

# The Nerve! Readers Speak

## Reader response: Symptom burden among individuals with Parkinson disease: A national survey

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We read with great interest the study by Tarolli et al.,<sup>1</sup> which explored the burden of disease in Parkinson disease (PD) by evaluating the prevalence of nonmotor symptoms and their association with quality of life. The authors selected nonmotor symptoms based on literature review, expert opinions, and patient interviews. We note that apathy, which has major consequences for patients and carers, was not included as a relevant nonmotor symptom in their study. We performed a subcohort analysis of 60 patients from a study of pain in PD in 110 outpatients (PaCoMo-study, registered trial number: NL6311402917 [toetsingonline.nl]). We retrospectively reviewed the medical records to check whether the clinician identified apathy in these patients in the previous year, which was the case in 15% of the patients (n = 9). Blind to those results, patients were examined with the Apathy Scale (AS).<sup>2</sup> In total, 63.3% (n = 38) of the patients scored positive on the AS. Only 18.4% of the patients who scored positive on the AS were also classified or mentioned with apathy in the medical records by clinicians.

Apathy, an important nonmotor symptom of PD, is often missed or minimized by clinicians. When apathy is acknowledged, treatment can lead to better outcomes for patients.<sup>3</sup>

1. Tarolli CG, Zimmerman GA, Auinger P, et al. Symptom burden among individuals with Parkinson disease: a national survey. *Neurol Clin Pract* 2020;10:65–72.
2. Starkstein SE, Mayberg HS, Preziosi TJ, Andrezejewski P, Leiguarda R, Robinson RG. Reliability, validity, and clinical correlates of apathy in Parkinson's disease. *J Neuropsychiatry Clin Neurosci* 1992;4:134–139.
3. Devos D, Moreau C, Maltête D, et al. Rivastigmine in apathetic but dementia and depression-free patients with Parkinson's disease: a double-blind, placebo-controlled, randomised clinical trial. *J Neurol Neurosurg Psychiatry* 2014;85:668–674.

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## Author response: Symptom burden among individuals with Parkinson disease: A national survey

Christopher G. Tarolli (Rochester, NY)  
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We appreciate the readers' comments on the prevalence and impact of apathy on quality of life among individuals with Parkinson disease. In constructing our survey instrument, we discussed the inclusion of apathy as a symptom. However, we ultimately opted against inclusion because of concerns about the specificity of terminology in our online survey. Patients and care partners may not be familiar with the term "apathy," and near-synonyms such as "reduced motivation" have substantial overlap with other nonmotor features. Still, as the readers point out, apathy is extremely common and under-recognized. Similar to many of the nonmotor symptoms identified in our study,<sup>1</sup> we agree that clinicians should be screening for apathy among those with Parkinson disease.

1. Tarolli CG, Zimmerman GA, Auinger P, et al. Symptom burden among individuals with Parkinson disease: a national survey. *Neurol Clin Pract* 2020;10:65–72.

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Author disclosures are available upon request (ncpjjournal@neurology.org)

## Reader response: Functional neurologic disorders: Bringing the informal and hidden curriculum to light

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I read with interest the editorial by Strom<sup>1</sup> about functional neurologic disorders (FNDs). As a treating physician, I have struggled with the multiple diagnostic labels attached to these patients by physicians of different medical specialties during the course of their clinical disease presentation. A neurologist may assign a patient who presents with chronic fatigue the diagnostic labels of narcolepsy, idiopathic hypersomnia, or chronic Lyme disease. A rheumatologist may assign the label of collagen vascular disease, and a psychiatrist may diagnose depression. This diagnostic ambiguity is troublesome for patients and clinicians alike. I contend that even the term FND needs to be revisited. A patient should be broadly labeled as having a functional disorder and only after characterization sub-labeled and referred to an appropriate specialty physician.

1. Strom LA. Functional neurologic disorders: Bringing the informal and hidden curriculum to light. *Neurol Clin Pract Epub* 2019 Dec 19.

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## Author response: Functional neurologic disorders: Bringing the informal and hidden curriculum to light

Laura A. Strom (Boulder, CO)

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Dr. Sethi raises an excellent point about the term functional neurologic disorder (FND) in his comment on the editorial.<sup>1</sup> It seems clear that reticence to use the term functional creates the ambiguity he mentions. Medically unexplained symptoms, categorized in the international classification of diseases as undifferentiated somatoform disorders, are a diagnosis that many providers are loathed to give. Whether that is because of concern about missing a diagnosis is not clear. Having evaluated and treated more than 400 of these individuals in the FND clinic at the University of Colorado, I can attest to the fact that patients arrive confused about their diagnosis. Multiple incorrect diagnoses, as Dr. Sethi points out, pack the medical histories of patients with FND, leading doctors and patients astray. I believe that the commentary by Perez et al.<sup>2</sup> gives us the best chance for a way forward, by teaching a new generation of residents and fellows how to approach patients in a nonjudgmental and open-minded fashion. It took 30 years to add Functional Neurologic Disorder to the Diagnostic and Statistical Manual, and it is still parenthetical to the term Conversion.<sup>3</sup> Stripping the diagnosis of FND of its stigma and empowering care providers to rule in functional disorders is an actionable step which should be taken.

1. Strom LA. Functional neurologic disorders: Bringing the informal and hidden curriculum to light. *Neurol Clin Pract Epub* 19 Dec 2019.

2. Perez DL, Hunt A, Sharma N, Flaherty A, Caplan D, Schmammann JD. Cautionary notes on diagnosing functional neurologic disorder as a neurologist-in-training. *Neurol Clin Pract Epub* 4 Dec 2019.

3. Kanaan RAA. Freud's hysteria and its legacy. *Handb Clin Neurol* 2016;139:37–44.

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Christopher G. Tarolli

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