



Reliability and Validity of the Subjective Cognitive Complaints Questionnaire for Parkinson's Disease (SCCQ-PD)

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Background and Purpose Subjective cognitive complaints (SCCs) are gaining attention as a self-perceived symptom for cognitive impairment in patients with Parkinson's disease (PD), but there are few suitable tools for assessing SCCs in PD. This study aimed to develop and validate a questionnaire for assessing SCCs in PD, called the Subjective Cognitive Complaints Questionnaire for Parkinson's Disease (SCCQ-PD).

Methods The SCCQ-PD consists of 12 yes/no questions on subjective cognitive function, and the questionnaire was completed by patients with PD (score-P) and their caregivers (score-C). The cognitive function of patients was examined using comprehensive neuropsychological tests.

Results This study included 73 patients (38 cognitively normal, 25 with mild cognitive impairment [MCI], and 10 demented) and their caregivers. Score-P and score-C had excellent reliability (Kuder-Richardson formula 20 coefficients of 0.893 and 0.931, respectively), and the scores exhibited a strong intercorrelation. Both score-P and score-C were negatively correlated with cognitive performance, and both were excellent in discriminating demented patients from those with normal cognition or MCI (areas under the receiver operating characteristic curve of 0.83 and 0.88, respectively).

Conclusions The SCCQ-PD is a reliable tool for assessing SCCs in patients with PD. SCCs measured using the SCCQ-PD are correlated with objective cognitive decline and useful for discriminating demented patients from nondemented patients.

Keywords Parkinson's disease; cognitive decline; cognition.

INTRODUCTION

Parkinson's disease (PD) is characterized by motor symptoms, but nonmotor symptoms also affect the daily living of patients with PD. Cognitive impairment is one of the most-disabling complications in PD,¹ and dementia develops in most patients with advanced PD.² The concept of mild cognitive impairment (MCI) in PD is well established, and regarded as a pre-dementia status.³ Furthermore, subjective experiences of cognitive decline, termed subjective cognitive complaints (SCCs), in the absence of obvious cognitive impairment have been tested as a potential predictor of subsequent cognitive deterioration.⁴ Although there is controversy about the predictive value of SCCs, more studies are investigating SCCs in both Alzheimer's disease (AD) and PD.

There are no reliable imaging or neurochemical biomarkers for SCCs, and so they have only been assessed using a simple question or questionnaire. Several questionnaires for SCCs have been developed,⁵⁻¹¹ but most focus on memory complaints because the concept of SCCs originated from cognitive impairment due to AD. However, PD affects not only memory function but also other cognitive domains including attention, executive function, and vi-

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suospatial ability from the early phase of cognitive decline.¹²⁻¹⁴ Therefore, a questionnaire for SCCs in PD should contain items assessing the subjective feeling related to various aspects of cognitive function beyond memory.

Several previous studies have found that the self-rated scores on questionnaires for SCCs tend to be lower for patients with dementia than for patients with MCI, with caregivers tending to assign higher scores for patients with dementia than for patients with MCI.^{9,10} The authors attributed this discrepancy to demented patients lacking awareness of their cognitive deterioration. However, it is unclear whether “cognitive anosognosia”¹⁵ is present in patients with PD, and so this needs to be explored further.

In this study, we developed a self-reported questionnaire for SCCs in PD, called the Subjective Cognitive Complaints Questionnaire for Parkinson’s Disease (SCCQ-PD). We compared SCCQ-PD scores between those rated by patients with PD and those rated by their caregivers, and validated its reliability and its ability to predict the cognitive level in patients with PD.

METHODS

Subjects

The study subjects were enrolled consecutively between November 2017 and January 2019 from a neurology outpatient clinic of a tertiary referral center. All patients were diagnosed with PD based on the criteria of the United Kingdom PD Society Brain Bank¹⁶ prior to enrollment into this study. To exclude dementia with Lewy bodies, patients who developed visual hallucinations or cognitive problems that impaired their social or occupational activities before or within 1 year of the onset of motor symptoms were not enrolled. Patients who had a vascular lesion or mass in the basal ganglia revealed by magnetic resonance imaging were also excluded from the study. Medical records were searched for the presence of a medical history, and atrophy of the medial temporal lobe was evaluated using a visual rating scale.¹⁷

This study received approval for human experimentation from the Institutional Review Board of the Yonsei University Wonju Severance Christian Hospital where the subjects were enrolled (approval number: CR317099), and written informed consent was obtained from all of the included patients and their caregivers. The caregivers were restricted to family members who lived with the patients and were not demented.

