

A Message from the Outgoing Chairperson

As I complete my Chair term I would like to extend my sincere thanks to the Neurology Section and particularly to the DDSIG membership for the support and inspiration that you have given me throughout the past three years. I especially want to thank the many wonderful Executive Committee members whose dedication and commitment to serving our SIG has made my term so pleasant and gratifying. I hope that you will find the articles in this newsletter informative for your practice. The article entitled "Toolbox of Outcome Measures for Individuals with Huntington's Disease" by myself and Lisa Muratori, PT, EdD is the fourth in our series of "toolbox" articles highlighting each of the major neurodegenerative diseases. Ashwini Rao, EdD, OTR has written an excellent critique of an article entitled "Falls and gait disturbances in Huntington's disease." The DDSIG programming at CSM 2011 was well received by participants. Many thanks to Eric Laborde, MD, Suzanne Badillo, PT, WCS, Katy Eichinger, PT, DPT, NCS and Kirk Personius, PT, PhD for their wonderful presentations. Con-

gratulations to Donna Fry, PT, PhD who

was the recipient of the 2010 DDSIG Service Award.

I encourage you to check out the DDSIG website for patient and therapist resources. Thanks to eight volunteers, we now offer a variety of "fact sheets" for patients about the role of physical therapy in the management of neurodegenerative diseases. If you are interested in volunteering to write one please contact me (Anne Kloos) at Kloos.4@osu.edu. People who volunteer will be asked to write a one-page fact sheet on a topic related to a neurodegenerative disease. Each fact sheet will undergo review by content experts and then be posted on the DDSIG website. This is a great opportunity for anyone who wants to get more involved in the DDSIG.

Best wishes, Anne

And

Many wishes for a healthy and productive new year. Donna Fry, DDSIG Chair

Table of Contents

CSM Past and Future	2
Outcome Measures Toolbox for Huntington's Disease	3
Call For Nominations	5
Welcomes and Thank Yous	12
Huntington's Disease Article Review	
News from the World Conference of PT	14

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DDSIG Programming at CSM 2011

The DDSIG provided some excellent programming at the 2010 Combined Sections Meeting of the APTA. Becky Farley, PT, MS, PhD presented at the DDSIG business meeting, and our own Anne Kloos, PT, PhD, NCS and Deb Kegelmeyer, PT, DPT, MS, GCS hosted the DDSIG Roundtable.

Dr. Farley's presented "An Intensive Whole Body "Forced Use" Exercise Approach for People with Parkinson's Disease: LSVT® BIG" to rave reviews. Drs. Kloos and Kegelmeyer led the DDSIG's annual roundtable. The spirited discussion was on the topic of "Fitness and Community Exercise Programming in Neurodegenerative Diseases"

The DDSIG leadership would like to extend its thanks to all of these presenters for continuing to further the SIG's mission to share the best current knowledge about the PT management of individuals with neurodegenerative disease.



DDSIG Programming at CSM 2012

The DDSIG is very excited to be heading to Chicago, Illinois for CSM 2012. At the DDSIG business meeting, we are happy to host Herb Karpatkin, PT, DSc, NCS, MSCS who will be presenting Multiple Sclerosis: PT Exam and Intervention Across the Spectrum of Disability. This presentation is scheduled for Thursday, February 9 beginning at 8:00 a.m. We hope to see you there!

Toolbox of Outcome Measures for Individuals with Huntington's Disease

Anne Kloos, PT, PhD, NCS (<u>Anne.Kloos@osumc.edu</u>) Associate Clinical Professor The Ohio State University, Columbus, OH

Huntington's Disease (HD) is an autosomal dominant, neurodegenerative disorder for which there are minimal treatment options and no cure. HD afflicts 1/10.000 people.¹ diminishing the affected individual's ability to walk, think, talk and reason. Progression from onset to death is approximately 10-15 years, with the need for total care occurring several years earlier.² Neural degeneration in HD occurs selectively in the striatum and deep layers of the cerebral cortex until progression of atrophy to other brain regions in advanced stages of disease.³ This degeneration leads to increasing cognitive and motor deficits, including dementia, dystonia, chorea, apraxia and bradykinesia. Impairments in gait and balance in HD are thought to arise secondary to bradykinesia, dystonia, disordered processing of sensory information and greater movement variability.^{4,5,6,7,8} Individuals with HD also exhibit posture and balance impairments during standing and walking.^{9,10} Deficits in balance and gait are associated with a higher risk of falls.^{6,11} As these impairments worsen with disease progression, patients deteriorate to the point of requiring an assistive device.¹² In addition, recent research shows that loss of independence in ambulation was the number one predictor of nursing home admissions in individuals with HD.¹³ As these deficits in functional mobility are primary predictors of quality of life in HD,^{4, 14,15,16} it is imperative that therapists perform detailed evaluations and re-evaluations aimed at the unique features of HD.

