

## Chronic Fatigue Syndrome: Have Flawed Assumptions Been Derived from Treatment-Based Studies?

### ABSTRACT

Chronic fatigue syndrome is a disabling disorder that has been studied primarily in clinical settings. In the absence of an adequate epidemiological database, cultural stereotypes have influenced the characterization of chronic fatigue syndrome as "the yuppie flu," similar to the 19th century characterization of neurasthenia as a disease of the affluent. The limited epidemiological data available and the overall medical-sociological literature call this assumption into question. Only a community "true" prevalence study that is unbiased by help seeking and access to health care can provide an accurate assessment of the risk factors for and the public health ramifications of this disease. (*Am J Public Health*. 1994;84:282-284)

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### Introduction

Chronic fatigue syndrome is characterized by severe fatigue, muscle weakness, and other symptoms including confusion, depression, and inability to concentrate. Although there are no clear-cut physical criteria for diagnosis,<sup>1</sup> chronic fatigue syndrome is a disabling disorder resulting in impaired functioning or inability to function in work and family roles.<sup>2,3</sup> Treatment is complicated by uncertainty about the roles that virologic, immunologic, endocrinologic, and/or psychiatric factors play in the etiology of the syndrome.<sup>4-10</sup> In this paper, we argue that epidemiology has not yet depicted the true prevalence of or sociodemographic risk factors for chronic fatigue syndrome. Research has been limited to cases obtained from treatment settings and has thus confounded help-seeking and diagnostic practices with true prevalence. In the absence of adequate epidemiological data, socio-cultural stereotypes have contributed to the characterization of chronic fatigue syndrome as "the yuppie flu." Moreover, chronic fatigue syndrome has also been considered a contemporary version of neurasthenia, a 19th-century disease with similar symptomatology.<sup>11</sup> In its time, neurasthenia was also assumed to be most prevalent among the "yuppies" of that era—the upper social classes who maintained an "unflinching devotion to work."<sup>12(p38)</sup> Female gender was also associated with neurasthenia. We suggest that empirical research and insights from the broader medical-sociological and epidemiological literatures may contradict these conclusions.

Clinical studies have varied in their measurement of chronic fatigue syndrome from the earlier focus on Epstein-Barr viral infection<sup>13,14</sup> through varied criteria for

fatigue-related impairment and symptomatology.<sup>15-17</sup> Many studies were carried out before the development and use of the Holmes et al.<sup>1</sup> criteria and recently modified criteria<sup>18</sup> that specify inclusion and exclusion criteria. Despite the varied criteria used, clinical studies all show an overrepresentation of females. Although few studies specify social class or ethnicity, those that do report an overrepresentation of middle- or upper-middle-class patients<sup>15-17</sup> and few Black,<sup>17</sup> Hispanic, or Asian patients (D. Buchwald, communication about her Seattle chronic fatigue clinic, April 1992).

Epidemiological studies have used samples obtained from physicians' referrals<sup>19-21</sup> or rosters of health maintenance organization enrollees (D. Buchwald and A.L. Komaroff, study in progress). The Lloyd et al.<sup>19</sup> sample comprised patients referred by general practitioners in an Australian community on the basis of complaints of chronic fatigue. Although Lloyd et al. found a chronic fatigue syndrome rate of 37.1 per 100 000, they depicted this rate as "a minimum estimate of the true prevalence in the community" (p 522). First, physicians skeptical of the validity of chronic fatigue syndrome may have overlooked actual cases. Second, the case definition of Lloyd et al. involved severe disability, thus eliminating individuals who forced themselves to function despite severe symptomatology. However, in contrast to studies carried out in indi-

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vidual clinical settings, Lloyd et al. found a weak predominance of cases among females. Moreover, at greater variance with clinical studies, 53% of the case patients were from lower- or working-class backgrounds and only 14% were professionals.

The Centers for Disease Control and Prevention (CDC) study seeks to estimate the prevalence of chronic fatigue syndrome in four US cities: Atlanta, Reno, Grand Rapids, and Wichita.<sup>20,21</sup> The sample is derived from physicians' referrals. Because the study is in progress, final prevalence rates are not available. However, more than two thirds of the case patients referred to the CDC are females, a proportion similar to that found in previous clinical studies but at variance with that found in the Lloyd et al. study. Also, as in the Lloyd et al. study, skepticism by physicians and patients' nonentrance into physicians' practices would likely result in an underestimation of the true prevalence of chronic fatigue syndrome but an overrepresentation of the sociodemographic groups most likely to seek help.

