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Use of the World Health Organization Quality of Life assessment short version in mild to moderate Parkinson's disease

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Abstract

Objective—To investigate the distribution, internal consistency reliability, and convergent and discriminant validity of the World Health Organization QOL assessment short version (WHOQOL-BREF) in persons with mild to moderate PD.

Design—Cross-sectional.

Setting—Movement disorders center.

Participants—Convenience sample of people with PD ($n = 96$) recruited from a movement disorders center and controls ($n = 60$) recruited from the community.

Interventions—Not applicable.

Main Outcome Measure—WHOQOL-BREF.

Results—The WHOQOL-BREF domain data were relatively normally distributed and internal consistency reliability was acceptable ($\alpha = 0.65-0.85$). PD participants reported lower QOL than controls in all except the Environment domain, and Physical QOL was the most impaired domain in the PD group. Age, fatigue and physical activity limitations predicted Physical QOL; depression, fatigue and apathy predicted Psychological QOL; education, executive dysfunction and apathy predicted Social QOL; and age, education, depression and apathy predicted Environment QOL.

Conclusion—The WHOQOL-BREF is a suitable tool to assess QOL in mild to moderate PD. It is relatively normally distributed, internally consistent, effectively discriminates between

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individuals with and without PD, and correlates with relevant demographic characteristics, PD-related impairments and activity limitations.

Keywords

Parkinson's disease; quality of life; outcome measures; psychometrics

Parkinson's disease (PD) has broad and heterogeneous effects on daily life^{1,2}. Patient-reported outcome measures (PROs) are increasingly used to understand these issues because they convey information not directly observable in research or clinical settings (e.g., satisfaction, daily function)³. The patient's experience is a determinant of treatment value, and using PROs can facilitate treatments that address patients' needs and priorities⁴.

Patient-reported quality of life (QOL) is an important outcome for chronic conditions like PD^{3,5}. 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" (p. 1405)⁶. It is a multidimensional construct encompassing physical and psychological health, independence, social relationships, the environment, and personal beliefs⁶. Health-related QOL (HRQOL), a specific type of QOL, focuses on the impact of disease and treatment on physical, psychological, and social functioning^{3,7}. Importantly, QOL and HRQOL (subsequently termed (HR)QOL when referencing both constructs) reflect the person's evaluation of, or reaction to, relevant aspects of their life rather than being merely a description of those aspects⁸.

A systematic review of so-called (HR)QOL scales used in PD found that most actually assess "health status"⁹. Health status scales assess perceived health and functioning but not the internal experience of said functioning^{7,8}. In other words, "[health status] indicates whether there are limitations whereas [HR]QOL also reflects to what extent a patient is bothered by these limitations in daily life" (p. 1052)¹⁰. Variability in the importance people assign to various aspects of function or in adaptation to functional changes limits extrapolation of (HR)QOL from health status data^{5,11}. Therefore, results from health status scales are an approximation of (HR)QOL at best^{9,11}. Using (HR)QOL scales in conjunction with health status scales provides a more comprehensive view of peoples' health, function, and well-being. There is a need to identify such scales to use in PD⁹.

The WHO Quality of Life assessment short version (WHOQOL-BREF)¹² was one of only two "real" (HR)QOL scales used in PD at the time of the aforementioned review⁹. The WHOQOL-BREF is a generic QOL measure developed from extensive research on QOL and health care and deemed reliable and cross-culturally valid from large field studies of well and sick people^{13,14}. Although it shows good psychometric properties, is an NINDS Common Data Element for PD¹⁵, and is widely used in non-PD populations, it was labelled "Suggested" rather than "Recommended" for PD due to limited use and clinimetric testing specifically in PD¹⁶. The WHOQOL-BREF's strong psychometric properties in other populations suggest it is an appropriate candidate for clinimetric testing in PD. If it has evidence for reliable and valid use in persons with PD, it could help fill the noted gap in measurement of (HR)QOL in this population. Moreover, since it has been validated across

many cultures and conditions and is available in most major languages, it could enhance our understanding of the impact of PD by facilitating multinational research and comparison of PD-related QOL to that of other clinical populations.

