

Nursing Care in Huntington's Disease Patients

Elaine Huang^{1,a,*}

¹*Campolindo High School, Moraga, CA 94556, USA*

a. elain3huang@gmail.com

**corresponding author*

Abstract: Huntington's Disease (HD) is a degenerative neurological condition that requires extensive nursing care because it has a significant influence on a patient's physical, mental, and emotional health. Even though there is a wealth of research on the clinical features of HD, less is known about the holistic nursing interventions that can greatly enhance the outcomes for both patients and caregivers. With an emphasis on specialized interventions that address physical symptoms, emotional support, and patient education, this review emphasizes the critical role that nursing care plays in managing HD. Promoting participation in worthwhile activities, offering emotional support, and highlighting the significance of culturally responsive treatment are some of the key tactics covered. The results highlight how important it is to combine these all-encompassing strategies in order to improve the quality of life for patients and their families dealing with patients' difficulties. This study aims to promote a comprehensive view of nursing care and identifies areas for future research that will focus on creating novel interventions that give HD patients both medical care and psychosocial support.

Keywords: Huntington's Disease, Nursing, Long-Term Healthcare.

1. Introduction

Huntington's disease (HD), a genetic neurological disorder, is typically identified by progressive physical impairment, cognitive decline, and psychiatric symptoms. Incidence rates for HD in the general population range from 4 to 10 cases per 100,000 people, with regional and ethnic variations [1]. The need for comprehensive nursing interventions targeting both physical and psychosocial needs aligns with findings from recent research. Since the illness usually first appears in mid-adulthood, it has a profound effect on patients and their families and necessitates extensive care as it advances. For people struggling with HD, proper nursing care is essential to improving their quality of life. According to recent research, comprehensive nursing interventions that target both physical and psychosocial requirements can enhance multiple aspects of HD patients' well-being [2]. These interventions, which aid in the efficient management of symptoms, include education, emotional support, and customized care plans to better help manage symptoms effectively. Given that HD frequently results in a substantial functional decrease over time, long-term care is especially important for these patients.

Consistent support can help prevent problems and advance the highest standard of living. The start of HD in midlife not only places significant physical demands on patients but also has a major effect on family dynamics since loved ones frequently take on caregiving responsibilities, which can be

emotionally and financially straining [1]. It is imperative that nursing care practices adapt to the growing understanding of HD. Enhancing the quality of life for patients and their families can be achieved by highlighting the significance of emotional, psychological, and social support in addition to medical therapy. A more all-encompassing management approach that respects the complexity of HD by integrating these various aspects of care. In the end, overcoming the obstacles this crippling illness presents will require strengthening patient wellbeing and building resilience in families [3].

This review summarizes the critical role of nursing care in managing HD, aiming to promote a more comprehensive management strategy by highlighting the importance of social, psychological, and emotional support in addition to medical care. Tackling the complex issues raised by HD will necessitate a dedication to improving patient well-being and bolstering family resilience.

2. Clinical characteristics of HD

The three main symptoms of (HD are motor, cognitive, and psychological. Every one of these symptom categories has a substantial impact on the day-to-day activities of those who are impacted by the illness, posing particular difficulties that make treatment and management more difficult. The most obvious signs of HD are frequent motor symptoms, which usually include chorea, dystonia, and bradykinesia. Bradykinesia is a term for sluggishness of movement, making routine activities like dressing, walking, and grooming more challenging. This condition increases the risk of falls and associated injuries and limits movement. Dystonia is a condition marked by involuntary contractions of the muscles, which causes aberrant postures and can be extremely painful and uncomfortable, making physical exertion even more difficult. The quick, uncontrollable movements associated with choreography exacerbate fine motor abilities, making writing and using utensils difficult. When combined, these motor symptoms cause a significant reduction in physical capacity, requiring extensive assistance and rehabilitation initiatives to help people retain as much independence as possible [1].

HD is also characterized by cognitive deterioration, which creates major obstacles to day-to-day functioning. Memory, executive function, and processing speed deficits are common in individuals. An inability to remember appointments or recent occurrences might be a symptom of memory issues, which can affect self-management and independence. Deficits in executive function make it more difficult to plan, organize, and make decisions, which makes managing daily tasks more challenging. Patients may need more time to process and respond to information, which can make processing slower even more problematic. The emotional toll that this cognitive impairment can take on patients and their families is greater reliance on caregivers and frustration [3].

