International Journal of Research in Medical Sciences
Natadidjaja S et al. Int J Res Med Sci. 2023 Apr;11(4):1060-1065
www.msjonline.org
pISSN 2320-6071 | eISSN 2320-6012
DOI: https://dx.doi.org/10.18203/2320-6012.ijrms20230692

Original Research Article

Validation of the Indonesian version of the non-motor symptoms scale for Parkinson's disease

Stella Natadidjaja*, Sekplin A. S. Sekeon, Rizal Tumewah

Department of Neurology, Faculty of Medicine, Sam Ratulangi University/R.D. Kandou Hospital Manado, Indonesia

Received: 26 February 2023
Accepted: 13 March 2023

***Correspondence:**
Dr. Stella Natadidjaja,
E-mail: stella.natadidjaja@yahoo.com

ABSTRACT

Background: Non-motor symptoms are common, have a wide range of symptoms, and have emerged as a key determinant of poor quality of life (QoL) in Parkinson's disease (PD) patients, contributing to severe disability, and shortened life expectancy. However, although common, the non-motor symptoms of PD are often not well recognized and under-reported in clinical practice. This study aimed to translate the origin non-motor symptoms scale for PD (NMSS), which was written in English, into an Indonesian version and to evaluate its reliability and validity.
Methods: Linguistic validation and psychometric analysis of the Indonesian version of NMSS were conducted in 70 patients with PD using a cross-sectional study. The acceptability, reliability, and construct validity of NMSS were analyzed. Test-retest reliability was assessed over a time interval of 14 days in all patients.
Results: The 70 patients were assessed (median age 67.5 years; 57.1% males; median duration of illness 48 months; median Hoehn and Yahr stage: 3). Mean NMSS was 51.86 (SD 44.02; median 37). Neither floor nor ceiling effect was observed on the Indonesian version of the NMSS total score. Validity test using Pearson product moment showed all 9 domains Indonesian version of NMSS were valid ($r=0.506-0.805$, $p<0.001$). NMSS total score showed satisfactory reliability (Cronbach's α coefficient on the total score was 0.852, the range for domains: 0.146-0.814).
Conclusions: Indonesian version of NMSS showed good reliability and validity for the assessment of non-motor symptoms in PD patients in Indonesia.

Keywords: PD, Non-motor symptoms scale, Validation, Reliability, Non-motor symptoms

INTRODUCTION

Parkinson's disease (PD) is a progressive and complex multi-systemic neurodegenerative disorder, characterized by a combination of cardinal motor symptoms (bradykinesia, rigidity, resting tremor, and postural instability) as well as a wide range of non-motor symptoms (NMS) that contribute to significant morbidity and disability.[1,2] Patients with PD experience a wide range of NMS which could manifest as sleep, neuropsychiatric, autonomic, and sensory disturbances, and the NMS worsen with disease progression.[3,4] Non-motor symptoms occur in both early and advanced stages of PD. Some symptoms, for example, olfactory disturbance, depression, rapid-eye-movement sleep behavior disorder (RBD), and constipation, can even precede the appearance of motor symptoms for many years (considered prodromal signs).[1,2] While common, they are still often underrecognized and undertreated in clinical practice because patients rarely mention them, and healthcare professionals fail to ask in details about them because they often don't recognize those symptoms are related to PD.[2,3] There is also a common perception that many of these symptoms are untreatable.[5] As the average age and life expectancy of the population increases, the NMS become increasingly important.[4,6] To improve the identification of NMS, and to evaluate new and existing strategies for PD treatment, quantitative and validated instruments for assessment of NMS individually and in an integrated way are needed.[6]

The introduction of self-reported tools such as the non-motoric symptoms questionnaire (NMSQuest, NMSQ) or a health professional administered tool such nonmotor symptoms scale (NMSS) makes systematic and comprehensive rather than an individual assessment of NMS now possible internationally.[7] The NMSS was developed and validated in 2007 as the first instrument for the objective, comprehensive and reliable assessment tool of a range of NMS in PD.[8,9] The NMSS has been translated from English into many languages, including German, Korean, Chinese, Italian, Spanish, Brazilian, and Japanese, and validity and reliability test were conducted.[9]

Early recognition and management of NMS in PD patients are important for maintaining a good QoL.[1] The NMSS can be used as a suitable tool for screening and early detection of NMS in clinical practice in Indonesia, but the NMSS has not yet been translated into Indonesian until now. This study aimed to evaluate the validity and reliability of the Indonesian version of NMSS so it can be used as a good measure for NMS in Indonesian patients with PD.