Design of the SCCQ-PD

The SCCQ-PD consists of 12 yes/no questions on subjective feelings about the everyday cognition of patients. Patients and caregivers were instructed to answer the questions based on

their experiences over the previous 6 months. The following questions were selected from items analyzed in previous studies^{7,9,11,18} with modifications to reflect the effects of SCCs in various cognitive domains:

1. Do you have difficulty in remembering where you left things?
2. Have you asked a family member to repeat the details of a recent conversation?
3. Do you often forget appointments?
4. Do you have difficulty in traveling to familiar places or recognizing a previously traveled route?
5. Do you have difficulty using public transportation or remembering a route you have driven often?
6. Do you have difficulty in understanding the speech of other people?
7. Do you have difficulty finding words that you want to say?
8. Has your mathematical ability deteriorated?
9. Do you have difficulty performing bank transactions or paying taxes?
10. Do you have difficulty using home electronics?
11. Have your social activities been reduced or do you need help to go out?
12. Have you become indifferent or less compassionate toward other people?

The SCCQ-PD was provided in Korean, and scoring was performed just before applying a comprehensive neuropsychological test. Subjects were instructed to answer each question as either “yes” or “no,” and the number of questions answered “yes” was used as the SCCQ-PD score. Scores for patients and caregivers are referred to here as score-P and score-C, respectively.

Before answering the questions, subjects were asked to respond to four questions regarding metacognition of general cognitive function:

1. Do you think that you have a cognitive problem?
2. Do you think that your cognitive function is worse than it was 1 year ago?
3. Do you think that your cognitive function is poor for your age?
4. Does your cognitive function cause inconvenience in your daily life?

Neuropsychological assessment

A comprehensive neuropsychological assessment were conducted by an experienced neuropsychologist using the following neuropsychological battery to fulfill the Level II criteria for MCI in PD³ proposed by the Movement Disorder Society (MDS): backward digit span¹⁹ and Stroop test (color reading)¹⁹ for attention, Korean version of the Boston Naming

Test (K-BNT)¹⁹ and the word similarity test of the Wechsler Adult Intelligence Scale-Fourth Edition²⁰ for language function, the copying task of the Rey Complex Figure Test (RCFT)¹⁹ and clock copying²¹ for visuospatial function, 20-min delayed recall using the Seoul Verbal Learning Test¹⁹ and the RCFT¹⁹ for memory, and category fluency (animals) using the Controlled Oral Word Association Test¹⁹ and the clock-drawing test²¹ for executive function. Additionally, general cognitive function and depressive symptoms were assessed using the Korean version of the Mini-Mental State Examination (K-MMSE),²² the Korean version of the Montreal Cognitive Assessment (K-MoCA),²³ and the Korean version of Beck Depression Inventory-II (K-BDI-II).²⁴

Diagnosis of MCI and dementia

MCI was diagnosed based on the criteria for MCI in PD proposed by the MDS (Level II category):³ 1) performance on at least 2 of the 10 subtests lower than the mean minus 1.5 standard deviations (SDs) of the normative data corrected for age, sex, and duration of education, and 2) no impairment in the activities of daily living (ADL) assessed using the Korean-Instrumental Activities of Daily Living.²⁵ Impairment in ADL due to motor or autonomic symptoms of PD was not reflected to the ADL assessment.

PD with dementia was diagnosed according to the following criteria proposed by the MDS:²⁶ 1) the mean z score for two tests in a cognitive domain lower than -1.5 in at least

two domains, and 2) impaired ADL.

Statistical analysis

Demographic characteristics and neuropsychological performance were compared among the included cognitive groups using one-way analysis of variance and the chi-square test, with Bonferroni's correction used for post-hoc analyses. The internal consistency reliability and construct validity of the SCCQ-PD were tested using Kuder-Richardson formula 20 and principal-components analysis (PCA). Pearson's correlation was used to explore the relationships between SCCQ-PD scores and cognitive performance, and partial correlations were analyzed while adjusting for age, sex, duration of education, and K-BDI-II score. The discriminative power of the SCCQ-PD was explored using receiver operating characteristic (ROC) curves and the area under the ROC curve (AUC). All of the statistical analyses were conducted using SPSS Statistics (version 25, IBM SPSS, Armonk, NY, USA).

