Educating Patients and Caregivers in the VUMC Movement Disorders Clinic on the Neuropsychiatric Symptoms of Huntington’s Disease

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BACKGROUND

- Up to 87-99% of patients with Huntington’s disease (HD) will suffer from at least one neuropsychiatric symptom during the course of their disease progression.
- Some of the most prevalent symptoms include depression, anxiety, irritability, apathy, impulsivity, perseveration, and psychosis.
- Patients often report being more bothered by these symptoms than by the sometimes more noticeable motor symptoms of HD.
- HD families often have difficulty recognizing these symptoms which hinders the ability to have informed discussions with their providers.
- There are few resources available on these symptoms, and those that are can be difficult to understand.

Hypothesis: lack of patient and caregiver education results in an inability to both identify neuropsychiatric symptoms and communicate them to clinicians. By providing HD families with easy-to-comprehend resources, we may give them the opportunity to better understand HD and become more effective advocates for themselves and those in their care.

AIMS

1. Assess if providing patients and caregivers with informational handouts improves their understanding of the neuropsychiatric symptoms of HD, using a pre-post study design.
2. Gather qualitative data on patient and caregiver perception of the handouts, including how helpful they found them, and what information they would have liked to see included.

METHODS

- Developed 6 handouts on the neuropsychiatric symptoms of HD:
  - Depression and HD
  - Anxiety and HD
  - Apathy and HD
  - Sleep Dysfunction and HD
  - Care for the Patient
  - Care for the Caregiver

- Administered a 10-question pre-study survey to patients and caregivers to assess their level of knowledge and understanding of the neuropsychiatric symptoms of HD.
- Distributed the handouts to participants and asked them to bring them home and read the information.
- Administered a follow-up survey to patients and caregivers to assess their level of knowledge and understanding of the neuropsychiatric symptoms of HD.
- Collected qualitative feedback from participants.

RESULTS

- Ran a McNemar’s Test for paired true/false data in order to detect if there was an increase in correct response rates between pre- and post-handout data. None of the questions revealed statistical significance.
- Some differences between patient and caregiver groups. Both patients and caregivers displayed an upward trend of correct responses, with patients improving from 29 to 33 correct responses, and caregivers improving from 36 to 37 correct responses.
- On a scale of 1-5, patient average rating for each handout was a 4.57 and caregiver average rating for each handout was a 4.88.
- Qualitative responses were overwhelmingly positive, with particular emphasis on how helpful, informative, and comprehensive participants found the handouts.

- Some notable comments include:
  - “I didn’t realize I was experiencing some of these symptoms but now that I read them, it’s changed my thinking. This should have been given to me from the beginning because they are easy to read.” – Patient.
  - “When you don’t understand what you’re dealing with, once you’ve read [the handouts], you know. Very helpful for those who have never experienced these symptoms.” – Caregiver.
  - “Would be nice to have a list of names or places to go to to see more resources. The forms are helpful for families.” – Caregiver.

DISCUSSION

- Feedback on the handouts was immensely positive. We observed positive trends for both caregivers and patients.
- A larger sample of participants may have resulted in significant improvements.
- Many participants were thankful to have the handouts as a resource. As some of the participants noted, the handouts helped them identify symptoms in themselves or their loved ones that they did not have a thorough understanding of before.
- Perhaps an assessment on concrete information about neuropsychiatric symptoms is not as valuable as HD families feeling empowered and comfortable in recognizing these symptoms, and subsequently addressing them with their providers.
- Next steps: revising the handouts, distributing handouts within the HD clinic, continuing to conduct meaningful conversations with HD families on the neuropsychiatric symptoms of HD, and conducting more in depth studies.

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