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Validation of the Oxford Participation & Activities Questionnaire (Ox-PAQ)

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Abstract

Purpose: There is growing interest in the management of long term conditions and in keeping people active and participating in the community. Testing the effectiveness of interventions which aim to impact upon activities and participation can be challenging without a well-developed, valid and reliable instrument. The present study has therefore aimed to develop a patient reported outcome measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ), which is theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health (ICF) and fully compliant with current best practice guidelines.

Patients and methods: Questionnaire items generated from patient interviews and based on the nine chapters of the ICF were administered by postal survey to 386 people with three neurological conditions; motor neurone disease, multiple sclerosis and Parkinson's disease. Participants also completed the MOS 36-Item Short Form Survey (SF-36) and EQ-5D-5L.

Results: 334 participants completed the survey, a response rate of 86.5%. Factor analytic techniques identified three Ox-PAQ domains, consisting of 23 items, accounting for 72.8% of variance. Internal reliability for the three domains was high (Cronbach's α 0.84-0.96), as was test-retest reliability (intra-class correlation 0.81-0.96). Concurrent validity was demonstrated through highly significant relationships with relevant domains of the MOS SF-36 and the EQ-5D-5L. Assessment of known-groups validity identified significant differences in Ox-PAQ scores between the three conditions included in the survey.

Conclusion: Results suggest that the Ox-PAQ is a valid and reliable measure of participation and activity. The measure will now be validated in a range of further conditions and additional properties, such as responsiveness, will also be assessed in the next phase of the instrument's development.

Keywords: activity, participation, patient reported outcome measure, PROM, questionnaire, FDA, ICF, validity, reliability

Running header: Ox-PAQ Validation

Introduction

The Oxford Participation and Activities Questionnaire (Ox-PAQ) is a newly developed patient reported outcome measure (PROM), theoretically grounded in the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF).[1] It is intended for generic use with patients experiencing a broad range of health conditions. The background and rationale for the measure have previously been published in a study protocol which readers may wish to refer to.[2] In brief, however, current measures of participation and activity lack theoretical underpinning and are largely disability and rehabilitation focused.[3-8] Additionally, there is no measure of participation and activity for generic use that fully meets current standards set by regulatory bodies such as the United States Food & Drug Administration (FDA)[9] and European Medicines Agency (EMA).[10]

The item generation process and pretesting procedures for the Ox-PAQ have been extensively reported eleswhere.[11-13] In summary, semi-structured interviews were conducted with 37 people experiencing a range of conditions, including arthritis, cancer, chronic back pain, diabetes, motor neurone disease (MND), multiple sclerosis (MS), Parkinson's disease (PD) and spinal cord injury. These interviews generated a preliminary pool of 222 items, which was subsequently reduced to 24 items via an iterative process in meetings between the authors. The resulting items were pretested through an expert review panel, a translatability assessment and a series of 13 cognitive interviews. The pretesting procedures lead to minor changes to a number of items and the addition of four new questions resulting in a draft measure of 28 items, answerable on a five-point Likert scale, for validation in a large scale survey.

The aim of this paper is to make the first psychometric assessment of the Ox-PAQ through its administration to people with one of three neurological conditions; MND, MS and PD. MND is a chronic degenerative neurological condition characterised by progressive degeneration of upper and lower motor neurons in the brain and spinal cord, resulting in rapid and severe disability. The majority of people with MND die of respiratory muscle weakness less than three years from the onset of symptoms.[14] MS is a chronic condition generally characterised by recurrent relapses followed by remissions, although approximately 20% of patients experience a chronic progressive form. People with MS (PwMS) can experience both physical and emotional symptoms, including chronic fatigue

and depression, with a significant proportion requiring assistance with walking within 15 years of onset.[15-17] PD is a chronic progressive condition characterised by tremor, bradykinesia and rigidity. People with Parkinson's (PwP) are susceptible to psychiatric symptoms such as depression, hallucinations and confusion, as well as the likelihood of falls and freezing of gait as the condition progresses.[18-19] Given the clinical characteristics of the conditions outlined, all three clearly have the potential to have a significant impact on participation and activity in a number of distinct ways, rendering them ideal candidates with which to test the Ox-PAQ.

