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Tools to assess the quality of life in patients with Parkinson's disease: a systematic review

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ABSTRACT

Introduction. The clinical, social, and economic implications of Parkinson's disease (PD) are significant; disability occurs leading to a low quality of life (QoL). Information on the QoL of patients with PD and studies on the relationship between QoL and motor and cognitive function are necessary for both research and clinical use to make informed decisions in healthcare and rehabilitation. The aim of this study was to determine which scales are most used to assess QoL in patients with PD.

Area covered. A literature search was conducted in MEDLINE, Scopus, CINAHL, PsycINFO, and Web of Science. Two authors independently identified eligible studies based on predefined inclusion criteria and extracted the data. Study quality and the risk of bias were assessed using the COSMIN checklist.

Expert opinion. 116 suitable studies were included, and 42 different instruments were identified. The most frequently used scales were the 39-items and 8-items Parkinson's Disease Questionnaire (PDQ-39) (PDQ-8). These findings suggest further investigation of existing PD outcome measures would benefit patients, researchers, and clinicians. Validated, universal outcome measures are required to allow comparisons across practice; therefore, we recommend that future researchers use a common set of outcome assessments based on the results of this review.

Keywords: Assessment tool; Outcome measure; Parkinson's Disease; Psychometric properties; Quality of Life; Systematic Review; Validation

1. INTRODUCTION

The clinical, social, and economic implications of Parkinson's disease (PD) are significant; disability occurs due to problems associated with walking, washing, and dressing, loss of dexterity, speech difficulties, fatigue, and social and emotional problems, leading to a low quality of life (QoL) for both patients and their caregivers. Information on the QoL of patients with PD and studies on the relationship between QoL and motor and cognitive function are necessary for both research and clinical use to make informed decisions in healthcare and rehabilitation. [1–3] To identify the best treatment methods and routines for people with PD the first step is to identify the correct assessment tool to robustly assess the efficacy of interventions both at the level of the clinical treatments and in the context of clinical trials. The classic clinical trial is designed to test the efficacy of a particular intervention as compared to another intervention or a control group. Facilitating comparison between groups requires a standard measure of outcome that is relevant and suited to the clinical question, valid for the population studied, and meaningful to the research team [4].

Therefore, it was decided to carry out this systematic review because clinicians and researchers need to know the most reliable, valid, and universally accepted measures currently available for evaluating people with SCI and to allow comparisons between different treatments.

The International Parkinson and Movement Disorders Society has published recommendations for the measurement of QoL in patients with PD that classify QoL as recommended, suggested, or listed. [5] Several scales have been proposed to evaluate the QoL of patients with PD; [6] in a systematic review, Martinez-Martin et al [7] classified four generic scales (i.e., the EuroQoL 5-dimension instrument, Nottingham Health Profile, 36-Item Short Form Health Survey, and Sickness Impact Profile) and five specific scales (i.e., the 8-Item Parkinson's Disease Questionnaire (PDQ-8), Parkinson's Disease Quality of Life Questionnaire, Parkinson's Impact Scale, Scales for Outcomes

in Parkinson's disease – (SCOPA-PS), and the 39-Item Parkinson's Disease Questionnaire (PDQ-39)) as recommended. Since the study by Martinez-Martin et al. was conducted in 2011 and only included articles from the PubMed database, we decided to update this topic. The primary objective of this study was to research and describe the tools most frequently used to evaluate QoL in individuals with PD through a systematic review. The secondary objective was to describe the languages in which these tools are validated.

2. BODY

This study was conducted by a research group composed by medical doctors and rehabilitation professionals from the “Sapienza” University of Rome and from “Rehabilitation & Outcome Measure Assessment” (R.O.M.A.) association. R.O.M.A. association in the last few years has dealt with several systematic reviews and the validation of many outcome measures in Italy [8–18].

2.1 Protocol and registration

After registration of the protocol on the International Prospective Register of Systematic Reviews (PROSPERO) website (CRD42019147041, available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019147041), this review was conducted in accordance with the 27-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist[19,20] based on the Methodological Expectations of Cochrane Intervention Reviews (MECIR) [21,22].

2.2 Eligibility criteria for considering studies for this review: types of studies and types of participants

A systematic review of the English-language literature was conducted and included a search for studies that evaluated the psychometric properties of outcome measures that explored QoL in people with PD. The terms health related QoL (HRQoL), and QoL are often used interchangeably.

Given that these are two key terms in the literature, their appropriate and clear use is important. A potential solution is to define HRQoL as the way health is empirically estimated to affect QoL or use the term to only signify the utility associated with a health state [23]. The World Health Organization (WHO) defines QoL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [24] QoL is a broad concept that is affected in a complex way by a person's physical health, psychological state, personal beliefs, social relationships, and relationship to salient features of their environment.

All studies that evaluated the psychometric properties of a clinician's report, a patient's self-report, and/or physical performance outcome measures that measured QoL in at least one domain of the tool were included. Studies were limited to people with PD, regardless of their clinical course or the length of time since diagnosis. Studies with mixed diagnosis samples were included if a subgroup of participants could be identified and for which separate data were available. No restrictions were applied to the publication period or to the country in which the study was conducted.

