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ORIGINAL ARTICLE

Validation of the Italian version of the PSP Quality of Life questionnaire

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Abstract

Background Progressive supranuclear palsy (PSP) is a rare rapidly progressive, neurodegenerative disease characterized by falls and ocular movement disturbances. The use of health-related quality of life (HR-QoL) measures allows assessing changes in health status induced by therapeutic interventions or disease progress in neurodegenerative diseases. The PSP-QoL is a 45-item, self-administered questionnaire designed to evaluate HR-QoL in PSP.

Methods and Results Here, the PSP-QoL was translated into Italian and validated in 190 PSP (96 women and 94 men; mean age ± standard deviation, 72 ± 6.5; mean disease duration, 4.2 ± 2.3) patients diagnosed according to the Movement Disorder Society criteria and recruited in 16 third level movement disorders centers participating in the Neurecanet project. The mean PSP-QoL total score was 77.8 ± 37 (physical subscore, 46.5 ± 18.7; mental subscore, 33.6 ± 19.2). The internal consistency was high (Cronbach's alpha = 0.954); corrected item-total correlation was > 0.40 for the majority of items. The significant and moderate correlation of the PSP-QoL with other HR-QoL measures as well as with motor and disability assessments indicated adequate convergent validity of the scale. Gender and geographic location presented a significant impact on the PSP-QoL in our sample with women and patients from the South of Italy scoring higher than their counterparts.

Conclusion In conclusion, the Italian version of the PSP-QoL is an easy, reliable and valid tool for assessment of HR-QoL in PSP.

Keywords Parkinsonism · Progressive supranuclear palsy · Quality of life · Clinical trials

Abbreviations

EQ-5D	The EuroQoL questionnaire
EQ-VAS	The EuroQoL Visual Analogue Scale
HADS	The Hospital Anxiety and Depression Scale
HR-QoL	Health-related Quality of Life
MDS	Movement Disorder Society
MoCA	Montreal Cognitive Assessment
PSP	Progressive supranuclear palsy
PSP-QoL	Progressive Supranuclear Palsy Quality of Life Questionnaire
PSP-RS	Progressive Supranuclear Palsy Rating Scale
S&E	The Schwab and England Scale
VAS	Visual Analogue Scale

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Introduction

Progressive supranuclear palsy (PSP) is a rare rapidly progressive, neurodegenerative disease characterized by falls and ocular movement disturbances with a prevalence of about 6 per 100,000 and associated with reduced life expectancy, increasing disability, and considerable impact on health-related quality of life (HR-QoL) [1]. Disease severity is commonly assessed with the PSP Rating Scale (PSP-RS) [2].

However, it is now widely acknowledged that patient-reported outcome measurement is an important addition to the evaluation of disease severity both in clinical and research contexts [3, 4]. As such, the use of HR-QoL measures may allow assessment of changes in health status induced by therapeutic interventions or disease progress [3].

The PSP-QoL is a 45-item, self-administered questionnaire designed to evaluate HR-QoL in PSP. The original study validated such instrument in a large sample of PSP native English speakers patient ($N = 188$) demonstrating high construct validity and reliability and potential usefulness as a patient-reported outcome measure in clinical trials [5]. The PSP-QoL includes items covering mobility, dysarthria, dysphagia, visual disturbances, self-care, and activities of daily living representing the physical health status (physical subscore, items 1–22) and questions of emotional, cognitive, and social functioning evaluating the mental health status (mental subscore, items 23–45) [5]. Each item consists of 5 rating categories, ranging from 0 (no problem) to 4 (extreme problem).

The aim of the present study was to validate the Italian version of the PSP-QoL and to investigate the relationships between HR-QoL and demographic and clinical variables in a large sample of PSP patients.

Methods

Questionnaire translation

The translation of the PSP-QoL in Italian was done according to a stepwise process as follows [6]: (a) the translation from the English original version into Italian was carried out by a movement disorders expert, Italian native speaker, fluent in English (M.P.); (b) the back translation of the Italian version into English was carried out by a native English-speaking translator, fluent in Italian, not involved in the original translation; (c) the English original version was compared with the back-translated one and possible differences were debated, thus resulting in the revision and change of the first Italian version; (d) a comprehension test for the new consensus version was carried out in order to assess if the questionnaire was easy to understand with an independent group of 10 PSP patients from the Centre for Neurodegenerative Diseases (CEMAND), University of Salerno, Italy. All the patients agreed to comment on the comprehensibility and relevance of the questionnaire items; (e) the final Italian version of the PSP-QoL was eventually produced (supplemental material online).

