



# Engaging Patients with Cognitive Deficit in Care

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**Struthers Parkinson's Center**  
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Methodist Hospital

# Identification of Cognitive Changes

- Routine screening for Mild Cognitive Impairment (MCI) / Parkinson's Disease Dementia (PD-D) at clinical visits
  - Clinic forms
  - Client generated concerns or problems
- Ask who completed the forms
- Look for changes from baseline
  - May or may not be significant functional decline

# Clinic Visit Observation

## Patient may:

- Be with a carepartner instead of alone
- Not be able to converse while walking to exam room
- Exhibit poor motor planning in transition to exam room
- Look to carepartner or family for answers to questions
- Be easily distracted
- Appear disheveled
- Have no insight into cognitive decline
  - Family may try to have a conversation without the patient before the appointment

# Clinic Visit Observation

Carepartner or family may:

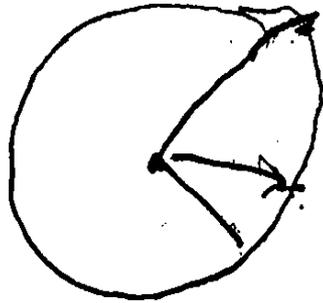
- Look stressed or tired
- Look angry
- Be tearful
- Try to cover for the patient and act as if everything is fine

# Objective Assessments

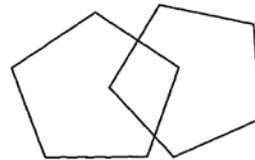
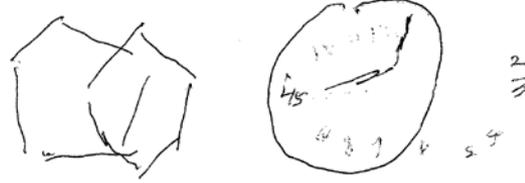
## Quantify Severity and Impact

- Montreal Cognitive Assessment (MOCA)
- 1 page, 30 point test
- Assesses 5 domains:
  - Attention
  - Memory
  - Executive function
  - Language
  - Visuospatial
- Mini Mental Status Exam (MMSE)
- Clock drawing
- PDQ-39 or other quality of life screening
- UPDRS part II - ADL
  - The multi-visit format allows comparison visit to visit, providing an excellent educational tool
- Caregiver strain

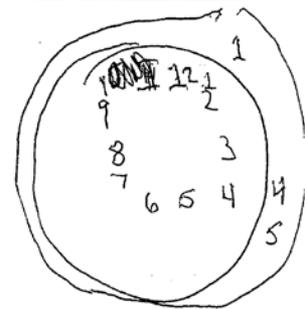
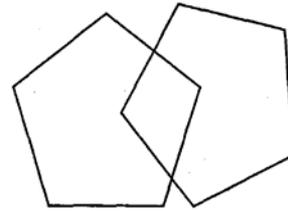
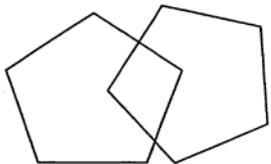
# Clock drawing 1:45



Martin asked me to ~~draw~~ <sup>close</sup> my eyes.



