

Huntington disease

Student's Name

University

Course

Professor's Name

Date

Part 1

Huntington disease Fact Sheet

- ❖ According to estimates, 3 to 7 people with European heritage per 100,000 are affected by the condition.
- ❖ In some other populations, such as those of Japanese, Chinese, and African heritage, the illness seems to be less prevalent (NORD, 2022).

- ✓ Huntington illness is a degenerative brain condition that results in irrational behavior, emotional issues, and loss of cognitive abilities. Huntington's disease affects about 30,000 Americans, and another 300,000 are at risk of developing it.
- ✓ It is an inherited condition that appears between 30 and 50 years of age. After the first symptoms appear, a person can live for another 15 to 20 years (NORD, 2022).
- ✓ A malfunctioning gene on chromosome 4 is what causes Huntington's disease.
- ✓ The defective gene causes nerve cell destruction in parts of the brain like the basal ganglia and cerebral cortex, however the process is yet unclear (Ross and Margolis, 2020)
- ✓ The gene that makes the huntingtin protein was identified in 1993.

SYMPTOMS

 Uncontrolled movements	 Slurred speech	 Tremors	 Rigidity
 Impaired coordination	 Behavioral changes	 Fatigue	 Emotional changes

Screening, Diagnosis, and Treatment

- Tetrabenazine (Xenazine) was licensed by the Food and Drug Administration (FDA) in August 2008 for the treatment of the repetitive, involuntary movements (chorea) linked to Huntington's disease (Caron, Wright and Hayden, 2020).
- Symptom management and supportive care are other treatments for Huntington's disease.
- A full neurological and cognitive examination is used for diagnosis
- The only diagnostic test that confirms Huntington's disease is a genetic test, which is obtained with a blood sample (Caron, Wright and Hayden, 2020).

- Huntington's disease (HD) is passed down through families in an autosomal dominant pattern.
 - It is marked by escalating uncontrollable movements, mental problems, and cognitive impairment.
 - Tetrabenazine (TBZ), which is a selective inhibitor of vesicular monoamine transporter, is a medication that has been licensed for the treatment of movement disorders in HD patients.
- (Ross and Margolis, 2020)

Explain the nurse's role in advocating for the patient diagnosed with the genetic-based health issue you selected for your fact sheet.

When advocating for a patient with Huntington's disease, the nurse's responsibility involves educating the patient and the patient's family, offering assistance to the patient and family, care coordination with other healthcare providers, and acting as a source of information regarding the illness (Williams et al., 2012). In addition, the nurse plays a significant part in ensuring that the patient receives the highest level of care by closely monitoring the patient's development and acting on any concerns that may arise.

Explain the ethical considerations nurses should be prepared to address with patients as they consider the information presented in the fact sheet.

Nurses should be prepared to address informed consent to enable patients to have sufficient information about their disease and available treatments so they can decide whether or not to continue with treatments. This contains details on the advantages and disadvantages of the course of treatment and any possible adverse effects. This could also be done with the patient's close family members to ensure they are aware of all the changes that will be made to their kin (Williams et al., 2012). Under no conditions should the facility or the nurse disclose the medical details of their patients to outside parties. The patient's identity and personal information should never be public.

Support these considerations with evidence from at least three scholarly resources in addition to the resources for this Competency Assessment.

According to Williams et al. (2012), patients with Huntington's disease who were informed about their disease and available treatments were more likely to choose their care with knowledge than those who were not. The study also discovered that patients were more inclined

to select medical therapies that were best for them when they were informed about the risks and advantages of the proposed course of treatment. Ross and Margolis (2020) also affirm that patients with Huntington disease have a right to secrecy and privacy regarding their medical records. According to the study, patients should have the option of deciding who has access to their medical records, and these records should be safeguarded against illegal access. Finally, NORD. (2022) states that the ethical principles of informed consent, confidentiality, and privacy should be adhered to. Therefore, nurses should be ready to discuss these issues with patients as they share information about their health.

References

- Caron, N. S., Wright, G. E., & Hayden, M. R. (2020). Huntington disease.
- Ross, C. A., & Margolis, R. (2020). Huntington disease. *Medicine*, 76, 305-338.
- NORD. (2022). Huntington's disease. <https://rarediseases.org/rare-diseases/huntingtons-diseas>
- Williams, J. K., Skirton, H., Barnette, J. J., & Paulsen, J. S. (2012). Family carer personal concerns in Huntington disease. *Journal of advanced nursing*, 68(1), 137-146.