A small percentage (5-7%) of individuals with HD develop symptoms before the age of 21, and are classified as juvenile HD.^{17,18} Although the same triad of motor, cognitive, and psychological or behavioral disturbances are present in juvenile HD as in adult onset HD, there are some distinct differences in the symptomatology. The most common presenting features of HD in the first decade of life are voluntary motor disturbances (i.e., abnormal gait, rigidity of limbs or trunk, slowed speech, swallowing problems, and drooling), cognitive deficits, behavioral disturbance, and seizures. Unlike adults who typically present with involuntary motor disturbances, chorea is uncommon in children with HD. Behavioral disturbances requiring medical or legal intervention may be the first symptom in an adolescent. Some children develop ataxia and other cerebellar signs and severe dystonia in later stages. Seizures, usually of a generalized or myoclonic type, affect up to 25% of children.

The Unified Huntington's Disease Rating Scale (UHDRS) is the standard assessment tool used to quantify disease severity and to track symptom changes Lisa M. Muratori, PT, EdD (<u>lisa.muratori@sunysb.edu</u>) Clinical Associate Professor, Physical Therapy Stony Brook University, Stony Brook, NY

over time.^{19,20} It was developed as a clinical rating scale to assess four domains of clinical performance and capacity in individuals with HD: motor function, cognitive function, behavioral abnormalities, and functional capacity. The motor portion of the UHDRS includes measures of eye movement (frequently an early clinical sign in HD), dysarthria, motor impersistence, coordination, rigidity, bradykinesia, dystonia, chorea, and gait. Scores can be calculated by summing questions from each section with higher scores indicating greater impairment. It has high reliability and validity,¹⁹ however, it is intended to be performed only after extensive training and certification to administer the different components of the test. A copy of the UHDRS motor section can be obtained at the website: http://www.neuropsicol.org/Protocol/Uhdrs.pdf.

An assessment for an individual with HD consists of the same elements as all physical therapy (PT) evaluations: patient's history, relevant systems review, and objective tests and measures. The Hypothesis-Oriented Algorithm for Clinicians (HOAC II)²¹ suggests that these tests should allow therapists to evaluate both existing and anticipated problems. This is particularly important in neurodegenerative diseases where progression leads to evolving limitations. The APTA Guide to Physical Therapy Practice²² classifies HD into the pattern for impaired motor function and sensory integrity associated with progressive disorders of the central nervous system (CNS) (Pattern 5E) and highlights the therapist's need to use evaluation data to develop and modify treatment strategies in this population. Below are outcome measures appropriate for individuals with HD.

Aerobic Capacity and Endurance. Studies that investigated daytime activity levels using activity monitors reported significantly lower (p < 0.005) motor activity levels in people with HD (n = 64) compared to healthy controls $(n = 67)^{23}$ and significantly lower (p < 0.01)daily step counts in people with HD who were recurrent fallers (n =14) compared to those who were nonfallers (n = 10). ²⁴ Lower daily activity levels were related to impaired voluntary movements (r = 0.37), balance and gait disturbances (r = 0.38) and reduced functional capacity (r = 0.51).²³ Since inactivity may lead to aerobic deconditioning, therapists should assess functional ability as it relates to cardiovascular endurance in this population. Walking endurance can be measured with the six-minute walk test (6MWT, see below).²⁵

Toolbox of Outcome Measures for Individuals with Huntington's Disease (continued from p3)

Anthropometric Characteristics. Many individuals with HD experience considerable weight loss throughout all stages of the disease.^{26,27} While the causes of weight loss are not well understood, multiple factors including dementia, depression, chewing and swallowing difficulties, orodental problems, motor disturbances, muscle atrophy from decreased activity, inadequate access to food, and side effects of medications have been found to contribute to weight loss in this population.²⁷ Girth and/or weight measurements may be appropriate to perform in individuals with HD with weight loss. Referral to a dietician for nutritional counseling is advised.

