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Energy envelope maintenance among patients with myalgic encephalomyelitis and chronic fatigue syndrome: Implications of limited energy reserves

Kelly O'connor[1], **Madison Sunnquist**[1], **Laura Nicholson**[1], **Leonard A Jason**[1], **Julia L Newton**[2], and **Elin B Strand**[3]

[1]Center for Community Research, DePaul University, Chicago, IL, USA

[2]Newcastle University, Tyne and Wear, UK

[3]Oslo University Hospital, Oslo, Norway

Abstract

Objective—The Energy Envelope Theory of myalgic encephalomyelitis and chronic fatigue syndrome postulates that individuals with myalgic encephalomyelitis and chronic fatigue syndrome may experience some increase in functioning if their level of exertion consistently remains within the limits of their available energy. Findings of several studies support this theory; however, the current study is the first to explore how an individual's initial level of available energy may influence the relation between energy envelope maintenance and level of functioning.

Method—The functioning, activity, and symptomatology of six groups of individuals with myalgic encephalomyelitis and chronic fatigue syndrome were compared. Groups were created based upon level of available energy (higher or lower) and energy envelope adherence (underextended, within, overextended).

Results—Results indicate that, as expected, individuals with myalgic encephalomyelitis and chronic fatigue syndrome who had higher available energy also had better functioning than individuals with lower available energy; however, this relation was less pronounced for individuals who were overexerting themselves.

Discussion—These results are consistent with the Energy Envelope Theory, and they suggest that overexertion was particularly impactful for individuals with higher levels of available energy.

Keywords

Myalgic encephalomyelitis; chronic fatigue syndrome; energy envelope; pacing; energy

Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are debilitating illnesses that affect over one million adults in the United States.[1] Individuals with ME and

Corresponding author: Leonard A Jason, Center for Community Research, DePaul University, 990 W. Fullerton Ave., Suite 3100, Chicago, IL 60614, USA. ljason@depaul.edu.

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CFS experience a marked decrease in their energy levels,[2] along with inconsistent daily energy levels.[3] Due to the decreased and inconsistent nature of patients' energy levels, overexertion can occur from simply completing daily activities (e.g., grocery shopping, walking up a flight of stairs). Overexertion often leads patients with ME and CFS to experience post-exertional malaise (PEM) and energy "crashes."[3–5] PEM (the worsening of fatigue and other symptoms after physical or mental exertion) is considered to be a cardinal symptom of ME and CFS that helps to distinguish these illnesses from depressive disorders.[6] PEM often negatively impacts physical, social, and occupational functioning.[7,8]

The Energy Envelope Theory posits that individuals with ME and CFS who expend an equivalent amount of energy to the amount they have available can reduce symptom flares and make modest gains in physical functioning.[3,9–11] This theory suggests that individuals with ME and CFS should avoid over- and underexertion.

Several studies provide supporting evidence for the Energy Envelope Theory. A case study analyzed daily data from an individual with CFS over a 16-month period.[11] The participant was asked to rate their levels of fatigue, available energy, and expended energy each day, and wore an ActiGraph monitor to objectively measure energy expenditures. Initially, the participant expended more energy than that available and reported high levels of fatigue.[11] However, as the participant began to reduce daily energy expenditures to align with levels of available energy, the participant reported less fatigue and greater available energy. By the end of the study, the participant reported sustained reductions in fatigue and more available energy. In another case study of the Energy Envelope Theory, three individuals with ME and CFS were provided with a "buddy" to assist them with daily tasks to allow them to conserve energy resources.[8] Post-test results indicated that participants experienced improvements in fatigue and somatic symptoms.

