Palliative and Hospice Care for Individuals with Late to End Stage Neurodegenerative Disease: Strategies for Optimizing Function and Quality of Life

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Objectives

- Describe the role of palliative and hospice care in the context of chronic disease management
- Describe the clinical features of late stage neurodegenerative disease including: Parkinson’s Disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis that are indications for palliative care and hospice
- Describe physical therapy interventions for both motor and non-motor symptoms of late to end stage neurodegenerative disease
- Describe valid and reliable outcome measures for the assessment of patients with late to end stage Parkinson’s Disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis

The Scope of Neurodegenerative Disease

- Caused by hereditary, environmental, inflammatory, viral, or traumatic antecedents, either alone or in combination.
- No specific causative agent has been identified for any of these diseases.
- Alzheimer’s Disease: 5.2 million in US, 500,000 new cases
- Parkinson’s Disease: Prevalence 1.5 million in US, 50–60,000 new cases each year
- Multiple Sclerosis: 400,000 in US, 10,000 new cases each year
- ALS: Prevalence: 30,000 in US, 5,000 new cases each year
- As the prevalence of each of these diseases increases, so will the economic burden:
  - Alzheimer’s: $ 203 Billion in 2013 (1.5 Trillion by 2050)
  - Parkinson’s: $ 6.3 billion (2012)

What is Palliative Care?

- Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.
- Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
- Care is provided and services are coordinated by an interdisciplinary team so that patient needs are met in all domains of well being
- Services are available concurrently with or independent of curative or life-prolonging care

Physical therapists are already providing palliative care; However…

- Our episodes of care are discretely isolated within the patient’s disease process
- We need to identify all members of the patient’s healthcare team and COMMUNICATE with them THROUGHOUT the patient’s disease course
- How can we promote collaborative care across all settings?
  - Electronic health records/patient portal can provide a common point of access for all providers
  - A consistent palliative to direct care throughout the disease trajectory (who to see, when, why…)
  - Use of advanced directives to clarify POA and pt desires
Four challenging cases

- Helen, aged 89 (deceased 2012). Eight year history of dementia, significant cognitive decline and resulting family distress. Unexpected hospice intervention after fall related hip fracture.
- Charlotte, age 79. Twenty-six history of Parkinson’s disease, early dementia. Fragmented care, needs palliative program, not currently a hospice candidate.
- Cindy, age 55. Twenty year history of Multiple Sclerosis. Symptoms of secondary progressive disease in recent years. Family overwhelmed; hospice assessment pending.

Guiding Concepts Related to Palliative Care in Neurodegenerative Disease

- In the later stages of neurodegenerative disease, multi-system non-motor symptoms increase the burden of disability and negatively impact patient quality of life.
- The increasing severity of non-motor symptoms, compromises effectiveness of medications and neuro-rehabilitative therapies (i.e. “on-off” cycles in PD)
- Interventions move from restorative to compensatory to comfort

When is Palliative Care Indicated?

(National Institute of Nursing Research)

- Whenever ....
  - a patient suffers from pain or other symptoms from ANY serious illness
  - a patient experiences physical or emotional pain that is NOT under control
  - a patient needs help understanding their condition
  - a patient needs help coordinating their care

An Emerging Area of Practice, Education and Research

- In 1995, 53 palliative care projects received NIH funding. In 2006, it was 309
- In 2000 only 2 systematic reviews related to palliative care were published in Pub Med. In 2013, it was 249
- By 2014, 80% of US hospitals over 50 beds will have a palliative care program
- 234 fellowships in palliative care as of 2013

The traditional model

* Palliative Care/Hospice
  - Curative Care
  - Confort Care
  - Disease Course
  - Death

Source: Center to Advance Palliative Care, 2013
In an integrated model of palliative care, the team follows the patient through the continuum of care.

Who pays for palliative care?
- Medicaid: No specific palliative care package. Care delivered and reimbursed as needed.
- Medicare:
  - No specific “palliative care package”.
  - Care is delivered and reimbursed as needed (i.e. movement disorder specialists, therapists, nurses etc)
  - Benefits provided under Medicare A (inpatient), B (outpatient) or D (medications)
- Medicare Hospice Benefit: A set per diem rate ($181.00) to cover comfort services related ONLY to hospice diagnosis.

