Comprehensive Care for End-stage Neurodegenerative disease

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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)
  - Parkinson Disease Foundation Conference Grants
  - Patient Centered Outcomes Research Institute (IHS-1408-20134)
  - National Institute on Nursing Research (3R01NR016037)
  - Palliative Care Research Cooperative (Lum PI)

Disclosure II

- UCH has a team-based Neuropalliative Care Clinic and Section
  - Everything I’m talking about comes from experiences in this clinic
  - We are open to new referrals
  - We are open to new collaborations

Objectives

- To be able to identify the needs of people affected by neurodegenerative illness.
- To understand the gaps in meeting these needs under current models of care.
- To implement principles of proactive, person-centered, team-based care to improve outcomes for this population.

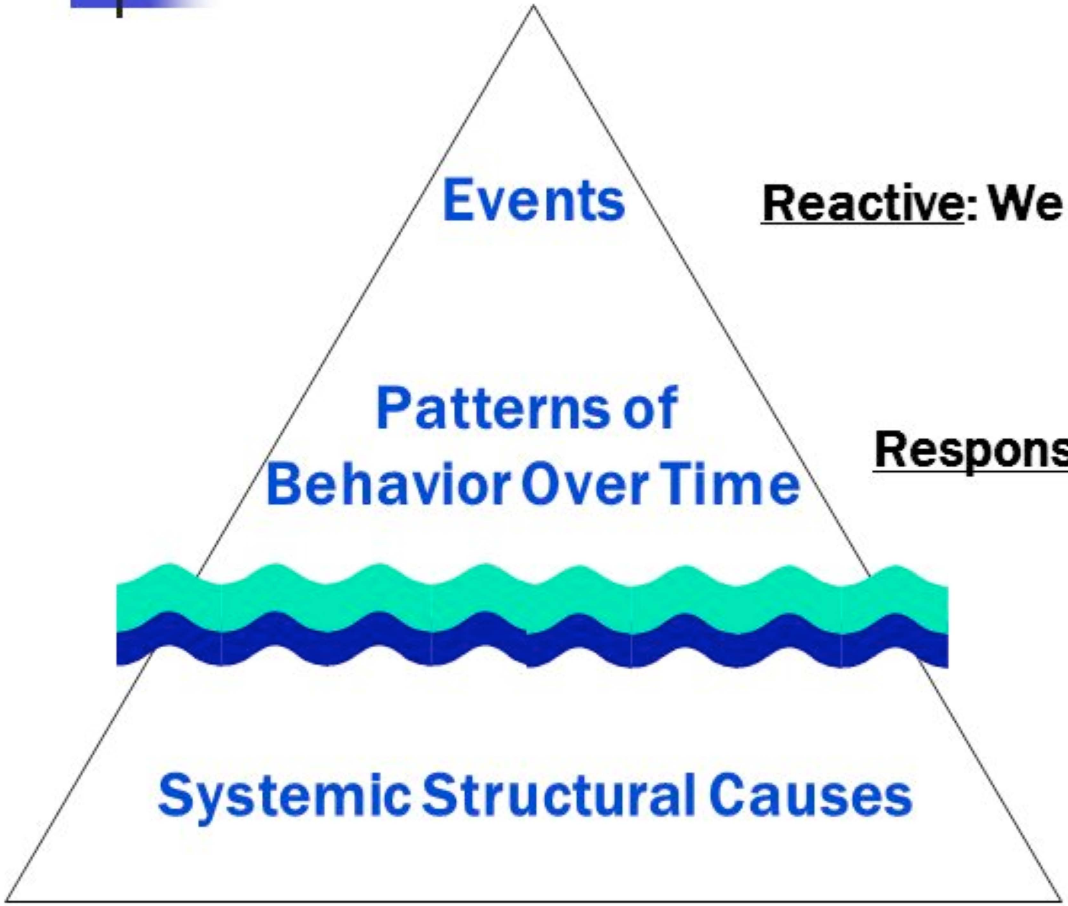
Outline

- Review the needs of patients and caregivers
- Review the evident for gaps in current models of care
- Discuss the potential elements needed for a comprehensive care approach
- Review models and evidence of effectiveness from clinical trials
- How to move from efficacy to implementation

Bottom Lines to Provide Comprehensive Care

- Be Proactive
- Accessible and approachable
- Interdisciplinary
  - Geriatrics, Neurology, Palliative
- Multispecialty
  - Medical, Social Work, Chaplain…
- Coordinated and Integrated System
- Person-Centered
- SUSTAINABLE

