

Research Volunteers' Attitudes Toward Chronic Fatigue Syndrome and Myalgic Encephalomyelitis

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Abstract

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are stigmatizing illnesses characterized by cognitive difficulties, post-exertional malaise, unrefreshing sleep, and other symptoms. Patients are often incapacitated and stigmatized as having a psychological disorder. The Chronic Fatigue Attitudes Test (CAT) assesses stigmatizing views toward individuals with Chronic Fatigue Syndrome, however, there is little research examining factors that may account for variation in stigmatizing attitudes toward this group. We examined CAT scores among college age research volunteers (N = 90), hypothesizing that exposure to information about ME and CFS as a result of volunteering on a ME and CFS-related research project would be associated with less stigmatizing attitudes compared to volunteers on unrelated projects. Findings indicated that ME and CFS research volunteers expressed less stigmatizing attitudes. Educational efforts aiming to disseminate accurate information about ME and CFS may mitigate stigma and the experience of stigma among individuals with ME and CFS.

Keywords: Chronic Fatigue Syndrome; Stigma; Attitudes; Myalgic Encephalomyelitis

Abbreviations

CFS: Chronic Fatigue Syndrome; ME: Myalgic Encephalomyelitis; CAT: Chronic Fatigue Attitudes Test

Introduction

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) affect about a million adults in the United States [1] and about 25% of diagnosed individuals are housebound [2]. Individuals with ME and CFS experience more debilitating symptoms than patients with other chronic illnesses like end stage renal disease, type 2 diabetes, congestive heart failure, or multiple sclerosis [3]. Individuals with ME and CFS have reported experiences being discredited or stigmatized as a result of the nature of ME and CFS symptomatology [4]. The name of the condition itself, "chronic fatigue syndrome" is a stigmatizing label that diminishes the seriousness of the illness.

Stigma occurs when an individual is regarded as inferior as a result of undesirable attributes that enhance the individual's differences [5]. ME and CFS disproportionately impacts middle-aged women [6] and some experiencing this illness have reported the experience of others assuming that they suffer from a form of mental disorder, attributing symptoms to menstruation or menopause [7]. Patients with ME and CFS may be discredited because people working full time jobs also experience symptoms of fatigue or exhaustion, but this is considerably different from the severe fatigue and post exertional malaise characterizing ME and CFS [8]. Those with ME and CFS may attempt to conceal the severity of symptoms in public situations to avoid further stigma, only to find that this effort exacerbates symptoms afterward [6]. For these individuals, stigma in the form of social disbelief and doubt can add to their overall burden [9].

Previous research discovered that 95% of patients felt alienated from those around them whereas 70% of patients' families or friends believed that their symptoms were a result of mental disorders [10]. Other patients undergoing treatment believed their symptoms became worse because their doctor misunderstood symptom origins or were disinterested in ME and CFS treatment [11]. For a medical professional, when symptoms are neither externally displayed nor evident in laboratory results, it is often interpreted as an indicator that symptomatology may be a result of mental illness [12]. The view that ME and CFS is psychological [4] may inhibit patients with ME and CFS from receiving appropriate care [13]. As a result, patients are confronted with the doubly taxing burden of not only coping with the illness, but defending or proving their illness's physiological components.

To date, a small number of studies have attempted to measure ME and CFS stigma, but more work is needed to understand factors that contribute toward these stigmatizing attitudes. The Chronic Fatigue Syndrome Attitudes Test (CAT) [13] was developed to measure attitudes toward individuals with ME and CFS in three domains: traits of individuals with ME and CFS, relevance of ME and CFS to society, and responsibility of individuals with ME and CFS for getting sick. Friedberg, Sohl, and Halperin [14] used the CAT to examine factors contributing to stigmatizing attitudes. They used a modified and shortened version of the CAT, and found that medical students' exposure to a 90 minute informational seminar about ME and CFS lead to more positive attitudes when assessed afterward.

