

Short communication

## The awareness of chronic fatigue syndrome: A comparative study in Brazil and the United Kingdom

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### Abstract

**Objective:** While in many Western affluent countries there is widespread awareness of chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), little is known about the awareness of CFS/ME in low- and middle-income countries. We compared the awareness of CFS in Brazil and the United Kingdom. **Methods:** Recognition and knowledge of CFS were assessed among 120 Brazilian specialist doctors in two major university hospitals using a typical case vignette of CFS. We also surveyed 3914 and 2435 consecutive attenders in Brazilian and British primary care clinics, respectively, concerning their awareness of CFS. **Results:** When given a typical case vignette of CFS, only 30.8% [95% confidence interval (CI), 22.7–39.9%] of Brazilian specialist doctors mentioned chronic fatigue or CFS as a possible diagnosis, a proportion substantially lower than that

**Keywords:** Chronic fatigue syndrome; Awareness; Brazil; United Kingdom

observed in Western affluent countries. Similarly, only 16.2% (95% CI, 15.1–17.4%) of Brazilian primary care attenders were aware of CFS, in contrast to 55.1% (95% CI, 53.1–57.1%) of their British counterparts ( $P < .001$ ). This difference remained highly significant after controlling for patients' sociodemographic and socioeconomic characteristics ( $P < .001$ ). **Conclusions:** The awareness of CFS was substantially lower in Brazil than the United Kingdom. The observed difference may influence patients' help-seeking behavior and both doctors' and patients' beliefs and attitudes in relation to fatigue-related syndromes. Attempts to promote the awareness of CFS should be considered in Brazil, but careful plans are required to ensure the delivery of sound evidence-based information.

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### Introduction

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a well-known condition in Western affluent countries [1]. With the frequent media coverage and formation of numerous patient organizations—which often conveyed an explicit purpose of political, media, and health service lobbying—during

the last two decades, awareness of the condition has substantially grown among the general population, politicians, and those responsible for health care delivery. Such widespread awareness of the condition may play a role in issues related to help-seeking behavior, reporting, recognition, labeling, referral, and management. In contrast, in low- and middle-income countries such as Brazil, the general impression is that CFS is hardly known even among health professionals [2]. In this article, we report on two studies about the awareness of CFS in Brazil and the United Kingdom. The overall hypothesis was that the awareness of CFS in Brazil would be far lower than that observed in the United Kingdom.

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## Methods

### *Study 1: CFS awareness among Brazilian specialist doctors*

In order to assess the awareness and recognition of CFS among Brazilian doctors, several specialist clinics in two major university hospitals were approached in São Paulo. Five specialties were chosen where CFS cases should most likely be found: internal medicine, rheumatology, infectious disease, neurology, and psychiatry. We chose specialist doctors rather than general practitioners (GPs) because we hypothesized that awareness of CFS in Brazil, were it to exist, would start from specialist clinics, mirroring circumstances elsewhere.

A questionnaire survey with 120 specialist doctors was conducted between November 2004 and February 2005. The questionnaire included a clinical vignette of a typical patient with CFS (see Appendix A) and questions on gender, age, graduation year, specialty, training level, probable diagnosis of the case (an open-ended question), probable causes of the case (a categorical question), and treatment options (a categorical question). The vignette was an adapted version of Nacul et al.'s [2], with the authors' permission, reflecting the Centers for Disease Control and Prevention (CDC)-1994 case definition [3]. Research workers visited the aforementioned clinics and distributed the questionnaires to doctors after their regular department meetings or between their outpatient consultations.

We categorized the answers for the open-ended question into seven groups, after a thorough inspection of the data: "organic disorders," "chronic fatigue or CFS," "asthenia or similar description," "fibromyalgia," "stress," "psychological disorders," and "no answer." Multiple answers were allowed for probable diagnosis, probable causes, and treatment options. Hence, percentage frequency of each group was estimated considering each answer rather than each responder as an observation unit. For the estimation of recognition rate, a new binary variable called "recognition of CFS" was created, which classified as "yes" the doctors who included chronic fatigue or CFS in their answers. Subsequently, the point estimate of CFS recognition and its 95% confidence interval (CI) were calculated.

