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Huntington's Disease: Assessing The Needs of Patients and Caregivers in Vermont

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Huntington's Disease: Assessing The Needs of Patients and Caregivers in Vermont

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Introduction

- Huntington's disease (HD) is an inherited neurological disorder that causes a progressive decline in motor, cognitive and psychiatric function.
- HD affects 30,000 people in the USA. In Vermont it is estimated that 69 individuals have HD and 420 people are at risk for developing the disease.
 - Crescent Manor Care Centers is currently the only long term care facility in Vermont that houses Huntington's patients. Patients receive care specific to HD including PT, OT, Speech Therapy and community activities. Currently, 13 of 40 beds are occupied.
 - There is one HD support group in the state located in South Burlington which meets once a month. Due to the low population of HD patients in the state, there is no single state government agency responsible for managing the care of HD patients.

Methods

A survey was conducted and was designed to investigate potential needs identified from our literature review and from information provided by the Huntington's Disease Society of America (HDSA). The survey was designed to be completed by either a patient, family member or professional caregiver. The survey contained categorical, Likert-style and open-ended questions. A draft of the survey was distributed for review to local health professionals, HD advocates, and patients in the Chittenden County HD support group. Edits were made based on the reviewers' recommendations. Paper copies were distributed to the support group and to Dr. James Boyd, who mailed the surveys to his patients and to Vermont neurologists. All surveys came with addressed, postage-paid envelopes to facilitate their return.

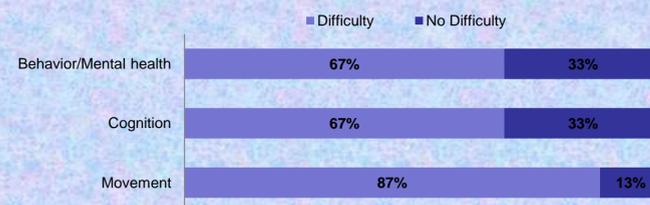


Photo: Kevin McGrath

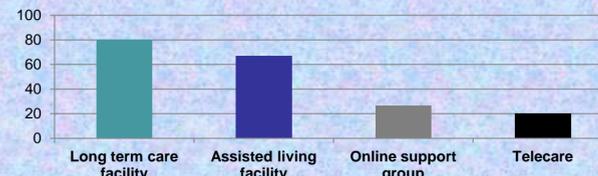
Results

- Age in years, median & SD: 52 ±14
- Of the respondents, 6 people were diagnosed within the past 3 years, 4 people were diagnosed between 3 and 8 years ago and 4 people have lived with an HD diagnosis for over 10 years.

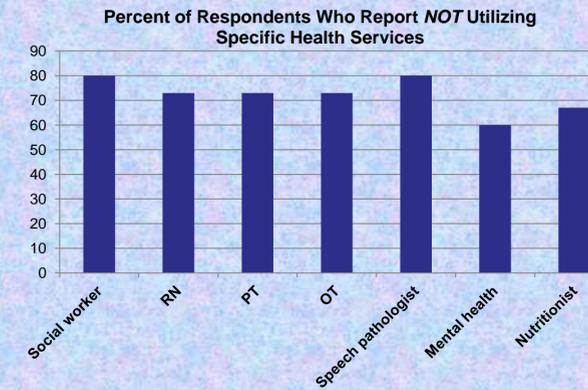
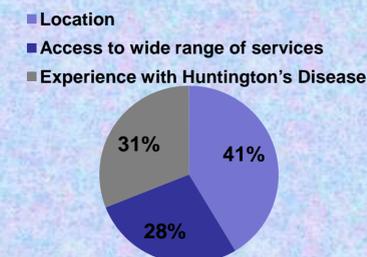
Symptoms with which patients reported having difficulty



Percent of respondents interested in:

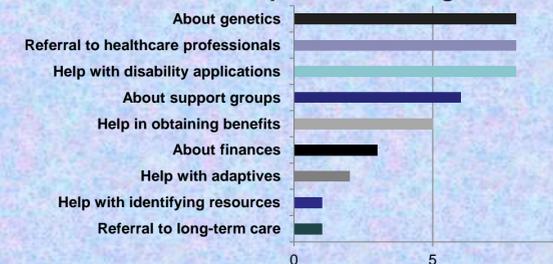


Priority for Outpatient Care



- Patients were generally satisfied or very satisfied with their access to all healthcare professionals. However, services appeared to be underutilized.

Number of respondents reporting information provided at diagnosis:



- Patients need more assistance with identifying resources.
- Currently, the vast majority of patients are driving 1 hour or less to see their neurologist and location is the top priority for outpatient care.

Discussion

- While most respondents were able to get help with healthcare referrals, financial disability applications and genetic counseling from their health care provider, only one individual was able to get help in identifying community resources. This omission highlights both the lack of social worker usage and an easily accessible central resource of information for Vermonters with HD.

- A very high percentage of respondents reported difficulty with movement and mental health, but only a minority of individuals utilized non-physician professionals in these areas. These results indicate that Vermont HD patients may need increased access to and coordination of care outside of regular neurological treatment.
 - Respondents reported a high level of interest in a long term care or assisted living facility in the Chittenden County, Vermont area. Currently no such facility exists, which leads to hardships for family members who must travel several hours to see HD residents at Crescent Manor in Bennington, VT.
- Limitations:**
- A limited number(15) of surveys were returned which did not allow for a statistically significant analysis.
 - The majority of responses (65%) were from patients with a HD diagnosis that was less than three years old, limiting the survey's accuracy by representing higher functioning patients' needs.

Conclusion

Having a case management system would potentially allow improved utilization of resources, including long-term care planning. An in-patient facility located in the Burlington area with easy access to multiple services would be of great benefit.

Acknowledgments

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