Lastly, the psychological effects of HD can have a big impact on people's general wellbeing. Depression is especially prevalent and is frequently accompanied by hopelessness and a loss of interest in once-enjoyed activities. Uncertainty over the course of the disease often gives rise to anxiety, which exacerbates mental suffering. Behavioral problems, such as impulsivity and irritability, can make relationships with family and caregivers difficult and complicate the management of the disease. It is crucial to treat mental health as a crucial part of comprehensive care because these psychiatric manifestations not only increase the load on caregivers but also present new issues for patients [4].

3. Long-term nursing care

Long-term nursing care is essential to managing the complex issues that surface as the disease worsens. Physical, emotional, and social needs are all taken care of in this all-encompassing approach to care. In order to relieve physical and psychological problems, nurses administer medications and provide supportive therapies. This is an important part of their function in symptom management.

Additionally, they offer psychosocial assistance, which helps patients, and their families communicate and become emotionally resilient. Long-term care providers place a strong emphasis on education, giving families the tools they need to understand the intricacies of their loved one's illness. Nurses promote engagement in mental and physical activities that are appropriate for the patient's level of ability, as this can improve quality of life overall. Table 1 summarizes long-term nursing care for HD patients. Through the integration of these components, nursing care guarantees that HD patients receive the necessary assistance throughout their journey, thereby improving their well-being and independence.

3.1. Physical care and exercise

Nurses play a critical role in the physical care of patients with HD, administering medications to alleviate symptoms and managing treatment side effects. Research indicates that effective nursing interventions can significantly improve patient outcomes, including symptom relief and overall well-being [2]. Nurses monitor vital signs, assess physical health, and modify care plans to ensure optimal support. They frequently coordinate physical therapy interventions to maintain mobility and prevent muscle atrophy. Additionally, nurses assist in implementing dietary plans tailored to address specific health concerns, emphasizing the importance of proper nutrition and hydration. Nurses also encourage engagement in both mental and physical activities appropriate for the patient's level of ability. Engaging in tailored activities such as cognitive exercises, creative pursuits, and gentle physical activities that can stimulate mental function and foster a sense of purpose. Research highlights that structured activities can significantly enhance the quality of life for HD patients, leading to improved mental well-being [5]. By collaborating with occupational and recreational therapists, nurses can develop individualized programs that align with the patient's interests and capabilities, enriching their lives.

3.2. Emotional care

Nurses not only give vital medical care but also crucial emotional and mental assistance. Beyond physical care, nurses provide essential emotional and psychosocial support that addresses the significant psychological burden of living with HD. Patients often experience anxiety, depression, and feelings of isolation, which can complicate their treatment journey [6]. Nurses are trained to recognize these symptoms and provide empathetic listening and counseling. They facilitate conversations between patients and their families, creating an environment of open communication that fosters emotional resilience. This support can empower families to express their concerns and share their experiences, ultimately enhancing their coping strategies [4, 6]. Nurses are also useful for connecting families with mental health resources, including counseling and support groups, ensuring they do not navigate the challenges of HD in isolation.

3.3. Patient education

A major focus of long-term nursing care is education, giving families the tools they need to comprehend the complexities of HD. Nurses serve as vital educators, providing insights into the progression of the disease, common symptoms, and effective coping mechanisms. By offering families educational resources and practical advice, nurses help caregivers feel more confident in their roles, thereby reducing caregiver stress and promoting better mental health for both patients and their families [2]. Furthermore, educating patients about self-care strategies and adaptive techniques fosters independence, allowing them to maintain control over their lives as much as possible.

3.4. Evaluation

A critical aspect of long-term nursing care for patients with HD is its direct impact on quality of life. Studies show that by addressing both the physical and psychosocial aspects of care, structured nursing interventions considerably improve the overall quality of life for people with HD [7]. Regular evaluations, individualized care plans, and encouraging participation in worthwhile activities that complement patients' interests and talents are some of these strategies. Notwithstanding the difficulties posed by their illness, nurses can assist patients in retaining a sense of purpose and normalcy by creating an atmosphere that encourages social engagement and emotional expression. In addition, the emphasis on patient-centered care helps people feel better overall by empowering them to continue being actively involved in their lives while also relieving symptoms [7].

3.5. End-of-life care

Conversations regarding end-of-life care become more crucial as Huntington's illness worsens. Due to the progressive nature of the illness and emotional stress, many families find it difficult to make decisions on advanced care planning [8]. In order to help families comprehend the ramifications of the disease and the significance of respecting patients' wishes, nurses and other healthcare professionals play a critical role in enabling these conversations. Some of the stresses related to end-of-life decisions can be reduced by offering resources for palliative care and making sure that families are aware of their options. In the end, putting an emphasis on compassionate end-of-life care may support families during this difficult period and guarantee that patients receive support in their final days that is courteous and dignified [8].