Inclusion criteria

- (1) Validation studies and cross-cultural adaptation studies;
- (2) Studies on QoL;
- (3) Studies on tests, questionnaires, and self-reported and performance-based outcome measures;
and
- (4) Studies with a population of patients with PD;

Exclusion criteria

- (1) Trials or studies that evaluated the effectiveness of interventions in which a questionnaire was used as an endpoint (without studying the measurement properties);

(2) Studies including measures of cognitive, motor, and other constructs without mention of QoL in any domain; and

(3) Studies with mixed diagnosis samples if a subgroup of PD participants could not be identified or did not have separate data.

2.3 Search methods to identify the studies

Studies were identified for inclusion through individualized systematic searches in five electronic databases. All potential studies were identified by two reviewers.

2.4 Electronic searches

The following electronic databases were systematically searched in July 2019: MEDLINE, CINAHL, PsycINFO (via EBSCO), Scopus, and Web of Science. The Medical Subject Headings (MeSH) of the United States National Library of Medicine were used to find the terms to be included in the search strategy. The MeSH terms used were Parkinson's disease, quality of life, and validation; these terms resulted in the search strategy which was built for MEDLINE and adapted for the other databases.

2.5 Study selection

Before starting the review, duplicate articles were filtered using Microsoft Excel. Following the guidelines of the PRISMA checklist[19], two reviewers (ER and GG) first independently screened the titles, keywords, and abstracts. After the first screening, the primary reviewer (ER) selected the relevant studies and assessed them using the following inclusion criteria: published quantitative studies that evaluate the psychometric properties of the outcome measures and then the validations of scales on the quality of life only if inherent to PD. Then, a second reviewer cross-checked the studies. After the second screening, studies that did not fit the inclusion criteria were systematically excluded, and others that appeared pertinent were identified. A final list of studies that were eligible for inclusion was compiled, and any disagreements were resolved by a third reviewer or by

consensus. The full text versions of studies that met the criteria were reviewed to determine whether they should be included in the review.

2.6 Data collection and data extraction

The approach to data collection and extraction was chosen based on the Cochrane methods [25]. Two reviewers independently extracted the demographics and descriptive information from the studies, and each study was keyworded for generic issues such as language, country, focus, and population. These characteristics were judged based on the information provided in the reports in the studies. Moreover, reviewers followed the recommendations from the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) initiative [26,27]. The outcome measures reported in each publication were recorded and categorized for comparison. The authors decided to report the following psychometric characteristics: Cronbach's alpha for internal consistency, the intraclass correlation coefficient for stability, and Pearson's correlation for validity. The aspects of validity were defined, and a checklist was used to determine which aspects had been evaluated.

2.7 Quality assessment

The studies' content and methodology were qualitatively analyzed. The methodological quality of each of the selected studies was assessed using the COSMIN checklist [26,27], a quality assessment tool for observational cohort and cross-sectional studies. The COSMIN checklist proposes ten consecutive steps, of which those from 5 to 8 evaluate the quality of the studies by evaluating measurement properties. Eight measurement properties are considered, and their presence and adequacy in the studies is verified (with an assignment of "+" when adequate, "?" when some information is missing, and "-" when inadequate). To define the quality of the studies, a score from 0 to 8 is given to each study.

3. CONCLUSION

Study selection

The research first identified 2160 matches. After the removal of duplicates, there were 1323 unique articles. The remaining studies were re-checked to remove irrelevant studies. A total of 847 studies did not concern QoL in individuals with PD, and 267 were not scale validations. The remaining 209 studies were selected for full text review. A flowchart summarizing the study selection is shown in Figure 1.

3.1 Excluded studies

After reading the full text versions of the articles, we excluded 93 studies: 45 that were not validations, 29 that did not concern QoL, and 19 that did not concern PD.

3.2 Included studies

After the application of the inclusion and exclusion criteria, the review included 116 different studies on the validations of scales that measure QoL in PD. Among these, 42 different assessment tools on the QoL of people with PD that were internationally validated were identified. Table 1 reports all assessment tools measuring QoL in patients with PD.

3.3 Study characteristics

All the studies were cross-sectional, psychometric studies. The sample size in the studies varied from 24[28] to 537[29]. The majority of the participants were in their mid to late 60s, and their mean age ranged from 47.9 years[30,31] to 72 years[32]. The most commonly used tools were the PDQ-39; 8-Item Parkinson's Disease Questionnaire (PDQ-8); SCOPA-PS; Scales for Outcomes in Parkinson's disease – Sleep (SCOPA-Sleep); Parkinson's Disease Sleep Scale-2 (PDSS-2); and Parkinson's Fatigue Scale (PFS).

3.4 PDQ-39

PDQ-39 is a scale that has been validated in multiple languages. It was created in English in 1997 by C. Jenkinson and has been validated in Swedish[33], Portuguese[34,35], Spanish[36], Filipino[37], American English[38], Greek[39], Italian[40], Chinese (Beijing)[41], Chinese

(Taiwan)[42], Korean[43], Estonian[44], Chinese (Singapore)[45], English (Singapore)[46], Chinese (mainland China)[47], English (online)[48], Danish[49], Serbian[50], Spanish (Ecuador) [51], French[52], German[53], and Japanese[54]. PDQ-39 is a specific scale for patients with PD that assesses their QoL in eight domains: mobility, daily activities, emotional well-being, stigma, social support, knowledge, communication, and physical discomfort. QoL is assessed on a 5-point scale for each of the 39 questions as follows: 0 = Never; 1 = Rarely; 2 = Sometimes; 3 = Often; and 4 = Always. The minimum score is 0 (good health), and the maximum score is 100 (bad health); a higher score corresponds to lower QoL. The results obtained in the published validations indicate that the PDQ-39 has discrete internal consistency, with a Cronbach's α value that varied from 0.33 to 0.98. Cronbach's α was less than 0.70 in 13 studies but only for some scale domains. The Intraclass Correlation Coefficient (ICC) values ranged from 0.34 to 0.96. The ICC was less than 0.70 in only five studies, indicating that the scale had good reliability. The validation data are shown in Table 2.

