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Psychometric properties of the Parkinson's disease Questionnaire–39 and its short form Parkinson's disease Questionnaire–8: A systematic review and *meta*-analysis

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ABSTRACT

Parkinson's disease (PD) affects Quality of Life (QoL), since it is responsible for cognitive impairment, non-motor, and motor symptoms. Outcome measures are fundamental for evaluating treatment's effect on QoL over time.

This systematic review aimed to identify the psychometric properties of PDQ-39 and PDQ-8 in the different populations in which they were validated.

The electronic databases systematically searched are MEDLINE (via PubMed), CINAHL, SCOPUS, and Web of Science; the research was conducted in July 2023. The psychometric properties considered were those of the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist. Risk of bias was assessed using the COSMIN checklist.

The search identified 1306 articles. 398 duplicates were eliminated; 908 articles were analyzed reading title and abstract; 799 were finally excluded because used PDQ-39 and PDQ-8 as outcome measures or were not dealing with psychometric properties; 66 articles were excluded after reading the full text. 43 articles were included in the review; *meta*-analysis showed all the Cronbach's alpha values were statistically significant for all the subscales of PDQ-39 and PDQ-8. PDQ-39 demonstrated to be a specific HRQoL questionnaire that is correlated with generic HRQoL questionnaires, in fact in many studies included in the review, correlations with SF-36 were found. In the last studies about psychometric properties of PDQ-8 emerged that it is a practical and informative instrument that can be easily used in clinical settings, especially in busy ones, but also in large-scale studies in which a brief instrument would be preferred.

1. Background

Parkinson's disease (PD) is one of the most common neurodegenerative diseases with a prevalence of more than 6 million individuals. The most significant risk factor for developing Parkinson's disease is age; furthermore men are more susceptible than women (prevalence ratio of 3:2) [1].

Parkinson's disease has been found to significantly affect Quality of Life (QoL), since it is responsible for cognitive impairment, non-motor, and motor symptoms [2]. Motor symptoms, include bradykinesia, rest tremor, muscle rigidity and gait disorders; non-motor symptoms include cognitive impairment, sleep disorders and constipation. These are found early in the disease course and can significantly contribute to patient disability and consequently impact their QoL [3]. The World Health Organization (WHO) defined 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." [4]. It is important to assess QoL in People with Parkinson

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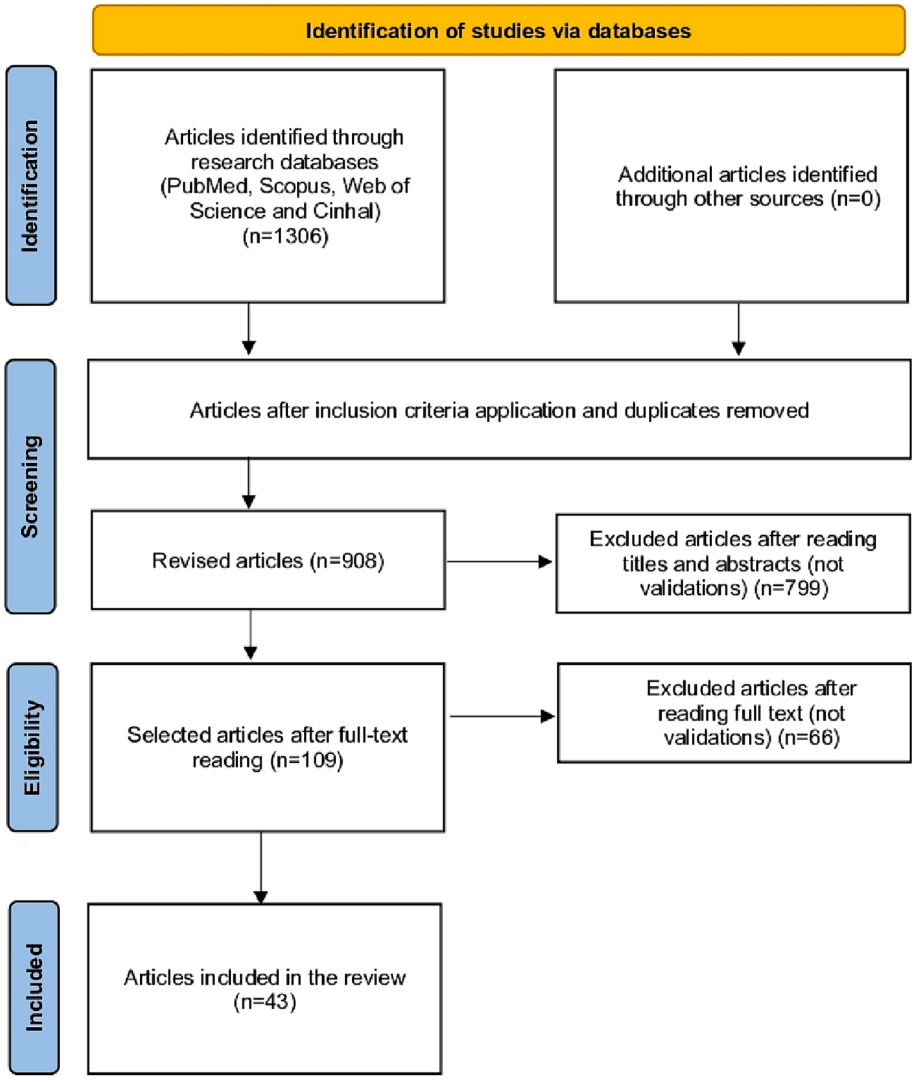


Fig. 1. Flowchart of search and screening process.

(PwP) to provide them appropriate therapies and management of the disease; furthermore, it is important for researchers, booth for rehabilitation professionals and medical doctors, to use validated outcome measures to assess QoL during clinical trials, to provide a higher level of evidence with comparable outcomes. The outcome measures are fundamental also for evaluating a treatment's effect over time [5].

They represent an important mean of communication between different health professionals. Furthermore, a measurement tool must possess a series of requirements called psychometric properties, to provide reliable data in the clinical and research settings; these properties are reliability and validity [6].

Reliability is defined as "the degree to which the measurement is free from measurement error" and depends on the instrument under investigation, the evaluators, and the patients under study. There are different types of reliability: test–retest reliability, when measurements are repeated over time; inter-rater reliability, when tests are conducted by different operators but on the same occasion; intra-rater reliability, when assessments are conducted by the same rater but on different occasions, and internal consistency, represents the level to which items belonging to an assessment tool assess the same construct [7,8]. Validity can be defined "the degree to which an instrument truly measures the construct it purports to measure". In the development of an assessment tool, an adequate definition of the construct is necessary. The construct must be part of the conceptual model within a theoretical and clinical framework. The different types of validity are content validity, criterion validity and construct validity [9,10]. In PD the most commonly used tool to assess QoL is Parkinson's Disease Questionnaire-39 (PDQ-39) and its short form Parkinson's Disease Questionnaire-8 (PDQ-8) [11]. PDQ-39 was created in 1995 by V. Peto et al. while PDQ-8 was validated by Jenkinson et al. in 2007 [12,13].

PDQ-39 assesses QoL of PwP in eight domains, that are the following: mobility, daily activities, emotional well-being, stigma, social support, knowledge, communication, and physical discomfort. It is 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 that means good health, while the maximum score is 100 that is bad health; a higher score indicates a lower QoL. As regards PDQ-8, the domains analyzed are the same as in the PDQ-39 but through a single question for each domain; a value from 0 to 4 is assigned to each question and a total score ranging from 0 (good health) to 100 (bad health) is obtained [14].

Systematic reviews of evaluation tools have become common in the last years to guide researchers and clinicians in the usage of validated tools for evaluating outcomes that are internationally comparable. These kinds of studies allow doctors to keep up to date [15,16], and are often used as a starting point for developing guidelines about clinical practice [17,18]. Investigation and knowledge concerning psychometric properties of these two tools is crucial for several reasons: PD is a condition that counts an increasing number of affected subjects among

Table 1
PDQ-39 validation data.

PDQ-39 validation data								
Author and Year	Language	Sample	Mean age	Sex (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Peto et al. 1995 [13]	English (UK)	227	70.3	57.4/42.6	Self-administred	0.89	–	SF-36
Jenkinson et al. 1997 [44]	English (UK)	227	70.30	57.4/42.6	Self-administred	0.84	–	H&Y
Peto et al. 1998 [37]	English (UK)	359	71.4	57.4/42.5	Self-administred	0.84	–	SF-36
Martinez et al. 1998 [45]	Spanish	103	65.85	53.4/46.6	Self-administred	0.63/0.94	0.57/0.87	SF-36
Bushnell et al. 1999 [46]	English (USA)	139	69.5	52/48	Self-administred	0.51/0.96	0.86/0.96	SF-36
Berger et al. 1999 [47]	German	105	66	51.4/48.6	Self-administred	0.55/0.96	–	SF-36
Katsarou et al. 2001 [48]	Greek	119	60.45	46.21/53.79	Self-administred	0.71/0.94	–	UPDRS
Auquier et al. 2002 [49]	French	Full text not available						
Tsang et al. 2002 [36]	Chinese	54	66.4	57.4/42.6	Interview	0.54/0.90	–	–
Kohmoto et al. 2003 [50]	Japanese	Full text not available						
Hagell et al. 2003 [51]	Swedish	71	69.1	62/38	Self-administred	0.73/0.96	–	NHP
Luo et al. 2005 [52]	Chinese	71	63.66	62/38	Self-administred	0.84/0.88	0.56/0.82	EQ-5D
Ma et al. 2005 [53]	Chinese	73	69.02	57.5/42.5	Self-administred	0.58/0.96	0.71/0.95	SF-36
Martinez et al. 2005 [54]	Spanish	137	69.4	67.9/32.1	Self-administred	0.33/0.96	–	UPDRS
Carod-Artal et al. 2007 [55]	Portuguese	144	62	53.5/46.5	Interview	0.61/0.85	0.86	SF-36
Ülle Krikmann et al. 2008 [56]	Estonian	81	66.9	67.9/32.1	Interview	0.81/0.86	> 0.7	H&Y
Marinus et al. 2008 [57]	Danish	177	65.2	56/44	Self-administred	0.59/0.91	0.40/0.75	SCOPA-PS, EQ-5D
Ziropada et al. 2009	Serbian	102	58.4	53.92/46.08	Self-administred	0.83	–	SF-36
Nojomi et al. 2010 [38]	Persian	200	57.3	67.5/32.5	Self-administred	0.93	0.47/0.90	SF-36
Luo et al. 2010 [58]	Chinese	63	65.0	58.7/41.3	Self-administred	0.64/0.90	0.94	SF-36
Kwon et al. 2012 [59]	Korean	102	65.3	50.98/49.02	Interview	0.58/0.80	–	UPDRS
Zhang et al. 2012 [60]	Chinese	126	63.90	54.8/45.2	Self-administred	0.457/0.887	–	SF-36
Park et al. 2013	Korean	93	65.13	41.9/58.1	Interview	0.7/0.97	0.69/0.094	H&Y
Morley et al. 2015 [61]	English (UK)	118	63.48	55.93/44.07	Self-administred	0.64/0.95	0.34/0.90	–
Ribeiro et al. 2017	Portuguese	100	65.8	42/58	Self-administred	0.66/0.98	0.49/0.96	SF-36
Suratos et al. 2018 [62]	Filipino	100	60.7	60/40	Self-administred	0.845/0.0.882	–	H&Y
Galeoto et al. 2018 [63]	Italian	104	65.7	62/38	Self-administred	0.69/0.92	0.85/0.96	SF-36
Scho¨nenberg et al. 2022 [64]	German	221	70.81	59.7/40.3	Self-administered	0.63/0.927	–	BDI-II
Scho¨nenberg et al. 2023 [39]	German	977	–	–	–	–	–	–
Bilge Kayapinar et al. 2023 [65]	Turkish	100	Full text not available					UPDRS, SF-36