Another HRQOL instrument is now available in which persons with PD participated in development. The Neuro-QOL Measurement System has a number of domains that are comparable to the WHOQOL-BREF¹⁷. However, Neuro-QOL does not include some of the environmental domains found in the WHOQOL-BREF (e.g., home environment, access to health care, transportation) that are relevant to rehabilitation professionals. It too requires further testing in PD, but like the WHOQOL-BREF, could enhance (HR)QOL measurement in PD.

This study investigated the data distributions, internal consistency reliability, and convergent and discriminant validity of the WHOQOL-BREF with a sample of persons with mild to moderate PD. The WHOQOL-BREF and measures of PD-related impairments and activities of daily living (ADL) were administered to individuals with mild to moderate PD and healthy adults. We hypothesized that, in addition to having near-normal data distributions and acceptable internal consistency, the WHOQOL-BREF would discriminate between individuals with and without PD, and within PD, QOL related to physical functioning would be the lowest. We also expected that physical function measures would be more strongly associated with physical QOL than psychological QOL and mental function measures would be more strongly associated with psychological QOL than physical QOL.

Methods

Participants

This study was approved by the university's internal review board, and all participants provided written informed consent. PD participants were recruited from a movement disorders center. All were diagnosed with idiopathic typical PD¹⁸ and were Hoehn and Yahr stage I-III¹⁹. Exclusionary criteria included: suspected dementia (by physician, caregiver report, or a score <25 on the Mini Mental Status Exam, MMSE²⁰), other neurological conditions, brain surgery, history/current psychotic disorder, or any condition that would interfere with participation (e.g., non-English speaking). Control participants were recruited from the community. The aforementioned exclusionary criteria applied to the control group plus the presence of PD, a biological family history of PD, and being a care-partner of someone with PD.

Procedure

The primary data reported in this manuscript were collected via PROs administered as part of a larger observational, cross-sectional study of daily function and QOL in PD. Participants completed the PROs during an in-clinic testing session or at home prior to the session. Demographic information was collected and the MMSE²⁰ was administered during the testing session. Trained research assistants performed all data collection.

Measures

The WHOQOL-BREF^{12,21} is a 26-item PRO that produces four domain scores (Physical Health, Psychological Health, Social Relationships, Environment). There are also two separately scored items that assess Overall QOL and General Health Satisfaction. Items are answered on a 5-point scale in relation to a two week timeframe. The mean of items within each domain is multiplied by four to yield the domain score (range 4–20). If 2 items are missing, the mean of the other items from the domain is substituted (except for the Social domain, for which only 1 item can be missing). Higher scores indicate higher QOL.

Standardized PROs and PD-related clinical characteristics were used to describe the PD sample and/or examine convergent and discriminant validity of the WHOQOL-BREF in PD. The Dysexecutive Questionnaire (DEX, 20 items)²² assessed everyday executive functioning, Beck Depression Inventory II (BDI-II, 21 items)²³ assessed depressive symptoms, Liebowitz Social Anxiety Scale (LSAS, 24 items)²⁴ assessed anxiety related to social situations, Apathy Evaluation Scale (AES, 18 items)²⁵ assessed apathetic thoughts, emotions, and actions, and Parkinson's Disease Fatigue Scale (PDFS, 16 items)²⁶ assessed physical aspects of fatigue. Higher scores on all of these measures indicate worse impairment. The self-report Performance Assessment of Self-Care Skills (PASS)^{27,28} assessed 12 physically and 14 cognitively demanding ADL with higher scores indicating better ADL function. PD-related clinical characteristics from within three months of data collection were obtained from clinic records (Hoehn and Yahr stage, Unified Parkinson's disease Rating Scale Motor subscale score [UPDRS Motor]²⁹, disease duration, levodopa equivalent daily dose, [LEDD]).