Arousal, Attention, and Cognition. Cognitive problems in individuals with HD occur early in the disease and include impaired attention, working memory, object and space perception, and executive functions.²⁸ In later stages, the cognitive deficits progress to global dementia. Patients often report difficulty with "multi-tasking" and studies have reported impaired dual-task performance, especially when a cognitive load is added to a motor task.^{29,30} General cognitive function can be measured with the Mini-Mental State Exam (MMSE).³¹ Therapists can obtain additional information about cognitive status from the Verbal Fluency Test, the Symbol Digit Modalities Test, and the Stroop Interference Test that are part of the UHDRS.¹⁹

Assistive, Adaptive, Orthotic, Protective, and Support devices. Due to balance and gait impairments, individuals with HD in the middle to late stages of the disease often experience falls. Assistive ambulatory devices such as canes and walkers are often prescribed for individuals who are experiencing falls although their effectiveness to prevent falls is not known. A four-wheeled walker with front swivel casters produced the most safe and efficient gait pattern during ambulation in a straight path and maneuvering around obstacles compared to other commonly prescribed assistive devices in ambulatory individuals with HD.³² Protective helmets and joint padding can be worn by the person with HD or padding can be applied to beds and chairs to prevent injuries from falls or uncontrolled movements. Ankle foot orthoses may be prescribed in the presence of dystonia causing ankle inversion.⁵ People with HD with a high degree of chorea or dystonia often have seating problems and stable chairs with tilt and recline features such as the Broda chair may be prescribed in later stages to maintain proper posture and patient safety.

*Circulation*_Studies have reported mild autonomic nervous system dysfunction in HD, with asymptomatic gene carriers and patients in the early to middle stages commonly reporting dizziness or light-headedness after standing up, excessive perspiration, and tachycardia.^{27,33} In patients reporting cardiovas-cular symptoms therapists should monitor vital signs.

Cranial Nerve Integrity. Patients with HD often have impaired saccadic and smooth pursuit eye movements that begin early in the disease and may affect balance and walking performance.³⁴ Therapists can obtain information about eye movements from

the UHDRS motor section. A decreased sense of smell and swallowing problems that manifest early in the disease may contribute to weight loss.²⁷ In the middle to late stages of the disease, individuals with HD experience speech difficulties and eventually lose bowel and bladder control. Referral to a speech-language pathologist for communication and swallowing evaluation and treatment is recommended.

Environmental, Home, and Work (Job/School). Ideally therapists should evaluate home and work environments to determine any factors that might contribute to falls and injuries (e.g., slippery surfaces, cluttered living and working areas, loose rugs, poor lighting, sharp or breakable objects, flammable materials if the person is a smoker). As symptoms of HD progress over time, therapists need to assess architectural, transportation, and other barriers to an individual's ability to participate in home, work, and recreational activities such as difficulty going up and down stairs or walking in open environments, not being able to drive, and being embarrassed or afraid of being ridiculed when out in public places.

Ergonomics and Body Mechanics. Therapists should assess for safety at home and worksites particularly when the person with HD is engaged in reaching or lifting, arising from and sitting down in chairs, coming to the edge of the bed and up to standing, and going up and down stairs. Exaggerated movements due to problems with force modulation control may cause people with HD to lose their balance by reaching outside of their base of support or by vaulting up from a chair or out of bed. Problems with eccentric motor control can cause falls when they sit down or descend stairs. Body mechanics of caregivers should be assessed if they are providing assistance.

Gait, Locomotion, and Balance. Gait impairments begin early in HD and typically include slower gait speed, shorter and more variable stride length, a wider base of support, increased double support time, and increased trunk sway compared to healthy adults.^{8, 35} Balance deficits usually occur in the earlymid stages of the disease and manifest as delayed motor responses to unexpected balance disturbances, and difficulties with tandem standing and walking and standing or walking with eyes closed.^{6,9,10} Specific gait, balance, and mobility tests that have been utilized with people with HD are described below. To obtain additional information and copies of many of these tests clinicians may refer to The European Huntington's Disease Network Physiotherapy Guidance Document that can be obtained at the website: http://www.euro-hd.net/html/ network/groups/physio. Since the reliability and validity of many of these tests has not been determined in individuals with HD, therapist should utilize research from other neurodegenerative diseases, especially Parkinson disease.

