Lack of Knowledgeable Healthcare Access for Neuro-endocrine-immune Diseases

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Objectives

Complex chronic diseases of the neuro-endocrine-immune systems include Myalgic Encephalomyelitis / chronic fatigue syndrome (ME/CFS), fibromyalgia, and post-treatment Lyme disease syndrome / chronic Lyme disease (Fuite, Vernon, & Broderick, 2008; Di Franco, Iannuccelli, & Valesini, 2010; Mohrenschlager et al., 2002). They all include dysfunctions in the hypothalamus-pituitary-adrenal axis and dysfunctions in the autonomic nervous system. They share many symptoms and are often comorbid and confused with each other (Buchwald, 1996; Dinerman & Steere, 1992).

Early diagnosis and treatment are important to producing optimum outcomes in these patients.

PANDORA Org sought to determine if these patients have access to knowledgeable healthcare of their disease, how long they must search for a diagnosis, and how many medical professionals they saw before being diagnosed.

Medical school deans and public health policy makers can benefit from this information.

Methods

In the summer of 2012, people in North America who identify themselves as having ME/CFS, fibromyalgia, or post-treatment Lyme disease / chronic Lyme disease answered a 7-question survey that was distributed through emails to patient support groups, social media, and patient-oriented websites.

Our study differs from prior studies that focused on one illness. Given the comorbidity and complexity of these diseases, we believed it is important to examine care for these patients as a group.

A limitation of this survey lies in the fact that it was distributed electronically to those with email, connected to support groups, connected to social media, or those who visit patient organization websites. Thus, patients who are not connected to these resources may not have known about the survey. Regardless of these limitations, the high number of respondents makes the survey a reliable way of reviewing the patient population with these chronic illnesses as a whole.

Results

Of 1,294 respondents in the continental United States, 54.4% (n=705) said they were not satisfied with the medical care they were receiving because their physicians had not been adequately trained about their disease. Only 24% of the respondents are satisfied with the medical care they receive within one hour of their residence.

Also, 71% (n=921) of 1,295 respondents in the continental Unites States visited 4 or more physicians before they received an accurate diagnosis. In their search for a diagnosis, the highest percentage of respondents stated that they had seen 4 to 6 physicians until they were able to obtain a proper diagnosis or medical advice. Only 6% of respondents were able to get a diagnosis or medical advice after seeing one physician.

Additionally, 63% (n=815) of 1,293 respondents spent 2 or more years searching before being appropriate diagnosed. Only 21% of respondents were able to receive a diagnosis or obtain medical advice for their disease within one year from when their search began. Thus, for a large majority (around 80%), they had to spend over a year trying to find a diagnosis or medical advice. For some (5%), their search spanned more than 22 years.
NEIDs Patients Satisfied or Not Satisfied with Expertise of Treating Clinician

- Satisfied & clinician within an hour's drive: 24%
- Satisfied but clinician is over 1 hour drive away: 13%
- Satisfied but must fly to clinician: 8%
- Not Satisfied: 55%

Physicians Visited before Diagnosis
(1,295 respondents)

Time before Diagnosis
(1,293 respondents)
Discussion

Medical professionals who focus on ME, CFS, and ME/CFS clinical care and research are found among many different specialties, including immunology, infectious disease, neurology, and others.

Although widespread pain leads rheumatologists to often diagnose the condition by excluding other rheumatologic causes of the pain, the American College of Rheumatology recommends that primary care physicians should provide fibromyalgia care and treatment.

Controversies between two factions of the medical community have left those with “chronic” Lyme or “post-treatment” Lyme disease syndrome to seek care from many different specialties or primary care physicians (Wormser et al., 2006).

A 2010 review of 119 medical school textbooks revealed that only 40.3% (n=48) mentioned CFS. Only 21% of the texts reviewed included the criteria for diagnosing CFS (Jason et al., 2010). A 2005 survey of French physicians found, “Of general practitioners and rheumatologists, 93.7% and 73.7% respectively, have not received any medical school training on fibromyalgia or chronic fatigue syndrome” (Blotman et al., 2005).

Conclusion

The current U.S. medical system has few specialty clinics for ME, CFS, ME/CFS, fibromyalgia, and post-treatment Lyme disease syndrome / chronic Lyme disease, and there is no specialty training about these diseases as a group in medical schools. As a result, the majority of these patients feel they do not have access to adequately knowledgeable clinicians.

It is necessary to increase medical school education for these complex, multi-system diseases through a new specialty because they are not embraced by other specialties.

There is also a need to establish additional multi-system specialty clinics in order to improve upon the notable delays in disease diagnosis and treatment.

References