The specific aims of this paper are threefold. Firstly, to identify the underlying factor structure of the Ox-PAQ through the use of factor analytic techniques. Secondly, to make an assessment of both the internal and external reliability of the new measure. Finally, to test the validity of the Ox-PAQ by assessing the magnitude of association with other similarly related constructs alongside an assessment of groups hypothesised to differ; specifically, given the disparate nature of the disease groups outlined above (MND, MS and PD), it is hypothesised that there will be significant differences in Ox-PAQ scores between the three conditions.

Material and methods

Ethical approval for this stage of the Ox-PAQ study was granted by the Medical Sciences Inter Divisional Research Ethics Committee of the University of Oxford (reference MSD-IDREC-C1-2014-089).

Participants: Recruitment of participants was undertaken over a period of six months with the assistance of three patient support organisations; the Motor Neurone Disease Association, MS Society and Parkinson's UK. Organisations advertised the study by various means, including social media, websites, print and electronic publications, research bulletin boards and emails inviting potential participants to contact the research team to express their interest in taking part.

Inclusion / exclusion criteria: Participants required a confirmed diagnosis of MND, MS or PD and the ability to complete the survey independently. Participants were also required to be competent in the use of English, be aged 18 years or over and living in the UK.

Materials: A survey booklet consisting of four sections was administered; demographic data (gender, age, age at diagnosis, marital status and ethnic origin), the Ox-PAQ (as detailed above) and two further instruments for the purpose of evaluating its validity:

Medical Outcomes Study 36-Item Short-Form Health Survey (MOS SF-36):[20-21] a 36-item questionnaire comprising eight domains of health; Physical Functioning, Role Physical, Role Emotional, Social Functioning, Mental Health, Energy/Vitality, Pain and General Health Perception. Response options vary across items from a simple dichotomous yes / no response, to a six-point Likert Scale. Raw scores for each health domain are transformed to have a range from 0 to 100 with higher scores indicating superior health status. The measure has been widely adopted in numerous research studies and demonstrates excellent psychometric properties.[22]

EQ-5D-5L:[23-24] a five-item generic measure assessing mobility, self-care, usual activities, pain / discomfort and anxiety / depression. Initially developed with questions answered on a three-point Likert Scale, a revised version of the measure now incorporates a five-point Likert scale. The EQ-5D-5L includes a visual analogue scale (VAS) to indicate general health, with a score of zero reflecting worst health status and 100 the best possible health status. Recent studies suggest the updated measure is both valid and reliable.[25-29]

Procedure: After contacting the research team by telephone or email, participants were sent the booklet of questionnaires and a consent form for completion and return. A follow-up email or letter was sent to non-responders after two weeks. Participants who agreed to take part in a test-retest procedure were sent the Ox-PAQ again two weeks after receipt of their original questionnaire booklet.

Statistical Analysis: Data was checked for normality of distribution and presence of outliers prior to statistical analysis. Missing values and floor and ceiling effects were calculated for each item of the Ox-PAQ. Raw scores were transformed to a range from zero to 100, with higher scores indicative of inferior functioning. Principal components analysis (PCA) with varimax rotation was performed to identify the underlying construct of the measure. The internal reliability of identified domains was assessed via corrected item-total correlations (ITCs) and Cronbach's alpha.[30] Test-retest reliability was calculated using the single measures (two-way mixed effects model) intra-class correlation coefficient (ICC).[31] Concurrent validity was determined through calculation of Pearson correlations[32]

between the Ox-PAQ and the MOS SF-36[20-21] and EQ-5D-5L.[23-24] Known groups validity was assessed through calculation of one-way analysis of variance (ANOVA) and Tukey post-hoc tests. Data were analysed using SPSS Version 20.[33]

Results

A total of of 334 participants completed the postal survey, a response rate of 86.5%. Mean age was 60.06 years (SD 12.10; range 24-88), mean age at diagnosis 52.82 years (SD 14.50; range 18-87) and mean disease duration 7.31 years (SD 7.52; range 0-50). The sample comprised 162 males (48.5%) and 172 females (51.5%). Further sample characteristics by disease group can be viewed in Table 1.