Palliative Care and the Affordable Care Act
- Abolished restrictions on coverage for pre-existing conditions, opening door to greater access to palliative care.
- Abolished limits on coverage for chronic conditions, enabling patients to receive care through the course of their illness.
- Provides for wellness and prevention to optimize health.
- Current emphasis on identifying initiatives to improve cost effective high quality palliative care.
  - The Joint commission: Advanced Palliative Care Certification for Hospital Based Services.
  - Palliative care programs can be provided within emerging models of care:
    - Accountable Care Organizations (Medicare)
    - Patient Centered Medical Homes
    - Bundled payments (currently on 5 year pilot).

Models of Palliative Care Delivery (Spragens and Jones, 2011)

Why aren’t more patients receiving palliative care?
- While the need for palliative and hospice care for patients with neurodegenerative disease is gaining increasing recognition, numerous barriers limit access to such care, particularly in the early stages.
Barriers to Palliative Care Access: Ambivalence Among Providers

(Regence Foundation and National Journal: Living Well At The End of Life: A National Conversation 2011)

- 96% percent of 500 board-certified physicians surveyed supported palliative care
- HOWEVER, 42% concerned that palliative care could interfere with treatments aimed at extending patient lives as long as possible.
- 25% percent are reluctant to recommend palliative care because their patients may perceive they are not doing everything possible to extend their lives.
- "Physicians are a much more difficult audience than consumers"

Do we appreciate the palliative needs of patients with neurodegenerative disease?

Neurodegenerative disease includes non motor symptoms "similar to advanced cancer" (Ghoche, 2012)

- MS
- PD
- AD
- ALS

Fatigue (58-86%)
Fatigue (83%)
Fatigue (100%)

Pain (up to 95%)
Pain (95%)
Pain (52%)

Diabetes
Depression
Cognitive changes
Nausea
Cytokines
Respiratory failure
Aspiration pneumonia
Severe infection/sepsis

End Stage Neurodegenerative Disease:
A convergence of complications leading to death

Neurodegenerative Disease Overview

- Alzheimer’s disease
- Parkinsons’ disease
- Multiple Sclerosis
- Amyotrophic Lateral Sclerosis

Neural degenerative process of AD
5 Clinical Manifestations Of Alzheimer’s Disease
- Memory loss
- Decreased language skill
- Visual-spatial dysfunction
- Apraxia
- Emotional/behavioral changes

Features of End Stage Dementia
- Loss of cognitive capacity: Profound confusion and disorientation. Combativeness, inability to initiate, psychotic reactions. Coma
- Loss of communication: Progressive worsening of speech, inability to communicate; patient eventually becomes incoherent, mute, then unresponsive.
- Loss of Function: Loss of independent mobility and capacity for self care. Patient becomes totally dependent and bed bound
- Loss of ability to sustain nutrition: progressive loss of appetite and ability to swallow or eat independently. Increasing risk for aspiration

Issues and Challenges
- Fragmented medical care system, limited access; Helen relied on very supportive adult children for transport to appointments, no central coordination of care provided by assisted living staff
- Helen’s cognitive decline compromising her health/safety (as well as that of her husband)
- Helen’s paranoia and cognitive changes were not addressed by assisted living staff.
- Family provided as much support as possible until…

Helen
- Beautiful 89 year old mother of 6, grandmother of 27
- Primary caregiver to husband (retired attorney) with moderate PD, married 63 years. Financially independent. Determined to provide all husband’s care despite stated concerns of family
- Hx of falls, ORIF L hip 2004. Independent with walker; limited community; kidney failure post surgery with progressive cognitive decline loss of memory, language ability
- Resident of assisted living facility (retirement community with independent living with attached SNF)
- Hx of HTN (beta blockers), statins for elevated cholesterol; adherence supported by assisted living staff and family
- Increasing paranoia and hallucinations in last month: Locking door of apartment, preventing husband from receiving medications, accusing staff of stealing. Significant family stress

What shouldn’t be
- Helen was found (by adult son) on the floor of her bedroom, confused and disoriented. Her husband was asleep in bed.
- Helen had spiral fracture of R femur and hip dislocation
- Helen refused surgery saying she didn’t want to live any longer; surgery performed as palliative measure
- Assisted living facility insisted that their hospice services be used, requiring transfer to their SNF. This prevented Helen from dying in the comfort of her home.
- Husband left unattended in apartment at night, found on floor in hallway by adult son one morning.
What can be

- Identification of palliative care team to support both Helen, her husband and family; ideally with home health liaison to provide care to both
- Helen and husband could have benefitted from expert palliative medical management of both of their diseases
- Coordination of care from point of arrival in assisted living through end of life for both (husband moved to different assisted living facility after Helen’s death and received excellent hospice care; he died in 2013.