Validation phase

This study was conducted in 16 third level movement disorders centers participating in the Neurecanet project coordinated by the CEMAND, University of Salerno. PSP patients were consecutively enrolled and included if (1) they provided written and signed informed consent; (2) were native Italian-speaking subjects of either sex; (3) were diagnosed with either possible or probable PSP according to the Movement Disorder Society (MDS) criteria [7]; (4) presented a mild to severe form of disease, based on clinical judgment; (5) were accompanied by a native Italian-speaking caregiver. Patients were excluded if they showed evidence of other central nervous system disorders or a degree of depression and/or dementia, which might prevent and/or affect ratings. Each center approached between 61 and 1 patients (total patients approached = 215) and enrolled between 1 and 46 subjects for a total of 190 PSP patients enrolled (Supplemental material online).

A neurologist experienced in movement disorders examined patients at each site and filled in the study questionnaire in order to collect socio-demographic data (age, gender), PSP history, and drug therapy. Disease severity was measured with the PSP-RS and general cognitive status with the Montreal Cognitive Assessment (MoCA). Disease-related disability was assessed with the Schwab and England Scale (S&E). Participants were asked to complete a booklet consisting of four health measures: PSP-QoL; the EuroQoL questionnaire (EQ-5D) and Visual Analogue Scale (EQ-VAS) of how satisfied the persons felt with their life, two generic HR-QoL measures used in several neurodegenerative disease [8]; the Hospital Anxiety and Depression Scale (HADS) [9].

Before starting the validation phase, involved centers participated in training sessions led by the Coordination Centre (University of Salerno) and aimed at standardizing the assessment methods.

The project was approved by the local Ethics committee.

Statistical analysis

The following psychometric properties were explored for the PSP-QoL: acceptability, internal consistency, and construct validity. Acceptability was considered appropriate for each PSP-QoL item if there were ≤ 5% of missing values and for the total score and subscores if there were ≤ 15% of the lowest and highest possible scores (floor and ceiling effect).

Moreover, skewness of total and two subscores (limits, − 1 to + 1) was determined [6].

Internal consistency was evaluated by means of Cronbach's alpha [10]. A value ≥ 0.70 was considered acceptable [11]. Scaling assumptions referring to the correct grouping of items and the appropriateness of their summed score were checked using corrected item-total correlation for both PSP-QoL total score and subscores (standard, ≥ 0.40; [12]).

Construct validity was explored with non-parametric Spearman's correlation between PSP-QoL total score and subscores, and other HR-QoL (EQ-5D, EQ-VAS), motor (PSP-RS), cognitive (MoCA), behavioral (HADS), and disability (S&E) assessments.

Spearman's correlation was used to verify the association between PSP-QoL total score and subscores and demographics (age) and PSP clinical history (age at onset and disease duration). The Mann-Whitney or Kruskal-Wallis test with post hoc, as appropriate, was used to verify the impact of gender and geographical location in Italy (North, Center, South) on PSP-QoL total score and subscores.

Correlations were considered strong with coefficient > 0.70 and moderate with a coefficient between 0.30 and 0.70. For the scale's internal validity, it was hypothesized that the correlation between the two subscores of the PSP-QoL would stand at 0.30–0.70. The significance threshold was set at $p \leq 0.05$.

The statistical analysis was performed with SPSS (Version 23).

Results

Two hundred and fifteen patients were included in the study, but 25 were excluded because of severe cognitive and/or motor impairment possibly preventing and/or affecting ratings. The Italian version of the PSP-QoL was administered to 190 PSP patients (96 women and 94 men, of whom 160 (84.2%) on dopaminergic treatment). The mean ± standard deviation PSP-QoL total score was 77.8 ± 37 and the median ± interquartile range (IQR) was 77.5 ± 45. The mean PSP-QoL physical subscore was 46.5 ± 18.7 and the median was 46 ± 25.5. The mean PSP-QoL mental subscore was 33.6 ± 19.2 and the median was 31.5 ± 26. Details on the enrolled cohort are displayed in Table 1.