The study by Buchwald and Komaroff involves a random sample of 4000 individuals on a health maintenance organization roster in the Seattle area. This study eliminates biases due to the nonutilization of medical services or the possibility that physicians fail to diagnose chronic fatigue syndrome when it is present given currently accepted diagnostic criteria. However, because this population consists of individuals with access to health care, it is likely to underrepresent disadvantaged individuals as well as ethnic groups that are underrepresented in the Seattle area. Again, because the study is in progress, prevalence rates and sociodemographic risk factors are not yet available.

Epidemiological studies of chronic fatigue syndrome are limited and methodologically less than ideal; nevertheless, the conclusions that can be drawn from them are at variance with those drawn from clinical studies. These inconsistencies can be understood from medical-sociological and social-psychological perspectives. Individuals vary greatly in their help-seeking behavior in response to illness and in their economic access to the health care system.<sup>22-26</sup> Most strikingly, Lloyd et al. showed that chronic fatigue syndrome does not appear to be a disorder of the affluent.<sup>18</sup> Moreover, lower-class patients generally experience higher levels of fatigue-related symptoms,<sup>27</sup> whereas upper-class patients are more likely to view such symptoms as a sign of a bona fide illness.<sup>28</sup> In addition, disadvantaged

minorities have been shown to manifest higher levels of chronic illness while being less likely to obtain adequate care; therefore they are less likely to be counted in epidemiological rates derived from treatment sources.<sup>23</sup> Diehr et al. estimated that 15% to 23% of all people in nine counties in Washington State have no health insurance<sup>29</sup> and thus would be less likely to obtain treatment and be counted in epidemiological research. From the perspective of social status and susceptibility to disease, Susser et al. argue that health research overall demonstrates a strong gradient increasing from the higher to lower class for most categories of diseases.<sup>30</sup> Moreover, disadvantaged minorities suffer significantly more disability from sickness. More specific to immune dysfunction (a potential source of chronic fatigue syndrome), Kaplan identified psychosocial risk factors such as chronic stressors, inadequate social support, and non-efficacious coping resources.<sup>31</sup> A large body of research has shown that these social experiences occur disproportionately among individuals of lower socioeconomic status.<sup>32-36</sup>

In sum, it is plausible to hypothesize that epidemiological studies to date have (1) underestimated the overall prevalence of chronic fatigue syndrome and (2) especially underestimated chronic fatigue syndrome in low-income populations with inadequate access to health care and a greater susceptibility to disease in general and immune dysfunctions in particular. Moreover, it is unclear whether women are at greater risk for chronic fatigue syndrome or are more visible because they seek health care services more frequently than men.<sup>36</sup> Because chronic fatigue syndrome is a disabling disorder, obtaining accurate epidemiological data is essential to assessing its public health ramifications. Only a community "true" prevalence study that is unbiased by help-seeking behaviors or access to treatment can provide such data. □

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## ABSTRACT

Data from the Institutional Population Component of the National Medical Expenditure Survey were used to provide national estimates of annual mental health service provision and use in nursing homes. In addition, the relationship between service provision and setting characteristics such as ownership, size, Medicaid certification, and chain status was examined. Although more than three quarters of residents with a mental disorder resided at a nursing home that provided counseling services, fewer than one fifth actually received any mental health services within the year. (*Am J Public Health.* 1994;84:284-287)

# The Provision and Use of Mental Health Services in Nursing Homes: Results from the National Medical Expenditure Survey

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## Introduction

Mental health services in nursing homes are in transition. The Nursing Home Reform Act of 1987 (Public Law 100-203), part of the Omnibus Budget Reconciliation Act of 1987, mandates screening and services for mentally ill elderly persons who are seeking admission to nursing homes. Even as the legislation is being implemented, estimates are needed to provide a benchmark for progress in service provision. Recent estimates of monthly service provision<sup>1</sup> are based on the 1985 national nursing home survey. The purpose of this report is to provide estimates of annual service provision based on the most recent national data, before implementation of the Omnibus Budget Reconciliation Act of 1987.

This article uses data from the Institutional Population Component of the 1987 National Medical Expenditure Survey<sup>2</sup> to examine the relationship between the annual provision of mental health services in nursing homes and the need for and use of these services among nursing home residents. Because previous work suggests that nursing home ownership affects service provision,<sup>3</sup> the analysis distinguishes between for-profit, not-for-profit, government ownership, and other organizational characteristics.

## Methods

Detailed information regarding the methodology for the Institutional Population Component of the 1987 National Medical Expenditure Survey is provided elsewhere.<sup>4,5</sup> This study examined only the resident sample obtained on January 1, 1987, which is a cross-sectional sample more likely to represent a longer staying and hence slightly more ill group.<sup>6</sup> The sample group of facilities analyzed here excluded those for mentally retarded persons because the focus is on the provision of mental health services in nursing homes. This sample also excluded facilities that were part of retirement centers or

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