3.5 PDQ-8

The second scale by the number of validations was the PDQ-8, which was validated by Jenkinson in 1996; it has been validated in English[55], Japanese[56], Chinese[57], Turkish[58], Persian[59], Italian[32], English (Singapore) [46], and Greek[60]. The domains analyzed in the scale are the same as those of the PDQ-39 but there is only a single question for each domain in the PDQ-8. A value from 0 to 4 is assigned to each question on the scale, and a total score ranging from 0 (good health) to 100 (bad health) is obtained. The results showed that the scale has good internal consistency, with a Cronbach's α value ranging from 0.56 to 0.94. The alpha value was less than 0.70 only in one domain of the scale of one of the studies analyzed. The ICC values showed greater variability, ranging from 0.24 to 0.983. The ICC value was less than 0.70 in only three studies. The validation data are shown in Table 3.

3.6 SCOPA-PS

The development of SCOPA-PS was part of a larger research project. The SCOPA, which are short, practical, and clinimetrically safe scales, were selected or developed for all relevant domains of PD. The SCOPA-PS consists of 11 elements and focuses on the evaluation of the psychosocial aspects of the life of a patient with PD and has been validated in French[61], Spanish[62], Persian[63], Spanish (Latin-America)[64], Brazilian Portuguese[34], and Danish[65]. The scale has a high internal consistency, with a Cronbach's α value varying from 0.83 to 0.93. The ICC varied from 0.43 to 0.99. The data are shown in Table 4.

3.7 SCOPA-Sleep

The SCOPA-Sleep has two sub-scales: one concerning nighttime sleep and one concerning daytime fatigue. The first consists of five elements that evaluate difficulty falling asleep, fragmentation of sleep, sleep duration, early waking, and the feeling of having slept little. The second includes six elements that evaluate the frequency at which the patient falls asleep in certain situations. The SCOPA-Sleep has been validated in German[66], Korean[67], Swedish[68], Spanish[69], and Danish[70]. Cronbach's alpha ranges from 0.801 to 0.880, indicating good internal consistency. The corresponding data are shown in Table 4.

3.8 PDSS-2

The PDSS-2 is an update of the previous PDSS with modifications to 6 of the 15 questions. It is composed of 15 questions on various sleep and nocturnal disturbances that are evaluated by patients as one of five answers, from 0 (never) to 4 (very frequent). The total PDSS-2 score ranges from 0 (no disturbance) to 60 (maximum night disturbance). The scale has been validated in German[71], Hungarian[29], Spanish[69], Italian[72], and Japanese[73]. The PDSS-2 has both excellent internal consistency (Cronbach's α from 0.730 to 0.863) and good ICC (0.800 to 0.943). The corresponding data are shown in Table 5.

3.9 PFS

PFS was created in English in 2004 by R.G. Brown et al.[74]. The objectives were to develop a valid and reliable measure of fatigue that resulted from the personal experiences of people with PD, that had minimal overlap with other motor and non-motor symptoms of PD, and that was practical for use in the clinic[74]. The scale, which consists of 16 questions, has been validated in Turkish[75], Chinese[76], Greek[77], and Spanish[78]. The Cronbach's α value ranges from 0.930 to 0.974, showing excellent internal consistency, while the ICC varies from 0.50 to 0.93. The corresponding data are shown in Table 6.

3.10 Other scales

The search retrieved 36 other validated tools. The validation data are presented in Table 6.

3.11 Risk of bias

The risk of bias in the included studies was mixed. The methodological quality of each of the selected studies was assessed using the COSMIN checklist[26]. The quality scores from the responsiveness subset of questions of the COSMIN checklist are reported in Table 7. In general, the studies were fairly good quality.

4. EXPERT OPINION

The implications of PD are significant for QoL, since this disease worsens the motor and non-motor function of individuals. The problems include issues with walking, washing, and dressing, loss of dexterity, speech difficulties, fatigue, and social and emotional problems. To improve the patient's QoL, it is necessary to measure their QoL. Therefore, the primary objective of this study was to research and describe the tools most frequently used to evaluate QoL and/or aspects of it, such as sleep quality, in patients with PD using a systematic review. The secondary objective was to evaluate the languages in which these tools have been validated and their methodological quality.

It is evident that the PDQ-39 has the highest number of international validations and that it is available in many languages. The results suggest that this scale is reliable. None of the studies

reported cutoff values for the scale. In future studies, it would be useful to investigate these values to define different ranges of QoL (i.e., poor, moderate, and good).

The second most frequently used scale is the PDQ-8, which is internationally available in eight languages. Like the PDQ-39, it has excellent psychometric qualities, which makes it valid and reliable.

There are also other tools that have been validated to assess QoL in patients with PD. These tools include the Parkinson's Disease Quality of Life questionnaire (PDQL). This is a self-administered questionnaire that has 37 questions, which are divided into four sub-scales: parkinsonian symptoms, systemic symptoms, social functioning, and emotional functioning. An overall score is obtained, and a higher score indicates a better perceived QoL[79].