Acceptability

Ninety-eight percent of data were totally computable and 2% were missing values. The percentage of missing values was ≤ 5% for all items. In the whole PSP sample, neither the ceiling nor the floor effects were observed for the PSP-QoL total score (lowest possible score = 0, 4%; highest possible score = 197, 0.5%) nor for the PSP-QoL physical subscore (lowest possible score = 7, 0.5%; highest possible score = 97, 0.5%) or the PSP-QoL

Table 1 Demographics and clinical features of the enrolled cohort

	The whole sample (190)	North (68)	Center (41)	South (81)	*p*
Age	73 (8.5)	75 (9.83)	72 (6)	72 (8)	0.014*
Gender (M/W, %)	94/96 (49.5/50.5)	29/39	22/19	43/38	0.400
Education	8 (8)	5 (6)	5 (3)	8 (8)	0.137
Age at onset	69 (8)	70 (9)	68 (6)	67 (10)	0.008^
Disease duration	4 (3)	4 (3)	4 (3)	4 (3)	0.223
PSP-RS	38 (21)	35 (18)	41.5 (16)	44 (25)	0.011@
MoCA	18 (8)	18 (8)	17 (5)	16.5 (11)	0.004§
S&E	50 (40)	50 (40)	40 (30)	45 (38)	0.413
EQ-VAS	50 (30)	50 (26)	50 (30)	40 (50)	0.966
HADS anxiety score	7 (6)	7 (6)	8 (5)	3 (7)	< 0.001°
HADS depression score	11 (6)	11 (6)	11 (3)	6 (13)	< 0.001ç

Data are expressed in median (interquartile range), unless otherwise specified

EQ-VAS Visual Analogue Scale, *HADS* the Hospital Anxiety and Depression Scale, *IQR* interquartile range, *M* men, *MoCA* the Montreal Cognitive Assessment, *PSP-RS* Progressive Supranuclear Palsy Rating Scale, *S&E* the Schwab and England Scale, *W* women

*North versus Center, $p = 0.015$; North versus South, $p = 0.011$; Center versus South, $p = 0.996$

^ North versus Center, $p = 0.034$; North versus South, $p = 0.003$

@ North versus Center, $p = 0.042$; North versus South, $p = 0.006$

§ North versus South, $p = 0.001$

° North versus South, $p < 0.001$; Center versus South, $p < 0.001$

ç North versus South, $p < 0.001$; Center versus South, $p < 0.001$

mental subscore (lowest possible score = 0, 1.5%; highest possible score = 100, 1%). The skewness of total and two subscores of PSP-QoL was within the standard limits (PSP-QoL total score = 0.4, PSP-QoL physical subscore = 0.1, PSP-QoL mental subscore = 0.7).

Reliability

Cronbach's alpha was 0.954 and, thus, it was considered acceptable for internal consistency. No item improved Cronbach's alpha if removed. Item-PSP-QoL total score correlation was ≥ 0.40 for all questions except for questions 5 (0.373), 7 (0.320), 10 (0.269), 29 (0.350), and 39 (0.338) (Table 2). Item-PSP-QoL physical subscore correlation was ≥ 0.40 for all questions except for questions 5 (0.376), 7 (0.323), and 10 (0.335) (Table 2). Item-PSP-QoL mental subscore correlation was ≥ 0.40 for all questions (Table 2).

Convergent construct validity

As for the PSP-QoL total score, the non-parametric Spearman's correlation showed no relation with demographic, education, or PSP clinical history. A moderate correlation emerged with PSP-RS, MoCA, S&E, and other health-related quality of life measures, but with the EQ-5D pain subscale. No correlation with HADS subscores was found (Table 3).

As for the PSP-QoL physical subscore, no correlation was found with demographic or PSP clinical history. A moderate correlation emerged with other health-related quality of life measures, but with the EQ-5D pain subscale. A strong correlation of PSP-QoL physical subscore with PSP-RS and S&E was found. No correlation with HADS subscores was shown (Table 3).

As for the PSP-QoL mental subscore, no correlation was shown with demographic or PSP clinical history. A moderate correlation emerged with PSP-RS, MoCA, S&E, and other health-related quality of life measures, but with the EQ-5D pain subscale. No correlation with HADS subscores was found (Table 3).

The correlation between PSP-QoL physical and mental subscores was moderate (rho = 0.592).

The Mann-Whitney test showed a significant impact of gender on the PSP-QoL total score with women scoring higher than man (Table 4). PSP-RS did not present gender differences (Table 4). The Kruskal-Wallis test showed a significant impact of geographic location on PSP-QoL total score and both subscores with patients from the South of Italy scoring higher than those from both the Center and North (Table 4). PSP-RS presented similar differences according to geographical location (Table 4).

Discussion

The present study showed that the Italian version of the PSP-QoL is acceptable, reliable, and easily applicable in the Italian PSP population. The scale as a whole showed high acceptability since data were computable for 98% and the percentage of missing values was ≤ 5% for all items. The acceptability of the Italian version is also supported by the absence of both ceiling and floor effects for the PSP-QoL total score and the physical and mental subscores, as reported in the original study [5].

