Novel Models for the Care of Older Adults Affected by Neurodegenerative Illnesses

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DISCLOSURES

• I have received support for this work from:
  — The University of Colorado Hospital Clinical Effectiveness and Patient Safety Grants Program
  — The Veterans Affairs Medical Center Clinical Research to Improve Care Coordination Grants Program
  — National Institute on Aging (K07AG030337-01A2)
  — Patient Centered Outcomes Research Institute (IHS-1408-20134)
  — National Institute on Nursing Research (R01NS102236)
Outline

• Review common neurodegenerative illnesses affecting older adults
• What are the needs of patients and families affected by these illnesses
• What are the gaps facing these persons under current models of care
• How might novel models of care be applied to better meet these needs

The Shark in the Silver Tsunami
The Burden of Neurodegenerative Illness

- US elderly population is expected to increase from 6 million to 9 million by 2030 to 19 million by 2050
- The two most common neurodegenerative illnesses affect 11% and 1% of persons over age 65 with prevalence rising with age
- These are the only leading causes of death which are on the rise with at least 1 in 3 elderly adults expected to die with or of one of these illnesses


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### The Economic Costs

- Over $100 billion currently in direct healthcare costs and lost opportunities
- Significant impact on caregivers and families
- Leading causes of nursing home placements

### Common Neurodegenerative Illnesses

- **Dementia**
  - Alzheimer’s disease
  - Other Dementias
- **Parkinsonism**
  - Parkinson’s disease
  - Secondary parkinsonism
  - Parkinson Plus Disorders
- **Motor Neuron Disease**
Dementia

- Defined by cognitive dysfunction in multiple domains of sufficient severity to impede self-care
- May by primary (neurodegenerative) or secondary (medications, metabolic, infectious, structural)
- Most common class of neurodegenerative illness, cause of death and cause of nursing home placement

Neurodegenerative Dementias

- Alzheimer’s Disease
- Frontotemporal Dementia
- Dementia with Lewy Bodies
- Vascular Dementia
Parkinsonism

- Defined by rigidity, bradykinesia, tremor and postural instability
- May be primary (neurodegenerative) or secondary (medications, vascular)
- Affect 1-2% of adults over age 65
- Nonmotor symptoms include dementia, pain, sleep, fatigue, anxiety, depression and autonomic dysfunction

Neurodegenerative Parkinsonism

- Parkinson’s disease
- Dementia with Lewy Bodies
- Multiple System Atrophy
- Progressive Supranuclear Palsy
- Corticobasal Degeneration
Motor Neuron Disease

- Defined by combination or lower motor neuron (weakness, atrophy) and upper motor neuron (spasticity) dysfunction
- Affects 1 in 300-450
- Amyotrophic Lateral Sclerosis (ALS) or Lou Gherig’s Disease
- Other variants include upper motor only (progressive lateral sclerosis) and lower motor only (spinal muscular atrophy)

Needs

“This prescription doesn’t cure anything, but it has fewer side effects than other drugs.”
General Needs

• Diagnosis and Prognosis
• Safety
• Planning for the future
• Caregiver Support
• Psychosocial Support
• Spiritual Wellbeing
• Medical and Psychiatric Symptoms
• End-of-life Care

Medical Symptoms

• Sleep disorders and Fatigue
• Dysphagia and sialorrhea
• Weight loss and nutrition
• Constipation and bladder dysfunction
• Pain
• Skin breakdown
Management of Comorbid Illness

- Osteoarthritis
- Cardiovascular Disease
- Diabetes
- Comorbid illness may interact with primary neurologic illness (e.g. increase cognitive decline, falls) and complicate management

Psychiatric Symptoms

- Depression
- Anxiety
- Hallucinations and Delusions
- Pathologic Laughter and Crying
- Apathy
- Grief
- Demoralization
Prozac is not always the answer.

“Could we up the dosage? I still have feelings.”

Psychosocial Issues

- Challenges to Identity
- Effects on relationships
- Cosmetic issues and social stigma
- Financial
- Worries about the future
- Fear of dementia
Disease Specific Issues

- Dementia behavioral symptoms (e.g. agitation, sundowning)
- Motor symptom management in PD
  - Dopaminergic Medications
  - Deep Brain Stimulation
- Consideration of ventilatory and feeding support for ALS

Colorado VA Study on PD & Palliative Care Needs

- Symptom burden, grief and QOL are similar across spectrum of PD with advanced cancer patients
- Distribution of symptoms are different between PD and Cancer
- Palliative issues (e.g. grief, symptom burden, medications) contribute to QOL even when controlling for disease severity and depression
Qualitative Study of PD Patients