RESULTS

Subjects and baseline demographics

This study included 73 patients (34 males and 39 females) and their caregivers. Patients were classified into three groups based on neuropsychological performance: cognitively normal (CN group, $n=38$), MCI group ($n=25$), and dementia (DMT group, $n=10$). The demographic characteristics of study subjects are

Table 1. Demographic characteristics of patient groups classified according to their cognitive status

	CN ($n=38$)	MCI ($n=25$)	DMT ($n=10$)	<i>p</i>	Significant pairs
Sex (male/female)	15/23	13/12	6/4	0.409	-
Age (yr)	73.7±7.2	72.8±6.9	80.2±5.2	0.016	CN<DMT, MCI<DMT
Age at onset of PD (yr)	69.3±8.2	68.4±7.9	75.9±6.9	0.041	MCI<DMT
Duration of PD (yr)	4.3±2.5	4.4±3.2	4.3±2.7	0.988	-
UPDRS motor score	26.4±11.4	29.7±11.1	33.2±10.7	0.331	-
LEDD (mg/day)	568.4±335.7	569.8±362.5	722.0±492.0	0.479	-
Duration of education (yr)	5.4±4.3	6.6±5.4	7.5±5.3	0.403	-
K-BDI-II score	14.4±8.7	17.2±10.0	17.0±9.9	0.465	-
Hypertension	14 (36.8)	4 (16.0)	2 (20.0)	0.164	
Diabetes mellitus	11 (28.9)	6 (24.0)	0 (0.0)	0.155	
Dyslipidemia	5 (13.2)	6 (24.0)	0 (0.0)	0.179	
Medial temporal lobe atrophy score				0.062*	
0	20 (52.6)	11 (44.0)	2 (20.0)		
1	11 (28.9)	9 (36.0)	3 (30.0)		
2	5 (13.2)	4 (16.0)	4 (40.0)		
3	2 (5.3)	1 (4.0)	1 (10.0)		
4	0 (0.0)	0 (0.0)	0 (0.0)		

Data are mean±standard-deviation or *n* (%) values.

*Linear-by-linear association.

CN, cognitively normal; DMT, dementia; K-BDI-II, Korean version of Beck Depression Inventory-II; LEDD, levodopa equivalent daily dose; MCI, mild cognitive impairment; PD, Parkinson's disease; UPDRS, Unified Parkinson's Disease Rating Scale.

presented in Table 1. Patients in the DMT group were older than those in the CN and MCI groups, and the age at PD onset was higher in the DMT group than in the MCI group. There were no intergroup differences in sex, duration of PD, motor score on the Unified Parkinson's Disease Rating Scale, levodopa equivalent dose, duration of education, K-BDI-II score, presence of hypertension, diabetes mellitus, or dyslipidemia, or score for medial temporal lobe atrophy. The neuropsychological performance of the subjects is presented in Supplementary Table 1 (in the online-only Data Supplement).

SCCQ-PD scores

Score-P was higher in the DMT group (9.3±3.4, mean±SD) than in the CN (4.4±3.6) or MCI (4.6±3.3) group, and did not differ significantly between the CN and MCI groups (Table 2). Score-C also was higher in the DMT group (9.6±3.2) than in the CN (3.2±4.0) and MCI (4.0±3.6) groups. The differences between score-P and score-C were similar across the three groups, and score-P and score-C were strongly correlated with each other ($r=0.69, p<0.001$).

Internal consistency reliability

The Kuder-Richardson formula 20 coefficient was 0.893 for score-P and 0.931 for score-C. Corrected item-total correlation coefficients for all items exceeded 0.4 (range=0.46–0.78) and 0.6 (range=0.63–0.79) for patients and caregivers, respectively.

Construct validity

The PCA of score-P revealed two components with eigenvalue >1 (5.555 and 1.225), which explained 46.3% and 10.2% of the variance, respectively (Kaiser-Meyer-Olkin [KMO] value=0.879, Bartlett's test statistic for sphericity <0.001). The PCA of score-C identified one component with eigenvalue >1 (6.853), which explained 57.1% of the variance (KMO value=0.914, Bartlett's test statistic for sphericity <0.001). Scree plots for score-P and score-C both showed sharp decreases in eigenvalues after the first factor (Fig. 1).