Systems Thinking: The Iceberg View



Events

Patterns of Behavior Over Time

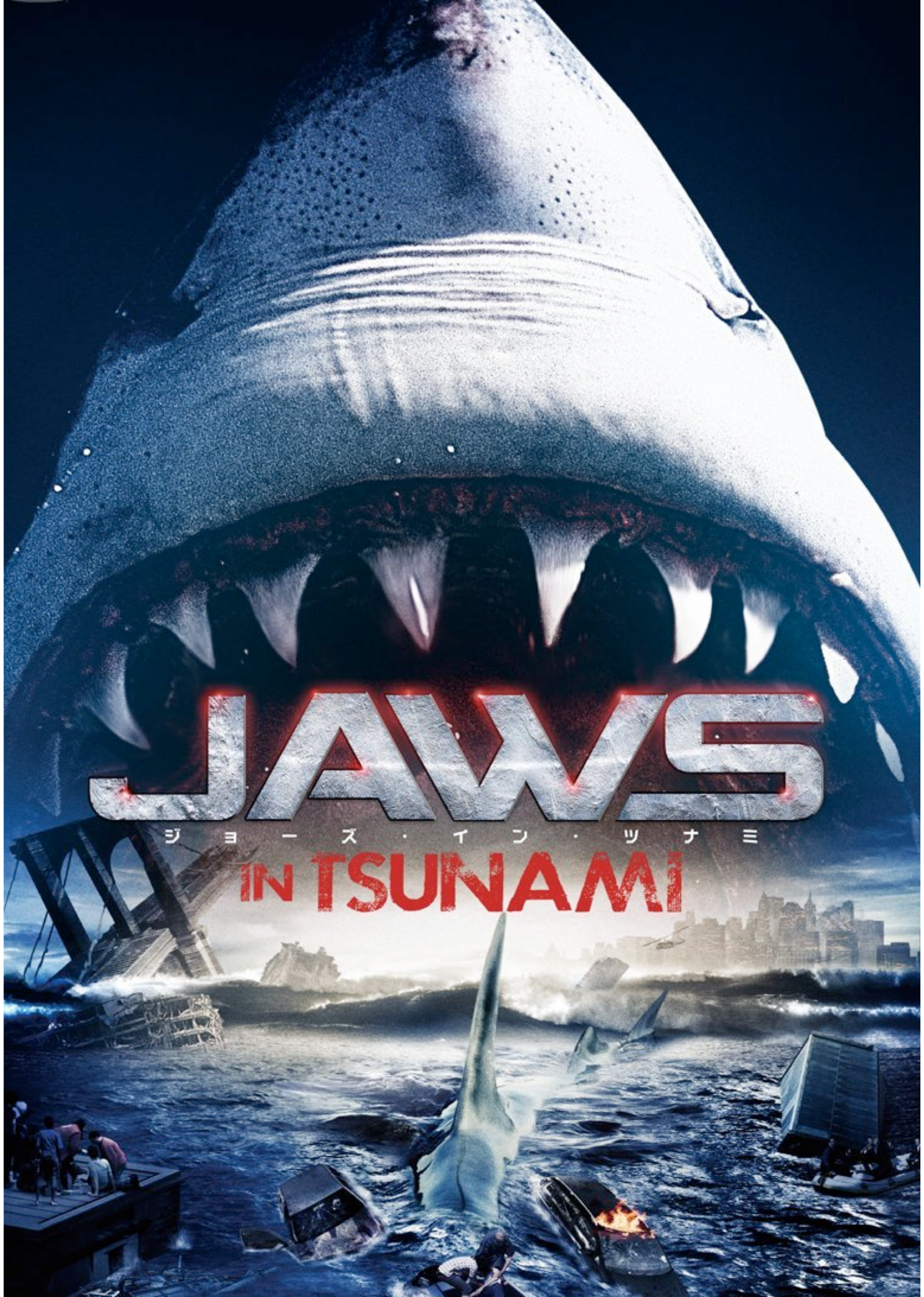
Systemic Structural Causes

Reactive: We react to each event as it happens

Responsive: We try to respond to patterns

Generative: We take the time to understand how the dynamic interaction of variables generates behavior

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

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

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

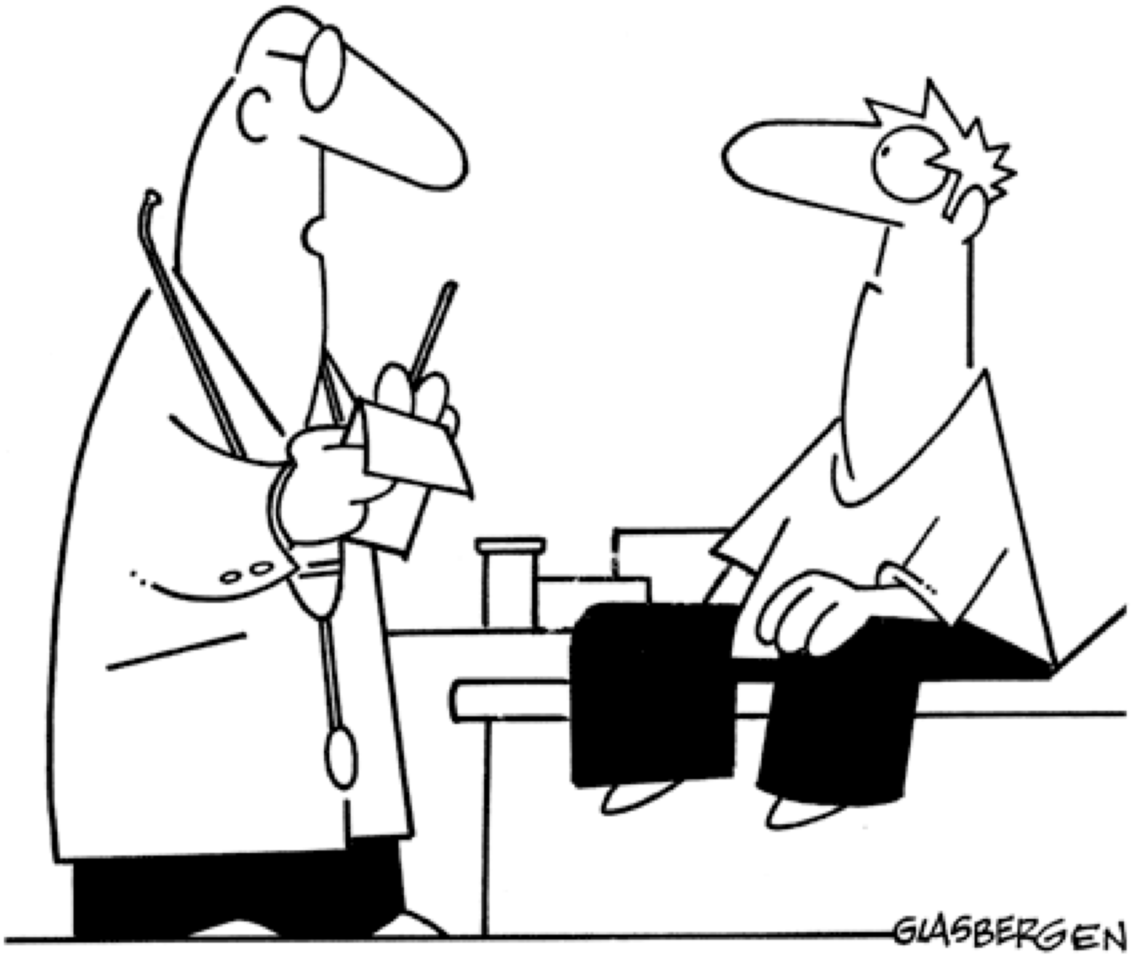
Neurodegenerative Parkinsonism

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

PD: The Quintessential Neurodegenerative Illness

- Motor Symptoms
- Dementia
- Psychiatric symptoms
- Nonmotor Symptoms
  - Pain, fatigue, sleep, autonomic
- High caregiver burden
- Heterogeneity in phenotype
- Variability in progression

Needs and Gaps



"This prescription doesn't cure anything, but it has fewer side effects than other drugs."

Gaps and Needs

"What if we don't change at all ...
and something magical just happens?"

General Needs

- Planning for the future
- Coordinating Care
- Caregiver Support
- Psychosocial Support
- Spiritual Wellbeing
- Medical and Psychiatric Symptoms
- End-of-life Care

Proactive: To meet End Stage Needs Well, Start at the time of Diagnosis

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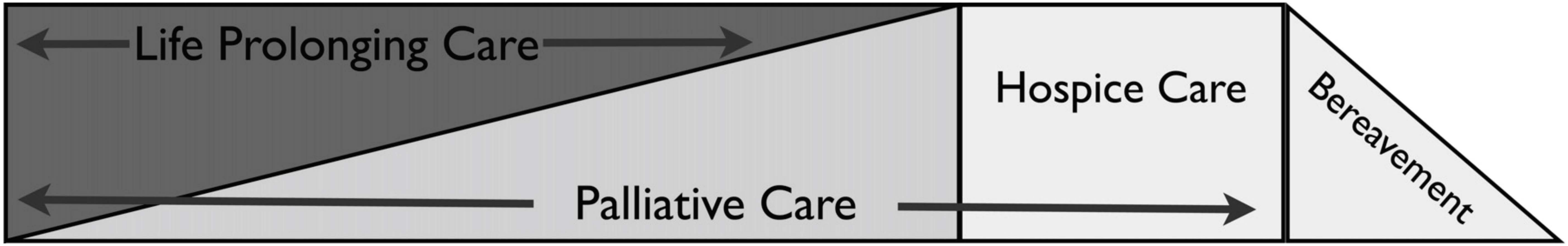
Originally published on 1992-05-21.