The current study investigates whether exposure to ME and CFS related information, as well as individual characteristics of age and gender are associated with stigmatizing views as measured by the CAT among a sample of volunteers at a university research center. Social cognitive theory predicts that exposure to information about ME and CFS may mitigate negative perceptions and stigma toward others with this chronic illness [15]. In addition, theory also predicts that exposure/interaction with outgroup members provides ways to reduce reliance on vague stereotypes to form social judgments. We hypothesized that individuals with an opportunity to gain exposure to accurate information about ME and CFS by volunteering on a CFS-related research project would report less stigmatizing attitudes compared to volunteers on a non CFS-related topic, and that longer participation on the CFS-related research project would also be associated with less stigmatizing views. In addition, in accordance with social dominance theory [16] and system justification theory [17], we anticipated that males across CFS related and unrelated research projects would express less positive attitudes toward individuals with ME and CFS.

Materials and Methods

Participants

Participants were N = 90 volunteers from a social science research center located at a private, urban university in the Midwest (Table 1). 77.78% were female, 66.67% had a partial college degree (i.e., current students), and 48.89% were earning course credit in exchange for their unpaid work on the research project. Weekly time spent on the research ranged from 2 to 12 hours per week and participants had been volunteering between less than 1 and up to 24 months.

	ME and CFS Volunteers		Other Volunteers	
	N = 52		N = 38	
Variable	M	(SD)	M	(SD)
Age	21.5	(2.85)	22.0	(2.19)
	%	(N)	%	(N)
Gender				
Male	19.2	(10)	26.3	(10)
Female	80.8	(42)	73.7	(28)
Educational Level				
High school degree or GED	9.6	(5)	7.9	(3)
Partial college (at least one year)	69.2	(36)	63.2	(24)
Standard college degree	19.2	(10)	21.1	(8)
Graduate or professional degree	1.9	(1)	7.9	(3)
Hours Spent Volunteering a Week				
1 - 2.9	5.8	(3)	5.3	(2)
3 - 4.9	44.2	(23)	18.4	(7)
5 - 6.9	38.5	(20)	52.6	(20)
7 - 8.9	3.8	(2)	18.4	(7)
9 or more	7.7	(4)	5.2	(2)
Months of Volunteering for Project				
0 to 2.9	34.6	(18)	65.8	(25)
3 to 4.9	25.0	(13)	7.9	(3)
5 to 6.9	17.3	(9)	18.4	(7)
7 to 8.9	3.8	(2)	5.2	(2)
9 and over	19.2	(10)	2.6	(1)
Course Credit				
Yes	46.2	(24)	52.6	(20)
No	53.8	(28)	47.4	(18)

Table 1: Demographics for Volunteers.

Inclusion criteria were that participants had to be volunteering in a research capacity on one of three ongoing research projects: Pediatric Epidemiology of ME and CFS research project (N = 52) [18] or an unrelated research project (N = 38), either an addiction recovery project (N = 5), or a violence prevention project (N = 35). Because our variable of interest was exposure to CFS and ME related information, participants were grouped as either part of the ME and CFS research team (N = 52) or not part of the ME and CFS research team (N = 38). Participants on the ME and CFS team received information about ME and CFS through their completion of the 3-hour volunteer training, implementation of a phone based interview designed to detect CFS-like symptoms, and phone interaction with parents from the community whose children may have CFS-like symptoms.

Instruments

Participants were first administered a series of demographic questions adapted and modified from the DePaul Symptom Questionnaire [19], and the 13-item Chronic Fatigue Syndrome Attitudes Test (CAT) [13]. We also asked participants if they were earning course credit in exchange for their time contributed at the research center. Students earning credit were obligated to fulfil their weekly hour requirement to earn a passing grade.

The 13-item CAT has been found to have a three factor structure with acceptable validity and internal reliability [13]. CAT response options ranged from 1 = "Strongly Disagree," to 4 "Neither Disagree nor Agree," to 7 = "Strongly Agree" and one item is reverse scored ("More federal funds should be allocated for research on CFS").

