



LUND UNIVERSITY

Self reported health in people with Parkinson's disease left untreated at diagnosis.

Hagell, Peter

Published in:
Journal of Neurology, Neurosurgery and Psychiatry

DOI:
[10.1136/jnnp.2006.109454](https://doi.org/10.1136/jnnp.2006.109454)

2007

[Link to publication](#)

Citation for published version (APA):
Hagell, P. (2007). Self reported health in people with Parkinson's disease left untreated at diagnosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 78(5), 442-442. <https://doi.org/10.1136/jnnp.2006.109454>

Total number of authors:
1

General rights

Unless other specific re-use rights are stated the following general rights apply:
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: <https://creativecommons.org/licenses/>

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00



Self-reported health in people with Parkinson's disease left untreated at diagnosis

Peter Hagell

J. Neurol. Neurosurg. Psychiatry 2007;78;442-; originally published online 29 Nov 2006;
doi:10.1136/jnp.2006.109454

Updated information and services can be found at:
<http://jnp.bmj.com/cgi/content/full/78/5/442>

These include:

References

This article cites 7 articles, 1 of which can be accessed free at:
<http://jnp.bmj.com/cgi/content/full/78/5/442#BIBL>

Rapid responses

You can respond to this article at:
<http://jnp.bmj.com/cgi/eletter-submit/78/5/442>

Email alerting service

Receive free email alerts when new articles cite this article - sign up in the box at the top right corner of the article

Notes

To order reprints of this article go to:
<http://www.bmjjournals.com/cgi/reprintform>

To subscribe to *Journal of Neurology, Neurosurgery, and Psychiatry* go to:
<http://www.bmjjournals.com/subscriptions/>

Self-reported health in people with Parkinson's disease left untreated at diagnosis

Peter Hagell

Early initiation of treatment in Parkinson's disease prevents patient-reported deteriorations, but what is gained?

The paper by Grosset *et al*¹ (see p 465) in this issue describes self-reported health in a "real-life" cohort of dopa-naïve people with Parkinson's disease (PD). Assessments using the Parkinson's Disease Questionnaire (PDQ)-39 at initial consultation and for up to 18 months thereafter suggest stable self-reported health among patients who were started on dopaminergic treatment, whereas those who remained dopa-naïve deteriorated.

These observations add valuable fuel to the discussion on when to start dopaminergic treatment in PD.^{2,3} However, it remains to be determined whether initial benefits last in the long term, or if potential early-treatment drawbacks³ will emerge. Furthermore, additional outcomes to those presented here will be required to clarify this issue.

Meanwhile, interpretation of the current findings calls for some caution. For example, exactly what deterioration(s) did the untreated group experience? Deteriorations of PDQ-39 domains exhibited effect sizes varying from small to large.¹ However, to appreciate these it must be clear what the scores are intended to measure and whether they are valid representations of those domains. Unfortunately, this does not seem to be the case for the PDQ-39 and similar rating scales for PD.⁴ This issue is

particularly relevant in view of emerging standards from the US Food and Drug Administration, which call for clear support regarding score validity to make claims based on patient-reported outcomes.⁵

Second, why did treated patients not improve? In contrast to the observations by Grosset *et al*,¹ recent trials of the same types of drugs in de novo PD have shown early and lasting clinician-reported and patient-reported improvements. One reason could relate to the usefulness of the PDQ-39 among people with relatively low (ie, better) scores, as information on its performance in early untreated PD seem to be lacking and studies have suggested ambiguousness with its responsiveness.⁶ If this is the case, it can have serious implications regarding interpretation of PDQ-39 outcomes, leading to valuable treatments being discarded when, in fact, people do benefit from them.

The study by Grosset *et al* adds an important aspect to the debate regarding when to initiate dopaminergic treatment in PD and its long-term extension will provide additional valuable insights. However, it also illustrates problems associated with rating scale endpoints, to which close attention needs to be paid since study design and statistics cannot compensate for measurement problems.⁷ Because measurement properties are

EDITORIAL COMMENTARY

sample dependent and not fixed scale characteristics, one remedy would be for investigators to routinely report information on reliability and validity of the data used in the analyses that the study inferences rest upon. Indeed, inclusion of such information in the report by Grosset *et al* would have aided interpretation of their findings and shed light on the performance of the PDQ-39 in early PD. If we take our patients and our studies seriously, we also need to be serious about our outcome measures. Unless rating scales are treated with full scientific rigour, advances in the clinical sciences will be hampered and opportunities to improve patient care may be lost.

J Neurol Neurosurg Psychiatry 2007;**78**:442.
doi: 10.1136/jnnp.2006.109454

Correspondence to: P Hagell, Department of Health Sciences, Lund University, PO Box 157, SE-221 00 Lund, Sweden; peter.hagell@med.lu.se

Received 16 November 2006

Revised 16 November 2006

Accepted 16 November 2006

Published Online First 29 November 2006

Competing interests: None.

REFERENCES

- 1 Grosset D, Taurah L, Burn DJ, *et al*. A multicentre longitudinal observational study of changes in self reported health status in people with Parkinson's disease left untreated at diagnosis. *J Neurol Neurosurg Psychiatry* 2007;**78**:465–9.
- 2 Schapira AHV, Obeso J. Timing of treatment initiation in Parkinson's disease: a need for reappraisal? *Ann Neurol* 2006;**59**:559–62.
- 3 Aminoff MJ. Treatment should not be initiated too soon in Parkinson's disease. *Ann Neurol* 2006;**59**:562–4.
- 4 Marras C, Lang AE. Outcome measures for clinical trials in Parkinson's disease: achievements and shortcomings. *Expert Rev Neurother* 2004;**4**:985–93.
- 5 Food and Drug Administration. Draft guidance for industry on patient-reported outcome measures: use in medicinal product development to support labeling claims. *Federal Regist*, 2006;**71**:5862–3.
- 6 Reichmann H, Boas J, Macmahon D, *et al*. Efficacy of combining levodopa with entacapone on quality of life and activities of daily living in patients experiencing wearing-off type fluctuations. *Acta Neurol Scand* 2005;**111**:21–8.
- 7 Hobart J. Rating scale for neurologists. *J Neurol Neurosurg Psychiatry* 2003;**74**(Suppl IV):iv22–6.