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Evaluating the content validity of generic preference-based measures for use in Parkinson's disease

Ayse Kuspinar[a,*], Kedar Mate[b], Anne-Louise Lafontaine[c,d], Nancy Mayo[b,e]

[a] School of Rehabilitation Science, McMaster University, Hamilton, ON, Canada
[b] Center for Outcomes Research and Evaluation, McGill University Health Centre – Research Institute, Montreal, QC, Canada
[c] Neurology, McGill University Health Centre, Montreal, QC, Canada
[d] Department of Neurology and Neurosurgery, McGill University, Montreal, QC, Canada
[e] Department of Neurology and Neurosurgery, McGill University, Montreal, QC, Canada

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ABSTRACT

Background: Generic preference-based measures are used to assess the cost-utility of different interventions in Parkinson's disease (PD). However, the difficulty of using them in people with a particular health condition is that these measures may not encapsulate all of the domains that are impacted by the disease.
Objective: To contribute evidence towards the content validity of generic preference-based measures in people with PD.
Methods: Participants with PD were interviewed on a personalized measure of quality of life, the Patient Generated Index (PGI). The domains identified with the PGI were then categorized using the WHO's International Classification of Functioning, Disability and Health. The extent to which the generic measures (EQ-5D-5L, SF-6D, HUI II, and HUI III) included domains important to persons with PD was qualitatively evaluated.
Results: The study included seventy-six participants with PD (mean age 69 years). Dexterity, the top domain nominated by participants, was only included in 1 out of 4 of the generic measures. Fatigue, another commonly reported problem, was not included in 3 out of 4 measures. Sleep, dyskinesia and bowel/bladder problems were not included in any of the measures.
Conclusion: Content validity is an essential step in the evaluation of whether a questionnaire truly measures the construct it purports to measure, in this case the construct being health related quality of life (HRQL). This study evaluated the content validity of the EQ-5D-5L, SF-6D, HUI II and HUI III in people with PD, and demonstrated that several important PD specific domains are missing from these measures.

1. Introduction

The main goal of a patient-centered healthcare system is to enhance patients' health and quality of life. Health outcomes, such as morbidity and mortality, are of primary importance but it is also important to incorporate the patient's perspective in the evaluation of therapies. Health-related quality of life (HRQL) measures provide a structured way of including the patient's perspective when evaluating the impairments, activities and social opportunities influenced by a disease and its treatment [1].

HRQL is multidimensional, represented by, but not limited to, the domains of physical, mental, social and role functioning [1]. HRQL measures generally fall into two categories based on how they are constructed and scored: (i) health profiles and (ii) preference-based measures.

Health profiles are scored by sub-scale, where each sub-scale represents a domain of HRQL. For example, the most frequently used health profile in clinical research, the Short Form-36 (SF-36) Health Survey [2], is divided into 8 domains. Each domain scores are transformed produce a value from 0 to 100, where 0 is the worse and 100 is the best health state. One of the challenge with using health profiles for clinical research and economic evaluation, is that the domains cannot be summed together to provide an overall score of HRQL. For instance, if an intervention has a positive impact on the physical sub-scale (i.e. physical health domain) but a negative one on the mental sub-scale (i.e. mental health domain), it is impossible to ascertain whether the intervention resulted in a net improvement or decline in one's HRQL [3,4].

Preference-based measures, in contrast, do attach a value to each domain of health [5]. Preference-based measures have the benefit of

* Corresponding author. School of Rehabilitation Science, McMaster University, 1400 Main St. W. Hamilton, ON, L8S 1C7, Canada.
E-mail address: kuspinaa@mcmaster.ca (A. Kuspinar).

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producing a single number (from 0 to 1) as the final score balances gains in one domain against losses in another. This is critical as preference-based measures can be used to estimate a Quality-Adjusted Life Year (QALY) and make decisions about the cost-effectiveness of interventions [6]. The QALY is an all-inclusive measure of health improvement that describes the impact of a treatment on both mortality (quantity of life) and morbidity (quality of life). If the cost of an intervention is known in terms of QALYs, then it can be used to calculate cost-utility ratios. The 'Q' in the QALY is typically obtained by asking participants to complete a preference-based measure like the EQ-5D [7].

