

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

- Assess if providing patients and caregivers with informational handouts improves their understanding of the neuropsychiatric symptoms of HD, using a pre-post study design.
- 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

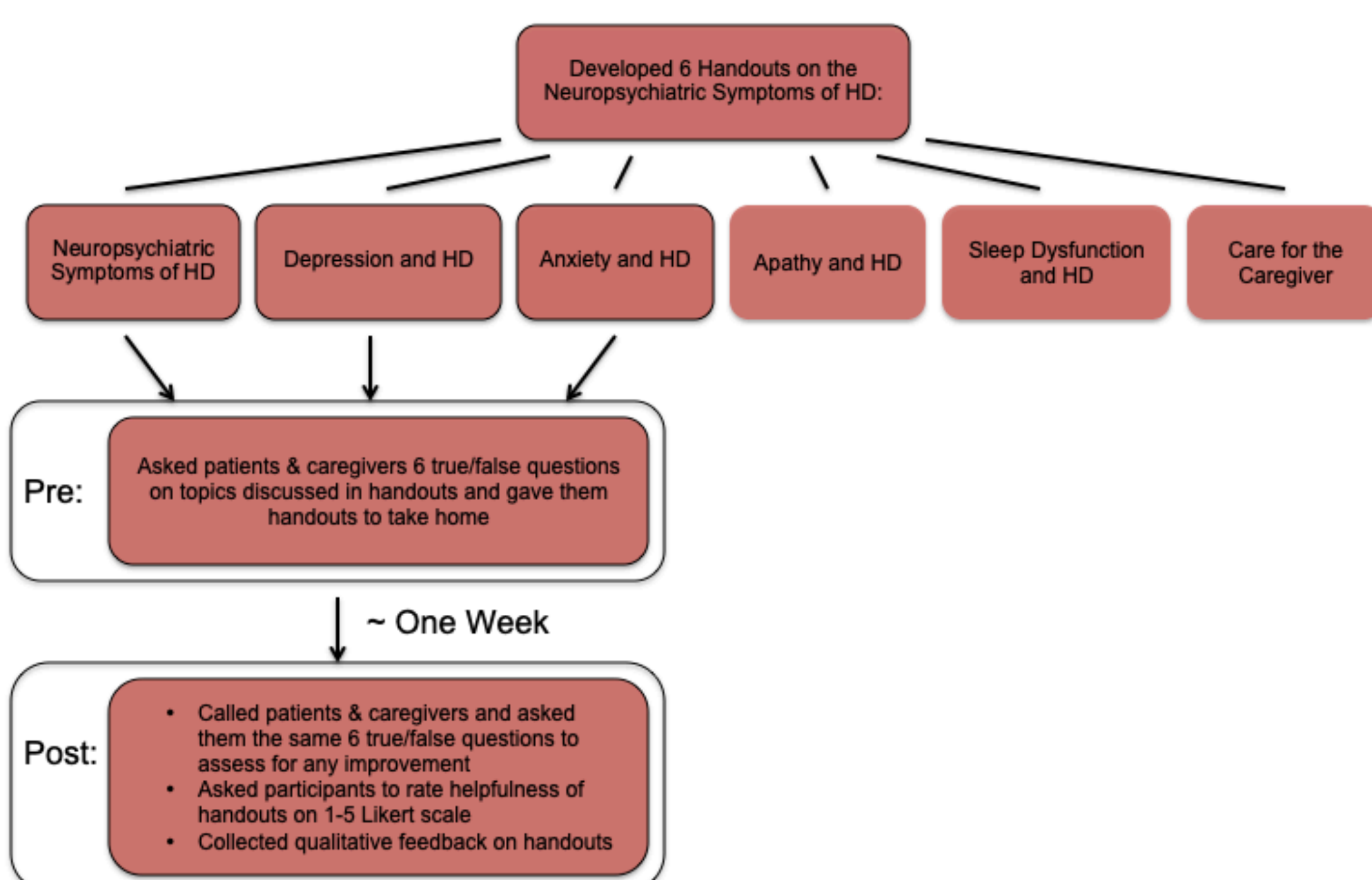


Figure 1. Study Flowchart

ACKNOWLEDGEMENTS

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RESULTS

- Ran a McNemar's Test for paired true/false data in order to detect if there was an difference 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 for certain types of help (e.g. social work, clinic, etc.) Would like to see more resources. The forms are helpful for families." – Caregiver.