Analysis

Data were stored and managed using REDCap electronic data capture tools³⁰ and analyzed using IBM SPSS Statistics 22^a. Descriptive statistics were calculated for all variables, and distributions were visually inspected for normality. For group comparisons of participant characteristics, independent samples *t*-tests were used for continuous data, and χ^2 tests were used for categorical data. Skewness, kurtosis, missing data (number of unanswered items), and floor/ceiling effects were calculated for the WHOQOL-BREF domains, Overall QOL and General Health Satisfaction. Skewness and kurtosis values ± 2 SE of skewness or kurtosis were considered to indicate skewed or leptoplatic distributions, respectively³¹. Floor or ceiling effects were considered present if $\geq 15\%$ of respondents achieved the lowest or highest possible score, respectively³². Internal consistency reliability was determined using Cronbach α . To assess discriminant validity, a mixed ANOVA compared WHOQOL-BREF scores across group (PD, control) and domain (Physical, Psychological, Social, Environment), and Mann-Whitney *U* tests compared Overall QOL and General Health Satisfaction across group. Correlational analyses were used to explore the relationships between WHOQOL-BREF domain scores and other variables to assess their convergent and discriminant validity. Bivariate correlations (Pearson *r*) assessed the relationships between participant characteristics (continuous variables only), impairments,

^aSuppliers

IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0 Armonk, NY: IBM Corp.

and ADL function and domain scores. Significant correlations between impairments and ADL function and the Physical and Psychological domain scores were then compared using Steiger's Z calculations to determine whether they differed significantly in strength^{33,34}. Specifically, to test the hypotheses that indicators of physical function would be more strongly associated with Physical QOL than indicators of mental function, and indicators of mental function would be more strongly associated with Psychological QOL than indicators of physical function. The PDFS and Physical ADL scores were physical function indicators while the DEX, BDI-II, LSAS, AES and Cognitive ADL scores were mental function indicators. Multiple linear regression analysis was then used to determine the strongest independent predictors of QOL in this sample. Separate models were conducted for each domain. Significant variables from the bivariate correlations were entered as predictors in two blocks using stepwise entry (due to the exploratory nature of the analysis and to obtain the most parsimonious models): demographic or clinical characteristics were entered in the first block (age, education, LEDD), and impairment and ADL scores were entered in the second block. All tests were two-tailed, and $p < 0.05$ was considered significant.

Results

Participant Characteristics

The PD and control groups were comparable on most characteristics (Table 1). However, the PD group included more Caucasian and fewer African American participants and had higher depression scores.

Distribution and Internal Consistency of the WHOQOL-BREF in PD (Table 2)

All subscales had relatively normal distributions (Figure 1), except Environment and Overall QOL were somewhat negatively skewed. There was a ceiling effect for Overall QOL, with 24% of the sample (and 47% of the control sample, Supplemental Table 1) having the highest score possible. There were 6 missing data points from 5 participants (2 Physical, 3 Social, 1 Environment); all participants had sufficient data to calculate domain scores using mean substitution. Internal consistency reliability was excellent for the full questionnaire ($\alpha = 0.93$), good for Physical, Psychological, and Environment, and questionable for Social. These data for the control group are in Supplementary Table 1.

Comparison of WHOQOL-BREF Scores across Participant Group and QOL Domain

Domain scores are in Figure 1. There was a main effect of group indicating that, in general, the PD group reported lower QOL than the control group, $F(1, 154) = 13.48$, $p < 0.001$, $\eta^2 = 0.13$. There was a main effect of domain indicating that, in general, Environment scores were higher than the other domains, $F(3, 462) = 31.54$, $p < 0.001$, $\eta^2 = 0.13$. These effects were qualified by a group by domain interaction, $F(1, 462) = 17.49$, $p < 0.001$, $\eta^2 = 0.07$. In terms of the group effect, the PD group had lower Physical, Psychological, and Social but not Environment scores than the control group. In terms of domain, within the PD group, Environment scores were the highest, Psychological and Social scores were intermediate and equivalent to each other, and Physical scores were the lowest. Within the control group, Physical and Environment scores were equivalent to each other and higher than Psychological and Social scores, which were equivalent to each other.

Differences were also observed between PD and control groups for the stand-alone items. The PD group reported lower Overall QOL (PD: $M = 3.97$, $SD = 0.80$; control: $M = 4.33$, $SD = 0.75$; $U = 2158$, $p = 0.004$) and General Health Satisfaction (PD: $M = 2.70$, $SD = 0.95$; control: $M = 3.68$, $SD = 0.95$; $U = 1398$, $p < 0.001$).

