PAPER

The relative health related quality of life of veterans with Parkinson's disease

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Objectives: To use databases of the US Veterans Health Administration (VHA) to describe the impact of Parkinson's disease on health related quality of life (HRQoL) of veterans; to compare the HRQoL of veterans with Parkinson's disease with that of veterans reporting eight other neurological or chronic conditions; and to estimate the unique effect of Parkinson's disease on HRQoL.

Methods: Respondents to the VHA 1999 large national health survey of veteran enrollees with a diagnosis of Parkinson's disease in VHA treatment files for the fiscal years 1997–1999 were identified by merging databases. The survey incorporated the Veterans SF-36, a well validated generic measure of HRQoL and functional status. This was used to compare patient groups. Mean physical (PCS) and mental (MCS) component summary scores were calculated for Parkinson's disease and eight other diseases by multivariable regressions that adjusted for age, sex, race, education, and 15 mental and physical co-morbid conditions that were self reported in the survey.

Results: Of 887 775 survey respondents, 14 530 (1.64%) had a Parkinson's disease diagnosis. Controlling for sociodemographic factors and co-morbidities, veterans with Parkinson's disease had PCS and MCS below veterans with angina/coronary heart disease, arthritis, chronic low back pain, congestive heart failure, diabetes, and stroke. Veterans with spinal cord injury reported slightly lower PCS than veterans with Parkinson's disease (32.38 v 32.72; 0.03 of 1 SD). Veterans with depression reported markedly lower MCS than veterans with Parkinson's disease (35.94 v 41.48; 0.55 of 1 SD). The unique effect of having Parkinson's disease on HRQoL was to lower PCS and MCS by 4.10 and 3.42 points (0.41 and 0.34 of 1 SD), respectively.

Conclusions: The analysis quantifies the negative impact of Parkinson's disease on HRQoL, after controlling for sociodemographic factors and co-morbidities. Compared with eight other chronic conditions, Parkinson's disease imposes a relatively heavy burden on US veterans in the VHA health care system.

P atients' perceptions about how their illness affects them in their daily lives can differ from those of their practitioners[1–3] and informal caregivers.[4] It is particularly important that clinicians understand how patients experience chronic and often incurable conditions such as Parkinson's disease, where the goals of treatment are to optimise their quality of life.[5] Parkinson's disease gives rise to a range of physically disabling and socially distressing symptoms.[6 7] Empirical information about the impact of disease can be gathered from patients by measures of health related quality of life (HRQoL).[8] In combination with clinical indicators, HRQoL data contribute to the appreciation of the overall impact of disease on patients.[9]

Formal study of HRQoL is only about 25 years old, and has grown substantially over the last decade.[8] Although methodological and conceptual challenges remain,[5 10] HRQoL as an outcome has become an important standard for use in health care interventions. It can also be used as a basis for assessing the health status of populations, and to judge the burden of disease by comparing clinical groups with the general population. At an individual level, HRQoL has been shown to be a sound predictor of mortality and morbidity,[11] although available measures are not always appropriate for use in routine clinical practice.[12]

The most commonly used HRQoL instruments are measures which characterise patients using multidimensions or scales.[13] A distinction is drawn between generic and disease specific measures of HRQoL.[3] Although there is debate about the appropriate dimensions to include,[14] generic assessments often cover measures of physical functioning, independence of living, emotional/mental wellbeing, and the effects of disease on work and social activity. They allow broad population level analyses and comparisons between patient groups, but they do not focus on the special features of particular conditions that cause concern to the sufferers.

The Veterans Administration health care system (VHA) is one of the largest integrated systems nationally in the USA, with around 145 medical centres in the 50 states. This system, which is federally funded, provides comprehensive care to most veteran patients with service connected disabilities or who qualify economically. Veterans who use the VHA tend to be more disabled, economically disadvantaged, and have more complex medical and mental health problems than the general US population or veterans who do not use the VHA system.[15] Because the VHA recognises the importance of monitoring the health outcomes of veterans using measures of functional status, HRQoL assessments are increasing on a national basis. One of the most widely used generic measures in the VHA is the Veterans SF-36 (V/SF-36), adapted and modified from the medical outcomes study (MOS) version of the SF-36.[16–19]

In this study we used the V/SF-36 to evaluate the impact of Parkinson's disease on HRQoL in a large VHA national sample (n = 14 530) of veterans diagnosed with Parkinson's disease.