Gait Tests and Measures

Six-Minute Walk Test.²⁵ Patients are timed walking around the perimeter of a set path for a total of six minutes. Assistive devices can be used. The distance covered in six minutes is measured. It is designed to measure exercise endurance.

continued on page 5

Ten-Meter Walk.³⁶ Using a 14 meter (m) area, 10m are marked off for the walk itself and 2m on either side area available to give space to start and stop. The total time to complete 10m, as well as the number of steps taken during those 10m are recorded. Average gait speed (distance/time) and cadence (step/min) can then be calculated. This test should be repeated twice and the average score for both tests documented.

Dynamic Gait Index.³⁷ The Dynamic Gait Index was designed to evaluate a person's ability to modify gait in response to changing task demands. It is indicated for use with ambulatory patients with balance impairments.

Balance Tests and Measures.

Berg Balance scale (BBS).³⁸ This scale entails 14 sub-tests of various activities related to balance control. Sub-tests include static postures (e.g. sitting, standing), transitions (e.g. sitting to standing, transferring between chairs), and challenging positions (e.g. standing with eyes closed). Quality of performance is scored on a five-point scale. This test takes 15 - 20 minutes to administer. The BBS predicted falls using a cutoff score of ≤ 40 seconds²⁴ and had fair (r_s =0.48) correlations with reported falls and poor to fair correlations with spatiotemporal measures of gait⁹ in people with HD.

Single leg stance.³⁹ In a study examining clinical measures of function in HD, the time individuals were able to maintain single leg stance was found to be highly correlated with measures of gait and overall function in early and middle stages of the disease.⁹ A component of the BBS, single leg stance is fast and easy to administer.

Functional Reach Test (FRT)⁴⁰ and **Multidirectional Functional Reach Test (MRT).**⁴¹ These two tests measure the limits of stability (LOS) and can be used in sitting and standing. The FRT is traditionally performed by reaching forward to a maximum distance without taking a step. After two practice trials, three more trials are performed and averaged for a single score. Scores less than 6 or 7 inches indicate limited functional balance. Most healthy individuals with adequate function balance can reach 10 inches or more. A MRT was developed to examine LOS backward and to the sides. The FRT has a high test-retest reliability $(0.89)^{42}$ and moderate concurrent validity with center of pressure excursion (0.65 to 0.71).^{42,40} Rao et.al. ⁸ found that the FRT test had no correlation (r_s =0.16) with reported falls and had fair to excellent correlations with spatiotemporal measures of gait in individuals with HD

Pull Test. The pull test is a component of the UHDRS motor section traditionally administered by the neurologist. However, variability in the administration of this test ⁴³ makes the test's usefulness unclear.

Falls History. Falls are common in people with HD and often occur while the person is performing multiple tasks simultaneously, while maneuvering around obstacles on the floor, and while climbing stairs.^{11,35} Many factors may contribute to falls including balance problems, gait impairments (especially bradykinesia, stride variability, and excessive trunk sway), cognitive deficits (decreased attention and ability to dual task), and possibly psychological changes (impulsiveness, impaired judgment leading to unsafe behaviors).^{11,35} A falls history should be taken even from early disease stages to include the frequency, location, and and circumstances of any falls that have occurred in the last 3 months. When possible it is best to corroborate the patient's falls history with that of a family member or caregiver to obtain the most accurate history.

continued on page 6

Call for Nominations



THE DD SIG WANTS YOU!

The Degenerative Diseases Special Interest Group is seeking nominations for two positions for the coming year: Secretary and Nominating Committee Member.

If you are interested, or know someone who is, please contact a member of the Nominating Committee

Mobility Tests and Measures

Timed Up and Go (TUG) Test.⁴⁴ This mobility test measures the time that it takes a person to stand up from a chair, walk 3 meters, turn around, walk back and sit on a chair. The test is repeated twice and the average of the two scores is recorded. The TUG predicted falls using a cutoff score of ≤ 14 seconds²⁴ and had moderate (r_s =0.68) correlations with reported falls and fair to excellent correlations with spatiotemporal measures of gait⁸ in people with HD.