In line with guidelines from major regulatory agencies [8,9], generic preference-based measures are utilized to assess the cost-utility of different interventions in people with Parkinson's Disease (PD). However, the difficulty of using such measures in people with a particular condition, like PD, is that they may not encapsulate all of the domains that are impacted by the disease state. If the measure fails to capture important areas of patient concerns, the scores obtained will be higher than the true impact leading to invalid comparisons between different treatments and health conditions.

Therefore, the purpose of this study is to contribute evidence towards the content validity of generic preference-based measures in people with PD.

2. Methods

2.1. Participants

Participants with PD were recruited from the McGill Movement Disorder Clinic in Montreal, Canada. Participants enrolled in this study were part of an interdisciplinary clinic that includes nurses, physiotherapists and occupational therapists. In addition to their regular physician visit, participants were evaluated every 6 or 12 months by a nurse, physiotherapist and occupational therapist and exercise recommendations were made as indicated.

Exclusion criteria were a major comorbid condition (e.g. severe dementia, severe psychiatric, neurological or other medical condition likely to have major impact on the quality of life, other than PD). During their routine clinical visit, a member of the Clinic staff explained to the patient the purpose of the study, and the patient indicated his/her consent to participate in the study. The information relevant to the project was obtained during participants' visit to the clinic. The protocol was approved by the local Institutional Review Board.

2.2. Outcome measures

2.2.1. Patient generated index

The Patient Generated Index (PGI) [10]is an individualized measure of HRQL that is administered in three steps. First, participants are asked to identify up to five of the most important areas of their lives affected by PD. Second, they are asked to rate the extent to which they are in the selected areas on a scale of 0–10, where 0 is the worst they can imagine and 10 exactly as they would like to be. An additional sixth box is provided to rate all other health or non-health related areas. Studies have demonstrated that a score of 4 or greater on a scale from 0 to 10 (where 0 is none and 10 is severe) would be considered a concerning score [11,12].Therefore, with a reverse scale on the PGI (where 0 is severe and 10 is none), a value of 6 or lower would be considered as concerning. In the third phase, participants are given twelve spending "points" to allocate across the areas. The more points a participant spends for an area, the more important that area is. An average of 2 points or more per area were considered meaningful (12/6). The PGI produces a single score of overall QOL from 0 to 100, where higher scores indicate better QOL.

2.2.2. EQ-5D-5L

The EQ-5D-5L [13]is a generic preference-based measure of HRQL that consists of two sections. The first part comprises of 5 domains, which are mobility, capacity for self-care, conduct of usual activities, pain/discomfort and anxiety/depression. Each domain has 5 response levels. The second part is a Visual Analogue Scale of self-rated health from 0 to 100. The EQ-5D-5L can define up to 3125 health states (5^5) and has been translated into 120 languages world-wide [14].

2.2.3. SF-6D

The SF-6D [15]is a generic preference-based measure derived from the SF-36 Health Survey. It has 6 domains, which are physical functioning, role limitation, social functioning, pain, mental health and vitality. Each domain includes 4 and 6 response options, defining a total of 18000 health states. A regression based scoring algorithm is used to produce a single value of HRQL from 0.3 to 1.0.

2.2.4. HUI II

HUI II [16]is a generic preference-based measure that consists of 7 domains, which are sensation, mobility, emotion, cognition, self-care, pain and fertility. Each domain has 3 to 5 response levels, describing a total of 24000 health states. A multiplicative multi-attribute utility function is used to produce a HRQL score from −0.03 to 1.0. The HUI II has been translated into over 30 different languages.

2.2.5. HUI III

The HUI3 [17]includes 8 dimensions, which are vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Each dimension has 5 or 6 levels, describing a total of 972 000 different health states. Similar to the HUI II, a multiplicative function combines the dimensions into a single value that can range from −0.36 to 1.0.Similar to the HUI II, the HUI III is available in over 30 languages worldwide and population norms have been reported.

2.3. Procedure

Participants with PD were interviewed on the individualized measure of QOL, the PGI. The domains generated with the PGI were then categorized using the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [18]. This methodology has been conducted in previous studies [4,19]. The ICF provided a coding framework and standardized description of health related problems at the level of body structure/function (e.g. fatigue, pain), activity (e.g. dressing, walking) and participation (e.g. work).

The top 10 domains were then mapped onto to 4 generic preference-based measures: the EQ-5D-5L, SF-6D, HUI II, and HUI III. The extent to which these measures included domains important to persons with PD was qualitatively evaluated. Fig. 1 presents an outline of the study process.