Three subscales correspond to responsibility for ME and CFS (i.e., whether or not patients are to blame for getting sick), relevance of ME and CFS (i.e., the relevance of ME and CFS to society), and traits of people with ME and CFS (i.e., opinions about the characteristics of individuals with ME and CFS). Subscale scores are calculated by adding the respective subscale items. The total scale score is the sum of all 13 items. Higher scores represent more stigmatizing attitudes.

Procedure

Participants were recruited in person and via email through the research center. They established informed consent and completed the survey materials online.

Results and Discussion

Results

Hypotheses were tested using linear regression in a model specified with gender, ME and CFS research team membership (0 = No, 1 = Yes), and total time volunteered as predictors of total CAT scores. Age and whether the volunteer was earning course credit (0 = No, 1 = Yes) were included as model covariates. Total time volunteered was computed by multiplying months volunteered by the hours per week and weeks per month to yield a cumulative time volunteered variable (in hours). Model variables are summarized in table 2.

Variable	Age	Female	ME/CFS Team	Course Credit	Length	CAT Resp.	CAT Rel.	CAT Trait	CAT Total
Female	-0.34**								
ME/CFS Team	-0.09	0.08							
Course Credit	-0.15	-0.04	-0.01						
Time Volunteered	0.15	-0.11	0.19	0.33**					
CAT Resp.	0.00	-0.18	-0.18	0.25*	0.04				
CAT Rele.	0.01	-0.11	-0.26*	0.11	-0.16	0.50**			
CAT Trait	0.00	-0.09	-0.35**	0.09	-0.16	0.49**	0.43**		
CAT Total	0.00	-0.17	-0.30**	0.20	-0.10	0.86**	0.79**	0.77**	
Mean:	21.72	0.78	0.58	0.47	91.14	8.16	9.16	12.48	29.79
SD:	2.59	0.42	0.50	0.50	94.00	4.42	3.57	3.32	9.14

Table 2: Summary of Variables (N = 90).

Note: * = p < 0.05, ** = p < 0.01. CAT = Chronic Fatigue Attitudes Test. Resp = CAT Responsibility Scale. Rel = CAT Relevance Scale. Trait = CAT Traits Scale. For Female, ME/CFS Team, Course credit: 1=Yes, 0=No. Time volunteered is overall duration of volunteering (in hours).

As expected, results showed that volunteers working on the ME and CFS research team did report significantly lower total CAT scores (i.e., less stigmatizing attitudes; B = -4.97, p < 0.01; Table 3). Time volunteered was not associated with CAT scores (B = -0.00, ns; Table 3). We further explored the interaction of time volunteered with ME and CFS research team affiliation to examine the possibility that

total time volunteered may contribute to decreased stigma for volunteers on the ME and CFS research project only, finding that time volunteered did not matter differentially for ME and CFS volunteers (B = -0.02, ns). An exploratory analysis of subscales revealed that the traits subscale appeared to drive the association of ME and CFS project affiliation with CAT scores: when the same regression model was repeated for each of the three subscales separately, the effect maintained for the traits subscale (B= -2.19, p < 0.01) but not the relevance (B = -1.36, p < 0.10) or responsibility (B = -1.42, ns).

DV: CAT Total Score		
	B	SE B
Age	0.02	0.39
Female	-3.13	2.34
ME and CFS Team	-4.97**	1.90
Course Credit	4.14*	1.99
Time Volunteered	-0.00	0.02
Time Volunteered x ME and CFS Team	-0.02	0.02
Constant	33.41***	2.71

Figure 3: Regression Model Predicting Chronic Fatigue Attitude Test (CAT) Total Scale Scores.