Tinetti Mobility Test (TMT).⁴⁵ The Tinetti Mobility Test, also called the Tinetti Gait and Balance Instrument or the Tinetti Performance Oriented Mobility Assessment (POMA), was initially designed to determine an elderly person's risk of falling. It takes about 5 minutes to complete. It is a 2-part evaluation that measures performance on various balance tasks and provides a quantitative ranking of various gait deviations. Kloos et al.⁴⁶ found that TMT scores correlated with UHDRS motor scores ($r_s = -0.751$, p < 0.0001) and using a cutoff value of <21, the TMT had a sensitivity of 74% and a specificity of 60% to identify fallers in people with HD. Tinetti scores improved significantly (p<0.001) by an average of 4.7 points following an intensive 3 week inpatient rehabilitation program in 40 patients with HD⁴⁷ which was well above the 0.8 group MDC₉₅ reported in the elderly.⁴⁸

Community Balance and Mobility Scale (CBMS).⁴⁹ Developed for individuals following a traumatic brain injury, the CBMS is a more challenging standardized test which can be used in the early stages of HD or even with pre-symptomatic, gene positive individuals.

Rivermead Mobility Index (RMI).⁵⁰ The RMI is a simple and short outcome measure, consisting of 14 questions and 1 observation. Its items cover a wide range of activities, from turning over in bed to running. The items are scored either unable or able (0-1) and added to produce a total score (0-15). A higher score reflects better mobility.

Physical Performance Test (PPT).⁵¹ The PPT measures the time that it takes a person to perform 9 standardized ADL tasks including writing a sentence, simulated eating, turning 360 degrees, putting on and removing a jacket, lifting a book and putting it on a shelf, picking up a penny from the floor, a 50-foot walk test, and climbing stairs. The maximum score is 36 with higher scores indicating better performance. PPT scores increased significantly (p<0.001) by an average of 5.21 points following an intensive 3 week inpatient rehabilitation program in 40 patients with HD.⁴⁷

Integumentary Integrity. Patients with HD may experience skin abrasions and lacerations from uncontrolled limb movements causing them to accidentally hit objects or from falls. Skin inspection is recommended in those individuals with a falls history and in individuals in later disease stages with severely limited mobility.

Motor Function (Motor Learning and Motor Control). Evaluation of voluntary and involuntary motor impairments is important to help therapists determine what factors are contributing to functional deficits and falls. Voluntary motor impairments include bradykinesia (slowness of movement), akinesia (delayed initiation of movement), apraxia, motor impersistence (inability to sustain a movement), diminished rapid alternating

continued on page 7

Contribute to your DDSIG!

Do you have any resources to share with our SIG? Home exercise materials, videos, books or even ideas for others to follow up with would help to advance our SIG and help our patients to achieve their goals!

Do you have ideas for a case study or a research project involving degenerative diseases? Contact us and we may be able to point you in the right direction regarding collaborators or other ideas! movements, and difficulties performing sequences of movements. Involuntary motor abnormalities in HD include chorea (involuntary, writhing movement) and dystonia (abnormal, sustained posturing of a part of the body). Therapists can obtain information about motor function deficits from the UHDRS motor section. Bra-dykinesia can be assessed by recording the time it takes to complete a task. The most prevalent types of dystonia were reported to be internal shoulder rotation, sustained fist clenching, excessive knee flexion, and foot inversion.⁵ Hand dexterity is often impaired^{52,53} and can be assessed using writing, dressing, cutting food and handling utensils tasks and tests such as the 9-Hole peg test.⁵⁴

Muscle Performance: Overall strength is not initially a problem in HD. Over time strength can be diminished. One study found that people with HD who were independent ambulators had significantly weaker leg muscles than age-matched controls.²⁴ It is not known whether muscle weakness is a primary impairment of the disease process or secondary to decreased mobility and disuse atrophy. Therapists should perform strength testing using manual muscle testing or functional observations (e.g. stair climbing or gait deviations) in individuals with HD who are experiencing functional declines.