PD Case Study

Charlotte

- 26 year history of PD
- Grew up around farming and military testing sites
- Diagnosed at age 54 (current age = 80)
- Medical History (in addition to PD)
  - R & L rotator cuff tear repairs (2005 & 2010)
  - Osteoporosis
    - 2 thoracic compression fx (1998)
    - 1 (really ugly) sacral fracture (2009) (with Sacralplasty)
    - 1 (really ugly) L5 compression Fx with Kyphoplasty (January 2012)
    - Hip Fracture August, 2013
    - Lumbar laminectomy December, 2013
- Medications
  - PD related only

Types of Parkinsonisms

Prevalence
(total number of current cases)

1-2 million USA
- b/w 100-347 per 100,000 cases > 40 yo
- Overall rate of 2% of population
- Rate increases with age
- 3% in patients >65 yo
- Men 1.5 X > women
- Mean age at onset: 52 to 58 yo
- 85% of PWP are over 65 yo

6-7 million worldwide

PD is the second most common neurodegenerative disease after Alzheimer’s

What Causes Parkinson’s Disease?

“genes load the gun”
William Langston, MD
Parkinson’s Institute, Sunnyvale, CA

“The environment pulls the trigger”

Age of On Set
• Age (one of the most common risk factor)
• The older you are the closer you are to having PD
  • Typical - 52-60 y/o
  • Young – 21-40 y/o
  • Late – 78+ y/o

Clinical Diagnosis of IPD

If:
Insidious onset - nonspecific non motor and early motor symptoms

If:
Asymmetrical distribution AND typical clinical presentation

Bradykinesia + one of these
rigidity/tremor/postural instability

Decreased arm swing when walking
Micrographia
Hypophonia
Masked face
Slow, shuffling gait
Stooped posture

As PD Progresses, Disability Increases and Independence Decreases

Transition from stage 2 to 3 is associated with the emergence of postural instability, a precursor of disability

Secondary Impairments and Complications

• Deconditioning
• Muscle atrophy and weakness
• Osteoporosis
• Circulatory changes
• Contractures
• Respiratory
• Medication side effects
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Multiple Parallel Circuits through BG contribute to ability to move and re-learn

Bradykinesia, akinesia, tremor, rigidity
Exec. Func. And Attentional deficits
Depression, apathy, anxiety

Nonmotor Symptoms
(Lök and Delbari, 2012)

- Anxiety / Depression
  - 25% major/40%-65% minor
  - precedes motor symptoms
  - may contribute to dementia

- Loss of higher cognitive functions
  - Shifting cognitive set
  - Slow thinking
  - Retrieval
  - Self-cueing
  - Sustaining attention

- Dementia
  - 30%-65%
  - occurs 6.6X as frequently than in elderly non-PD
  - shortens survival

- Autonomic abnormalities (80%)
  - hypotension, bowel / bladder, sexual, blurry vision, short of breath

- Sensory changes (50-83%)
  - Pain, tingling, burning
  - Generalized decreased kinesthetic proprioceptive awareness
  - Self-perception/monitoring
  - Loss of smell

- Sleep Disorders*

= signs prior to motor signs...can lead to earlier diagnosis

The Dopamine Slide

Birth

Normal Dopamine Decline
Nonmotor Neuroprotection
ParAimons Dopamine Decline
Death

Red Flags = movement problems prior to Dx

Neurorestoration
Compensation

Exercise and PD Timeline

1950s
Normal dopamine decline

1960s
Levodopa introduced

1970s
Drugs improved
Exercise not helpful

1980s
Exercise adjunctive-falls

1990s
Deep Brain Stimulation
Exercise additive/complementary with meds

2000s
Exercise and disease modification - animal PD
Exercise and brain reorganization – human PD
Gene/Cell Therapy - restoration/protect
Early Detection - Biomarkers
Neuroprotection
Exercise and Enrichment

2010 +
It’s a revolution!