M = Male; F = Female; PDQ-39 = Parkinson Disease Questionnaire 39; SF-36 = 36-item short form health survey; H&Y = Hoehn & Yahr; UPDRS = Unified Parkinson's Disease Rating Scale; NHP = Nottingham Health Profile; EQ-5D = EuroQol; SCOPA-PS = Scales for Outcomes in Parkinson's Disease- Psychosocial; BDI-II = Beck Depression Inventory-II.

Table 2
PDQ-8 validation data.

PDQ-8 validation data								
Author and Year	Language	Sample	Mean age	Sex (M/F)	Administration	Cronbach's Alpha	Test-retest	Construct validity
Martinez et al. 2004 [66]	Spanish	64	67.09	41.5/58.5	Self-administred	0.842	0.83	EQ-5D
Katsarou et al. 2004 [67]	Greek	228	59.3	57.4/42.6	Self-administred	0.72	0.90	SF-36
Tan et al. 2004 [68]	English speaking patients in Singapore	88	63.1	70.5/29.5	Self-administred	0.56/0.94	0.67/0.87	EQ-5D
Tan et al. 2007 [69]	English (USA)	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 et al. 2007 [43]	English (UK)	227	70	57/43	Self-administred	0.84	>0.79	PDQ-39
Franchignoni et al. 2008 [70]	Italian	200	72	42.5/57.5	Self-administred	0.72	0.24/0.59	H&Y, UPDRS
Huang et al. 2010 [71]	Chinese	100	62.04	56/44	Self-administred	0.81	–	PDQ-39
Dal bello-Haas et al. 2010 [40]	English (Canada)	24	64.9	75/25	Self-administred	0.72	0.82	PDQ-39
Fereshtehnejad et al. 2014 [72]	Persian	114	61.4	78.1/21.9	Self-administred	0.740	0.983	PDQ-39
Chen et al. 2017 [42]	Chinese	283	57	58.7/41.3	Self-administred	0.80	0.96/0.98	PDQ-39, H&Y, UPDRS
Kahraman et al. 2018 [73]	Turkish	83	68.3	50.6/49.4	Self-administred	0.78	0.97	SF-36
Ramadhan et al. 2022 [41]	English (UK)	558	76 (median)	54.11/45/89	self-administered	–	–	EQ-5D-3 L, EQ-VAS, UPDRS part 1–4, MMSE

M = Male; F = Female; PDQ-8 = Parkinson Disease Questionnaire 8; EQ-5D = EuroQol; SF-36 = 36-item short form health survey; H&Y = Hoehn & Yahr; UPDRS = Unified Parkinson's Disease Rating Scale; PDQ-39 = Parkinson Disease Questionnaire 39; MMSE = Mini Mental State Examination.

Table 3
Quality Assessment - PDQ-39.

Author and Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
Peto et al. 1995 [13]	X	X	–	X	X	–	–	–	–	–
Jenkinson et al. 1997 [44]	X	X	–	X	X	–	–	–	–	–
Peto et al. 1998 [37]	X	X	–	X	X	X	X	X	–	X
Martinez et al. 1998 [75]	X	X	–	X	X	–	X	–	–	–
Berger et al. 1999 [47]	Full-text not available in english									
Bushnell et al. 1999 [46]	X	X	–	X	X	–	X	–	–	–
Katsarou et al. 2001 [48]	X	X	–	–	X	–	X	X	–	–
Tsang et al. 2002 [36]	X	X	–	x	x	–	x	–	–	–
Hagell et al. 2003 [51]	X	X	X	–	X	–	–	–	X	X
Ma et al. 2004 [53]	X	X	–	X	X	–	X	–	–	–
Luo et al. 2004 [52]	X	X	–	X	X	X	X	–	–	–
Martinez et al. 2005 [54]	X	X	X	X	X	–	X	–	X	–
Marinus et al. 2007 [57]	X	–	–	X	X	–	–	–	–	–
Krikmann et al. 2008 [56]	X	X	–	X	X	–	–	–	–	–
Ziropada et al. 2009 [76]	X	X	–	X	X	X	–	–	–	–
Luo et al. 2010 [58]	X	X	–	X	X	–	X	–	–	–
Nojomi et al. 2010 [38]	X	X	–	X	X	X	X	–	–	–
Zhang et al. 2011 [60]	X	X	–	X	X	–	X	–	–	–
Kwon et al. 2012 [59]	X	X	–	X	X	–	X	–	–	–
Carod-Artal et al. 2012 [55]	X	X	X	–	X	X	X	–	–	–
Park et al. 2013 [77]	X	X	–	X	X	–	X	X	–	–
Morley et al. 2015 [61]	X	X	–	X	X	–	–	–	–	–
Ribeiro et al. 2017 [78]	X	X	–	X	X	–	X	X	–	–
Suratos et al. 2018 [62]	X	X	–	–	X	X	X	–	–	–
Galeoto et al. 2018 [63]	X	X	–	X	X	–	X	–	–	–
Schonenberg et al. 2022 [64]	X	X	–	–	X	–	X	–	X	–
Schonenberg et al. 2023 [39]	–	–	–	–	X	–	–	–	–	–
Bilge Kayapinar et al. 2023 [79]	Full-text not available									

world population; consequently, a huge number of clinicians and researchers deal with PwP every day, and to better setup a correct and tailored therapy (pharmacologic, rehabilitation or psychological) they need to know, in addition to the visible symptoms, the perception of patients about their QoL and participation [19]. To investigate this important aspect, it is necessary to be informed about validity and reliability of the instruments used, because these psychometric properties could change among different countries, depending on the different cultures and lifestyles of people, but also on other variables, for example age, sex, disease severity or disease duration [20].

Given this situation, this systematic review aimed to identify the psychometric properties of the PDQ-39 and the PDQ-8 in the different populations in which they were validated, because of the wide use of these two tools worldwide.

2. Methods

This systematic review was conducted by a research group of Sapienza University of Rome (RES - Riabilitazione Evidenze e Sviluppo) who were involved in different studies on rehabilitation [21–2324–30].

Table 4
Quality Assessment - PDQ-8.

Author and Year	Internal consistency	Reliability	Measurement error	Content validity	Structure Validity	Hypothesis Testing	Cross-cultural Validation	Criterion Validity	Responsiveness	Interpretability
Martinez et al. 2004	X	X	–	X	X	–	–	–	–	–
Kim et al. 2004	X	X	–	X	X	X	X	–	–	–
Jenkinson et al. 2006	X	X	–	X	X	–	X	–	–	–
Jenkinson et al. 2007	X	X	–	X	X	–	–	X	–	–
Tan et al. 2007	X	X	X	–	X	X	X	–	–	–
Franchignoni et al. 2008	X	X	X	X	X	–	–	–	–	–
Huang et al. 2010	X	X	X	X	X	–	–	X	–	–
Fereshtehnejad et al. 2014	X	X	–	X	X	X	X	X	–	–
Chen et al. 2017	X	X	–	X	X	X	X	X	–	–
Kahraman et al. 2018	X	X	–	X	X	X	X	–	–	–
Ramadhan et al. 2022	–	–	–	–	X	–	–	X	–	X

The systematic review followed the 27-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist and COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) methodology for systematic reviews of Patient-Reported Outcome Measures (PROMs) [8,18,31,32].

2.1. Information sources

The authors of this systematic review searched for studies evaluating PDQ-39 psychometric properties. The electronic databases that were systematically searched are: MEDLINE (via PubMed), CINAHL, SCOPUS, and Web of Science; the research was conducted in July 2023. The Medical Subject Headings (MeSH) of the United States National Library of Medicine were used to find the terms included in the search strategy. The MeSH term used in this case were “Parkinson’s Disease Questionnaire 39” and “Parkinson’s Disease Questionnaire 8”.

The reviewers chose to conduct the research in the mentioned databases to include only journals that follow the peer review process; in this way it is possible to keep the methodological quality of the study high.

2.2. Eligibility criteria

No restrictions were applied regarding publication dates, the country where the study was conducted, or the age of patients; however, only validation studies, psychometric studies and cross- sectional studies were included. The psychometric properties considered were those of the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) study design checklist.

Inclusion criteria comprised: (1) studies evaluating the psychometric properties of the JTHFT, according to the COSMIN study design checklist measurement properties; (2) validation studies and cross-sectional studies. Studies using PDQ-39 as an assessment tool were excluded.

2.3. Study selection

The literature search was carried out by two physiotherapists (IR, GS), in compliance with the inclusion and exclusion criteria. The two therapists then made an initial selection based on titles and abstracts. Articles not excluded were then subjected to further selection based on a reading of the full text. A list of eligible studies was compiled, and disagreements were resolved in a consensus meeting. Finally, the two therapists carried out reference checking and citation tracking to identify other studies for inclusion in the review.

2.4. Data collection

Descriptive characteristics were extracted from the included articles: authors, year of publication, language, characteristics of the sample, administration modality, comparison scales.

2.5. Risk of bias

Risk of bias was assessed using the COSMIN checklist [33]. The COSMIN Risk of Bias tool includes two parts: (1) Part A assesses how the study results disclose the reliability or measurement error of the instrument under study. (2) Part B assesses if we can trust the result obtained in the study by assessing the risk of bias.