A more recent study revealed similar results in support of the Energy Envelope Theory.[10] This study compared two groups of individuals who had recently completed a non-pharmacologic intervention: one group had overexerted during the intervention, while the other group had stayed within their energy envelope. Those latter group experienced significantly more improvements in physical functioning and fatigue severity during the intervention.[10]

Taylor et al.[12] evaluated an illness management and treatment planning intervention that included an energy envelope component. Individuals with CFS were randomly assigned to either an intervention or control group. The intervention group participated in sessions that involved goal-setting and education on various topics, including the Energy Envelope Theory. Participants developed an individualized action plan and received supportive services from case coordinators. Those who were provided this comprehensive intervention had an overall significant increase in their self-esteem, well-being, mastery, work, energy, and interpersonal relationships.

Another study involving the energy envelope evaluated a buddy program.[13] Thirty participants with CFS were randomly assigned to a four-month buddy intervention or a control condition. The intervention group had significantly greater reductions in fatigue and

increases in vitality. The study concluded that monitoring and staying within energy boundaries led to important improvements.

Studies that examine the impacts of overexertion provide further evidence for the Energy Envelope Theory. Jason et al.[5] examined the relationship between energy envelope maintenance and functioning in a sample of 110 individuals with ME and CFS. Findings indicated that overexertion was associated with increased disability, pain, fatigue, depression, anxiety, problems sleeping, and poorer quality of life.[5] Brown et al.[7] applied cluster analysis to classify 91 patients with ME and CFS into three groups based on their self-reported physical functioning, PEM severity, and available and expended energy levels. Clusters 1 (symptomatic and highly overextended) and 2 (less symptomatic and moderately overextended) were consistent with findings that indicate a relationship between overexertion and negative health outcomes. However, cluster 3 (symptomatic and mildly overextended) was similarly impaired to cluster 1. These findings suggest that symptomatology and energy envelope maintenance may not have the same relationship for all patients.

The current, cross-sectional, study examines the Energy Envelope Theory within the context of participants' level of available energy. The study hypothesized that individuals with higher amounts of available energy would report better functioning and less severe symptoms than individuals with lower available energy. Additionally, the study hypothesized that individuals with higher levels of available energy who remained within their energy envelopes would have the highest level of functioning among all participants.

Method

Participants

The study aggregated data from four samples. The primary measure used in this study, the DePaul Symptom Questionnaire (DSQ), is shared freely with other research groups in an effort to create large samples to more robustly analyze ME and CFS illness characteristics, including energy envelope information. At the time of this study, DSQ data from the four sites described below had been collected and aggregated for the current analysis. All samples were collected following approval from institutional review boards, and all participants completed a written, informed consent process. Individuals were excluded from the current study if they had medical or psychiatric conditions identified as exclusionary in the Fukuda et al.'s criteria.[2] Table 1 displays the demographic characteristics of participants from each recruitment site.

[Redacted] sample—This convenience sample consisted of adults with current diagnoses of CFS or ME who could read and write in English. Following institutional review board approval (#ME120710PSY-FR), participants completed study measures electronically, over the phone or via hard copy.

Newcastle sample—Participants in the Newcastle sample were referred to the Newcastle-upon-Tyne Royal Victoria Infirmary clinic due to a suspected diagnosis of ME or CFS. A physician performed a comprehensive physical examination, and individuals who met

eligibility criteria completed a written informed consent process (institutional review board approval #LREC 1 – 08/H0906/5).

Norway sample 1—Adults with a physician-confirmed diagnosis of ME or CFS were recruited from several cities in Norway to participate in a randomized controlled trial of a self-management program (institutional review board approval #2011/894/REK Nord).

Norway sample 2—Participants were recruited from an inpatient medical ward and a multidisciplinary ME and CFS Center (institutional review board approval #2012/18573 OUH). Individuals were aged between 18 and 65 and capable of reading and writing Norwegian. Individuals with a suspected diagnosis of CFS were interviewed to recount their medical history and participate in a medical examination. These interviews were conducted by experienced physicians and a psychologist.