### *Study 2: CFS awareness among primary care attenders in Brazil and the United Kingdom*

The screening questionnaire of a cross-sectional survey with Brazilian and British primary care attenders [4] contained a yes/no question on the awareness of CFS: "Have you ever heard of or read about CFS or ME?" The screening questionnaire also included questions on socio-demographic variables.

Consecutive attenders of 11 primary care practices in São Paulo and 5 in London, aged 18 to 45 years, were invited to fill out the questionnaire. The percentage of CFS awareness and its 95% CI were calculated for each sample. The  $\chi^2$  test

was used to compare proportion of awareness between the two samples. We used logistic regression to test whether the association between CFS awareness and country of residence was due to differences in sociodemographic and socio-economic variables between samples.

## Results

### *Study 1: CFS awareness among Brazilian specialist doctors*

The mean age of the sample was 34.5 years, and the mean time since graduation was 10.1 years. The highest training level completed was residency for 64% of them. There were similar numbers of doctors in each of the five specialties included in the study, except for neurology, with just one. Therefore, neurology was merged with psychiatry as the same category. In practice, although all the doctors were approached in the abovementioned specialist departments, 39 (32.5%) doctors identified their specialty as "other" (Table 1).

Thirty-seven out of the 120 Brazilian specialist doctors mentioned chronic fatigue or CFS as one of the probable diagnoses of the case vignette (30.8%; 95% CI, 22.7–39.9). Allowing for multiple answers, psychological disorder was the most frequently mentioned diagnosis for the case vignette (39.1%), followed by chronic fatigue or CFS (23.0%), organic disorder (14.3%), fibromyalgia (12.4%), stress (7.5%), and asthenia/psychasthenia (3.7%). The most frequently mentioned cause for the case vignette was either stress/overworking (30.0%) or psychological problems (30.0%), followed by hormonal alteration (13.6%), virus (11.5%), immunological alteration (7.0%), and other (7.8%). The treatment option most frequently indicated for the case was antidepressants (24.1%), followed by exercise therapy (17.3%), counseling or traditional psychotherapy (17.3%), relaxation (13.9%), cognitive behavioral therapy (11.4%),

Table 1  
Characteristics of 120 Brazilian specialist doctors and their recognition of CFS

Characteristics	Value
Female gender, <i>n</i> (%)	63 (52.5)
Age (24–60 years), mean (SD)	34.5 (9.1)
Time since graduation (0–32), mean (SD)	10.1 (8.8)
Highest training level completed, <i>n</i> (%)	
Medical school	21 (17.5)
Residency	77 (64.2)
Master	10 (8.3)
PhD	12 (10.0)
Specialty, <i>n</i> (%)	
Internal medicine	29 (24.2)
Rheumatology	18 (15.0)
Infectious disease	11 (9.2)
Psychiatry and neurology	23 (19.2)
Other	39 (32.5)
Recognition of CFS, <i>n</i> (%)	37 (30.8)

rest (4.0%), nutritional supplement (2.2%), immunotherapy (1.5%), hormones (1.2%), antiviral (0.6%), homeopathy (0.6%), and other (5.9%).

### Study 2: CFS awareness among primary care attenders in Brazil and the United Kingdom

The characteristics of the study participants are described in Table 2. The two samples differed in all sociodemographic and socioeconomic variables, except for age. Brazilian participants had a lower educational level and were more likely to be female, to have a stable partner (i.e., married or cohabiting), to have a manual occupation, and to be unemployed. All the Brazilian participants ( $n=3914$ ) answered the awareness question, and 635 (16.2%; 95% CI, 15.1–17.4) reported awareness of CFS. Of 2459 British participants, 2435 answered the awareness question and 1341 (55.1%; 95% CI, 53.1–57.1) answered affirmatively. The difference was highly significant ( $P<.001$ ) and remained significant ( $P<.001$ ) after controlling for sociodemographic and socioeconomic characteristics (age, gender, education, marital status, employment status, and occupation).