Need for a Road Map

PALLIATIVE CARE INTEGRATIVE MODEL

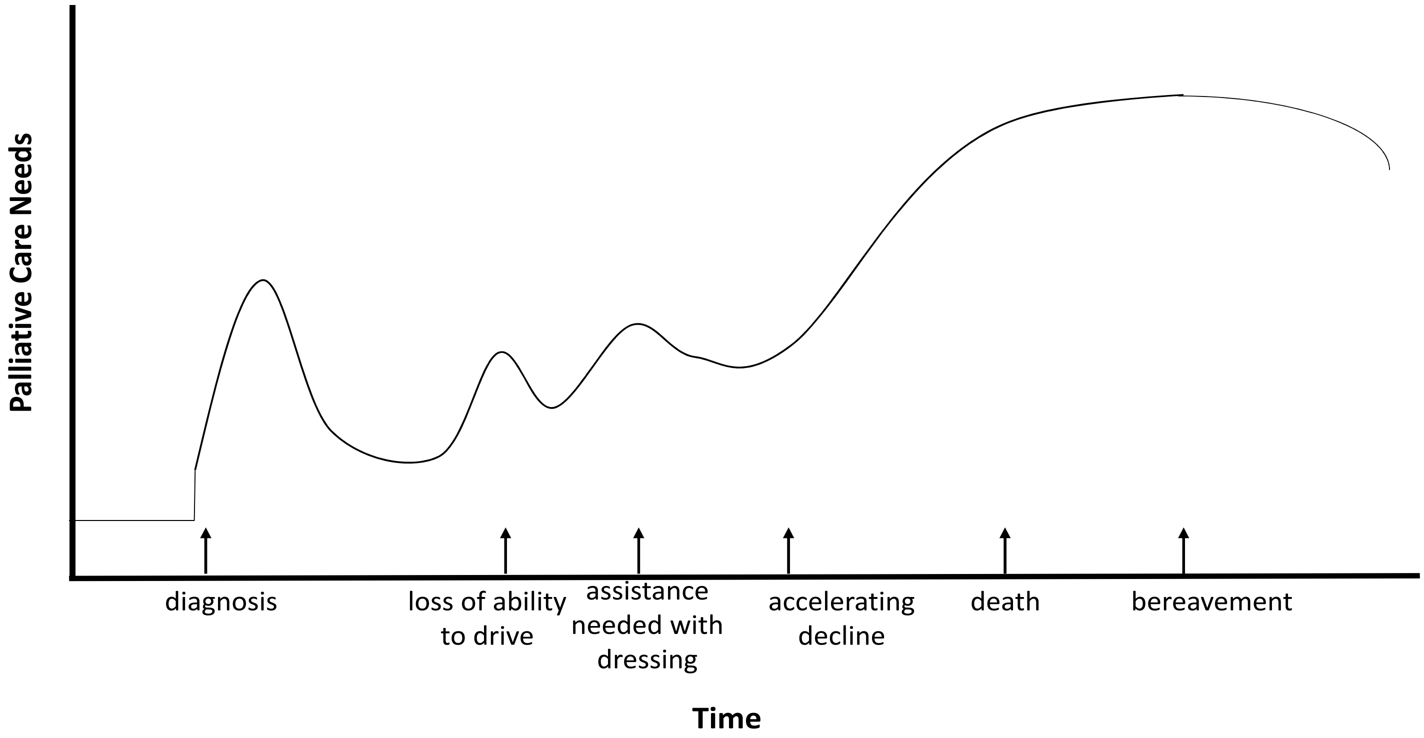


Adler E D et al. Circulation 2009;120:2597-2606

American Heart Association
Learn and Live

Integration of Palliative Care:

Figure 1: Continuum of Palliative Care



No "right time" for starting palliative care

THE TIME DOCTOR

Why Waiting for The Right Time Can Be a Mistake?

How are neurologists doing?

Advance Care Planning

- In one study 55% of PD patients die in a hospital and less than 10% at home
- Hospice deaths range from less than 1-5% for community to 50% in nursing home study
- Significant variability in use and quality of advance directives
- Place of death is often incongruent with patient wishes which are overwhelming to die at home (>85% in most surveys)

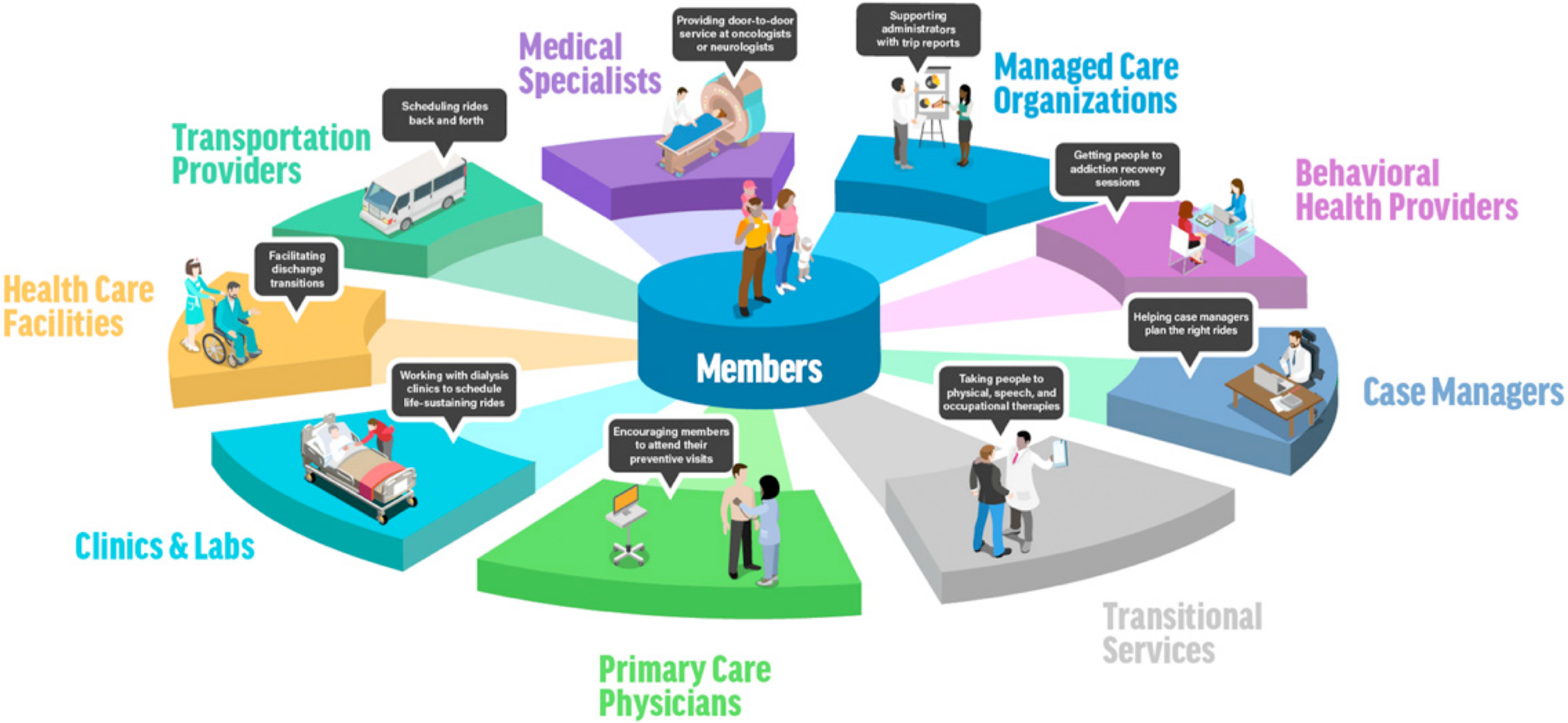
UCH Inpatient Palliative Care Consults for Neurology Patients

- Chart Review of 211 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)

Qualitative Data

- Patients did not think their providers were interested in ACP
- Frequently did ACP with family and lawyer if at all
- Significant worries about the future including finances, being a burden
- Many misperceptions including the “mortality myth”