Measures

DePaul Symptom Questionnaire—All participants completed the DSQ.[14] This questionnaire measures ME and CFS symptomatology and obtains information on demographics and relevant history. The DSQ has demonstrated good test–retest reliability among control groups and patients.[15] A factor analysis of these symptoms resulted in three factors with good internal consistency.[16] Murdock et al.[17] found that the DSQ demonstrated excellent internal reliability and optimally differentiated patients from controls. The instrument is available in the shared library of Research Electronic Data Capture (REDCap), hosted at [Redacted] University: https://redcap.is.depaul.edu/surveys/?s=tRxytSPVVw.

Two items from the DSQ were examined in the current study to assess energy envelope adherence. These items asked participants to rate their perceived available and expended energy levels over the past week on a 100-point scale. Available energy refers to the participants' estimation of their energy resources over the past week ("For the past week, please rate the amount of energy you had available using a scale from 1 to 100 where 1 = no energy and 100 = your pre-illness energy level"). Expended energy refers to how much energy they felt they used in the past week ("For the past week, please rate the amount of energy you have expended using a scale from 1 to 100 where 1 = no energy and 100 = your pre-illness energy expended"). These items assessing participants' available energy and expended energy over the past week have test–retest reliability coefficients of .81 and .64, respectively.[15]

In order to assess whether participants were within their energy envelope, overexerting themselves, or underexerting themselves, energy quotient scores[5] were calculated as follows: Expended Energy/Available Energy × 100. A score greater than 100 indicates that the participant overexerted (i.e., expended energy exceeded available energy). The more one's energy quotient exceeds 100, the greater the individual's level of overexertion. Conversely, an energy quotient of less than 100 indicates that the participant underexerted, or did not use as much energy as they had available over the past week. A score of 100 indicates that the participant was within their envelope by maintaining a balance between their energy expenditure and available energy.

The current study also analyzed the DSQ's symptom variables to calculate participants' total symptom score. The DSQ asks participants to rate the frequency and severity of 54 symptoms on a five-point Likert-type scale that ranges from 0 to 4. For each symptom, Likert ratings are multiplied by 25 to transform them to a 100-point scale. To calculate a participant's total symptom scores, the 100-point scale ratings of all 54 symptoms were averaged; higher scores indicate more frequent and severe symptoms.

Finally, participants' reported the average weekly number of hours they spent on household, family, social, and work activities over the past month. To calculate the total number of hours spent on activities, these values were summed.

Medical outcomes study 36-item short-form health survey (SF-36)—The SF-36 measures the degree to which participants' health impacts their physical and mental functioning, and evidences strong psychometric properties.[18] The measure is composed of 36 items that make up eight subscales: Physical Functioning, Role Physical, Bodily Pain, General Health, Social Functioning, Mental Health, Role Emotional, and Vitality. Each subscale score ranges from 0 to 100, with lower scores indicating greater impairment. The SF-36 is a validated assessment tool for individuals with ME and CFS.[19] The current study utilized participants' standardized Physical Functioning subscale, a measure of the number of standard deviations the 100-point Physical Functioning score is from the population norm.

Case definition fulfillment

In order to be included in the current study, participants were required to meet the Fukuda et al.'s CFS criteria.[2] To determine whether participants fulfilled these criteria, their DSQ and SF-36 responses were examined. Participants needed to report six or more months of fatigue and the occurrence of four of the following eight symptoms: PEM, unrefreshing sleep, memory and concentration problems, joint pain, muscle pain, headaches of a new place or type, tender or sore lymph nodes, or sore throat. Additionally, participants needed to demonstrate a substantial reduction in functioning by meeting two of the following SF-36 criteria: a Role Physical score of less than or equal to 50, a Social Functioning score of less than or equal to 62.5, or a Vitality score of less than or equal to 35.

Analytical plan

We hypothesized that available energy level and energy envelope maintenance would be associated with level of symptoms and functioning. Six groups were created for subsequent analyses. Participants were categorized into these groups by their available energy rating and their energy quotient score. The methods for creating these groups are described below.

