivities can make many places intolerable for them.

ME/CFS patients often find that they have a difficult time getting friends, family, employers, medical professionals and others to take their condition seriously. The disease has historically received little media coverage, and the name “Chronic Fatigue
Syndrome” misleads people about its seriousness. The CDC and certain advocacy organizations have focused public attention mostly on milder cases, meaning that most people are unaware of how severe the disease can be. A cultural stereotype of the “Yuppie Flu” still is pervasive, with many people believing that the disease is due to a combination of depression and laziness.

-Lisa Petrison, Ph.D.
ME/CFS AND SOCIETAL ISSUES

RESEARCH LITERATURE

Societal Costs:


In Georgia, a state with roughly 5.5 million people age 18-59, illness could account for $452 million in total healthcare expenditures and $1.2 billion of lost productivity.

* 


The direct and indirect cost of ME/CFS to society was estimated to be $18,677,912,000 for a community sample and $23,972,300,000 for a tertiary sample.

* 


The authors looked at a surveillance study of CFS in Wichita, Kansas, and estimated a 37% decline in household productivity and a 54% reduction in labor force productivity among people with CFS. This would translate to an annual total value of lost productivity in the United States of $9.1 billion, which represents about $20,000 per person with CFS or approximately one-half of the household and labor force productivity of the average person with this syndrome.

Health Care System:

This article presents to doctors a hypothetical case to give guidance on methods for negotiating the diagnosis and treatment of chronic fatigue syndrome.


Medical school students were more likely to believe that patients with “myalgic encephalomyelitis” had a disease state than patients with “chronic fatigue syndrome.”


Live Sequence Charts (LSC) were used to formalize the narrative text obtained during an interview with a patient eventually diagnosed with CFS.

Burns D. Chronic fatigue syndrome or myalgic encephalomyelitis. Nurs Stand. 2012 Feb 22-28;26(25):48-56; quiz 58. PMID: 22455228

This article written for nurses focuses on the knowledge, understanding and skills necessary to recognise, assess, manage and support patients with CFS/ME.

Changes in attitudes of health practitioners, policy makers and general public and more flexibly organised health and social care provision are needed to address equity issues in support needs expressed by people with CFS/ME, to be underpinned by research-based knowledge and communication, for public and professional education.

* 


After reviewing 119 medical text books from various medical specialties, the authors found that 48 (40.3%) of the medical text books included information on CFS. However, among the 129,527 total pages within these medical text books, the CFS content was presented on only 116.3 (0.090%) pages. Other illnesses that are less prevalent, such as multiple sclerosis and Lyme disease, were more frequently represented in medical text books.

* 


The authors measured time to diagnosis and services accessed, and concluded that there is a greater need for education on this condition to alleviate the burden on the CFS sufferers.

* 


In a survey, overall, 96% of physicians had heard about CFS, more than 40% reported ever giving a CFS diagnosis, and more than 80% of correctly identified CFS symptoms.

CFS patients described themselves as experiencing limited medical care and attention but restricted criticisms to 'legitimate', pragmatic or ancillary matters such as a clinicians' unwillingness to prescribe untested treatments. Participants also described themselves as active in seeking a resolution to their problems. They thus attended to possible negative attributions of being 'complaining' or unmotivated to seek recovery.


Physicians' diagnosis of a psychiatric illness when at least one psychiatric disorder was present ranged from 40 percent in the psychiatrically explained group, 50 percent in the control group, and 64.3 percent in the CFS group.


GPs in Britain hesitated to confer a diagnosis of CFS/ME, suggesting that the label could be potentially harmful for the patient.


In Belgium, heterogeneity of CFS and the controversy surrounding this condition seemed to overwhelm GPs and strain medical encounters with patients. Patients with CFS seemed unsatisfied with the interaction with their doctor. CFS is not addressed well
by the medical community, and the failure to diagnose leads to a lack of empathetic care.

