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The DePaul Symptom Questionnaire-2: A Validation Study

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Abstract

Background—The DePaul Symptom Questionnaire (DSQ) was developed to assess the symptomatology and case definition fulfillment of individuals with myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). The questionnaire was recently revised to improve its psychometric properties, increase its diagnostic reliability, and assess symptoms required by case definitions. The resulting instrument was named the DSQ-2.

Purpose—The current study sought to evaluate the utility and reliability of the new and revised items in the DSQ-2.

Method—A cross-sectional sample of 399 adults with ME or CFS was recruited to complete the DSQ-2.

Results—Descriptive analyses of the DSQ-2 suggest that the new and revised items enhance the instrument's ability to assess certain symptom domains and evaluate recent case definitions. Additionally, an exploratory factor analysis resulted in an eight-factor solution: post-exertional malaise, cognitive impairment, fever and flu, pain, sleep disruption, orthostatic intolerance, genitourinary issues, and temperature intolerance. The items within each factor demonstrated strong internal consistency reliability (Cronbach's alphas = .73–.91).

Conclusion—These analyses indicate that the DSQ-2 offers a more thorough and precise understanding ME and CFS symptomatology and case definition fulfillment.

Keywords

DePaul Symptom Questionnaire; chronic fatigue syndrome; myalgic encephalomyelitis; symptom assessment; case definitions

Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) are characterized by debilitating symptoms, including post-exertional symptom exacerbation. As researchers have not yet discovered a biomarker for the illness, ME and CFS must be diagnosed by case definition using self-report items [1]. However, this process can become complex, as over twenty case definitions exist [2], and many contain vague or ambiguous criteria. The more commonly used case definitions include: the Fukuda et al. (1994) CFS criteria [3], the

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Disclosure of Interest

The authors report no conflict of interest.

Canadian ME/CFS criteria [4], the Myalgic Encephalomyelitis International Consensus Criteria (ME-ICC) [5], and the Institute of Medicine criteria [1].

Each case definition differs in its diagnostic requirements, and as a result, captures a different subset of individuals based upon their reported symptoms and functioning. For example, the most commonly used case definition [2], the Fukuda et al. CFS criteria [3], will permit a diagnosis of CFS if six or more months of unexplained fatigue is accompanied by any combination of four out of eight possible symptoms (post-exertional malaise, memory or concentration problems, unrefreshing sleep, joint pain, muscle pain, sore throat, tender lymph nodes, or headaches). The latter requirement allows for 163 different combinations of symptoms to meet this criterion. In addition to challenges related to symptom heterogeneity, the Fukuda et al. CFS criteria [3] have been criticized for lacking guidance on required symptom frequency and severity, resulting in poor discriminative validity between ME and CFS and psychological illnesses [2].

In response to these critiques, the Canadian ME/CFS [4] and ME-ICC [5] case definitions required an increased number of symptoms, allowed for less variation in the symptom profiles that would meet criteria, and provided additional guidance on the frequency and severity necessary for a symptom to fulfill case definition requirements. Research has found that individuals who meet these case definitions are more impaired than those who meet the Fukuda et al. CFS criteria, e.g., [6,7].

As some research has indicated that requiring larger numbers of symptoms could increase the rate of psychiatric comorbidity of those who fulfill criteria [8], the Institute of Medicine case definition [1] requires a smaller set of core symptoms: a substantial reduction in functioning (compared to pre-illness functioning), post-exertional malaise, unrefreshing sleep, and either cognitive impairment or orthostatic intolerance. The IOM report [1] recommended that these criteria be further researched and evaluated to contribute to their eventual refinement.

The DePaul Symptom Questionnaire (DSQ-1) [9] was developed in 2010 to measure ME and CFS symptomatology and determine whether individuals meet existing case definitions. The DSQ-1 has demonstrated strong test-retest reliability [10] and content validity [11]. Furthermore, DSQ-1 responses accurately differentiate individuals with ME and CFS from healthy controls and participants with other chronic illnesses [12,13].

Since the release of the DSQ-1, the ME-ICC [5] and IOM [1] case definitions were published, new research was conducted on existing case definitions, and patients provided feedback on the questionnaire. In response to these developments, the DSQ-2 was created by Jason and colleagues to revise items (primarily in response to feedback from research participants with ME and CFS) and add items that better assess criteria from newly developed case definitions. To facilitate comparison with past research, the DSQ-2 also retained all items from the DSQ-1. The current study evaluates these item revisions and additions, and examines differences in the percentage of participants who fulfill various ME and CFS case definitions, given these item changes. Furthermore, an exploratory factor analysis was conducted to examine the underlying factor structure of the DSQ-2 symptom

items, highlighting the symptom domains of ME and CFS that this revised instrument is able to measure.