## Discussion

### Study 1: CFS awareness among Brazilian specialist doctors

The recognition rate (30.8%) of CFS among specialist doctors in São Paulo observed by the current study was similar to that (27.8%) of a previous questionnaire survey assessing CFS-related knowledge and practices of 72 Brazilian doctors in Northeast Brazil [2]. In contrast, the

recognition rate observed in the present study was substantially lower than those found in surveys with GPs from Western affluent countries [5–7]. When asked about recognition of CFS cases, 73% of all Dutch GPs who answered the survey [5], 78% of a national random sample of Irish GPs [6], and 88% of GPs in a region of New Zealand [7] identified at least one case of CFS in their surgery. As all these studies were conducted more than a decade ago, current recognition rates in those settings are likely to be still higher (and hence the differences with Brazilian medical practice). Another study investigated familiarity with CFS among American medical trainees, half of whom were medical students and the other half were residents [8], and found that 93% had heard of CFS, 50% had read articles about CFS, and 27% knew someone with CFS.

The two university hospitals included in the current study are probably the most important centers of medical research and training in Brazil, and many professionals from these two hospitals frequently travel to international conferences and maintain close collaborations with their American or European colleagues. Therefore, the awareness of CFS must be even lower among health professionals in nonacademic centers and in other regions of Brazil, where access to international scientific information is probably more limited.

We did not give a similar vignette to United Kingdom specialists, but it would be unexpected to find a practitioner who professed not to have heard of CFS. The fictional nature of the case vignette may be another limitation of the study. Although the vignette was devised to reflect the current case definition of CFS, a real patient with this history could indeed have other illnesses than CFS. Conversely, a real patient with CFS may not necessarily resemble the vignette. Hence, it should be noted that the study examined the recognition of the currently accepted diagnostic concept of CFS rather than a real case of CFS.

### Study 2: CFS awareness among primary care attenders in Brazil and the United Kingdom

The present study brings clear evidence that there is less awareness of CFS among Brazilian primary care attenders compared to those in the United Kingdom. Our finding is also consistent with a primary care study from Hong Kong, which also observed a very low rate of CFS awareness among 100 patients with medically unexplained fatigue lasting 6 months or more—none reported any prior awareness of CFS [9]. The following limitations should be considered. False-positive answers could have happened given the simple nature of the question used. It is unknown whether the current findings can be generalized to other regions of the two countries.

### Possible reasons and implications

Since the prevalence of CFS according to the CDC-1994 criteria is not very dissimilar between Brazilian and British

Table 2

Participant characteristics and awareness of CFS compared between Brazil ( $n=3914$ ) and the United Kingdom ( $n=2435$ ) by  $\chi^2$  or  $t$  tests

Characteristics	Brazil	United Kingdom	<i>P</i>
Age in years, mean (SD)	31.7 (7.9)	31.6 (7.2)	.53
Female gender, <i>n</i> (%)	3120 (79.7)	1739 (71.4)	<.001
Education in years, mean (SD)	8.7 (4.4)	15.3 (4.5)	<.001
Marital status, <i>n</i> (%)			<.001
Married or cohabiting	2188 (55.9)	1293 (53.1)	
Single	1366 (34.9)	978 (40.2)	
Separated, divorced, or widowed	360 (9.2)	164 (6.7)	
Employment status, <i>n</i> (%)			<.001
Employed	2645 (67.6)	1667 (68.5)	
Student	206 (5.3)	200 (8.2)	
Homemaker	535 (13.7)	312 (12.8)	
Unemployed	444 (11.3)	157 (6.4)	
On sick leave	84 (2.1)	99 (4.1)	
Occupation, <i>n</i> (%)			<.001
Nonmanual	1519 (38.8)	1479 (60.7)	
Manual	2092 (53.4)	580 (23.8)	
Student or never worked	105 (2.7)	185 (7.6)	
Homemaker	198 (5.1)	141 (5.8)	
No response	0	50 (2.1)	
Aware of CFS, <i>n</i> (%)	635 (16.2)	1341 (55.1)	<.001

