Letter to the Editor

Associations between spiritual well-being and quality of life in Parkinson disease

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We thank Drs. Kilpatrick and Robinson for their comments. Regarding the diagnosis of patients, the majority of patients had a diagnosis of Parkinson disease (PD) (including PD dementia and Lewy Body Disease) in addition to a smaller number of patients with Parkinson plus disorders (progressive supranuclear palsy, multiple system atrophy and Corticobasal syndrome for a total of 11.5% in Standard Care and 12.3% in the Palliative Care group) (1). Given many patients have an alternative diagnosis after many years of follow-up (less than 60% accuracy of diagnosis), we do not believe that generalizability is limited due to the mixed population (2). In clinical practice, neurologists and other providers will be faced with a patient with parkinsonism that is most likely PD, but over time may have an alternative diagnosis.

All patients completed all quality of life questionnaires since it is not clear which quality of life instruments are valid in a palliative PD population.

While we excluded those with immediate palliative needs, this is based on an ethical concern that delaying access to palliative care would be to the detriment of our participants. Further, randomizing a palliative or hospice population may be also misleading since those "accepting" hospice care may either have higher spiritual distress or be more open to palliative approaches.

We agree that identifying spiritual distress is important. We are not clear that those with most spiritual distress will have advanced illness. The existential questions of "why has this happened to me?", "how can I carry on?", "how can I find hope?" are not exclusive to the most advanced and may in fact, be more acute in those newly diagnosed, and therefore less motor impaired. As demonstrated by our work, those without spiritual distress report higher quality of life, lower anxiety, lower depression, fewer non-motor symptoms, reduced palliative symptoms and less prolonged grief. This provides support for the presence of spiritual care providers in Neuropalliative care teams.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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References

1. Kluger BM, Miyasaki J, Katz M, et al. Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders: A Randomized Clinical Trial. JAMA Neurol 2020. [Epub ahead of print].
2. Adler CH, Beach TG, Hentz JG, et al. Low clinical diagnostic accuracy of early vs advanced Parkinson disease: clinicopathologic study. Neurology 2014;83:406-12.