Difficulties Coordinating Care



Members

Medical Specialists

Providing door-to-door service at oncologists or neurologists

Managed Care Organizations

Supporting administrators with trip reports

Behavioral Health Providers

Getting people to addiction recovery sessions

Case Managers

Helping case managers plan the right rides

Transitional Services

Taking people to physical, speech, and occupational therapies

Primary Care Physicians

Encouraging members to attend their preventive visits

Clinics & Labs

Working with dialysis clinics to schedule life-sustaining rides

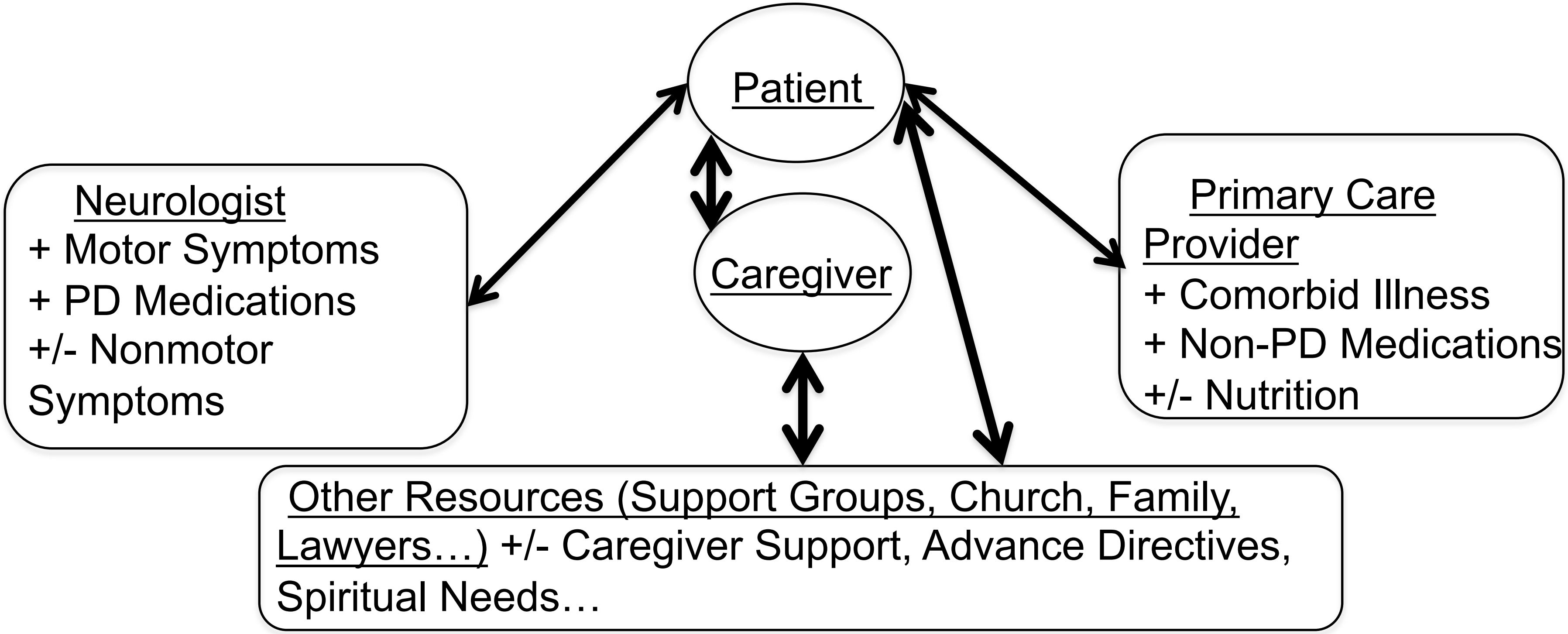
Health Care Facilities

Facilitating discharge transitions

Transportation Providers

Scheduling rides back and forth

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

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

Patient and Caregiver Perceptions

- Did not know what we meant by healthcare “team”
- Caregiver is the captain
- Very resourceful families can do OK
- Caregivers bear the brunt of the burden to coordinate care, often neglecting their own care in the process
- Difficulties reaching healthcare providers and knowing who to call

Other Gaps in Care

- Medical issues may be missed
  - Osteoporosis significantly under-recognized and treated despite high fracture risk
- People are not seen
  - E.g. problems reduced to a prescription
- 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

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

Medical Symptoms

- Sleep disorders and Fatigue
- Dysphagia and sialorrhea
- Weight loss and nutrition
- Constipation and bladder dysfunction
- Pain
- Skin breakdown

Psychiatric Symptoms

- Depression
- Anxiety
- Hallucinations and Delusions
- Pathologic Laughter and Crying
- Apathy
- Grief
- Demoralization

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

End of Life Care in PD

- There are NO medicare hospice guidelines specific to PD
- Hospice is under-utilized and referrals are late
- Studies suggest that ineffective care (e.g. feeding tubes) still often recommended
- Need for education of palliative medicine practitioners
  - Remove Haldol from hospice kits
  - Be cautious in discontinuing PD medications

End of Life Care II

- Feeding tubes don’t work
- Medicare guidelines for dementia, failure to thrive and neurologic disease (ALS) may be used
- Other Red Flags include:
  - Recurrent infections, falls, hospitalizations
  - Weight loss with or without dysphagia
  - Dysphagia for liquids with or without weight loss
  - Accelerating loss of function
  - Withdrawal, increase sleep and Loss of will to live

Current “Model” of Care

- Chronic Care model
- 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
- Undertreatment of nonmotor symptoms
- End of life care is reactive rather than proactive

Novel Models of Care

Novel Models of Care

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

Chronic Care *versus* Palliative Care:

Chronic Care	Palliative Care
Focuses on disease-related medical symptoms	Focuses on the *total pain* of serious illness (physical, psychosocial, spiritual, and practical challenges)
Focuses on improving physical health	Focuses on improving overall well-being and reducing suffering
Prolongs life	Affirms & values life, while planning for the inevitable decline of health & end to life.
Focuses on patient	Focuses on patient and family
Variable use of team approach	Interdisciplinary team approach

Chronic Care *versus* Palliative Care:

Chronic Care	Palliative Care
Focuses on enhancing **quantity** of life	Focuses on enhancing **quality** of life

You don't need to choose between:
Quantity of life and Quality of life…

Palliative care is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life.