Charlotte’s Medication

- Sinemet (carbidopa/levodopa)
- Eldepryl (selegiline) (MOA inhibitor)
- Mirapex (increase activation on DA receptor)
- Sleeping med
- Stool softener
- Anti anxiety

Schedule
- Sinemet every 3-4 hours
- (extended release at night)

Neuroplasticity PD Brain Change

(from Morris et al., 1998)

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**Neuroplasticity Concepts**

- **Intensity (Dosage)**
  - Total time of practice (freq/ dur)
  - Amount of energy expenditure – effort/ work/ force requirements

- **Specificity – Target the deficits – Forced Use**
  - Use it or lose it (defer the “expected” deficits)
  - Use it and Improve it (defeat the “existing” deficits)
  - Different deficits may require different exercise approaches

- **Repetition – Repetition - Repetition**

- **Difficulty/Complexity (Cognitive engagement)**
  - Progressive challenge, constant high attentional focus and engage
  - Manipulate environmental/movement/cognitive parameters
  - Effort alone may not ameliorate “highly skilled” coordination activities

- **Saliency (Emotional engagement)**
  - Drive internal motivational circuits; empower/education/reward success
  - Social reinforcement/networks
  - Patient driven FUNCTIONAL training!

By Becky Farley PWR4life.ORG

**Test & Measures 2004-present**

<table>
<thead>
<tr>
<th>Test Category</th>
<th>Test Description</th>
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<tbody>
<tr>
<td>Walking Speed</td>
<td>10 meters (10 years)</td>
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<tr>
<td></td>
<td>6 min (10 years)</td>
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<tr>
<td>Mobility</td>
<td>TUG (reg, manual, cog…10 years)</td>
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<tr>
<td></td>
<td>FGA (10 years)</td>
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<tr>
<td></td>
<td>5 times sit to stand (3 years)</td>
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<td></td>
<td>4 square step test (5 years)</td>
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<td></td>
<td>3 meters backwards walk (10 years)</td>
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<td>Freezing of Gait Questionnaire (2 years)</td>
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<td></td>
<td>Mini Best (2 years)</td>
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<td>Cognition</td>
<td>Mini Mental (10 years)</td>
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<td></td>
<td>MOCA (5 years)</td>
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<td></td>
<td>UPDRS (motor 10yr)</td>
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<td></td>
<td>Fine Motor (10 years)</td>
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<td>9 whole peg test</td>
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<td>WOLF Motor</td>
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<td></td>
<td>OQL, PDQ 3.6 (2 yrs)</td>
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<td></td>
<td>Activities Specific Balance (10 yrs)</td>
</tr>
<tr>
<td>QOL - PDQ 36</td>
<td>Fear of Falling (10 yrs)</td>
</tr>
</tbody>
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Evidence that annual intensive bouts of exercise may reduce the need for medication overtime in human PD

Effectiveness of Intensive Inpatient Rehabilitation Treatment on Disease Progression in Parkinsonian Patients: A Randomized Controlled Trial With 1-Year Follow-up.
Giuseppe Frazzitta, MD et al. Neurorehab Neural Repair Aug 15, 2011

By Becky Farley PWR4life.ORG

**Charlotte: Changes After Intensity Training 2004**

**Parkinson Treatment Options**

Provide symptomatic relief; improve function

- Medication
- Deep Brain Stimulation
- Exercise

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**PWR!Project**

Parkinson Wellness Recovery Exercise4BrainChange®

- Neuroplasticity principles
- Intermittent Intensive bouts for LIFE
- Forced use
- Continuous Access

www.pwr4life.org

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Research Approaches in PD that Adhere to Neuroplastic Principles
- Tandem cycling (Forced spinning)
- LSVT Loud/LSVT BIG
- Treadmill Rotating treadmill
- Sensory Motor Agility Program
- Sensory Focused Coordination Training
- High Resistance training
- Tango
- Dual task Training
  - BIG and LOUD
  - Walk and Talk

Dance/Tai Chi/Music Therapies, Pole Walking, Boxing

The Dopamine Slide
- 26 year history of PD
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Advanced Phases of PD
- Research shows exercise can mediate disease modification in PD animal models