The internal consistency of the Italian version of the PSP-QoL is high, acceptable (alpha = 0.954; item-PSP-QoL total score correlation ≥ 0.40 for all items except for 5 (falls), 7 (opening eyes), 10 (drooling), 29 (sleeping issues not related to movements), and 39 (memory problems)), and close to values obtained in the original study [5]. The lack of significant item-total correlation for few items may suggest either that such questions were not able to measure the related problems or the corresponding issues were less pronounced compared with other problems included in the questionnaire. The latter hypothesis is supported by the high percentage of the lowest possible scores for items 5 (15.6%), 7 (51.8%), 10 (47.7%), 29 (27.1%), and 39 (33.3%). However, item 39 presented an adequate interrelation with the PSP-QoL mental subscore, thus suggesting this item is more related to the corresponding subscore than the total score (Table 2).

As for convergent and divergent construct validity, the PSP-QoL total score and both subscores showed unnoticeable association with demographics, education, and PSP clinical history. Such low correlation may be indicative of a satisfactory divergent validity and suggest that the scale is suitable for PSP patients of any age, age at onset and disease duration.

The adequate construct validity of the Italian version of the PSP-QoL was supported by a moderate correlation between the total score and both subscores of the PSP-QoL with other HR-QoL measures (i.e., EuroQoL 5D and EQ-VAS). Furthermore, the PSP-QoL total score and mental subscore presented a moderate association with severity of disease as assessed with the PSP-RS and S&E, while in the case of the physical subscore, the association was strong. Indeed, these data support the hypothesis that both subscores are related but measure different aspects of disease. On the other hand, the PSP-QoL total score and subscores present also a moderate association with a cognitive measure as the MoCA, while no association was shown with HADS for any PSP-QoL score suggesting the scale does not reflect anxiety and depression burden in PSP patients.

Internal construct validity was supported by the moderate interscale correlation between the physical and mental subscales (0.637), as in the original study, implying that the two PSP-QoL subscales measure related but different health constructs [5].

Table 2 Item-total correlation for the PSP-QoL total score and physical and mental subscores

Item	PSP-QoL total score	PSP-QoL physical subscore	PSP-QoL mental subscore
1	0.677*	0.748*	–
2	0.600*	0.649*	–
3	0.642*	0.758*	–
4	0.525*	0.563*	–
5	0.373*	0.376*	–
6	0.459*	0.513*	–
7	0.320*	0.323*	–
8	0.652*	0.696*	–
9	0.594*	0.641*	–
10	0.269*	0.335*	–
11	0.632*	0.615*	–
12	0.592*	0.629*	–
13	0.723*	0.775*	–
14	0.703*	0.792*	–
15	0.489*	0.541*	–
16	0.634*	0.637*	–
17	0.524*	0.650*	–
18	0.636*	0.730*	–
19	0.601*	0.669*	–
20	0.498*	0.602*	–
21	0.565*	0.642*	–
22	0.382*	0.490*	–
23	0.705*	–	0.685*
24	0.658*	–	0.705*
25	0.585*	–	0.678*
26	0.624*	–	0.723*
27	0.465*	–	0.537*
28	0.516*	–	0.615*
29	0.350*	–	0.420*
30	0.439*	–	0.526*
31	0.610*	–	0.667*
32	0.616*	–	0.709*
33	0.502*	–	0.591*
34	0.541*	–	0.576*
35	0.550*	–	0.632*
36	0.464*	–	0.548*
37	0.550*	–	0.695*
38	0.508*	–	0.517*
39	0.338*	–	0.451*
40	0.439*	–	0.529*
41	0.647*	–	0.629*
42	0.578*	–	0.644*
43	0.607*	–	0.706*
44	0.648*	–	0.754*
45	0.698*	–	0.737*