Method

Participants

A cross-sectional sample of adults with chronic illnesses was collected as part of a larger study [14]. Participants were recruited from email requests to national foundations and posts to support groups, research forums, and social media platforms. All study methods were approved by the DePaul University Institutional Review Board. Informed consent was established online, and participants subsequently completed an online questionnaires.

Although the larger sample was comprised of individuals with various chronic illnesses [14], the present study included only individuals with a diagnosis of ME or CFS ($n = 399$).

Measures

DePaul Symptom Questionnaire 2 (DSQ-2)—Participants completed the DePaul Symptom Questionnaire-2 (DSQ-2), a self-report measure of ME and CFS symptomatology, demographics, and medical, occupational and social history. The DSQ-2 is available in the shared library of Research Electronic Data Capture (REDCap) [15–16] hosted at DePaul University, as well as at Jason and Sunnquist [17]. The full questionnaire can be viewed here: <https://redcap.is.depaul.edu/surveys/?s=4NJ9CKW7JD>

As discussed above, the DSQ-2 includes all items from the DSQ-1, which has evidenced strong reliability and validity [10,12,13]. Participants report on the frequency and severity of ME and CFS symptoms over the past six months. Frequency of symptoms are rated on a 5-point Likert scale: 0 = none of the time, 1 = a little of the time, 2 = about half the time, 3 = most of the time, and 4 = all of the time. Similarly, severity of symptoms are rated on a 5-point Likert scale: 0 = symptom not present, 1 = mild, 2 = moderate, 3 = severe, 4 = very severe. Symptom scores are analyzed in two ways: (1) Composite scores are created by averaging the frequency and severity scores of each symptom and multiplying it by 25 to create a 100-point composite score; and (2) A binary “2/2 threshold” variable is created by examining the frequency and severity scores of each symptom; participants who endorse ratings of 2 or higher for both frequency (about half the time, most of the time, or all of the time) and severity (moderate, severe, or very severe) are considered to have the symptom.

DSQ-2 Revised Items—Two DSQ-1 items were found to be double barreled (i.e., inquired about two symptoms within one item): *unable to focus vision or attention* and *losing or gaining weight without trying*. These items were separated into four items: *unable to focus vision*, *unable to focus attention*, *losing weight without trying*, *gaining weight without trying*. Additionally, past research participants highlighted an issue related to the *alcohol intolerance* item in the DSQ-1; these participants noted that the DSQ-1 inquires about the presence and severity of symptoms over the past six months; however, individuals who had not consumed alcohol within the past six months due to an intolerance might have difficulty responding to this item (i.e., Should they endorse a symptom frequency of 0 (none of the time), since they did not consume alcohol, or a frequency of 4 (all of the time) since

they avoided alcohol due to a known, omnipresent intolerance?). To account for this possibility, the following two items were added to the DSQ-2: *Over the last 6 months, did you avoid alcohol due to an alcohol intolerance (feeling sick after drinking alcohol)* (response options: *Yes; No, I drank alcohol; No, I do not drink alcohol for other reasons*), and (if participants respond, *Yes*) *If you were to drink alcohol, how severe would the intolerance be* (rated on the 0 to 4 severity scale).

DSQ-2 New Items—A total of 36 new items were added to the DSQ-1, generating the DSQ-2. Table 2 displays each new item and the reason for its inclusion. The majority of these items were added to assess symptom domains required by the ME-ICC [5] and IOM [1], as these case definitions were released after the development of the DSQ-1. Additionally, several items were appended due to patient feedback and renewed interest in Ramsay's [18] descriptions of ME [19].

Case Definitions

The DSQ-1 case definition algorithms were updated for the DSQ-2 in order to include the new and revised items. Brief descriptions of each case definition's symptom requirements are included below. As all of the DSQ-1 items were retained in the DSQ-2, both the DSQ-1 and DSQ-2 algorithms were applied to all participants.

Fukuda CFS criteria—Meeting the Fukuda et al. [3] case definition requires the presence of fatigue of six months or longer that results in substantial reduction in pre-illness levels of occupational, educational, social or personal activities must be endorsed. In addition, at least four of the following eight symptoms must have been present for six months or longer and cannot predate the onset of fatigue: impaired memory or concentration, sore throat, lymph node pain, muscle pain, joint pain, headaches of a new or different type, unrefreshing sleep, and post-exertional malaise. The DSQ-2 includes additional items that participants could endorse to fulfill the post-exertional malaise criterion: *muscle fatigue after mild physical activity*; *worsening of symptoms after mild physical activity*; and *worsening of symptoms after mild mental activity*.

