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Are Stamina and Fatigue Polar Opposites? A Case Study

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Abstract

Most individuals with Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Carruthers et al., 2003), Myalgic Encephalomyelitis (ME) (Carruthers et al., 2011), and chronic fatigue syndrome (CFS) (Fukuda et al., 1994) indicate that they experience fatigue and sharp decreases in energy levels, which hinder the ability to engage in physical activities (Friedberg & Jason, 1998). However, there are some individuals who reduce activity engagement in order to avoid a worsening of symptoms; thus these individuals may endorse lower levels of fatigue. Accordingly, those with low levels of fatigue but low endurance/stamina might be inadvertently excluded from some criteria based on the fatigue requirement. The current study serves as an exploration of the relationship between fatigue and stamina and the effects of these constructs on illness symptomology and their implications for assessment and diagnosis.

Keywords

stamina; fatigue; Myalgic Encephalomyelitis/chronic fatigue syndrome; Myalgic Encephalomyelitis; chronic fatigue syndrome

Most individuals with Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Carruthers et al., 2003), Myalgic Encephalomyelitis (ME) (Carruthers et al., 2011) and chronic fatigue syndrome (CFS) (Fukuda et al., 1994) indicate that they experience sharp decreases in energy levels, which causes a reduction of physical activities (Friedberg & Jason, 1998). For individuals with these illnesses, energy levels are often inconsistent and unpredictable, which can contribute to drastic changes between good and bad days in managing the severity of the illness. For instance, individuals with these illnesses are often unable to engage in many daily social, work, or family activities (Jason, Melrose, et al., 1999). In more severe cases, patients may have to stop working and drastically reduce the time they spend on family responsibilities (Pesek, Jason, & Taylor, 2000). For the Fukuda et al. (1994) criteria, chronic fatigue is considered an essential feature of CFS. On the other hand, Hyde (1999) has suggested that chronic fatigue itself may not be an essential factor among individuals with ME; rather, the loss of stamina and slow recovery experienced after activity may be the more prominent features. In Jason et al. (2011)'s investigation of the sensitivity and specificity of fatigue scales, the majority of participants with CFS experienced high levels of post-exertional fatigue and some participants did not actually

experience high levels of general fatigue. These findings suggest that Hyde's (1999) emphasis on stamina loss may also apply to individuals with CFS.

According to the Energy Envelope Theory, when patients maintain expended energy levels within their "envelope" or perceived energy capacity, they are better able to sustain physical and mental functioning while reducing the severity and frequency of their symptoms (Jason et al., 2008). The act of staying within the 'energy envelope' allows individuals to work within the limits posed by the disease rather than fight against them. Over time, perceived energy levels may increase, which would allow individuals to engage in higher levels of physical activity. If individuals are effectively reducing activity levels to stay within their energy envelope, they may not experience high levels of fatigue, and therefore may not meet the Fukuda et al. (1994) criteria, which requires the presence of fatigue that persists and relapses for over six months. Such criteria do not capture those who choose to participate in minimal amounts of activity in order to reduce overall levels of fatigue, but still do not have stamina and therefore experience fatigue after moderate amounts of exertion.

The experience of an illness may differ across individuals, and it is important to have self-report questionnaires phrased in such a way that is representative for individuals with ME, ME/CFS, and CFS. For instance, in a study conducted by Jason et al. (2009), the ME/CFS Fatigue Types Questionnaire (MFTQ) was developed to better measure different types of fatigue. This instrument categorizes five hypothesized dimensions of fatigue with high internal consistency: post-exertional, wired, brain fog, energy, and flu-like fatigue. While only one factor of general fatigue was found for healthy controls, these five factors of fatigue clearly emerged in individuals with ME/CFS. This study indicated that fatigue is actually viewed in a different manner by individuals with ME/CFS versus a healthy control sample.

While low stamina is usually associated with high fatigue among individuals with ME, ME/CFS, and CFS, this may not be true of all individuals within this illness group. The aim of the current case study is to explore the relationship between fatigue and stamina and its effects on illness symptomology. We examined individuals who reported low levels of fatigue, but still had low levels of stamina. By doing so, it is hoped that meaningful information would be provided about individuals who may not fit the clinical case definitions of ME, ME/CFS, and CFS due to a lack of reported fatigue, but who still report the experience of key symptoms and substantial disability.

