EDITORIAL

Neurologists and Palliative Care

Are We Doing Enough?

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Neurology: Clinical Practice December 2022 vol. 12 no. 6 386-387 doi:10.1212/CPJ.0000000000200114

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With an aging population, the prevalence of neurodegenerative disorders is increasing.[1,2] The natural history of neurodegenerative diseases is one of increasing disability, loss of function, immobility, and eventual demise. As McKenzie et al.[3] show in this issue of *Neurology® Clinical Practice*, end-stage neurologic diseases including Parkinson disease are accompanied by increasing inpatient health care 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 patients with terminal cancer to include persons suffering from degenerative neurologic diseases, the effect on health care 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, progressive supranuclear palsy, multiple systems atrophy, and Huntington 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.[3] also show the extent of acute health care use among sufferers of end-stage movement disorders in the last year of life. Over 60% had at least 1 emergency department visit, with nearly a quarter having 3 or more ED visits. More than half experienced one or more hospitalizations, and 23% were hospitalized for greater than a month. Critical care use was unusual, but mostly occurred in the month before 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 neurologic and palliative care are integrated for patients with neurodegenerative movement disorders as they near death, is presented by McQueen, et al.,[4] 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 2 studies highlight that palliative care is currently vastly underutilized in neurodegenerative diseases and that financial incentives exist to rectify this situation. McKenzie, et al.

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Funding information and disclosures are provided at the end of the article. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

emphasize that more than 80% of persons in this 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 most of the 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.[5] 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.

Study Funding

The author reports no targeted funding.

Disclosure

The author reports no relevant disclosures. Full disclosure form information provided by the authors is available with the full text of this article at Neurology.org/cp.

Publication History

Received by *Neurology: Clinical Practice* October 8, 2022. Accepted in final form October 12, 2022.

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Neurol Clin Pract 2022;12;386-387 Published Online before print October 18, 2022
DOI 10.1212/CPJ.0000000000200114