I ~~like~~ I like to eat copy



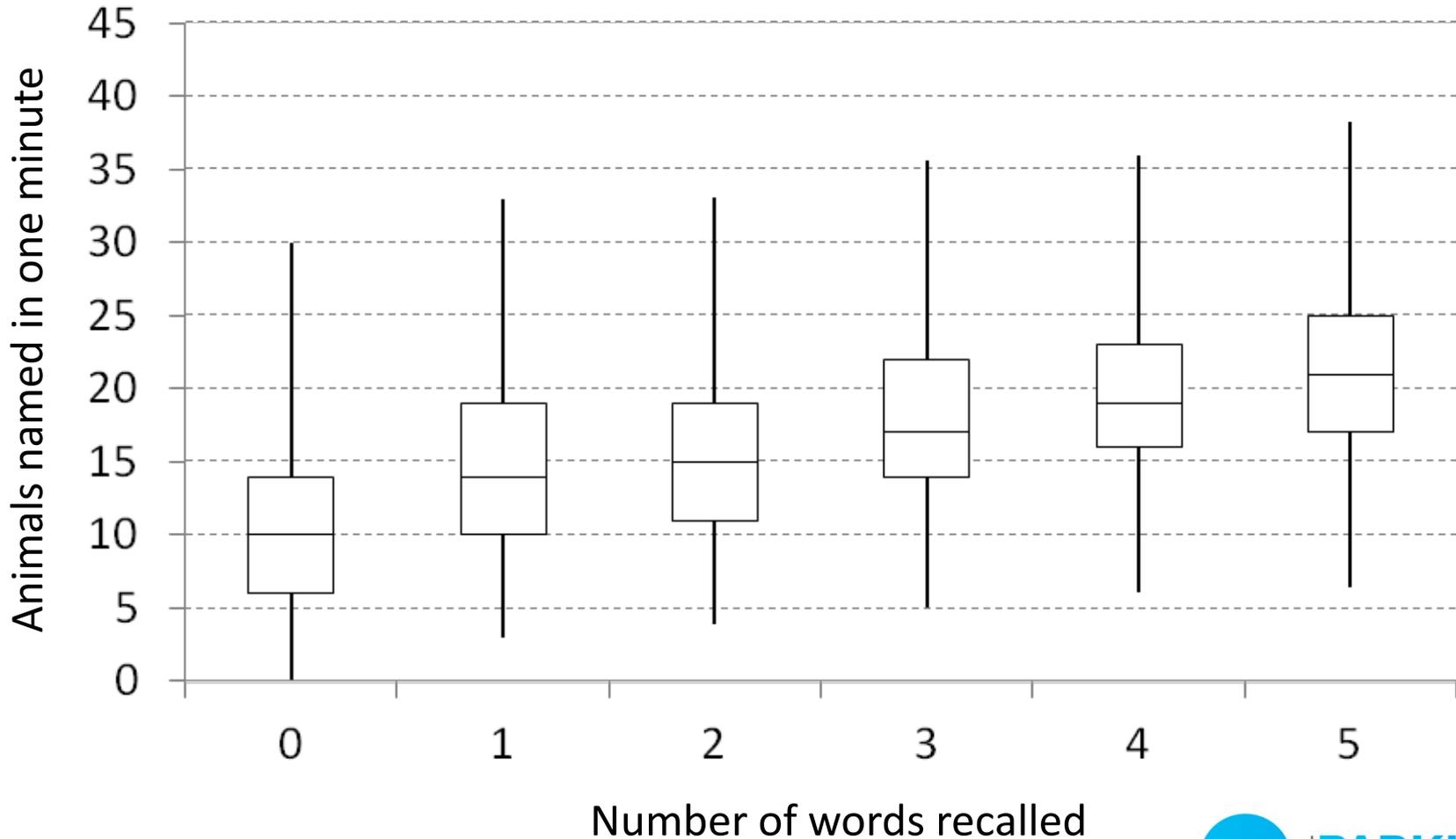
# Additional Objective Assessment

## NPF QII - The NPF Registry

An opportunity for annual screening of:

- Immediate and delayed recall
- Verbal fluency
- PDQ-39
- Multidimensional Caregiver Strain Index (MCSI)
- Additional measures

# QII data: Delayed Recall vs. Verbal Fluency



# Engaging Patients in Care

- Acknowledge and discuss objective data. If possible, compare new to old data.
  - Make eye contact
  - Get your listeners attention
  - Be succinct
  - Allow plenty of time for response
- Interview to dig deeper
  - How do you spend your day?
  - Do you participate in hobbies or activities you enjoy?
  - How much do Parkinson's symptoms interfere in day to day activities?
- Encourage point of view from patient and carepartner
- Emphasis on safety

# Engaging Patients

- Encourage changes in the environment to help memory
  - Calendar for appointments or crossing off days
  - Dry erase board for appointments or activities
  - Reduction of clutter
  - Consistent placement of frequently used items

# Engaging Carepartners in Care

- Need participation from patient and carepartner/family or other support system
- Educate about cognitive changes in PD
    - Bradyphrenia
    - Mild Cognitive Impairment
    - Moderate to advanced impairment
  - Carepartner may assume:
    - Not paying attention or listening
    - Can't hear
    - Purposeful manipulation or abstinence
  - Carepartner/family needs to be aware and reinforce strategies

# Engaging the Carepartner

- Develop daily routines
  - Helps to know what to expect next
- Keep things simple, avoid a long series on information
  - Offer limited choices
- Remove distractions
- Retain important rituals
- Maintain dignity
- Carepartner support
  - Carepartner support groups, adult day programs, skills building classes

