



# COPING AND ILLNESS COGNITIONS: CHRONIC FATIGUE SYNDROME

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**ABSTRACT.** *The chronic fatigue syndrome (CFS) is described, and research on coping with this illness reviewed and analysed. CFS is a severely disabling illness of unknown etiology, which has occurred in epidemic forms all over the world. However, the number of sufferers has dramatically increased over previous years. The heterogeneous symptomatology of CFS was reviewed, and diagnostic criteria were discussed. The difficulty in establishing causality was emphasized. An interaction of factors appears most likely to be associated with illness onset and maintenance. As the mediating factor could be sufferers' coping behavior, the existing coping literature was reviewed. There might be an association between coping and physical and psychological well-being. Finally, recommendations are made for longitudinal research on coping and coping effectiveness, and for the development of therapeutic interventions.* © 2001 Elsevier Science Ltd.

**KEY WORDS.** Chronic fatigue syndrome, Coping, Cognition, Therapy, Carer.

THE CHRONIC FATIGUE syndrome (CFS) is a disabling condition of unknown etiology and prognosis. Parallel to an apparent increase in the number of sufferers over the past decade (currently there are half a million diagnosed sufferers in the United States; Friedberg & Jason, 1998), CFS has received increasing attention in the scientific literature. Most studies have been concerned with researching possible causes and treatment of the main symptom, fatigue.

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## THE IMPORTANCE OF COPING WITH CFS

Research into interventions to increase psychological well-being has been rare, as most cognitive-behavioral interventions are aimed at increasing physical functioning. It is argued here that greater attention should be paid to the patient's emotional and psychological state. This could be achieved by focusing on the patient's coping behavior. In accordance with this, the literature on coping with CFS was reviewed.

It has been recognized that literature reviews are often influenced by the authors' discipline (Joyce, Rabe-Hesketh, & Wessely, 1998). In this case of CFS, researchers frequently belong to areas of, for example, psychology, psychiatry, and immunology, and so an additional aim was to overcome this problem by reviewing the literature from a multidisciplinary perspective.

CFS has been called the "disease of a thousand names" (Bell, 1991). It has been referred to as myalgic encephalomyelitis (ME), postviral fatigue syndrome (PVFS), chronic fatigue immune dysfunction syndrome (CFIDS), and yuppie flu, to name a few. The variety of names stems from the fact that the etiology of CFS is not known. Some people have argued that CFS is an umbrella term and therefore that ME, PVFS, and other conditions are really subclasses of CFS (Jason et al., 1995). The diagnoses of CFS, ME, and PVFS are variously given by physicians, but there is insufficient evidence supporting the existence of such subclasses, and therefore physicians' and researchers' use of CFS to embrace the various symptoms will be adopted here. While names such as ME or PVFS imply specific causes, CFS only points to the most prominent symptom, fatigue.

Reports suggest the CFS affects predominantly young (20- to 50-year-old) White women (Fuhrer & Wessely, 1995; Fuller & Morrison, 1998; Hilgers, Krueger, Lembke, & Ramon, 1991; Kroenke, Wood, Magelsdorff, Meier, & Powell, 1988), many of whom are working in highly demanding jobs before the onset of the illness. This led to the assumption by some physicians that the so-called yuppies, young and successful professionals, and especially women struggling with work and family responsibilities, had finally succumbed to stress (Ho-Yen, 1990). Such suggestions implied that CFS was a product of the stressful Western way of living. However, these assumptions are being challenged now as men, children, and generally people of all ages and who do not report extreme stress prior to the onset of CFS, also appear to be affected (Shepherd, 1992). For instance Bell (1991) suggests that up to 30% of reported cases are children (although there are only few cases under the age of 5). Nevertheless, it appears that overall about 75% of reported cases are adult white females (Bell, 1991; Showalter, 1997; Wessely & Sharpe, 1995). Similar figures are often reflected in study samples. For example, Lewis, Cooper, and Bennett (1994) obtained a sample of 23% males and 77% females, while Ray, Jefferies, and Weir (1995) obtained a female sample of 68%. It must be emphasized that the greater number of females diagnosed with CFS might be related to increased symptom reporting in females and stigma (Lewis & Wessely, 1992). Nevertheless, such figures underline the difficulty associated with recruiting male patients or those from ethnic minorities (an exception is Buchwald et al., 1995).

The illness gained widespread recognition only in the last decade when the number of cases increased for no apparent reason. However, some experts argue that it has existed before. For example, Bell (1991) has pointed out that CFS has occurred in epidemic and endemic forms in at least 50 recorded outbreaks all over the world. It is now recognized that previous outbreaks of CFS occurred in the United States (e.g., Gilliam, 1938), New Zealand (e.g., Poore, 1984), Iceland (e.g., Sigurdsson, 1950) and Britain (e.g., Medical Staff of the Royal Free Hospital, 1957). The most severe of these

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