Canadian ME/CFS criteria—The Canadian ME/CFS clinical case definition [4] criteria requires the presence of fatigue of a new onset that results in substantial reductions in activity levels. Additionally, individuals must endorse symptoms from the following categories: at least one post-exertional malaise symptom, one sleep dysfunction symptom, one pain symptom, two neurological/cognitive symptoms, and at least one symptom from two of the following domains: autonomic, neuroendocrine, and immune manifestations. The DSQ-2 provides additional symptoms through which an individual could fulfill the post-exertional malaise criterion (*muscle fatigue after mild physical activity*; *worsening of symptoms after mild physical activity*; and *worsening of symptoms after mild mental activity*), the sleep dysfunction criterion (*daytime drowsiness*), the pain criterion (*sensitivity to pain* and *pressure on parts of your body cause pain in other parts of your body*), the neurological/cognitive criterion (*feeling disoriented*; *poor coordination*; *sensitivity to vibration*; *unable to focus vision*; and *unable to focus attention*), the autonomic criterion (*heart beats quickly after standing*; *blurred or tunnel vision after standing*; *graying or*

blacking out after standing; urinary urgency; waking up at night because you need to urinate; and inability to tolerate an upright position), and the neuroendocrine criterion (intolerance of extremes of temperatures; fluctuations in temperature throughout the day; losing weight without trying; gaining weight without trying; and avoiding alcohol due to an intolerance).

Myalgic Encephalomyelitis International Consensus Criteria (ME-ICC)—In order to meet the ME-ICC [5] case definition, there must be a 50 percent reduction in activity, and symptoms must be experienced from each of the following four categories: post-exertional neuroimmune exhaustion (e.g., post-exertional malaise), neurological impairments (at least one symptom from three of the following four domains: neurocognitive impairment; pain; sleep disturbance; or neurosensory, perceptual, and motor disturbance), immune, gastrointestinal, and genitourinary impairments (at least one symptom from three of the following five domains: flu-like symptoms; susceptibility to viral infections with prolonged recovery periods; gastrointestinal tract issues; genitourinary impairment; and sensitivities to food, medications, or chemicals), and energy production/transportation impairments (at least one symptom from one of the following domains: cardiovascular; respiratory; loss of thermostatic stability; or intolerance of temperature extremes).

For the ME-ICC criteria, the DSQ-2 items that participants could now endorse to fulfill the post-exertional neuroimmune exhaustion criterion include: *muscle fatigue after mild physical activity; worsening of symptoms after mild physical activity, and worsening of symptoms after mild mental activity*). New items related to the neurological impairment criterion include: *feeling disoriented* (neurocognitive); *slowed speech* (neurocognitive); *difficulty reading after mild physical or mental activity* (neurocognitive); *unable to focus attention* (neurocognitive); *unable to focus vision* (neurocognitive); *aching of the eyes or behind the eyes* (pain); *sensitivity to pain* (pain); *pressure on parts of your body cause pain in other parts of your body* (pain); *daytime drowsiness* (sleep); *sensitivity to vibration* (neurosensory/perceptual/motor); *poor coordination* (neurosensory/perceptual/motor).

New DSQ-2 items related to the immune, gastrointestinal, and genitourinary impairment criterion include: *sinus infections* (flu-like); *viral infections with prolonged recovery periods* (susceptibility to viral infections); *urinary urgency* (genitourinary); *waking up at night because you need to urinate* (genitourinary), and *avoiding alcohol due to an intolerance* (sensitivities to foods/medications/chemicals). Finally, new items related to the energy production/transportation criterion include: *heart beats quickly after standing* (cardiovascular); *blurred or tunnel vision after standing* (cardiovascular); *graying or blacking out after standing* (cardiovascular); *inability to tolerate an upright position* (cardiovascular); *fluctuations in temperature throughout the day* (loss of thermostatic ability); and *intolerance of extremes of temperatures* (temperature intolerance).

Institute of Medicine (IOM) criteria—The IOM [1] case definition requires a substantial reduction in pre-illness levels of occupational, educational, social, or personal activities. Additionally an individual must experience post-exertional malaise, unrefreshing sleep, and either cognitive impairment or orthostatic intolerance. New items from the DSQ-2 that participants could endorse to fulfill the IOM criteria are from the following domains: post-exertional malaise (*muscle fatigue after mild physical activity; worsening of symptoms after*

mild physical activity; and worsening of symptoms after mild mental activity), cognitive impairment (unable to focus attention and feeling disoriented), and orthostatic intolerance (heart beats quickly after standing; blurred or tunnel vision after standing; graying or blacking out after standing; and inability to tolerate an upright position).

Factor Analysis

IBM SPSS Statistics version 24 was used to conduct an exploratory factor analysis of the 100-point symptom composite scores. Consistent with an exploratory factor analysis performed on data collected using the DePaul Symptom Questionnaire [11], a promax rotation ($kappa = 4$) was used to allow the factors to correlate, and the principal axis factoring extraction method was selected in order to determine the maximum amount of common variance using the smallest number of factors. Two symptoms were excluded from analysis due to being too highly correlated with another (*eye pain* and *aching of or behind the eyes*; $r = .797$, $p = .000$).