# Impact of Secondary Symptoms

## Consider other factors

- On/off, wearing off
  - Thinking is often better at peak dose
- Orthostatic hypotension
- Fatigue
- Depression/anxiety
- Pain
- Sleep disturbance
- Apathy
- Stress

# Engaging Patients in Care

- Medications may be helpful
- Referral to rehab team can greatly impact quality of life
  - Offer specific information regarding assessment and potential outcome and impact
    - Will learn practical information
    - Will better understand how to help and what to say
- Carepartner instruction

# Rehab Cognitive Assessments

## Cognitive retraining for MCI

- Cognitive retraining focuses on improving attention
- The ability to “attend” is a key skill which drives other cognitive domains
- At Struthers, SLP and OT use a structured program which addresses 5 areas of attention:
  - Sustained (simple and complex), divided, alternating and selective
    - Auditory attention - Speech-Language Therapist
    - Visual attention - Occupational Therapist

# Rehab Cognitive Assessments

## Improvement of Short Term Memory

- SLP and OT
- Strategize with client and family about exact situations where memory is a problem
  - Develop a strategy for improvement
- Practice helps strategies become familiar and can then be used in novel situations
- Strategies include:
  - Organization
  - Repetition
  - Association
  - Visualization

# Rehab Cognitive Assessments

Assessments for mild to advanced deficits

## Speech therapy

- Cognitive Linguistic Quick Test (CLQT)
  - Provides domain specific information on cognitive deficits

## Occupational Therapy

- Cognitive Performance Test (CPT)
  - Evaluation of specific functional tasks
- Important to have carepartner/family present for the evaluations

# Rehab Cognitive Assessments

## Physical Therapy

Physical activity helps mental focus

- Modified exercise or ROM program due to cognitive deficits
  - Incorporate familiar movements
- Use repetition and consistent cueing within the session
- Falls assessment
- Carepartner education