Available energy—Participants who perceived their available energy level over the past week to be above 30 (50th percentile) were considered to have "higher available" energy (n = 233), while those who perceived their weekly available energy to be equal to or less than 30 were considered to have "lower available" energy (n = 201). It is important to note that the terms "lower" and "higher" refer to the available energy levels of the current sample of

patients with ME and CFS; individuals with "higher" available energy in this study have substantially lower energy levels than the general population.

Energy envelope maintenance—An energy envelope quotient of 100 indicates that the individual maintained a perfect balance between their available and expended energy. In order to group participants who were only slightly over or underextended as accurately as possible based on the distribution of the overall sample, individuals with an energy quotient score greater than 93 (25th percentile) or less than 120 (75th percentile) were considered to be within their envelope ($n = 204$; "within"). Participants with energy quotients less than or equal to 95 were considered "underextended" ($n = 103$) and participants who were classified as "overextended" ($n = 127$) had scores equal to or greater than 120.

Six groups were created based upon participants' available energy group and their energy quotient score: Underextended, Lower Available ($n = 37$); Underextended, Higher Available ($n = 66$); Within, Lower Available ($n = 82$); Within, Higher Available ($n = 122$); Overextended, Lower Available ($n = 82$); and Overextended, Higher Available ($n = 45$). Analyses of Covariance (ANCOVAs) were utilized to assess the statistical differences in symptomatology and physical functioning among these groups and post hoc Scheffé tests were utilized to examine pairwise differences.

Results

Demographic characteristics

Table 2 displays the demographic characteristics of the full sample. An ANOVA of groups' mean age revealed significant differences, $F(5, 423) = 3.90$, $p = .002$. Post hoc Scheffé tests indicated that the Underextended, Lower Available was significantly younger than the Within, Lower Available group. Subsequent analyses enter age as a covariate to control this difference. Recruitment site was also entered as a covariate in order to control for any site-specific differences. A chi-square analysis of work status was also significant, $\chi^2(30) = 52.15$, $p = 0.007$. Groups with less available energy were more frequent in disability compared to those with more available energy. Conversely, groups with more available energy were more likely to have been working full- or part-time. Work status was not employed as a covariate in the following analyses, as it was conceptualized as an outcome variable related to overall functioning. No significant differences were found for gender, race, or education level.

Symptoms and functioning

Table 3 presents the age- and site-adjusted means, standard errors, and significance results of the ANCOVAs that compared the six groups' Physical Functioning scores (standardized), Hours Spent on Activities, and Total Symptom scores. Results indicated that the groups had significantly different scores on all of these measures: Physical Functioning, $F(5, 418) = 7.93$, $p < 0.001$; Hours Spent on Activities, $F(5, 367) = 6.22$, $p < 0.001$; Total Symptom score, $F(5, 421) = 7.27$, $p < 0.001$. Pairwise comparisons indicated that, in general, groups with higher available energy had significantly better Physical Functioning scores, Total Symptom scores, and engaged in more hours of activity than groups with lower available

energy. There were two exceptions of note. The Underextended, Lower Available group did not evidence significantly different physical functioning scores than any other group. Additionally, the Overextended, Higher Available group evidenced similar scores to groups with lower available energy.

Discussion

Findings from this study indicate that individuals with ME and CFS who have higher levels of available energy tended to have better functioning than those with lower levels of available energy. However, among those with higher available energy, participants who were overexerting had similar levels of symptom severity as those with lower available energy. Consistent with the Energy Envelope Theory, these results indicate that overexertion may counteract the benefit of higher energy levels. Previous research links overexertion with lower Physical Functioning, Role Physical, and Vitality scores.[5,10] Energy envelope maintenance may be especially beneficial for individuals with higher available energy who are pushing themselves beyond their energy limitations.

