

MATTERS ARISING

Desirable properties for instruments assessing quality of life: evidence from the PDQ-39

de Boer *et al* describe the development of a Dutch instrument to measure quality of life in patients with Parkinson's disease.¹ Two important properties that such instruments need to have are not given attention in their study. Questionnaires should produce reproducible data in the sense that they yield the same results on repeated trials under the same conditions and they need to be responsive in the sense that they detect clinically significant changes over time.²

We developed a 39 item questionnaire—the PDQ-39—to assess health related quality of life in patients with Parkinson's disease. A sample of 223 patients were asked to complete the questionnaire on two occasions three days apart.³ A group of 56 patients were omitted from analyses of reproducibility because they reported that their health changed over this time period. In the remaining 167 stable patients reproducibility for the eight scales of the PDQ-39 was very satisfactory when expressed as correlation coefficients: mobility 0.94, activities of daily living (ADL) 0.93, emotional well-being 0.90, stigma 0.90, social support 0.68, cognitions 0.86, communication 0.86, and bodily discomfort 0.80.

We have now examined responsiveness in a longitudinal study with assessments of 146 patients four months apart. Changes in scores for five of the eight scales show significant correlations with changes in a validated general health status measure, the SF-36,⁴ ranging from 0.21, $P < 0.05$ for the ADL scale, to 0.39, $P < 0.001$ for mobility. In other words, as patients report improvement or deterioration in general health, so these trends are reflected in changes for the PDQ-39. Such preliminary evidence of responsiveness is essential as therapeutic effects of interventions for Parkinson's disease are often small and difficult to detect. The PDQ-39 is being used in appropriate language versions in clinical trials of drugs in several countries and is a primary measure of outcome in a multicentre trial run by Professor Jarman, St Mary's Hospital Medical School, London, to evaluate the Parkinson's disease nurse specialist. By including such measures, evidence will be obtained of outcomes of concern to the patient.

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- 1 de Boer A, Wijker W, Speelman J, de Haes C. Quality of life in patients with Parkinson's disease: development of a questionnaire. *J Neurol Neurosurg Psychiatry* 1996;61:70-4.
- 2 Cox D, Fitzpatrick R, Fletcher A, *et al*. Quality of life assessment: can we keep it simple? *Journal of the Royal Statistical Society* 1992;155:353-93.
- 3 Peto V, Jenkinson C, Fitzpatrick R, Greenhall R. The development and validation of a short measure of functioning and well being for individuals with Parkinson's disease. *Quality of Life Research* 1995;4:241-8.
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How far are we in understanding the cause of Parkinson's disease?

The article by Ben-Shlomo is excellent although the issue of prevalence of Parkinson's disease in the black population is only briefly mentioned.¹ We have been studying the pattern of parkinsonism in AfroCaribbean and Indian (originating from the Indian subcontinent) subjects living in London and believe parkinsonism may be commoner in these ethnic groups than previously recognised.² Using a door to door assessment for parkinsonism in one electoral ward in London with a high AfroCaribbean population and reviewing the case files of 150 consecutive patients attending movement disorders and general neurology clinics at King's College, Lewisham and Hammersmith Hospitals we identified 18 cases of parkinsonism in patients of AfroCaribbean and Asian origin.^{3,4} 14 out of 18 (83.3%) cases have non-familial atypical parkinsonism, much higher than an expected 20%-30% in the white population. Our preliminary finding suggests that parkinsonism is probably more common than realised in the AfroCaribbean and Asian populations and these patients may be more susceptible to atypical parkinsonism. The reason for this is unclear and may reflect genetic or environmental factors as has been postulated in relation to the higher incidence of diabetes and ischaemic heart disease in migrant Asian populations in the United Kingdom. Further epidemiological studies on this issue are required.

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- 1 Ben-Shlomo Y. How far are we in understanding the cause of Parkinson's Disease? *J Neurol Neurosurg Psychiatry* 1996;61:4-16.
- 2 Richards M, Ray Chaudhuri K. Parkinson's disease in populations of African origin: a review of literature. *Neuroepidemiology* 1996;15:214-21.
- 3 Ray Chaudhuri K, Richards M, Brooks DJ. Atypical parkinsonism in AfroCaribbean and Asian populations in the UK. *Mov Disord* 1996;11(suppl1):534.
- 4 Richards M, Ray Chaudhuri K. A pilot investigation of Parkinson's disease in an AfroCaribbean migrant community in London. *J Neurol Neurosurg Psychiatry* 1996;60:119.

NOTICE

British Neurosurgery Research Group Meeting

The fourth British Neurosurgery Research Group Meeting will be held in Newcastle on 20-21 March 1997.

For further information contact: Professor A David Mendelow, Newcastle General Hospital, Regional Neurosciences Centre, Westgate Road, Newcastle-upon-Tyne, NE4 6BE, UK.

BOOK REVIEWS

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Cancer in the Nervous System. Edited by VICTOR A LEVIN. (Pp 472; price £75.00). 1995. Published by Churchill Livingstone, Edinburgh. ISBN 0443088802.

Primary malignancies of the central nervous system are uncommon, representing only about 1% of all primary cancers. However for those involved with their management they present fascinating and often frustrating features. There has long been a need for a good reference text on these tumours. This new book, edited by a distinguished American neuro-oncologist, has gathered together a large team of coauthors from many of the main cancer centres in the United States. They have produced a volume which goes a long way to filling that need.

Multiauthorship can result in many problems. This book has avoided most of the traps by assembling teams of surgeons, neuro-oncologists, pathologists, and others who clearly get their contributions together. References are reasonably up to date with some as late as 1994. They are generally comprehensive although omission of some appropriate European references in favour of North American journals is noticeable. However, particular pleasure was given to this reviewer by the inclusion of a long quotation from an article by Hughlings Jackson on a case of midline cerebellar tumours in the *British Medical Journal* of 1871! The book is structured on the basis of site oriented chapters covering all aspects of the appropriate malignancies. In addition there