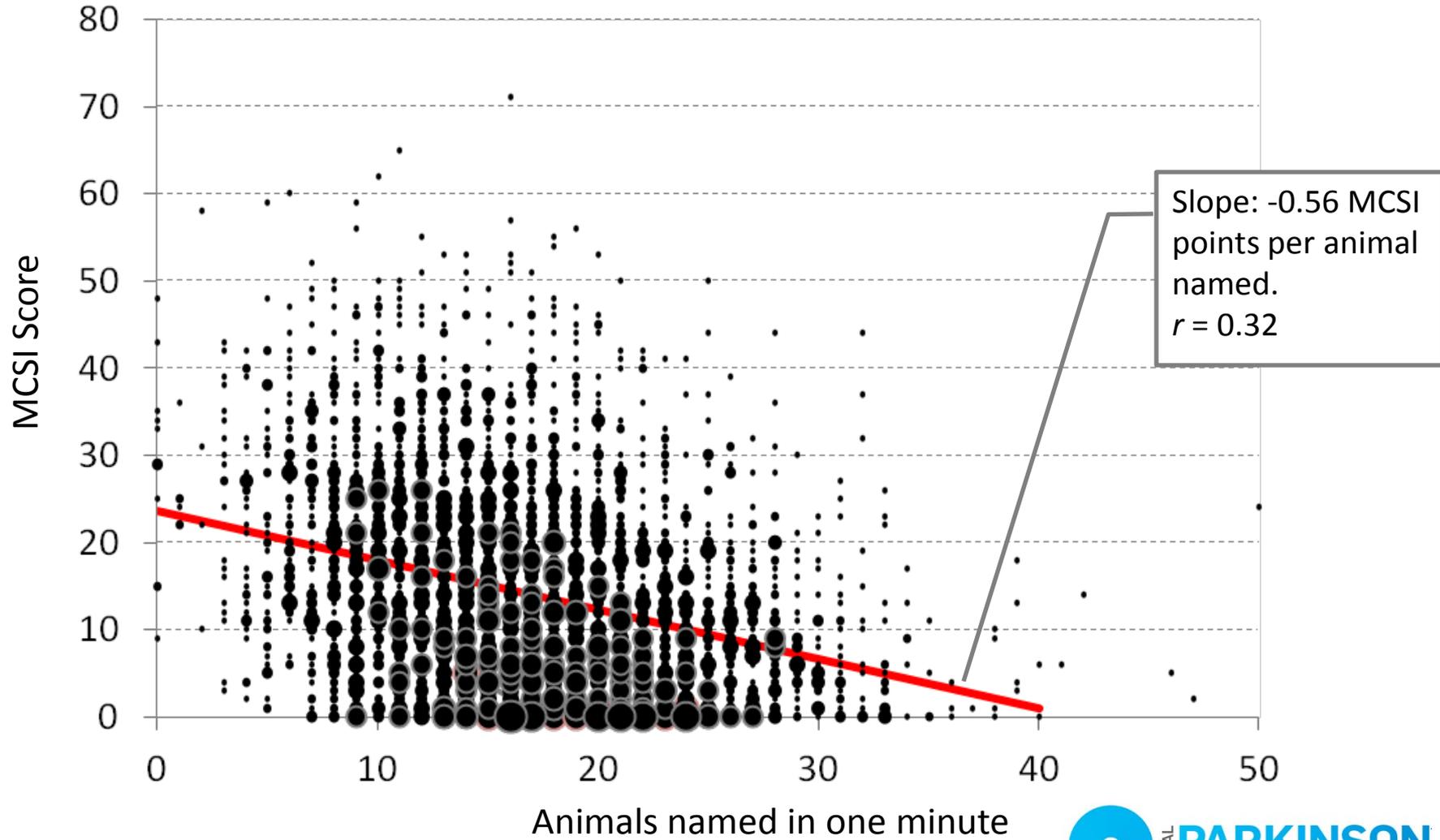
## Music Therapy

- Pattern sensory enhancement
  - Movements mirror musical changes
- Attention and cognitive stimulation

# Rehab Cognitive Assessments

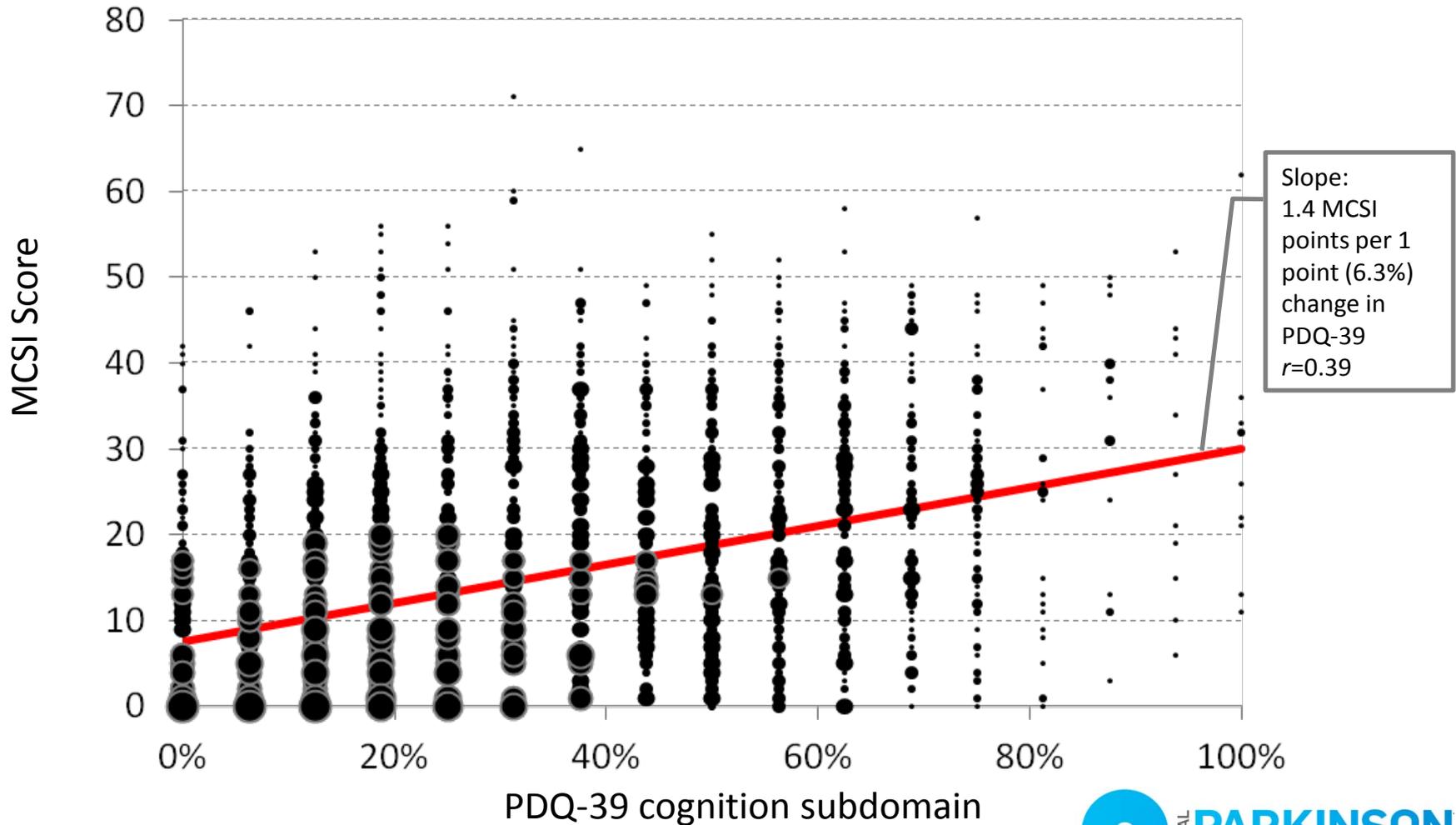
- Helps bolster patient self esteem
  - Optimization of strengths
  - Support for weaknesses
- Provides communication strategies for carepartners
  - Specific auditory and visual cues
  - Will help to decrease frustration
- Takes practice, repetition and compliance