Results

Demographics

Table 1 describes the demographic characteristics of the sample. The mean age for this sample was 48.7 years ($SD = 13.6$). Participants were predominately female (88.0%), Caucasian (96.7%), and were married or living with a partner (48.9). The majority of participants had obtained a college degree or higher (69.1%), and approximately half of the sample reported being on disability (48.6%).

Composite Score and Threshold Analysis

Revised items—Table 3 displays participants' mean 100-point composite scores and the percentage of participants who met the "2/2 symptom threshold" (i.e., endorsed frequency and severity scores of 2 or greater) for the double-barreled and alcohol intolerance items in the DSQ-1 and the associated DSQ-2 revisions. The analyses demonstrate the differences in symptom endorsement that resulted from these revisions. Specifically, while 61.2% of participants endorsed the DSQ-1 *unable to focus vision/attention* item (i.e., met the 2/2 threshold), participant responses to the revised DSQ-2 items indicate that the majority of these participants were likely reporting that they were unable to focus their attention (endorsed by 62.4% of participants), as opposed to unable to focus vision (endorsed by 34.6% of participants). Similarly, while 45.1% of participants endorsed the DSQ-1 item *losing or gaining weight without trying*, responses to the revised DSQ-2 items indicate that most participants were gaining weight (40.9%), not losing weight (6.5%).

When responding to the DSQ-1 *alcohol intolerance* item, 35.3% of participants met the 2/2 threshold. However, when participants were asked whether they had avoided alcohol over the past six months, 53.1% of participants reported that they had avoided alcohol due to intolerance. Of these individuals, 90% rated the severity of their alcohol intolerance as moderate or greater. Furthermore, 23.7% of participants reported that they avoid consuming alcohol due to reasons other than intolerance, suggesting that approximately three-quarters of this study's sample had not consumed alcohol within the past six months.

New items—Table 4 contains the mean 100-point composite scores and 2/2 symptom threshold results for the new items in the DSQ-2, arranged from most- to least-endorsed. New items related to post-exertional malaise items (*worsening of symptoms after mild physical activity*, *muscle fatigue after mild physical activity*, and *worsening of symptoms after mild mental activity*) were the most frequently-endorsed items, and they also had the highest mean composite scores.

Case Definition Fulfillment

The DSQ-1 and DSQ-2 case definition algorithms were applied to the sample. For each case definition, the percentages of participants who met these algorithms were compared. The DSQ-1 and DSQ-2 Fukuda et al. CFS [3] algorithms yielded equivalent results: 97.3% of participants fulfilled these criteria. The percentage of individuals who met the Canadian ME/CFS criteria [4] was slightly higher when the DSQ-2 algorithm was applied, due to the addition of new items within several symptom domains (DSQ-1 algorithm: 78.1%; DSQ-2 algorithm: 81.8%). The IOM [1] algorithms resulted in similar findings: 84.5% met the DSQ-1 IOM [1] algorithm, and 85.2% met the DSQ-2 algorithm.

The DSQ-2 algorithm revisions were most impactful for the ME-ICC [5] case definition. While 53.9% of participants met criteria when the DSQ-1 algorithm was applied, 66.3% met the DSQ-2 algorithm. This increase resulted from the new DSQ-2 items that were added to better assess the symptom domains required by the ME-ICC.

Factor Analysis

To select the appropriate number of factors to retain, the scree plot was examined for its point of inflection. As the scree plot showed multiple points of inflection, each solution was examined to identify the most interpretable and parsimonious solution. Symptoms that did not load onto any factor (rotated loadings <0.4) were removed, and the analysis was repeated until all symptoms loaded onto a factor. In total, 39 out of 72 total symptoms loaded onto factors.

The exploratory analysis yielded an eight-factor solution: post-exertional malaise, cognitive impairment, fever and flu, pain, sleep disruption, orthostatic intolerance, genitourinary, and temperature intolerance. Percent of variance explained was 29.95, 8.44, 6.04, 5.70, 4.04, 3.61, 3.45, and 2.94 for factors one through eight, respectively. Cronbach's alphas were .90, .91, .73, .80, .77, .80, .78, .73 for factors one through eight, respectively, demonstrating good internal consistency of the items within each factor. Table 5 displays the items that loaded onto each factor, and new DSQ-2 items are italicized.

Discussion

The current study compared the DSQ-1 and the DSQ-2 in order to examine the utility of the symptom revisions and additions. Overall, item revisions provided a more accurate depiction of participants' symptomatology. The splitting of double-barreled items revealed large differences in the percentage of individuals who endorsed each part of the original item (e.g., the majority of individuals who endorsed *losing or gaining weight without trying* were *gaining weight*, while much fewer were *losing weight*). Furthermore, incorporating feedback

from past participants allowed for a better understanding of the alcohol intolerance experienced by participants. Analysis results suggest that many participants skipped this question or indicated that this symptom was not present because they had not consumed alcohol during the time period of interest (the past six months) due to their alcohol intolerance. The revised alcohol intolerance items appear to better capture participants' experience with this phenomenon, further highlighting the need for specific language for assessing symptoms of ME and CFS.