* Lin JM, Brimmer DJ, Boneva RS, Jones JF, Reeves WC. Barriers to healthcare utilization in fatiguing illness: a population-based study in Georgia. BMC Health Serv Res. 2009 Jan 20;9:13. PMID: 19154587

CFS patients have a hard time using healthcare services.


A program designed to train physicians and other medical practitioners about CFS was implemented.


A qualitative study suggested that medical scepticism and ignorance regarding CFS shapes the context of medical care and the illness experiences of CFS patients, who report patronizing attitudes and ignorance amongst doctors.


The CDC confirmed CFS diagnoses in a population of residents of Wichita, Kansas. Only 16% had been previously diagnosed as having CFS. Only 21% had sudden fatigue onset, and tender lymph nodes (23%) and a sore throat (19%) were the least common symptoms.

The unsuccessful investigation of CFS illustrates how non-falsifiable hypotheses are insufficient to advance medical knowledge, even when there is an abundance of empirical data.


Attributions about CFS were measured in three groups of medical trainees. All groups read the same case study of a person with classic symptoms of chronic fatigue syndrome, with the only difference being in the type of name given. Across name conditions, most trainees appeared to consider the symptom complex of CFS a serious illness resulting in poor quality of life. In addition, findings indicated that the name, chronic fatigue syndrome, may be regarded less seriously than the Myalgic Encephalopathy name.


Individuals with CFS frequently used alternative medical treatments yet rarely communicated this use to their medical doctor. Future research should ascertain the usefulness of alternative practices in the management of CFS.

The authors contrast Western medical views of chronic fatigue syndrome (CFS) etiology, diagnosis, and treatment with views maintained by a predominantly female CFS population, arguing that the failure of Western medicine to demonstrate a viral etiology for CFS led to a paradigmatic shift in research perspectives, which then embraced psychiatric and sociocultural explanations for CFS.

**Societal Attitudes and Recognition:**

Brooks J, Daglish J, Wearden A. Attributions, distress and behavioural responses in the significant others of people with Chronic Fatigue Syndrome. J Health Psychol. 2012 Nov 23. PMID: 23180874

In this study of significant others of CFS patients, distress and negative behavioural responses were associated with attributing illness events to causes personal and internal to the patient.

*Anderson VR, Jason LA, Hlavaty LE. A Qualitative Natural History Study of ME/CFS in the Community. Health Care Women Int. 2012 Jul 24. PMID: 23445264

Issues involving the illness experience for CFS patients, including community response, are examined.


In CFS patients and fatigued employees, social support is worse than in disease-free cancer patients and healthy controls.

This study created a scale that measured attitudes toward individuals with CFS—the Chronic Fatigue Attitudes Test (CAT).

Capen K. Chronic fatigue syndrome gets court’s nod of approval as legitimate disorder. CMAJ. 1998 Sep 8;159(5):533-4. PMID: 9757183

A legal case in Alberta, Canada, recognizes CFS as a legitimate disorder.


Social scientists have the expertise to more precisely define CFS and to develop appropriate and sensitive research strategies for understanding this disease.


In the absence of an adequate epidemiological database, cultural stereotypes have influenced the characterization of CFS as "the yuppie flu," similar to the 19th century characterization of neurasthenia as a disease of the affluent.

The authors review the literature on management strategies for pediatric CFS.

*Crawley EM, Emond AM, Sterne JA. Unidentified Chronic Fatigue Syndrome/myalgic encephalomyelitis (CFS/ME) is a major cause of school absence: surveillance outcomes from school-based clinics. BMJ Open. 2011 Dec 12;1(2):e000252. PMID: 22155938

Chronic fatigue is an important cause of unexplained absence from school.


Children with CFS in the UK were not diagnosed in a timely manner. Parents described difficulties accessing specialist services because of their own as well as their GP’s and Paediatrician’s lack of knowledge. They experienced negative attitudes and beliefs towards the child’s condition when they consulted GPs, Paediatricians and Child Psychiatrists. Parents struggled to communicate an invisible illness that their child and not themselves were experiencing.


