

APPROACHES TO COLLECTION OF DATA

Definition and Measurement of Fatigue

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Although fatigue is a key component of the chronic fatigue syndrome, its definition and measurement remain relatively undeveloped. Most research on fatigue has been oriented towards work or performance of tasks and has involved laboratory studies of healthy individuals, while the study of fatigue as encountered in clinical settings has received minimal attention from investigators. This paper recommends that the natural history of chronic fatigue in its various clinical presentations be studied and that standardized assessment tools be used in this process. An investigation of the tools available for the assessment of fatigue yielded single-item, unidimensional, and multidimensional instruments. Additionally, the apparent association between affective illness and the chronic fatigue syndrome is addressed, and the fact that this relationship depends on issues of measurement is explored.

Fatigue is the most prevalent symptom of the chronic fatigue syndrome (CFS), yet the natural history of fatigue is poorly understood and relatively little attention has been given to its reliable and valid measurement. Of most concern is the absence of efforts to establish exactly what the term *fatigue* means when it is used in different research settings. Table 1 lists some of the kinds of studies that have been done on fatigue and some of the ways the term has been used in these studies. Thus, there are no reports in the literature that differentiate among the exertional fatigue of the patient with Parkinson's disease, the pain-related fatigue of the arthritic, or fatigue due to weakness in the patient with terminal cancer. Similarly, when used as a measure of decrement in performance, fatigue that might be due to physical exertion, inadequate rest, or sedentary life style is not separately defined. Several factors further confound the situation: fatigue has been operationally defined in both physiological and psychological terms; it has been described as part of both somatic and psychiatric disorders; it has been considered an outcome measure (e.g., a symptom); it has been used as an intervening variable to account for change; and it has been thought of as either an acute or a chronic phenomenon.

These problems suggest the possibility that the research on CFS may be confounded by the imprecision of the measurement of fatigue. Fortunately, there is extensive literature on the measurement of subjective states that have multiple meanings and applications. For example, pain and anxiety are terms that are semantically diverse as is the term *fatigue*, yet they are measurable in clinically useful ways [1, 2].

One approach to the operational definition of an emotional state is to include all clinical uses of the term as separate items in a measurement instrument. This was the approach that was used in the original design of instruments for the measurement of depression. The advantage of this approach is that patients with overlapping but different profiles are placed in the same category. A second approach is the use of a theoretical construct to organize and select items for inclusion in an assessment instrument. A third approach allows each respondent to characterize his or her particular emotional state by selecting alternatives from a broad array of descriptors. The McGill Pain Questionnaire [1] is an example of the last type of measurement instrument. The patient is provided with alternative pain descriptors and selects those that reflect his or her particular experience. This last approach acknowledges that the task of individualized classification is a necessary component of the precise definition of a subjective state.

This paper proposes a research agenda with the objective of developing a clinically relevant measure of fatigue that also differentiates among uses of the term. Specific recommendations include studies of the natural history of fatigue (both within the same day and between 2 or more days) among patients with CFS as well as among others with debilitating fatigue (e.g., patients receiving chemotherapy or patients with AIDS); development of a standardized interview schedule so that the classification of fatigue becomes reliable; and development of a self-report instrument for patients with fatigue, since the development of new treatments for CFS will require that the fatigue status of the patient be monitored.

Definition of Fatigue

Early investigators, such as Muscio [3], despaired of the development of an acceptable definition or measure of fatigue. Others persisted, limiting their definitional task to a specific area of investigation [4]. Efforts at a comprehensive defini-

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Table 1. Fatigue: current areas of research.

Decrements in performance
Physical exertion
Inadequate rest/sleep
Sedentary life style
Consumption-oriented behaviors
Caffeinism
Alcoholism
Abuse of drugs
Food and diet patterns
Correlate of psychiatric disorders
Situational distress
Neuroticism
Depression and grief
Somatization disorder
Manic-depressive illness
Decrements in perception/cognition
Mental fatigue
Eye strain
Impaired vigilance
Environmental/occupational effects
Boredom
Stress-induced (noise, heat, vibration)
Correlate of somatic disorders
Arthritis
Cancer
Congestive heart failure
Inflammatory bowel disease
Parkinson's disease
CFS

NOTE. This table is meant to be illustrative, not exhaustive.

tion take two basic forms: those that incorporate all known uses of the term and those that use a theoretical construct as a principle for defining fatigue. Piper [5], following in the tradition of Bills [6], integrates several approaches to the measurement of fatigue: behavioral, phenomenologic, and biologic. She defines fatigue as "an overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work." Major characteristics include verbalization of lack of energy and an inability to maintain usual routines. She also describes a variety of minor characteristics and related factors that result in a comprehensive definition.

