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Occupational Therapy Education to Support Families Affected by Huntington's Disease and Their Care Team

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Background

- Huntington's Disease (HD) is a genetic, neurodegenerative disease that consists of motor, cognitive, and psychiatric and behavioral changes (Frich et al., 2014; Morreale, 2015).
- Current treatment for HD is to manage symptoms and improve the overall quality of life (Frich et al., 2014).
- Multidisciplinary approach is optimal for symptom management of HD and typically involves both pharmacological and non-pharmacological interventions (McColgan & Tabrizi, 2018).
- Most common losses identified for individuals with HD include managing finances independently, driving, and supervising children (Morreale, 2015).
- Occupational therapy interventions can address motor, cognitive, and behavioral deficits for individuals with HD throughout disease progression (Wyant et al., 2017).
- Occupational therapy (OT) can provide supportive interventions to maximize independence in meaningful occupations and improve quality of life (Frich et al., 2014).
- Effective caregiver support includes information, advice, and emotional support. Professionals should include caregivers in skills training and enable them to support the process of rehabilitation (Clare et al., 2019)

Purpose

This project aimed to understand the benefits of incorporating OT education in an HD clinic for individuals with HD and their caregivers, as well as create educational material to support HD care teams.

Theoretical Foundation

Model of Human Occupation (MOHO)

- Focuses on a holistic and client-centered perspective that looks at the dynamic interaction between volition, habituation, performance, and environmental subsystems (Taylor, 2017).
- HD directly affects the performance subsystem within this dynamic system.
- This guided educational handouts by focusing on the volition, habituation, and environmental subsystems to maximize independence in meaningful occupations.
- Educational handouts provided knowledge on maintaining participation in valued occupations, developing routines to support goal-directed behaviors, and adaptive equipment and strategies to implement in one's everyday life.

References



Methods & Activities

- This capstone project was completed at a university-affiliated HD clinic to incorporate OT education.
- Observation of an interdisciplinary HD clinic day was completed at another HD clinic via Zoom during the first week of the project to gain a foundational understanding of occupational therapy's role on these teams as well as informed educational handout topics.
- Participation on the University of South Dakota's interdisciplinary team for a national case competition that looked at radical belonging within a healthcare system was completed remotely via Zoom.
- Capstone experience was guided by the following objectives and deliverables:
 - Objective 1:** I will gain an understanding of occupational therapy's role in an interdisciplinary HD clinic.
 - Summary reports from observation of HD clinic day and understanding of the Unified HD Rating Scale.
 - Objective 2:** I will advocate for occupational therapy within an interdisciplinary team and provide education at the university-affiliated HD clinic to support patient and caregiver care.
 - Needs assessment summary report
 - Pre- and post-assessment summary report
 - 14 educational handouts
 - Clinic manual to supplement educational handouts
 - Patient and family resource
 - Case analysis presentation for national case competition
 - Objective 3:** I will develop an educational case study on HD to educate occupational therapy students on disease processes and their impact on caregiver and client occupational performance.
 - Recorded PowerPoint presentation for OCH 731: Physical and Psychosocial Health Conditions course
 - Final case video of a client with HD engaging in activities along with an interview with both client and caregiver to supplement the presentation
 - Completed occupational profile of the client
 - Discussion questions for faculty use

Results

OT Education in HD Clinic

- There was an overall increase in familiarity with occupational therapy topics.
- A larger increase in familiarity with education topics for the participant who had not previously received OT services.
- Results also showed that four of the five clients found the home exercise programs to be the most helpful, two of which specifically identified the fine motor coordination home exercise program.
- One client also reported the following on the post-assessment: "I think what you did was really helpful. It took me years to figure out what you just told me in 30 minutes."
- Occupational therapy education was reported as overall extremely beneficial, and families affected by HD found the educational handouts to be highly valuable.

OT Curriculum

- Recorded PowerPoint and case video of a real client with HD demonstrated the synthesis of knowledge learned from the literature and from the knowledge learned while working in an HD clinic.
 - This educational material provided a positive extension to the OT curriculum by demonstrating the impact HD has on both the occupational performance of the client and the well-being of caregivers.
- Interdisciplinary Team
- Observations of an interdisciplinary HD clinic allowed for a foundational understanding of the role and benefits of having an OT on the team.
 - A presentation, along with supplementary material, was created with an interdisciplinary team that provided feasible solutions to support radical belonging for all employees within a healthcare system with interventions provided on individual, team, and organizational levels.

Example of Educational Handout

Meal Times



References

Adaptive Equipment

- Built up handles
- Bendable utensils
- Weighted utensils
- Plastic dishes with edges
- Plate guard
- Cups with lid and straw
- Nosey cups
- Dycem mats



Positioning

- Upright, supported sitting
- Neck at 45 degrees of flexion
- Elbows supported
- 90-90-90 for hip, knees, and ankle positioning
- Feet supported

Avoid:

- Posterior pelvic tilt
- Awkward head/trunk position
- Dangling feet
- Inappropriate table height or inability to reach food
- Reclined position

Other Recommendations

- Reduce external stimuli
- Eat smaller meals to prevent fatigue
- Maintain a consistent eating schedule
- Take smaller bites
- Modify diet to soft foods
- Chin tuck
- Double swallow
- Hard swallow
- Supraglottic swallow- swallow while holding breath
- Mendelsohn maneuver- push tongue to roof of mouth



Consult with a speech and language therapist if experiencing signs of dysphagia and difficulties impacting the ability to safely eat such as coughing or choking, gurgling voice, or recurrent pneumonia.

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Implications

- OT provides a unique role in maximizing independence in meaningful occupations through supportive interventions.
- Results show that education is highly valued by clients of varying ages and disease progression.
- OT has the knowledge and skill to take a family-focused approach to support occupational performance.
- OT education can empower and equip families affected by HD with valuable information necessary to self-manage throughout disease progression.
- Advocacy of OT on interdisciplinary teams provides a distinct set of skills to support families affected by HD and to foster a sense of belonging for all individuals on the care team.

Conclusion

With the complexity of neurodegenerative diseases, future healthcare professionals should have an understanding of family dynamics and ways to evaluate the subsystems that could be impacting occupational performance. Incorporation of OT education within an HD clinic shows to be helpful and valued by both the clinicians and families receiving education. Through advocacy of OT on interdisciplinary teams and education of future OTs, families affected by HD will be able to receive supportive and valuable services to assist in managing symptoms and improve quality of life throughout disease progression.