Method

Participants

An international convenience sample of adults (over the age of 18) self-identifying as having ME, ME/CFS, or CFS were recruited for this study ($N=217$) from a variety of sources: postings on internet forums, support group visits, re-contacting of individuals who had participated in the DePaul Research Team's studies in the past and had indicated interest in future studies, and contacting individuals who had emailed the team in the past with interest in future studies. From the original 217, a total of 189 participants were included in the present study. Twenty-eight participants were excluded due to lifelong fatigue and/or active

medical or psychological conditions that precluded a diagnosis of CFS based upon the Fukuda et al. (1994) criteria. All participants provided consent to a protocol approved by the local Institutional Review Board before inclusion in the study.

In the present case study, there were 16 individuals who indicated low levels ('none of the time' or 'a little of the time') of feeling worn out and/or tired out of the 189 participants self-identifying as having ME, ME/CFS, or CFS. As a means of understanding the relationship between fatigue and stamina, data is presented in depth for two of these participants who exhibited both low fatigue and low stamina.

Procedure

Participants were able to complete the questionnaire as an electronic survey, a hard-copy survey, or a verbal survey over the telephone. Participants were given the opportunity to complete these surveys at home or in person at the Center for Community Research at DePaul University. Since ME, ME/CFS and CFS can be unpredictable and could result in a rapid decline of functioning on any given day, participants were not given a timeline for survey completion. The first 100 individuals who completed the survey received a \$5.00 gift card to Amazon.com for their participation. All participants were sent a follow-up debriefing email explaining the purpose of the study.

Measures

Symptom Assessment—The DePaul Symptoms Questionnaire (DSQ) (Jason et al., 2010) is a self-report measure that provides a structured way to gather standardized information that can be used to aid a ME, ME/CFS, and CFS diagnosis. Six classic symptom categories are measured: fatigue; substantial reduction in functioning; post-exertional malaise; myofascial pain, joint pain, abdominal and/or head pain; neurological/cognitive manifestations; and autonomic, neuroendocrine, or immune manifestations.

One specific item on the DSQ inquires about the frequency and severity of 'fatigue/extreme tiredness' during the last six months. Frequency is rated on a five-point Likert scale from 0 to 4 (which corresponds to: none of the time, a little of the time, about half the time, most of the time, and all of the time). Severity is also rated on a five-point Likert scale from 0 to 4 (which corresponds to: symptom not present, mild, moderate, severe, or very severe). A composite score is obtained by multiplying frequency and severity, with greater numbers indicating more fatigue and tiredness.

Stamina and Fatigue—The Medical Outcomes Study-Short Form-36 (MOS SF-36) (Ware & Sherbourne, 1992) is a broadly-based 36 item self-report measure of functional status related to health and identifies eight health concepts: physical functioning, role functioning, role emotional, bodily pain, general health, vitality, mental health, and health transition. Test construction studies (McHorney, Ware & Raczek, 1993; McHorney, Ware, Lu, & Sherbourne, 1994) have shown adequate internal consistency, significant discriminate validity among subscales, and substantial differences between patient and non-patient populations in the pattern of scores. It also has indicated sufficient psychometric properties

as a measure of functional status in a CFS population (Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996).

In particular, there are 4 MOS SF-36 items that pertain to stamina or fatigue. Participants are asked ‘How much of the time during the past four weeks did you..’: 1) feel full of pep, 2) have a lot of energy, 3) feel worn out, and 4) feel tired on a six-point Likert scale (which corresponds to: none of the time, a little of the time, some of the time, a good bit of the time, most of the time, and all of the time). For the purposes of the current study, stamina refers to levels of pep and energy, while fatigue refers to levels of feeling worn out and tired.

Perceived and Expended Energy—Participants were also asked to rate perceived energy and expended energy over the past 24 hours on a 100-point scale, with 0 referring to no energy and 100 referring to abundant energy similar to when the person was completely well. Perceived Energy refers to the participants’ estimation of their available energy resources and Expended Energy is defined as the participants’ estimation of the total amount of energy exerted. The percentage of Available Energy expended was derived by dividing the participants’ Expended Energy by their Perceived Energy. This number was then multiplied by 100. This represents the Daily Energy Quotient: numbers below 100 indicate that the participants expended less than their perceived maximum available energy, whereas numbers above 100 indicate that the participants expended more energy than their perceived maximum available energy. Hence, Expended Energy can be greater than Perceived Energy, particularly when participants push themselves over their energy limits. Fatigue was also rated on a 100-point scale, with higher scores indicating higher fatigue over the past 24 hours. Hawk, Jason, and Torres-Harding (2007) found test-retest reliability for perceived energy, expended energy, and fatigue to be .73, .50, and .84, respectively.