World Health Organization, 2002

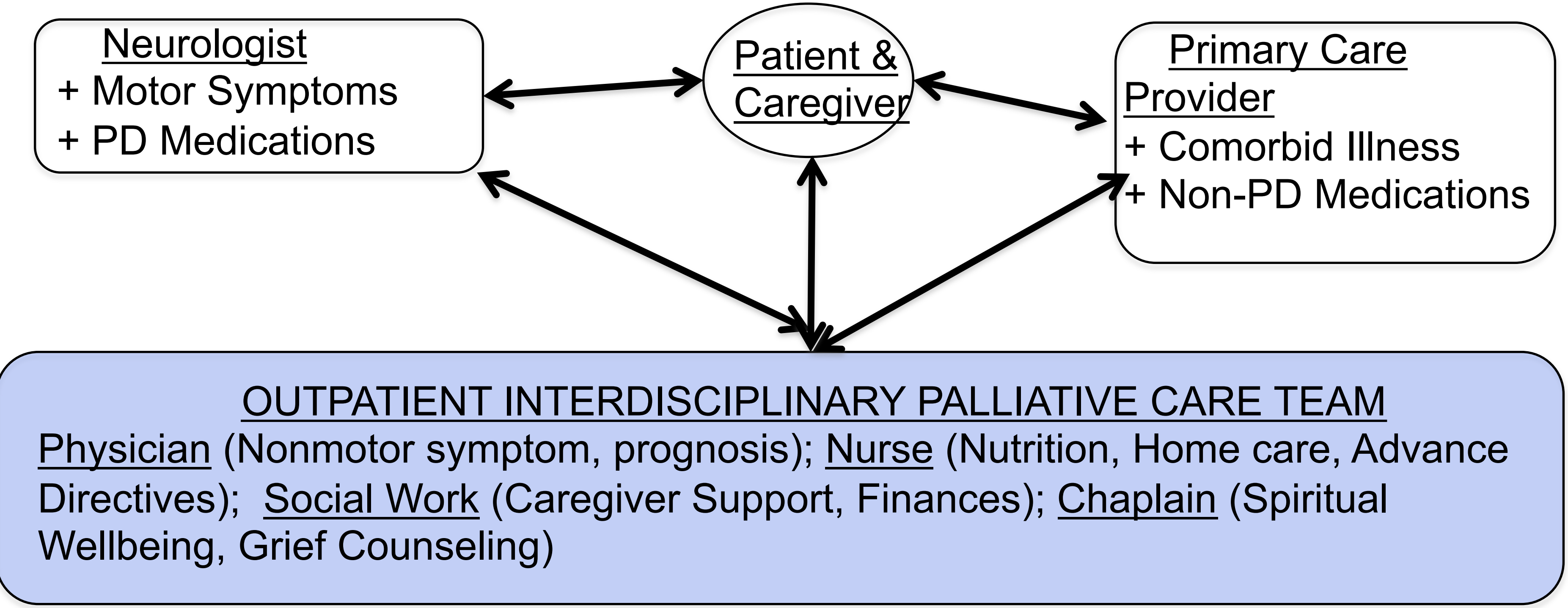
What is the Focus of Care?

- Disease Centered
  - Treatment and cure (survival)
- Patient Centered
  - Coordination and health-related QOL
- Person Centered
  - Values and general QOL (living)

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)
- Data collection completed

Palliative Care Model for Parkinson's Disease



Neurologist
+ Motor Symptoms
+ PD Medications

Patient & Caregiver

Primary Care Provider
+ Comorbid Illness
+ Non-PD Medications

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

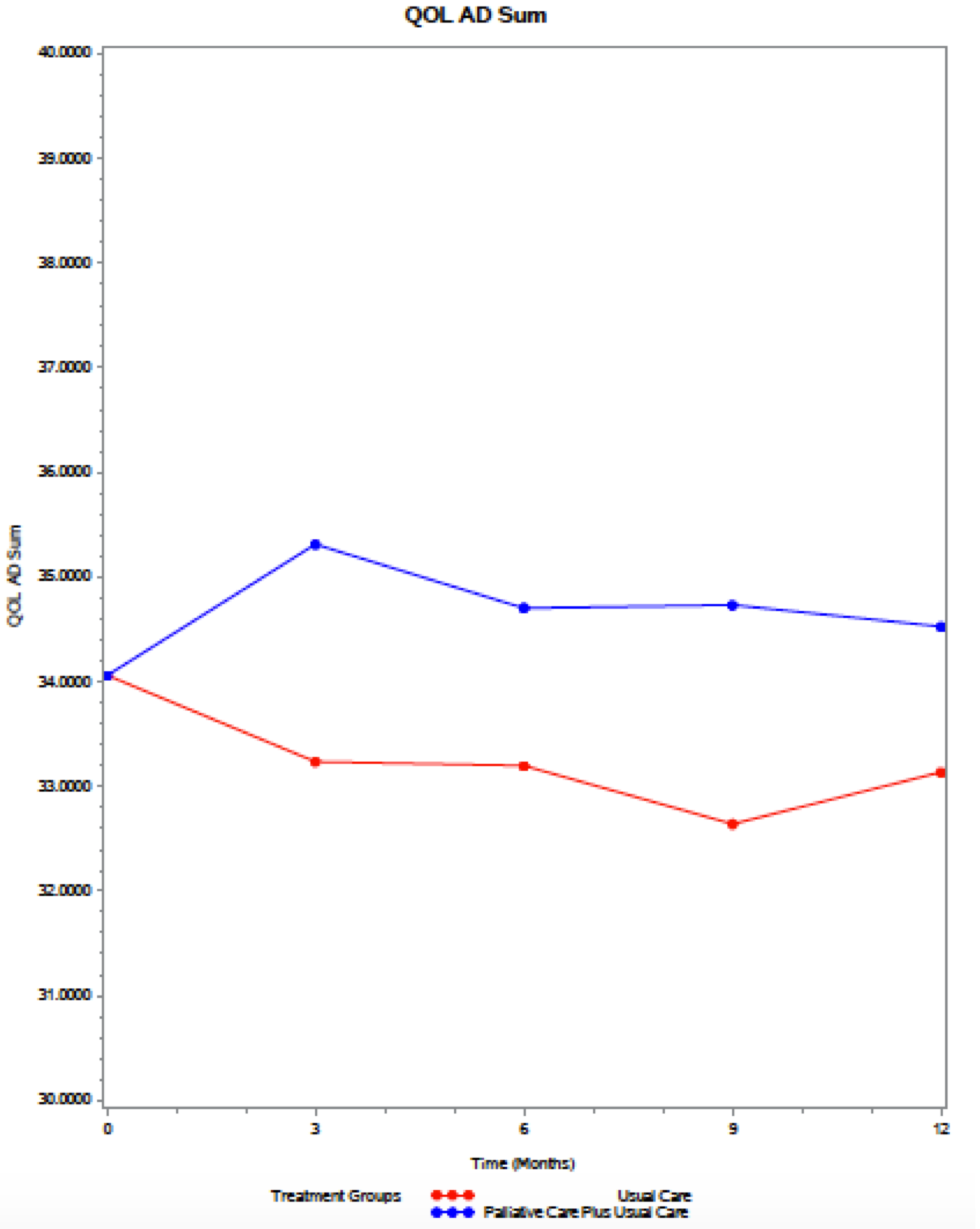
The Intervention

- Neurologist, social worker, chaplain and nurse
- Quarterly visits plus calls
- Use of checklists
  - ACP
  - Symptom management
  - Psychosocial Support
  - Coordination of Care
  - Accessible team