Pain. Individuals with HD can experience pain. Musculoskeletal pain can arise from dystonia, muscle imbalances, immobility, and injuries. There are some reports of people in late stages of HD with severe "central" pain presumably due to deafferentation from the disease process.⁵⁵ Therapists can measure pain using numerical or visual analog scales or the Wong-Baker FACES pain rating scale may be useful in later stages.⁵⁶

Posture/Range of Motion. Individuals with HD may develop muscle tightness and postural changes due to poor postural habits, dystonic posturing, and immobility. In sitting, individuals with HD tend to adopt a slouched position with excessive thoracic kyphosis and posterior pelvic tilt. In later stages, patients often assume a more massed flexion posture. Standard assessment of range of motion and posture should be conducted at all stages, with particular attention to those with moderate to severe dystonia.

Psychological function. Personality changes are one of the cardinal features of HD.¹⁷ Depression, apathy, irritability, impulsiveness, and antisocial and suicidal be-

havior may be demonstrated by individuals with HD. Depression and apathy may occur early in the disease before motor symptoms have progressed, indicating that they may be part of the disease process rather than a response to functional decline. Depression and anxiety can be assessed using the Behavioral Assessment portion of the UHDRS or the three-question depression screener.^{19,57}

Reflex integrity and Tone. Deep tendon reflexes may be increased in HD. People with chorea may exhibit "hung-up" reflexes in which after the tendon is tapped and the reflex action takes place, the limb slowly returns to its neutral position. Rigidity can be assessed using items in the motor examination section of the UHDRS.

Self-Care and Home Management (Including ADL and IADL). Basic ADLs and IADLS can be assessed using the Function Assessment section of the UHDRS which consists of the Functional Capacity Scale, the Independence Scale, and a checklist of common daily tasks.¹⁹ The total score on the Functional Capacity Scale is reported as the total functional capacity (TFC) score. The Independence Scale is rated from 0 to 100. Higher scores indicate better functioning. Another instrument that can be used to assess ADLs is the Barthel Index.⁵⁸ The Barthel Index is a 10 category rating scale that evaluates the level of assistance needed by a patient to perform the following tasks: feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfer, mobility and stairs. A referral to an occupational therapist is recommended for more extensive evaluation of basic and instrumental ADLs.

Sensory Integrity. Abnormalities in skin sensations have been reported in individuals in the later stages of HD, presumably due to disturbances in cortical processing of somatosensory information (deafferentation).⁵⁵ Assessments of skin sensations and proprioception should be performed in individuals with HD with sensory complaints and balance problems. Ventilation and Respiration. Respiratory function is affected in people with HD and is highlighted by obstructive or restrictive disorders of the respiratory system.⁵⁹ However, most people do not report respiratory symptoms until later stages of the disease. Since pulmonary infections may contribute to morbidity and mortality in individuals with HD, therapists may desire to include respiratory function assessments in their examinations of people in the later stages of the disease.

Work, Community, and Leisure Integration. HD symptoms can affect an individual's ability to function at home, work, and in community activities. Thus therapists should include quality of life, general health, and community participation measures in their evaluations such as the ones listed below.

Medical Outcomes Study 36-item Short-Form Health Survey (SF-36).⁶⁰ This is a patient questionnaire that measures quality of life and level of participation. The 36 questions are grouped into 8 sub-scales. Each of the sub-scales can be used alone, and higher scores are indicative of better health.

HD-ADL.⁶¹ This is an informant rated instrument designed to follow disease progress. An ADL total score is calculated by summing all of the values for the five domains of Personal Care, Home Care, Work and Money, Social Relationships, and Communication. Validity and reliability has been demonstrated for subjects with HD on the

Category	Test or Measure
Disease Specific Scale	Unified Huntington's Disease Rating Scale ¹⁹
Aerobic Capacity and Endurance	Aerobic capacity during functional activities, or during standardized exercise test (early stages) Cardiovascular and pulmonary signs and symptoms in response to exercise or increased activity
Anthropometric Characteristics	Weight measurements Girth measurements of extremities
Arousal, attention, and cognition	Ability to follow multistep commands Alert, oriented times 4 Mini Mental State Examination (MMSE) ³¹ Verbal Fluency Test, the Symbol Digit Modalities Test, and the Stroop Interference Test (cognitive part of UHDRS) ¹⁹
Assistive, Adaptive, Orthotic, Protective, and Supportive Devices	Assessments of different devices and equipment used during functional activities including the safety during use, alignment, fit, and the patient's ability to care for the devices or equipment
Circulation	Blood pressure measurement Heart rate and rhythm

Table 1: Toolbox of Outcome Measures for Individuals with Huntington's Disease (HD)

continued on page 9

For more resources on Huntington's disease, check the resources page of the DDSIG's website!

