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### **Early View**

Correspondence

# The Post-COVID-19 Functional Status (PCFS) Scale: a tool to measure functional status over time after COVID-19

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The Post-COVID-19 Functional Status (PCFS)

Scale: a tool to measure functional status over

time after COVID-19

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#### To the editor:

Since the outbreak of the Coronavirus disease 2019 (COVID-19) pandemic, most attention has focused on containing transmission of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) and addressing the surge of critically ill patients in acute care settings. Indeed, as of April 29<sup>th</sup> 2020, over 3 million confirmed cases have been accounted for globally. In the coming weeks and months, emphasis will gradually involve also post-acute care of COVID-19 survivors. It is anticipated that COVID-19 may have a major impact on physical, cognitive, mental and social health status, also in patients with mild disease presentation. Previous outbreaks of coronaviruses have been associated with persistent pulmonary function impairment, muscle weakness, pain, fatigue, depression, anxiety, vocational problems, and reduced quality of life to various degrees. 3-5

Given the heterogeneity of COVID-19 in terms of clinical and radiological presentation, it is pivotal to have a simple tool to monitor the course of symptoms and the impact of symptoms on the functional status of patients — a scale that can measure the consequence of the disease beyond binary outcomes such as mortality. Considering the massive number of COVID-19 survivors that require follow-up, an easy and reproducible instrument to identify those patients suffering from slow or incomplete recovery would help guiding pondered use of medical resources and will also standardize research efforts.

The optimal instrument for this purpose is an ordinal scale assessing the full range of functional limitations to capture the heterogeneity of post-COVID-19 outcomes. Ordinal scales rank patients in meaningful categories and do not differentiate between underlying causes to be of general value. These scales can be used to track improvement over time and answer meaningful clinical questions, e.g. "How will I come out of this corona infection?", or for research purposes. They may be either self-reported or assessed in a formal standardized interview.

Recently, our group proposed an ordinal scale for assessment of patient-relevant functional limitations following an episode of venous thromboembolism (VTE): the post-VTE functional status

(PVFS) scale. <sup>7,8</sup> It covers the full spectrum of functional outcomes, and focuses on both limitations in usual duties/activities and changes in lifestyle in six scale grades. In short, grade 0 reflects the absence of any functional limitation, and the death of a patient is recorded in grade D. Upward of grade 1, symptoms, pain or anxiety are present to an increasing degree. This has no effect on activities for patients in grade 1, whereas a lower intensity of the activities is required for those in grade 2. Grade 3 accounts for inability to perform certain activities forcing patients to structurally modify these. Finally, grade 4 is reserved for those patients with severe functional limitations requiring assistance with activities of daily living (ADL). This scale was developed after discussion with international experts (via a Delphi analysis) with input from patients (via patient focus groups). The inter-observer agreement of scale grade assignment was shown to be good-to-excellent with kappa's of 0.75 (95%CI 0.58-1.0) and 1.0 (95%CI 0.83-1.0) between self-reported values and independent raters, respectively. <sup>7</sup>

The idea of using ordinal scales for COVID-19 research is not new. The WHO proposed the "Ordinal Scale for Clinical Improvement" on February 18<sup>th</sup> 2020 with categories mainly based on the type of treatment to be used as the primary endpoint in acute phase trials (e.g. NCT04292899, NCT04351724). However, due to its focus on in-hospital treatment, this scale is not a useful measure of the long-term outcomes of COVID-19 and its treatment after discharge.

There is a high incidence of pulmonary embolism itself, alongside myocardial damage/myocarditis and neurological complications, in critically ill patients with COVID-19. 9,10

Therefore, we consider our scale -after slight adaptation- to be useful in the current COVID-19 pandemic too (Figure 1). The proposed "Post-COVID-19 Functional Status (PCFS) Scale" could be assessed upon discharge from the hospital, at another 4 and 8 weeks post-discharge to monitor direct recovery, and at 6 months to assess functional sequelae. We have implemented the scale in our own clinical practices in Leiden University Medical Center and Kantonsspital Winterthur, and are planning to incorporate it in the LEOSS registry (LEOSS.net) and Maastricht University Medical Center. Notably, the scale is not meant to replace other relevant instruments for measuring quality

of life, tiredness or dyspnoea in the acute phase, but to be used as an additional outcome measure to evaluate the ultimate consequences of COVID-19 on functional status. We acknowledge that this 'PCFS scale' is currently not validated, and its usefulness will depend on the local conditions under which it is implemented. However, if implemented alongside existing outcomes, we will be able to generate sufficient evidence to make formal conclusions on its use to guide post-COVID-19 care.

This correspondence is a call for action to use and validate ordinal scales such as the one proposed by us for determining functional recovery of COVID-19. The full manual for patients and physicians or study personnel can be requested from the corresponding author (free of charge).

#### **Author contributions**

FAK, GJAMB and BS drafted the first version of the manuscript. All authors revised the review critically for important intellectual content and provided final approval for submission

#### **Disclosures**

**FAK** reports research grants from Bayer, Bristol-Myers Squibb, Boehringer-Ingelheim, Daiichi-Sankyo, MSD and Actelion, the Dutch Heart foundation and the Dutch Thrombosis association, outside the submitted work.

**GJAMB** has nothing to disclose.

**SB** has nothing to disclose.

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**JJMG** has nothing to disclose.

**SK** has nothing to disclose.

**SAR** has nothing to disclose.

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**BS** NA

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#### **Figures**

Figure 1: Patient self-report methods for the Post-COVID-19 Functional Status (PCFS) Scale

Note: A) flowchart, B) patient questionnaire. Instructions: 1) to assess recovery after the SARS-CoV-2 infection, this PCFS Scale covers the entire range of functional limitations, including changes in lifestyle, sports and social activities; 2) assignment of a PCFS Scale grade concerns the average situation of the past week (exception: when assessed at discharge, it concerns the situation of the day of discharge); 3) symptoms include but are not limited to: dyspnoea, pain, fatigue, muscle weakness, memory loss, depression and anxiety; 4) in case two grades seem to be appropriate, always choose the highest grade with the most limitations; 5) measuring functional status before the infection is optional; 6) alternatively to this flowchart and patient questionnaire, an extensive structured interview is available. The full manual for patients and physicians or study personnel can be requested from the corresponding author (free of charge).