Results also indicated that individuals with lower available energy who were underexerting had better physical functioning scores than individuals with lower available energy who were within their energy envelope. These results suggest that underexertion may be beneficial for individuals with particularly severe energy limitations. This finding contradicts the argument that reducing activity causes symptoms to worsen via deconditioning.[19,20] Furthermore, these results are consistent with results of patient surveys in which patients suggest that Graded Exercise Therapy (GET), a treatment that prescribes gradual increases in activity, makes them feel worse.[21] A review of GET intervention studies suggests that GET is often associated with increases in symptomatology and prolonged recovery times; the authors of this review posited that this treatment may exacerbate preexisting immune dysfunction.[22]

Results from the current study indicate that health care professionals should monitor patients' available and expended energy levels and provide education on the potential benefits of avoiding overexertion. By staying within their energy envelopes, individuals with ME and CFS may reduce the frequency of energy crashes while experiencing some relief from symptoms. Furthermore, logging available and expended energy levels on a daily basis is a cost-effective illness self-management intervention, and this strategy may be helpful for patients in understanding their symptom patterns or when discussing their energy levels and symptomatology with health care providers.

The current study has several limitations. Data were aggregated from several sites with different recruitment procedures; however, we controlled the site-specific differences in our analyses. The samples also included individuals who had undergone extensive medical and psychological exams to receive a diagnosis, as well as those who self-reported a diagnosis. The samples also lacked racial and ethnic diversity. This study should be replicated with a diverse, community-based sample, as other research shows similar or greater prevalence rates among other racial groups.[1] Additionally, data on available energy and the energy

quotient are self-reported ratings of energy levels over the past week, which may increase measurement error due to recall bias and different interpretations of the scales.

Future research should examine energy maintenance and available energy by utilizing longitudinal and experimental designs. These methodologies would allow for further exploration of the six groups identified in this study. Specifically, a longitudinal design would elucidate how available energy and energy envelope maintenance might influence functioning and energy levels over time, while an experimental design might highlight if or how these groups react to different treatments or interventions.

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Table 1

Demographics by recruitment site.

	[Redacted] *n* = 181 M (*SD*)	**Newcastle *n* = 83 M (*SD*)**	**Norway 1 *n* = 152 M (*SD*)**	**Norway 2 *n* = 45 M (*SD*)**
Age	**52 (11)**	**44 (13)**	**43 (12)**	**38 (12)**
	% (*n*)	**% (*n*)**	**% (*n*)**	**%(*n*)**
Gender				
Female	83 (151)	81 (67)	88 (137)	82 (37)
Male	17 (30)	19 (16)	12 (18)	18 (8)
Race				
Caucasian	98 (177)	99 (82)	99 (155)	98 (43)
Other Race	2 (4)	1 (1)	1 (1)	2 (1)
Education				
Less than high school	0 (0)	3 (2)	24 (13)	4 (19)
Some high school	0 (0)	9 (7)	0 (0)	2 (7)
High school degree	7 (13)	15 (12)	41 (22)	24 (110)
Some college	18 (32)	22 (17)	0 (0)	11 (49)
College degree	35 (64)	31 (24)	26 (14)	36 (163)
Graduate degree	40 (72)	21 (16)	9 (5)	24 (110)
Work status				
On disability	55 (101)	35 (29)	83 (130)	76 (34)
Student	4 (8)	5 (4)	3 (5)	2 (1)
Homemaker	5 (9)	1 (1)	1 (2)	0 (0)
Retired	12 (22)	17 (14)	2 (3)	0 (0)
Unemployed	12 (22)	6 (5)	1 (1)	0 (0)
Working part-time	8 (14)	21 (17)	9 (14)	20 (9)
Working full-time	4 (7)	15 (12)	1 (1)	2 (1)

Table 2

Demographic comparison by energy envelope group.