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Abbreviations: HRQoL, health related quality of life; MCS, mental component summary score of SF-36; MOS, medical outcomes study; PCS, physical component summary score of SF-36; RE, role, emotional; RP, role, physical; SF-36, short form 36 item health status questionnaire; VHA, Veterans Administration health care system; V/SF-36, Veterans short form 36 item health status questionnaire

Table 1 SF-36 items, scales, and component summaries*

Scales (items)	Component summary measure	Scales (items)	Component summary measure
Physical functioning (PF) (10 items: ability to undertake activities, carry, walk, climb stairs, bend, kneel, bathe, dress)	Physical component summary (PCS)	Vitality (VT) (four items: energy, fatigue)	Mental component summary (MCS)
Role physical (RP) (four items: physical limitations to activity)		Social functioning (SF) (two items: engagement in social activity)	
Bodily pain (BP) (two items: magnitude and interference of pain)		Role emotional (RE) (three items: emotional limitations to activities)	
General health (GH) (four items: perceptions of health status)		Mental health (MH) (five items: nervous, peaceful, sad, happy)	

*Adapted from references 18 and 25.

The statistical power from this large number of subjects has advantages over previous studies that collected data from fewer than 250 respondents.[20–22] The self reported HRQoL of veterans with Parkinson's disease is compared with that of the veterans without Parkinson's disease, and also with that of veterans reporting eight other neurological or chronic diseases. To our knowledge, there have been no previous studies that have examined the relative illness burden of Parkinson's disease. Many people with chronic disease suffer from multiple conditions, and the use of a generic instrument enables the health status of these people to be monitored.[23] We used multivariable statistical techniques to control for sociodemographic differences and co-morbid conditions so that the independent impact of particular diseases can be calculated and the unique effect of Parkinson's disease on HRQoL can be estimated.

METHODS
Data
The study population is US veterans enrolled in the VHA. All veterans have the option of enrolling in VHA, and eligibility is defined by seven priority categories:

- groups 1, 2, and 3: veterans with service connected disability of ≥ 50%, 30–40%, and 10–20% respectively, and former prisoners of war;
- group 4: veterans who are catastrophically disabled, housebound, needing aid and attendance;
- group 5: veterans with income and net worth below established thresholds;
- group 6: veterans of World War I, "agent orange," and "Gulf War syndrome";
- group 7: veterans who do not qualify under priority areas 1–6 but may make co-payments for VHA services according to fixed schedules.

Overall, 72.6% of VHA enrollees have alternative health care coverage besides VHA: 52.7% have Medicare (federal coverage for the aged or disabled), 19.1% have only private insurance, and 1% have only Medicaid (public coverage for the indigent). In 1999, 38.2% of enrollees exclusively used VHA for health care.[24]

Inspection of VHA administrative data for the fiscal years 1997 to 1999 showed there were 55 637 veterans with a diagnosis of Parkinson's disease (ICD-9-CM codes 332.0: Parkinson's disease; 333.0: other degenerative diseases of the basal ganglia, including Parkinsonian syndromes; 333.1: essential and other specified forms of tremor). This file was merged with data from the 1999 VHA large national health survey of

veteran enrollees,[19] which had randomly sampled 1.4 million VHA enrollees, stratified for priority status, from a total VHA population of approximately 3.5 million, between July 1999 and January 2000. In this way we were able to identify survey respondents with a recent diagnosis of Parkinson's disease.