METHODS

Study participants

Seventy consecutive patients with PD were enrolled in the outpatient neurology clinic Kandou hospital in Manado, Indonesia, between July and October 2022.

Definition and inclusion/exclusion criteria

Patients with age ≥18 years old, diagnosed according to the clinical diagnostic criteria of the United Kingdom Parkinson's Disease Society Brain Bank were recruited in this study.[10] Those patients with other neurological disorders besides PD, such as stroke, for example, were excluded from this study. Written informed consent to participate was obtained from all patients. The institutional review board has approved the study protocol.

Assessment

Demographic data including age, gender, and information on the disease (such as length of disease) were retrieved from patients through interviews. All patients underwent a clinical examination, and their PD severity was evaluated by Hoehn and Yahr scale.

All patients were interviewed using the Indonesian version of NMSS in regular follow-up visits. The NMSS is a 30-item measure whose items are grouped into nine relevant domains: Cardiovascular (2 items); sleep/fatigue (4 items); mood/apathy (6 items); perceptual problems/ hallucinations (3 items); attention/memory (3 items); gastrointestinal tract (3 items); urinary function (3 items); sexual function (2 items); and miscellaneous (4 items). The score for each item (NMS symptomatic burden) is based on a multiple of severity (from 0 to 3) and frequency scores (from 1 to 4) and the time frame covered is the past month. The range for the NMSS total scores is 0-360.[8,9]

To evaluate the stability of the Indonesian version of NMSS (test-retest reliability) was assessed through repeated interviews over a time interval of 14 days to all patients.

Adaptation of the NMSS

The NMSS was adapted into the Indonesian language from the original English version following a translation protocol based on international standard protocol. First, the NMSS was translated into Indonesian by two professional translators, and then a reconciled version was elaborated by discussion and consensus. This reconciled version was pre-tested on 5 patients with PD to assess their understanding of the questions. The results of the interviews were discussed, and modifications were made. Second, a professional translator, who is different from the translators who performed the original English-to-Indonesian translation, had no knowledge of the English original NMSS scale, translated the reconciled version back into English. This backward translation was compared to the original version to verify the equivalence of the two English versions in terms of meaning and conceptual content and evaluate the discrepancies between the original English version and this backward translation. The final translated instrument was then pre-tested on 5 more patients with PD to assess their understanding of the final questions. No major issues were found during the last pre-testing phase. These processes resulted in the final Indonesian version of NMSS.[11] The International Parkinson and Movement Disorder Society (MDS) who own the original NMSS scale has given the permission to translate and validate this NMSS scale into Indonesian.

Data analysis

The range of scores, the floor and ceiling effects (proportion of patients who obtained minimum and maximum scores, respectively; maximum acceptable for both, 15%) were calculated.

Validity was tested by Pearson product moment methods, where calculated r was compared to table r value, if calculated r was significantly higher than table r value, it was considered valid (table r value was taken by Pearson correlation table, table r value using 2-tailed, $p<0.05$ for 70 samples was 0.232).[12]

Reliability was tested for both internal consistency and the stability of measures. Internal consistency was assessed by Cronbach's α coefficient (values ≥ 0.70 was considered acceptable).[13] Test-retest reliability with time interval of 14 days was assessed by using intraclass correlation coefficients (ICC, value ≥0.75 was considered good reliability).[14] Statistical analyses were conducted

using the Statistical Package for the Social Science (SPSS 23).