In addition to completing the Patient Generated Index, during the study visit participants completed standardized physical performance-based tests. The Berg Balance Scale (BBS) was administered to measure balance, the Time Up and Go (TUG) test was administered to measure functional mobility, and gait speed to measure walking capacity. A cut-off of < 45/56 on the BBS [20] and > 12 seconds on the TUG [21,22] is indicative of being at high risk for falls, and gait speed < 1.0m/s is indicative of poor community ambulation [23].

3. Results

Table 1 provides a summary of the sample characteristics, including age, sex and number of years with PD. Seventy-six participants with PD were interviewed on the PGI. Participants had an average age of 69 (Standard Deviation 9.5), and 59% were men. The mean number of years since diagnosis was 6, and mean number of years since symptom onset was 8. Participants had a mean of 2.3 and median of 2.0 on the

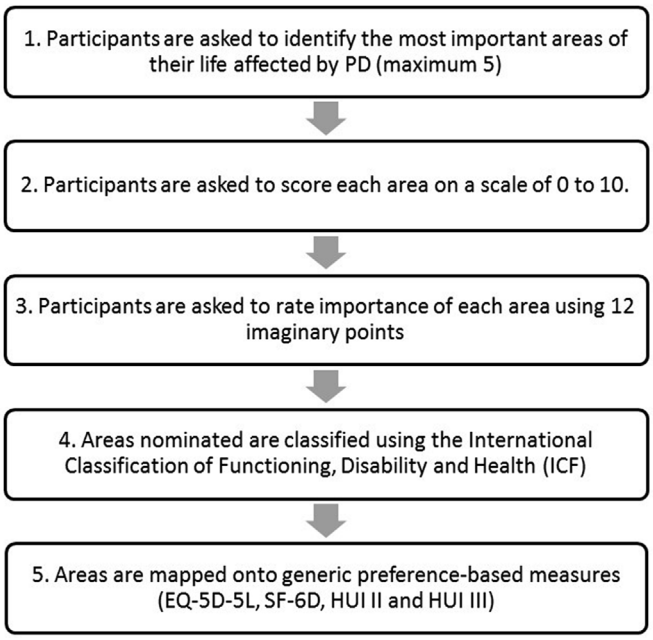

Fig. 1. Flow diagram explaining the stages of the Patient Generated Index and mapping of domains onto generic preference-based measures.

Table 1
Demographic and clinical characteristics of sample (n = 76).

Characteristics	Mean (SD) or N (%)
Age (y)	69.1 (9.5)
Women	31 (41%)
Years since diagnosis	6.0 (4.1)
Years since symptom onset	8.2 (5.1)
Tremor dominant/Akinetic Rigid	46 (71)/19 (29)
History of falls (none/rare/monthly)	41 (63)/16 (25)/8 (12)
Levodopa Equivalent Dose (mg/day)	770.4 (523.7)
Hoehn and Yahr stage (1–5)	2.3 (0.9)
Berg Balance Test (0-56)[a]	53.3 (4.9)
Time Up and Go (time in seconds)[a]	11.6 (4.4)
Gait speed (m/s)[a]	1.2 (0.3)

SD, standard deviation; N, number.
[a] N = 43 for Berg Balance Test; N = 40 for Timed Up and Go; N = 50 for gait speed.

Table 3
The domains identified by PD subjects compared with items in generic preference-based measures.

PD Domain	Preference-Based Measure			
	EQ-5D-5L	SF-6D	HUI II	HUI III
Dexterity/Fine Hand Use	N	N	N	Y
Walking	Y	N	Y	Y
Sleep	N	N	N	N
Fatigue	N	Y	N	N
Cognition	N	N	Y	Y
Tremor/Dyskinesia	N	N	N	N
Sports	N	Y	Y	N
Depression/Anxiety[a]	Y	Y	Y	Y
Self-care	Y	Y	Y	N
Speech/Voice	N	N	Y	Y
Socializing	Y	Y	N	N
Household tasks	Y	Y	N	N
Bowel & Bladder	N	N	N	N
Work/Employment	Y	Y	N	N
Balance/Falls	N	N	N	N
Total Yes (%)	**40%**	**47%**	**40%**	**33%**

PD Domains ordered from the largest to the smallest proportion of people with PD who identified that domain.
Y, Yes; N, No; HUI II, Health Utilities Index Mark 2; HUI III, Health Utilities Index Mark 3; SF-6D, EQ-5D-5L, EuroQol-5D 5-Level; Short Form-6D.
[a] In the HUI3 this was happiness.

