

Public Comment
Lily Chu

Dear Sirs and Mesdames,

Thank you for this opportunity to address official and ex-officio members of CFSAC.

In the early 1990s, it was a habit of mine to watch the newsmagazine show “20/20” every Friday. One evening, the show was about Dr. Jack Kevorkian and the controversy over physician-assisted suicide; as a pre-medical student, I was interested in anything medically related and paid extra attention. I learned that one of the persons he assisted was Judith Curren, a nurse affected by fibromyalgia and chronic fatigue syndrome (CFS), who had suffered from severe pain and other symptom prior to her death. Later on, as a medical student and then a physician working with elderly patients, I remembered the case because of the ethical situation but not because of CFS.

Now, however, what stands out to me is that Ms. Curren suffered from CFS and was affected enough that she chose death over life. When I first encountered this illness six years ago, one of the first persons I spoke to was a good friend who also happened to be an excellent physician. She told me she had taken care of a very sick man in his 30s with CFS, so sick that a short car ride to her office was hardly tolerated. Not long after she had changed medical practices, she heard he had passed away. She was particularly upset because she did not think people could die from this illness. It was a revelation to me too and I put it down to a rare incident. However, since that time, I have known two young people personally that have passed away within the last year and have heard/ read of many others (1- 5) yet outside of the patient community and a few ME/CFS researchers and clinicians, the fact that people do die from ME/CFS is hardly acknowledged anywhere and rarely investigated.

My intention is not to cause anxiety, fear, or alarm – many people with CFS continue to live years to decades, albeit at much reduced function/ quality compared to their lives pre-CFS – but rather to encourage governmental agencies and researchers to take this illness seriously and urgently examine areas of ME/CFS that have been neglected.

1) Study the effects of ME/CFS long-term through cross-sectional and longitudinal studies.

A few studies have looked at the effects of ME/ CFS superficially in people who have lived with this for more than a decade but there are practically no longitudinal studies beyond a few years. Just 2 weeks ago, Chang et al., utilizing a large national cancer registry and a case-control design, showed that there was a statistically significant increased risk of non-Hodgkin’s lymphoma in people with CFS over the age of 65. (6) Since Paul Levine’s studies in the mid-1990s, this increased risk has been theorized to exist but there was no follow-up until recently. (7)

Furthermore, Chang or other researchers should consider replicating the study in a younger population. In 2006, Jason et. al. studied a list of ME/CFS deaths and concluded that 20% of the deaths were not only related to cancer but that the cancer deaths occurred 15 years earlier on average than cancer deaths in the population (48 vs. 72). (8) Thus, Chang et al., confining their study to those over the age of 65, would have missed any findings from this younger group.

2) Encourage researchers to include homebound and bedbound subjects in their studies.

There have been no studies on how many or what percentage of US ME/CFS patients are homebound or bedbound but using figures from British studies, at least 25% of patients fall into this category. (9) Having done home visits in the past for the elderly, I know that this type of population is particularly vulnerable – they are some of the sickest patients yet receive the least amount of care. This is further compounded by the fact that these ME/CFS patients rarely show up in emergency rooms or hospitals, as very sick patients with other illnesses do, and thus continue to stay invisible to the medical/ scientific community. Part of this is that patients feel these places have very little to offer them but the other part is that medical staff may not believe that they could be so sick and not take patients' symptoms seriously nor treat them appropriately.

Furthermore, there are only two studies that have been published including this population, both based in the UK. (10, 11) Yet, treatment goals and suggestions are routinely made for this group originating from clinic-based studies, which often involve less severely affected patients. In other areas of medicine, such as diabetes or hypertension, treatment suggestions, such as what should be the initial first drug of choice, are made based partly on severity of illness and goals may change based on the individual, not a one-size-fits-all paradigm. (12, 13) Why can't the same concept be applied to ME/CFS? At the same time, symptoms these patients DO suffer from including uncontrolled pain, inability to sit up without passing out, light/ noise sensitivity, difficulty swallowing/ eating, and severe cognitive dysfunction are neither studied nor treated appropriately to the best of medicine's current ability. Thus, it is not surprising that many of the deaths I am aware of occurred in this group, because of suffering/ despair/ hopelessness and/ or underlying biological processes the scientific/ medical community has yet to understand.

Over the last 2 decades, technology has advanced to the point where some tests and procedures that were once confined to the clinic or hospital are now able to be done during home visits. Aside from researchers visiting subjects, blood tests, certain x-rays, ultrasounds, and other portable diagnostic testing should be explored in investigating this group.

3) Consider autopsy and tissue sample studies and communicate with clinicians/ researchers involved in these studies.

Autopsy studies are a valuable method of gaining insight into the pathophysiology of illnesses. In 2005, Sophie Mirza, a 32-year old woman from the United Kingdom, died of ME/CFS after having been bedridden for 6 years. Before her death, Ms. Mirza was subjected to healthcare professionals who thought her illness was entirely psychological and who tried to have her placed in a psychiatric hospital. A preliminary autopsy revealed ME/CFS to be the main cause of death and the neuropathologist involved, Dr. Dominic O'Donovan, stated:

“the spinal chord [sic] looked normal but...4 out of 5 dorsal root ganglia were abnormal and showed disease. [I was unable] to find exactly what had caused this but the result was dorsal root ganglionitis – an inflammation.”

“dorsal root ganglionitis is a pathological condition....psychiatrists were baffled by her illness but... “It lies more in the realms of neurology than psychiatry, in my opinion.” (3)

Since then, Dr. O'Donovan and Dr. Abhijit Chaudhuri have performed at least 3 other autopsies with each individual consistently showing evidence of inflammation of the dorsal root ganglion and/or degenerative changes in the spinal cord or brain. (14, 15) Such inflammation may explain some of the severe pain and other neurologic symptoms some patients suffer from. They, along with other groups in the UK are currently working on establishing a post-mortem ME/CFS tissue bank to continue to study these unfortunate incidents systematically. (16)

In the United States, as far as I know, no such study is ongoing or has been proposed although I am aware that the CFIDS Association of America, Dr. Dan Peterson's group, as well as possibly the Whittemore-Peterson Institute may have some tissue samples and have thought about this topic. I suggest that government officials and researchers communicate with these groups as well with Drs. O'Donovan and Chaudhuri.

Finally, it has been brought to my attention that governmental officials would not allow submission of photographs or short videos involving homebound/ bedbound people as a means of testimony although videos have been allowed in the past. (17) Photographs and videos allow officials, researchers, clinicians, and the public a glimpse of the bedrooms that severely ill people are confined to for years to decades in a way that words on a page or a voice on the telephone do not. Would this not add to the picture of the illness the government needs to formulate an appropriate response to this illness? Are people afraid of seeing the truth? I suggest officials see the film "Voices from the Shadows," about severely ill ME/CFS patients, which is now available online and won the Audience Favorite award at the Mill Valley Film Festival in November of 2011. (18)

If some of what I have written sounds familiar, it is because some of the same ideas have been suggested in the past. Please take action on these issues soon. I hope to never hear about another preventable death nor to attend another funeral due to ME/CFS. Thank you for your attention.

Sincerely,

Lily Chu, MD, MSHS

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