The core section of the 1999 VHA large national health survey, which was completed by all respondents, collected data by means of a structured questionnaire on sociodemographic factors and health status. To measure the prevalence of chronic diseases, veterans were asked whether or not a doctor had ever told them they had each of 15 conditions (angina/coronary heart disease, arthritis, benign prostatic hypertrophy, cancer, chronic low back pain, chronic lung disease, congestive heart failure, depression, diabetes, hypertension, myocardial infarction, post-traumatic stress disorder, schizophrenia, spinal cord injury, stroke). Health status was measured using V/SF-36.

As shown in table 1, SF-36 comprises 36 items, which are combined into eight scales and summarised into the physical (PCS) and mental summary (MCS) scores. Items from each SF-36 scale were summed and raw scores were rescaled with a standard range 0 (worst) to 100 (best). The eight scales were combined into the two component summaries (PCS and MCS), using weights derived from a national probability sample. Each summary was then standardised with a mean of 50 and a standard deviation of 10. This process allows comparison across populations. Summaries have a consistent power advantage over scales, given their increased precision.[25]

The reliability and validity of the modified SF-36 is well established in VHA populations and, as in the MOS SF-36 version, normalised to a US population.[25–32] The V/SF-36 uses five point ordinal choices (no, none of the time, to yes, all of the time) in the physical role limitations (RP) and emotional role limitations (RE) scales, instead of dichotomised two point choices (yes/no), and adds about 5% to the precision of the PCS and MCS scores compared with the MOS SF-36.[18 19 26]

In addition to the core questionnaire, the VHA large national health survey included five modules—each allocated to a random 20% of sample members—on smoking and alcohol, diet and physical activity, satisfaction with care and the doctor–patient relationship, social support, and health care insurance and utilisation. Two sets of weights were applied to responses: first, to make the samples representative of the complete veteran enrollee population; and second, to correct for the extent that responses were not randomly distributed across all demographic groups.

Analysis
First, the socioeconomic, demographic, health, and service utilisation characteristics of survey respondents with Parkinson's

Table 2 Comparison of characteristics of veterans with and without a diagnosis of Parkinson's disease

Characteristic	Per cent of veterans with PD	Per cent of veterans without PD
(1) Age ≥65 years	76.26	44.04
(2) Male	97.56	95.18
(3) Race		
White	83.42	72.74
Black	7.95	15.52
(4) Employment		
Employed	10.08	35.17
Retired	65.86	43.10
Unable to work	22.44	16.55
(5) Education ≤12th grade	64.47	53.60
(6) VHA priority		
4 (catastrophic disability)	8.71	2.64
7 (no disability: co-pay)	9.31	12.77
(7) Source of health care in past three years		
VHA only	42.23	34.94
No VHA use	3.15	14.25
Dual use	53.22	45.71
(8) Planned future use of VHA		
Primary source	78.16	66.22
Back up	15.11	26.69
Prescription only	5.57	4.12
None	1.16	2.98
(9) Takes no regular exercise	57.77	35.89
(10) Physical health worse than one year ago	56.98	39.36
(11) Emotional health worse than one year ago	37.80	26.89
(12) Enrolled in Medicare	78.80	52.30
With private insurance (no Medicare)	4.44	19.13
Rely 100% on VHA outpatient care	45.07	33.16

Differences are significant for all characteristics (p < 0.001).
Data were calculated from the 1999 VHA large national health survey of veteran enrollees.
Items 1–11 were drawn from the core questionnaire (n = 887 775, of which 14 530 (1.64%) had a diagnosis of Parkinson's disease). Item 12 was taken from the insurance and utilisation module (n = 152 253, of which 2335 (1.53%) had Parkinson's disease).
PD, Parkinson's disease.

disease were compared with those of respondents without a diagnosis of Parkinson's disease using χ^2 tests of association.

