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A brief, comprehensive measure of post-exertional malaise

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Abstract

Aim: Post-exertional malaise (PEM) has been a challenging construct to measure, particularly with self-report instruments, which have the benefits of being less expensive and less invasive than cardiopulmonary exercise tests. Existing PEM questionnaires have often been used for diagnostic purposes and less frequently as outcome measures. Few self-report PEM measures address comprehensive PEM domains, including types of triggers, duration of symptoms, delayed symptom onset, number of symptoms, frequency and severity of symptoms, as well as whether pacing or other strategies reduce or eliminate PEM. Without characterizing these features, salient aspects of PEM would be overlooked. However, efforts to assess all these domains can be time-consuming and potentially burdensome.

Methods: The current study offers investigators a brief but comprehensive instrument of critical PEM domains, called the DePaul Symptom Questionnaire (DSQ)-PEM-2, to assess PEM. Validation data were derived from a large sample of individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Results: The DSQ-PEM-2 was developed using an existing dataset of individuals with ME, CFS, or both ME and CFS, allowing comprehensive coverage of key PEM domains.

Conclusions: The DSQ-PEM-2 can be used either for diagnostic purposes or as an outcome measure. The instrument's time frames for symptom manifestation can be adapted to suit a variety of research or clinical contexts. Future validation studies need to include a healthy control group.

Keywords

myalgic encephalomyelitis/chronic fatigue syndrome, post-exertional malaise, DePaul Symptom Questionnaire-PEM-2

Introduction

Sub-maximal and maximal cardiopulmonary exercise tests are the gold standard for evaluating post-exertional malaise (PEM) [1–3]. When PEM is assessed in the laboratory, the challenges involve motor

activities such as walking or using a bike, and these assessments measure physical types of exertion. However, they are expensive, requiring specialized equipment, and can cause a sharp worsening of symptoms. As an alternative, noninvasive handgrip tasks [4, 5] have been used to elicit symptoms of PEM; however, they are not able to measure the types of triggers that occur in more naturalistic settings. There is at least a consensus that whatever challenge is used (e.g., treadmill, bike, tilt-table, mentally fatiguing tasks), it should be described in enough detail, including the type, intensity, frequency, and duration of the stimuli [6].

Given the importance of measuring PEM in more real-world settings for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [7, 8], there is a need for inexpensive, reliable, and accurate screening and assessment instruments. Self-report surveys offer a less costly and less intrusive method of evaluating PEM, but variations in the wording of questions can lead to issues with reliability and validity [8–10]. However, when questionnaires are carefully constructed, it is possible to measure PEM validly and thus be able to differentiate PEM experienced by patients with ME/CFS from the symptoms of those with other disorders such as Major Depressive Disorder [11].

Over the last few years, there have been several new self-report approaches to measure PEM, some also involving cardiopulmonary exercise testing. Using two maximal exercise tests at five time points, Mateo et al. [12] found that fatigue, cognitive dysfunction, and sleep disturbances were the most frequently reported symptoms when using open-ended questionnaires. Patients with ME/CFS who underwent cardiopulmonary exercise testing were evaluated by Stussman et al. [13], who found that changes in PEM severity and symptom quality could be effectively captured through semi-structured qualitative interviews, whereas visual analog scales failed to provide adequate assessment. The PEM/PESE Activity Questionnaire, developed by Davenport et al. [14], focused on activities of daily living and demonstrated varying levels of reliability from fair to excellent. The modified Yorkshire Rehabilitation Scale, adapted by Sivan et al. [15] for Long COVID patients, examined how different exertion types (cognitive, physical, emotional) trigger PEM and catalogued the resulting PEM symptoms [16]. Accounting for PEM consequences when measuring functional capacity has been well assessed by the FUNCAP [17].