The addition of new items further enhanced the DSQ-2's ability to assess participants' symptoms. The newly added PEM items (*worsening of symptoms after mild physical activity*, *muscle fatigue after mild physical activity*, and *worsening of symptoms after mild mental activity*) were highly endorsed by study participants. These items, sourced from Ramsay [18] emphasize the need for better understanding this symptom domain. Recent research has shown that the wording of Ramsay's item above, "worsening of symptoms after mild physical activity", was most liked by patients in describing post-exertional malaise [20].

Case definition fulfillment results of the DSQ-1 and DSQ-2 algorithms were similar for the Fukuda et al. [3] CFS, Canadian ME/CFS [4], and IOM [1] case definitions. However, the percentage of individuals who met the DSQ-2 ME-ICC [5] exceeded the percentage that met the DSQ-1 algorithm. This increase directly resulted from the addition of items related to the symptom domains outlined in the ME-ICC. Due to these additions, participants had more symptom options through which to fulfill criteria. For example, multiple new items assessed genitourinary impairment, so participants who did not endorse the genitourinary symptom included in the DSQ-1, *bladder problems*, may have endorsed *urinary urgency*, a symptom added to the DSQ-2. Overall, with the exception of the ME-ICC, case definition findings were consistent across DSQ-1 and DSQ-2 algorithms, suggesting that both measures reliably provide diagnostic assessments for this illness.

The eight-factor solution yielded from this study demonstrated that the instrument has high content validity in assessing the following ME and CFS symptom domains: PEM, cognitive impairment, fever and flu, pain, sleep disruption, orthostatic intolerance, genitourinary, and temperature intolerance. Two prior studies have examined the factor structure of the DSQ-1 [11,21]. The first study [21] identified a three-factor solution: neuroendocrine, autonomic, and immune dysfunction; neurological/ cognitive dysfunction; and post-exertional malaise. The subsequent study [11] extracted a four-factor solution. The first three factors were similar to those extracted in the prior study, and the fourth factor was associated with sleep disruption. As the items that loaded onto the neuroendocrine, autonomic, and immune dysfunction factor were heterogeneous, the authors conducted a second factor analysis that included only items that loaded onto this factor. This subsequent analysis revealed three underlying factors: circulatory; orthostatic intolerance; and gastrointestinal impairment. The authors hypothesized that reducing the number of items included in the second analysis provided additional power to extract additional factors.

Similar to both DSQ-1 factor analysis studies, the current study's eight factor solution included post-exertional malaise and cognitive impairment factors. However, the post-

exertional malaise factor explained 30% of the variance in the current analysis, the largest percentage explained by this analysis, and a higher percentage than found in prior analyses (4.9% and 3.8%, respectively). This increase likely resulted from the addition of new PEM items that loaded onto this factor (*worsening of symptoms after mild physical activity* and *muscle fatigue after mild physical activity*), providing further evidence of their utility. Furthermore, the importance of PEM in this factor structure is congruent with its characterization as a defining symptom of the illness.

The DSQ-2 factor analysis also extracted an orthostatic intolerance factor, similar to that found previously [11]. The DSQ-2 orthostatic intolerance factor was comprised primarily of new DSQ-2 items, indicating that additions to the DSQ-2 allow the instrument to better assess this symptom domain. Only one of the new orthostatic intolerance items did not load onto this factor (*inability to tolerate an upright position*); however, its factor loading score (0.39) was just below the cutoff (0.40).

The DSQ-2 sleep and temperature intolerance factors included similar items to those included in the sleep and circulatory factor extracted in the second DSQ-1 analysis [11]. Additionally, the DSQ-2 pain factor included similar items to the DSQ-1 gastrointestinal factor (*abdomen/stomach pain*, *irritable bowel problems*, and *bloating*); however, the DSQ-2 pain factor was somewhat broader, as it also included a symptom related to general muscle pain. The remaining DSQ-2 factors (fever and flu, genitourinary) have not been identified in past analyses, as these factors were comprised primarily of new items. The results of this factor analysis indicate that the DSQ-2 more thoroughly assesses symptoms from these domains.

The symptom domains identified in these factor analyses highlight their importance in better understanding ME and CFS. Two recent, national reports, from the National Institutes of Health Pathways to Prevention Workshop [22] and Institute of Medicine [1], identified many of these domains as critical to the diagnosis and treatment of ME and CFS. Specifically, the Institute of Medicine committee included post-exertional malaise, unrefreshing sleep, cognitive impairment, and orthostatic intolerance in their recommended case definition [1]. Furthermore, a report made by the National Institutes of Health Pathways to Prevention Workshop emphasized that fatigue, post-exertional malaise, cognitive impairment and pain are necessary for further study in order to improve ME and CFS diagnosis and treatment [22].