Correlation between SCCQ-PD score and neuropsychological performance

Score-P was negatively correlated with the K-MMSE score, K-MoCA score, and the performance on all items of the neu-

Table 2. Score-P and Score-C on the Subjective Cognitive Complaints Questionnaire for Parkinson's Disease according to cognitive status

Score	CN (n=38)	MCI (n=25)	DMT (n=10)	p	Significant pairs
Score-P	4.4±3.6	4.6±3.3	9.3±3.4	0.001	CN<DMT, MCI<DMT
Score-C	3.2±4.0	4.0±3.6	9.6±3.2	<0.001	CN<DMT, MCI<DMT
Score-P + score-C	7.6±7.0	8.6±6.0	18.9±5.5	<0.001	CN<DMT, MCI<DMT
Score-P - score-C	1.3±2.9	0.6±3.5	-0.3±3.8	0.372	N/A

Data are mean±standard-deviation values.

CN, cognitively normal; DMT, dementia; MCI, mild cognitive impairment; N/A, not applicable; score-C, score rated by caregivers; score-P, score rated by patients.

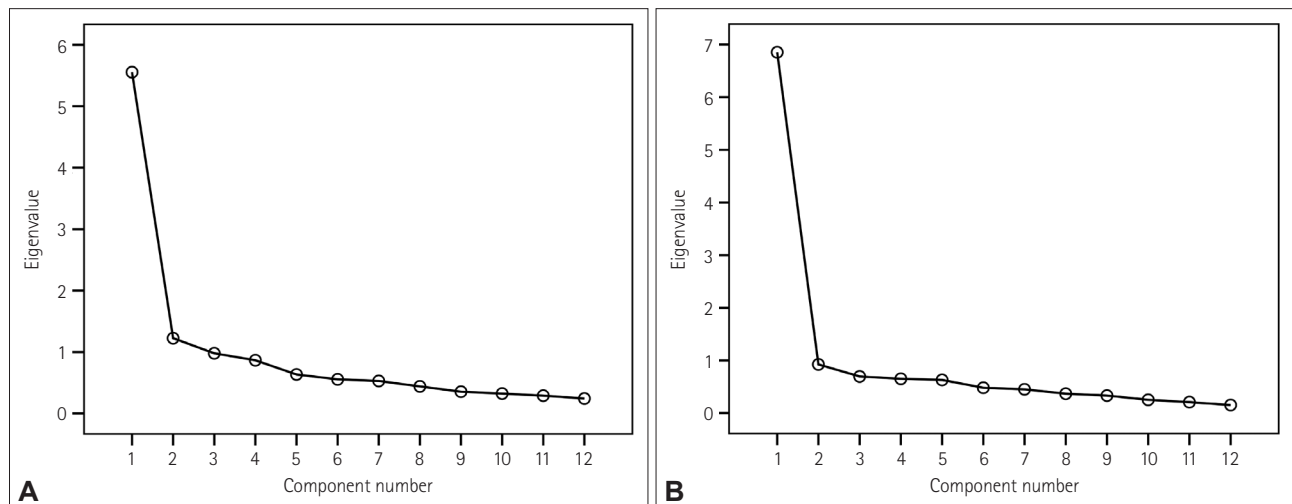


Fig. 1. Scree plots from exploratory factor analyses of the scores on the Subjective Cognitive Complaints Questionnaire for Parkinson's Disease (SCCQ-PD) for patients with Parkinson's disease (score-P) (A) and their caregivers (score-C) (B). A sharp decrease in the eigenvalues after the first component was evident on both scree plots.

ropsychological battery, and was strongly positively correlated with the K-BDI-II score (Table 3 and Fig. 2). When the covariates (age, sex, duration of education, and K-BDI-II score) were adjusted, score-P was correlated with the K-MMSE score, K-MoCA score, and the performance on the K-BNT, copying task of RCFT, clock copying, delayed recall on the RCFT, and clock-drawing test.

Score-C was negatively correlated with the K-MMSE score, K-MoCA score, and the performance on all items of the neuropsychological battery, and positively correlated with the BDI-II score (Table 3 and Fig. 2). After adjusting for covariates, score-C was correlated with the K-MMSE score, K-MoCA score, the performance on the Stroop test (color reading), copying task of RCFT, clock copying, delayed recall on the RCFT, category fluency test (animals), and clock-drawing test.