Second, differences in HRQoL between groups of survey respondents were assessed. We used SUDAAN, a software package specifically designed for statistical testing of complex sample datasets.[33] Two multivariable least squares regression models (for PCS and MCS) calculated the mean V/SF-36 summary scores for veterans with Parkinson's disease and veterans with eight other chronic diseases (angina/coronary heart disease, arthritis, chronic low back pain, congestive heart failure, depression, diabetes, spinal cord injury, stroke). These eight neurological and chronic conditions were selected for comparison with Parkinson's disease from the 15 self reported by survey respondents, because of their established adverse effects on HRQoL.[19]

Twenty variables were entered into the regression models: four sociodemographic characteristics (age, sex, race, education) that are known to influence HRQoL,[28] a dichotomised variable showing whether or not respondents had a diagnosis of Parkinson's disease in VHA treatment files in the fiscal years 1997 to 1999, and 15 dichotomised variables for whether or not respondents had self reported each of the chronic conditions included in the survey. The age and race variables were each split into three categories for the purposes of the regression analysis (18–50, 51–65, > 65 years; white, black, other races). Education was divided into two categories, defined by whether or not the respondent had received more than 12 years of education.

The regression coefficients for each disease indicate an effect size: the difference in PCS (or MCS) between veterans with the disease and veterans without it, after controlling for the effect of four sociodemographic features and 15 co-morbidities. The effect size indicates the independent or unique impact of each disease on HRQoL. Results are presented here for Parkinson's disease and the eight selected comparison conditions.

RESULTS

Descriptive analysis of sample

Of 887 775 respondents to the 1999 VHA large national health survey (overall response rate 63.1%), 14 530 (1.6%) had a diagnosis of Parkinson's disease in VHA treatment files for fiscal years 1997 to 1999.

The characteristics of survey respondents with a diagnosis of Parkinson's disease are compared with those of respondents without Parkinson's disease in table 2. As might be expected with denominators of this magnitude, differences between groups were significant for all characteristics (p < 0.001), but small differences may not be important. Compared with other veterans, those with Parkinson's disease were more likely to be 65 years of age or older, white, retired, have had 12 or fewer years of education, be catastrophically disabled, be enrolled in Medicare, rely exclusively on the VHA for health care services, and report recent deteriorations in physical and mental health.

Veterans with Parkinson's disease reported, on average, 4.0 co-morbid conditions, compared with 3.2 among veterans without Parkinson's disease. All recorded conditions were significantly more prevalent among veterans with Parkinson's disease (p < 0.001). Table 3 shows that the largest differences between subjects with and without a diagnosis of Parkinson's disease were recorded for stroke, arthritis, benign prostatic hypertrophy, depression, and heart problems. Unadjusted mean PCS and MCS scores for veterans with Parkinson's disease were, respectively, 6.9 and 5.7 points (0.69 and 0.57 of 1 SD) below those of veterans without Parkinson's disease.

Table 3 Self reported co-morbidities and unadjusted component summary scores of veterans with and without Parkinson's disease

Self reported co-morbidity	Per cent of veterans with PD	Per cent of veterans without PD
Angina/coronary heart disease	25.05	18.55
Arthritis	58.01	50.10
Benign prostatic hypertrophy	35.64	23.15
Cancer	14.66	10.83
Chronic low back pain	42.87	39.86
Chronic lung disease	21.83	19.26
Congestive heart failure	20.49	13.29
Depression	42.80	29.40
Diabetes	21.33	18.74
Hypertension	52.96	49.57
Myocardial infarction	20.01	15.36
Post-traumatic stress disorder	17.66	14.02
Schizophrenia	6.15	4.12
Spinal cord injury	4.60	3.62
Stroke	19.39	8.65
Mean number of chronic conditions	4.03	3.19
Unadjusted physical component summary (PCS)	30.09	37.01
Unadjusted mental component summary (MCS)	39.42	45.16

Difference are all significant (p < 0.001).
Data were calculated from 1999 VHA large national health survey of veteran enrollees, core module, n = 887 775, of which 14 530 (1.64%) had a diagnosis of Parkinson's disease.
PD, Parkinson's disease.