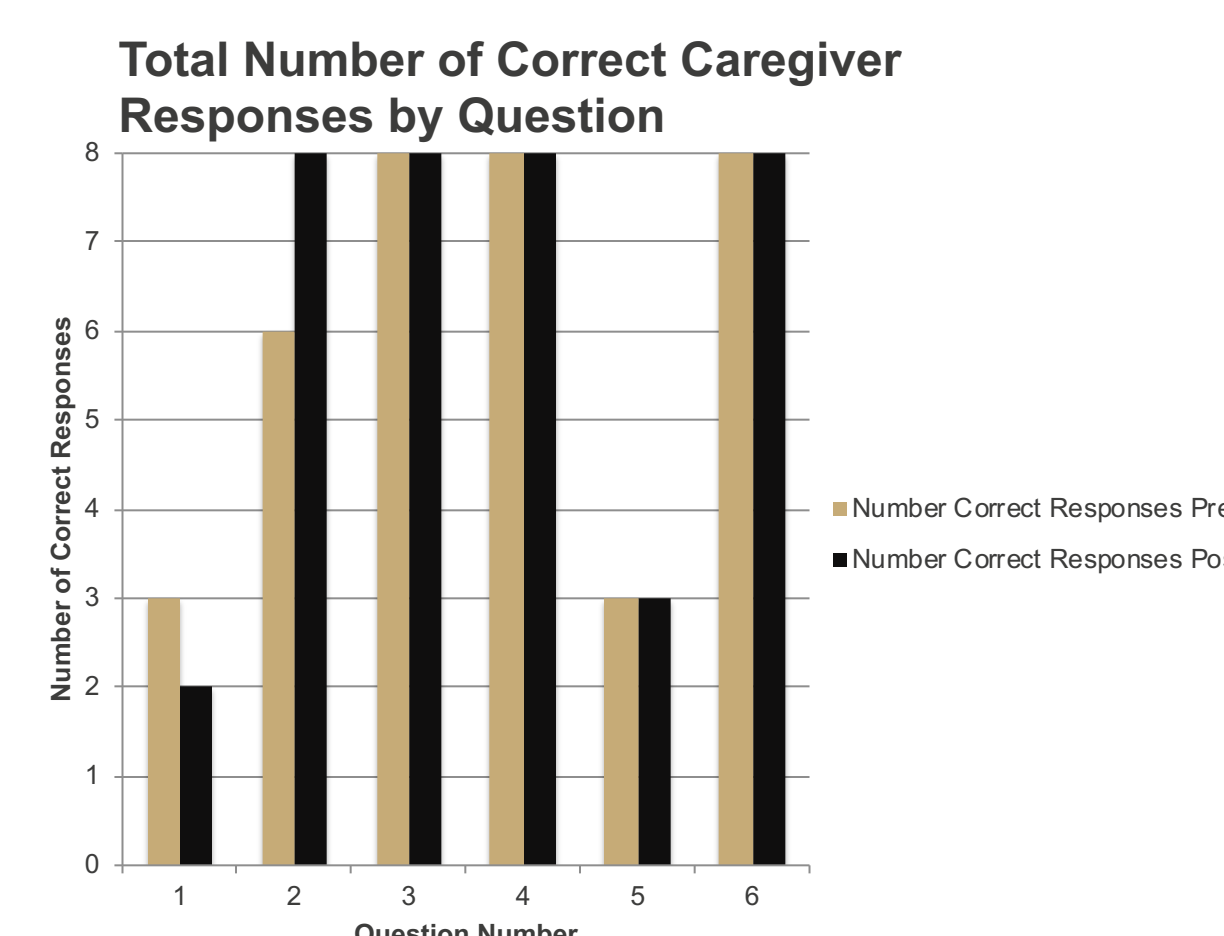
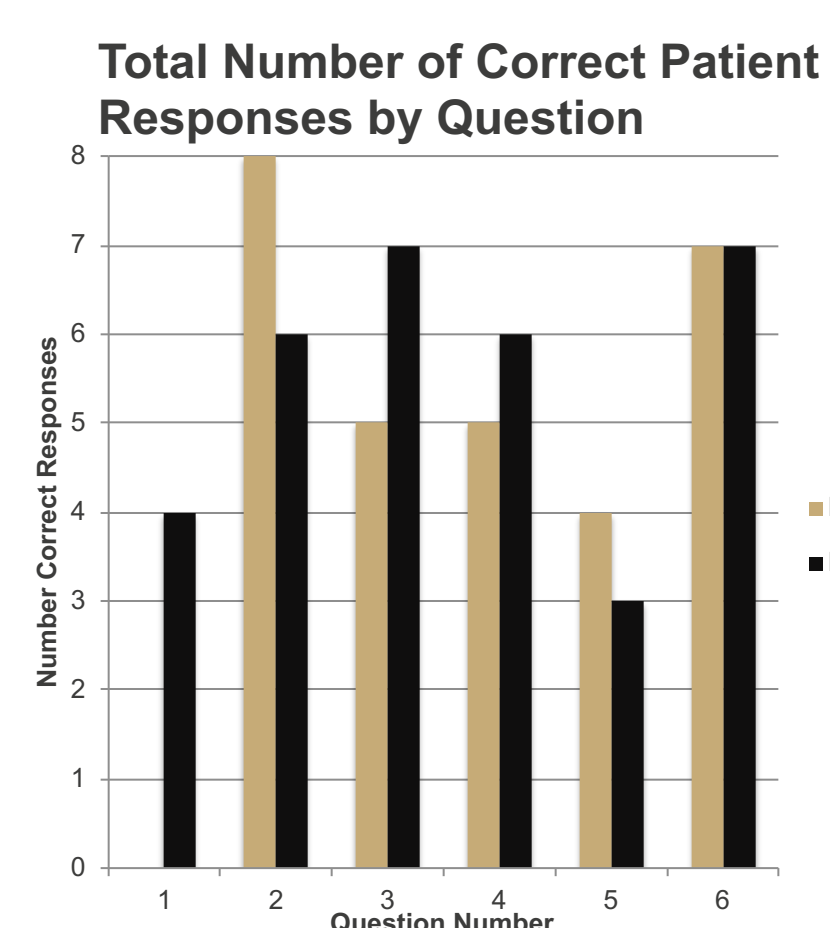


