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## **Neurologists and Palliative Care: Are We Doing Enough?**

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John Ney: Drafting/revision of the manuscript for content, including medical writing for content; Major role in the acquisition of data; Study concept or design; Analysis or interpretation of data

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With an aging population, the prevalence of neurodegenerative disorders is increasing.<sup>1,</sup>

<sup>2</sup> The natural history of neurodegenerative diseases is one of increasing disability, loss of function, immobility, and eventual demise. As McKenzie, et al<sup>3</sup> show in this issue of Neurology: Clinical Practice, end-stage neurological diseases including Parkinson's Disease are accompanied by increasing inpatient healthcare utilization culminating often with prolonged intensive care stays and in-hospital death. As the role of palliative care has expanded over time from its original application in terminal cancer patients to

include persons suffering from degenerative neurological diseases, the effect on healthcare use in the final year of life bears examination.

Using Canadian provincial administrative claims data, McKenzie, et al examine the exposure to palliative care on the outcome of in-home death for persons with neurodegenerative movement disorders. In their final year of life, residents of Alberta with Parkinson's, progressive supranuclear palsy, multiple systems atrophy, and Huntington's disease received an outpatient palliative care consultation in only a small minority of cases (8.8%.) These persons were much more likely to experience death at home (OR 2.49, 95% CI, 1.48, 4.21.) than those who did not receive such care. Furthermore, earlier receipt of palliative care (>90 days prior to date of death) was associated with greater likelihood of death at home than in the hospital.

McKenzie, et al,<sup>3</sup> also show the extent of acute healthcare use among sufferers of end-stage movement disorders in the last year of life. Over sixty percent had at least one emergency department visit, with nearly a quarter having three or more ED visits. More than half experienced one or more hospitalizations, and twenty three percent were hospitalized for greater than a month. Critical care use was unusual, but mostly occurred in the month prior to death.

Implicit in the authors' analysis is the notion that a death at home, with palliation for pain and alleviated suffering, is preferable to an in-hospital death. Much of our training as physicians is focused on bringing our most potent treatments and resources available to bear on the most severe disease. Understanding the futility of providing care to merely prolong life can be a hard lesson. That outpatient neurologist care led to a greater chance of in-hospital death and no changes to use of ED and hospitalization in the last

year of life suggests that as a profession we have little comfort with issues of death and dying even where death is anticipated.

A path forward, where neurological and palliative care are integrated for patients with neurodegenerative movement disorders as they near death, is presented by McQueen, et al,<sup>4</sup> in this issue of NCP. They use time-based cost accounting and Medicare reimbursement rates to examine the cost and return on investment for establishment of a neuropalliative care clinic for a hospital system. The ultimate finding is that a neuropalliative care clinic would generate 68% more income for the hospital system in reimbursement over the cost in space and labor of funding the clinic.

These two studies highlight that palliative care is currently vastly underutilized in neurodegenerative diseases, and that financial incentives exist to rectify this situation. McKenzie, et al, emphasizes that over eighty percent of persons in the study had no contact with palliative care, and of those who did, palliative care was consulted once the patient was already in the hospital in the majority of cases. Greater use of palliative care indicates a willingness to accept and plan for a comfortable death in the absence of cure or effective treatments. As specialists with understanding of the needs of our unique patient population, we should advocate both to improve our patients' quality of life and, when appropriate, a better end of life.<sup>5</sup> That imperative, coupled with alignment of hospital-level fiscal goals, should provide the motivation for increased use of palliative care in a population that requires not just our expertise but our compassion.

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