Discriminative validity of the SCCQ-PD

The discriminative power of the SCCQ-PD was explored using ROC curves and the AUC. Score-P was excellent in discriminating the DMT group from the CN and MCI groups (AUC=0.83, 95% CI=0.69–0.97) (Fig. 3). The optimal screening and diagnostic criterion was score-P ≥ 8 , which yielded a sensitivity of 0.80 and a specificity of 0.81.

Score-C was also excellent in discriminating the DMT group from the CN and MCI groups (AUC=0.88, 95% CI=0.78–0.98) (Fig. 3). The optimal screening and diagnostic criterion was score-C ≥ 8 , which also yielded a sensitivity of 0.80 and a specificity of 0.81.

However, neither score-P (AUC=0.62) nor score-C (AUC=0.68) was useful for distinguishing the cognitively impaired patients (MCI and DMT groups) from the CN group.

DISCUSSION

This study has developed and validated the SCCQ-PD, a questionnaire that assesses SCCs in patients with PD. The results showed that the SCCQ-PD is a reliable and useful self-rating tool for screening dementia.

Because cognitive impairment affects multiple cognitive domains in patients with PD,^{12–14} self-perceived cognitive complaints should be accessed regarding not only memory function but also other types of cognitive functioning. New tools for SCCs in patients with PD were recently examined for assessing all cognitive domains.^{27,28} The SCCQ-PD developed in the present study was also designed to reflect diverse aspects of cognitive function: memory, visuospatial function, language, executive function, and neuropsychiatric function.²⁶ These tools seem to be suitable for SCCs in PD, but further studies are required to confirm their practical usefulness.

Many previous studies have found that dementia patients show poor insight into their cognitive impairment^{15,29} and that the correlations between cognitive complaints and objective cognitive dysfunction were stronger for reports by informants than for patient self-reporting.^{9,10,29,30} However, Sitek et al.³¹ reported that self-awareness of memory function is preserved well in patients with PD. Similarly, the present study found that SCCQ-PD scores rated by patients and care-

Table 3. Correlations between SCCQ-PD scores and neuropsychological performance

	Uncorrected				Corrected			
	Score-P		Score-C		Score-P		Score-C	
	rho	p	rho	p	Partial rho	p	Partial rho	p
K-MMSE	-0.461	<0.001	-0.428	<0.001	-0.360	0.002	-0.339	0.004
K-MoCA	-0.489	<0.001	-0.458	<0.001	-0.379	0.001	-0.350	0.003
Backward digit span	-0.326	0.005	-0.257	0.028	-0.179	0.142	-0.094	0.442
Stroop-color reading	-0.351	0.003	-0.519	<0.001	-0.228	0.068	-0.427	<0.001
K-BNT	-0.376	0.001	-0.288	0.013	-0.302	0.012	-0.181	0.136
Word similarity	-0.254	0.030	-0.293	0.012	-0.091	0.456	-0.187	0.125
Copying task of RCFT	-0.357	0.002	-0.347	0.003	-0.297	0.013	-0.282	0.019
Clock copying	-0.288	0.013	-0.340	0.003	-0.244	0.043	-0.310	0.010
Delayed recall (verbal)	-0.343	0.003	-0.384	0.001	-0.170	0.163	-0.200	0.100
Delayed recall (visual)	-0.366	0.001	-0.426	<0.001	-0.260	0.031	-0.334	0.005
Category fluency	-0.247	0.035	-0.387	0.001	-0.114	0.351	-0.279	0.021
Clock-drawing test	-0.322	0.005	-0.406	<0.001	-0.265	0.027	-0.380	0.001
K-BDI-II	0.465	<0.001	0.384	0.001				

K-BDI-II, Korean version of Beck Depression Inventory-II; K-BNT, Korean version of the Boston Naming Test; K-MMSE, Korean version of the Mini-Mental State Examination; K-MoCA, Korean version of the Montreal Cognitive Assessment; RCFT, Rey Complex Figure Test; SCCQ-PD, Subjective Cognitive Complaints Questionnaire for Parkinson's Disease; score-C, score rated by caregivers; score-P, score rated by patients.