Over the past 15 years, the DePaul Symptom Questionnaire (DSQ) has been developed to allow investigators to determine if patients meet a variety of ME/CFS case definitions [18, 19], and there have been efforts to adopt this questionnaire to measure five core PEM symptoms [20]. As an example of this work, Twomey et al.'s [21] study involving 213 adults found 95% of those with Long COVID met the threshold for at least one of the five DSQ-PEM items. The DSQ-PEM instrument was developed by Cotler et al. [22], combining five established PEM items from the original DSQ plus five supplementary DSQ-PEM items. These supplementary items included domains such as the duration of symptom exacerbation following activity, recovery timeframes, and whether patients avoided exercise due to symptoms worsening. The five core DSQ-PEM symptoms demonstrate strong internal reliability [23], and when used together with the supplementary items, were able to differentiate patients with ME/CFS versus other conditions (e.g., multiple sclerosis and post-polio syndrome) [22]. However, other aspects of PEM were not assessed with this instrument, such as the variety of PEM triggers.

In a collaborative effort with the patient community, Jason et al. [24] later developed a more comprehensive PEM tool called the DePaul PEM Questionnaire (DPEMQ). Although this instrument did assess multiple PEM domains, including triggers, duration, delayed onset, frequency/severity of symptoms, pacing, etc., the questionnaire was long, and it was unclear how to provide a PEM score for each of the core domains. Our current study has shortened this DPEMQ instrument, so it is more user-friendly for researchers and clinicians and provides concrete overall PEM scoring directions for different domains. PEM instruments have sometimes been used for diagnostic purposes, such as determining whether PEM symptoms meet ME/CFS criteria, as well as for outcome measures of clinical trials, but rarely have they been used for both purposes. Our revised and briefer instrument, called the DSQ-PEM-2, can be used as a diagnostic measure for ME/CFS case definitions as well as to measure the amount and intensity of PEM symptoms, triggers, severity, frequency, and effects of pacing.

Materials and methods

Participants

Adults aged 18 or older with an ME, CFS, or both ME and CFS diagnosis who could read and write English qualified for participation in this research. Recruitment occurred through patient advocacy organizations and social media platforms. Data collection utilized Research Electronic Data Capture (REDCap), a secure online survey platform [25]. The DePaul University Institutional Review Board granted study approval, with additional study details available in the referenced publications [24, 26] (IRB protocol #CH031518PSY-R2).

The final sample comprised 1,534 adults with self-reported ME, CFS, or both ME and CFS who provided complete data. Geographic distribution showed 41.1% resided in the United States, while international participants came predominantly from Great Britain (26.1%), followed by Australia (7.8%), Canada (6.6%), Norway (3.2%), the Netherlands (2.5%), and New Zealand (2.4%), with remaining participants from various other countries representing less than 1% each. Demographic characteristics revealed a predominantly female (84.6%) and White/Caucasian (97.5%) sample, with only 2% identifying as Latino or Hispanic. Relationship and education statistics indicated 56.6% were married or cohabitating with partners, and 39.3% held standard college degrees. Nearly half (45.7%) received disability payments. Regarding specific diagnoses, 50.7% reported CFS, 22.0% reported ME, and 27.2% reported both ME and CFS diagnoses. Medical doctors had diagnosed 94.4% of participants with either ME, CFS, or both ME and CFS.

Measures

DSQ-PEM-2—this abbreviated questionnaire is two pages long, covering the major domains of PEM (see Supplementary material). All statistical analyses were conducted using IBM SPSS Statistics for Windows, Version 25.0 (IBM Corp., Armonk, NY, USA).

The first question determined whether a person had PEM by asking the following question: Over the past 6 months, have you experienced PEM, which is defined as an abnormal response to minimal amounts of physical and/or cognitive exertion, with symptom severity and duration out of proportion to the initial trigger?

The second question asked about triggers, of which over 50% of respondents with ME/CFS answered affirmatively: minimal amounts of physical and/or cognitive exertion, basic activities of daily living, positional changes, emotional stress, chemicals, foods, light, heat, cold, noise, visual overload, watching movement, sensory overload, and mold. For scoring purposes, each trigger was counted as one episode, and the summary trigger score can range from 0 to 14. See Figure 1 to view all the PEM domains.