Teenagers with CFS/ME (12-18 years old) report lower perceived competency, and compromises in physical functioning, school performance, social activities, emotional functioning and general health.

About half of the adolescents in a study in the Netherlands had recovered from CFS at follow-up. The other half was still severely fatigued and physically impaired. Health care use had been high, and school and work attendance were low. Older age at inclusion was a risk factor, and pain, poor mental health, self-esteem, and general health perception at outcome were associated with an unfavorable outcome.


The quality of life of children with CFS/ME is profoundly reduced, compared with that of their healthy counterparts.


Adolescents with CFS 6 months after infectious mononucleosis have a lower degree of fitness and efficiency of exercise than recovered adolescents.


Of 211 UK children with CFS, 62% attended 40% of school or less.

Disability in the under-12 age CFS group was high, with low levels of school attendance, high levels of fatigue, anxiety, functional disability and pain. The clinical pattern seen is almost identical to that seen in older children.


Since 1997, it has been known that myalgic encephalomyelitis/chronic fatigue syndrome constitutes the biggest cause of long-term sickness leading to absence from school, in both staff and pupils. Many affected children struggle for recognition of their needs, and are bullied by medical and educational professionals.


The experiences of children and adolescents with CFS are considered.

Elderly


Compared to younger CFS patients, older CFS patients demonstrate increased fatigue, a greater tendency toward depression, greater autonomic dysfunction (with reduced
parasympathetic function and increased sympathetic function), reduced baroreflex sensitivity, and prolonged left ventricular ejection time.


Issues involved in the treatment of CFS in the elderly population are discussed. Patient dissatisfaction with the care for their fatigue is a common problem.

**Research Funding:**


Increasing amounts of medical research are being done on fibromyalgia, but studies on CFS have remained level.

**Symptom & Severity Measurement:**


The authors present a severity score measure for CFS.

The authors discuss the idea that it has become difficult to compare data collected in different laboratories due to the variability in basic information regarding descriptions of sampling methods, patient characteristics, and clinical assessments. To address this problem, they present their consensus on the minimum data elements that should be included in all CFS research reports, along with additional elements that are currently being evaluated in specific research studies that show promise as important patient descriptors for subgrouping of CFS.


The authors examine the sensitivity and specificity of several fatigue scales that have attempted to define severe fatigue within CFS.


This study evaluates the Multidimensional Fatigue Inventory (MFI-20) in terms of a population of CFS patients in Georgia.

* Jason L, Muldowney K, Torres-Harding S. The Energy Envelope Theory and myalgic encephalomyelitis/chronic fatigue syndrome. AAOHN J. 2008 May;56(5):189-95. PMID: 18578185

CFS patients’ daily energy quotient was related to several indices of functioning including depression, anxiety, fatigue, pain, quality of life, and disability.
Stouten B. Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution. BMC Health Serv Res. 2005 May 13;5:37. PMID: 15892882

CFS fatigue rating scales are discussed.


This paper introduces the self-report CDC CFS Symptom Inventory and analyzes its psychometric properties.


This study provided an overview of design, reliability, and validity of the CFS Activities and Participation Questionnaire (CFS-APQ).


This study examined the Fennell Phase Inventory, an instrument designed to measure the phases typically experienced by individuals with chronic fatigue syndrome (CFS).

Behavioral data collection methods were used in a case study to show some of the benefits that can be derived from monitoring CFS symptoms hourly and daily.


This study provides two CFS case studies to illustrate the advantages of using self-reporting rating scales in combination with a device used to measure the frequency and intensity of activity.


This study of a 45-yr.-old man evaluated the relationships between scores on self-rating scales used to measure Chronic Fatigue Syndrome and actigraphy. Measured activity was related to predictors of fatigue but not to fatigue.
ME/CFS AND SOCIETAL ISSUES

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