Hoehn and Yahr scale. Participants had a mean score of 53 on the BBS, 11.6 seconds on the TUG, and 1.2m/s for gait speed.

Table 2 lists the top 10 domains (and ties) nominated by people with PD. The top domains nominated were dexterity/fine hand use (36%), walking (28%), sleep (25%) and fatigue (24%). The other domains were cognition, dyskinesia and sports which were nominated by 21% of the sample, followed by depression/anxiety (17%), self-care (16%), speech (14%), socializing (14%) and household tasks (11%). Bowel and bladder, work/employment, and balance were tied with a prevalence of 9% each. All of these domains had an average rating of less than 6 out of 10, which would be considered in the concerning range. Also, the mean number of points allocated to each area was higher than the expected average of 2, indicating that the areas nominated were important to the respondents' quality of life.

Table 3 presents the mapping of the domains onto the EQ-5D-5L, SF-6D, HUI II, and HUI III. Dexterity and fine hand use, which was the top domain nominated by participants, was only included in 1 out of 4 of the generic preference-based measures. Sleep, the 3rd most commonly reported domain was not included in any of the preference-based

Table 2
Top domains identified by subjects using the Patient Generated Index.

Domain	ICF Code(s)	Proportion of subjects reporting problem (%)	Degree to which subjects are affected Mean (SD)[a] (0–10 highest is best)	Number of tokens spent Mean (SD)[b] (out of 12)
Dexterity/Fine Hand Use	d440	36	3.6 (1.9)	3.0 (1.7)
Walking	d450	28	4.9 (2.2)	3.5 (2.0)
Sleep	b134	25	3.7 (1.5)	3.4 (2.9)
Fatigue	b4552	24	4.5 (1.2)	3.3 (1.8)
Cognition	b140, b144, b164	21	4.8 (2.5)	2.2 (1.7)
Tremor/Dyskinesia	b765, b7651	21	5.1 (2.5)	3.3 (2.2)
Sports	d9201	21	3.8 (2.0)	2.1 (1.7)
Depression/Anxiety	b152, b1263	17	3.8 (1.4)	2.7 (1.1)
Self-care	d510, d540, d550	16	4.3 (1.9)	3.0 (1.7)
Speech/Voice	b310, b330	14	3.8 (2.0)	2.8 (1.3)
Socializing	d9205	14	4.2 (2.0)	2.0 (1.2)
Household tasks	d630, d640	11	3.8 (2.1)	2.1 (1.0)
Bowel & Bladder	b525, b6201	9	4.0 (2.9)	3.7 (3.8)
Work/Employment	d845	9	4.1 (0.9)	2.4 (2.5)
Balance/Falls	b235, b2402	9	6.4 (2.1)	2.7 (2.4)

[a] Scored out of 10, higher is worse.
[b] Scored out of 12, higher indicates that the domain was more important.

measures. Similarly, dyskinesia and bowel/bladder problems were also not included in any of the measures. Fatigue, the 4th most commonly reported problem, was not included in 3 out of 4 measures. However, walking and self-care were included in most of the measures (3 out of 4), and depression was found in all of the measures. The SF-6D included 47% of the top domains nominated by participants, the EQ-5D-5L and the HUI II included 40% of the domains, and the HUI III included 30%.

4. Discussion

In this study, we interviewed people with PD on a personalized measure to identify the domains that are most important to their quality of life. These generated domains were then mapped onto commonly used generic preference-based measures to evaluate the content validity of these measures in PD.

The domains nominated by the participants were relatively severe and important to their quality of life. However, many of these domains were missing from generic preference-based measures. For example, dexterity, walking and sleep (the top 3 domains nominated by participants) was not included in the SF-6D, as well as cognition, tremors, and speech. The EQ-5D-5L included walking, but did not cover any of the other top domains nominated by participants, specifically dexterity, sleep, fatigue, cognition, tremors and speech. The HUI II included walking and cognition, but was missing dexterity, sleep, fatigue and tremors. The HUI III was the only generic measure that included dexterity, however, many of the other domains such as sleep, fatigue and tremors were missing from this measure. Furthermore, bowel and bladder problems, which had an average rating of 4 out of 10 (where 0 is the worst), was not covered by any of the generic measures.

