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Utilizing a Clinical Framework to Comprehend Psychological Distress in Individuals Affected by Huntington's disease: A Detailed, Evidence-Driven Approach

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Abstract

Huntington's disease (HD) is a hereditary neurodegenerative condition that significantly impacts individuals' lives, leading to cognitive, motor, and emotional changes. Particularly in later stages, individuals with HD may exhibit behaviours that are distressing to both professionals and caregivers, such as aggression, impulsivity, and inappropriate comments. Despite the absence of a specific formulation framework tailored to HD, clinical formulation-a personalized approach utilized by mental health professionals to articulate an individual's challenges-has proven valuable in conceptualizing patients' well-being.

Existing evidence highlights the efficacy of formulation in guiding clinical interventions, enhancing consistency across multidisciplinary teams, refining risk management strategies, and fostering empathy and understanding among staff and caregivers. Consequently, this paper proposes a novel clinical formulation model for comprehensively understanding distress among individuals with HD, grounded in a biopsychosocial framework.

Keywords: Huntington's disease; Neurodegenerative disease; Sclerosis

Introduction

Huntington's disease (HD) is a multifaceted hereditary neurodegenerative disorder transmitted through an autosomal dominant mechanism. It manifests in a spectrum of motor, cognitive, and psychological challenges, ultimately necessitating round-the-clock care and assistance as the condition progresses. Clinical diagnosis typically hinges on the emergence of physical symptoms, which commonly surface between the ages of 30 and 50, though instances of "juvenile" and late-onset HD have also been documented [1-3]. These symptoms encompass impaired motor control, chorea (involuntary movements), bradykinesia, incontinence issues, and dysarthria, among others. Regrettably, the life expectancy of individuals with HD is typically shortened, spanning approximately 15 to 20 years post-diagnosis.

Presently, no definitive cure for HD exists, but ongoing research endeavors are yielding promising disease-modifying therapies. Beginning at the age of 18, individuals at risk of inheriting HD can opt for predictive genetic testing to ascertain the presence of the HD gene expansion. In this context, individuals possessing the gene expansion yet devoid of clinical symptoms are classified as "pre-manifest HD," while those clinically diagnosed are referred to as "manifest HD" individuals.

Clinical product

Clinical formulation is the methodology employed by mental health professionals to conceptualize mental health issues. It involves crafting hypotheses regarding the nature and origins of an individual's clinical presentation, drawing from relevant theories, and conducting a thorough clinical assessment to explore past experiences, triggers of distress, perpetuating factors, and potential intervention objectives [4,5]. Formulation serves as an alternative or complement to psychiatric diagnosis, offering guidance for psychological interventions and interdisciplinary team approaches. Collaboratively developed with patients, caregivers, or teams, clinical formulations are iterative and adaptable throughout the evaluation or intervention process.

The biopsychosocial model, an advancement of the biomedical model, underscores the interconnectedness of biological, psychological, and socio-environmental elements in elucidating health issues [6,7]. With a rich history in mental health, this model has been extended to neurodegenerative conditions like Huntington's disease, as well as other disorders affecting cognition, movement, and emotion, such as dementia, Parkinson's disease, and multiple sclerosis. Given the multifaceted contributions of biological, psychological, social, and environmental factors to the distress experienced by individuals with Huntington's disease, the biopsychosocial approach emerges as a valuable guiding framework in their care and treatment.

Cognitive symptoms

Huntington's disease is characterized by a range of cognitive deficits that progressively worsen over time. These impairments are particularly notable in areas such as memory, psychomotor speed, executive function, and, later on, language abilities. In individuals in the pre-manifest stage, significant language or long-term memory issues are typically not reported. However, early deficits in working memory and executive function have been documented.

Furthermore, individuals with overt Huntington's disease often experience considerable difficulty in accurately recognizing emotions, particularly negative ones such as fear, disgust, and anger. This challenge is evident in studies assessing the interpretation of facial expressions, as well as in responses to auditory stimuli and body language. Studies involving individuals in the pre-manifest stage of Huntington's disease

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have yielded inconsistent results, with some indicating selective impairment in processing negative emotions, notably disgust. [8].

Discussion

The current model has emerged from the necessity for a formulation framework tailored to the unique experiences of individuals living with Huntington's disease (HD). Consequently, numerous potential applications for this model can be identified. One such application is to complement and structure team formulation sessions, providing dedicated time for team members to deepen their collective understanding of individuals and devise intervention plans. These team sessions, encompassing diverse professions and theoretical perspectives, mitigate the risk of overlooking or underestimating crucial elements in patient care. Additionally, they enhance the team's comprehension of working with complex patients and facilitate a more comprehensive consideration of risk management.

Conclusion

In conclusion, this article outlines the first prescribing model specifically crafted to assist individuals with HD in understanding their distress. Employing a temporal approach, the model encapsulates life histories, HD-related experiences and narratives, socio-environmental factors, symptom triads, and future expectations, thereby fostering a comprehensive comprehension of HD-related conditions. The resultant clinical tools are adaptable to various clinical needs and service contexts, serving as aids in crafting narrative clinical formulations. Successful implementation of this model holds promise for enhancing personalized care for individuals with HD by fostering psychological understanding, identifying unmet needs, and expanding intervention options, all grounded in a personalized, evidence-based approach.

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