Mode of action: Adaptation
- Reliance on undamaged systems increased
- Autonomic and metabolic adaptations included
  - Cardiac
  - Respiratory
  - Peripheral muscle systems
- Angiogenesis in striatum increased
- Expression of brain damage markers in the striatum decreased
- Partial behavioral recovery

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Charlotte Rehab Following L5 Compression Fracture (summer 2012)

Repetitive training of compensatory steps (improves postural control mechanisms)

Repetitive pulls and pushes multidirectional: progressive, reward FB; 180 to 230 pulls per session; 10 days; 20’; 2x/day; within 2 weeks

Jöbges M et al. J Neurol Neurosurg Psychiatry 2004;75:1682-1687

Fall Progression Summer 2013

Exercise IS Medicine – Take it EVERY DAY!

Time For New Paradigms in PD

DX

Exercise

Improve function

Disease severity – H&Y

Loss of postural stability

Optimize brain health/brain function

Advance Stage

1 2 3 4

Pre-motor symptomatic period

Disease severity – H&Y

Loss of postural stability

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Palliative Care Considerations

- Optimal Care….. Optimal Outcomes
  - Well Educated Family
  - Movement Disorder Specialist
  - Optimal medication
  - Expert progressive Physical Therapy, Speech Therapy
  - Husband support
- Difficult!
- Palliative Care Can HELP SMOOTH THE PATH

Questions
- Hospice referral…. When do we say no more ….
Meet Cindy

- AGE: 55 years old
- Wife and Mother of 2 children (in their 20s)
- Lives at home with husband and son in Flagstaff, AZ
- Diagnosed in (2000)
  - Numbness and tingling in the legs
  - Retrospect: First vision loss in 1989
- Locomotion: Wheel Chair
- Assistance required
- Interventions
  - scattered

WHAT IS M.S.?

- A disease that...
  - attacks and destroys the myelin in CNS
  - causes axonal destruction and transection
  - has a continuous disease process
  - is often clinically silent at first
- MS pertains to multiple, diffuse areas of sclerotic myelin plaques
  - Characterized by
    - Multiple signs and symptoms
    - Fluctuating periods of exacerbations and remissions
    - 6 main disease courses on the MS disease Spectrum

Common Signs

- No Typical Picture
  - Fatigue
  - Spasticity
  - Weakness, poor force production
  - Dysmetria or tremor
  - Nystagmus and diplopia
  - Impaired sensation
  - Facial weakness
  - Changes in intellectual function
  - Pain
  - Bowel and bladder dysfunction

MS Progression Time Line

- 1989: DOB
- 1989: Birth of 2nd child vision problems - “went away”
- 1995: Cindy reports she was very clumsy
- 1999: Numbness and tingling of legs
- 2000: MS Diagnosis
- 2005: Still walking (WC for community mobility)
- 2010: Slowly just getting worse
- 2012: More quickly getting worse

Cindy’s Type of MS

- RELAPSING/REMITTING: (RRMS)
  - 85-90% of new DX are this type
  - Self-limited acute attacks lasting days to weeks.
  - Partial recovery in following weeks or months.
  - Benign form in up to 20%

- SECONDARY PROGRESSIVE(SPMS)
  - In 80%, begins as RRMS for first 10-20 years, then attack rate decreases, deterioration becomes steady and progressive, unrelated to attacks

Cindy’s Primary Complaints

- Decreased Vision
  - Fatigue
- Weakness
  - Fatigue
- Decreased fine motor function
  - Fatigue
- Decrease in independence
  - Fatigue
- Headaches
Fatigue
- Most common symptom (75% of patients)
- Not related to disease severity
- Major impact on quality of life
  - Unplugged
  - Overwhelming
- Primary (less manageable)
  - Symptom of disease itself
  - Motor Unit Fatigue
  - Lassitude
- Secondary (more manageable)
  - Body's response to disease (physical, emotional)
  - Effect of trying to compensate for disease
    - Inactivity - can bring it on
    - Over activity - can bring it on

Impact of Fatigue
- Reduced Participation
  - Exacerbates motor symptoms
  - Exacerbates cognitive symptoms
  - Adequate rest is most important management tool
  - Effect of fatigue on disease progression is unclear in research
  - Management of fatigue is an important element of PT
  - Medication for motor fatigue: Ampyra