• High needs at time of diagnosis
• Significant impact on roles and identity
• Cosmetic effects (a flamboyant illness)
• Worries about the future (e.g. dementia, being a burden)
• Financial Concerns

Mixed Methods Study on QOL

• PDQ-39 is most commonly used QOL measure in PD
• Subscales generally match qualitative comments
• Overall QOL does not
  – Does not weight items similar to patients
  – Missing issues (e.g. finances)
  – No points added for coping strategies
Qualitative Interviews with PD Caregivers

- Need for individual attention and support
- Desire for education and more preparation for their role
- Effects of symptoms, particularly cognitive decline
- Worries about the future

Gaps in Our Current Model
Current “Model” of Care

- Significant heterogeneity with some variability explained by geography, race and socioeconomic factors
- Variable involvement of neurologist
- Variable involvement of Geriatrics
- Low recognition or use of quality metrics
- Chronic Care model

Gaps in Care

- Over 40% of PD patients do not see a neurologist
  - Patients not seeing neurologist 14% more likely to fracture a hip, 21% more likely nursing home placement & 22% more likely to die within 6 years of diagnosis
- High rates of in hospital death
- Undertreatment of nonmotor symptoms
- Poor caregiver, psychosocial and spiritual support
Current Chronic Care Model for Parkinson’s Disease

Patient

Caregiver

Neurologist
+ Motor Symptoms
+ PD Medications
+/- Nonmotor Symptoms

Primary Care Provider
+ Comorbid Illness
+ Non-PD Medications
+/- Nutrition

Other Resources (Support Groups, Church, Family, Lawyers…) +/- Caregiver Support, Advance Directives, Spiritual Needs…

TYPICAL OUTCOMES: GOOD: Motor Symptom Control; FAIR: Nonmotor Symptom Treatment POOR: Advance Care Planning, Caregiver Support, Psychosocial & Spiritual Needs

How are neurologists doing?

CLOSE ENOUGH.
Use of Advance Directives

- Hospice deaths range from less than 1% for PD to 12% for MND
- Advance directives are rarely documented even in chronic dementia with rates generally below 20%
- Place of death is often incongruent with patient wishes which are overwhelming to die at home (>85% in most surveys)

UCH Inpatient Palliative Care Consults for Neurology Patients

- Chart Review of 164 patients with neurologic diagnoses receiving inpatient palliative care consults
- > 70% were unable to communicate at time of consult
- <20 % had advance directives in place at time of consultation
- < 50% of diagnoses were acute (e.g. stroke)
PD Patient Impressions of Physicians

- Did not recognize potential impact of the words: “You have Parkinson’s”
- Would not be interested in discussing advance care plans
- All problems are reduced to a prescription
- “Healthcare Team” is not really a team

Novel Models of Care
Novel Models of Care

- Palliative Care
- Telemedicine
- Neurodegenerative Medical Home
- Patient Navigators
- Group Clinics
- Caregiver Clinics

Palliative Care Model for Parkinson’s Disease

OUTPATIENT INTERDISCIPLINARY PALLIATIVE CARE TEAM
Physician (Nonmotor symptom, prognosis); Nurse (Nutrition, Home care, Advance Directives); Social Work (Caregiver Support, Finances); Chaplain (Spiritual Wellbeing, Grief Counseling)

IMPROVED OUTCOMES: Aim 1- Patient QOL, Caregiver Distress, Symptom Burden, Grief; Aim 2- Patient Costs, Adv. Care Plans; Aim 3- Optimize Patient Selection, Service & Delivery
Chronic Care vs Palliative Care

- Palliative
  - Relieve suffering
  - Plan for death and decline
  - Focus on patient and family
  - Focus on physical, psychosocial and spiritual issues
  - Team approach

- Chronic Care
  - Preserve function
  - Prolong Life
  - Focus on patient
  - Focus on medical and psychiatric symptoms
  - Variable use of team approach

What is palliative care?
Palliative Care is NOT

• Palliative care includes but is not the same as hospice
• Euthanasia or Death Squads
• Giving up on patients
• Only for the imminently dying
• Only for patients with cancer
• Only for palliative care specialists

Palliative Care Defined

• Primary goal is the prevention and relief of suffering for patients and their families
• Includes control of pain and other hard to control physical symptoms
• Also addresses psychological, social, and spiritual issues
• Palliative care affirms and supports life while addressing death as a normal and expected process
Definition Continued

- Can be used alone or to augment curative treatments
- May be appropriate at any point of an illness, including diagnosis
- Is an approach to care that often benefits from a team
- May be delivered in inpatient, outpatient, community, home and hospice settings
Types of Palliative Care

- Primary: Basic skills and competencies required of all clinicians
- Secondary: specialist clinicians and teams including inpatient palliative care, outpatient/home palliative care and hospice
- Tertiary: most complex and subspecialty cases, research and education