Quantitative Results

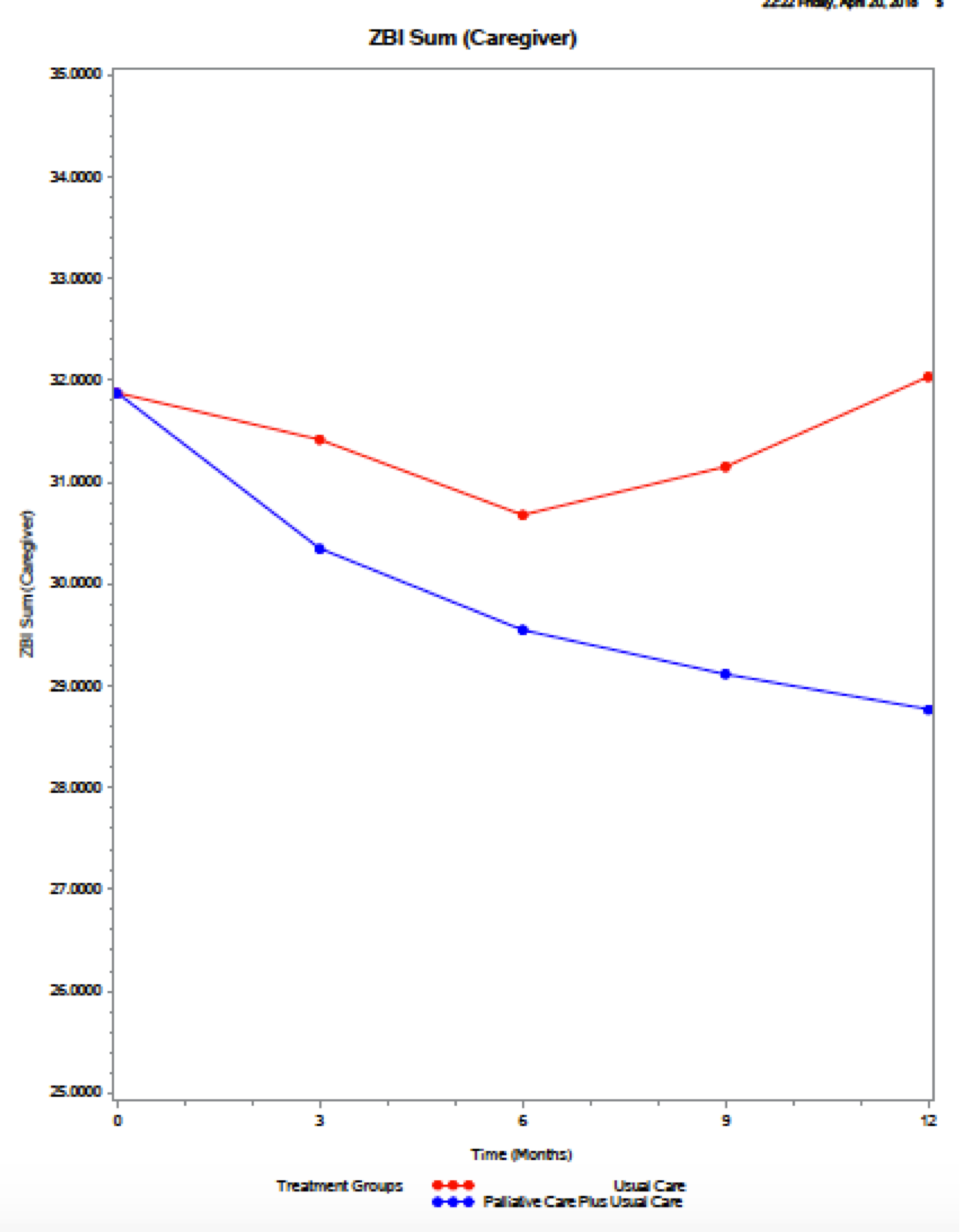
- Improved patient QOL starting at 3 months
- Improved caregiver burden at 12 months
- Improved symptom burden, grief and motor function (small)
- Caregivers do better in Canada

QOL-AD



QOL AD Sum
40.0000
39.0000
38.0000
37.0000
36.0000
35.0000
34.0000
33.0000
32.0000
31.0000
30.0000
QOL AD Sum
0
3
6
9
12
Time (Months)
Treatment Groups
Usual Care
Palliative Care Plus Usual Care

Zarit Burden Inventory



Qualitative Results

- Both patient and caregiver felt supported
- Knew how to access help
- Appreciated team-based approach
- Appreciated open and honest (and sometimes difficult) conversations
- Felt seen and heard as a person

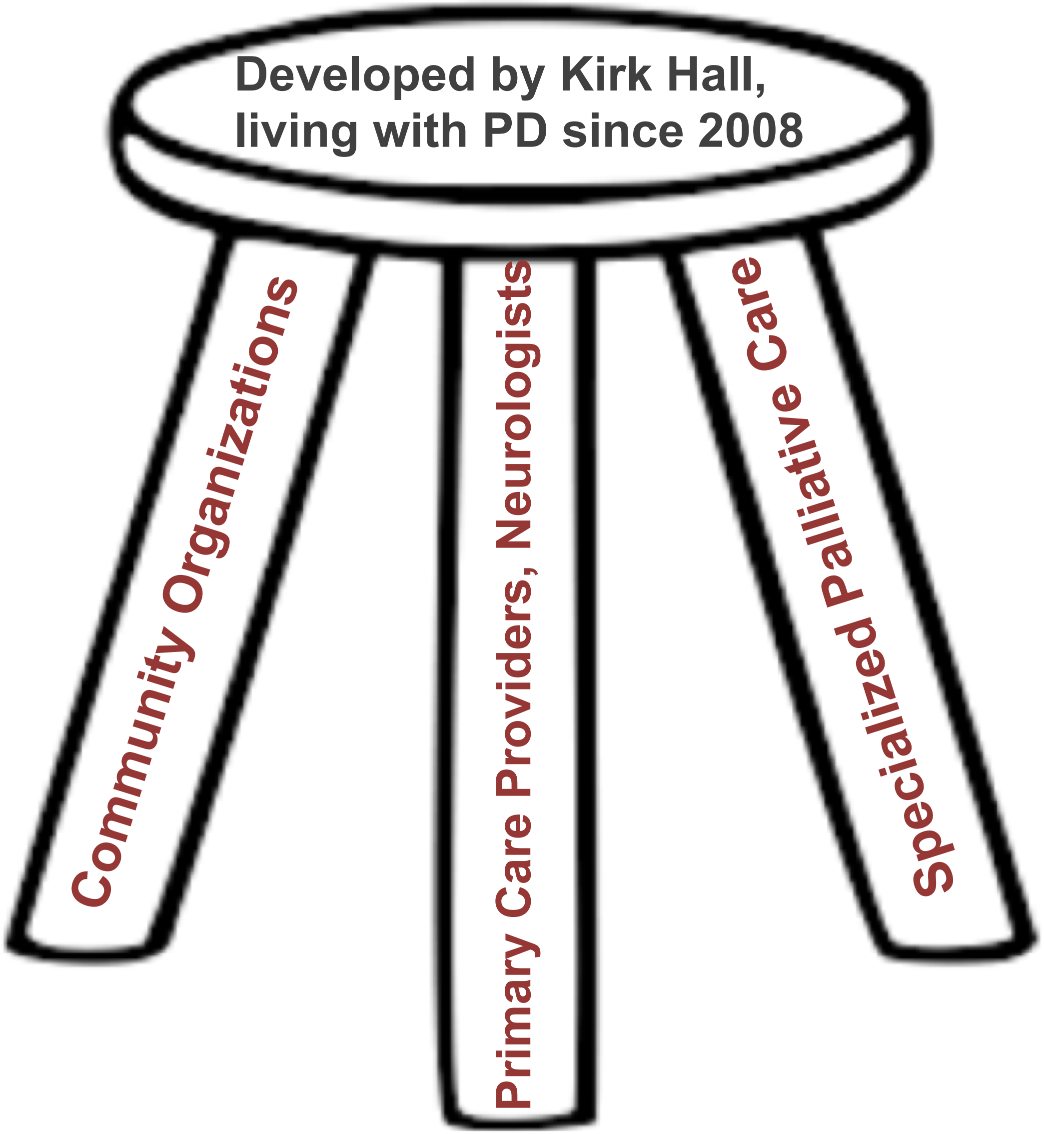
Benefits of Advance Care Planning

Suggestions for Optimization

- Better patient selection and needs assessment
- Patient and caregiver peer navigators
- Improve caregiver assessment and support
- Decrease time and travel

Palliative Care as a System

The 3-Legged Stool Model



Developed by Kirk Hall, living with PD since 2008

Community Organizations

Primary Care Providers, Neurologists

Specialized Palliative Care

Primary Palliative Care Skills:

CENTER
TO
ADVANCE
PALLIATIVE
CARE

"There's no easy way I can tell you this, so I'm sending you to someone who can."