RESULTS

Total of 70 patients were recruited in this study (median age 67.5, range 42-83 years old; 57.1% males; median duration of PD 48 months, range 2-250 months). Based on Hoehn and Yahr scale, there were 4 patients at stage 1 (5.7%), 29 patients at stage 2 (41.4%), 26 patients at stage 3 (37.1%), 11 patients at stage IV (15.7%), and 0 patients at stage 5 (Median Hoehn and Yahr scale was 3) (Table 1). This finding was compared with similar data from original study (Chaudhuri et al), Chinese, Italian, Korean, and Brazilian studies.

Mean NMSS total score was 51.86±44.02 (range 4-199, from possible maximum score of 360; median 37). Pearson product moment method showed all calculated r results for 9 domains Indonesian version of NMSS >r table, so all domains in the Indonesian version of NMSS were valid (Table 2).

Cronbach's α coefficient for NMSS total score was 0.853. The Cronbach's α coefficients for the 9 NMSS domains were 0.274, 0.565, 0.702, 0.534, 0.806, 0.666, 0.701, 0.814, and 0.146 respectively (Table 4). Corrected item-total correlations showed tools had good construct validity (r≥0.3), except item restless leg, double vision, frequency, taste/smell, and excessive sweating (Table 3). For those dimensions with only 2 items, the item-total (corrected) correlation was the inter-item correlation.

Table 1: Characteristics of patients with PD.

Variables	N (%)
Sex	
Male	40 (57.1)
Female	30 (42.9)
Age (years)	67.5 (42-83)
Duration (months)	48 (2-252)
Hoehn and Yahr scale	
Stage 1	4 (5.7)
Stage 2	29 (41.5)
Stage 3	26 (37.1)
Stage 4	11 (15.7)
Stage 5	0

Data in median (min-max), except stated in other forms.

ICC values obtained from test-retest reliability of the Indonesian version of NMSS ranged from 0.97-0.99 and ICC value for the total NMSS score was 0.99 (Table 4).

Table 2: Calculated R for each domain of the Indonesian version of NMSS.

Domain	Table R	Calculated R	Result	P value
Cardiovascular	0.232	0.670	Valid	<0.001
Sleep/fatigue	0.232	0.770	Valid	<0.001
Mood/cognition	0.232	0.805	Valid	<0.001
Perceptual problem/ hallucination	0.232	0.692	Valid	<0.001
Attention/ memory	0.232	0.719	Valid	<0.001
Gastrointestinal	0.232	0.741	Valid	<0.001
Urinary	0.232	0.669	Valid	<0.001
Sexual dysfunction	0.232	0.665	Valid	<0.001
Miscellaneous	0.232	0.506	Valid	<0.001

Table 3: Item-total correlation of the Indonesian version of NMSS.

Non-motor symptoms scale	Corrected item-total correlations*	Cronbach's α if item deleted
Cardiovascular		
Light-headedness	0.528	0.730
Fainting		0.741
Sleep/fatigue		
Daytime sleep	0.499	0.733
Fatigue	0.627	0.729
Difficulty falling asleep	0.553	0.728
Restless legs	0.211	0.739
Mood/cognition		
Lost interest in surroundings	0.385	0.737
Lack motivation	0.565	0.732
Feel nervous	0.579	0.731
Seem sad	0.650	0.731
Flat mood	0.304	0.739
Difficulty experiencing pleasure	0.384	0.737
Perceptual problems		
Hallucinations	0.659	0.729
Delusions	0.548	0.735
Double vision	0.05	0.742

Continued.

Non-motor symptoms scale	Corrected item-total correlations*	Cronbach's α if item deleted
Attention/ memory		
Concentration	0.544	0.742
Forget things or events	0.597	0.728
Forget to do things	0.624	0.729
Gastrointestinal		
Saliva	0.494	0.732
Swallowing	0.573	0.730
Constipation	0.573	0.728
Urinary		
Urgency	0.614	0.728
Frequency	0.284	0.737
Nocturia	0.586	0.730
Sexual dysfunction		
Interest in sex	0.687	0.727
Problems having sex		0.727
Miscellaneous		
Pains	0.464	0.735
Taste or smell	0.140	0.740
Weight change	0.347	0.739
Excessive sweating	0.031	0.742

*In domains with two items, interitem correlation.