Table 4 The relative health related quality of life of veterans with Parkinson's disease and self reporting eight other chronic diseases, adjusted for age, sex, race, education, and 15 co-morbid conditions

Chronic condition (1)	Per cent of core population (weighted n)* (2)	Mean (SD) number of self reported chronic conditions (3)	Mean (SE) physical component summary score		Mean effect of condition on PCS in points† (SE) (6)	Mean (SE) mental component summary score		Mean effect of condition on MCS in points† (SE) (9)
			With condition (4)	Without condition (5)		With condition (7)	Without condition (8)	
Spinal cord injury	3.6% (116 189)	5.10 (0.006)	32.38 (0.069)	36.93 (0.013)	−4.55 (0.070)	44.00 (0.075)	44.89 (0.014)	−0.89 (0.077)
Depression	29.6% (946 693)	4.96 (0.005)	35.88 (0.026)	37.17 (0.017)	−1.29 (0.033)	35.94 (0.030)	48.89 (0.018)	−12.95 (0.038)
Parkinson's disease	1.2% (39 405)	4.01 (0.024)	32.72 (0.096)	36.82 (0.013)	−4.10 (0.096)	41.48 (0.106)	44.91 (0.014)	−3.42 (0.107)
Congestive heart failure	13.4% (428 538)	6.39 (0.007)	33.68 (0.035)	37.25 (0.014)	−3.57 (0.038)	42.78 (0.040)	45.19 (0.015)	−2.41 (0.044)
Stroke	8.8% (281 760)	5.82 (0.009)	33.69 (0.041)	37.06 (0.013)	−3.37 (0.06)	43.13 (0.046)	45.03 (0.014)	−1.89 (0.048)
Chronic low back pain	39.9% (1 276 539)	4.60 (0.004)	33.76 (0.021)	38.89 (0.018)	−5.14 (0.028)	43.67 (0.023)	45.70 (0.019)	−2.04 (0.031)
Arthritis	50.2% (1 606 481)	4.46 (0.003)	34.15 (0.018)	39.59 (0.020)	−5.44 (0.028)	44.57 (0.020)	45.16 (0.021)	−0.59 (0.030)
Diabetes	18.8% (600 805)	5.06 (0.006)	35.04 (0.028)	37.18 (0.014)	−2.14 (0.031)	44.22 (0.031)	45.01 (0.015)	−0.79 (0.034)
Angina/coronary heart disease	18.6% (596 323)	5.94 (0.005)	35.49 (0.032)	37.07 (0.015)	−1.58 (0.037)	44.66 (0.039)	44.85 (0.016)	−0.25 (0.041)

*Total weighted core population, 3 199 209.
†An effect size of −4.55 is equivalent to 0.46 of one standard deviation.
All coefficients are significant at p < 0.001.
MCS, mental component summary score of the short form-36 questionnaire; PCS, physical component summary score.

Relative burden of Parkinson's disease

After adjusting for age, sex, race, education, and 15 self reported co-morbidities, the mean PCS and MCS scores of veterans with Parkinson's disease were lower than those of veterans with seven other chronic conditions by one to three points (table 4, columns 4 and 7). Subjects with spinal cord injury had a slightly lower mean PCS score than subjects with Parkinson's disease (32.38 v 32.72; 0.03 of 1 SD). Depression patients had a markedly lower mean MCS score (35.94 v 41.48; 0.55 of 1 SD).

Unique effects

The adjusted PCS and MCS scores of veterans with Parkinson's disease were, respectively, 4.10 and 3.42 points (0.41 and 0.34 of 1 SD) lower than those of veterans who did not have Parkinson's disease (table 4, columns 6 and 9). Three other diseases had larger unique effects on PCS (arthritis, −5.44; chronic low back pain, −5.14; spinal cord injury, −4.55), but subjects self reporting arthritis and low back pain had higher adjusted PCS scores than subjects with Parkinson's disease (34.15 and 33.76 v 32.72). Only depression had a larger

Table 5 The independent effects of age, sex, race, and education on health related quality of life, controlling for Parkinson's disease and 15 self reported co-morbid conditions