The 3-Legged Stool

- Community Organizations
  - Education, support groups
- Primary Care Providers and Neurologists
  - Symptoms management, primary palliative care, appropriate referrals
- Specialized Palliative Care Teams
  - Complex symptom management and goals of care, hospice and home palliative care services
PALLIATIVE CARE INTEGRATIVE MODEL

Primary Palliative Care Skills for Neurologists and Geriatricians

- Communication at time of Diagnosis
- Symptom Assessment
- Symptom Management
- Advance Care Planning
- Caregiver Assessment
- Appropriate Referral for Secondary and Tertiary Service


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Types of Secondary & Tertiary Palliative Care

- Inpatient palliative care
- Outpatient palliative care
- Home palliative care
- Home hospice
- Inpatient hospice

UCH Palliative Clinic for Neurology

- Began March 2013
- First visit typically lasts 2-3 hours
- Care and team approach will depend on issues
- Recommend family and caregivers are present
- Can be consulted for single issue, co-management or transfer of care
UCH Outpatient Neurology
Palliative Care Team

• Neurologist
• Nurse
• Nurse Practitioner
• Social Worker
• Psychologist
• Chaplain
• Acupuncturist

What does our clinic actually do?

• Help families with transitions (e.g. hospice, nursing home)
• Provide resources for home health and community services
• Assess capacity in the context of power of attorney disputes
• Assist patients and families in planning for the future and goals of care
• Assist with feeding tube decisions
Appropriate Referrals

• Assistance with End of Life Care
• Discussion of Feeding Tubes
• Planning for the future
• Counseling for spiritual, social and psychological concerns
• Caregiver support or absence of caregiver
• Need for greater assistance at home
• Difficult to control physical symptoms
• Communication issues within family

Other Interdisciplinary Clinics

• Team-based care is the standard of care for ALS
• In PD, we have an annual interdisciplinary team-based clinic and DBS team
• Few trials of interdisciplinary models for dementia have had small but positive effects on caregiver burden and patient symptoms
Telemedicine

• Office-to-office clinic visits
• Virtual house calls
• Nursing Home Care
• Group visits
• Mobile Office
• Training and consultation

Group Visits

• Group visits for PD care have been shown to be equivalent to one-on-one care
• Currently utilizing group model for a newly diagnosed PD clinic
• May be useful for caregivers
Neurodegenerative Medical Home

- Concept of a patient-centered team to provide holistic and integrated care with a focus on quality and safety
- Neurologists and/or geriatrics could serve as a medical home neighbor
  - Visiting neurologist for low neuro-needs
  - Visiting geriatrician for high comorbid illness burden

Patient Navigators

- ABC Medhome (dementia) utilized RN as care coordinator overseeing 5 high school graduate care coordinator assistants
- UCSF has medicare demonstration project underway using patient navigators, each with a case load of 30-60 patient/caregiver dyads
Caregiver Clinics

• Dyadic Interventions
• Caregiver Support
• Integrating Caregiver Care into Medical Home
  – Save trips
  – Increased risk for several health outcomes
  – Reduce stress
  – Increase focus on self-care

Paying for Novel Models of Care

• Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) is coming
• Merit-Based Incentive Payment System (MIPS)
  – Payment based on value
  – High patient/caregiver satisfaction ratings
  – Advance directives, depression screens are part of AAN quality Metrics for PD and ALS
• Alternative Payment Models (APMs)
  – Shared cost savings
  – > 70% of our patients die in hospice or at home
Future Directions

Research and Education

- Defining Needs
- Outcome Measures
- Interventional Trials
- Implementation and Dissemination
- Education for palliative care, geriatrics, neurologists
PCORI Health Systems Grant

- 3 center randomized controlled trial of outpatient palliative care vs usual care for PD
- Primary outcomes patient QOL and caregiver distress
- Secondary outcome of patterns of healthcare utilization (e.g. home health services vs. ER and hospitalizations)
- 25% Enrollment completed

R01 Community Based Palliative Care for PD

- NINR-R01 funded multisite pragmatic trial
- Use of focused palliative care training for community neurologists
- Telemedicine for team-based resources (e.g. social work) and coaching
Acknowledgments

• Jean Kutner
• David Bekelman
• Janis Miyasaki
• Julie Carter
• Jacquelyn Jones
• Steve Ringel
• Jeannie Youngwerth
• Laura Palmer
• Holly Prigerson
• Maya Katz
• Nick Galifianakis
• Wendy Cernik
• MK Christian
• Cynthia McRae
• Ryan Khan
• Cari Friedman
• Jessica Barr
• Traci Yamashita
• Patients from our palliative care clinic

QUESTIONS?