In an effort to improve the measurement and study of core ME and CFS symptoms, the National Institute of Neurological Diseases and Stroke assembled a working group to identify and recommend common data elements (CDEs) for use in research on this illness [23]. This group focused its efforts on identifying measures for fatigue, post-exertional malaise, sleep, pain, cognitive, autonomic, neuroendocrine, and immune symptoms, reiterating their importance in understanding and diagnosing ME and CFS.

Overall, the revisions and additions made in the development of the DSQ-2 in response to patient feedback and newly released case definitions appear to have enhanced the instrument's ability to assess and measure core symptoms of ME and CFS, consistent with

goals identified by the National Institutes of Health [22], Institute of Medicine [1], and Common Data Elements workgroups [23]. In summary, the DSQ-2 offers a thorough evaluation of ME and CFS symptomatology that may prove useful in medical and research settings.

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References

1. Institute of Medicine. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington (DC): The National Academies Press; 2015.
2. Bruberg KG, Fønhus MS, Larun L, et al. Case definitions for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review. *BMJ Open*. 2014;4(2). doi:10.1136/bmjopen-2013-003973
3. Fukuda K, Straus SE, Hickie I, et al. The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Ann Intern Med*. 119;121(12):953–959. [PubMed: 7978722]
4. Carruthers BM, Jain AK, De Meirleir KL, et al. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working case definition, diagnostic and treatment protocols. *J Chronic Fatigue Syndr*. 2003;11(1):7–115.
5. Carruthers BM, van de Sande MI, De Meirleir KL, et al. Myalgic encephalomyelitis: international consensus criteria. *J Intern Med*. 2011;270(4):327–338. [PubMed: 21777306]
6. Jason LA, Torres-Harding SR, Jurgens A, et al. Comparing the Fukuda et al. criteria and the Canadian case definition for chronic fatigue syndrome. *J Chronic Fatigue Syndr*. 2004;12:37–52.
7. Jason LA, Sunnquist M, Brown A, et al. Are Myalgic Encephalomyelitis and chronic fatigue syndrome different illnesses? A preliminary analysis. *J Health Psychol*. 2016;21(1):3–15. [PubMed: 24510231]
8. Brown AA, Jason LA, Evans MA, et al. Contrasting case definitions: The ME International Consensus Criteria vs. the Fukuda et al. CFS criteria. *North Am J Psychol*. 2013;15(1):103–120.
9. Jason LA, Evans M, Porter N, et al. The development of a revised Canadian myalgic encephalomyelitis chronic fatigue syndrome case definition. *Am J Biochem Biotechnol*. 2010;6(2):120–135.
10. Jason LA, So S, Brown AA, et al. Test–retest reliability of the DePaul Symptom Questionnaire. *Fatigue Biomed Health Behav*. 2015;3(1):16–32.
11. Jason LA, Sunnquist M, Brown A, et al. Factor analysis of the DePaul Symptom Questionnaire: Identifying core domains. *J Neurol Neurobiol*. 2015;1(4).

12. Jason LA, Sunnquist M, Brown A, et al. Examining case definition criteria for chronic fatigue syndrome and myalgic encephalomyelitis. *Fatigue Biomed Health Behav.* 2014;2(1):40–56.
13. Murdock KW, Wang XS, Shi Q, et al. The utility of patient-reported outcome measures among patients with myalgic encephalomyelitis/chronic fatigue syndrome. *Qual Life Res.* 2016;26(4):913–921. [PubMed: 27600520]
14. Ohanian D, Brown A, Sunnquist M, et al. Identifying Key Symptoms Differentiating Myalgic Encephalomyelitis and Chronic Fatigue Syndrome from Multiple Sclerosis. *Neurol (E-Cronicon).* 2016;4(2):41.
15. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* 2009;42(2):377–381. [PubMed: 18929686]
16. Obeid JS, McGraw CA, Minor BL, et al. Procurement of shared data instruments for Research Electronic Data Capture (REDCap). *J Biomed Inform.* 2012. doi:10.1016/j.jbi.2012.10.006.
17. Jason LA, Sunnquist M. The development of the DePaul Symptom Questionnaire: Original, expanded, brief and pediatric versions. *Front Pediatr.* 2018;6:330 10.3389/fped.2018.00330 [PubMed: 30460215]
18. Ramsay AM. Myalgic encephalomyelitis and postviral fatigue states: The saga of Royal Free disease. Gower Medical for the Myalgic Encephalomyelitis Association; 1988.
19. Sunnquist M, Jason LA, Nehrke P, et al. A comparison of case definitions for myalgic encephalomyelitis and chronic fatigue syndrome. *J Chronic Dis Manag.* 2017;2(2).
20. Jason LA, McManimen SL, Sunnquist M, et al. Patient perceptions of post exertional malaise. *Fatigue Biomed Health Behav.* 2018;6(2):92–105.
21. Brown AA, Jason LA. Validating a measure of myalgic encephalomyelitis/chronic fatigue syndrome symptomatology. *Fatigue Biomed Health Behav.* 2014;2(3):132–152.
22. Green CR, Cowan P, Elk R, et al. National institutes of health pathways to prevention workshop: advancing the research on myalgic encephalomyelitis/chronic fatigue syndrome. *Ann Intern Med.* 2015;162(12):860–865. [PubMed: 26075757]
23. NINDS Common Data Elements [Internet] Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Highlight Summary Document; [cited 2019 Jun 10]. Available from: https://commondataelements.ninds.nih.gov/Doc/MECFs/Myalgic_Encephalomyelitis_Chronic_Fatigue_Syndrome_CDE_Highlight_Summary.pdf