Bartley [7] has suggested that incapacitation is a construct common to all usage of the term *fatigue* (subjective, objective, or physiologic) and that human fatigue is a form of biologic incapacitation. Specific subsystems may become incapacitated, such as a sensory receptor or a muscle, or the entire system may be incapacitated, as occurs with decrements in performance. In addition, incapacitations of subsystems may be overridden by a larger system, as occurs when psychological factors override physiologic fatigue in specific muscle groups.

Holding [4] takes an intermediate approach: fatigue is treated as an intervening variable, comparable in function to

such psychological variables as hunger and the ability to learn. Hours of food deprivation operationally define hunger, and hours of performance of work are used to define fatigue. As he states, however, "this approach neglects some of the usual connotations of the term, excluding cases like chronic fatigue as well as sleep loss, but offers the only practical starting point for research" [4].

Piper's operational definition of fatigue, which incorporates all three major aspects of the term [5], increases the chances that the instrument will be reliable but also increases the chances that the individual respondents' use of the term will not be clear. In contrast, Bartley's approach conceptualizes all uses of the term into one abstract category that loses its precision when applied across settings. Holding's approach [4], while practical for research, would lead to multiple definitions of fatigue, depending on the area of study. What has not been reported to date is the development of a tool for assessment of fatigue that is similar to the McGill Pain Questionnaire and that provides the respondent with semantic leeway within which to define his or her meaning of the term *fatigue*.

Defining fatigue is only one part of establishing a case definition for CFS. If cases of CFS can be identified according to a case definition, the etiology of the syndrome can be traced and new treatments can be developed and evaluated. There is another body of literature [8] that suggests that there are a variety of social and psychological disturbances found among patients with CFS. These data suggest that CFS may be accounted for on the basis of established psychiatric principles (e.g., a somatization disorder) and that the disorder will respond to psychological therapy. Wessely and Powell [8], for example, believe that a patient who has CFS is suffering from the confounding effects of physical inactivity and depression; this can be demonstrated by the contribution of cognitive behavioral therapy to the rehabilitation of these patients.

Recognition of CFS as a clinical syndrome will come when a differential diagnosis is formulated and a treatment program exists. Determination that CFS is a unique clinical syndrome, a mental or physical disorder, or some combination of the above is a task of classification. Classification is an iterative process that depends upon the systematic accumulation of information. This process makes possible differentiation between one condition and another.

The development of a working definition of CFS [9] was an attempt to provide a prototype case definition. However, it has some limitations. The major criteria in this definition are that the fatigue be a "persistent, relapsing or debilitating fatigue, new for the individual, not resolve with bedrest, and be associated with a 50% reduction in a patient's premorbid activity for a period of at least 6 months" [9]. The most troublesome aspect of these criteria is that a patient must estimate his or her premorbid level of activity as a basis for calculating his or her current level of activity. This estimate would be accurate only if it were possible to identify someone who is going to develop CFS so that an estimate of premorbid ac-

tivity could be obtained before onset of illness. Alternatively, the estimate would be accurate if a person could recall his or her premorbid level of activity after meeting the criterion of being fatigued for 6 months. Since neither condition is feasible, data obtained from the method proposed in the working definition are compromised from the outset.

One of the problems in establishing a case definition of CFS is that fatigue accompanies many disorders, and it is not clear whether the meaning of fatigue is the same in these different settings. In addition, a large proportion of patients with CFS appear clinically depressed [8, 10, 11], but the nature of the depression in the patient with CFS may not be the same as that in other patients considered to be depressed. It would be necessary to show that comparable criteria were used to establish the diagnosis for these two groups of patients. Also, evidence that antidepressants may be effective for managing symptoms of the patient who has CFS does not provide direct evidence that such a patient is depressed since antidepressant medications have more than one mechanism of action (cholinergic, serotonergic, and adrenergic). Therefore, the same mechanism of action of the drugs would have to be established for comparable groups of patients. This assertion is supported by data that indicate that measures of depression among medically and psychiatrically ill patients generate different diagnostic profiles [12] and that drug treatment of medically ill patients who appear clinically depressed [13, 14] may not be as effective as such treatment is for patients who have psychiatric diagnoses of depression.

Thus, whether it will be possible to develop a case definition of CFS remains unclear. What is clear is that the adequacy of subsuming this disorder under an established disease classification such as depression has not been proven.