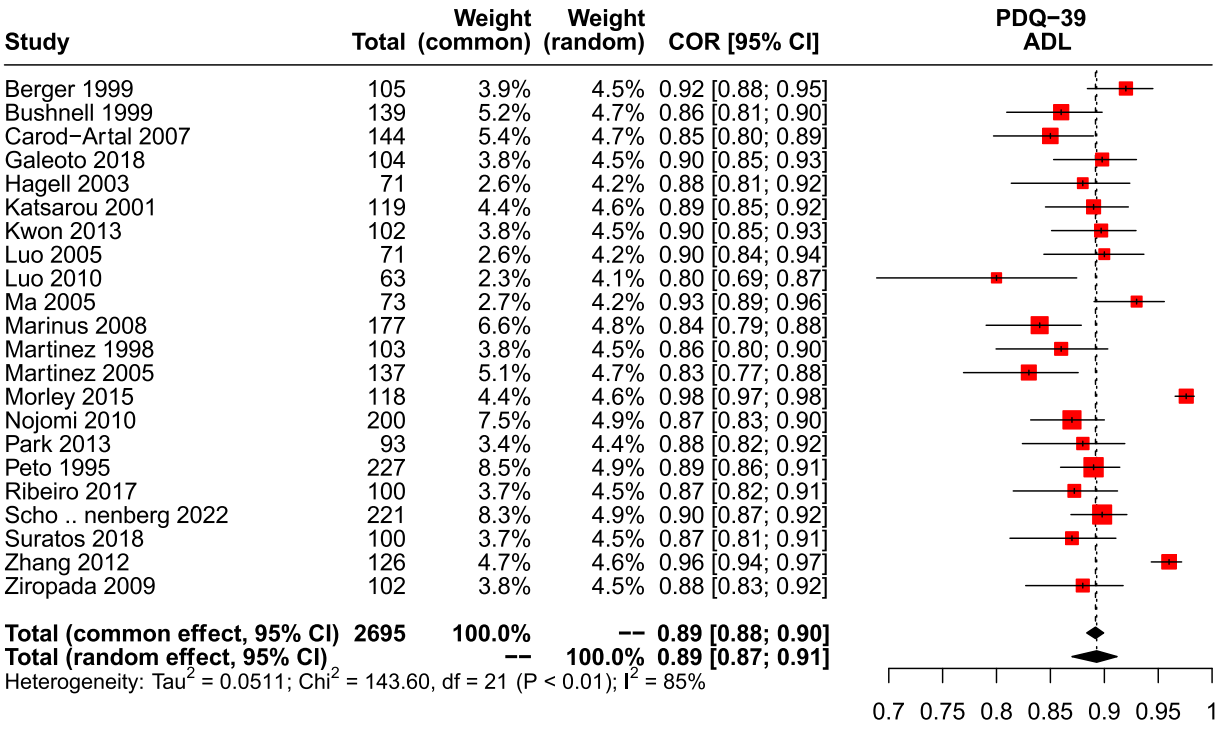
The COSMIN study design checklist consists of 10 boxes. The first box regards general recommendations to design a study about psychometric properties, it is relevant to all studies.

The other boxes include standards for specific studies on each of the nine measurement properties, in particular: Content validity, that is defined as the degree to which the content of a health-related patient-reported outcome tool (HR-PRO) adequately reflects the construct to be measured; Structural validity, that is the degree to which the scores of an HR-PRO instrument are an adequate reflection of the construct to be measured; Internal consistency that concerns the interrelation between elements; Cross-cultural validity/measurement invariance that indicates the degree to which the performance of the elements on a translated or culturally adapted HR-PRO is an adequate reflection of the performance of elements of the original version of the assessment tool; Reliability that indicates stability over repeated measurements; Measurement error that consists in systematic and random error in a patient’s score that is not attributed to actual changes in the phenomena under study; Criterion validity that is the degree to which the score of an instrument adequately reflects a “gold standard”; Hypothesis testing for construct validity that is the degree to which the scores of a tool are consistent with the study hypotheses; Responsiveness that is considered as the ability of an HR-PRO instrument to detect change over time [34].

2.6. Data analyses

A descriptive statistic was used to describe the characteristics of the included studies.

A *meta*-analysis was carried out for studies that investigated internal consistency through Cronbach’s alpha. The analysis was performed with



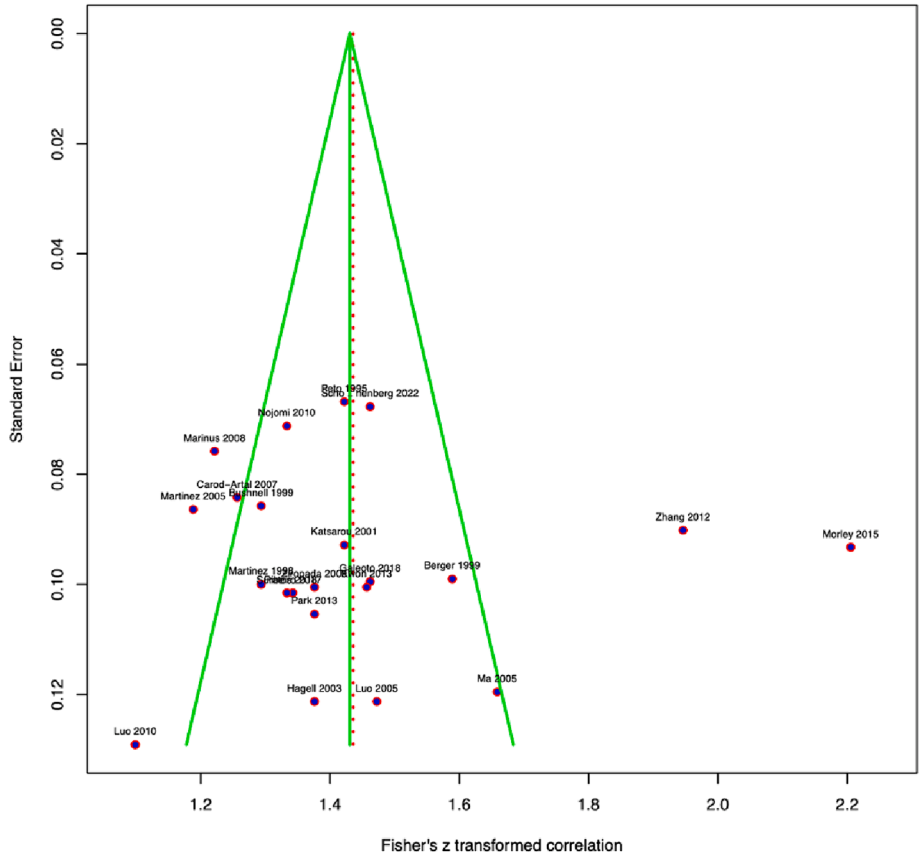
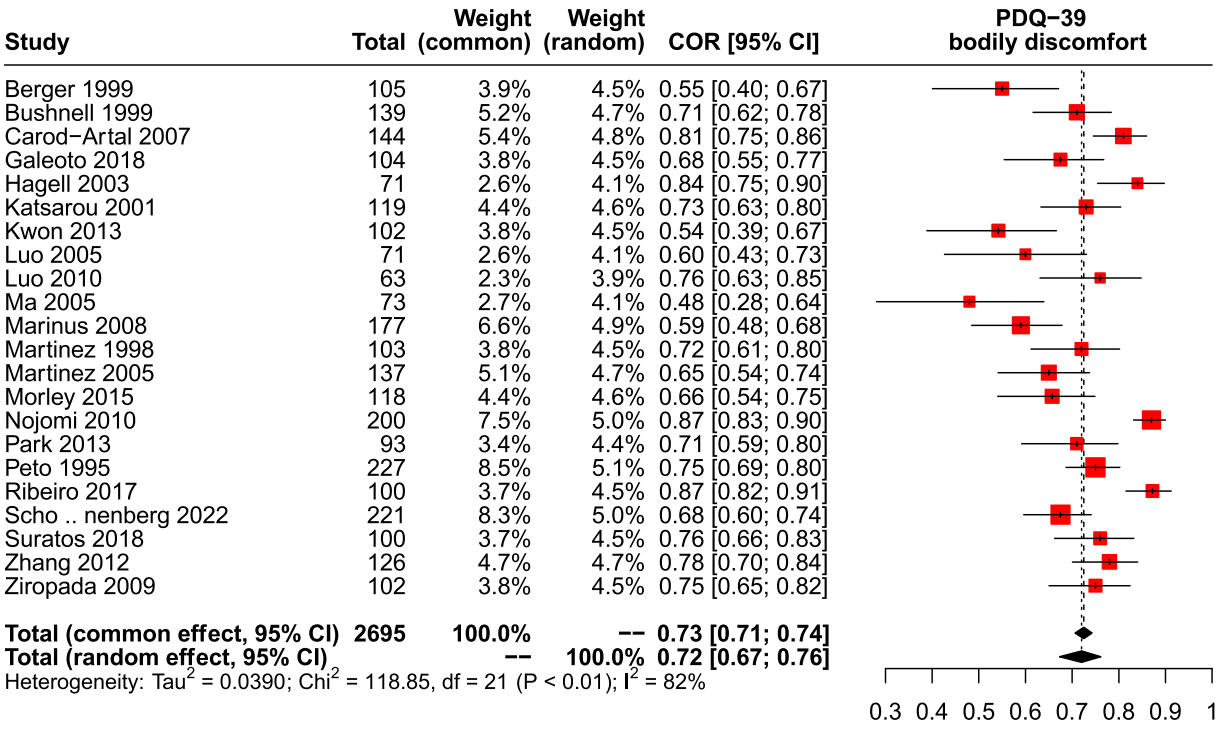


Fig. 2. A. forest plot for internal consistency of adl domain of pdq-39. b. funnel plot for internal consistency of adl domain of pdq-39.

R, using the package "meta"; the function "metacont" was used for the analysis of continuous data. The results were combined using the fixed and random effect models (DerSimonian-Laird method). Heterogeneity between studies was assessed with the I2 statistic, which is a proxy of the proportion of variance due to heterogeneity rather than chance and is not sensitive to the number of studies involved. I2 values ranged from 0% to 100% and were interpreted as low-moderate if less than 50%.

Results are shown through forest plot; the publication bias was investigated through funnel plot graphs.