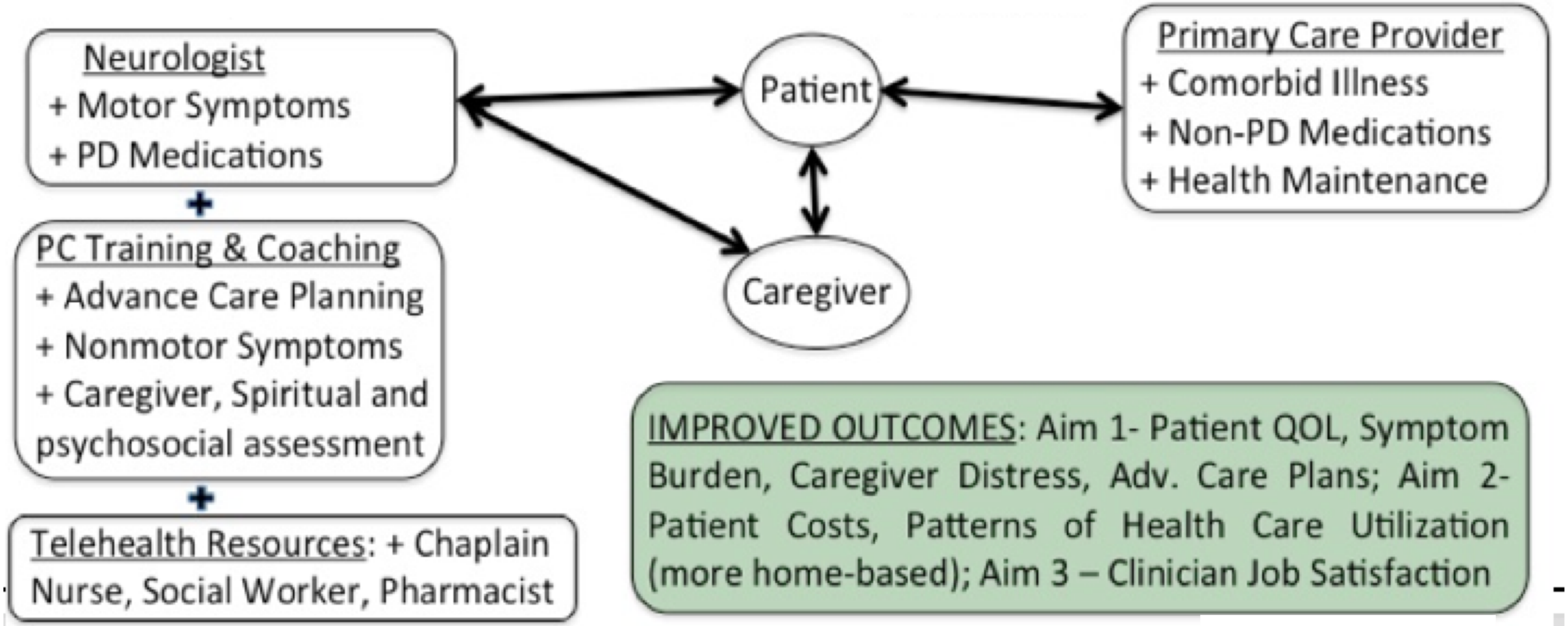
cine

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

Study Overview: Comparison Groups

Usual Care *plus* Community Primary Palliative Neurology *augmented* by a Multidisciplinary Palliative Care Clinic (INTERVENTION)



<u>Neurologist</u>
+ Motor Symptoms
+ PD Medications

\+

<u>PC Training & Coaching</u>
+ Advance Care Planning
+ Nonmotor Symptoms
+ Caregiver, Spiritual and psychosocial assessment

\+

<u>Telehealth Resources</u>: + Chaplain Nurse, Social Worker, Pharmacist

Patient

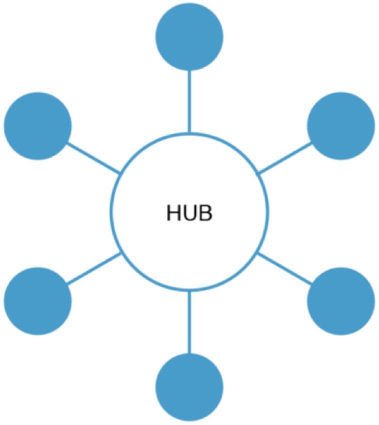
Caregiver

<u>Primary Care Provider</u>
+ Comorbid Illness
+ Non-PD Medications
+ Health Maintenance

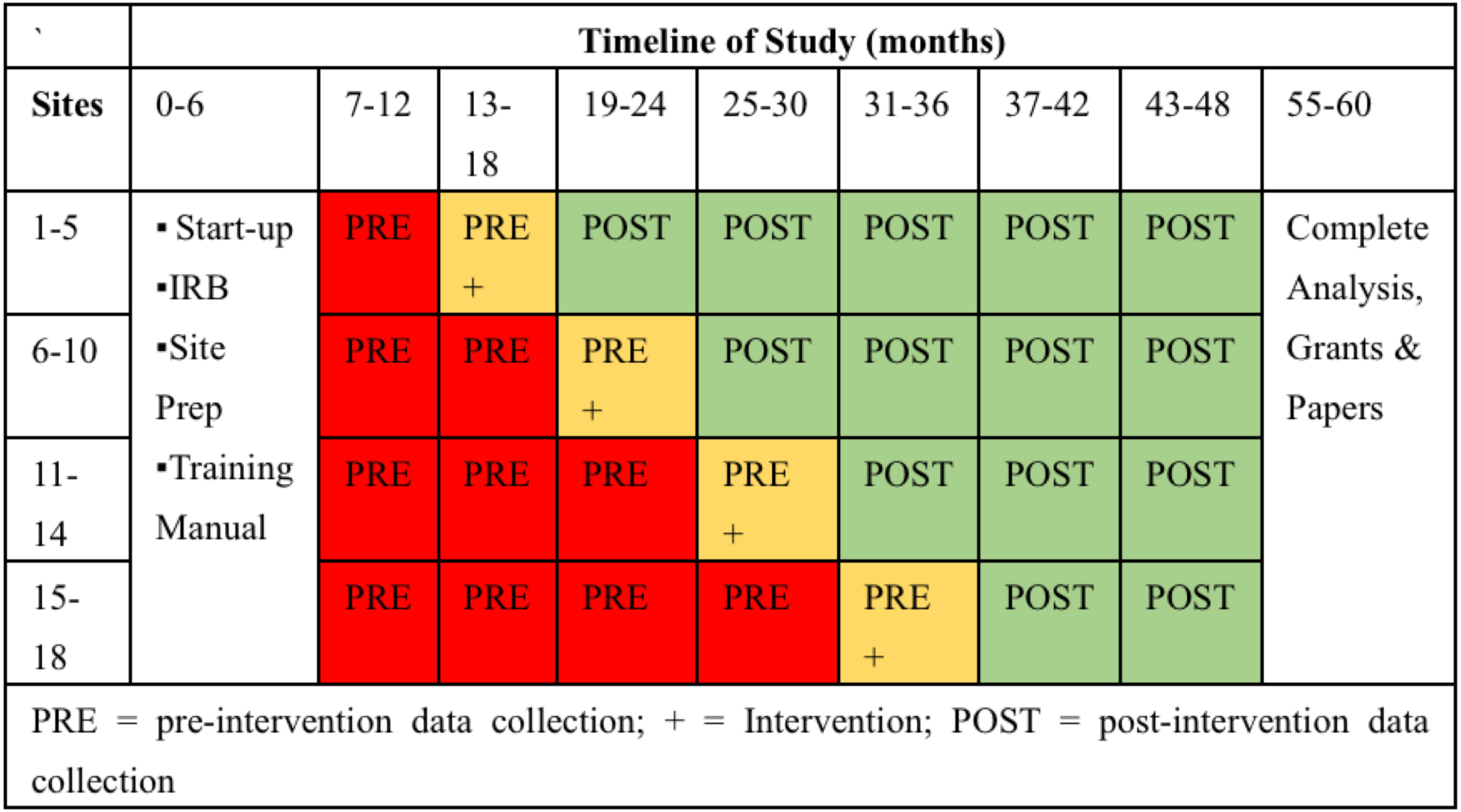
<u>IMPROVED OUTCOMES</u>: Aim 1- Patient QOL, Symptom Burden, Caregiver Distress, Adv. Care Plans; Aim 2- Patient Costs, Patterns of Health Care Utilization (more home-based); Aim 3 – Clinician Job Satisfaction