Table 1.**Demographic Characteristics ($n = 399$)**

	M	(SD)
Age	48.7	13.6
	%	(n)
Gender		
Female	88.0	(344)
Male	11.8	(46)
Other	0.3	(1)
Race		
White/Caucasian	96.7	(386)
Asian/Pacific Islander	1.0	(4)
American Indian/Alaskan Native	0.3	(1)
Other	1.8	(7)
Latino or Hispanic Origin	2.0	(8)
Marital Status		
Married/Living with partner	48.9	(195)
Never married	27.8	(111)
Divorced	17.0	(68)
Separated	3.0	(12)
Widowed	2.8	(11)
Work Status (<i>can select all that apply</i>)		
On disability	48.6	(194)
Working	23.6	(94)
Retired	12.5	(50)
Unemployed	13.3	(53)
Student	5.0	(20)
Homemaker	5.0	(20)
Education Level		
Graduate or professional	39.8	(159)
College	29.3	(117)
Partial college	19.3	(77)
High school	8.0	(32)
Some high school	2.8	(11)
Less than high school	0.3	(1)

Table 2.**Item Revisions and Additions to the DSQ-2****Item Revisions:**

Items revised, as they were previously double-barreled:

Unable to focus vision

Unable to focus attention

Losing weight without trying

Gaining weight without trying

Item revised to better understand alcohol intolerance and post-exertional malaise:

What would occur if you were to drink alcohol

If you were to engage in exercise of vigorous activity, would you feel physically drained or sick

Item Additions:

Items from the ME-ICC case definition and primer:

Feeling disoriented

Slowed speech

Difficulty reading (dyslexia) after mild physical or mental activity

Aching of the eyes or behind the eyes

Sensitivity to pain

Pressure on parts of your body causes pain in other parts of your body

Daytime drowsiness

Sensitivity to vibration

Poor coordination

Sinus infections

Urinary urgency

Waking up at night because you need to urinate

Inability to tolerate an upright position

Fluctuations in temperature throughout the day

Items from the ME-ICC case definition that were revised to assess frequency and severity:

Intolerance to extremes of temperature

Viral infections with prolonged recovery periods

Items added from the Ramsay (1988) case definition:

Muscle fatigue after mild physical activity

Worsening of symptoms after mild mental activity

Worsening of symptoms after mild physical activity

Items added to better assess orthostatic intolerance, a criterion in the IOM (2015) case definition:

Heart beats quickly after standing

Blurred or tunnel vision after standing

Items added based upon patient feedback

Since the onset of your fatigue/energy related illness

Have you stopped getting sick with colds or flus

Sensitivity to mold

Table 3.

Comparison of Original (Double-Barreled) Items and Revised Items:

Original and New Items	Mean Score (100-point Composite)	% Participants at 2/2 Threshold
Unable to focus vision/attention	51.0	61.2%
<i>Unable to focus attention</i>	<i>54.2</i>	<i>62.4%</i>
<i>Unable to focus vision</i>	<i>38.5</i>	<i>34.6%</i>
Losing/Gaining weight without trying	42.2	45.1%
<i>Gaining weight without trying</i>	<i>50.3</i>	<i>40.9%</i>
<i>Losing weight without trying</i>	<i>16.8</i>	<i>6.5%</i>

Table 4.**Participant Responses to New DSQ-2 Items**

New Item:	Mean Score (100-point Composite)	% Participants at 2/2 Threshold
Worsening of symptoms after mild physical activity	78.0	90.2
Muscle fatigue after mild physical activity	72.7	86.2
Worsening of symptoms after mild mental activity	62.5	74.7
Daytime drowsiness	62.3	73.7
Intolerance of extremes of temperatures	64.8	73.2
Sensitivity to pain	50.2	57.1
Poor coordination	46.3	51.9
Inability to tolerate an upright position	47.6	50.9
Difficulty reading (dyslexia) after mild physical or mental activity	46.1	50.1
Fluctuations in temperature throughout the day	44.9	48.4
Heart beats quickly after standing	44.4	47.4
Waking up at night because of need to urinate	47.1	47.1
Urinary urgency	40.3	44.1
Aching of the eyes or behind the eyes	37.2	38.4
Viral infections with prolonged recovery periods	35.3	31.8
Pressure on parts of your body cause pain in other parts of your body	27.9	31.3
Slowed speech	33.0	30.8
Feeling disoriented	36.4	30.6
Sensitivity to vibration	29.7	30.3
Blurred or tunnel vision after standing	30.2	28.8
Sensitivity to mold	27.2	28.8
Sinus infections	23.1	19.3
Graying or blacking out after standing	23.7	17.3