Another specific tool to assess the QoL in patients with PD is the Parkinson Impact Scale (PIMS), which is a short and practical 10-element tool; however, the scale has only been validated in three languages [80].

The European Quality of Life Questionnaire 5-level version (EQ-5D-5L) is also a scale for QoL, but it is not specific for patients with PD. It includes a five-dimensional questionnaire (EQ-5D-5L) and a visual analog score (EQ-VAS). The EQ-5D-5L assesses mobility, self-care, daily activities, pain and discomfort, and anxiety and depression. Each article was evaluated using a five-point Likert scale as follows: 1 = No problem, 2 = Mild, 3 = Moderate, 4 = Serious, and 5 = Extreme[81].

Another scale on QoL, which emerged from the review, is the WHO QoL[82]. It is not specific for patients with PD composed of six aspects: sensory skills; autonomy; past, present, and future activities; social participation; (thoughts on) death; and intimacy. Neuroquality of life (Neuro-qol), a scale created specifically to assess neurological diseases and validated for PD, emerged among the research results. This scale includes 13 groups of questions (a series of questions covering a single

construct) that address issues common in many neurological diseases and those most relevant to certain diseases. These groups of questions evaluate mental, physical, and social well-being[83].

In addition to the scales that evaluate QoL as a whole, various scales have also emerged that focus on a series of aspects or on a single factor that affects QoL. Previously, the psychometric properties of SCOPA-PS, SCOPA-Sleep, PDSS-2, and PFS, which evaluate the psychosocial component of PD, sleep problems, and the incidence of fatigue in the QoL, respectively, have been analyzed. In addition to these scales, we found scales on the impact of autonomic system dysfunction[84,85] (in particular, systematic research identifying specific scales for dysphagia in patients with PD[86]), on problems related to the risk of falling[79,80] and the phenomenon of freezing[87], on cognitive factors[88] (specifically, on apathy[89] and depression[90] and validated in patients with PD), and on the influence of pain on QoL[91].

There are some limitations to this review that need to be considered. While we systematically searched five electronic databases, it is possible that not all relevant studies were identified. The studies may have been published in journals that were not covered by the databases. In addition, this review only included published studies. Therefore, studies that have been submitted and not accepted for publication or that have only recently been accepted for publication were excluded. Therefore, it is possible that this systematic review is not a complete representation of the evidence available worldwide.

The data presented in the literature up to October 2019 permitted the identification of 42 QoL assessment tools in patients with PD. Many of the tools identified are specific for the evaluation of a single domain of QoL. Internationally, the instruments with the most validations are the PDQ-39 and PDQ-8. The PDQ-39 has been validated in 15 languages and uses 39 questions divided into eight domains to evaluate the QoL in patients with PD, whereas the PDQ-8 uses eight questions, one for each domain. They are both psychometrically valid and reliable scales. This systematic review has highlighted a strong heterogeneity of validated tools among the various national contexts

can be seen, moreover, The many tools available show the tendency for new scales to be created. This heterogeneity can be assumed to have a positive meaning if one thinks about the multiple needs of the clinical context, but certainly leads to the need to make the tools more suitable for various cultural contexts. These findings suggest further investigation of existing outcome measures would benefit patients, researchers, and clinicians. Universal, validated outcome measures are needed to allow comparisons across practice. Therefore, we recommend that future researchers use a common set of outcome assessments based on the results of this review. Building an international consensus in this area will ensure an improvement in the quality of care, rehabilitation and efficiency of health care systems.

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Declaration of interest

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

Reviewers Disclosure

Peer reviewers on this manuscript have no relevant financial relationships or otherwise to disclose.