The value attribute associated with preference-based measures is very useful when evaluating the effectiveness of clinical interventions. These measures produce a single index/score of HRQL that ranges from 0 (death) to 1 (perfect health). They overcome a major challenge associated with the use of health profiles such as the SF-36 and the Parkinson's Disease Questionnaire-39 (PDQ-39) - that domains cannot be combined into an overall indicator of health. For example, Hagell et al. [24] have demonstrated using Rasch analysis (a probability model used to evaluate the psychometric properties of questionnaires), that the PDQ-39, the recommended HRQL measure for PD, does not form a unidimensional measure. This means the total score has no valid interpretation, which is clearly a problem if it is to be used as a clinical trial outcome. The same limitation was demonstrated for the PDQ-8 [25].

Furthermore, an additional strength of preference-based measures is their ability to take the health index score and link it to life expectancy to provide a QALY value. The QALY is a single comprehensive measure of health improvement that captures the effect of an intervention on both mortality (quantity of life) and morbidity (quality of life) [7]. The QALY is a generic measure that can be used to compare the effectiveness of different interventions. Furthermore, if the costs of the interventions are known QALYs can be used to calculate cost-utility ratios, which is the difference between the costs of two treatments divided by the difference in the QALYs. The assumption with cost-utility analysis is that, all else being equal, the treatment with the lowest cost per QALY is favored, because it produces the most health benefit for the least cost. To date, the use of QALYs has been for economic evaluations of health programs, however, its use is not just restricted to these applications. In a paper by Kind et al. [26] the use of QALYs in non-economic applications (i.e. clinical and patient decision-making) were encouraged. Kind suggested that QALYs can be used in monitoring health status in individual patients, in measuring population health and in assessing the impact of interventions in clinical research.

Despite their many advantages, generic preference-based measures may not be applicable to all health conditions. This has been shown in MS [4], mental health [27] and cancer [28]. Although the EQ-5D-5L, SF-6D, HUI II and HUI III are the recommended measures for economic evaluation by major regulatory agencies such as the National Institute for Health and Clinical Excellence (NICE) and the Canadian Agency for Drugs and Technologies in Health (CADTH), one needs to be cognisant of the validity of these measures in the context of the specific health condition under study. If crucial domains are missing from these measures, the final score obtained will be higher than the true impact, leading to inaccurate evaluations across interventions and health conditions [4]. Furthermore, a recent systematic review [29] on the construct validity of generic preference-based measures in PD revealed that these measures may lack responsiveness to change, which is critical for economic evaluation.

A number of recent studies have shown that non-motor symptoms are important to the quality of life of individuals with PD. Although diagnosis is based on motor symptoms, research has shown that non-motor symptoms are highly prevalent and amenable to therapy. Studies have shown that non-motor symptoms such as sleep, fatigue and depression, are more disabling than motor symptoms and are associated with lower quality of life [30–33]. Our data on the PGI support this, as six of the top 15 areas identified were non-motor symptoms.

A limitation of this study is that the results may not be generalizable to all individuals with PD as we recruited from only one clinical site. However, the study sample was representative of people with both minor and severe stages of the disease. The median value on the Hoehn and Yahr scale was 2.0, indicating that 50% of the sample were in the early stages of the disease, and the other 50% were in the mid-stages of the disease or more severe. Future work will involve administering the PGI in more severe or compromised participants with PD. Moreover, the primary domain nominated by participants was dexterity raising the question as to whether dopaminergic therapy was adequate. In this sample, the mean dose was 770 md/day, and as these participants were treated at a PD specialty clinic it is likely that therapy was optimized. We also do not yet have longitudinal data on the sample to ascertain whether participants had good motor compensation, therefore we cannot conclude if this level of functioning was because of good therapeutic control or they have not deteriorated yet. However, these patients were seen at a specialty clinic by neurologists specializing in PD and hence they were treated optimally. Given that they were in relatively early stages of the disease, they probably did not have significant motor fluctuations.

This study evaluated the content validity of the EQ-5D-5L, SF-6D, HUI II and HUI III in people with PD. Content validity is an essential step in the evaluation of whether a measure truly measures the construct it purports to measure [34], in this case the construct being HRQL. This study demonstrated that the domains important to the HRQL of people with PD is unique and different from the domains that are covered in generic preference-based measures. The addition of 'bolt-on' domains to generic measures, and the development of a disease specific preference-based measures are potential areas for future research in PD.

Conflicts of interest

The authors have no conflict of interest to report.

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