*$p < 0.001$

PSP-QoL Progressive Supranuclear Palsy Quality of Life Questionnaire

Table 3 Convergent validity of the PSP-QoL total score and subscores

	PSP-QoL total score	*p*	PSP-QoL physical subscore	*p*	PSP-QoL mental subscore	*p*
Age	0.025	NS	0.004	NS	− 0.036	NS
Education	− 0.094	NS	− 0.080	NS	− 0.079	NS
Age at onset	− 0.060	NS	− 0.103	NS	− 0.092	NS
Disease duration	0.223	< 0.05	0.307	< 0.001	0.143	NS
EuroQoL 5D motility	0.445	< 0.001	0.491	< 0.001	0.343	< 0.001
EuroQoL 5D self-care	0.668	< 0.001	0.700	< 0.001	0.547	< 0.001
EuroQoL 5D usual activities	0.500	< 0.001	0.527	< 0.001	0.424	< 0.001
EuroQoL 5D pain	0.275	< 0.001	0.236	< 0.05	0.242	< 0.05
EuroQoL 5D anxiety	0.471	< 0.001	0.324	< 0.001	0.519	< 0.001
EuroQoL 5D total score	0.486	< 0.001	0.447	< 0.001	0.483	< 0.001
EuroQoL EQ-VAS	−0.534	< 0.001	− 0.449	< 0.001	− 0.552	< 0.001
PSP-RS	0.656	< 0.001	0.719	< 0.001	0.451	< 0.001
MoCA	−0.404	< 0.001	− 0.394	< 0.001	− 0.311	< 0.001
HADS anxiety score	0.239	< 0.001	0.194	< 0.05	0.299	< 0.001
HADS depression score	0.246	< 0.001	0.235	< 0.05	0.280	< 0.001
S&E	−0.625	< 0.001	− 0.720	< 0.001	− 0.462	< 0.001

EQ-VAS the EuroQoL Visual Analogue Scale, *HADS* the Hospital Anxiety and Depression Scale, *MoCA* the Montreal Cognitive Assessment, *NS* not significant, *PSP-RS* Progressive Supranuclear Palsy Rating Scale, *S&E* the Schwab and England Scale

Differently from the original study, gender has a significant impact on PSP-QoL total score in our sample. Different explanations may account for such discrepancy. First, similarly to other neurodegenerative diseases, it is likely gender differences in PSP exist, although there is scant of such studies in PSP [13]. Second, the majority of the cohort of the original study was based in the UK [5]. The cultural background has a well-known impact on gender discrepancies. Finally, although we did not find differences by gender for the PSP-RS (Table 4), we cannot exclude women in our cohort presented a more severe form of the disease not captured by the PSP-RS.

We also showed significant differences for the PSP-QoL total score and subscores in relation to the geographic location with patients from the South of Italy scoring higher than those from both the Center and North (Table 4). First, we cannot exclude some cultural background differences may in part account for such result. Also, such data can be explained in light of both the demographic and disease-related differences shown by patients according to geographic location. As such,

Table 4 Impact of gender and geographic location in Italy on PSP-QoL total score and physical and mental subscores

Variable	Type	PSP-QoL total score	PSP-QoL physical subscore	PSP-QoL mental subscore	PSP-RS
Gender	Men (*N* = 94)	70 (42)	44 (26.5)	28 (20.5)	39 (21)
	Women (*N* = 96)	87 (49)	50 (25)	33 (33.5)	42 (23)
	p	0.035	0.053	0.086	0.169
Geographic location	North (*N* = 68)	73 (41)	44 (23)	30 (28)	See Table 1
	Center (*N* = 41)	69 (38)	42.5 (27.2)	26 (20)	
	South (*N* = 81)	93 (46)	54 (28)	37 (32)	
	p	0.003*	0.012§	0.021°	

Data are expressed in median (interquartile range)

*Center versus South, $p = 0.005$; North versus South, $p = 0.03$;

§ Center versus South, $p = 0.002$; North versus South, $p = 0.03$

° Center versus South, $p = 0.271$

patients from the North of Italy were older, with older age at onset, higher MoCA and HADS scores, and lower PSP-RS. On the other hand, disease duration, gender distribution as well as disease-related disability, and quality of life as assessed with the EQ-VAS did not show significant differences over the country (Table 1). Although interesting, regional differences in such measures were out of the scope of the present work, which aimed at validating the PSP-QoL for Italian-speaking PSP patients. Thus, these data need to be further explored.

Our study has several strengths. Firstly, this is the largest sample of Italian PSP patients collected to date, as large as in the original study [5]. Secondly, several centers across Italy joined the study; thus, the results are representative of all the country. On a total of 215 patients approached, Movement Disorders Centers located in the North, Center, and South equally contributed to the study according to local possibilities (Supplemental material) demonstrating the feasibility of an Italian network on a rare, neurodegenerative disease [14]. Furthermore, all included patients underwent a thorough evaluation by a movement disorder expert in a third level center and were diagnosed according to recent MDS criteria [7, 15]. Finally, the low proportion of missing data increases the reliability of our findings.

Our study has limitations. Although we sought to include patients at all stages of PSP, it is likely that patients in more advanced stages who cannot respond accurately on their own, particularly those with cognitive impairment or unable to communicate, were underrepresented in our sample.

In conclusion, the PSP-QoL Italian version is an applicable and valid tool to measure HR-QoL in Italian PSP patients.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The project was approved by the local Ethics committee.

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