Utilization of Hospice Services in a Population of Patients with Huntington’s Disease (TH307-C)

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Objectives
- To describe a population of patients with Huntington’s disease enrolled in hospice.
- To compare the population of patients with Huntington’s disease enrolled in hospice with other populations to highlight characteristics and considerations unique to this population.

Original Research Background: Although the trajectory of Huntington’s disease and its complications have been well described, much less is known about the course of late-stage illness. In particular, little is known about the population of patients who enroll in hospice.

Research Objectives: To describe a population of patients with Huntington’s disease who enrolled in hospice.

Methods: Retrospective cohort study of electronic medical record data from 12 not-for-profit hospices in the United States.

Results: Of 164,032 patients admitted over 5 years, 101 (0.06%) had a primary diagnosis of Huntington’s disease. The median age was 57 (IQR: 48-65) and 53 (52.5%) were female. These patients were generally cared for by a spouse (n=36) or adult child (n=20). At the time of admission, most patients were living either at home (n=39) or in a nursing home (n=41). All were either bedbound or could ambulate only with assistance. The most common symptom reported during enrollment in hospice was pain (n=34) followed by anxiety (n=30), nausea (n=18), and dyspnea (n=10). Patients had a median length of stay in hospice of 42 days, which was significantly longer than for other hospice patients in the sample (17 days). Of 101 patients who were admitted to hospice, 73 died, 11 were still enrolled at the time of data analysis, and 17 left hospice either because they no longer met eligibility criteria (n=14) or because they decided to seek aggressive treatment (n=3). Of the 73 patients who died while on hospice, most were likely to die in a nursing home (n=29; 40%), followed by a hospital or inpatient hospice unit (n=27; 37%). Only 17 patients (23%) died at home.

Conclusions: Patients with Huntington’s disease are admitted to hospice much earlier than other patients are, but nevertheless have a significant symptom burden and limited functional status. Although hospice care emphasizes the importance of helping patients to remain in their homes, only a minority of patients with Huntington’s Disease were able to die at home.