Table 1: Toolbox of Outcome Measures for Individuals with HD (continued)

Cranial Nerve Integrity	Oculomotor tests including saccades and smooth pursuit eye movements (part of UHDRS motor section) ¹⁹ Assessment of oral motor function, phonation and speech production through interview and observation
Environmental, home and work barriers	Evaluation of patient's home and work environments for current and potential barriers, and access and safety issues
Ergonomics and Body Mechanics	Assessment of ergonomics and body mechanics during self-care, home management, work, community, or leisure activities (may include caregivers)
Gait, Locomotion, and Balance	<u>Gait Assessment</u> : six minute walk test, ²⁵ 10-meter walk test, ³⁶ Dynamic Gait Index ³⁷ <u>Balance</u> : Berg Balance test, ³⁸ Functional Reach/ Multidirectional Functional Reach, ^{40,41} Pull test, ¹⁹ Single limb stance, ³⁹ and falls history <u>Mobility tests</u> : Timed up and go, ⁴⁴ Tinetti Mobility Test, ⁴⁵ Community Balance and Mobil- ity Scale, ⁴⁹ Rivermead Mobility Index, ⁵⁰ Physical Performance Test ⁵¹
Integumentary Integrity	Skin inspection in fallers and those with severe mobility limitations
Motor Function (Motor Learning and Motor Control)	UHDRS motor section ¹⁹ 9-hole peg test ⁵⁴
Muscle Performance (Strength, Power, and Endurance)	Manual muscle testing (MMT) Hand-held dynamometry
Pain	Pain numerical rating scale Pain visual analog scale (VAS) Wong-Baker FACES pain rating scale ⁵⁶
Posture	Assessment of spinal alignment
Psychological Function	UHDRS Behavioral assessment section ¹⁹ Three-question depression screener ⁵⁷
Range of Motion (ROM)	Goniometry End feel assessment Multisegment flexibility tests
Reflex Integrity/ Tone	Deep tendon reflexes Rigidity testing in the UHDRS motor section ¹⁹
Self-Care and Home Management	UHDRS Functional assessment section ¹⁹ Barthel Index ⁵⁸
Sensory Integrity	Sensory testing
Ventilation and Respiration/ Gas Ex- change	Respiratory rate, rhythm, and pattern Auscultation of breath sounds Cough effectiveness testing Vital capacity (VC) testing in supine and upright positions or Forced vital capacity (FVC) testing
Work, Community, and Leisure Integra- tion	SF-36 Health Survey ⁶⁰ HD-ADL ⁶¹

Degenerative Diseases Special Interest Group

continued on page 10

Page 9

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End ■

Page 11

Merci! Danke! Grazie! Thanks!

The Leadership of the DDSIG would like to extend its gratitude to the outgoing members of the Executive Committee: Anne Kloos, PT, PhD, NCS the outgoing DDSIG Chair, and Kirk Personius, PT, PhD, the outgoing DDSIG Nominating Committee Member.

Anne and Kirk, please accept our sincerest thanks for your service to the SIG and your profession. Your contributions will long be remembered. We hope that you will both continue your involvement with the DDSIG!

The DDSIG Leadership would like to extend it warmest welcome to the newly elected Leaders. Donna Fry, PT, PhD was elected as the new Chair. Tara McIsaac, PT, PhD was elected to the vacant position on the SIG Nominating Committee.

Thanks are also due to Deb Kegelmeyer, PT, DPT, MS, GCS, who will Chair the Nominating Committee for the coming year.

Bienvenue! Willkommen! Benvenuto! Welcome!

Would you like to contribute to the DDSIG Newsletter?

<u>Contact us</u> and let us know what you are interested in writing about!



A Huntington's Disease Article Review

Ashwini K. Rao, EdD, OTR Associate Professor of Clinical Rehabilitation Columbia University, New York, New York <u>akr7@columbia.edu</u>

The Article

Grimbergen YA, Knol MJ, Bloem BR, Kremer BP, Roos RA, Munneke M. Falls and gait disturbances in Huntington's disease. Movement Disorders. 2008; 23(7): 970-6.

The Review

The purpose of this article was to evaluate the contributions of risk factors and pathophysiology (such as chorea, balance impairment, and cognitive/behavioral impairments) underlying falls in manifest Huntington's disease (HD).