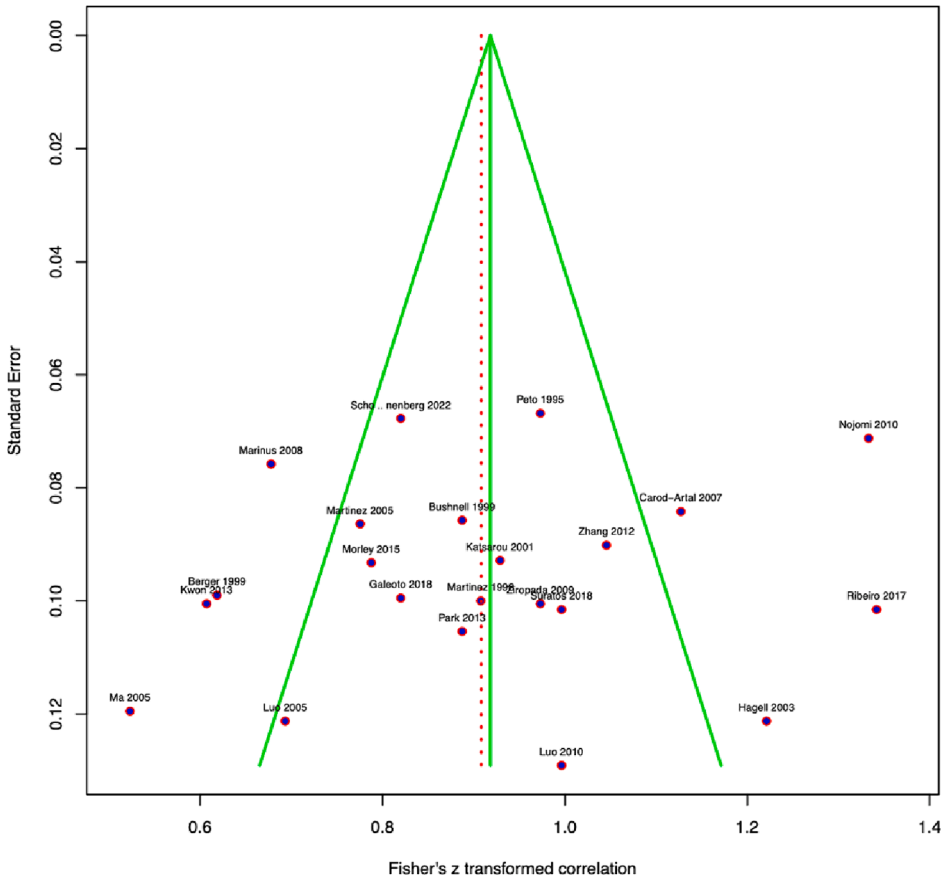
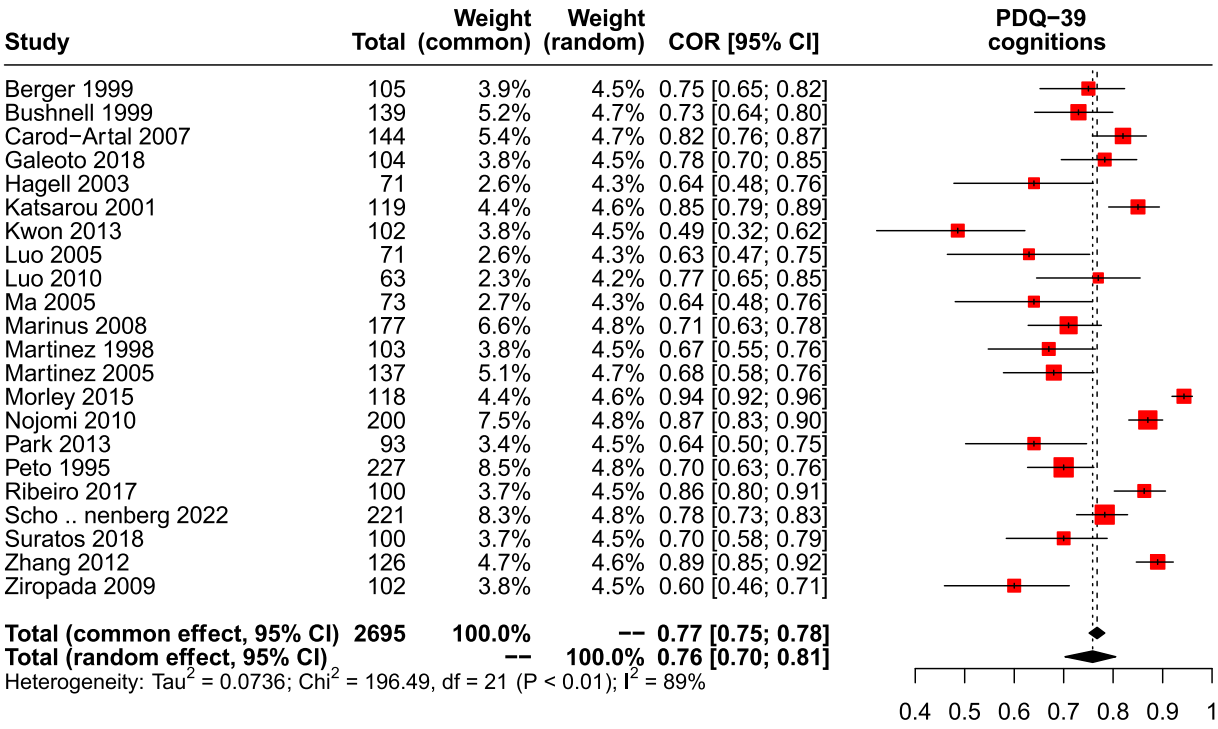


Fig. 3. A. forest plot for internal consistency of "bodily discomfort" domain of pdq-39. b. funnel plot for internal consistency of "bodily discomfort" domain of pdq-39.



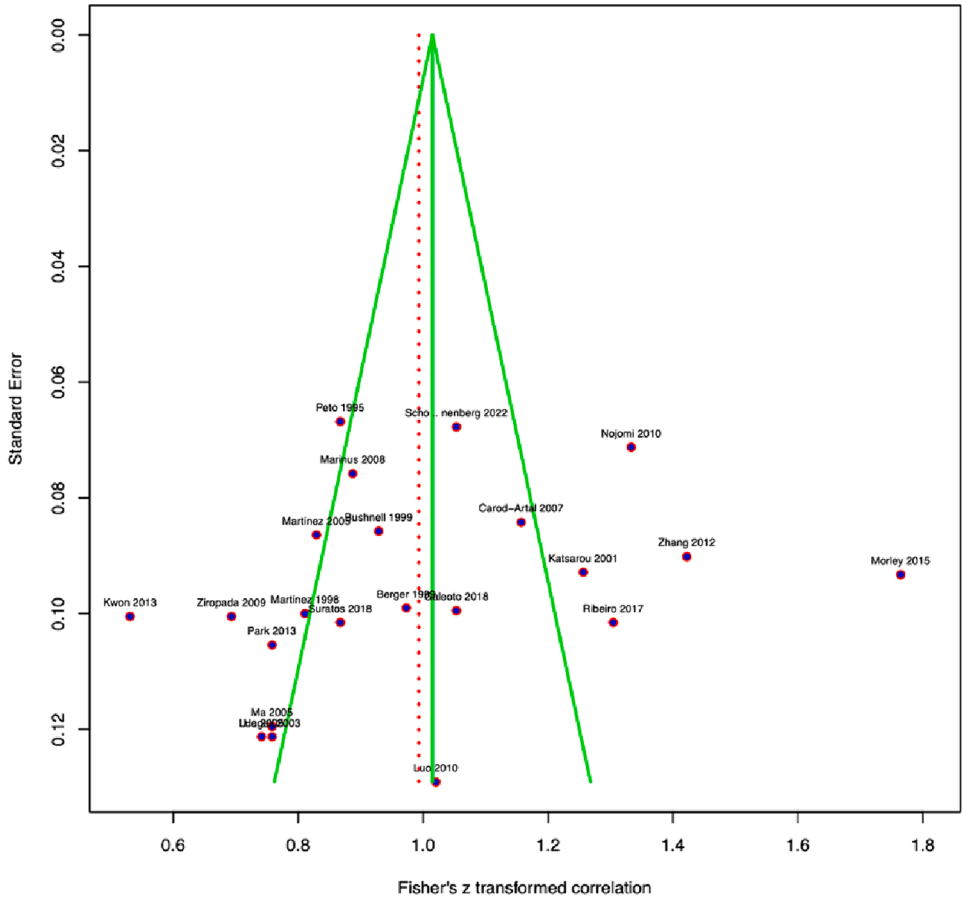


Fig. 4. A. forest plot for internal consistency of "cognitions" domain of pdq-39. b. funnel plot for internal consistency of "cognitions" domain of pdq-39.