For the third question, respondents indicated the duration of symptoms, with responses ranging from less than one hour to longer than one month. For scoring purposes, longer durations were provided higher scores, with scores ranging from 0 (no prolonged recovery time) to 7 (greater than 24 months). For our final revised questionnaire, because most respondents indicated a duration of PEM symptoms between “no prolonged recovery time” and “1 week–1 month”, we included intermediary time points to capture a more comprehensive scope of PEM symptom durations.

The fourth question referred to whether there was a delay in symptoms (answers range from no delay to 3 days or longer). For scoring purposes, the scale went from 0 (no delay) to 4 (3 days or more), with higher scores indicating more of a delay in PEM symptoms.

The fifth question assessed whether a person either does not experience PEM or reduces PEM by pacing or some other activity, and the stem question was: Some individuals can reduce or avoid PEM by pacing, identifying warning signs, or decreasing, breaking up, and rescheduling activities based on available energy levels. How effective are strategies like these in avoiding or reducing PEM? Scoring for this item ranged from 0 (very effective) to 4 (not effective), with higher scores indicating pacing is less effective.

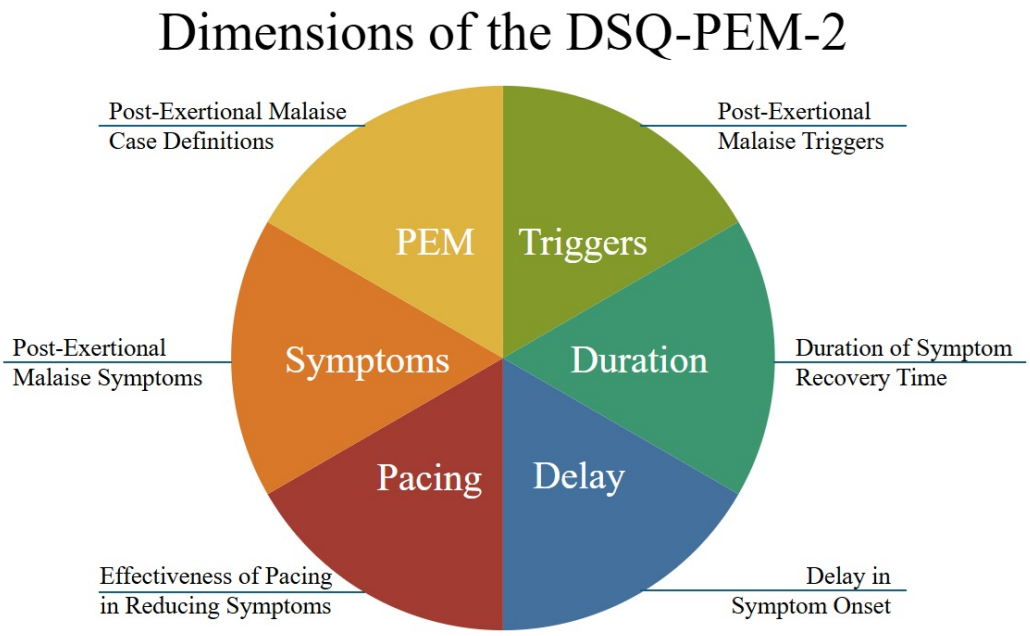

Figure 1. Dimensions of DSQ-PEM-2.

The sixth question assessed whether physical and cognitive-related symptoms worsened after PEM. This section incorporated PEM items from multiple sources: the DSQ [18], the ME clinical description [27], the ME-ICC [28], and the CDC's PEM characterization. Participants rated symptom frequency over the previous six months using a 5-point scale ranging from "none of the time" (0) to "all of the time" (4). Additionally, severity ratings for the same period used a 5-point scale from "symptom not present" (0) to "very severe" (4). We included those 13 key symptoms, as they had been experienced by at least 80 percent of respondents with ME/CFS. These symptoms included physical fatigue, reduced stamina and/or functional capacity, cognitive exhaustion, problems thinking, unrefreshing sleep, muscle weakness/instability, physically fatigue while mentally wired, insomnia, aches all over your body, muscle pain, flu-like symptoms, dizziness, and temperature dysregulations. The method for determining PEM symptom composite scores was calculated by adding frequency and severity scores for each symptom, dividing by 2, and multiplying by 25 to create a value on a 0 to 100-point scale. Scores of 50 or higher met a threshold of PEM symptom burden (occurring for at least half the time with at least moderate severity). For scoring purposes, the average of the 13 scores was used.