Energy envelope group	**Underextended**		**Within**		**Overextended**		
Available energy	**Lower n = 37 M (*SD*)**	**Higher n = 66 M (*SD*)**	**Lower n = 81 M (*SD*)**	**Higher n = 120 M (*SD*)**	**Lower n = 81 M (*SD*)**	**Higher n = 44 M (*SD*)**	**Significance**
Age	**43 (12)**	**45 (12)**	**51 (13)**	**48 (12)**	**45 (13)**	**43 (12)**	**
	% (*n*)	**% (*n*)**	**% (*n*)**	**% (*n*)**	**% (*n*)**	**% (*n*)**	
Gender							
Female	73 (27)	83 (54)	80 (66)	87 (105)	85 (70)	93 (42)	
Male	27 (10)	17 (11)	20 (16)	13 (16)	15 (12)	7 (3)	
Race							
Caucasian	100 (37)	98 (65)	100 (82)	98 (118)	100 (82)	93 (42)	
Other Race	0 (0)	2 (1)	0 (0)	2 (2)	0 (0)	7 (3)	
Education							
Less than high school	11 (4)	2 (1)	4 (3)	3 (4)	4 (3)	7 (3)	
Some high school	0 (0)	5 (3)	2 (2)	1 (1)	1 (1)	0 (0)	
High school degree	28 (10)	23 (15)	16 (13)	28 (33)	22 (18)	22 (10)	
Some college	6 (2)	14 (9)	12 (10)	10 (12)	5 (4)	18 (8)	
College degree	33 (12)	33 (22)	38 (31)	38 (44)	43 (35)	27 (12)	
Graduate degree	22 (8)	24 (16)	28 (23)	20 (23)	25 (20)	27 (12)	
Work status							
On disability	76 (28)	42 (28)	74 (61)	59 (71)	72 (59)	58 (26)	**
Student	3 (1)	6 (4)	0 (0)	4 (5)	5 (4)	4 (2)	
Homemaker	3 (1)	3 (2)	1 (1)	3 (4)	1 (1)	2 (1)	
Retired	5 (2)	11 (7)	11 (9)	11 (13)	5 (4)	4 (2)	
Unemployed	11 (4)	8 (5)	6 (5)	3 (3)	7 (6)	4 (2)	
Working part-time	3 (1)	21 (14)	5 (4)	12 (14)	7 (6)	24 (11)	
Working full-time	0 (0)	9 (6)	2 (2)	8 (10)	2 (2)	2 (1)	

** $p < 0.01$;

*** $p < 0.001$.

Table 3

Energy envelope group comparison of symptomatology and functioning.

Energy envelope group	Underextended		Within		Overextended		
Available energy	**Lower *n* = 37**	**Higher *n* = 66**	**Lower *n* = 80**	**Higher *n* = 119**	**Lower *n* = 81**	**Higher *n* = 43**	**Significance**
Physical Functioning[a]	−2.25 (0.14)	−1.77 (0.11)^{wl,ol}	−2.62 (0.10)^{uh,wh,oh}	−1.94 (0.08)^{wl,ol}	−2.41 (0.10) ^{uh,wh}	−1.96 (0.13)^{wl}	***
Weekly activity hours	13.58 (2.81)^{uh}	24.50 (2.23)^{ul,wl,ol}	13.95 (1.84)^{uh,wh}	22.45 (1.61)^{wl}	16.70 (1.90)^{uh}	23.21 (2.55)	***
Total symptom score[b]	53.91 (2.01)^{uh}	43.78 (1.51)^{ul,wl,ol,oh}	53.11 (1.37)^{uh,whc}	47.32 (1.12)^{wl,ol}	52.77 (1.34)^{uh,wh}	51.05 (1.85)^{uh}	***

Superscripts indicate that the group is significantly different from: Underextended, Low Available (*ul*); Underextended, High available (*uh*); Within, Low Available (*wl*); Within, High Available (*wh*); Overextended, Low Available (*ol*); Overextended, High Available (*oh*).

[a] Physical Functioning scores are normalized based upon general population norms, with a mean of 0 and standard deviation of 1; scores indicate the number of standard deviations below the population mean.

[b] Higher scores indicate more frequent/severe symptoms.

*** $p < 0.001$.