Fatigue Severity Scale

During the past week, I have found that:

1. My motivation is lower when I'm fatigued
2. Exercise brings on my fatigue
3. I am easily fatigued
4. Fatigue interferes with my physical function
5. Fatigue causes frequent problems for me
6. My fatigue prevents sustained physical function
7. Fatigue interferes with carrying out certain duties and responsibilities
8. Fatigue is among the three most disabling symptoms
9. Fatigue interferes with my work family or social life

Scores: Average (Total/9)

Subjective
- Cindy Self Report
  - I can complete independently
  - In and out of bed
  - In and out of shower
  - On and off toilet
  - Dressing
  - In and out of WC level surfaces
  - In need help with
    - On and off floor
    - Getting legs into the bed
    - Fixing meals
    - House keeping
  - I fall occasionally
  - I wear a depends because a leak

Physical Therapy Evaluation
- Summer 2013

COGNITIVE CHANGES
- Affects up to 65% of patients with MS
- Attention deficits
- Poor mental acuity
- Processing delays
- Problems with planning and organization
- Impulsivity
- Comprehension difficulties
- Memory deficits
- Depression (up to 50%)
- Euphoria
PT Interventions

- Video

Home PT request

- Val: "let's try 2 days per week"
- Cindy: "I don't have time for that" (I'm too tired)
- Val: "how about if I come to your home"
- Cindy: "OK… I want to be able to work on exercises at home to strengthen my legs"

Subjective

Cindy Self Report

- I can complete independently:
  - In and out of bed
  - In and out of shower
  - On and off toilet
  - Dressing
  - In and out of WC level surfaces

- In need help with:
  - On and off floor
  - Getting legs into the bed
  - Fixing meals
  - House keeping
  - I fall occasionally

Husband's Report

- Cindy is able to:
  - Help from 8:00-10:00 with transfers out of bed and some dressing
  - After that, she is total care
  - Falls sometimes 2x daily
  - Cut off her seat belt
  - Wet 24/7 with zero bladder control
  - PT wipes her out… she is a mess
  - Sometimes after PT it takes her 2 days to recover
  - After PT I am more worried about her falling so I have her stay in bed

What Did I Miss?

- I knew there was a disconnect... a gap

I Need Help!!!!

- Palliative Care Expert (PT)
- Home Health Care (team)
  - OT (Gillian Porter)
  - Physician
  - Nurse
- Issues
  - Catheter insertion and care
  - Hoyer Lifts
  - Shower Chair
  - Palliative Care Referral Coordination

Catheter Conversation

- Cindy
  - I don't want or need a catheter
  - I am wet occasionally, but my skin is fine
  - I take care of all my bladder needs
- Husband
  - She is wet 24/7
  - Refuses to get a catheter
  - Bamboozled the MD with the last report
  - She can't transfer onto the toilet
Catheter Conversation

- Cindy finds the depends liberating
- She does not think she is wet that often
- She does not think she needs a Catheter
- John says she is wet 24/7

Pain: Medical Marijuana Conversation

- Cindy reports she does not have pain
- We are talking to her about the pain she has reported
- She has medical Marijuana that she has not used
- Cindy will drink wine at night and her husband reports she is total care after that

Husband Report

- His frustrations
  - He will hire a CNA and Cindy will not let them do much
  - She will leave the showering, toileting, depends changes for him
  - She does not want any NEW equipment offered at first
  - She is unsafe...cut off her seat belt
    - She doesn’t remember she is unsafe and can’t do it

John Needs Help/Support

- 

What Did I Learn

- Palliative Care Connection
  - The earlier the better
  - Can prevent fragmentation of care
  - Reduce frustration and fear
  - Improve quality of life
  - Reduce costs
  - Assist in the transition to hospice
  - Slow disease progression
  - Neuroprotective medication
What Else Needs to be Discussed?

- Promote coordinated effort for Cindy?
  - Earlier Diagnosis?
  - Earlier Neuroprotective Medications
    - Show delay expression and severity of symptoms
    - 55% reduction in progression of brain atrophy with Interferon Beta

Where is Cindy on the Palliative Care / Hospice Continuum?

