



Sarah Moroz

M.P.H. Candidate, Epidemiology Track
sarah.moroz.1@vanderbilt.edu

Practicum Site:
Vanderbilt Movement Disorders Clinic
Vanderbilt University Medical Center
Nashville, TN

Practicum Site Supervisor:
Daniel Claassen, M.D., M.S.

Educating Patients and Caregivers on the Neuropsychiatric Symptoms of Huntington's Disease

The most commonly recognized symptoms of Huntington's disease (HD) are movement disorders such as chorea and dystonia. However, HD is also defined by psychiatric disorders such as depression, anxiety, and sleep dysfunction, among others. Patients and their caregivers are often caught off guard by the mood and personality changes that occur before the onset of motor symptoms. For my practicum, I created educational handouts on some of the most prevalent neuropsychiatric symptoms in order to provide a resource for patients and their families. This should hopefully facilitate more informed discussions on these symptoms between patients and their providers.

Sixteen patients and caregivers were recruited to assess the educational value of the handouts that were created. Participants were asked six true or false questions before receiving the handouts, and then the same six questions after being asked to review the handouts for one week. Qualitative feedback on how helpful participants found the handouts was collected. Each participant was asked them to rate each one on a Likert-type scale from (1) very unhelpful to (5) very helpful. MacNemar's test was utilized to determine change in response and did a thematic analysis of the qualitative data.

The quantitative data had no statistical significance, but did show a positive upward trend in improvement, most noticeably for the patients. Qualitative responses were overwhelmingly positive. Several participants expressed how helpful it would have been to have these

handouts at the start of their or their loved one's illness. A limitation of this study was the low sample size and perhaps quick follow up time. Although results may not have been statistically significant, patients and caregivers both expressed how helpful they found the handouts, and hope that they may be integrated into HD clinic.

Although we were focusing on HD families in particular, it is not uncommon for individuals in the general public to be unfamiliar with the symptoms or manifestations of mental health disorders. Creating an easy-to-comprehend resource in an important first step to helping people understand what they or their loved ones may be experiencing, as well as promoting informed discussions with their providers.