Independent variable		Per cent of core population	Weighted n*	Physical component summary			Mental component summary		
				β	SE	p Value	β	SE	p Value
Age	18 to 50 years	25.8%	824 213	1.821	(0.041)	†	−3.244	(0.044)	†
	51 to 64 years	29.7%	950 155	0.959	(0.031)	†	-1.755	(0.033)	†
	≥65 years	44.5%	1 422 415	0.000	(0.000)		0.000	(0.000)	
	Total	100.0%	3 196 784						
Sex	Male	95.2%	2 914 712	−0.048	(0.069)	0.486	−0.935	(0.074)	†
	Female	4.8%	146 518	0.000	(0.000)		0.000	(0.000)	
	Total	100.0%	3 061 230						
Race	White	72.9%	2 237 175	0.266	(0.041)	†	1.237	(0.045)	†
	Black	15.4%	473 000	−0.323	(0.052)	†	0.286	(0.058)	†
	Other	11.7%	359 036	0.000	(0.000)		0.000	(0.000)	
	Total	100.0%	3 069 211						
Education	≤12 years	53.8%	1 584 082	−1.981	(0.027)	†	−2.479	(0.029)	†
	>12 years	46.2%	1 362 705	0.000	(0.000)		0.000	(0.000)	
	Total	100.0%	2 946 787						

*Total weighted core population, 3 199 209, but data are incomplete for some variables.
†p < 0.001.

negative impact on MCS than Parkinson's disease (−12.95 *v* −3.42; 1.3 *v* 0.34 of 1 SD).

The independent effects on PCS and MCS of age, sex, race, and education are shown in table 5. Men had a lower MCS on average by 0.94 of a point than women. Younger age groups had higher mean PCS scores (by one to two points) and lower mean MCS scores (by 1.75 to 3.24 points) than subjects aged over 65 years. Having no education beyond high school reduced PCS and MCS scores by 1.98 and 2.48 points, respectively.

DISCUSSION

The analysis quantifies the extent of the negative impact of Parkinson's disease on HRQoL, as measured by the V/SF-36, controlling for the effect of four sociodemographic variables and 15 co-morbid conditions. The results confirm that people with Parkinson's disease carry a relatively heavy illness burden in both physical and mental dimensions of HRQoL compared with those suffering from eight other neurological or chronic conditions.

After removing the effect of sociodemographic factors and other diseases, the PCS and MCS scores for veterans with Parkinson's disease were lower than those for veterans with angina/coronary heart disease, arthritis, diabetes, chronic low pack pain, congestive heart failure, and stroke. Only subjects with spinal cord injury and depression recorded a lower HRQoL than those with Parkinson's disease. Individuals with spinal cord injury had mean PCS scores that were slightly below (by 0.34 points) those of the Parkinson's disease subjects, but their mean MCS scores were 2.52 points higher. On average, the MCS of subjects with depression was 5.44 points lower than that of subjects with Parkinson's disease, although their mean PCS was 3.16 points higher. The relatively low HRQoL of subjects with Parkinson's disease was not surprising, given the plethora of physical and social problems attributed to this disease.[34]

The unique effect of Parkinson's disease is to lower PCS by an average of 4.10 points below that of people without a diagnosis of Parkinson's disease. Although chronic low back pain and arthritis imposed larger negative effects on the physical dimensions of HRQoL than Parkinson's disease, the mean PCS scores for those conditions were higher. Many people with Parkinson's disease suffer these co-morbidities (43% and 58% with self reported chronic low back pain and arthritis in the VHA large national health survey, respectively).

Only depression had a larger unique effect on mental health dimensions of HRQoL than Parkinson's disease, and markedly so (−12.95 *v* −3.42; a difference equivalent to almost 1 SD). Recent international evidence confirms that depression has a major effect on the HRQoL of people with Parkinson's disease,[20 22 35 36] but the debate as to whether depression in this disorder is reactive or endogenous remains unresolved.[37 38] If depression is triggered by the same biological mechanisms that cause Parkinson's disease, the logic of calculating independent effects for both Parkinson's disease and depression might be questioned. We therefore repeated our regression analyses for PCS and MCS controlling for the same four sociodemographic variables and for a diagnosis of Parkinson's disease, but replacing the 15 individual co-morbidities with a count of the co-morbidities reported by survey respondents.