Percentage of missing responses and floor and ceiling effects for each of the 28 items of the Ox-PAQ are presented in Table 2. Missing data were minimal at between 0% and 1.8%. Items 2, 21 and 22 (highlighted) were subsequently removed from further analysis due to floor effects greater than 40%. A preliminary PCA of the remaining 25 Ox-PAQ items was performed as a means of identifying the underlying construct (scale structure) of the measure. Based on inspection of factors by two of the authors (DM and CJ), two further items, relating to making small movements with hands and coping with pain, were removed due to lack of relevance with the factor onto which they loaded. A further PCA of the remaining 23 Ox-PAQ items resulted in a three factor solution, explaining 72.7% of variance. Item factor loadings and percentage of explained variance by factor can be viewed in Table 3. Factor 1, *Routine Activities* (14 items), assesses individuals' capacity to engage in regular activities that form the basis of daily life. Factor 2, *Emotional Well-Being* (5 items), provides a snapshot of current mental health status. Factor 3, *Social Engagement* (4 items), reflects how well, or otherwise, individuals are able to maintain relationships, both personal and from a wider community perspective.

Reliability:

Internal Reliability: Corrected ITCs and Cronbach's alpha values for each domain can be viewed in Table 4. ITCs ranged from 0.87–0.63, with Cronbach alpha values for the three identified domains ranging from 0.84–0.96.

External Reliability: Test-retest reliabilty was assessed in 127 participants who indicated no change in health status when completing the Ox-PAQ two weeks after their first completion. ICCs were calculated at 0.96 for *Routine Activities*, 0.85 for *Emotional Well-Being* and 0.81 for *Social Engagement*.

Validity:

Concurrent validity: Pearson Correlations between the Ox-PAQ and MOS SF-36 are presented in Table 5. Correlations range from -0.39 to -0.86, all being highly statistically significant. Domains of the MOS SF-36 deemed most similar to those of the Ox-PAQ correlated more highly, for example Physical Function and *Routine Activities* ($r = -0.86$, $p < 0.001$), Emotional Well-Being and *Emotional Well-Being* ($r = -0.80$, $p < 0.001$) and Social Function and *Social Engagement* ($r = -0.65$, $p < 0.001$).

Pearson Correlations between the Ox-PAQ and EQ-5D-5L are presented in Table 6. Correlations range from 0.42 to 0.80, all being highly statistically significant. As with the MOS SF-36, those EQ-5D-5L items deemed most similar to those of the Ox-PAQ correlated more highly, for example, Mobility and *Routine Activities* ($r = 0.80$, $p < 0.001$), Usual Activities and *Routine Activities* $r = 0.79$, $p < 0.001$ and Anxiety / Depression and *Emotional Well-Being* ($r = 0.74$, $p < 0.001$).

Known groups validity: Mean Ox-PAQ domain scores and standard deviations by disease group are given in Table 7. ANOVA results indicate statistically significant differences between the three conditions for all three domains; *Routine Activities*, $F(2, 331) = 44.86$, $p < .001$; *Emotional Well-Being*, $F(2, 331) = 10.19$, $p < .001$; *Social Engagement*, $F(2, 331) = 10.42$, $p < .001$. Post-hoc tests (Tukey's HSD) at the .05 level of significance confirm significantly inferior scores in *Routine Activities* for people with MND when compared to those with MS ($p < .001$) and PD ($p < .001$), alongside significantly inferior scores for PwMS compared to PwP ($p < .001$). For *Emotional Well-Being* significantly inferior scores are evident when comparing those with MND and PD ($p < .001$), and those with MS and PD ($p < .001$). Assessment of *Social Engagement* identifies significantly inferior scores for people with MND compared to those with MS ($p < .001$) and PD ($p < .001$).

Discussion

This paper has presented the first psychometric evaluation of the newly developed Ox-PAQ. Prior to identifying the underlying factor structure of the new measure the percentage of missing responses and floor and ceiling effects for the original 28 items were inspected. Missing data by item was low with no item exceeding 2%, indicating a high level of acceptability to respondents. Analysis of floor and ceiling effects lead to the removal of three items, due to floor effects exceeding 40%, a criterion incorporated in the validation of previous measures.[34-35] Following a preliminary PCA, two further items were removed due to a lack of relevance with the factor onto which they loaded. Twenty-three items were subsequently included in a further PCA to confirm the factor structure of the Ox-PAQ, resulting in a three factor solution. All factor loadings are above the 0.55 level regarded as good, with the majority above the 0.71 level regarded as excellent.[36]

