A Short Progressive Supranuclear Palsy Quality of Life Scale: Data from the PSP-NET

We read with interest the article by Jensen and colleagues who proposed a condensed version of the Progressive Supranuclear Palsy Quality of Life scale (PSP-ShoQoL) as a reliable and practical tool to evaluate quality of life in PSP patients.[1]

The proposed PSP-ShoQoL included 12 items divided into two subscales representing physical (seven items) and mental symptoms (five items) and was administered to 245 patients from the German PSP network. The internal consistency of both total and subscores was high within 0.83 and 0.90. The PSP-ShoQoL significantly correlated with the Progressive Supranuclear Scale-Rating Scale (PSP-RS) and the Geriatric Depression Scale (GDS) but not with the Montreal Cognitive Assessment scale (MoCA). With 12-month follow-up data on a subgroup of 94 patients, the authors showed that the PSP-ShoQoL presented fair sensitivity to change and test–retest reliability.

Herein, we present data on the PSP-ShoQoL on an independent PSP cohort, the Italian PSP-NET supported by Fondazione LIMPE.[2,3] 413 PSP patients performed the same evaluations used by Jensen et al. except for the GDS that was substituted by the Hospital Anxiety and Depression Scale (HADS). Compared with the German cohort, the PSP-NET included older (age: mean ± standard deviation [SD] 71.2 ± 8.1 vs. 69.2 ± 7.4) and more severe patients (PSP-RS: 40.56 ± 16.85 vs. 33.8 ± 13.8) while disease duration was similar (years: 4.44 ± 2.70 vs. 4.1 ± 2.6). Accordingly, PSP-ShoQoL total and subscores were higher within the PSP-NET (PSP-ShoQoL total: 25.33 ± 11.3 vs. 19.27 ± 11.10; PSP-ShoQoL Physical: 18.6 ± 8.2 vs. 13.74 ± 8.25; PSP-ShoQoL Mental: 6.7 ± 5.1 vs. 5.53 ± 4.67). We confirm a fair internal consistency for both the total score (Cronbach's alpha: 0.87) and subscores (Physical: 0.89; Mental: 0.80). The PSP-ShoQoL correlated significantly with the original PSP-QoL ($r = 0.945$, $P < 0.001$), the PSP-RS ($r = 0.646$, $P < 0.001$), the MoCA (-0.340, $P < 0.001$), and the HADS ($r = 0.602$, $P < 0.001$). With 6-month follow-up data available for 80 patients, we revealed a significant increase in both PSP-ShoQoL total score ($t = 5.24$, $P < 0.001$) and Physical ($t = 5.45$, $P < 0.001$) and Mental (-2.78, $P < 0.05$) subscores. Test–retest reliability was good both for PSP-ShoQoL total score (intraclass correlation coefficient [ICC] = 0.78, $P < 0.001$), as well as for its subscales (Physical ICC = 0.80, $P < 0.00$; Mental ICC = 0.68, $P < 0.001$). Finally, by analyzing the area under the curve (AUC) we identified a value of 34.5 as a discriminating cutoff for a significant impairment of quality of patients' life measured by the PSP-ShoQoL within the PSP-NET (sensibility: 0.97; specificity: 0.15; AUC: 0.93) (Fig. 1).

Jensen and coworkers proposed a brief instrument with fair psychometric properties for assessing quality of life in PSP patients. Herein, we have demonstrated the application of the PSP-ShoQol in an independent, large PSP cohort. Our results largely replicate those of