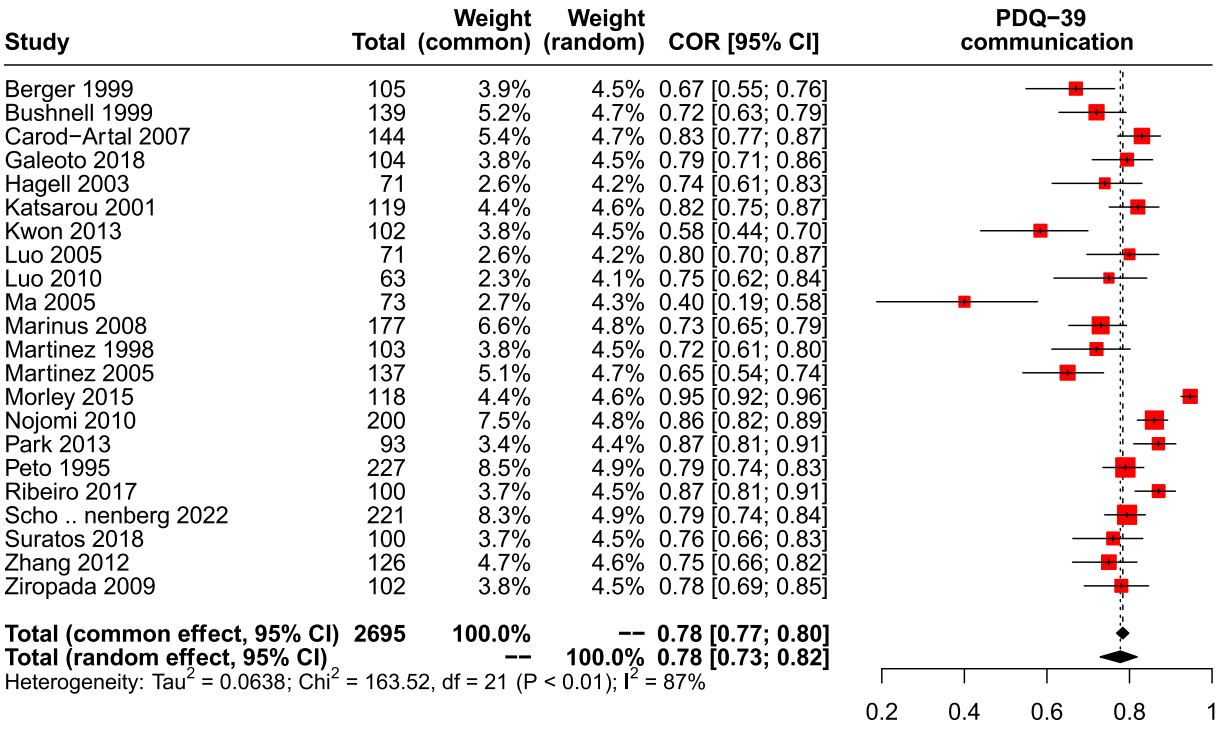


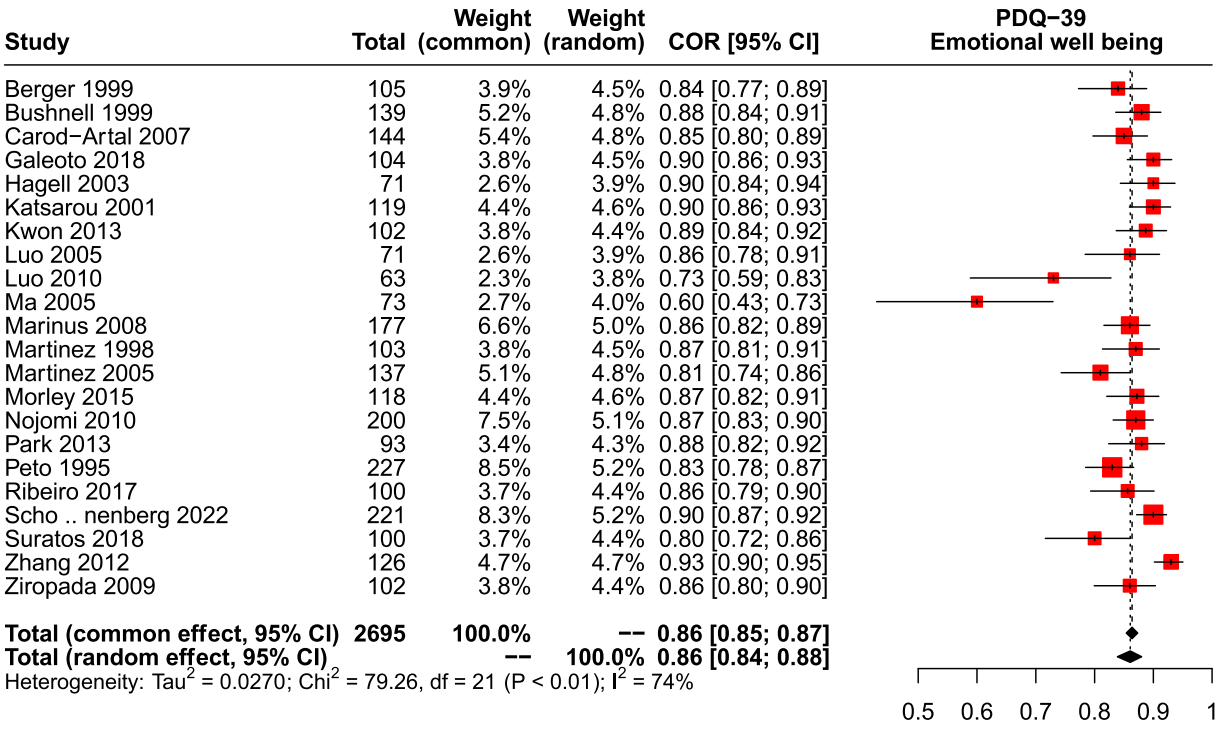
Fig. 5. A. forest plot for internal consistency of "communication" domain of pdq-39. b. funnel plot for internal consistency of "communication" domain of pdq-39.

3. Results

3.1. Study selection

Thew search was conducted on July 31, 2023, by two physiotherapists (IR, GS) on MEDLINE, CINAHL, SCOPUS, and Web of Science databases identifying 1306 articles.

398 duplicates were eliminated; 908 articles were analyzed reading title and abstract; 799 were finally excluded because were studies using the PDQ 39 and the PDQ 8 as outcome measures or were not dealing with psychometric properties; 66 articles were excluded after reading the full text. At the end, 43 articles were included in the review. The



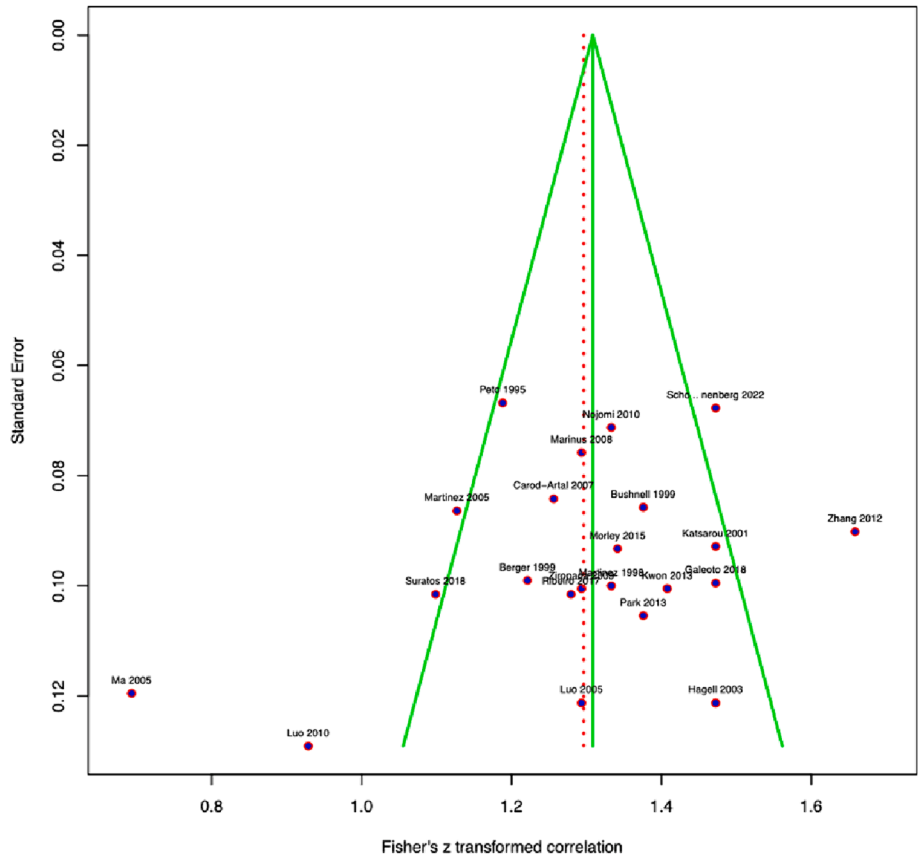
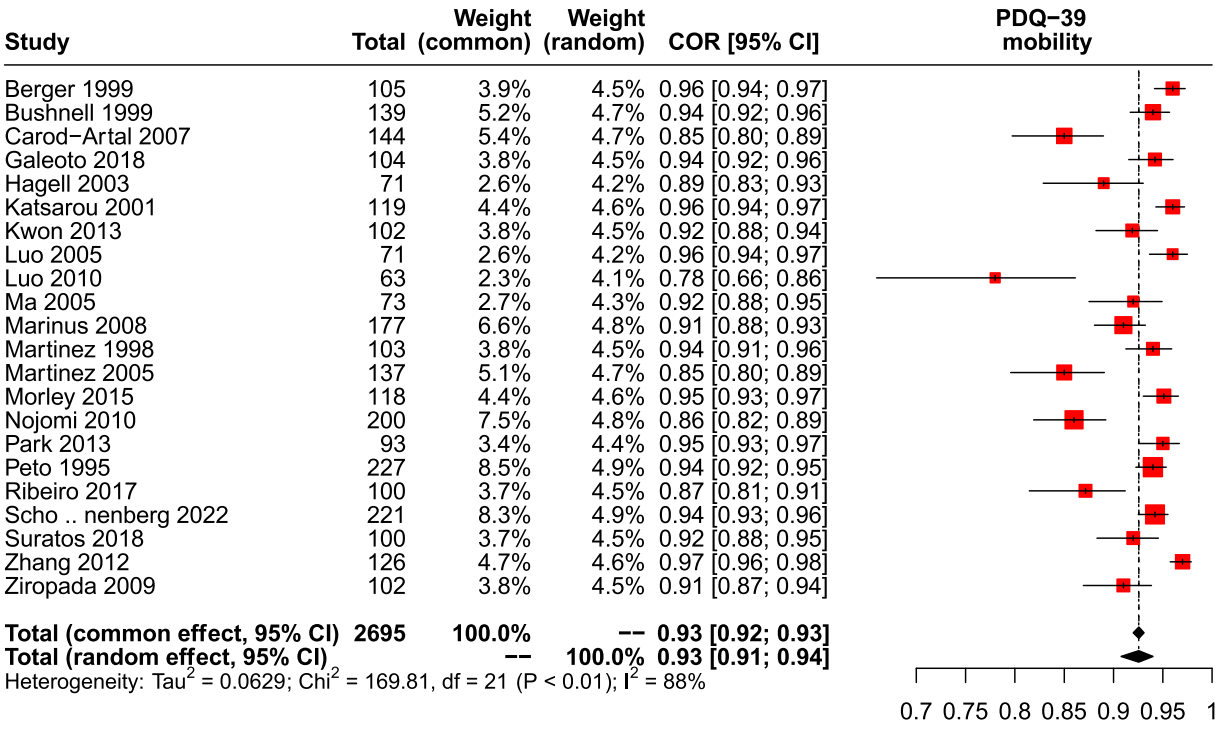


Fig. 6. A. forest plot for internal consistency of "emotional well being" domain of pdq-39. b. funnel plot for internal consistency of "emotional well being" domain of pdq-39.

selection methodology is showed in Fig. 1, according to the PRISMA guidelines for reporting systematic reviews and *meta*-analyses [35].