Availability of data and material

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

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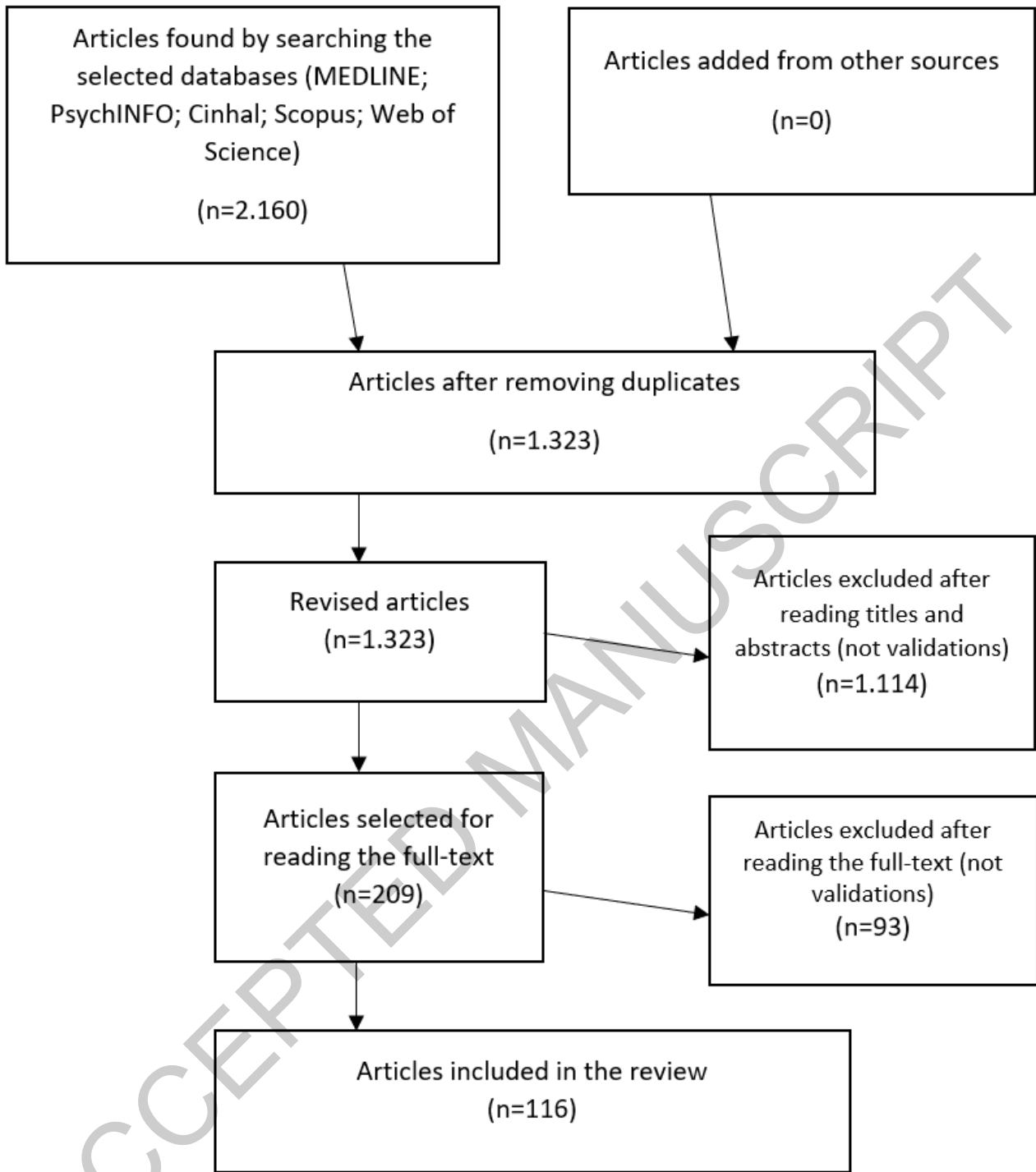


Figure 1 – Flowchart of included studies

Table 1 - Outcome measures for quality of life in Parkinson's Disease

Scale	First Author	Year	Scale	First Author	Year
ABC	Lohnes	2010	NMSS	Martinez	2009
BELA-P-k	Ortelli	2017	PDQ-39	Peto	1995
DAS	Santangelo	2017	PDQ-8	Jenkinson	2006
DextG	Vanbellingen	2016	PDQL	Hobson	1999
D-FIS	Martinez	2005	PDSS	Martinez	2004
DYPAGS	Cremers	2012	PDSS-2	Trenkwalder	2011
EC-PC	Ambrosio	2016	PFS	Fu	2017
EQ-5D	Garcia	2013	PHQ-9	Hortes	2013
FES	Jonasson	2014	PIMS	Calne	1995
FOG-Q	Baggio	2012	PROMIS	Baldini	2017
FSS	Valderramas	2012	PSAS	Zhang	2015
HADS	Marinus	2002	PsychH-Q	Shine	2014
HAMD	Broen	2014	RDP	Defazio	2015
HQL	Damiano	2000	SCOPA-Aut	Blazquez	2009
KPS	Chaudhuri	2015	SCOPA-PS	Marinus	2002
MFI	Elbers	2012	SCOPA-Sleep	Marinus	2003
MoCA-TR	Ozdilek	2014	SDS	Chagas	2009
MQoL-PD	Gofton	2015	SDQ	Yamamoto	2011
Neuro-QoL	Martinez	2004	SEND-PD	Martinez	2012
NHP	Hagell	2003	SWLS	Rosengren	2014
NMS	Li	2014	WHOQOL	Hirayama	2007

Table 2 – 39 item- Parkinson's Disease Questionnaire (PDQ-39) publications and validation data