Correlates of WHOQOL-BREF Domain Scores in PD

Bivariate correlations (Table 3)—Age correlated with Physical and Environment scores and education correlated with Social and Environment scores, such that older age and higher education were associated with better QOL in these domains. LEDD correlated with Physical and Environment scores such that people taking more antiparkinsonian medication had lower QOL in these domains. Disease duration, UPDRS Motor and MMSE did not correlate with QOL and thus were not included in any of the regression models reported below. All other measures correlated with virtually all of the QOL domains, such that people with more severe impairment and activity limitations had lower QOL. The exception is Physical ADL, which did not correlate with Psychological or Social QOL and thus was not included as a predictor in those regression models.

Steiger's Z analysis (Supplementary Table 2) indicated that the PDFS and Physical ADL were more strongly correlated with Physical QOL than the DEX, BDI-II, LSAS, AES and Cognitive ADL. In addition, the DEX, BDI-II, LSAS, and AES were more strongly correlated with Psychological QOL than Physical ADL; however, the BDI-II was the only mental function indicator more strongly correlated to Psychological QOL than the PDFS.

Independent predictors of QOL (Table 4)—Age, PDFS and Physical ADL accounted for 63% (95% CI: 47-70%) of the variance in Physical QOL, $F(3, 85) = 32.52$, $p < 0.001$. BDI-II, PDFS, and AES accounted for 66% (95% CI: 52-72%) of the variance in Psychological QOL, $F(3, 85) = 52.57$, $p < 0.001$. Education, DEX and AES accounted for 42% (95% CI: 24-52%) of the variance in Social QOL $F(3, 85) = 19.83$, $p < 0.001$. Age, education, BDI-II and AES accounted for 53% (95% CI: 36-63%) of the variance in Environment QOL, $F(4, 79) = 22.85$, $p < 0.001$.

Discussion

This study investigated the WHOQOL-BREF in mild to moderate PD. The WHOQOL-BREF had acceptable distributions and internal consistency reliability, discriminated between individuals with and without PD, and correlated with relevant participant characteristics, impairments and ADL function. These findings support the use of the WHOQOL-BREF as a measure of QOL in PD.

The WHOQOL-BREF had acceptable distributions and internal consistency. Data were relatively normally distributed in each of the subscales with minimal missing data points. The ceiling effect in Overall QOL in both groups indicates this item may not discriminate well in healthy adults or persons with PD. The entire scale and the Physical, Psychological and Environment domains had slightly higher internal consistency reliability than the initial international validation study¹³ and validation studies in other clinical populations^{14,35-37}. Previous studies also found lower reliability in the Social domain, likely because it has only

three items. These findings indicate that the WHOQOL-BREF produces reliable reflections of QOL experiences of individuals with PD and is suitable for use in research.

PD participants reported lower QOL than controls in Physical, Psychological, Social, Overall QOL and General Health Satisfaction. These results are consistent with the body of evidence demonstrating the negative impact of PD on daily function and well-being³⁸. Physical scores were the lowest in PD, which adheres to the categorization of PD as a movement disorder that impacts physical functioning. It is important to note, however, that the WHOQOL-BREF Physical domain includes items assessing non-motor problems, activity limitations, and medical treatment. Given that all of these areas are affected by PD, it is not surprising that QOL was the lowest in this broad domain. Control and PD participants reported similar and relatively high levels of Environment QOL, suggesting this domain may not be as disrupted as other life areas in earlier stages of PD. A study with individuals in later stages or with longer disease duration may uncover important effects of longstanding disease on environment-related QOL.

QOL was not associated with UPDRS Motor score. Previous research in PD has found that motor impairment is a weaker predictor of health status than non-motor problems or functional independence^{39,40}. This study extends these findings to QOL, suggesting motor impairment *per se* is less relevant to patients' lives than non-motor problems or the impact of motor and non-motor problems on functional independence. Alternatively, the lack of correlation between the UPDRS Motor score and WHOQOL-BREF may be due to the mismatch between clinician-rated and patient-reported scales, so future studies should use patient-reported motor function. Regardless, our findings provide further support for the notion that observed motor impairment is an inadequate surrogate marker of QOL in PD.