The last 5 questions were from the DSQ-PEM and involved the frequency and severity of PEM over the last 6 months. These 5 items were a screening tool for PEM, and according to research by Jason et al. [29], 97% of a sample of patients with ME/CFS indicated having one of these items at a moderate severity or higher and occurring at least half the time. The five key indicators included 'Dead, heavy feeling after starting to exercise', 'Next day soreness or fatigue after non-strenuous, everyday activities', 'Mentally tired after the slightest effort', 'Minimum exercise makes you physically tired', and 'Physically drained or sick after mild activity'. Statistical analysis confirmed the items' reliability with a strong Cronbach's alpha coefficient averaging 0.84 [30]. For the current study, each person was provided with an average frequency score and an average severity score across the 5 items. Frequency scores were calculated by adding the 5 DSQ-PEM frequency items and dividing by 5, and severity scores by adding the 5 DSQ-PEM severity items and dividing by 5. These scores ranged from 0 to 5, with higher scores indicating higher frequency and greater severity.

Medical outcomes study 36-item Short-Form Health Survey (SF-36 or RAND questionnaire)

The impact of participants' health on physical and mental functioning was measured using the SF-36's Physical Functioning scale [31]. The average score was 27.33 (SD = 20.96), with scores ranging from 0 to 100. Featuring a scoring system where higher subscale values indicate lower impairment levels, previous

research has established the SF-36's robust psychometric properties, demonstrating both strong internal consistency and effective discriminant validity [32]. In our study, we only included the Physical Functioning subscale. The SF-36 instrument is omitted from the questionnaire as it is not a measure of PEM but rather an outcome measure of functioning. Researchers requiring this instrument for their own studies can readily access and use it from the standard source.

Results

Question 1 was a screen for PEM, and it was important to be able to identify all those who might have PEM. In our dataset of 1,534 patients with ME/CFS with complete data, 97.3% (n = 1,492) responded affirmatively to having "an abnormal response to minimal amounts of physical and/or cognitive exertion", and 97.4% (n = 1,494) responded affirmatively to the question: "A severity and duration of symptoms out of proportion to the initial trigger". This combined question has high sensitivity and can identify almost all those with PEM in an ME/CFS sample. This question could be used as a screen, and only those responding positively would need to be asked the remaining questions on the DSQ-PEM-2.

Question 2 assessed the most frequently mentioned PEM triggers, and Table 1 provides a list of them, with minimal amounts of physical and/or cognitive exertion, and emotional stress as the two most frequent. These are the types of triggers that occur in daily life, and this is why self-report instruments are so valuable, as they provide the causes of PEM in naturalistic environments. The average number of triggers was 9.23 (SD = 2.98).

Table 1. Triggers of PEM.

Triggers	% (*n*)
Minimal amounts of physical and/or cognitive exertion	97.3 (1,492)
Emotional stress	93.2 (1,429)
Noise	85.3 (1,308)
Sensory overload	83.6 (1,282)
Visual overload	79.7 (1,223)
Basic activities of daily living	78.2 (1,199)
Heat	74.4 (1,141)
Light	68.8 (1,055)
Cold	66.3 (1,017)
Positional changes	64.5 (990)
Foods	61.0 (935)
Chemicals	58.0 (889)
Watching movement	52.5 (806)
Mold	39.4 (605)

Question 3 responses for PEM duration are in Table 2. Individuals who had filled out the original scale could select multiple responses, and in this table, we have tabulated the most extreme scores, which is why over 60% of respondents indicated a week or longer. However, many respondents (58%) also reported experiencing PEM symptoms for less than a week [26]. Our new scale requires respondents to indicate one response (their typical duration of PEM), so some durations will likely be briefer. The average was 3.36 (SD = 1.84), with the score of three indicating a duration between 1 week and 1 month.