PDQ-39 validation data										
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity	
Peto	1995	English	227	70.3	57.4/42.6	Self-administred	0.89	-	SF-36	
Jenkinson	1997	English	227	70.30	57.4/42.6	Self-administred	0.84	-	H&Y	
Peto	1998	English	359	71.4	57.4/42.5	Self-administred	0.84	-	SF-36	
Martinez	1998	Spanish	103	65.85	53.4/46.6	Self-administred	0.63/0.94	0.57/0.87	SF-36	
Bushnell	1999	English (USA)	139	69.5	52/48	Self-administred	0.51/0.96	0.86/0.96	SF-36	
Berger	1999	German	105	66	51.4/48.6	Self-administred	0.55/0.96	-	SF-36	
Katsarou	2001	Greek	119	60.45	46.21/53.79	Self-administred	0.71/0.94	-	UPDRS	
Auquier	2002	French	Full text not available							
Tsang	2002	Chinese	54	66.4	57.4/42.6	Interview	0.54/0.90	-	-	
Kohmoto	2003	Japanese	Full text not available							
Hagell	2003	Swedish	71	69.1	62/38	Self-administred	0.73/0.96	-	NHP	
Luo	2005	Chinese	71	63.66	62/38	Self-administred	0.84/0.88	0.56/0.82	EQ-5D	
Ma	2005	Chinese	73	69.02	57.5/42.5	Self-administred	0.58/0.96	0.71/0.95	SF-36	
Martinez	2005	Spanish	137	69.4	67.9/32.1	Self-administred	0.33/0.96	-	UPDRS	
Carod-Artal	2007	Portuguese	144	62	53.5/46.5	Interview	0.61/0.85	0.86	SF-36	
Ülle Krikmann	2008	Estonian	81	66.9	67.9/32.1	Interview	0.81/0.86	> 0.7	H&Y	
Marinus	2008	Danish	177	65.2	56/44	Self-administred	0.59/0.91	0.40/0.75	SCOPA-PS, EQ-5D	
Ziropada	2009	Serbian	102	58.4	53.92/46.08	Self-administred	0.83	-	SF-36	
Nojomi	2010	Persian	200	57.3	67.5/32.5	Self-administred	0.93	0.47/0.90	SF-36	
Luo	2010	Chinese	63	65.0	58.7/41.3	Self-administred	0.64/0.90	0.94	SF-36	
Kwon	2012	Korean	102	65.3	50.98/49.02	Interview	0.58/0.80	-	UPDRS	
Zhang	2012	Chinese	126	63.90	54.8/45.2	Self-administred	0.457/0.887	-	SF-36	
Park	2013	Korean	93	65.13	41.9/58.1	Interview	0.7/0.97	0.69/0.094	H&Y	
Morley	2015	English	118	63.48	55.93/44.07	Self-administred	0.64/0.95	0.34/0.90	-	
Ribeiro	2017	Portuguese	100	65.8	42/58	Self-administred	0.66/0.98	0.49/0.96	SF-36	
Suratos	2018	Filipino	100	60.7	60/40	Self-administred	0.845/0.0.882	-	H&Y	
Galeoto	2018	Italian	104	65.7	62/38	Self-administred	0.69/0.92	0.85/0.96	SF-36	

Table 3 – 8-Item Parkinson's Disease Questionnaire (PDQ-8) publications and validation data.

PDQ-8 validation data – Tab									
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Martinez	2003	Spanish	64	67.09	41.5/58.5	Self-administred	0.842	0.83	EQ-5D
Katsarou	2004	Greek	228	59.3	57.4/42.6	Self-administred	0.72	0.90	SF-36
Tan	2004	English	88	63.1	70.5/29.5	Self-administred	0.56/0.94	0.67/0.87	EQ-5D
Tan	2007	English	104	59.9	73.1/26.9	Self-administred	0.81	0.44/0.67	H&Y, UPDRS
		Chinese	79	62.5	63.3/36.7		0.87	0.57/0.68	
Jenkinson	2007	English	227	70	57/43	Self-administred	0.84	>0.79	PDQ-39
Franchignoni	2008	Italian	200	72	42.5/57.5	Self-administred	0.72	0.24/0.59	H&Y, UPDRS
Huang	2010	Chinese	100	62.04	56/44	Self-administred	0.81	-	PDQ-39
Dal bello-Haas	2010	English	24	64.9	75/25	Self-administred	0.72	0.82	PDQ-39
Fereshtehnejad	2014	Persian	114	61.4	78.1/21.9	Self-administred	0.740	0.983	PDQ-39
Chen	2017	Chinese	283	57	58.7/41.3	Self-administred	0.80	0.96/0.98	PDQ-39, H&Y, UPDRS
Kahraman	2018	Turkish	83	68.3	50.6/49.4	Self-administred	0.78	0.97	SF-36

Table 4 - Scales for Outcomes in Parkinson's disease (SCOPA) publications and validation data.

SCOPA-PS validation data								
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest
Marinus	2002	Danish	177	65.2	56/44	Self-administred	0.83	0.85
Carod-Artal	2006	Portuguese	144	62	53.5/46.5	Interview	0.84	0.71
Virues-Ortega	2008	Spanish	331	64.7	57.7/42.3	Self-administred	0.87	0.43/0.71
Martinez	2009	Spanish	387	65.8	54.3/45.7	-	0.85	-
Soulas	2015	French	154	63.79	56.49/43.51	Self-administred	0.86	0.88
SCOPA-Sleep validation data								
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest
Marinus	2002	Danish	143	65.6	60.5/39.5	Self-administred	0.88	0.94
Martínez	2006	Spanish	68	69.63	61.8/38.2	-	0.83	-
Martinez	2008	Spanish	187	64.1	70.6/29.4	Self-administred	0.84	-0.60
Hagell	2016	Swedish	149	64.9	60/40	Interview	>=0.85	0.08
Sung	2017	Korean	136	66.8	47.79/52.21	Interview	0.88	>=0.70
Goebel	2018	German	85	68.38	55/45	Interview	0.801/0.806	0.81
SCOPA-AUT validation data								
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest
Rodriguez-Blasquez	2009	Spanish	378	65.8	54.3/45.7	Self-administred	0.64\0.95	-
Carod-Artal	2010	Portuguese	150	63.1	56.7/43.3	Self-administred	0.56/0.81	0.15/0.71
Kim	2016	Korean	127	66.6	50.4/49.6	Interview	0.727	-

Table 5 - Parkinson's Disease Sleep Scale (PDSS) publications and validation data.