Figure 2. Total Number of Correct Responses by Question for Patients and Caregivers

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.

Neuropsychiatric Symptoms of HD

Huntington's Disease (HD) is a genetic disorder that affects every 3-7 per 100,000 people. It is passed on through families. Every person who has one parent with HD has a 50% chance of carrying the gene responsible for causing the disease.

You may be familiar with the visible motor symptoms of HD, but it is important to be aware that this disease can result in some psychological changes as well. Knowing about these harder to see symptoms and the resources available can help you to better manage and tackle HD.

Depression

Symptoms of depression include loss of pleasure or interest in usual activities, change in sleep patterns, loss of energy, feelings of unworthiness or guilt, difficulty concentrating, and having suicidal thoughts.

Depression can often be treated with medications such as SSRIs or SNRIs or other antidepressants. Engaging in regular exercise, hobbies, schedules and routines has also been found to help with depressive symptoms.

Anxiety

If you are experiencing anxiety, you may feel excessively worrisome or restless, easily fatigued or irritable, have difficulty concentrating, feel muscle tension, and have trouble sleeping.

Anxiety can be treated with medications such as antidepressants or benzodiazepines. Cognitive Behavioral Therapy, or CBT, is also effective at identifying anxiety triggers, challenging problematic thoughts, and developing successful coping strategies.

Apathy

Symptoms of apathy include withdrawal from activities and surroundings, difficulty initiating activities, and feelings of sluggishness. **Experiencing apathy does not necessarily mean you are depressed.**

It is important to note that apathy is not "laziness." It can be combatted by encouragement from caregivers to participate in activities. Once starting, you may find that you have no trouble participating.

Anger and Irritability

Anger and irritability can be demonstrated through loss of temper, aggressive behaviors, feeling frustrated, and stubbornness, even if it is unusual for you feel or behave in such a way.

Symptoms can be reduced with the use of medications such as mood stabilizers. Speaking to a specialist about anger management strategies, learning how to identify triggers, and breathing techniques can all help reduce symptoms.

Obsessive Compulsive Behaviors

Obsessive Compulsive Behaviors (OCBs) may include repetitive thoughts, words, actions, or emotions and preoccupation or fixation on them. You may not necessarily be aware that these behaviors or feelings are out of place.

OCBs can be managed with medications such as SSRIs and behavioral interventions, such as distracting/redirection, setting limits, modifying activity, and readjusting expectations.

Delusions and Hallucinations

Hallucinations involve seeing, hearing, or experiencing things that are not real. Delusions are false beliefs that are held with certainty about unreal situations. These symptoms can be harmless or bothersome, and are generally rare.

These symptoms can sometimes be difficult to treat as they often appear in later stages of the disease. It is best to consult with a psychiatrist about symptom management and consider the use of antipsychotic medications.

Sleep Dysfunction

Sleep dysfunction may be due to the effect that HD has on the brain or related to underlying issues such as depression and anxiety. It includes difficulty falling asleep, poor quality sleep, frequent awakenings, and daytime fatigue.

Because sleep dysfunction can intensify other symptoms of HD like impaired cognitive function, change in mood & loss of motor control, it is important to address. You may find the use of sleep therapy or sleep medications effective.

REFERENCES

- Dale, Maria, and Erik Van Duijn. "Anxiety in Huntington's Disease." *The Journal of Neuropsychiatry and Clinical Neurosciences*, vol. 27, no. 4, 2015, pp. 262-271. doi: 10.1176/appi.neuropsych.14100265.
- Lious, S. (2018). *The Behavioral Symptoms of Huntington's Disease – HOPES Huntington's Disease Information*. [online] HOPES Huntington's Disease Information. Available at: http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/the-behavioral-symptoms-of-huntingtons-disease/ [Accessed 5 Nov. 2019].
- Ossig C, Storch A. (2015) Depression in Huntington's Disease. In: Reichmann H. (eds) Neuropsychiatric Symptoms of Movement Disorders. Neuropsychiatric Symptoms of Neurological Disease. Springer, Cham.
- Thompson, Jennifer C., et al. "Longitudinal Evaluation of Neuropsychiatric Symptoms in Huntingtons Disease." *The Journal of Neuropsychiatry and Clinical Neurosciences*, vol. 24, no. 1, 2012, pp. 53-60. doi:10.1176/appi.neuropsych.11030057.