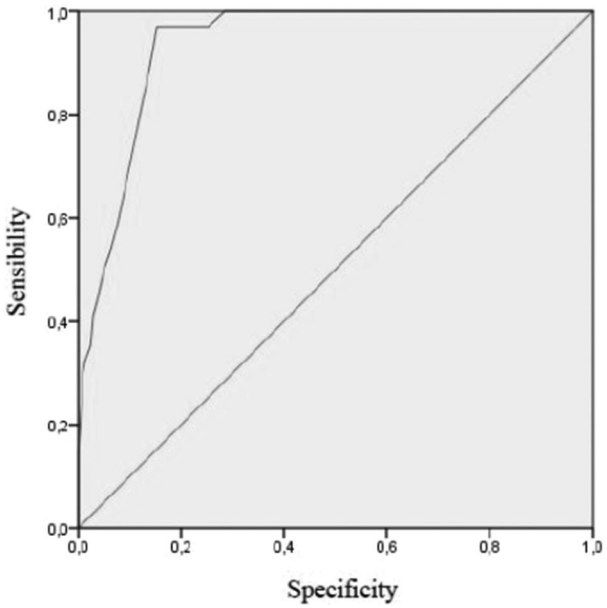

FIG. 1. Receiver operating characteristic (ROC) curve of the Short Progressive Supranuclear Palsy Quality of Life scale (PSP-ShoQoL).

Key Words: progressive supranuclear palsy, quality of life, parkinsonism

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Members of the PSP-NET Study Group are listed in Appendix A.

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Jensen et al. except for the relationship between the PSP-ShoQoL and the MoCA. Furthermore, we propose a cutoff of 34.5 as a discriminating value for a significant impairment of quality of patients' life measured by the PSP-ShoQoL.

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Appendix A

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Reply to: "A Short Progressive Supranuclear Palsy Quality of Life Scale: Data from the PSP-NET"

We thank Dr. Cappiello and colleagues for evaluating the Short Progressive Supranuclear Palsy Quality of Life Scale (PSP-ShoQoL)[1] in their letter "A Short Progressive Supranuclear Palsy Quality of Life Scale: Data from the PSP-NET" and supporting the value of the PSP-ShoQoL as an effective tool to measure quality of life.

The PSP-ShoQoL is a condensed version of the Progressive Supranuclear Palsy Quality of Life Scale (PSP-QoL)[2] designed to assess the quality of life in PSP patients in both research and routine clinical care. In their evaluation, colleagues confirmed the high internal consistency for the total score and subscores of the PSP-ShoQoL in an independent Italian cohort of 413 PSP patients.[3,4] They replicated significant correlations of the scale with the original PSP-QoL and the PSP Rating Scale. Additionally, they found a significant correlation between the PSP-ShoQoL and the Montreal Cognitive Assessment scores, which contrasts with our findings and might be explained by the higher age and greater disease severity of their participants. Within a shorter follow-up interval of 6 months (in contrast to our 12-month interval) with 80 patients, they also revealed a significant increase in both PSP-ShoQoL total score and subscores and a fair test–retest reliability.

Furthermore, colleagues suggested a cutoff value of 34.5 as a threshold for "significant impairment" in patients' quality of life. When developing the PSP-ShoQoL we made a conscious decision not to define a cutoff for the following reasons: First, cutoffs are typically used to indicate the necessity of therapeutic intervention once a threshold is reached (e.g., assigning a care level or offering psychological support), which is not the intended purpose of the PSP-ShoQoL. Second, to establish a reliable cutoff, we would suggest to validate the PSP-ShoQoL classification against an objective external criterion. This would require a measurement tool or diagnostic framework that categorizes individuals as impaired or nonimpaired to assess how accurately the PSP-ShoQoL classifies individuals. For diagnostic clarity, a comparison group (without PSP or without impairment) would be necessary in a cutoff evaluation study. The suggested cutoff seems to be valid in the present sample only: if this cutoff is applied to our German cohort, only very few patients would be classified as impaired, as our mean score is 19.27 ± 11.1 (standard deviation). This might imply that the PSP-ShoQoL was developed in a nonimpaired cohort, which, as demonstrated in our study, is not the case. This aspect could also be explored in future validation studies regarding the cutoff across different cohorts.

In summary, the PSP-ShoQoL proves to be a reliable instrument for disease-specific QoL assessment in PSP, as confirmed by Cappiello et al in their important and excellent powered independent validation study. However, its use in clinical practice and for research purposes will provide more experience and knowledge in the future.

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Ethics Statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Data Availability Statement

Data are available on reasonable request to I.J.

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