SUPPLEMENTARY MATERIAL

Chronic fatigue and post-exertional malaise in people living with long covid: an observational study

Supplemental Methods: Scoring of the DSQ-PEM, SF-36 and IPAQ-SF

DSQ-PEM Scoring

Historically, there has been difficulty in defining and measuring PEM [1, 2], but for the purposes of this study, PEM was used to denote concepts related to post-exertional symptom exacerbation[1]. The DSQ-PEM asks participants about symptoms over a 6-month timeframe. However, we stipulated in the questionnaire instructions that if symptoms had been present for less than six months, participants should consider symptoms since the acute phase of COVID-19 or a positive COVID-19 test. Scoring step 1 and 2 are used in the manuscript. The use of the supplementary DSQ-PEM items in this way was intended for the discrimination of people with ME/CFS from other conditions[3], and this was not our aim. Here, we use it as a stricter method of identifying PEM, considering our use of the DSQ-PEM outside of the context of ME/CFS. The DSQ-PEM was not used to comment on whether any of the participants in the present study have ME/CFS because this would require a more comprehensive clinical evaluation involving differential diagnoses and identification of other core symptoms [5, 6].

SF-36 Scoring

The SF-36 measures eight multi-item health concepts (physical functioning, role limitations due to physical health problems, role limitations due to personal or emotional problems, energy/fatigue, emotional wellbeing, social functioning, bodily pain, and general health perceptions). It also includes a single item that provides an indication of perceived change in health. Responses are recoded so that each

item is scored from 0-100%, with higher scores defining a more favorable health state. This questionnaire is a generic health-related quality of life tool that is useful for comparing general and specific populations and the relative burden of a health condition[6].

IPAQ-SF Scoring

Data were processed according to standardized protocols available at www.ipaq.ki.se. The IPAQ-SF measures the self-reported frequency and duration (min) of vigorous-intensity activity, moderate-intensity activity, and walking performed in bouts of ≥10 minutes in the past week. Total weekly minutes for these activities were calculated, converted to metabolic equivalents (MET) and expressed as MET-minutes per week[8, 9]. A summary indicator was used to categorize physical activity as 'high' (either 3 days of vigorous-intensity activity plus an accumulation of ≥1500 MET-min/week, or ≥5 days of any combination of activity that resulted in ≥3000 MET-min/week), 'moderate' (either ≥3 days of vigorous-intensity activity of ≥20 min/day, ≥5 days of moderate-intensity activity or walking for ≥30 min/day, or ≥5 days of any combination of activity that resulted in ≥600 MET-min/week), or 'low' (no physical activity reported or activity below the criteria for 'moderate'). The IPAQ-SF also measures the duration (minutes per day) of time spent sitting on a usual weekday. This includes time spent sitting at a desk, visiting friends, or reading, or sitting or lying down while watching television across various contexts, including work, home, or leisure [9]. This data was reported as minutes per day.

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Supplemental Results: IPAQ-SF

Most participants reported no vigorous physical activity (77.6%). In the remaining subset of participants (*n*=46) who did report vigorous physical activity, this took place on 2 (1-3) days per week, for 60 (30-65) minutes (median and IQR). However, most of these participants indicated that rather than those vigorous activities suggested by the IPAQ-SF (e.g., heavy lifting, digging, aerobics, or fast bicycling), they answered for typical daily activities, which were now rated as vigorous. This should be considered against the description of vigorous activities in the IPAQ-SF as "activities that take hard physical effort and make you breathe much harder than normal." Over half of the participants reported no moderate physical activity (58.5%; note that the IPAQ-SF excludes walking from this category). In the remaining subset of participants (*n*=83) who did report moderate physical activity, this took place on 2 (1-4) days per week, for 50 (20-90) min, and participants made similar comments about the perceived effort of daily activities. Total physical activity over the past week was equivalent to 503 (99-1361) MET-minutes. Physical activity levels were categorized as none/low in 59.8%, moderate in 31.4%, and high in 8.8% of the sample (Table 4). Because the vigorous and moderate activity descriptors may not be valid in this population, later exploratory analysis uses only the walking variable as a measure of physical activity (because it is not based on perceived physical effort or breathing harder).

There were *n*=8 missing responses for time spent sitting for unknown reasons, though presumably because some participants found the wording unclear for this item. During data inspection, we noticed that some participants answered in total hours for five weekdays or for the full week rather than estimated a single weekday (and one participant left a comment to this effect). We also noticed that

some participants included sleep in their estimate of sitting time (and one participant left a comment to this effect). Rather than devise a rule for correcting this data, we removed all responses >24 hours (*n*=18) and all responses between 19-24 hours (to remove data where sleep was included in the estimate; *n*=11). Therefore, the estimate of sitting time was in *n*=169 participants, who reported 525 (383-620) min [or 8.8 (6.4-10.3) hours] of time spent sitting per day on weekdays. However, this may be a poor surrogate for daily inactivity because *n*=10 of these participants left a comment to elaborate on spending time both sitting and lying down (or on the orthostatic challenges of sitting versus lying down. Because the IPAQ-PA specifically asks about time spent sitting as opposed to time spent awake but inactive, a median of 510 min may be an underestimate of sedentary time. Including actigraphy may be necessary in future studies requiring an estimate of physical activity/sedentary time in this population.

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