This revised specification does not show disease relativities, and compared with the extended models it reduces explanatory power (R^2 of PCS, 28.1% *v* 33.1%; MCS, 22.3% *v* 38.7%). The results of the reduced model (not reported here in full) showed that the mean impact of one chronic disease was to lower HRQoL by about 0.25 of 1 SD (PCS, β −2.678, SE 0.006, p < 0.001; MCS, β −2.540, SE 0.006, p < 0.001). The impact of age, sex, race, and education were very similar to those in the extended version.

Removing adjustment for individual diseases had very little effect on mean PCS of veterans with Parkinson's disease or on the associated effect size coefficients (32.93 *v* 32.72; −3.90 *v* −4.10 in the reduced and extended models, respectively). However, when depression was not explicitly controlled for, the mean MCS of subjects with Parkinson's disease fell by nearly two points (from 41.48 to 39.56), and the negative unique effect of Parkinson's disease became −5.37 (compared with −3.42). This is not surprising given that depression is a major determinant of MCS, 43% of survey respondents with Parkinson's disease self reported a previous diagnosis of depression, and the mean MCS, of subjects with depression was lower than that of subjects with Parkinson's disease by a considerable margin. It has been shown that people with Parkinson's disease adapt differently to their illness, depending on their physical status, psychological attitude, and social support.[39 40] While there is no simple relation between disability and depression,[41] coping and behavioural strategies may reduce depressive symptoms.[42 43]

Published reports have shown that the MOS version of the SF-36 is psychometrically sound for measuring HRQoL of people with Parkinson's disease. More advanced disease stage (measured by the unified Parkinson's disease ranking scale and the Hoehn and Yahr index), and complications such as dyskinesia, have been associated with lower SF-36 component and scale scores. Also, few floor or ceiling effects were found when SF-36 was used with people with Parkinson's disease.[9 44 45] Moreover, high correlations have been recorded between SF-36 and similar scales on the disease specific PDQ-39.[46]

There are several limitations to this study. First, it was a cross sectional sample and therefore the associations between variables described were purely descriptive and cannot imply causality. Second, co-morbidities and HRQoL were self reported, and correlated error may inflate the regression coefficients in some of these models and exaggerate the unique effects. However, the magnitude of the impact of co-morbidities on HRQoL has been described previously and our results corroborate those findings.[27] Third, there are selection effects arising because patients chose to use the VHA. We do not have internal data to model those effects, so adjustments for age or other demographics may be biased. However, the coefficients generated in the models presented are not all that different from those reported using a non-VHA population.[17]

The VHA population is different in many respects from the general populations, including the predominance of service related occupations and of male enrollees. The VHA population (mean PCS, 36.91; MCS, 45.08) carries a greater disease burden than the US civilian population (mean PCS, 43.60; MCS, 52.30) by more than one half of 1 SD.[19] Moreover, the distribution of illness is different in VHA in that younger groups in VHA have worse SF-36 scores in all but the physical functioning scale.[27] A community based study that used SF-36 to investigate the HRQoL of 228 people with Parkinson's disease in Finland found that women scored significantly lower than men in five of the scales, and confirmed the central role of depression in impairing HRQoL.[46]

Some observers have noted that people with chronic diseases rate their HRQoL higher than their physicians.[47] In this regard, the concept of response shift has received attention.[48] Like the disability paradox,[49] it refers to the possibility that people with chronic illnesses adjust their internal standards and values to accommodate the realities of their condition. It is suggested that they recalibrate their assessment of disability[50] and, as a result of lowered expectations,[51] they self report a higher quality of life than a healthy person would assign to any given level of impaired functioning. Existing measures of HRQoL do not show response shift because they do not relate self reported experiences to expectation.[52] To the extent that it occurs, response shift depresses disease effect sizes which are calculated as the

difference between a clinical group and the general population. It is unimportant in intercondition comparisons, however, unless it has differential impact across diseases.

