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Original Study

Clinical, Demographic, and Pharmacologic Features of Nursing Home Residents With Huntington's Disease

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A B S T R A C T

Background: The purpose of this descriptive, retrospective analysis was to develop a demographic and clinical profile of nursing home residents with a diagnosis of Huntington's disease (HD).
Methods: Queries were made of a large data repository of linked and de-identified Minimum Data Set version 3.0 and prescription claims records, for the time period of October 1, 2010 through March 31, 2012.
Results: Of 249,811 residents, 340 (0.14%) had a diagnosis of HD; 61% were female and 77.9% were Caucasian. The age range mode was 55–59 years (15%). Approximately one-half of the residents with HD exhibited communication difficulties, 78% had moderate or severe cognitive impairment, and most have significant functional limitations. Depression, dementia, anxiety, psychosis, and bipolar disease were present in 59.4%, 50.9%, 35.9%, and 23.2%, and 9.7%, respectively. Only 21% of residents with HD exhibited troublesome behavioral symptoms. Comorbidities of diabetes and cancer were uncommon (0.3%). Use of physical restraints (excluding bed rails) was considerably higher in residents with HD than in the general nursing home population. Falls were documented in almost one-half of residents. Antipsychotics were used in 61.6% of residents; 16.2% had psychotic symptoms. One was treated with tetrabenazine. Anxiolytics were received by 59.1% of residents, whereas only 35.9% had anxiety noted on Minimum Data Set records.
Conclusions: The prevalence of HD in US nursing homes is very low (0.14%). Affected residents have significant cognitive and functional impairments, but problematic behaviors are present in only a minority. Serious comorbidities such as cancer and diabetes are rare. Antipsychotics, antidepressants, and anxiolytics are the mainstays of treatment.

The prevalence of Huntington's disease (HD) in the nursing home setting is not well-studied, however, analysis of a prospectively obtained, observational database of subjects with HD found that 7.4% resided in skilled nursing facilities (SNFs).[1] The average age of these residents was 52 years, and 63% were women. Compared with community-dwelling HD patients, those residing in SNFs had worse motor function (eg, chorea, bradykinesia, gait abnormality, and imbalance); were more likely to have obsessions, compulsions, delusions, and auditory hallucinations; and had more aggressive, disruptive, and irritable behaviors. Bradykinesia, impaired gait, and impaired tandem walking were predictive of nursing home placement.[1]

In addition to the motor, psychiatric, and behavioral features of HD described above, affected individuals can exhibit a wide array of other disease-related symptoms, including depression, anxiety, impulsiveness, apathy, cognitive impairment, sleep disturbance, dysarthria, dysphagia, weight loss, and in the later stages, incontinence, mutism, dystonia, and immobility.[2,3] There is little published information about the clinical profile and drug therapy regimens of residents with HD residing in SNFs, related to either the motor symptoms (eg, chorea), or the nonmotor symptoms (eg, behavioral, psychiatric, cognitive).

Because of the chronic and debilitating nature of HD, the significant quality of life and safety concerns, and the potential for medication-related adverse consequences, an analysis of residents with this condition in the nursing home setting is an important contribution to the understanding of the complexities of HD in SNF patients. The objective of this retrospective study was to characterize the prevalence of HD in residents of US SNFs and to develop a profile of these residents, including demographic information, concurrent

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diagnoses, use of medications, and functional and quality of life parameters.

Methods

After obtaining an exemption from Institutional Review Board Review and Waiver of Authorization from Sterling Institutional Review Board, data extracts were obtained from Omnicare's repository of Minimum Data Set (MDS) version 3.0 and prescription claims records for residents in Omnicare-serviced SNFs for the time period of October 1, 2010 through March 31, 2012. Prescription claims data are collected from about 200 pharmacies serving more than 1.4 million residents in about 19,000 long term care and other healthcare facilities in 48 states (excludes Hawaii and Alaska) and Canada. The database stores over 600 million prescription claims processed within last 6 years. Initially, a count of unique residents for whom MDS data existed in the database was obtained and served as the denominator for determining the prevalence of a HD diagnosis in MDS records.