Results

Overall Sample

Shown in Table 1, Spearman’s correlations revealed that within the overall sample (N=189), feelings of pep and energy were significantly correlated, as were feelings of worn out and tired. On the other hand, feelings of pep and energy were significantly negatively correlated to feelings of worn out and tired. Similarly, feelings of pep and energy were significantly negatively correlated to the fatigue/extreme tiredness composite score, while feelings of worn out and tired were significantly positively correlated to the fatigue/extreme tiredness composite score. However, all of these characteristics were not present for several participants, of which two are presented below.

Case Study A

Participant A reported feeling pep, energy, and worn out ‘none of the time.’ However, when asked about feeling tired, she wrote that she did not feel “tired,” but rather she felt “ill.” Additionally, Participant A demonstrated low levels of fatigue and tiredness on the DSQ, with a composite score of 0.

Participant A identified as a 63 year old, white female, divorced with 4 children. She was a retired lawyer and for the six months prior to completing the study, she reported that she was

able to do light housework, but she could not work part-time. She reported that she could not exercise because it made her symptoms worse. Furthermore, engaging in mental effort or minimal physical effort caused a worsening in her fatigue/energy related illness. She reported that when she did engage in activity, she felt worse for more than four days and possibly up to several weeks. Her issues with fatigue and energy consistently did not get alleviated with rest. She reported that there was definitely a physical cause to her fatigue and energy and she also experienced sore throats, tender lymph nodes/swollen glands, muscle aches, joint pain, memory problems, and concentration problems. At the time of participation, she reported that a medical doctor was overseeing her fatigue and energy problems.

Participant A also reported experiencing substantial reductions in activity by at least 50% as a result of her fatigue and energy problems. Prior to the onset of her illness, she reported spending 20 hours on household related activities, 5 hours on social related activities, 20 hours on family related activities, and 50 hours of work related activities weekly. Yet, at the time of the study, she was only able to spend 3 hours on household related activities, 1 hour on social related activities, 1 hour on family related activities, and 0 hours on work related activities per week. Specifically, on the day prior to the study, Participant A had a Daily Energy Quotient of 100, in which she indicated her Perceived Energy to be 20 and Expended Energy to be 20. However, she did not provide a fatigue rating because she indicated that she did not have general fatigue. She stated “Fatigue is the normal physiological process of recovery after exertion which is precisely what I no longer have. I feel as though I have simultaneous flu and mumps with a raft of nasty extras.”

She was officially diagnosed with CFS by a medical doctor in 1991. Her maternal grandmother (deceased), mother (87 years old), sister (60 years old), son (31 years old), and another son (29 years old) were also diagnosed with ME/CFS. In addition, two of her younger children (27 years old and 24 years old) also showed signs of a similar disease, but were not formally diagnosed. She reported that she was also diagnosed with allergies in 1992 and thought that mold might be a contributing factor to her fatigue and energy problems. Participant A also reported that her problems with fatigue and energy could have begun after an infectious illness, cumulative pesticide exposure, or dental treatment that included dental metals. She reported that her symptoms developed over three or more years and have persisted in her daily life.

Case Study B

Participant B indicated that she felt pep and energy ‘none of the time,’ while she felt worn out and tired ‘a little of the time.’ Additionally, she demonstrated low levels of fatigue and tiredness on the DSQ, with a composite score of 1. Despite low fatigue, she still exhibited other symptoms.

Participant B identified as a 69 year old, white female, divorced with 2 children. She reported that she was unemployed at the time of participation, but her most recent occupation was a registered nurse. In the six months prior to the study, she reported that she could only work part-time or on some family responsibilities. She was unable to exercise because it made her symptoms worse and she reported that engaging in mental effort or

minimal physical effort caused a worsening in her fatigue/energy related illness. After engaging in activity, she reported feeling worse for one to two weeks. Rest partially alleviated her fatigue and energy problems, but she reported that she typically did not have refreshing sleep. She believed that there was definitely a physical cause to her fatigue and energy and she reported experiencing joint pain, headaches, memory problems, and some concentration problems.

Similar to Participant A, Participant B also reduced her activity levels by at least 50% in response to her fatigue and energy problems. Prior to the onset of illness, she reported spending 9 hours on household related activities, 7 hours on social related activities, 7 hours on family related activities, and 30 hours of work related activities weekly. However, at the time of participation she reported that she was only able to spend 2 hours on household related activities, 0 hours on social related activities, 0 hours on family related activities, and half an hour on work related activities per week. In particular, on the day prior to the study, Participant B had a Daily Energy Quotient of 100, with her Perceived Energy at 75 and her Expended Energy at 75. Participant B rated her fatigue level to be 10 out of 100, which was consistent with her reported ability to stay within her Energy Envelope.