Note: * = p < .05, ** = p < .01, *** = p < .001. N = 90 volunteers. Age and Time Volunteered are mean centered. For Female, ME/CFS Team, Course credit: 1=Yes, 0=No. Time volunteered is overall duration of volunteering (in hours). Higher CAT score indicate a more negative attitude

We also predicted that that male participants would express more stigmatizing attitudes, however, there was no main effect of gender (B = -3.13, ns). Of our model covariates, age was not associated with CAT scores (B = 0.02, ns), but course credit earners expressed significantly less positive views (B = 4.14, p < 0.05).

To contextualize the current results, table 4 summarizes CAT scores from three existing studies that used the measure: the original scale development study by Shlaes and colleagues [13] in which the scale consisted of 19 items that were administered to 240 students in an introductory psychology course at DePaul University as well as Freidberg and Sohl's [14] examination of the attitude intervention with medical students using an abbreviated adaptation of the instrument; and the results of the current study.

	Current Study		Shlaes et al., 1999	Friedberg, Sohl & Halperin, 2008	
	ME/CFS Team (N = 52)	Other (N = 38)	Students (N = 240)	Before (N = 45)	After (N = 45)
	M (SD)	M (SD)	M	M	M
Responsibility Subscale Score	7.50 (3.39)	9.05 (5.44)			
People with CFS are just depressed.	1.71(0.96)	2.11 (1.33)	2.62	2.84	2.74
People with CFS are just lazy.	1.44 (0.85)	1.68 (1.34)	2.23	2.56	2.44
I would not sit on the same toilet that a person with CFS had just used.	1.81 (1.67)	1.89 (1.37)	2.76	-	-
People with CFS are to blame for getting sick.	1.46 (0.94)	1.95 (1.43)	2.62	-	-
CFS is a form of punishment from God.	1.08 (0.39)*	1.42 (1.00)	1.61	-	-
Relevance Subscale Score	8.44 (3.30)	10.13 (3.74)			
Employers should be permitted to fire those with CFS.	1.88 (1.26)	2.39 (1.41)	2.46	-	-
More federal funds should be allocated for research on CFS.	2.31 (1.13)	2.39 (1.22)	3.24	3.88	2.98
CFS is not a real medical illness.	1.67 (1.18)	2.13 (1.76)	3.00	-	-
CFS is not as big a problem as the media suggests.	2.58 (1.39)*	3.21 (1.51)	3.47	-	-
Traits Subscale Score	11.48 (2.73)	13.84 (3.60)			
The majority of people with CFS were competitive, driven to achieve, and compulsive before they got sick.	4.25 (1.44)	4.37 (1.26)	3.89	-	-
People with CFS would get better if they really wanted to be healthy.	1.87 (1.09)**	2.76 (1.65)	3.09	3.67	3.28
CFS is primarily a psychological disorder.	3.08 (1.34)*	3.76 (1.30)	3.91	3.63	3.09
If people with CFS rest then they will get better.	2.29 (1.11)*	2.95 (1.36)	3.22	2.79	2.44
Total Scale Score	27.42 (7.50)	33.03 (10.23)			

Table 4: Chronic Fatigue Syndrome Attitudes Test (CAT) Means.

Note: * = p < 0.05, ** = p < 0.01 indicates if ME/CFS team volunteers differed from the volunteers on unrelated research projects in the current study. (R) = Reverse scored. 1 = "Strongly Disagree," 4 = "Neither Agree nor Disagree," 7 = "Strongly Agree." Standard deviations were only available for the current study.

Discussion

Results supported our hypothesis that individuals with an opportunity to gain exposure to information regarding ME and CFS expressed less stigmatizing views toward this group, as measured by the CAT. In addition, an exploratory finding revealed that the trait subscale of the CAT appeared to drive the overall effect. We did not find that length of time volunteering on the CFS-related research project was associated with additional decreases in stigmatizing views. Gender was not associated with stigmatizing views in our sample, but students contributing hours toward research in exchange for course credit (rather than on a purely volunteer basis) reported more stigmatizing attitudes.