The MDS is a comprehensive, standardized resident assessment instrument that is utilized in SNF to develop care delivery and planning, monitor clinical indicators such as falls, fractures, cognition, and behavior, and for payment from Medicare.[4] The MDS is completed on admission to the facility, quarterly, annually, and upon significant changes in patient condition. With the implementation of MDS version 3.0 in October, 2010, "Huntington's disease" appears as a distinct data field. The MDS data elements have been validated, and there is evidence for inter-rater reliability.[5] Over 85% of MDS data elements have been found to be reliable with adequate inter-rater reliability and overall good agreement.[5,6] The strongest reliability is with elements related to activities of daily living (ADLs). ADLs, pain, distressed mood, behavioral disturbances, and social engagement elements of the MDS have manifested discriminant validity.[7] Although there are limitations to this caregiver-related assessment instrument, it is a standardized tool that provides the "best available evidence" of resident status and outcomes in the SNF setting.

To perform the data match, prescription claims data and MDS data were obtained from the warehouse for the time period of interest. Once the 2 data sets were extracted, they were matched using resident demographics, and then the matched records were de-identified using a "safe harbor" method where all 18 identifiable data elements listed in section 164.514(b)(2) of the Health Insurance Portability and Accountability Act Privacy Rule are removed and replaced with internal identifiers.

During the study period, many residents had more than 1 MDS assessment completed and received multiple medications. To avoid counting MDS data elements multiple times, if a resident had more than 1 MDS assessment during the study period and had different answers for the same MDS data element, then the answer representing the more severe condition or state was used. All medications prescribed during the study period were included, without determining start or stop dates; thus, an individual listed as taking haloperidol and olanzapine could have taken the drugs sequentially (in either order), or could be taking the 2 drugs concurrently.

Results

Demographics

Of a total of 249,811 unique SNF residents identified in the MDS dataset, there were 340 (0.14%) with a diagnosis of HD. Of these, 61% were female (Table 1), and the majority were white (77.9%). Fifty-six percent of HD residents were between the ages of 50 and 69, with a mode of 15% in the age range of 55–59 (Figure 1).

Table 1
Demographic Characteristics of SNF Residents With HD

Diagnosis	Total Number	Percent
HD	340	0.14%
Residents in MDS database	249,811	
MDS Data Element	**Total Number**	**Percent**
Sex		
Male	134	39.4%
Female	206	60.6%
Age category		
<30 years	1	0.3%
30–34 years	7	2.1%
35–39 years	17	5.0%
40–44 years	15	4.4%
45–49 years	23	6.8%
50–54 years	48	14.1%
55–59 years	51	15.0%
60–64 years	46	13.5%
65–69 years	44	12.9%
70–74 years	20	5.9%
75–79 years	22	6.5%
80–84 years	21	6.2%
85–89 years	14	4.1%
>90 years	11	3.2%
Race/ethnicity		
White	265	77.9%
Black or African American	35	10.3%
Hispanic or Latino	29	8.5%
Other	11	3.2%

HD, Huntington's disease; MDS, Minimum Data Set; SNF, skilled nursing facility.

Functional Impairments

Communication and comprehension problems affected over one-half of residents (Table 2). Nearly one-half were unable to complete a cognitive interview (brief interview for mental status), and 44.9% of those who did showed severe cognitive impairments.

Significant functional limitations in the performance of ADLs were noted in HD residents (data not shown). Extensive assistance or total dependence on staff was noted in the following domains: bathing (94.8%), personal hygiene (85.9%), dressing (84.7%), toileting (84.1%), transfers (80%), bed mobility (76.5%), and eating (65.9%). Mobility was similarly affected, with 55.9% of residents not walking in their room at all in the look-back assessment period, and only 4.1% of residents able to walk in their room independently. Three-quarters of these residents used a wheelchair as their primary mode of locomotion; only 3.2% used a walker, with the remainder using no device. Almost three-quarters (73.2%) of residents were "always incontinent."

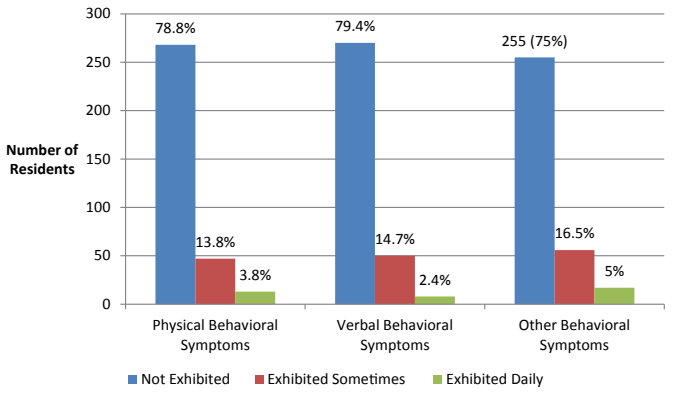

Fig. 1. Frequency of behavioral symptom manifestations in skilled nursing facility (SNF) residents with Huntington's disease (HD).