Participant B reported that her problems with fatigue began one to two years prior to her participation in the study and she reported that she was officially diagnosed by a medical doctor and an alternative practitioner at that time. Moreover, two of her sisters were also diagnosed with CFS. She was diagnosed with Lyme disease in 2000 and was treated intermittently until 2008. When she was completing the study, she was receiving treatment for hypothyroidism and was taking thyroid, hydrocortisone, Zithromax, Valtrex, magnesium, and many supplements. She believed that her problems with fatigue and energy could have begun after her history of Lyme disease or because of her thyroid problems. Over the 6 months prior to the study, her symptoms had been relapsing and remitting, in which there were “good” periods with no symptoms and “bad” periods with worse symptoms.

Discussion

The typical clinical profile of this illness includes individuals who have low stamina, but high fatigue. This means that low pep and energy are usually associated with high feelings of worn out and tired. This was reflected in the overall sample, as pep and energy were significantly and positively correlated to each other and feelings of worn out and tired were also significantly positively correlated to each other. On the other hand, stamina (pep and energy) was significantly negatively correlated to fatigue (feeling worn out and tired). However, there were some people in our sample who did not necessarily fit into this profile.

While most people endorsed low pep or energy, there is a possibility that some individuals may think that certain phrases, like using ‘worn out,’ may trivialize their illness, so they would prefer not to endorse this item. On the contrary, using ‘tired’ may better reflect their physical and bodily exhaustion. However, in cases like Participant A, she did not feel that ‘tired’ or ‘fatigue’ characterized the experience of her symptoms. She explicitly stated that in regards to fatigue, one generally has a “physiological process of recovery.” However, in

her case, along with many other individuals who experience symptoms, she did not feel like this recovery process occurs. Thus, she had to avoid exercise and other forms of physical or mental exertion in order to prevent a worsening of symptoms. In either case, it is crucial to convey to participants how certain phrases in these self-report measures are defined in order to accurately understand the experiences that these individuals may be going through.

On the other hand, as suggested by Hyde (1999), stamina and fatigue may function separately from each other. In a study by Lerdal et al. (2012) about women with HIV/AIDS, the concepts of energy and fatigue were also inversely related, but they were not polar opposites. As in Case B, Participant B reported low stamina and low fatigue. Similar to Participant A, she reduced her daily activity levels drastically as a means of managing her fatigue. Thus, she had a composite score of 1 on fatigue/extreme tiredness of the DSQ and only a fatigue rating of 10 out of 100 on the Energy Envelope. Since she only spent approximately two and a half hours on household, social, family, and work related activities on a given week, she was able to avoid feeling extreme fatigue. However, it is important to note that she still reported experiencing low levels of pep and energy. There is a possibility that stamina and fatigue may not always be linked, but rather they may have separate effects on various symptoms. Thus, patients may not merely be too tired or physically exhausted to engage in physical or mental exertion, but they may not have the energy or motivation to engage in activity. In other words, there is an additional problem with their levels of stamina and endurance along with their feelings of fatigue.

If this were the case, stamina and fatigue may be two entities that should not necessarily be put together in one category. Fatigue and energy should not always be used interchangeably in measurement or when interpreting outcomes in research (Lerdal et al., 2012). It appears that there might be a distinction between how stamina and fatigue may be experienced by individuals. While overall, there appears to be a fairly consistent picture of how stamina and fatigue may look in individuals, it must be noted that some exceptions seem to occur. Most importantly, given the possibility for subtypes within these illnesses, a single clinical profile may not be able to encompass everyone who may have ME/CFS, ME, and CFS. Depending on the specific subtype, some individuals may have different levels of fatigue or stamina. This is especially relevant in those who may be avoiding activity in order to prevent the onset of certain debilitating symptoms. For these individuals, their fatigue levels may be low, but because of a lack of stamina, they are still unable to function as they did before the appearance of illness in their lives. As is evidenced in the case studies presented, individuals within this fatigue/energy sub-type are still inflicted with severe symptoms of illness in their daily lives and should still be recognized under the diagnostic criteria.

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Table 1

Spearman's rank correlation coefficients between pep, energy, worn out, tired, and the fatigue/extreme tiredness composite score in the overall sample (N=189)

	Pep	Energy	Worn Out	Tired	Fatigue/ extreme tiredness
Pep	—				
Energy	.62***	—			
Worn Out	-.29***	-.32***	—		
Tired	-.35***	-.395***	.65***	—	
Fatigue/ extreme tiredness	-.18*	-.22**	.36***	.41***	—

Note.

 $p < .001$.

**
 $p < .01$.

*
 $p < .05$.