3.2. Study characteristics

For each included study, the following data were obtained: author name(s), year of publication, language, population, demographic information (sample size, average age, sex ratio), and comparison scales.



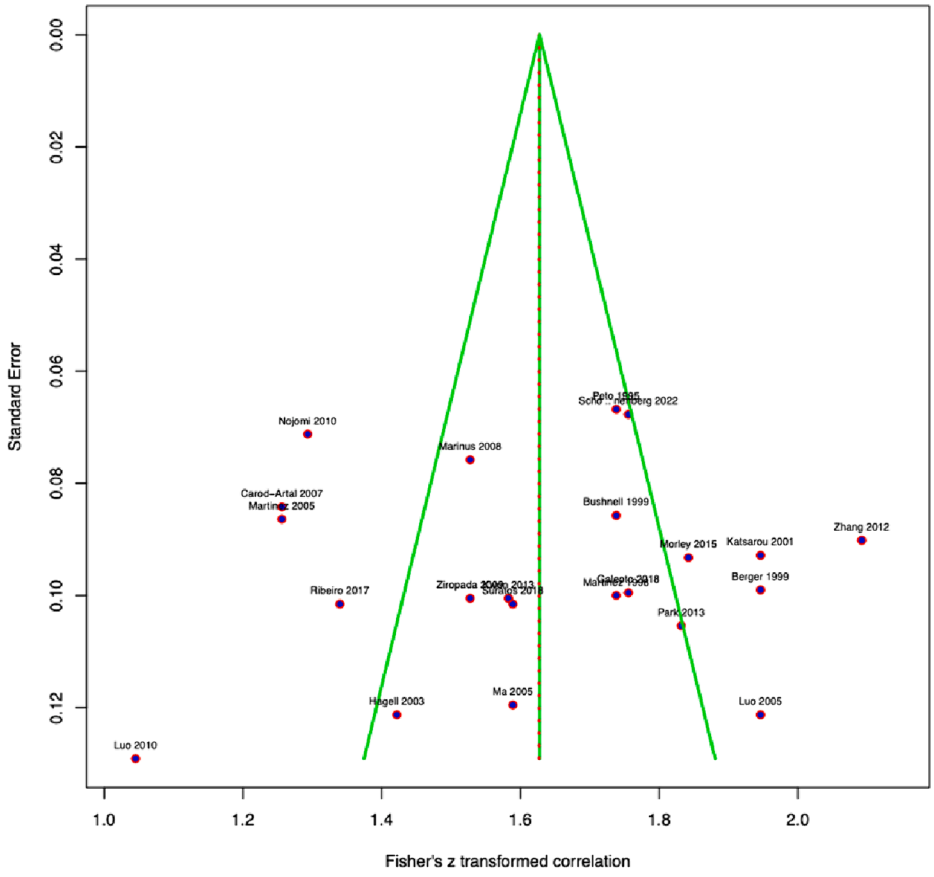


Fig. 7. A. forest plot for internal consistency of "mobility" domain of pdq-39. b. funnel plot for internal consistency of "mobility" domain of pdq-39.

3.3. Sample size

As regards PDQ-39 sample sizes ranged from 54 to 977; mean age ranged from 57.3 to 71.4 years [36–39]. As regards PDQ-8 sample sizes ranged from 24 to 558; mean age ranged from 57 to 70 years [40–43].

The data are shown in Tables 1 and 2.

3.4. Countries

PDQ-39 has been validated in the following languages and relative

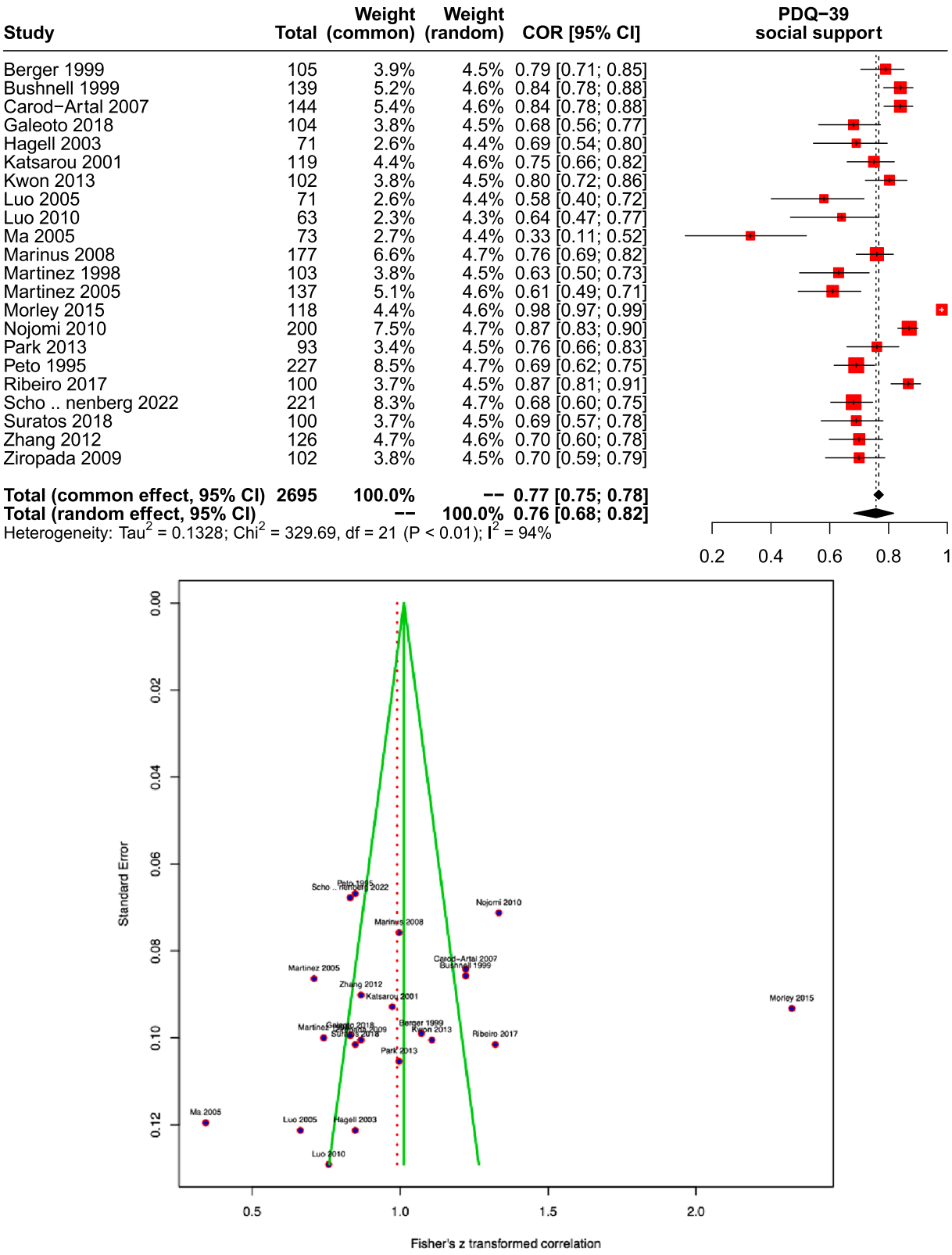


Fig. 8. A. forest plot for internal consistency of "social support" domain of pdq-39. b. funnel plot for internal consistency of "social support" domain of pdq-39.

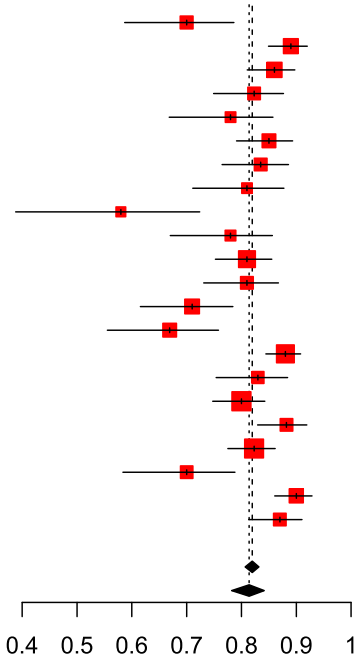
countries: Swedish [51], Portuguese [74], Brazilian [55], Spanish [75], Filipino [62], American English [46], Greek [48], Italian [63], Chinese (Beijing) [36], Chinese (Taiwan) [53], Korean [59], Estonian [56], Chinese (Singapore) [52], English (Singapore) [68], Persian [38], Chinese (mainland China) [58], English (online) [61], Danish [57], Serbian [76], Spanish (Ecuador) [54], French [49], German [39], Japanese [50], Turkish [65].

PDQ-8 and has been validated in English [13], Japanese [43], Chinese [71], Turkish [73], Persian [72], Italian [70], English (Singapore) [68], and Greek [67].

These validation studies included the investigation of the psychometric properties and both demonstrated to have good psychometric

Study	Total	Weight (common)	Weight (random)	COR [95% CI]
Berger 1999	105	3.9%	4.5%	0.70 [0.59; 0.79]
Bushnell 1999	139	5.2%	4.8%	0.89 [0.85; 0.92]
Carod−Artal 2007	144	5.4%	4.8%	0.86 [0.81; 0.90]
Galeoto 2018	104	3.8%	4.5%	0.82 [0.75; 0.88]
Hagell 2003	71	2.6%	4.0%	0.78 [0.67; 0.86]
Katsarou 2001	119	4.4%	4.6%	0.85 [0.79; 0.89]
Kwon 2013	102	3.8%	4.5%	0.83 [0.76; 0.89]
Luo 2005	71	2.6%	4.0%	0.81 [0.71; 0.88]
Luo 2010	63	2.3%	3.9%	0.58 [0.39; 0.72]
Ma 2005	73	2.7%	4.1%	0.78 [0.67; 0.86]
Marinus 2008	177	6.6%	4.9%	0.81 [0.75; 0.86]
Martinez 1998	103	3.8%	4.5%	0.81 [0.73; 0.87]
Martinez 2005	137	5.1%	4.7%	0.71 [0.62; 0.78]
Morley 2015	118	4.4%	4.6%	0.67 [0.56; 0.76]
Nojomi 2010	200	7.5%	5.0%	0.88 [0.84; 0.91]
Park 2013	93	3.4%	4.4%	0.83 [0.75; 0.88]
Peto 1995	227	8.5%	5.1%	0.80 [0.75; 0.84]
Ribeiro 2017	100	3.7%	4.4%	0.88 [0.83; 0.92]
Scho .. nenberg 2022	221	8.3%	5.1%	0.82 [0.78; 0.86]
Suratos 2018	100	3.7%	4.4%	0.70 [0.58; 0.79]
Zhang 2012	126	4.7%	4.7%	0.90 [0.86; 0.93]
Ziropada 2009	102	3.8%	4.5%	0.87 [0.81; 0.91]
Total (common effect, 95% CI)	**2695**	**100.0%**		**0.82 [0.81; 0.83]**
Total (random effect, 95% CI)			**100.0%**	**0.81 [0.78; 0.84]**