Measurement of Fatigue

Most measures of fatigue are incorporated into indices that measure broader categories of conditions or functions. All of the major measures of depression have one or two questions related to fatigue. However, the wording used with these instruments may differ. For example, the Beck Depression Inventory requires patients to select the degree to which they "get tired"; on the Zung Self-Rating Depression Scale, the patients are asked to affirm that they "get tired for no reason"; while the Center for Epidemiologic Studies-Depression Scale requires patients to affirm if they felt that "everything they did was an effort." While these different questions appear to result in equivalent measures of fatigue, no available data support such an assumption.

The history of the process of coding fatigue on the National Ambulatory Medical Care Survey (NAMCS) illustrates the impact that the meaning of a term can have on the data generated by an assessment process. Patients' reports of symptoms on the NAMCS are recorded verbatim and then coded. Until 1976 fatigue was classified as a symptom, and exhaustion,

general weakness, and "being pooped, run-down, tired, or worn out" were also scored as indications of fatigue. After 1977 a new coding system was created and "tiredness and exhaustion" became the classification; the terms *fatigue*, *no energy*, *run-down*, and *worn out* were listed as synonyms. "General weakness" is listed as a separate category of symptom. Of interest is the observation that a 17% reduction in the incidence of reports of fatigue followed adoption of the new system in the first year, and this reduction has continued as shown by data from the most recent survey [15, 16]. These frequencies were compared with the frequency of reports of fatigue before 1977; reports of tiredness and exhaustion were combined with reports of general weakness for data after 1977. Whether this reduction in reports of fatigue was due to the recoding or due to a change in the population studied could not be determined. It is clear that the questions included for coding a symptom may be a major determinant of the data generated by the survey.

Besides single-item instruments, multi-item, unidimensional self-report instruments such as the Pearson Byars Fatigue Feeling Checklist [17] also have been developed. More recently, multidimensional instruments for the measurement of fatigue have appeared [5, 8, 18, 19]. For example, the Piper Fatigue Self-Report Scale consists of seven dimensions: a temporal dimension (10 items); an intensity/severity dimension (12 items); an affective dimension (five items); a sensory dimension (18 items); an evaluative dimension (13 items); an associated-symptoms dimension (11 items); and a relief dimension (seven items). Wessely and Powell [8] reported a 13-item fatigue-symptom questionnaire; eight of the items measure physical fatigue and five of the items measure mental fatigue.

Changes in performance can also be used as a measure of fatigue. LaPorte et al. [20] indicated that at least 30 different instruments exist for the measurement of physical activity. These instruments usually cover a wide range of activities and can be helpful in determining if the patient with CFS maintains much the same level of activity, although less frequently, as persons who do not have CFS or if the patient with CFS has a different activity profile.

Health-related quality-of-life assessments can also be used to characterize different groups of patients. The Sickness Impact Profile [21] is one such instrument that could be quite useful for measuring fatigue. It includes seven items that deal with rest and sleep and that overlap with what could be considered to be fatigue. Whether these items cover all fatigue-related factors is an empiric question.

A major concern, especially with the use of self-report instruments, is whether the subject is telling the truth when reporting fatigue. Although it is possible to design paper-and-pencil tests that have "lie detectors," they have not been found to be universally effective in the detection of lying. Psychologists have developed a variety of approaches to this issue, including incorporating two different ways of asking the same question into an assessment tool. Lack of consistency is con-

sidered an indication of potential deception. It is reassuring that there are a variety of ways to deal with the test results of malingers and subjects who feign symptoms.

The Diagnostic Interview Schedule [22] is appropriate for use in establishing the psychiatric background of the patient with CFS. It is less appropriate for establishing the nature of the fatigue experienced by patients with CFS or those who have other chronic diseases. It has become evident from this symposium on CFS that patients with this illness have a potentially unique set of factors that have contributed to onset of their illness. Allergies, individual exposures to toxic agents, family history of CFS, home heating sources, and exposures to animals all may predispose a person to the development of CFS following an immunologic assault. Therefore, all such items should be included in an interview schedule to be used for the diagnosis of fatigue.

At this stage in the understanding of CFS, it seems evident that a major descriptive task lies ahead. To use the epidemiologic phrase, the task is to describe fatigue as a "manifestational entity" rather than to describe it in etiologic terms. In fact, it can be argued that classification on the basis of etiology may be premature and counterproductive. We suggest that at least one of the elements in the equation be fixed by vigorously pursuing the description and classification of fatigue.

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