All of the measured non-motor impairments and ADL function correlated with almost all of the WHOQOL-BREF domains. Taken together, these correlations are in line with concept of (HR)QOL as multifaceted and incorporating many aspects of health and function. However, further analysis revealed specific patterns of association across the QOL domains. Physical and Psychological QOL more strongly correlated with physical and mental function, respectively. Similarly, fatigue and physical activity limitations were independent predictors of Physical QOL while depression, fatigue and apathy were independent predictors of Psychological QOL. Although initially categorized as an indicator of physical function, fatigue was a strong correlate of Physical and Psychological QOL, which corroborates studies showing fatigue is an extremely salient physical and mental experience of people with PD^{41,42}. Overall, these findings provide evidence that the Physical and Psychological WHOQOL-BREF domains can produce reliable and valid measurement of the respective underlying constructs for persons with mild to moderate PD.

Correlations with the Social and Environment domains were generally supportive of their construct validity. Older age was associated with greater Environment and Physical QOL. This is consistent with the notion that PD is more disruptive to QOL earlier in life⁴³. Younger patients may stop working earlier, have a greater disruption in family life, or experience more motor-related complications than older patients who have amassed more environmental supports, are closer to traditional retirement age, have fewer familial

responsibilities, or have developed transferrable coping strategies from other age-related conditions. More education was associated with greater Social and Environment QOL. This corresponds with the link between education and access to economic resources, paid work, stable social relationships and opportunities for social participation⁴⁴. The associations of executive dysfunction and apathy with Social QOL corroborate existing literature on the relevance of these impairments to social functioning in PD⁴⁵⁻⁴⁷; however, it was surprising that social anxiety was not an independent predictor of this domain. The associations of depressive symptoms and apathy with Environment QOL likely represent the pervasive impact of these mood disorders on all aspects of life^{46,48} or a negative bias in responding.

Study Limitations

The assessment battery was admittedly incomplete regarding factors that can impact QOL in PD such as other motor and non-motor impairments (e.g., mobility, autonomic dysfunction), social function and the environment. This limitation can be addressed in future work to further investigate convergent and discriminant validity. In addition, comparison of the WHOQOL-BREF with other life satisfaction, health status or HRQOL (e.g., Neuro-QOL) measures used in PD would further support its validity and added value to the field. Studies with more diverse (e.g., disease severity, cognitive status, race) samples and longitudinal measurement to determine test-retest reliability, sensitivity to change and predictive relationships are warranted. Finally, we treated our education variable as continuous although it is truly ordinal.

In summary, QOL comprises more than perceived health and functioning. It represents the personal interpretation of health- and non-health-related aspects of life, both of which can impact medical decision making and satisfaction with treatment^{8,11}. Understanding QOL is critical for the development of interventions that will improve people's lives in meaningful ways, but typical outcome measures used in PD do not adequately address this construct^{7,9}. The WHOQOL-BREF is a brief QOL measure that could fill this gap. Evidence supports reliable and valid applications of the WHOQOL-BREF across numerous cultures and health conditions. This study used a relatively large and well-characterized sample to begin to substantiate its construct validity in PD.

Conclusions

This study supports the reliability and validity of the WHOQOL-BREF in mild to moderate PD and represents an important initial step in the clinimetric testing required for the WHOQOL-BREF to be considered a recommended tool for use in PD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

AES	Apathy Evaluation Scale
ADL	Activities of daily living
BDI-II	Beck Depression Inventory, 2 nd Edition
DEX	Dysexecutive Questionnaire
HRQOL	Health related quality of life
(HR)QOL	used when referencing HRQOL and QOL
LEDD	Levodopa equivalent daily dose
LSAS	Liebowitz Social Anxiety Scale
MMSE	Mini Mental State Exam
PASS	Performance Assessment of Self-care Skills
PD	Parkinson's disease
PDFS	Parkinson's Disease Fatigue Scale
PRO	Patient-reported outcome measure
QOL	Quality of life
UPDRS Motor	Unified Parkinson's Disease Rating Scale, Motor subscale score
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life assessment short version

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Figure 1.

Box and whisker plot of the WHOQOL-BREF domain scores for the PD and Control groups. Asterisks (*) indicate significant group differences from ANOVA, $p < 0.05$. Domain score differences within groups are described in the text.

Table 1Participant characteristics ($N = 156$).