Table 2. Duration of PEM.

Duration	% (*n*)
No prolonged recovery time	5.6 (86)
< 24 hours	0.5 (8)
24 hours–1 week	33.0 (506)

Table 2. Duration of PEM. (*continued*)

Duration	% (*n*)
1 week–1 month	22.6 (347)
1 month–6 months	17.5 (269)
6 months–12 months	5.1 (78)
12 months–24 months	3.3 (51)
> 24 months	12.3 (189)

Note. Question 3's data is presented in Table 2, which displays options provided in the original questionnaire. At the time of data collection, participants were allowed to select all duration options that applied to their experience of PEM. This approach accounts for the detailed breakdowns beyond one month and the higher proportion of respondents reporting symptoms lasting over a month. Within the DSQ-PEM-2, this has been revised to require participants to select only one response to improve clarity and consistency. Although some individuals do have PEM for more than a month and even beyond 2 years, our revised questionnaire only stipulates the time of 'greater than one month' because in most cases PEM occurs for less than one month.

Question 4 assessed the amount of time symptoms are delayed, and this is one of the unique symptoms for patients with ME/CFS. Table 3 provides the findings indicating that this delay does occur for the majority of patients. The average score was 2.51 (SD = 1.11), with 3 indicating a delay of 1–2 days. In our revised questionnaire, we have added the response "I do not experience post-exertional malaise" as this allows the questionnaire to be used by control groups and individuals who do not experience PEM.

Table 3. Onset delay of PEM symptoms.

Delay	% (*n*)
No delay	10.0 (154)
1 hour or less	2.0 (30)
2–23 hours	31.9 (490)
1–2 days	39.0 (599)
3 days or more	17.0 (261)

Note. Question 4's data is presented in Table 3, which depicts options provided in the original questionnaire.

Question 5 dealt with the use of strategies to reduce PEM, as there will be some individuals who can avoid the experience of PEM due to pacing, identifying warning signs, and/or restructuring activities. We have rewritten this question to be more inclusive of different activities, but Table 4 provides the responses of participants to how effective pacing has been in reducing PEM, with most participants indicating this strategy was mildly or barely effective. The average score was 1.81 (SD = 1.11), with 2 indicating mildly effective. In the questionnaire, question 5 includes a few additional response options so that respondents can indicate whether pacing completely helps them avoid PEM or whether they are healthy controls who do not experience PEM.

Table 4. Effectiveness of pacing.

Pacing	% (*n*)
Very effective	7.6 (117)
Moderately effective	37.2 (570)
Mildly effective	34.2 (525)
Barely effective	8.2 (126)
Not effective	12.8 (196)

The first 13 items from question 6 listed in Table 5 involve symptoms of PEM. They were the most frequent symptoms mentioned, and their composite scores ranged from 0 to 100, with higher scores indicating more burden. Symptoms were counted if they had composite scores of 50 or higher. The average score was 79.16 (SD = 10.68). As indicated in the methods section, the composite scores are computed by adding the frequency and severity, dividing by 2, and then multiplying by 25, so all scores can range from 0 to 100.

Table 5. PEM symptoms.

Symptoms	Composite score M (SD)
Physical fatigue	88.63 (15.50)
Reduced stamina and/or functional capacity	87.97 (13.08)
Unrefreshing sleep	80.50 (17.07)
Aches all over your body	80.30 (23.39)
Cognitive exhaustion	79.77 (21.57)
Temperature dysregulation	73.70 (25.74)
Muscle pain	73.65 (19.02)
Muscle weakness/instability	72.32 (19.97)
Insomnia	71.87 (25.97)
Physically fatigued while mentally wired	71.59 (18.43)
Problems thinking	71.53 (17.48)
Flu-like symptoms	68.85 (25.49)
Dizziness	57.44 (26.94)

The last 5 items from question 6 identify the average percentage of the overall frequency and severity scores of 5 key PEM items, and these data are in Table 6. The average score for frequency was 3.27 (SD = 0.63) (with 3 indicating most of the time), and severity was 3.09 (SD = 0.63) (with 3 indicating severe).