primary care settings (1.6% and 2.1%, respectively) [4], the findings may be explained mostly by sociocultural differences rather than biological or environmental factors. First, the medical education and practice in Brazil place great emphasis on infectious diseases and other disorders unseen in developed countries; hence, Brazilian doctors may be less concerned about newly emerging disorders like CFS. Second, in Brazil, there are virtually no activities promoting the awareness of CFS such as media coverage, patient organizations, and governmental endorsement. Finally, the construct of CFS is an essentially biomedical concept originated from Western developed countries and may not fit well to the Brazilian society, which may be more familiar with other constructs such as *nervoso* (nervous) and *mau olhado* (evil eye). Like *shenjing shuairuo* (weakness of nerves) in China [9], both constructs, characterized by miscellaneous physical and mental symptoms including fatigue, have a flexible symptom configuration and causal attribution beyond the mind–body dichotomy [10,11]. Thus, the applicability of the CFS/ME label, an inflexibly biomedical construct primarily focused on its physical symptom profile and etiological postulation, may be more limited in Brazil.

The observed difference will clearly have some influence in patients' help-seeking behavior and both doctors' and patients' beliefs and attitudes in relation to fatigue-related syndromes. The original epidemiological study from which some of the current data are derived found that, despite the similar prevalence of chronic fatigue in both countries, Brazilian primary care patients were less likely to present with fatigue, and Brazilian GPs were less likely to make a fatigue-related diagnosis than their British counterparts [4]. Furthermore, the findings suggest that Brazilian medical curricula should include CFS and other fatiguing illnesses. Obviously, this change should be firmly based on evidence as some practices based on conventional beliefs were shown to be ineffective in the treatment of CFS [12]. This, in turn, means that more research is required in Brazil to provide medical educators and practitioners with locally produced evidence, especially on what to do about fatigue-related syndromes. Such an experience has previously occurred in Sri Lanka [13]. Finally, observing that biased media coverage often aggravated misunderstanding and suffering of CFS patients in Western countries [1], any attempt to promote the awareness of CFS to the general public should be even more carefully planned so that sound evidence-based information can be delivered.

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### Appendix A. Clinical vignette describing a typical patient with CFS according to the CDC-1994 case definition (translation from the original version in Portuguese)

"Ms. MLS," a 31-year-old female patient, primary school teacher, complains of intense tiredness that began 12 months ago after a flulike episode, persisting until today. She also reports the following symptoms that have developed during the last 12 months: constant muscle pain, headache and sore throat, difficulties with concentration and memory, especially for recent events, and disturbed sleep. Her tiredness and muscle pain worsen after any physical or mental exertion (such as reading), and malaise and nausea after the exertion persist for 2 or 3 days. As a consequence of her symptoms, she had to reduce her working time from 40 to 20 h per week. Despite this, it is difficult for her to fulfill her work requirements, leading to frequent absences from work. She interrupted her job for 2 months at the onset of the illness. From then on, she has

not been able to keep up with household chores, which she did without any difficulty before, and now, she has to count on her sister for doing the chores. Since the development of the symptoms, she has interrupted her daily walk of 1 h, which she had been practicing every morning. Currently, she manages to walk for about 10 min, being forced to stop and rest after this period. She says she had been a healthy and active person until the beginning of the symptoms, denying prior personal history of physical or mental disease. She also denies use of illicit drugs; she used to drink only occasionally before but stopped drinking because her symptoms worsened with intake of

alcoholic drinks. She does not use medications except for aspirin she occasionally takes for pain. She has no important prior family history of physical or mental disease. Her grandparents died of “natural causes” in advanced ages. She has a hypertensive father and a healthy mother. On physical examination, the patient appeared in a good general state, hydrated, in a good nutritional state, and without abnormalities. Neurological examination revealed no abnormalities either (blood pressure=110×70 mmHg, heart rate=84/min, axillary temperature=36.6°C, weight=57 kg, height=1.63 m). The repeatedly conducted laboratory tests were normal.