Conclusions

Despite differences between the VHA and non-VHA populations, the proportion of people with Parkinson's disease in the VHA (1.6%) is equivalent to broader population estimates.[53] Other American evidence, based on a sample of 193 individuals with Parkinson's disease completing SF-36 in an outpatient setting, confirms that most subjects had lower scores than the general public on most dimensions, but showed that PCS, and to a lesser extent MCS, varied with disease severity.[9 45 54] The scores calculated in the present study are averages, and closer inspection of available data is required to see how generic self reported HRQoL in the VHA population varies with clinical indicators and service utilisation. The findings so far suggest, however, that the relative illness burden of veterans in the VHA with Parkinson's disease is high in both physical and mental dimensions of HRQoL, and thereby reinforce the case for multiprofessional team approaches to management.[55 56]

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HISTORICAL NOTE...

Pick's disease

Arnold Pick (1851–1924)[1] was born of German-Jewish parents on 20 July 1851 in Velké Mezirici, in Moravia.[2] He studied medicine in Vienna, where Theodore Meynert (1833–1892) stimulated his neurological interests. As with many medical scholars of his time, he was trained in clinical neurology, psychiatry, and neuropathology, a wide spectrum of disciplines now seldom feasible. In 1874 he trained in Berlin with Westphal, and from 1875 he worked at the later infamous asylum of Wehnen. Then he became lecturer in neurology and psychiatry in Prague where he met Otto Kahler, with whom he published papers on oculomotor palsies, cortical localisation, and syringomyelia. They established 'Kahler-Pick's law'—incoming fibres in the posterior columns of the cord from a higher level displace medially those that enter at a lower level.

He found promotion to the chair of neuropsychiatry in Prague but encountered many problems related to academic teaching in both German and Czech languages, controlled by the Austro-Hungarian empire. Essential provisions were often lacking and he met with much hostility and resentment[1] that often hampered his work. Despite this, his remarkable ability to communicate with patients with psychoses and aphasia was admired, and his history-taking became legendary.

An intellectual man, Pick loved classical music and in his home his books in many languages were piled from floor to ceiling. He was described as a "noble minded, excessively modest but fearless man, the essence of calm serenity".[2] He retired in 1921, but continued some work, despite troublesome cataracts and urinary tract stones. On 4 April 1924, at the age of 73, he died of urinary sepsis following bladder surgery.

Pick published about 350 papers on diverse topics. Many were case reports dealing with neuropsychology and behavioural neurology. He was among the first to give reliable descriptions of visual hallucinations, micrographia, palilalia, and reduplicating paramnesia. He wrote important papers on apraxia and aphasia.[3] He described the fibre bundles in the medulla oblongata (Pick's bundle). His 1898 book on neuropathology was a landmark in this field.[4]

In his work on aphasia he introduced the term agrammatism. Agrammatical speech was the basic defect of aphasic disorders. Wernicke influenced his views on language but Jackson probably had a greater influence on his concepts of how language was disrupted. They had great mutual respect and shared a distaste for speculation; both wrote in terse prose.

Pick's disease

In 1892, Pick described a 71 year old man who presented with progressive loss of language and a failing mind.[5] After death, the brain showed asymmetrical atrophy as opposed to the more diffuse atrophy of Alzheimer's disease. The condition described by Pick "on the relationship between senile atrophy of the brain and aphasia"[6] was often confused with Alzheimer's and vascular dementias. Pick published three further papers, in which he showed patients with severe aphasia and apraxia who had a "progressive circumscribed atrophy" of the cortex.[7–9] He regarded these patients as suffering from a variant of senile dementia. Attention was drawn to the aphasic and later the apraxic side of the syndrome, but eventually the distinctive pathology established it as an entity.

Alzheimer in 1911 confirmed the circumscribed cortical (lobar) atrophy,[10] and found the characteristic Pick bodies: ovoid, homogeneous, smooth-edged, and intensely argyrophilic neuronal inclusions. Gans introduced the name Pick's disease in 1922.[11]

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