PDSS-2 validation data								
Author	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Kovacs	Ungarian	537	66.8	58.3/41.7	Self-administred	0.863	-	Spearman's rho

PDSS validation data								
Author	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Martinez	Spanish	100	61.75	51/49	Self-administred	0.77	0.94	Spearman's rho
Martinez	Spanish, Danish	187	64.1	70.6/29.4	Self-administred	0.82	-0.60	Spearman's rho
Martinez	Spanish	399	67.81	56.89/43.11	Self-administred	0.84	0.83	Spearman's rho
Suzuki	Japanese	93	69.7	53.76/46.24	Self-administred	0.86	0.90	Spearman's rho
Arnaldi	Italian	123	70.1	61.78/38.22	Self-administred	0.77	0.943	Spearman's rho
Trenkwalder	German	113	65	58.4/41.6	Self-administred	0.73	0.80	Spearman's rho

Table 6 - Neuroquality of life (Neuro-qol), European Quality of Life Questionnaire 5-level version (EQ-5D-5L), Parkinson's Fatigue Scale (PFS) and Parkinson's Disease Quality of Life questionnaire (PDQL) publications and validation data.

Neuro-QoL validation data									
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	
Martinez	2004	Spanish	633	70.95	57.62/42.38	Self-administred	0.72/0.85	0.48/0.75	
Kozlowski	2015	English	14	-	-	Self-administred	-	-	
Nowinski	2016	English	120	66	62/38	Interview	0.81/0.94	0.66/0.80	
Karsidag	2019	Turkish	152	47.9	35/65	Self-administred	0.95	0.33/0.82	
EQ-5D-5L validation data									
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	
Garcia-Gordillo	2013	Spanish	133	64.33	71.4/38.6	Self-administred	-	0.67/0.87	
Alvarado-Bolanos	2015	Spanish	585	62.9	54.4/45.6	Self-administred	0.828	-	
Garcia-Gordillo	2015	Spanish	133	64.33	71.4/38.6	Self-administred	-	0.85	
PFS validation data									
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	
Fu	2017	Chinese	115	62.83	56.52/43.48	Self-administred	0.94	>0.70	
Ozturk	2018	Turkish	144	62.9	59.72/40.28	Interview	0.974	0.887	
Dagldis	2018	Greek	99	62.75	72.7/27.3	Self-administred	0.96	0.93	
Ozturk	2018	Turkish	138	62.8	60.9/39.1	Interview	0.954/0.941	0.650/0.875	
Martinez	2019	Spanish	59	68.02	60.7/39.3	Self-administred	0.93	0.50/0.84	
PDQL validation data									
Author	Year	Language	Sample	Mean age	Gender (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Hobson	1999	English	136	72.4	53/47	Self-administred	0.95	-	NHP, SF-36
Duenas	2004	Spanish	137	69.43	67.8/32.2	Self-administred	0.92	-	PDQ-39
Campos	2011	Portuguese	53	64.83	69.2/30.8	Interview	0.93	-	UPDRS
Dereli	2015	Turkish	89	64.83	56.2/43.8	Self-administred	0.97	0.81/0.96	UPDRS, H&Y

Table 7 – Quality assessment through the COSMIN checklist of included studies

Quality Assessment – ABC												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
ABC	Lohnes	2010	X	X	-	-	X	-	-	-	-	-
ABC, PDQ-8	Haas	2010	X	X	X	X	X	-	-	X	-	-
FES, ABC	Jonasson	2014	X	X	X	X	X	-	X	-	X	-
Quality Assessment – D-FIS												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
D-FIS	Martinez	2005	X	X	X	-	X	X	X	-	X	-
D-FIS	Duenas	2018	X	X	X	-	X	-	-	-	-	-
Quality Assessment – EQ-5D												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
EQ-5D	Garcia	2013	-	X	-	X	X	-	X	-	X	-
EQ-5D	Alvarado	2015	X	-	-	X	X	X	X	-	-	-
EQ-5D	Garcia	2015	-	X	-	X	X	-	-	-	X	-
Quality Assessment – FES												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
FES, ABC	Jonasson	2014	X	X	X	X	X	-	X	-	X	-
FES	Jonasson	2017	X	X	X	-	X	-	-	-	-	-
Quality Assessment – MoCA-TR												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
MoCA-TR	Krishnan	2015	X	X	-	-	X	-	X	-	-	-
MoCA-TR	Ozdilek	2014	X	X	-	-	X	-	-	X	X	-
Quality Assessment – Neuro QoL												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural	Criterion Validity	Responsiveness	Interpretability