Table 4: Acceptability, internal consistency, and test-retest reliability of the Indonesian version of NMSS.

NMSS	Median	Min	Max	Floor effect, (%)	Ceiling effect, (%)	Cronbach α	ICC
Cardiovascular	1	0	15	42.9	1.4	0.274	0.977
Sleep/ fatigue	6	0	30	17.1	1.4	0.565	0.991
Mood/ cognition	2	0	45	34.3	1.4	0.702	0.996
Perceptual problem/ hallucination	0	0	24	61.4	1.4	0.534	0.999
Attention/ memory	3	0	33	27.1	1.4	0.806	0.995
Gastrointestinal	4	0	32	22.9	2.9	0.666	0.993
Urinary	5	0	36	5.7	2.9	0.701	0.997
Sexual dysfunction	4	0	24	24.3	5.7	0.814	0.996
Miscellaneous	0	0	14	51.4	1.4	0.146	0.979
Total score	37	4	199	1.4	1.4	0.853	0.997

*ICC, intraclass coefficient correlation.

DISCUSSION

Scales that can be used to detect and evaluate the severity of the wide and complex range of NMS in patients with all stages of PD are important for comprehensive PD management and QoL in patients with PD. This study translated the NMSS into Indonesian and evaluated its validity and reliability for NMS assessment in Indonesia. The subject populations in the present study were similar to Chaudhury et al study (original study), Cova et al study (Italia), Carod-Artal et al study (Brazilian), Seong-Beom et al study (Korea), and Gang-Wang et al study (China), which reported characteristics of subjects were predominantly males, with median or mean age was in the sixth decade, and most patients were in Hoehn & Yahr Stage 2-3, but differed in the duration of illness, this study subjects had a shorter duration (48 months or 4 years vs 6.4 years [Chaudhuri et al] vs 8.5 years [Carod-Artal et al Brazilian study] versus 6.3 years [Cova et al, Italian study]). This finding was in accordance with the PD epidemiology study that stated the female was less affected than male and that PD usually starts at age 40-70 years old and reached its peak in the sixth decade.[3,8,15-18] In this study, there were only 5.7% patients in Hoehn and Yahr stage 1 and none in stage 5. Patients in Hoehn and Yahr stage 5 were rarely brought to the outpatient clinic, possibly because their conditions may be too severe and bed-bound, and it may explain why this study had none patients in Hoehn and Yahr stage 5. This result could cause an underrepresented NMS profile, especially for the most extreme severity classification. Patients in Hoehn and Yahr stage 1 usually had mild symptoms and few complications, so they often got treated at satellite hospitals or public health centers, and didn't go to Kandou hospital as the main referral hospital in North Sulawesi.

The mean Indonesian version of the NMSS total score was 51.86±44.02, range 4-199, median 37, not as severe as in the original Chaudhuri study (56.5±40.7, range 0-243), but higher than that found using the NMSS in the Korean study (43.87±42.34, range 0-194), in Italian study (39.7±31.9, range 0-154), in Brazilian study (48.9±36.3, range 1-211) and in Chinese study (31.06±30.88, range 0-177).[8,15-18] The differences in age, duration of illness, ethnicity, and motor severity stages in the recruited subject populations may cause this results.[15]

As in the original validation study and an Italian study, the Indonesian version of the NMSS total score was free of both floor and ceiling effects. Similarly, none of the domains showed a ceiling effect, while a significant floor effect (>15%) was found in all domains except the urinary domain (in the Italian study, floor effect was found in all domains). The most prominent floor effects in this study were observed in the cardiovascular domain (42.9%), perceptual problems/hallucinations domain (61.4%), and miscellaneous domain (51.4%).[8,15] NMSS is a comprehensive tool assessing many different and often unrelated symptoms not necessarily related to each other domains. Therefore, there was expectation that a proportion of patients will have symptoms in one or more domains, but rarely in all the included domains. This explanation may answer why the less prevalent symptoms have the highest floor effects for their domains.[8] Carod-Artal et al in a Brazilian study also explained that the prevalence of hallucinations and other perceptual disorders is scarce in epidemiological studies on PD and this fact may explain the result of the highest floor effect of the domain perceptual problems/hallucinations found in the NMSS, as this study showed the same result.[16]