Table 5.Exploratory Factor Analysis of Patients ($n = 399$)

	Factor							
	I	II	III	IV	V	VI	VII	VIII
Post-Exertional Malaise								
Physically drained or sick after mild activity	.94	-.06	.01	-.08	-.05	.01	.01	-.02
Minimum exercise physically tired	.90	-.05	-.01	-.13	-.03	.02	.04	-.02
<i>Worsening of fatigue due to mild physical activity</i>	.81	-.02	-.07	-.02	-.02	.09	.08	.02
Next day soreness	.78	.09	-.05	.04	-.04	-.07	-.02	-.01
Fatigue/extreme tiredness	.74	.04	-.03	.05	.08	-.06	-.05	-.11
Dead, heavy feeling after exercise	.65	-.01	-.08	.08	.02	.10	-.10	.06
<i>Muscle fatigue due to mild physical activity</i>	.62	.03	-.05	.17	-.12	.05	.08	.07
Unrefreshing sleep	.48	.03	.09	.04	.16	-.08	.00	-.03
Cognitive Impairment								
Problems remembering things	-.07	.86	.11	.13	.00	-.05	-.12	-.10
Difficulty finding right word	-.11	.86	-.09	.16	.04	-.04	-.09	.01
Difficulty understanding	-.01	.79	-.21	-.02	.03	.12	.10	.03
Absent-mindedness	-.07	.78	.17	.04	.00	-.05	-.05	.01
Slowness of thought	.09	.72	-.03	-.14	-.07	-.09	.14	.14
Can only focus on one thing at a time	.11	.68	-.02	-.17	.01	.01	.02	.08
Difficulty paying attention	.18	.57	.16	-.06	.07	.00	-.03	-.18
<i>Slowed speech</i>	.00	.54	-.10	-.05	-.17	.19	.11	.13
Mentally tired after effort	.29	.43	.07	-.04	.15	.03	.00	-.14
Fever and Flu								
Fever	-.10	-.02	.72	-.07	-.02	.06	.04	-.06
High temperature	-.01	-.02	.72	.11	-.08	.04	.05	-.09
Flu-like symptoms	.20	-.03	.57	-.07	.00	.01	-.09	.09
<i>Viral infections with prolonged recovery</i>	-.13	.01	.54	-.04	-.01	.06	.13	-.07
<i>Fluctuations in temperature</i>	.02	.00	.43	.09	.03	.01	.07	.24
Pain								
Abdomen/stomach pain	-.01	-.01	.03	.83	.02	.04	-.01	-.01
Irritable bowel	-.07	-.06	-.10	.74	.01	.05	.12	.05
Bloating	.04	.03	-.02	.68	.01	.00	.05	.03
Pain or aching in muscles	.30	.02	.14	.42	-.03	-.13	-.03	.12
Sleep Disruption								
Problems staying asleep	.02	-.05	-.08	-.02	.99	.06	.02	.03
Waking up early in morning	-.09	.08	-.04	-.01	.69	-.03	.05	.14
Problems falling asleep	.09	.01	.07	.11	.45	-.03	-.03	-.02
Orthostatic Intolerance								

	Factor							
	I	II	III	IV	V	VI	VII	VIII
<i>Graying or blacking out after standing</i>	-.05	-.02	.10	.03	.03	.80	-.05	-.10
<i>Blurred or tunnel vision after standing</i>	.01	.08	-.03	-.01	-.01	.75	.05	.03
<i>Heart started to beat quickly after standing</i>	.13	-.06	.08	-.03	.02	.51	-.08	.12
<i>Dizziness or fainting</i>	.05	.03	.16	.13	-.01	.51	-.07	.00
Genitourinary								
<i>Urgent needs to urinate</i>	.00	.06	.06	.11	-.02	-.04	.77	-.03
<i>Bladder problems</i>	.01	.00	.08	.07	-.03	-.07	.74	.00
<i>Waking up at night to urinate</i>	.01	-.08	.05	-.03	.33	.05	.52	-.10
Temperature Intolerance								
<i>Chills or shivers</i>	-.05	.03	.34	-.12	.05	-.03	.00	.67
<i>Low temperature</i>	-.17	.07	-.11	.13	.01	.01	-.02	.62
<i>Cold limbs</i>	.11	-.03	-.14	.04	.09	.00	-.07	.76