Table 1: Long-term nursing care of Huntington's disease (HD) patients

Care	Patients	Protocol and results	Ref (s)
Tailored exercise programs	Stable HD patients	Improved physical function and quality of life; individualized programs recommended	[5]
Nutritional support	Complex HD patients	Dietary modifications lead to better nutritional status; importance of monitoring	[2]
Cognitive interventions	Initiating HD patients	Cognitive training can improve cognitive function; need for structured programs	[4]
Palliative care	Advanced HD patients	Existing evidence is low; focus on symptom management and quality of life	[8]

4. Social support

4.1. Family

HD has significant societal ramifications that impact not only the patients but also their caretakers and relatives. Among these ramifications are the ways in which the dynamics of marriage and the cultural setting influence the experiences of individuals affected by the illness. When one partner receives an HD diagnosis, marriages frequently experience significant difficulty [8]. The physical and psychological effects of the illness can throw off the equilibrium of the relationship, as caregivers often feel more stressed, anxious, and depressed than before [3]. Support from the spouse becomes essential, but as they work through the intricacies of the illness, many couples report difficulties with intimacy and communication [9]. Research suggests that having a candid conversation about expectations and feelings might improve marital connections and assist couples in adjusting to the

challenges that HD imposes. Couples can exchange experiences and pick up coping mechanisms from other people going through comparable struggles by joining support networks, which might include counseling and support groups [9].

4.2. Culture

The experience of HD is greatly influenced by cultural variables, which also shape attitudes toward the disease, ways of providing care, and patient support in general. Families may approach caregiving and seeking support differently depending on the cultural perspectives they have toward neurological illnesses [9]. Family support may be highly valued in some cultures, which may lead to home-based caregiving arrangements that, while emotionally reassuring, may also place a heavy strain on family members. Healthcare professionals must be aware of these cultural quirks in order to provide patients with care that is more engaging and treatment-adherence-oriented. Furthermore, promoting early intervention and lessening the stigma around HD within particular cultural contexts can eventually help patients and their families [9,10].

5. Conclusion

Effective nursing care is paramount in managing the multifaceted challenges posed by HD. This genetic neurological disorder not only affects patients physically and cognitively but also imposes significant emotional and psychological burdens on both individuals and their families. Comprehensive nursing interventions that integrate physical care, emotional support, education, and tailored therapeutic activities are essential for enhancing the quality of life for HD patients. As highlighted throughout this review, a holistic approach that considers the psychosocial aspects of care can lead to improved patient outcomes and greater family resilience. By fostering open communication, providing educational resources, and promoting engagement in meaningful activities, nurses can empower both patients and caregivers to navigate the complexities of HD with greater confidence and support. Recognizing the cultural dynamics that influence caregiving and health perceptions can enhance the efficacy of nursing practices, ensuring they are culturally sensitive and patient-centered. As the disease progresses, ongoing assessment and adaptation of care plans will be crucial in addressing the evolving needs of patients and their families. Ultimately, a commitment to compassionate, comprehensive nursing care not only alleviates the physical symptoms of HD but also promotes emotional well-being, enabling patients and families to face the challenges ahead with dignity and strength.

References

- [1] Exuzides A, Reddy SR, Chang E, Ta JT, Patel AM, Paydar C and Yohrling GJ 2022 *Neuroepidemiology* 56 192-200
- [2] Mühlbäck A, et al. 2023 *Orphanet J. Rare Dis.* 18 19
- [3] Ekkel MR, Veenhuizen RB, van Loon AM, Depla MFIA, Verschuur EML, Onwuteaka-Philipsen BD and Hertogh CPM 2023 *Brain Cogn.* 169 106002
- [4] Gibson JS, Isaacs DA, Claassen DO and Stovall JG 2021 *Arch. Psychiatr. Nurs.* 35 284-289
- [5] Al-Wardat M, Schirinzi T, Hadoush H, Kassab M, Yabroudi MA, Opara J, Nawrat-Szoltysik A, Khalil H and Etoom M 2022 *Int. J. Environ. Res. Public Health.* 19 14915
- [6] Kalkers K, Schols JMGA, van Zwet EW and Roos RAC 2021 *J Huntingtons Dis.* 10 493-503
- [7] Engels J and van Duijn E 2022 *J. Huntingtons Dis.* 11 313-320
- [8] Boersema-Wijma DJ, van Duijn E, Heemskerk AW, van der Steen JT and Achterberg WP 2023 *BMC Palliat. Care.* 22 54
- [9] Winder JY, Achterberg WP and Roos RAC *J. Huntingtons Dis.* 7 251-257
- [10] Grimstedt TN, Miller JU, van Walsem MR and Feragen KJB 2021 *Int. J. Lang. Commun. Disord.* 56 330-345