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Title:

Growing evidence base on condition-specific patient-reported outcomes measures for Long Covid

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We read with interest Ye and colleagues[1] recently reported study on the development and validation of the Long Covid Symptoms and Severity Score (LCSSS). The authors rightly highlight the significant global challenges of Long COVID on patients and healthcare systems alike. This study is therefore a welcome addition in the ongoing efforts to both capture the individual symptom burden and impact of long COVID, as well as in endeavours to develop effective therapeutic strategies and appropriate healthcare. However, there is a noticeable absence within this study of any reference to the extant and growing body of literature on Long Covid (LC) specific patient-reported outcome measures (PRO). Other limitations include the reliance on a limited pool of participants in the validation process (namely college students, a limitation acknowledged by the authors), the lack of external verification of either a SARS-CoV-2 infection or post-COVID syndrome clinical diagnosis (entirely self-reported), and lack of items on functional abilities and health-related quality of life in their instrument.

Whilst the robustness of the psychometric properties of the LCSSS is acknowledged here, the instrument is not unique in its purpose nor is the methodology adopted in its design novel. The LCSSS is indeed a LC-specific PRO but the authors do not acknowledge the measures that have already been developed and validated for the condition. Ye et al.1 do cite a single other PRO, the Symptom Burden Questionnaire for Long Covid (SBQ-LC)[2], yet remark this instrument being too lengthy and cumbersome ([p. 1090]).

The COVID-19 Yorkshire Rehabilitation Scale (C19-YRS)[3] was the first condition-specific measure not mentioned or reviewed in this paper. Our own experiences - and that of others - in the development and validation of the C19-YRS^m have demonstrated the instrument's robust psychometric properties in terms of content validity, reliability and responsiveness to change.[4,5] Other LC-specific PROs, including, but not limited to the Symptoms Evolution of long COVID-19 (SE-LC19)[6], the post-acute (long) COVID-19 quality of life (PAC-19QoL)[7] have also been overlooked.

The symptom list and severity grading (mild/moderate/ severity) selected by the authors for LCSSS closely matches that of C19-YRS. The C19-YRS was developed in 2021. The scale has 10 Symptom Severity items (SS subscale) and 5 Functional Disability items (FD subscale) items (as well as 1 item overall health OH subscale item). The scale is also available in digital format on a PRO platform[8] that has lent itself readily to use in clinical practice and patient management supported by the instrument's validation with people with LC.[9]

Further afield, the C19-YRSm has been translated, validated into different languages as well as employed in several countries in the evaluation of intervention and management of LC.[10-14]

It is important to capture functional limitations and quality of life in any long-term condition.[15] The LCSSS must include these domains to make it a comprehensive and condition-specific tool. Ye et al claim their unique aspect of using the scale to identify severity clusters. A number of previous studies have assessed LC clinical phenotypes akin to Ye et al, and shown evidence of clinical severity clusters.[16,17] Importantly, cluster stability over time has also been explored in some studies.[18]

There is an extensive existing published research on validated LC-specific PROs that needs to be added in the Ye et al. paper and the authors need to describe how the LCSSS differs from other existing PROs for the condition. LCSSS is a relatively new instrument and needs further development work, especially exploring adding items to reflect functional ability and overall health. The criterion validity of the new scale needs to be compared to other well-established PROs for the condition. We would therefore respectfully disagree with Ye and colleagues that the LCSSS represents a significant milestone in LC research [p. 1090].

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