Study Design:

- Pragmatic stepped-wedge cluster randomized control trial
- Academic Hub and Community Spoke design
- Two universities, 18 community practices, 300+ patients
- Primary outcomes:
  - Patient quality of life
  - Caregiver Burden
  - Cost and service utilization
  - Clinician Satisfaction
  - Qualitative Interviews



Stepped Wedge Design



`	**Timeline of Study (months)**								
Sites	0-6	7-12	13-18	19-24	25-30	31-36	37-42	43-48	55-60
1-5	▪ Start-up ▪IRB ▪Site Prep ▪Training Manual	PRE	PRE +	POST	POST	POST	POST	POST	Complete Analysis, Grants & Papers
6-10		PRE	PRE	PRE +	POST	POST	POST	POST	
11-14		PRE	PRE	PRE	PRE +	POST	POST	POST	
15-18		PRE	PRE	PRE	PRE	PRE +	POST	POST	

PRE = pre-intervention data collection; + = Intervention; POST = post-intervention data collection

Other Models of Care

- Specialist Nurse Practitioners (e.g. UCLA Dementia Care Managers model)
- Multidisciplinary Clinic (e.g. ParkNet in Belgium)
- E-consult support (advanced dementia)

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 demonatration project underway using patient navigators, each with a case load of 30-60 patient/caregiver dyads

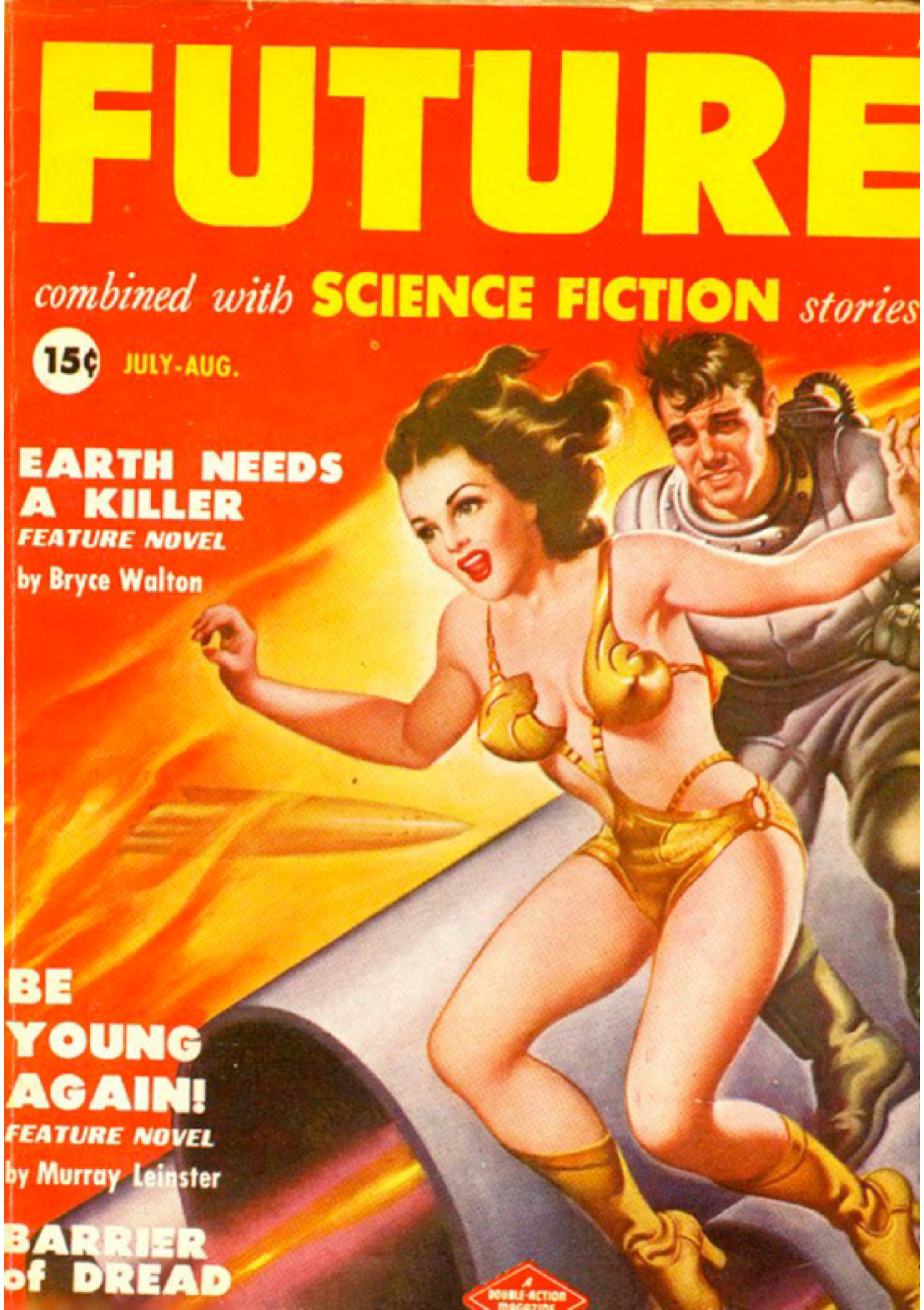
Caregiver Clinics

- 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) may be 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



High Priority Areas

- Education for palliative care, geriatrics, neurologists
- Cost-effectiveness studies
- Collaborative clinics with disease rather than specialty focus
- Implementation and dissemination research

Acknowledgments

- Jean Kutner
- Hillary Lum
- David Bekelman
- Janis Miyasaki
- Julie Carter
- Jacquelyn Jones
- Steve Ringel
- Jeannie Youngwerth
- Laura Palmer
- 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?