The NMSS total score had a free floor effect and ceiling effect (both 1.4%) this finding was similar to the original study (Chaudhuri et al) and the Italian study.[8,15] It is possible to have a unified score that is free of floor effect considering the diversity of symptoms and their relative prevalence.[8]

The validity test using Pearson product moment showed that calculated r for 9 domains the Indonesian version of NMSS were larger than the table r value so all 9 domains were valid. The corrected item-total correlations showed that the Indonesian version of NMSS had good enough construct validity ($r \geq 0.3$) except for the item restless leg, double vision, frequency, taste or smell, and excessive sweating. Chaudhuri from the original study also found low item-total correlation values for item saliva, swallowing, constipation, pains, weight change, and excessive sweating. But the items are maintained because they contained relevant and important symptoms, as the results of the NMSQuest study showed.[8] Restless leg, double vision, frequency, and excessive sweating were also maintained in this study, because they were also regarded as important as well as the relevant to make NMSS a tool that can evaluate a wide range of symptoms in the PD.

Cronbach's α-coefficient estimates the reliability of a tool, by determining the internal consistency or the average correlation of domains within the tool. It has range from 0 to 1, with higher score indicating a more reliable scale. The considered acceptable reliability is 0.7.[18] Cronbach's α-coefficient for the Indonesian version of NMSS total score was 0.853, indicating a good internal consistency.

In this study, Cronbach's α-coefficient for each of 9 domains NMSS was 0.274 for the cardiovascular domain, 0.565 for the sleep/fatigue domain, 0.702 for the mood/cognition domain, 0.534 for the perceptual problems/hallucination domain, 0.806 for the attention/memory domain, 0.666 for the gastrointestinal domain, 0.701 for the urinary domain, 0.814 for the sexual dysfunction domain, and 0.146 for the miscellaneous domain. The original study (Chaudhuri et al) also found only four domains showed Cronbach's α-coefficient ≥ 0.70, but the rest was less than 0.70.[8] The low alpha value detected in some NMSS domains may be explained by the inclusion of some items for assessment of complex non-motor domains, when items are not strongly related to each other.[16]

The test-retest reliability from the Indonesian version of NMSS exhibited very satisfactory results, the range of ICC value was 0.97-0.99. The test-retest reliability of the Indonesian version of the NMSS total score was 0.99. This finding was better than the original study (Chaudhuri et al) which showed all dimensions had ICC values higher than 0.80, except for cardiovascular (ICC=0.45) and the China study which had range of ICC 0.28-1, with an ICC value of NMSS total score was 0.99.[8,17] The good reliability result was probably caused by time interval repeat examination in this study was 14 days, too short to get a significant change of NMS or for a new NMS emerge from the previous assessment.

The main limitation of the present study, similar to a few previous studies, is the relatively low number of PD patients at both extreme of the severity stage, especially Hoehn and Yahr stage 5 (none patient). The advanced stage of PD may have been underrepresented. Therefore, a large scale study including more patients with PD, especially in either extreme severity stage, may help to provide a more complete profile of NMS in Indonesian patients with PD, and the next study could compare the Indonesian version of NMSS to other measures such as, for instance, MMSE, Scopa-Aut INA, Epworth Sleepiness Scale, to evaluate the correlation between such measures to support the Indonesian version of NMSS as a comprehensive tool.

CONCLUSION

In conclusion, this study suggests that the Indonesian version of NMSS is a reliable and valid instrument to assess the NMS of PD patients and can be properly used and helpful in the assessment of patients PD in clinical practice in Indonesia.