Reliability of the Ox-PAQ is demonstrated through a number of analyses. The internal reliability of the measure is confirmed through item-total correlations that are in excess of previously defined criteria,[37] confirming that item scores within each domain are related to the overall domain score. Further evidence is provided by Cronbach's alpha values of between .84 and .96 for the three Ox-PAQ domains, indicating good to excellent internal reliability.[38] Intraclass correlation coefficients that fall between .81 and .96 for the three Ox-PAQ domains, indicate excellent external reliability and are significantly above the recommended level of .60.[39]

Validity of the Ox-PAQ is demonstrated via assessment of concurrent and known groups validity. Correlations with the MOS SF-36 and EQ-5D-5L indicate strong concurrent validity. The majority of correlations between Ox-PAQ domains and those of the MOS SF-36 and EQ-5D-5L fall in the 0.40 to 0.60 range typically observed, with those most similarly related domains in excess of the 0.60 level, representing a high degree of concurrent validity.[40] Assessment of known groups validity is made where there are good reasons to hypothesise that scores on a measure of interest will differ between groups,[41] as has been incorporated in previous research.[42-44] Previous studies have made comparisons between PwMS and PwP,[45-46] with results reported here largely confirming this previous research; MS can have a significantly greater impact on physical functioning and emotional well-being than PD. Whilst no study appears to have compared MND with other neurological conditions, given its

clinical characteristics (as outlined in the introduction of this paper) it would seem reasonable to hypothesise that scores are likely to be significantly inferior to those of people with MS and PD. Results from the study would seem to confirm this, with people with MND reporting significantly greater problems as measured by all three domains of the Ox-PAQ when compared to those with MS and PD.

A number of limitations from the current study are acknowledged. Firstly, the reported analyses are confined to three neurological conditions, MND, MS and PD. Further assessment and validation in alternative disease groups is required to facilitate wider use of the new measure. Additionally, current analyses are confined to traditional psychometric techniques. Further investigation into the operating characteristcs of the Ox-PAQ using modern tecniques such as Rasch analysis[47-49] may be beneficial in due course. Finally, it is recognised that the method of recruitment for the study was self-selecting in nature, and the sample may not therefore be fully representative of the disease groups that participated.

In conclusion, results from this first psychometric analysis of the Ox-PAQ are promising, with results indicating that the instrument is a valid and reliable measure of participation and activity. The next phase of the instrument's development will involve migrating the Ox-PAQ to e-based format, alongside validation in a range of further conditions and an assessment of the responsiveness of the measure. Further details regarding the development and validation of the Ox-PAQ can be found at the University of Oxford Health Services Research Unit website: http://www.ndph.ox.ac.uk/research/health-services-research-unit-hsru/research/oxpaq-initiative Information regarding the use of the Ox-PAQ can be obtained from DM or CJ.

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Table 1: Sample characteristics by disease group

Condition	N=	Male: Female	Mean age (years)	Mean age at diagnosis (years)	Mean disease duration (years)
MND	97	65:32	62.96 *(8.93; 42-80)*	60.18 *(9.66; 35-78)*	2.78 *(4.11; 0-27)*
MS	100	21:79	49.12 *(11.26; 24-80)*	36.98 *(9.71; 18-63)*	11.94 *(9.32; 0-50)*
PD	137	76:61	66.12 *(8.83; 40-88)*	59.60 *(10.35; 30-87)*	6.93 *(5.57; 0-31)*
Total Sample	**334**	**162:172**	**60.06 *(12.10; 24-88)***	**52.82 *(14.50; 18-87)***	**7.31 *(7.52; 0-50)***

(standard deviation; range)

Table 2: Percentage of missing data and floor / ceiling effects by Ox-PAQ item

Item No	% missing responses	% Floor	% Ceiling
1	0.3	28.2	16.5
2	0.0	46.7*	14.1
3	0.0	33.2	17.4
4	0.0	34.4	16.5
5	0.3	22.2	30.0
6	0.3	19.5	16.8
7	0.6	29.5	26.8
8	0.6	14.5	26.5
9	1.2	24.5	31.8
10	0.3	25.8	14.7
11	0.0	25.4	10.2
12	0.6	13.3	38.6
13	0.0	38.0	8.4
14	0.3	39.9	7.2
15	0.9	34.4	11.2
16	0.0	15.3	32.3
17	0.9	27.8	21.8
18	1.2	32.7	22.7
19	1.8	35.7	28.4
20	0.3	36.9	9.3
21	0.3	40.2*	7.8
22	0.0	42.5*	6.6
23	0.9	22.3	7.3
24	0.0	16.8	18.6
25	0.0	13.2	6.3
26	0.3	15.6	6.6
27	0.0	13.8	6.9
28	0.0	28.1	6.0