Amyotrophic Lateral Sclerosis

- Progressive degeneration of UMN and LMNs in the cortex, medulla, and anterior horn of SC
- Initiated by mutations in superoxide dismutase 1
- Begins in bulbar or limb muscles, spreads to contiguous, and eventual respiratory muscles
- Frontotemporal dementia (FTD) occurs in approximately 15% of cases, but up to 50% are impaired
  - Involves mitochondrial dysfunction, oxidative stress, excitotoxity, inflammation and apoptosis.
  - Diagnosis via clinical history, EMG, MRI, biopsy

The good and the ugly

- Tim got excellent palliative care and hospice management. Pain and respiratory distress well managed until end.
- Physical therapy intervention improved comfort, posture, ROM, as well as emotional support.
- Palliative sedation would have likely managed respiratory distress and promoted peaceful death;
- Patient autonomy is key; Tim wanted this intervention
- Revocation of hospice for ventilator placement could result in hospital expenses not being covered through Medicare Hospice Benefit.

How can we assess our patients palliative care needs?

Tests and measures we can use: TUG, Gait Speed, Six Minute Walk, Sit to Stand, Start stand.
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Assessing the Need for Palliative Care and Referral to Hospice

- Palliative Outcome Scale (POS)
  - Subjective measure of severity:
    - 10 symptoms relative to palliative care from best to worst (0=best, 4=worst) over previous 2 weeks

- Palliative Outcome Scale-Multiple Sclerosis (POS-MS)
  - POS + 17 additional MS specific symptoms relative to palliative care from best to worst (0=best; 4=worst) over previous 2 weeks

- Palliative Outcome Scale- Parkinson’s Disease (POS-PD)
  - POS + 20 additional PD related symptoms relative to palliative care from best to worst (0=best; 4=worst) over previous 2 weeks
  - The POS-MS and POS-PD are identical except for the addition of “falls, dribbling of saliva, and hallucinations” as PD symptoms

Indications for Hospice: Dementia

- Complete dependence in ADL’s
- Incontinent bladder and bowel
- Inability to ambulate, dress or bathe without assistance
- Ability to speak is limited to 6 or fewer intelligible words
- Aspiration pneumonia
- Pyelonephritis or septicemia
- Pressure Ulcer
- Recurrent fever despite antibiotics
- 10% weight loss in six month or serum albumin <2.5 gm/dl

Primary Triggers for Palliative Care

- You would not be surprised if the patient died within 12 months
- Lack of goals of care clarity and documentation
- Frequent hospital admissions
- Difficulty controlling physical or psychological symptoms
- Complex care requirements
- Decline in function, feeding intolerance or unintended weight loss
- No history of advance care planning discussion or documentation
- Admission to hospital from long-term facility or medical foster home
- Cognitively impaired, elderly patient with acute trip threat
- Metastatic or locally advanced incurable cancer
- Chronic home oxygen use
- Out-of-hospital cardiac arrest
- Limited social support such as family stress or chronic mental illness
Indications for Hospice: PD, MS, ALS

- Critically impaired breathing or swallowing
- Rapidly progressive decline predicts high risk of death
- Life threatening complications often seen prior to death:
  - Recurrent aspiration pneumonia
  - Pyelonephritis or other sepsis
  - Weight loss or dehydration
  - Stage 3 pressure ulcers

Implications for Physical Therapy

- PT should be a resource for accessing and collaborating within palliative care programs. We should advocate to see patients earlier in disease process, and for longer periods.
- Neuromotor problems lead to contractures, weakness and difficulty executing skilled movement; restorative efforts will need to be increasingly replaced by compensatory and comfort based ones.
- Patient and family need information to assist in planning for increasing limitations in function; need for increasing equipment, assistance in securing needed devices.
- PTs should help patient to identify goals related to optimal wellness (exercise, stress management, sound nutrition, social support, energy conservation, sleep).

Final Considerations

- Our role in “transforming society” .... “to improve the human experience” should include compassionate end of life care.
- As 80 million baby boomers enter their elderly years, we must work to integrate our professional vision into the emerging arena of palliative care by utilizing our skills and knowledge to improve:
  - Quality
  - Collaboration
  - Value
  - Access/equity
  - Advocacy
  - Consumer-Centricity
  - Innovation

Role of End of Life Care

- PT Palliative Care
  - Don’t give up on your patient’s ability to improve their QOL
  - Willard

- PT Hospice Care
  - Can Improve quality of life
  - Tom

Selected References