ACKNOWLEDGEMENTS

Author would like to thanks to Dr. Chaudhuri for his permission to translate and use the NMSS in this research.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

REFERENCES

1. Lee HM, Koh SB. Many faces of Parkinson's disease: non-motor symptoms of Parkinson's disease. JMD. 2015;8(2):92-7.
2. Valkovic P, Harsany J, Hanakova M, Martinkova J, Benetin J. Nonmotor Symptoms in early- and advanced-stage Parkinson's disease patients on dopaminergic therapy: how do they correlate with quality of life? Neurology. 2014;2014:1-4.
3. Syamsudin T, Akbar M. Buku panduan tatalaksana penyakit Parkinson dan gangguan gerak lainnya. PERDOSSI. 2015.
4. Ragab OA, Elheneedy YA, Bahnasy WS. Non-motor symptoms in newly diagnosed Parkinson's disease patients. Egypt J Neurol Psychiatry Neurosurg. 2019;55(1):24.
5. Chaudhuri KR, Schapira AH. Non-motor symptoms of Parkinson's disease: dopaminergic pathophysiology and treatment. The Lancet Neurol. 2009;8(5):464-74.
6. Chaudhuri KR, Healy DG, Schapira AHV. Non-motor symptoms of Parkinson's disease: diagnosis and management. The Lancet Neurol. 2006;5:235-45.
7. Sauerbier A, Jitkritsadakul O, Titova N, Klingelhoefer L, Tsuboi Y, Carr H et al. Non-motor symptoms assessed by non-motor symptoms questionnaire and non-motor symptoms scale in Parkinson's disease in selected asian populations. Neuroepidemiology. 2017;49(1-2):1-17.
8. Chaudhuri KR, Martinez-Martin P, Brown RG, Sethi K, Stocchi F, Odin P et al. The metric properties of a novel non-motor symptoms scale for Parkinson's disease: results from an international pilot study. Mov Disord. 2007;22(13):1901-11.
9. Van Wamelen DJ, Martinez-Martin P, Weintraub D, Schrag A, Antonini A, Falup-Pecurariu C et al. The non-motor symptoms scale in Parkinson's disease: validation and use. Acta Neurol Scand. 2021;143(1):3-12.
10. Aninditha T, Wiratman W, editors. Buku Ajar Neurologi. Vol. Buku 1. Tangerang: Penerbit Kedokteran Indonesia. 2017;342.
11. Leman MA. Cara praktis melakukan uji validitas alat ukur penelitian. Yogyakarta: Gosyen Publishing. 2018;133.
12. Hastono SP. Modul analisis data. Jakarta: Fakultas Kesehatan Masyarakat UI. 2006;219.
13. Heale R, Twycross A. Validity and reliability in quantitative studies. Evid Based Nurs. 2015;18(3):66-7.
14. Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. J Chiropractic Med. 2016;15(2):155-63.
15. Cova I, Di Battista ME, Vanacore N, Papi CP, Alampi G, Rubino A et al. Validation of the Italian version of the non-motor symptoms scale for Parkinson's disease. Parkinsonism Rel Disorders. 2017;34:38-42.
16. Carod-Artal FJ, Martinez-Martin P. Independent validation of the non motor Symptoms Scale for Parkinson's disease in Brazilian patients. Parkinsonism Rel Disord. 2013;19(1):115-9.
17. Wang G, Hong Z, Cheng Q, Xiao Q, Wang Y, Zhang J et al. Validation of the Chinese non-motor symptoms scale for Parkinson's disease: results from a Chinese pilot study. Clin Neurol Neurosurg. 2009;111(6):523-6.
18. Koh SB, Kim JW, Ma HI, Ahn TB, Cho JW, Lee PH et al. Validation of the Korean-Version of the nonmotor symptoms scale for Parkinson's disease. J Clin Neurol. 2012;8(4):276.

Cite this article as: Natadidjaja S, Sekeon SAS, Tumewah R. Validation of the Indonesian version of the non-motor symptoms scale for Parkinson's disease. Int J Res Med Sci 2023;11:1060-5.