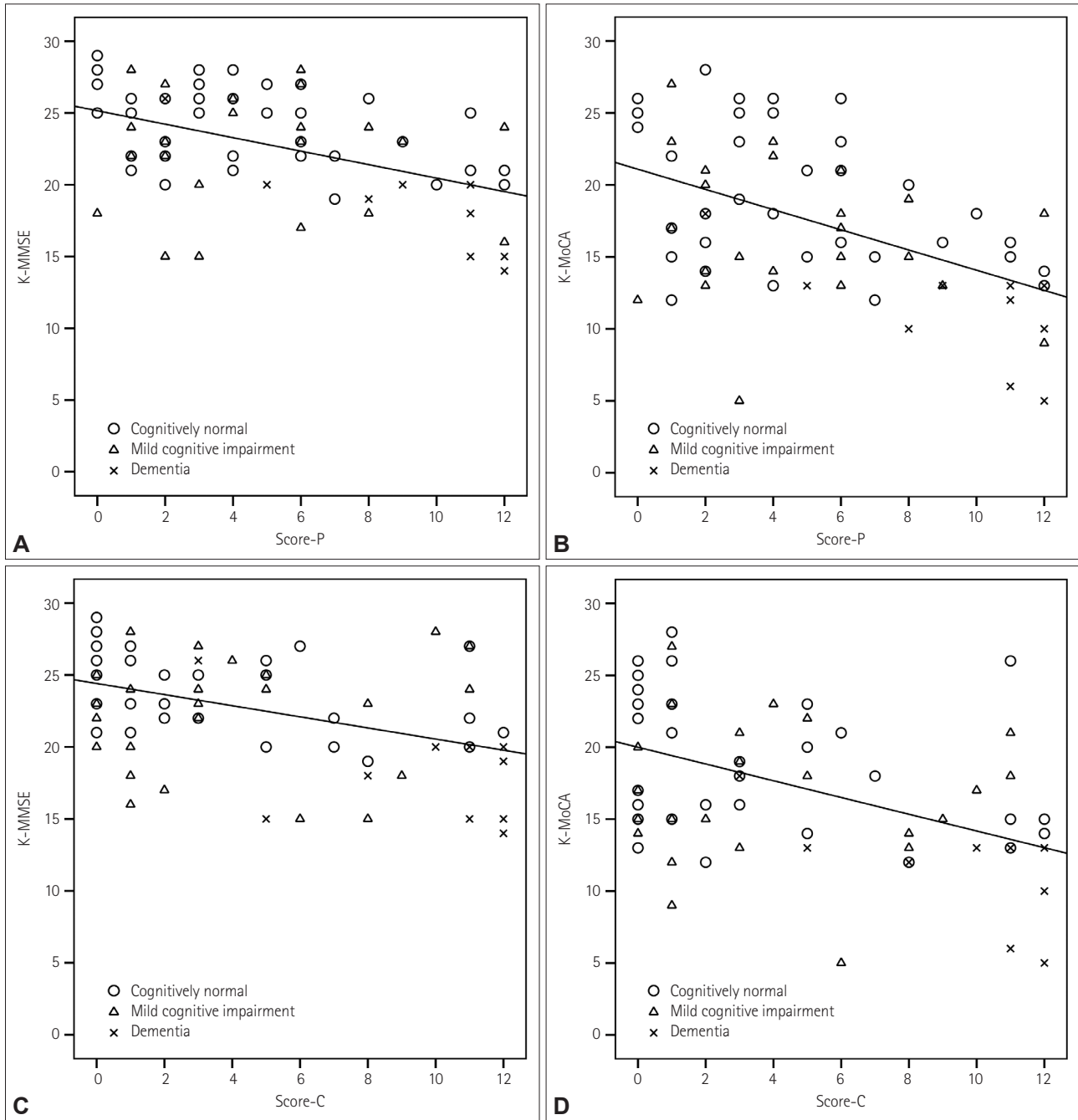


Fig. 2. Correlations between SCCQ-PD scores and general cognition. Both score-P (A, B) and score-C (C, D) were negatively correlated with both K-MMSE and K-MoCA scores. K-MMSE, Korean version of the Mini-Mental State Examination; K-MoCA, Korean version of the Montreal Cognitive Assessment; SCCQ-PD, Subjective Cognitive Complaints Questionnaire for Parkinson's Disease; score-C, score rated by caregivers; score-P, score rated by patients.

givers were comparable. It is unclear why cognitive anosognosia is absent in patients with PD, but this might be due to differences in the pathophysiology of cognitive impairment between AD and PD.