Table 6. PEM frequency and severity.

The last 5 items from question 6	Post-exertional malaise	% (*n*)
Next day soreness or fatigue after non-strenuous, everyday activities.	Frequency	
	None of the time	
Mentally tired after the slightest effort.	A little of the time	2.1 (20)
Physically drained or sick after mild activity.	About half the time	10.2 (96)
Dead, heavy feeling after starting to exercise.	Most of the time	33.5 (314)
	All of the time	54.1 (508)
Minimum exercise makes you physically tired.	Severity	
	Symptom not present	
	Mild	1.8 (17)
	Moderate	15.3 (143)
	Severe	44.3 (413)
	Very severe	38.4 (358)

Table 7 is a correlation matrix with each of the PEM components, including the Physical Functioning scale of the SF-36. Physical functioning was most highly correlated with the number of PEM Triggers, the overall PEM symptoms, and the frequency and severity of PEM.

Table 7. Correlation matrix of standardized PEM components.

	Triggers	Duration	Delay	Pacing	Symptoms	Frequency	Severity
Duration	0.26**						
Delay	0.07*	0.20**					
Pacing	0.05	0.06*	–0.18**				
Symptoms	0.34**	0.20**	–0.19**	0.26**			
Frequency	0.28**	0.22**	–0.13**	0.21**	0.62**		
Severity	0.27**	0.22**	–0.15**	0.25**	0.63**	0.71**	
SF-36	–0.47**	–0.28**	0.01	–0.13**	–0.40**	–0.52**	–0.46**

*: $p < 0.05$; **: $p < 0.01$.

Discussion

Our prior 10-item DSQ-PEM instrument [22] did not assess several important PEM domains, including the delayed onset of symptoms or PEM triggers, and our more comprehensive DPEMQ was extremely long and did not contain summary scores of the total PEM burden to a participant. The newly created DSQ-PEM-2 is a briefer, yet comprehensive measure of PEM that includes both a PEM screener, the major PEM triggers, the duration of PEM, the delayed onset of PEM, pacing and other efforts that might reduce PEM, major PEM symptoms, and the frequency and severity of PEM. This scale can be completed in 10 minutes and thus can be used by clinicians and researchers for multiple purposes.

The DSQ-PEM-2 was designed to assess PEM diagnostically to meet ME/CFS case definitions, but it could be used for PEM assessment with other diseases like Long COVID. Our screening questionnaire has a high sensitivity for identifying cases, and the other questions provide an assessment of the major domains of PEM. Summary scores are now available that could provide a marker of the severity of the critical domains. The DSQ-PEM-2 could also be used as an outcome measure, and if used in this capacity, the time frames for the questions could be reduced from over the past 6 months to the past month, week, or day. Our scales, along with an abbreviated 14-item brief instrument called the DSQ-SF [33], have been used as outcome measures to chart symptoms over time. This occurred with a study by Oliveira et al. [34], who used a 14-item short form of the DSQ. If the new DSQ-PEM-2 scale were to be used following an exercise challenge, the 13 symptoms from question 6 could be used with a time frame that is even briefer. If the number of PEM episodes that have occurred in the past week were of interest, clinicians and researchers could decide to use this instrument for diagnostic purposes for a briefer period. Modifications to the DSQ timeframe have already been implemented in several contexts. The pediatric RECOVER study utilizes a pediatric DSQ version with questions referencing the past month rather than six months (Personal Communication, Melissa Stockwell, Nov 2, 2023). Similarly, an adult COVID-specific DSQ adaptation has been developed with adjusted timeframes [35]. Serving as the primary endpoint measurement in the RECOVER-VITAL [36] COVID clinical trial, the DSQ-PEM was adjusted to have a condensed one-week retrospective period (Personal Communication, David Yanez, Oct 28, 2023). The RECOVER-ENERGIZE [37] clinical trial implemented the DSQ-PEM with multiple time frame options, allowing participants to report symptoms experienced during the past 3 months, the previous 7 days, or since their most recent clinical visit.