Variable	Control	PD	Group comparison statistic	p-value
<i>n</i>	60	96		
Male/female ratio (<i>n</i>)	29/31	53/43	$\chi^2 = 0.70$	0.40
Age (in years)	61.7 (5.9)	62.4 (5.3)	$t(154) = -0.78$	0.44
Education (in years)	15.9 (2.5)	15.3 (2.3)	$t(154) = 1.44$	0.15
Race (<i>n</i>)*			$\chi^2 = 12.22$	0.02
White or Caucasian	50	90		
Black or African American	8	1		
American Indian/Alaska Native	0	2		
Asian	0	1		
Declined to State	2	2		
BDI-II	6.4 (8.2)	11.4 (8.0)	$t(154) = -3.83$	< 0.001
MMSE	29.2 (1.0)	29.0 (1.2)	$t(154) = 0.97$	0.33
UPDRS Motor (on medications)	NA	17.7 (8.3)		
Disease duration (in years)	NA	5.0 (4.3)		
LEDD (mg)	NA	966 (6801)		
Hoehn & Yahr Stage (<i>n</i>) 1/2/2.5/3	NA	5/78/11/2		

Note. Numbers represent means (standard deviation) or number of participants.

Table 2

Distribution and internal consistency reliability of the WHOQOL-BREF in the PD sample ($N = 96$).

Domain or Item	Floor (%)	Ceiling (%)	Skewness	Kurtosis	Internal Consistency (Cronbach α)
Physical Health (7 items)	0	0	-0.05	-0.61	0.85
Psychological Health (6 items)	0	1.0	-0.48	0.19	0.85
Social Relationships (3 items)	0	4.2	-0.31	-0.16	0.65
Environment (8 items)	0	3.1	-0.53	0.38	0.84
Overall QOL (1 item)	0	24.0	-0.60	0.31	NA
General Health Satisfaction (1 item)	7.3	2.1	0.17	-0.53	NA

Note. Floor and Ceiling are defined as scoring at the lowest and highest endpoints of the scale, respectively.

Correlations (Pearson r) between WHOQOL-BREF domain scores and demographic and clinical characteristics, impairment and disability within the PD group.

Table 3

	WHOQOL-BREF Domain			
	Physical Health	Psychological Health	Social Relationships	Environment
Age	0.25 *	0.19	0.15	0.29 **
Education	0.19	0.16	0.22 *	0.38 **
Disease duration	-0.14	0.02	0.16	-0.11
LEDD	-0.31 **	-0.20	-0.05	-0.31 **
UPDRS Motor	-0.01	-0.01	-0.10	-0.01
MMSE	-0.24	0.96	0.16	0.01
DEX	-0.42 **	-0.55 **	-0.44 **	-0.37 **
BDI-II	-0.45 **	-0.72 **	-0.51 **	-0.58 **
LSAS	-0.44 **	-0.57 **	-0.43 **	-0.50 **
AES	-0.40 **	-0.61 **	-0.57 **	-0.56 **
PDFS	-0.75 **	-0.56 **	-0.40 **	-0.47 **
Physical ADL	0.42 **	0.23	0.13	0.23 *
Cognitive ADL	0.26 *	0.33 **	0.22 *	0.26 *

* $p < 0.05$;

** $p < 0.01$

Table 4

Significant predictors of the QOL domain scores.

QOL Domain	Step	Predictors	Model R ²		Coefficients	
			R ²	p	β	p
Physical	1.	Age	0.12	0.01	0.19	0.01
	2.	PDFS	0.49	< 0.001	−0.66	< 0.001
	3.	Physical ADL	0.02	0.03	0.18	0.03
Psychological	1.	BDI-II	0.57	< 0.001	−0.54	< 0.001
	2.	PDFS	0.06	< 0.001	−0.23	0.003
	3.	AES	0.02	0.02	−0.20	0.02
Social	1.	Education	0.06	0.02	0.18	0.03
	2.	DEX	0.27	< 0.001	−0.36	0.001
	3.	AES	0.09	0.001	−0.35	0.001
Environment	1.	Education	0.14	< 0.001	0.22	0.008
	2.	Age	0.10	0.002	0.26	0.002
	3.	BDI-II	0.25	< 0.001	−0.35	0.001
	4.	AES	0.07	0.002	−0.31	0.002