EUROPEAN RESPIRATORY *journal*

FLAGSHIP SCIENTIFIC JOURNAL OF ERS

Early View

Correspondence

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F.A. Klok, G.J.A.M. Boon, S. Barco, M. Endres, J.J.M. Geelhoed, S. Knauss, S.A. Rezek, M.A. Spruit, J. Vehreschild, B. Siegerink

Please cite this article as: Klok FA, Boon GJAM, Barco S, *et al*. The Post-COVID-19 Functional Status (PCFS) Scale: a tool to measure functional status over time after COVID-19. *Eur Respir J* 2020; in press (https://doi.org/10.1183/13993003.01494-2020).

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

Klok FA[1,2], Boon GJAM[1], Barco S[2,3], Endres M[4,5], Geelhoed JJM[6], Knauss S[5], Rezek SA[7], Spruit MA[8-10], Vehreschild J[11-13], Siegerink B[4,14]

[1] Department of Thrombosis and Haemostasis, Leiden University Medical Center, Leiden, The Netherlands

[2] Center for Thrombosis and Haemostasis (CTH), University Medical Center of the Johannes Gutenberg University Mainz, Mainz, Germany

[3] Clinic of Angiology, University Hospital Zurich, Zurich, Switzerland

[4] Center for Stroke Research Berlin, Charité-Universitätsmedizin Berlin, Berlin, Germany

[5] Department of Neurology, Charité-Universitätsmedizin Berlin, Berlin, Germany

[6] Department of Pulmonology, Leiden University Medical Center, Leiden, The Netherlands

[7] Institute of Therapies and Rehabilitation, Kantonsspital Winterthur, Winterthur, Switzerland

[8] Department of Research and Development, CIRO+, Horn, The Netherlands

[9] Department of Respiratory Medicine, Maastricht University Medical Center (MUMC+); NUTRIM School of Nutrition and Translational Research in Metabolism, Maastricht, The Netherlands

[10] REVAL Rehabilitation Research Center, BIOMED Biomedical Research Institute, Faculty of Rehabilitation Sciences, Hasselt University, Diepenbeek, Belgium

[11] University of Cologne, Faculty of Medicine and University Hospital Cologne, Department I for Internal Medicine, Cologne, Germany

[12] German Centre for Infection Research (DZIF), partner site Bonn-Cologne, Cologne, Germany

[13] Department of Internal Medicine, Hematology/Oncology, Goethe University Frankfurt, Frankfurt am Main, Germany

[14] Department of Clinical Epidemiology, Leiden University Medical Center, Leiden, The Netherlands

Corresponding author:

Frederikus A. Klok, MD, FESC; Department of Thrombosis and Haemostasis, Leiden University Medical Center, Leiden, the Netherlands; Albinusdreef 2, 2300RC, Leiden, the Netherlands; Phone: +31-715269111; E-mail: f.a.klok@LUMC.nl

Word count: 814

References: 10

Number of tables/figures: 1

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 29th 2020, over 3 million confirmed cases have been accounted for globally.[1] 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.[2] 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.[6]

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.[7,8] 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.[7]

The idea of using ordinal scales for COVID-19 research is not new. The WHO proposed the "Ordinal Scale for Clinical Improvement" on February 18th 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 is available from https://osf.io/qgpdv (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, all outside the submitted work.

GJAMB has nothing to disclose.

SB has nothing to disclose.

ME received funding from DFG under Germany´s Excellence Strategy – EXC-2049 – 390688087 and reports grants from Bayer and fees paid to the Charité from Bayer, Boehringer Ingelheim, BMS, Daiichi Sankyo, Amgen, GSK, Sanofi, Covidien, Novartis, Pfizer, all outside the submitted work.

JJMG has nothing to disclose.

SK has nothing to disclose.

SAR has nothing to disclose.

MAS reports grants from Netherlands Lung Foundation, grants and personal fees from AstraZeneca, grants and personal fees from Boehringer Ingelheim, and grants from Stichting Astma Bestrijding, all outside the submitted work.

JV NA

BS NA

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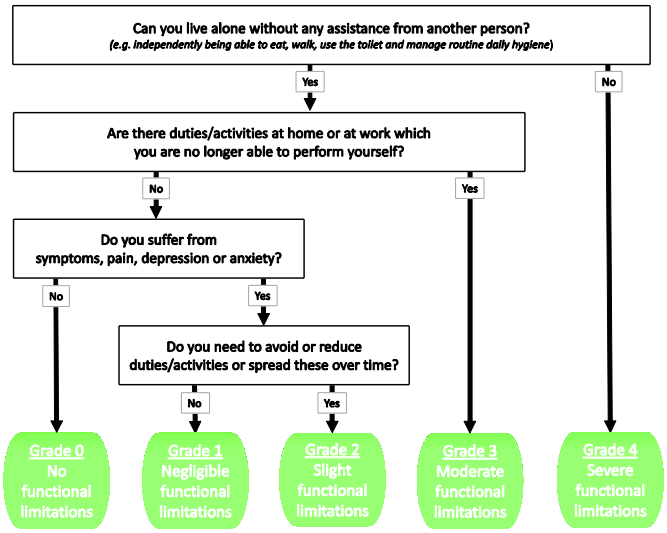
Figures

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 is available from https://osf.io/qgpdv (free of charge).

A



B

How much are you currently affected in your everyday life by COVID-19? Please indicate which one of the following statements applies to you most.	Corresponding PCFS scale grade
I have no limitations in my everyday life and no symptoms, pain, depression or anxiety related to the infection.	0
I have negligible limitations in my everyday life as I can perform all usual duties/activities, although I still have persistent symptoms, pain, depression or anxiety.	1
I suffer from limitations in my everyday life as I occasionally need to avoid or reduce usual duties/activities or need to spread these over time due to symptoms, pain, depression or anxiety. I am, however, able to perform all activities without any assistance.	2
I suffer from limitations in my everyday life as I am not able to perform all usual duties/activities due to symptoms, pain, depression or anxiety. I am, however, able to take care of myself without any assistance.	3
I suffer from severe limitations in my everyday life: I am not able to take care of myself and therefore I am dependent on nursing care and/or assistance from another person due to symptoms, pain, depression or anxiety.	4