*Item removed

Table 3: PCA solution, factor loadings and percentage of explained variance for the Ox-PAQ

Domain	Item	Factor loading	% explained variance	% cumulative variance
Routine Activities			57.17	57.17
	Doing household chores	.887		
	Going to shops	.873		
	Physical activities for enjoyment	.841		
	Daily activities you like to do	.834		
	Getting around home	.813		
	Being as independent as would like	.781		
	Getting dressed	.755		
	Doing work, paid or unpaid	.746		
	Using public transport	.736		
	Engaging in community life	.642		
	Using own transport	.632		
	Social life	.607		
	Leisure activities	.565		
	Getting up in the morning	.558		
Emotional Well-Being			9.64	66.82
	Anxious	.865		
	Sad	.861		
	Depressed	.856		
	Stressed	.829		
	Control over life	.598		
Social Engagement			5.95	72.77
	Communicating with others	.852		
	Engaging in the community	.791		
	Maintaining friendships	.631		
	Maintaining close relationships	.566		

Table 4: Ox-PAQ item-total correlations, Cronbach alpha values and domain mean scores

Draft Ox-PAQ No	Item	Corrected ITC	α	Mean score (SD)
Routine Activities (14 Items)			.96	58.43 (24.29)
5	Doing household chores	.87		
7	Going to shops	.87		
12	Physical activities for enjoyment	.82		
8	Daily activities you like to do	.87		
4	Getting around home	.79		
16	Being as independent as would like	.85		
3	Getting dressed	.77		
9	Doing work, paid or unpaid	.79		
19	Using public transport	.79		
17	Engaging in community life	.81		
18	Using own transport	.72		
10	Social life	.79		
11	Leisure activities	.76		
1	Getting up in the morning	.66		
Emotional Well-Being (5 Items)			.92	55.29 (20.48)
26	Anxious	.83		
27	Sad	.84		
28	Depressed	.80		
25	Stressed	.85		
24	Control over life	.71		
Social Engagement (4 Items)			.84	46.11 (21.25)
20	Communicating with others	.65		
15	Engaging in the community	.72		
14	Maintaining friendships	.68		
13	Maintaining close relationships	.63		

Table 5: Pearson correlations between domains of the Ox-PAQ and MOS SF-36

	Physical Function	Role limitation physical	Role limitation emotional	Energy / fatigue	Emotional well-being	Social function	Pain	General health
RA[a]	-.86	-.60	-.39	-.62	-.47	-.75	-.49	-.58
EWB[b]	-.48	-.49	-.62	-.67	-.80	-.59	-.47	-.58
SE[c]	-.53	-.43	-.48	-.46	-.46	-.65	-.46	-.48

[a]Routine Activities, [b]Emotional Well-Being, [c]Social Engagement; all correlations significant at $P < 0.001$

Table 6: Pearson correlations between domains of the Ox-PAQ and the EQ-5D-5L

	Mobility	Self-care	Usual activities	Pain / discomfort	Anxiety / depression	VAS
RA[a]	.80	.77	.79	.46	.43	.72
EWB[b]	.46	.43	.50	.47	.74	.60
SE[c]	.51	.53	.54	.42	.46	.50

[a]Routine Activities, [b]Emotional Well-Being, [c]Social Engagement; all correlations significant at $P < 0.001$

Table 7: Mean Ox-PAQ scores and standard deviations by disease group

	Condition	Mean	Standard Deviation
Routine Activities	MND	73.58	22.60
	MS	60.04	22.51
	PD	46.53	20.17
Emotional Well-Being	MND	60.91	20.12
	MS	57.68	21.37
	PD	49.58	18.69
Social Engagement	MND	54.17	24.27
	MS	42.60	19.39
	PD	42.96	18.73