

Coping strategies in twins with chronic fatigue and chronic fatigue syndrome

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Abstract

Objectives: Individuals with chronic fatigue and chronic fatigue syndrome (CFS) face debilitating symptoms as well as stressful life situations that may result from their condition. The goal of this study was to examine the coping strategies used by fatigue-discordant twin pairs. **Methods:** We utilized a co-twin design to assess how twin pairs discordant for chronic fatigue and CFS cope with stress. All twin pairs were administered the Revised Ways of Coping Checklist. **Results:** Overall, the pattern of coping strategies was similar for fatigued and non-fatigued twins. However, twins with chronic fatigue or CFS utilized

more avoidance strategies than their non-fatigued counterparts; those with chronic fatigue also used more avoidance relative to problem-focused coping than their co-twins. **Conclusions:** These results suggest that while fatigue-discordant twins generally exhibit similar behavior patterns in order to cope with stress, there may be an association between fatigue and avoidance coping. Future research should focus on the role of avoidance and its relationship to fatiguing illnesses. © 2000 Elsevier Science Inc. All rights reserved.

Keywords: Chronic fatigue syndrome; Coping; Fatigue; Twins

Introduction

Fatigue is a common symptom in a variety of medical and psychological conditions. It is reported by 20–40% of patients seeking medical care [1–3] and large community surveys indicate that up to half of the general population experiences fatigue [4–6]. Unexplained persistent and debilitating fatigue is the hallmark of chronic fatigue syndrome (CFS). CFS is also characterized by sleep disturbances, depression, myalgia, neurocognitive difficulties, and other symptoms [7]. In clinical settings, CFS is most commonly diagnosed in educated, previously healthy, and productive women [8]. Because the etiology remains unknown, CFS is a diagnosis of exclusion [7].

Along with the debilitating symptoms, those with CFS often face many stressful life situations. For example, between 26% and 37% of patients with chronic fatigue or CFS were unemployed at their initial clinic visit [9]. In addition, patients with CFS have exhibited significantly worse functional status than the general population and depressed or medically ill patients [10,11].

Coping has been defined broadly as a person's cognitive and behavioral efforts in reducing or tolerating the demands of stressful events [12]. This view of coping also suggests that a person may cope by trying to actively manage a distressful situation and/or by attempting to reduce the emotional consequences of experiencing distress; depending on the demands of the situation, each coping strategy could be adaptive or dysfunctional. Individuals with chronic fatigue and CFS have been reported to employ a variety of coping strategies to deal with the debilitating consequences of fatigue. A study of 58 female patients with CFS reported using significantly more escape/avoidance strate-

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gies than 104 healthy controls [13]. In a retrospective study, CFS patients reported an increased use of escape/avoidance coping strategies after the onset of illness [14]. A more recent study found that primary care patients with chronic fatigue used an escape/avoidance coping style more frequently than age- and gender-matched patients without chronic fatigue [15].

Coping behaviors, in turn, can influence prognosis. While little is known about adaptive coping strategies in patients with CFS, the use of problem-focused coping has been associated with less depression [16] and better perceived health status [17] in other populations. In terms of maladaptive coping, however, avoidance strategies have been associated with greater fatigue, impairment, and other psychosocial disturbances in patients with CFS [18,19]. However, it is difficult to interpret these diverse findings because studies of coping and CFS suffer from numerous methodological shortcomings. These include poorly-defined methods for CFS sample selection, the absence of the consistent application of the Center for Disease Control and Prevention (CDC) criteria to diagnose CFS [7], and the use of inadequate or poorly described comparison groups.

The purpose of the present study was to conduct a co-twin control study of coping strategies in twin pairs discordant for chronic fatigue and CFS. The co-twin control design provides one of the most sensitive approaches for assessing the association of a specific condition, such as chronic fatigue, with subtle clinical, laboratory, or behavioral findings [20]. Since the non-ill twins serve as natural controls for their ill siblings, the co-twin design is especially helpful when the appropriate comparison groups are not well-defined. The twins included in this study were members of the newly constructed Chronic Fatigue Twin Registry.

Methods

Ascertainment of twins and data collection

Twin pairs in which at least one member was chronically fatigued (a specified fatigue duration or diagnosis of CFS was not required) were solicited through advertisements placed in twin organization and patient support group newsletters, electronic bulletin boards for CFS, from existing twin registries, and by contacting clinicians and researchers familiar with CFS. Of the 216 pairs identified through these sources, data were available for both members of 193 pairs (89.4%). Written informed consent was obtained from each subject in accordance with the regulations of our institutional Human Subjects Office.

A detailed account of the construction of the Registry has been presented elsewhere [21]. Briefly, the Registry questionnaires included information on demographics; zygosity; habits and life-style; social support; distress; coping strategies; a section on the nature, extent, and consequences of fatigue; and a checklist of the 1994 CDC criteria for CFS

[7]. For non-fatigued individuals, a control version of these questions was used that did not reference fatigue. Physical health was determined by self-report using a checklist of medical disorders. In addition, the Diagnostic Interview Schedule Version III-A (DIS) [22], a highly structured interview that assigns current and lifetime diagnoses based on DSM-III-R criteria [23], was administered by telephone to ascertain psychiatric conditions.

Definitions of chronic fatigue and CFS

Our analysis used three, progressively more stringent case definitions of chronic fatigue.

Chronic fatigue

This definition was based on the response to a single question: “Have you been fatigued for at least 6 months?” Pairs in which one twin responded “yes” and the co-twin responded “no” constituted the Level 1 analytic sample.

Presumptive CFS

The Level 2 definition classified chronically fatigued twins according to the CDC CFS research definition using data obtained from the mailed questionnaires and telephone interview. A criteria-based algorithm was developed that made a presumptive diagnosis of CFS (PCFS) using both the inclusionary and exclusionary components of the CDC case definition. Identical exclusionary criteria were applied to the fatigued and non-fatigued twins. To be classified as PCFS, twins were required to report fatigue for ≥ 6 months that was not lifelong and resulted in a substantial reduction of their occupational, educational, social, or personal activities. Furthermore, individuals had to endorse the presence at least four of the following eight complaints, which comprise the CDC CFS symptom criteria: impaired memory or concentration, sore throat, tender glands, aching or stiff muscles, multi-joint pain, new headaches, unrefreshing sleep, and post-exertional fatigue.

Twins were excluded from the Level 2 analytic sample for obesity (body mass index ≥ 45) or the presence of specific physical and psychiatric disorders. A checklist of self-reported physical health problems was used to determine the presence of diverse health conditions; twins indicated whether a condition was currently active and whether a physician had evaluated them for this condition. Examples from the comprehensive list of exclusionary disorders included (but were not limited to) steroid-dependent asthma, infectious hepatitis, diabetes, cancer (other than skin), congestive heart failure, stroke, cirrhosis, multiple sclerosis, and systemic lupus erythematosus. Consistent with the CDC case definition, the exclusionary psychiatric disorders included the DIS generated diagnoses of lifetime mania, hypomania, bipolar disorder, schizophrenia, major depression with psychotic or melancholic features, anorexia or bulimia nervosa, and current alcohol or substance abuse or dependence.

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