In our sample, exposure to ME and CFS related information may contribute to less stigmatizing attitudes, however, this may be specific to the trait subscale. This includes items such as, "CFS is primarily a psychological disorder" or "If people with CFS rest then they will get better" [13]. During initial trainings and throughout their time working on the ME and CFS related project, volunteers were exposed to information about the various stigmas tied to this debilitating illness, especially the stigma assuming ME and CFS is simply a psychological disorder. This result is not surprising also in light of the primary objective of the ME and CFS research project, which is to contribute to the effort to identify biomarkers for the illness to which could counter the thesis that ME and CFS are fundamentally psychological. In addition, volunteers on the ME and CFS related project had an opportunity to speak with parents regarding children's ME and CFS like symptoms, so this further legitimizes that these symptoms were real. From a social cognitive standpoint, this kind of individuating information combats reliance on negative stereotypes to make judgments about the "out group" of patients with ME and CFS

The hypothesis that length of time volunteering on a ME and CFS research team would create less stigmatizing views was not supported. This could indicate that there is no cumulative increasing effect of ME and CFS team membership on attitudes over time. Most of the information about ME and CFS that individuals on this research team receive was delivered in the initial orientation training at the beginning of the volunteer experience. It is possible that the ongoing information about ME and CFS received as a result of the volunteer work itself (i.e., speaking to parents of CFS-like children over the phone) might have less of an impact on volunteers' overall access to ME and CFS information compared to the initial formal training.

It is noteworthy that across studies the three studies that have assessed stigma using the CAT, most participant responses fall below the scale midpoint (4 "Neither Agree nor Disagree"), indicating relatively low stigma toward ME and CFS [13,14]. In our study as well, even a participant predicted by the model to express the most stigmatizing view—a member of a non ME/CFS related research team who is earning credit rather than contributing time on a purely volunteer basis—expressed CAT scores that fell, on average, below the neutral scale midpoint, that is, on the positive side of the attitude spectrum. For all three studies that have employed the CAT, the nature of the samples as medical students [14], and volunteers (the current study) is certainly expected to contribute to the less stigmatizing views expressed, in comparison to the general population. With this limitation of the current study in mind, it is relevant to note that our goal was to explore sources of variation in attitudes toward ME and CFS rather than to attempt to report on levels of stigma present in a general population. Future studies should examine samples representative of the general population to produce improved estimates of stigma.

Several limitations of the current study should be noted. We were unable to employ an experimental design with respect to our manipulation, but future researchers could randomly assign people to the ME and CFS research topic (or other educational intervention) to better understand the difference of opinion between those exposed to information regarding ME and CFS and those who are not. Also, in this study responses were only recorded at one time point. Future research could combine random assignment and multiple time points of measurement to establish causal evidence that attitudes are amenable to change as a result of exposure to ME and CFS information. Finally, selection effects are an alternative explanation for our finding, as people with less stigmatizing views toward individuals with CFS could reasonably be more likely to join a CFS research team. Related to this, our volunteer sample was subject to known positivity biases given that volunteers are more likely to have prosocial personality traits and internalized prosocial roles, which should be inversely related to negative attitudes toward chronic illness groups [20]. We believe this has contributed to the relatively low levels of stigma detected in our current sample (and other studies such as Friedberg, Sohl and Halperin [14] in which medical professionals would also be expected to express relatively low stigma). However, our finding that course credit earners expressed more stigmatizing views is related to this. Among our sample of volunteers (all credit earners were required to first participate in the research on a purely volunteer basis for 10 weeks), those who at the time of assessment were contributing their time to research to meet a course requirement are a better representation of a non-volunteer sample. We expect that future investigations with non-volunteers or non-health professionals would express greater stigma.

Conclusion

We encourage further use of the CAT to examine sources of variability in CFS stigma. This is especially important given that stigmatizing beliefs toward ME and CFS have the ability to impact the way patients are treated.

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Conflict of Interest

There are no conflicts of interest to report.

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