										Validation			
Neuro-QoL	Kozlowski	2015	-	-	X	-	-	-	-	-	-	X	-
Neuro-QoL	Nowinski	2016	X	X	X	-	X	-	-	-	-	X	-
Neuro-QoL	Karşıdağ	2019	X	X	-	X	X	-	-	-	-	-	-
Quality Assessment – NMS/NMSS													
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability	
NMS	Li	2014	X	X	-	X	-	-	-	-	X	X	
NMS	Li	2015	X	X	X	X	X	X	-	-	-	-	
NMSS	Martinez	2009	X	X	X	-	X	X	X	-	X	X	
NMSS	Cova	2016	X	X	X	X	X	-	X	-	-	-	
Quality Assessment – PDQ													
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability	
PDQ-39	Peto	1995	X	X	-	X	X	-	-	-	-	-	
PDQ-39	Jenkinson	1997	X	X	-	X	X	-	-	-	-	-	
PDQ-39	Peto	1998	X	X	-	X	X	X	v	-	X	-	
PDQ-39	Martinez	1998	X	X	-	X	X	-	X	-	-	-	
PDQ-39	Berger	1999	Full-text not available in english										
PDQ-39	Bushnell	1999	X	X	-	X	X	-	X	-	-	-	
PDQ-39	Katsarou	2001	X	X	-	-	X	-	X	X	-	-	
PDQ-39	Tsang	2002	X	X	-	X	X	-	X	-	-	-	
PDQ-39, NHP	Hagell	2003	X	X	X	-	X	-	-	-	X	X	
PDQ-39	Ma	2004	X	X	-	X	X	-	X	-	-	-	
PDQ-39	Luo	2004	X	X	-	X	X	X	X	-	-	-	
PDQ-39	Martinez	2005	X	X	X	X	X	-	X	-	X	-	
PDQ-39	Marinus	2007	X	-	-	X	X	-	-	-	-	-	
PDQ-39	Krikmann	2008	X	X	-	X	X	-	-	-	-	-	
PDQ-39	Ziropada	2009	X	X	-	X	X	X	-	-	-	-	
PDQ-39	Luo	2010	X	X	-	X	X	-	X	-	-	-	

PDQ-39	Nojomi	2010	X	X	-	X	X	X	X	-	-	-
PDQ-39	Zhang	2011	X	X	-	X	X	-	X	-	-	-
PDQ-39	Kwon	2012	X	X	-	X	X	-	X	-	-	-
PDQ-39, NMSS	Carod-Artal	2012	X	X	X	-	X	X	X	-	-	-
PDQ-39	Park	2013	X	X	-	X	X	-	X	X	-	-
PDQ-39	Morley	2015	X	X	-	X	X	-	-	-	-	-
PDQ-39	Ribeiro	2017	X	X	-	X	X	-	X	X	-	-
PDQ-39	Suratos	2018	X	X	-	-	X	X	X	-	-	-
PDQ-39	Galeoto	2018	X	X	-	X	X	-	X	-	-	-

Quality Assessment – PDQ-8

Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
PDQ-8, Neuro-QoL	Martinez	2004	X	X	-	X	X	-	-	-	-	-
PDQ-8	Kim	2004	X	X	-	X	X	X	X	-	-	-
PDQ-8	Jenkinson	2006	X	X	-	X	X	-	X	-	-	-
PDQ-8	Jenkinson	2007	X	X	-	X	X	-	-	X	-	-
PDQ-8	Tan	2007	X	X	X	-	X	X	X	-	-	-
PDQ-8	Franchignoni	2008	X	X	X	X	X	-	-	-	-	-
PDQ-8	Huang	2010	X	X	X	X	X	-	-	X	-	-
PDQ-8	Fereshtehnejad	2014	X	X	-	X	X	X	X	X	-	-
PDQ-8	Chen	2017	X	X	-	X	X	X	X	X	-	-
PDQ-8	Kahraman	2018	X	X	-	X	X	X	X	-	-	-

Quality Assessment – PDQL

Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
PDQL	Hobson	1999	X	-	-	X	-	X	X	-	-	-
PDQL	Duenas	2004	X	-	X	X	X	X	X	-	X	-
PDQL	Campos	2011	X	X	-	X	X	X	X	-	-	-
PDQL	Dereli	2015	X	X	-	X	X	-	X	-	-	-

Quality Assessment – PDSS/PDSS-2

Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
PDSS	Martinez	2004	X	X	X	-	X	-	-	-	-	-
PDSS-2	Trenkwalder	2011	X	X	X	X	X	-	X	-	-	-
PDSS-2	Suzuki	2012	X	X	-	X	X	-	X	-	-	-
PDSS-2	Arnaldi	2015	X	X	X	-	X	-	X	-	-	-
PDSS-2	Kovacs	2016	X	X	-	X	X	X	X	-	X	-
PDSS-2	Martinez	2019	X	X	X	X	X	-	X	-	-	-
Quality Assessment – PFS												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
PFS	Fu	2017	X	X	-	X	X	-	X	-	-	-
PFS	Ozturk	2018	X	X	X	X	X	X	X	-	-	-
PFS	Daglkis	2018	X	X	-	X	X	-	X	-	-	-
PFS	Ozturk	2018	X	X	-	X	X	-	X	-	-	-
PFS	Martinez	2019	X	X	X	X	X	-	-	-	X	-
Quality Assessment – PIMS												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
PIMS	Calne	1995	X	X	-	X	X	-	-	-	-	-
PIMS	Schulzer	2002	X	X	-	-	X	-	-	-	X	-
PIMS	Duenas	2007	X	X	-	-	X	-	X	-	-	-
Quality Assessment – SCOPA-Aut,PS,Sleep												
Scale	Author	Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
SCOPA-Aut	Blazquez	2009	X	X	X	-	X	-	X	-	-	-
SCOPA-Aut	Carod-Artal	2010	X	X	X	X	X	X	X	-	-	-
SCOPA-Aut	Kim	2016	X	X	-	-	X	-	X	-	-	-
SCOPA-PS	Marinus	2002	X	X	-	X	X	-	-	-	-	-
SCOPA-PS	Carod-Artal	2006	X	X	X	X	X	X	-	-	-	-
SCOPA-PS	Ortega	2008	X	-	X	X	X	X	X	-	-	-
SCOPA-PS	Martínez	2009	X	-	X	X	X	-	-	-	-	-