Using the DSQ instruments, Wold et al. [38] categorized patients into three groups: those experiencing fatigue, those with PEM, and those with multi-dimensional PEM (who experience malaise after exceeding thresholds in physical, mental, or social activities, requiring extended recovery periods). This type of subtyping is useful and our instrument provides other options as well. For example, research indicates that pacing—staying within individual activity thresholds—helps minimize symptom severity. For patients with ME/CFS in particular, pacing strategies that incorporate activity planning, consistency, and energy management techniques have proven effective at reducing PEM occurrences [39]. Some individuals can reduce or even eliminate their PEM through strategies such as pacing, and given this reality, any self-report PEM scale might misclassify such patients if it did not attempt to account for patient activities that moderate the influence of PEM.

The correlation matrix in Table 7 indicated that most of the PEM domains did contribute to physical functional problems, with the highest correlations for symptom frequency and severity, as well as triggers and overall symptoms. Even though several domains contributed less to patient burden, they are still important in helping researchers and clinicians characterize unique PEM characteristics, such as the delay of symptoms. Researchers who are particularly interested in some aspect of PEM, such as duration of symptoms or triggers, can study these domains independently. Although the domains were for the most part significantly correlated with each other, the amount of variation explained was relatively low, suggesting that these are unique features. Even the highest correlated domains involving frequency and severity were only correlated at the 0.71 level, indicating that only about 50% of the variance was explained.

A few case studies from our database can illustrate how these different domains can help provide a unique picture of PEM characteristics. One case study involved a patient who had 8 triggers, including minimal amounts of physical and/or cognitive exertion, basic activities of daily living, emotional stress, foods, noise, visual overload, watching movement, and sensory overload. The typical duration of PEM was from 24 hours to 1 week, with a delay in symptoms from 24 to 48 hours. Pacing was considered moderately effective. Five symptoms achieved scores of 50 or higher (signifying a frequency of at least half the time and a severity of moderate) and they included reduced stamina, physically fatigued while mentally wired, cognitive exhaustion, problems thinking, and physical fatigue. This person's overall experience of PEM occurred with a frequency of most of the time (M = 3), and it was severe (M = 3.2), with an SF-36 physical functioning score of 45, indicating moderate limitations in physical activities due to health problems, suggesting a health status below average but not severely impaired.

In contrast, another patient's SF-36 physical functioning score was 5, which indicates an extremely low level of physical functioning, suggesting significant limitations in daily activities, with pacing not considered effective. This person had 11 triggers of PEM (i.e., minimal amounts of physical and/or cognitive exertion, basic activities of daily living, positional changes, emotional stress, foods, heat, cold, noise, visual overload, watching movement, sensory overload). The duration of PEM was greater than 1 month with a symptom delay of 24 to 48 hours. Thirteen symptoms had composite scores of 50 or higher (i.e., reduced stamina, physically fatigued while mentally wired, cognitive exhaustion, problems thinking, unrefreshing sleep, insomnia, muscle pain, muscle weakness, aches all over your body, dizziness, flu-like symptoms, temperature dysregulation, physical fatigue). The PEM frequency was all the time (M = 4), and the PEM severity was very severe (M = 4).

From examining these two cases, both patients are impaired, but the second case indicates a person who is more disabled, given the SF-36 physical functioning score, and who also had a higher number of PEM symptoms that met the threshold, as well as a higher number of triggers. Pacing was less effective with the second person. Even though high impairment occurred for both, it is critical to consider not only an overall PEM score, but also different domains within PEM. Each domain provides an appreciation of the complex nature of PEM, and just examining one narrow area might overlook other key features of PEM. A person could have severe symptoms when they occur, but perhaps the frequency would be only a little of the time. Such a person would be rather different from a person who had symptoms at both a high frequency and severity. In addition, a person with only physical exertion triggers might be rather different from a person with a wide variety of triggers.