Impairments in motor function (chorea and bradykinesia), cognitive function (inattention, motor recklessness), and behavior (anxiety, aggression) are commonly seen in early HD and increase the risk for falls, which result in injuries and placement in long-term care. Falls are likely to result from a complex interaction of many factors including motor, cognitive and behavioral impairments, alcohol intake, medication and environmental factors. Given the emotional, health and financial cost of falls, this is a very important research question.

The authors recruited 45 patients in early to mid-stage HD and 27 healthy control subjects. Subjects underwent a clinical assessment including the Unified HD Rating Scale (UHDRS), the Total Functional Capacity (TFC) scale, the Berg Balance Scale (BBS), the Activities of Balance Confidence Scale (ABC scale), fall history, living circumstances, daily medications, and alcohol intake. Quantitative gait analysis (with the GaitRITE mat) and balance analysis (with the Swaystar) were also performed. Following the baseline assessment, subjects were prospectively followed up for 3 months during which they maintained a falls calendar (including circumstances and consequence of the first five falls). The methodology, with retrospective and prospective assessment of fallers and non-fallers with a range of disease severity, was appropriate for the research question.

Falls occurred in 40% of cases. Most falls occurred in familiar environments (92%) and indoors (57%), primarily as a result of obstacles on floor (25%), slippery or uneven surface (17%). Patients fell most often when they were multi-tasking (35%) or climbing stairs (20%), which led to minor injuries in 72% of cases. Fallers had lower balance confidence and poorer motor function (lower UHDRS motor scores and lower BBS scores). Fallers also tended to have greater cognitive impairment and more aggression, and as a result demonstrated greater functional limitations. Quantitative analysis confirmed that fallers demonstrated lower gait velocity, stride length and greater variability in walking, and greater trunk displacement in quiet stance.

The study confirmed that falls were common in HD and identified specific motor (poor balance, bradykinesia), cognitive (inattention and recklessness) and behavioral (aggression) impairments that were associated with fallers. The study also provides important insight into the circumstances of most falls (during multi-tasking and stair climbing) which can be a target for future therapeutic interventions. While the study is important, future work should include a larger range of disease severity from a large sample. Given the cost and effort associated with quantitative assessment, their inclusion needs to be clearly justified. It is also important to evaluate the sensitivity of clinical and quantitative assessment in identifying fallers, which will be a useful tool for clinicians.

By Donna Fry, PT, PhD

The World Confederation of Physical Therapy (WCPT) conferences are a great opportunity to see physical therapy from a different light. I am always struck by both the dissimilarities and similarities in education and practice. Support for physical therapy for people with degenerative diseases seemed to vary widely between countries. Hospital visits were available through the conference. I visited Lucas Andreas Hospital which has a special program for people with Parkinson's disease (PD). People referred to this program get a full day of evaluation across disciplines with follow up home visits by a nurse practitioner and physiotherapy services as needed. In Amsterdam there is Parkinson network (ParkinsonNet) composed of PD providers. Through this online network of health providers who specialize in PD, physiotherapists can easily find providers to assist with transitional care when patients leave the hospital or need specific services. Therapy for chronic conditions is covered in the Netherlands and they are able to offer group exercise programs through their hospitals. In contrast, in some of the developing countries, there are so few physical therapists that any form of physical therapy is difficult to provide.

The WCPT neurology content was heavily weighted in the areas of stroke and spinal cord injury. Degenerative disease poster and platform presentations ranged from "Using musical keyboard to train motor skill recover in subjects with multiple sclerosis" (Lambiase, et a - Italy) to "Aerobic training and muscular strengthening improve functional performance and physical activity in persons with Parkinson's disease" (Rodrigues-de-Paula, et al – Brazil).

Before the conference I was able to visit the University Hospitals Geneva Medical Center in Switzerland. As we toured the facility, I noticed a rock climbing wall which they are able to pull out from the wall and adjust the degree of incline to modify the difficulty. Lara Allet, faculty member from the Applied Sciences University in Geneva demonstrates the climbing wall that was designed by hospital physical therapist Jean-Luc Ziltener who is a rock climber. They use this for both neurologic and orthopedic patients.



I encourage our members to consider presenting their research at the next WCPT conference in Singapore in 2015! See you there!



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