Both score-P and score-C were strongly correlated with the K-MMSE score, K-MoCA score, and all subsets of the neuropsychological battery. While many previous studies have

found significant correlations between SCCs and cognitive performance,^{27,28,32,33} several studies did not.³⁴⁻³⁶ This discrepancy could be due to differences in methodologies, including in the assessment of SCCs, cognitive level of subjects, neuropsychological tests, and adjusted factors. SCCs in both AD and PD have been reported to be associated with psychiatric symptoms, especially depression. This was also observed in

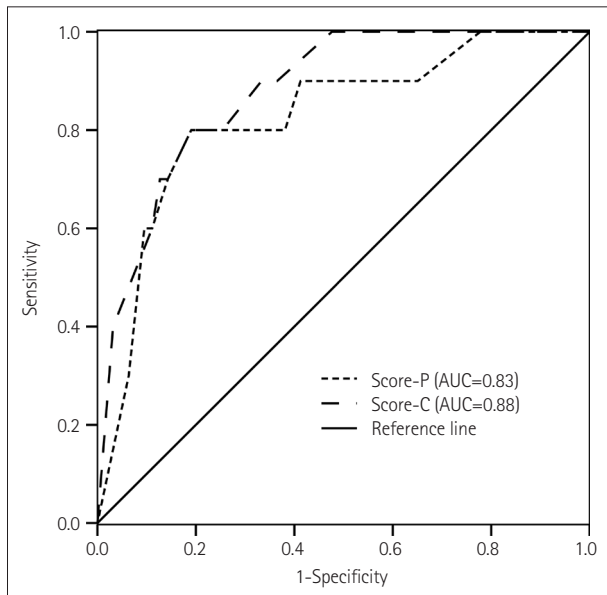


Fig. 3. Receiver operating characteristic curves for discriminating dementia from mild cognitive impairment and normal cognition. AUC, area under the receiver operating characteristic curve; score-C, score rated by caregivers; score-P, score rated by patients.

the present study, with both score-P and score-C being strongly correlated with the depression score. However, after adjustment for covariates including depression score, both score-P and score-C were correlated with the K-MMSE and K-MO-CA scores as well as the performance in approximately half of the items of the neuropsychological battery. Therefore, the SCCQ-PD score is correlated with cognitive performance independently of depression severity.

The ROC curves showed that both score-P and score-C have excellent discriminative power, and both scores have the same optimal criterion of ≥ 8 for a diagnosis of dementia. Indeed, both scores increase as cognitive level declines, and the two scores exhibit a moderate intercorrelation. SCCQ-PD scores were significantly higher in patients with dementia than in those with normal cognition or MCI, while they did not differ significantly between the cognitively normal and MCI patients. This pattern has also been observed in a previous study, which found that the Cognitive Complaint Interview (CCI), a SCC questionnaire, was excellent in discriminating dementia but not cognitive impairment (MCI and dementia) from normal cognition.³² Dujardin et al.¹⁸ reported that the CCI is poor in discriminating cognitive impairment from normal cognition. These findings indicate that SCCs are useful for detecting dementia but not MCI. In the same context, several previous studies involving patients with normal cognition³⁵⁻³⁸ and MCI³⁶ but not dementia did not observe significant differences in cognitive performance between patients with and without SCCs.

This study had several limitations. First, the number of subjects was relatively small, especially for patients with dementia. Second, the study subjects were relatively old and had a relatively short duration of education, and so floor effects of the K-MMSE and K-MoCA might have weakened in the findings. Third, it is unclear whether SCCs measured by the SCCQ-PD are clinically meaningful. Further studies are therefore needed to test the relationship between SCCQ-PD scores and pathological burden, and to explore the predictive value of the SCCQ-PD for long-term cognitive decline. Finally, this study did not include pathological data or functional neuroimaging data, and hence it is possible that coexisting beta-amyloid pathology was present.^{39,40}

In summary, the SCCQ-PD is a reliable tool for assessing SCCs in patients with PD. SCCQ-PD scores rated by patients and caregivers were both strongly correlated with the objective cognitive performance of patients, and therefore useful for discriminating between patients with and without dementia.

Supplementary Materials

The online-only Data Supplement is available with this article at <https://doi.org/10.3988/jcn.2022.18.2.171>.

Availability of Data and Material

The datasets generated or analyzed during the study are available from the corresponding author on reasonable request.

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Conflicts of Interest

The authors have no potential conflicts of interest to disclose.

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