Our DSQ-PEM items have demonstrated robust psychometric properties, including test-retest reliability, construct validity, predictive validity, sensitivity/specificity, and discriminant validity. Our PEM instruments have been utilized across multiple investigations [5, 21, 36, 40–48]. Furthermore, a COVID study involving 2,445 participants primarily from Egypt, India, Pakistan, Syria, and Yemen has recently implemented the DSQ [49]. We expect that our most recent measure of PEM, the DSQ-PEM-2, will also be widely used by investigators.

In the USA, the initial ME/CFS Common Data Elements released in 2018 included PEM as a core symptom, and these standards were updated in 2022 to include 68 items, again including PEM as a core domain (both efforts had a recommendation to use the five DSQ-PEM questions) [50]. Currently, three working groups are developing Common Data Elements related to three areas, with one being PEM [51]. The adoption of these Common Data Elements for the ME/CFS field will ultimately improve the standardization and quality of data collection and analysis.

There were several limitations in the study. The sample was mostly white and female, and future studies need to include a more demographically diverse sample. Another limitation in our sample was that it did not include a healthy control group for comparison purposes or other illness contrast groups. The new DSQ-PEM-2 that is in the Supplementary material has several changes from the DPEMQ [24]. The original investigation allowed participants to select multiple responses, such as different amounts of time symptoms were delayed. The revised DSQ-PEM-2 now requests participants to select one typical response.

Certainly, the duration of symptoms and delays in symptoms do vary, but we felt that trying to select the usual amount would allow us to further concretize and operationalize this question. Future studies are needed that will incorporate wearable data, including heart rate and step count [52], to provide continuous passive data collection as well as at-home testing kits, which have not been widely utilized [53].

Another limitation in our study is that the data presented in Tables 1 and 4 were derived from a previously published dataset [24]. In that prior study, the same cohort was used to evaluate the diagnostic properties of the original DPEMQ. In the current study, we performed a secondary analysis to extend those findings to develop and assess a simplified version of our PEM questionnaire. Accordingly, certain clinical characteristics (such as the number and types of triggers, alongside patients' effectiveness of pacing) are shared across both studies. This overlap is noted to ensure transparency and does not represent duplication of findings, as the present study addresses the development of a simplified PEM questionnaire. Future studies are needed to further validate the DSQ-PEM-2, as well as to use more outcome measures to determine its concurrent validity.

In summary, we have crafted a relatively brief questionnaire, based on work that we had previously conducted, to measure the construct known as PEM. We believe that this measure does capture the main domains of PEM, in contrast to our previous work as well as most other scales that have been developed. Given the key importance of PEM in the symptomatology of ME/CFS, and probably other post-viral conditions, the creation of an instrument that allows researchers to use parts of this scale or the entire scale could be beneficial to our efforts to better document the domains of PEM, as well as lead to a better understanding of PEM.

Abbreviations

DPEMQ: DePaul Post-Exertional Malaise Questionnaire

DSQ: DePaul Symptom Questionnaire

ME/CFS: myalgic encephalomyelitis/chronic fatigue syndrome

PEM: post-exertional malaise

SF-36: 36-item Short-Form Health Survey

Supplementary materials

The supplementary material for this article is available at: https://www.explorationpub.com/uploads/Article/file/1004116_sup_1.pdf.

Declarations

Author contributions

LAJ: Conceptualization, Investigation, Methodology, Writing—original draft. KJC: Data curation, Formal analysis, Writing—review & editing. Both authors read and approved the submitted version.

Conflicts of interest

Both authors declare that they have no conflicts of interest.

Ethical approval

The DePaul University Institutional Review Board granted study approval (IRB protocol #CH031518PSY-R2). The study complied with the Declaration of Helsinki (2024 version).

Consent to participate

Informed consent to participate in the study was obtained from all participants.

Consent to publication

Not applicable.

Availability of data and materials

More information regarding the dataset analyzed for this study can be found at [24].

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