Heterogeneity: $Tau^2 = 0.0346$; $Chi^2 = 101.26$, df = 21 ($P < 0.01$); $I^2 = 79\%$



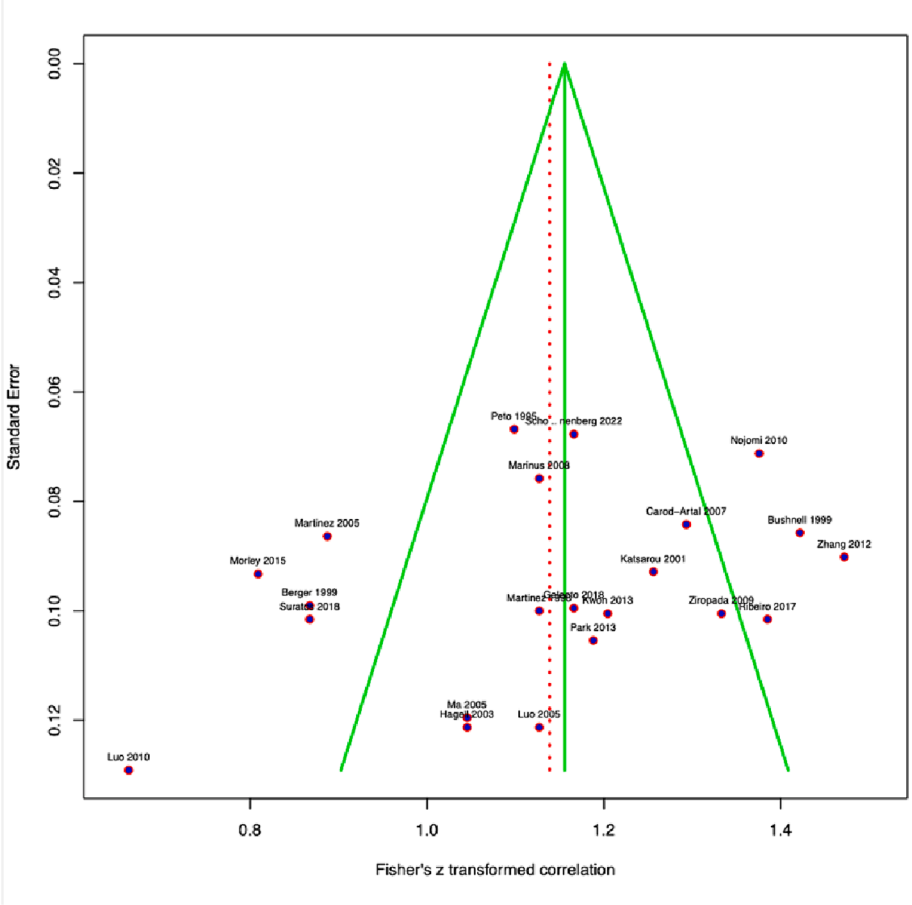


Fig. 9. A. forest plot for internal consistency of "stigma" domain of pdq-39. b. funnel plot for internal consistency of "stigma" domain of pdq-39.

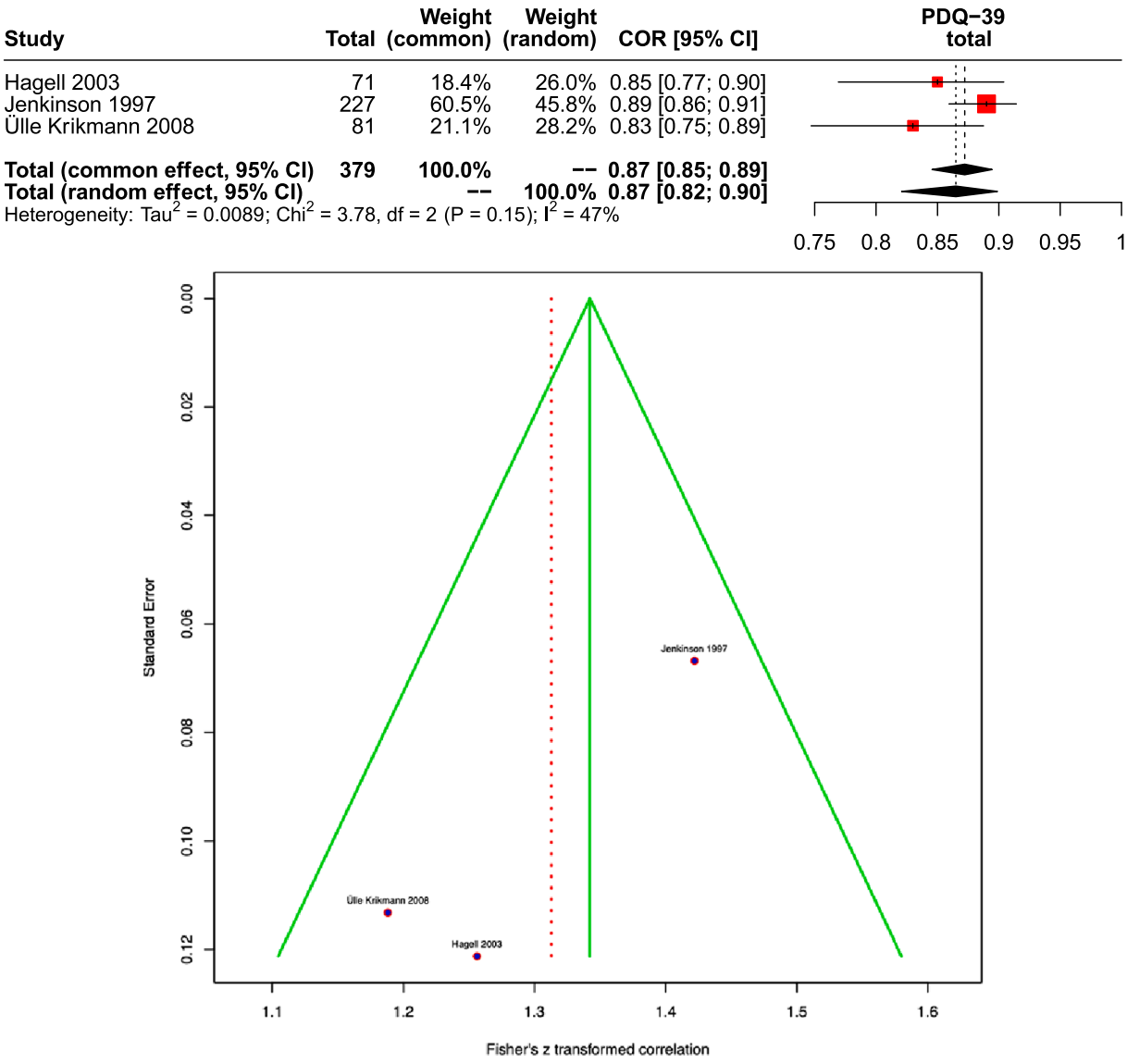


Fig. 10. A. forest plot for internal consistency of pdq-39. b. funnel plot for internal consistency of pdq-39.

properties [14].

3.5. Risk of bias

Methodological quality of the studies was assessed using the COSMIN checklist [8]; quality scores are reported in tables 3 and 4 for both PDQ-39 and PDQ-8. In general, the studies showed to have fairly good quality.

Internal Consistency, Reliability and Structural Validity had the highest levels of positive ratings as regard both PDQ-39 and PDQ-8. The study evaluating psychometric properties of PDQ-39 with the highest quality was by Peto et al. [37]. For PDQ-8, the studies with the highest methodological quality were by Fereshtehnejad et al. [72] and Chen et al. [42].

3.6. Meta-Analysis

A *meta*-analysis was performed for internal consistency of all the subscales of PDQ-39 and PDQ-8.

Regarding evaluation of reliability of the PDQ-39: Fig. 2a shows reliability of ADL subscale of PDQ-39; Cronbach's alpha was 0.89 (95% CI:0.88–0.90, I =85%). As regards "Bodily Discomfort" domain, alpha value was 0.73 (95%CI:0.71–0.74, I=82%) and it is shown in Fig. 3a; Fig. 4a-10a show Cronbach's alpha of the following domains: cognition (Cronbach's alpha=0.77, 95%CI:0.75–0.78, I=89%), communication (Cronbach's alpha=0.78, 95%CI:0.77–0.80, I=87%), emotional well Being (Cronbach's alpha=0.86, 95%CI:0.85–0.87, I=74%), mobility (Cronbach's alpha=0.93, 95%CI:0.92–0.93, I=88%), social support (Cronbach's alpha=0.77, 95%CI:0.75–0.78, I=94%), stigma (Cronbach's alpha=0.82, 95%CI:0.81–0.83, I=79%).

For the total scale Cronbach's alpha was 0.77 (95%CI:0.75–0.76, I=94%). All the Cronbach's alpha values were statistically significant.

As regards PDQ-8, Cronbach's Alpha value was 0.80; it is statistically significant, as shown in Fig. 11a.

As for risk of bias, results are shown in Fig. 2b-11b. For ADL domain of PDQ-39 data analyses shows as follows: publication bias value for Cronbach's alpha is 1,09 (SE 3,13; Intercept 1,33) with p-value 0,73; the results concerning all the other domains are the following:

- Bodily discomfort: the publication bias value for Cronbach's alpha is −2,02 (SE 2,82; Intercept 1,1) with p-value 0,48 (Fig. 3b).
- Cognitions: the publication bias value for Cronbach's alpha is −3,8 (SE 3,57; Intercept 1,35) with p-value 0,29 (Fig. 4b).

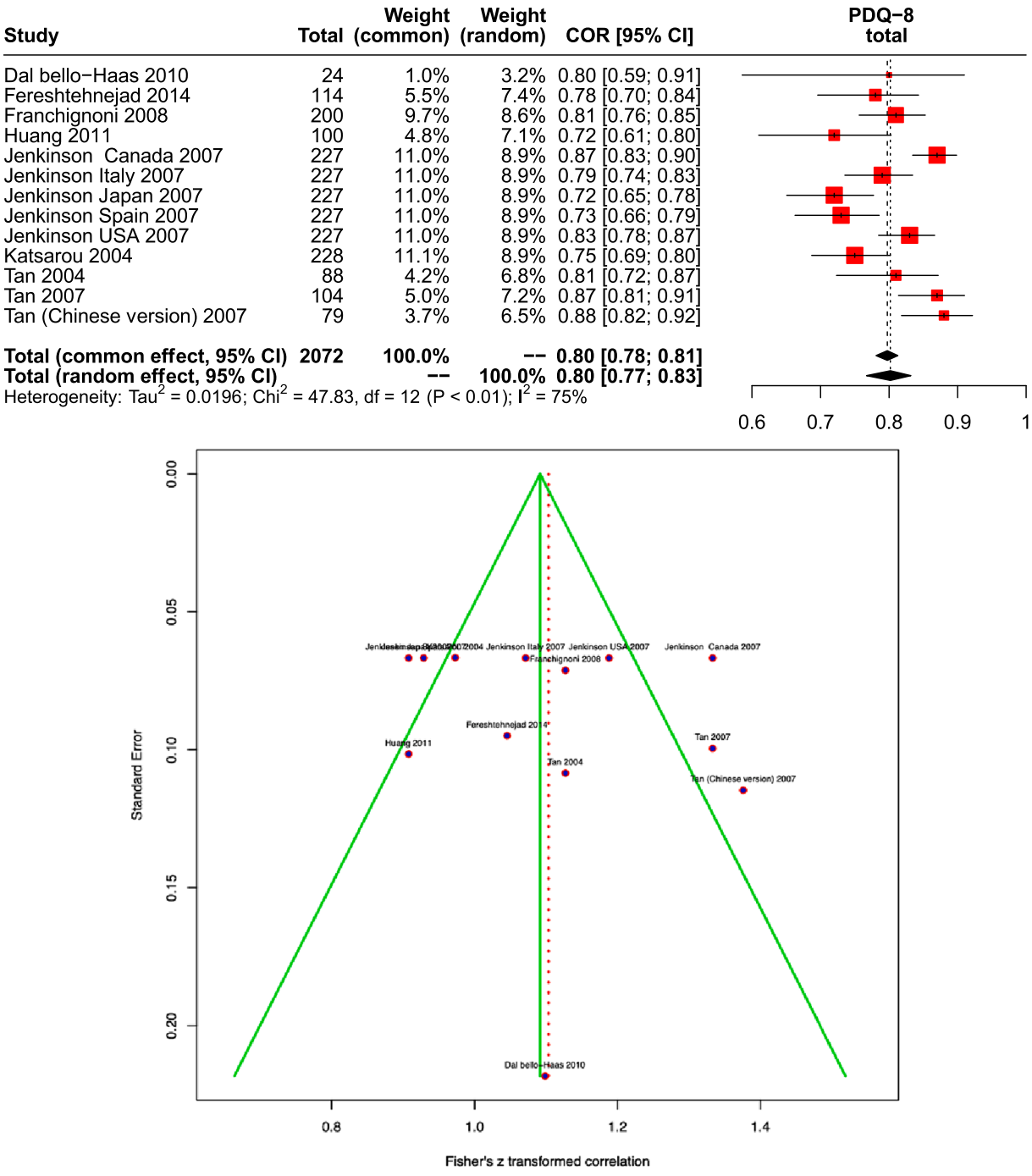


Fig. 11. A. forest plot for internal consistency of pdq-8. b. funnel plot for internal consistency of pdq-8.

- Communication: the publication bias value for Cronbach's alpha is −2,91 (SE 3,29; Intercept 1,31) with p-value 0,38 (Fig. 5b).
- Emotional Well Being: the publication bias value for Cronbach's alpha is −2,6 (SE 2,26; Intercept 1,54) with p-value 0,26 (Fig. 6b).
- Mobility: the publication bias value for Cronbach's alpha is −0,01 (SE 3,41; Intercept 1,62) with p-value 0,99 (Fig. 7b).
- Social Support: the publication bias value for Cronbach's alpha is −3,38 (SE 4,7; Intercept 1,31) with p-value 0,48 (Fig. 8b).
- Stigma: the publication bias value for Cronbach's alpha is −3,4 (SE 2,52; Intercept 1,46) with p-value 0,19 (Fig. 9b).
- Total score PDQ-39: the publication bias value for Cronbach's alpha is −3,89 (SE 1,27; Intercept 1,67) with p-value 0,2 (Fig. 10b).

As for PDQ-8 data analyses shows that the publication bias value for Cronbach's alpha is 1,38 (SE 2,15; Intercept 0,98) with p-value 0,53 (Fig. 11b).

4. Discussion

This *meta*-analysis aimed to identify studies that evaluate the psychometric properties of the two most frequently used tools for the assessment of QoL in PwP (PDQ-39 and its short form PDQ-8) and investigate their psychometric properties. Overall, Cronbach's Alpha values for the subscales of PDQ-39 were excellent; in particular, in the validation studies conducted by Zhang et al. and Morley et al. the values were higher than others [60,61]. As regards PDQ-8, results show a

general good reliability in all the included studies.

Data available in the worldwide literature until 2023 allowed the identification of 42 studies that evaluated the psychometric properties of PDQ-39 and PDQ-8. In particular, psychometric properties of PDQ-39 were studied in 29 studies, while psychometric properties of PDQ-8 in 13 studies.

As regards PDQ-39, internal consistency and test–retest reliability values were fairly good, although test–retest reliability is missing in 13 studies. For PDQ-8 internal consistency values seem to be better than those of PDQ-39, but it must be considered that the studies that investigated PDQ-8 psychometric properties are less, and the least number of items can influence the internal consistency values.

PDQ-39 demonstrated to be a specific HRQoL questionnaire that is correlated with a generic HRQoL questionnaire, in fact in many studies included in the review, correlations with SF-36 were found. The short-form 36 (SF-36) health survey questionnaire is a generic health assessment tool used in a wide variety of illnesses and in surveys among the general population, while PDQ-39 has been designed to propose domains of specific concern to conditions of PwP; Peto et al. who developed the scale in 1995 was also the first to study the correlation between SF-36 and PDQ-39, and between these scales with other tools measuring disease severity (for example H&Y); they found that complexity of the disease was highly correlated with all the domains of PDQ-39 and SF-36. As regards PDQ-39 and SF-36, correlations were highest with physical aspects of health status (i. e. mobility and ADL) on PDQ-39, and physical and social function on SF-36 [13]. However, literature provides support for the use of a disease-specific tool to assess the impact of illness among PwP: in fact, also considering H&Y scores, it has been shown that worsening PD is associated with higher disability in the domains of cognition, communication and especially self-perceived social stigma [80]. Another generic health questionnaire compared to PDQ-39 in two studies was EQ-5D; through this correlation resulted that mobility dimension of PDQ-39 was not correlated with mobility domain of EQ-5D, probably because PDQ-39 assesses mobility in terms of activities of daily living, while EQ-5D mobility dimension only assesses walking [52].

About correlation with UPDRS scale, in several studies PDQ-39 demonstrated to better investigate several aspects belonging to a more personal perception of the condition, such as bodily discomfort, stigma, social support and cognitions; in fact, UPDRS (in particular part I and III) are not self-administered and evaluate objective aspects observed by raterr, and consequently don't consider perception of stigma, bodily discomfort and communication. The other domains, such as ADL and mobility, instead, are highly associated with UPDRS items [48,59,79].

Other studies investigated correlations between H&Y stage and PDQ-39 domains: results demonstrate that domains of mobility and ADL report statistically significant differences between disease severity, while the differences for the domains of stigma, social support, emotional well-being and bodily discomfort were not so clearly related to the severity of PD stages. Overall, these last domains seem to be not related to the severity of PD stages, and social support is not greatly influenced by disease severity in PD patients [56,62,77].

These findings support the use of PDQ-39 in clinical settings, because of its consideration of participation and QoL as perceived by the subjects; understanding how patients live the disease in terms of participation, could help to suggest them different and personalized care pathways, such as physical therapy, occupational therapy or psychological therapy, in order to improve their general QoL.

Studies show that it can be used to measure QoL also in patients with cognitive impairment, but in several of the included studies this scale showed floor effect as regards the domains of social support, communication and stigma [13,58,59].

In the last years studies about psychometric properties of PDQ-8 emerged that it is a practical and informative instrument that can be easily used in clinical settings, especially in busy ones, but also in large-scale studies in which a brief instrument would be preferred [73]. It can be used in busy clinical settings with less time and at the same time acceptable accuracy, helping to ease administration, reduce burden of respondents and improve medical and/or rehabilitation decisions, and in particular when conducting a longitudinal study. Furthermore, in the longitudinal study conducted by Chen et. al in 2017, the PDQ-8 had good test–retest reliability with values that agreed with the PDQ-39 ones, in each follow-up year, showing that the PDQ-8 is sufficiently reliable for its use in the longitudinal evaluation of PD patients [42].

Finally, very few studies investigated responsiveness of the scales, in fact it is recommended in future studies to evaluate this property to assess the ability of PDQ-39 and PDQ-8 to relieve changes in the QoL of PwP. Overall, both PDQ-39 and PDQ-8 showed to be valid and reliable tools.

This review presents some limitations. 4 electronic databases were systematically searched, but it is possible that not all relevant studies were identified, because studies may also have been published in journals not indexed in these databases. Moreover, this review included only published studies, as studies that have been submitted but not yet accepted for publication or that have only recently been accepted for publication were excluded.

Reaching an international consensus regarding the usage of assessment tools will ensure an improvement in the quality of care, rehabilitation, and efficiency of health care systems. The studies considered in this review provide researchers two PD assessment tools that are used worldwide according to the specific necessities of patients, settings, type of therapy, time availability. These instruments should be employed in high-quality and comparable randomized controlled trials, investigating outcomes related to different fields, such as pharmacological, psychological or rehabilitation field, in order to provide a higher level of evidence, such as the conduction of *meta*-analyses.

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CRediT authorship contribution statement

Ilaria Ruotolo: Conceptualization, Writing – original draft, Writing – review & editing. **Giovanni Sellitto:** Supervision, Methodology, Conceptualization. **Anna Berardi:** Investigation, Supervision. **Rachele Simeon:** Data curation, Writing – original draft. **Francescaroberta Panuccio:** Data curation, Writing – review & editing. **Emanuele Amadio:** Investigation. **Alessandro Ugolini:** Formal analysis. **Giovanni Fabbrini:** Supervision, Methodology, Conceptualization. **Giovanni Galeoto:** Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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