# MCSI vs Fluency



Circle sizes indicates # of subjects at value.

# MCSI vs Patient-Reported Cognition



Circle sizes indicates # of subjects at value.

# Engaging Carepartners in Care

## Tips for carepartners

- Create lists
- Prioritize activities for each day
  - Be prepared to abandon plans
- Accept help
- Rest when you can
- Laugh when you can
- Take time to enjoy each other

# Engaging Patients- lessons from team

- Try to find out what interests the patient
  - Do they become animated in response to questions about past hobbies, certain individuals in their lives?
- Ask the patient how they think they will do in the testing?
  - How many steps do you think it will take?
  - How many animals do you think you can name?
- The “generation effect”
  - Enhanced ability to remember self-generated information rather than passively presented
- Value of group participation
  - Help individual pattern after what others are doing

# Other considerations

- Reduce distractions in the environment
- Give time to respond
- Make only one request at a time
- Don't shift quickly between tasks or requests

# Social Work and Cognition

- Health care directives and health care agent
- Disability paperwork
- Resources for caregiver respite
  - Adult day programs
- Transition to another living environment

# Nursing

- Nutritional intervention:
  - Brain health
  - Weight loss
  - Constipation
  - Dehydration
- “Case manager” for triage to physician or PD care team
- Evaluation of patient safety
- Ensure understanding of medication schedules and reliable system for administration
- Caregiver needs
  - Family will need to accept more care and responsibility



# Cognitive Deficit in Parkinson Disease



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# Bad News

- **There are Cognitive Changes in Parkinson's disease**
- **PD-MCI is common in non-demented patients with a mean prevalence of 27% and is associated with subsequent development of PDD. (Litvan et al, 2012)**
- **60-80% of patients show some cognitive decline.**
- **30-40% eventually meet criteria for Parkinson's Disease Dementia (PDD)**

# Obstacles to Recognition of Cognitive Changes

- Providers may think cognitive changes:
  - only occur at later stages
  - are associated with *MAJOR* changes in activities of daily living
- Some providers may not ask unless the caregiver brings it to their attention- primarily focus on the motor symptoms
- May not know how to assess
- May not know how to treat
- Treatment not available

# Cognitive Changes

- Risk Factors
  - Age
  - PIGD subtype
  - MCI at baseline
  - More severe disease



# Neuropsychiatric symptoms that may impact QOL

- Depression\*
  - Cognitive Decline\*
  - Hallucinations\*
  - Falls
  - Postural instability
  - Gait impairment
  - PIGD
- Schrag et al, 2000
  - Hely et al., 2005
    - Most disabling

# Other Factors that can affect Cognition

- Stress
- Medications
  - Anticholinergics
  - Sedatives
- Depression
- Sleep disturbances
- Infections

**Communication is KEY!**

# Changes in Executive Function

- Working memory
- Problem solving
- Switching set
- Maintaining set
- Initiating a response
- Serial ordering
- Generating strategies
- Cognitive slowing
- Abstract reasoning
- Decision making
- Coordinating
- Sequencing
- Monitoring
- Inhibition
- Sharing resources
- Divided attention

# Executive Dysfunction in Daily Life

## Domain

- Planning
- Set shifting
- Inhibition

## Daily Activity

- Can't make vacation plans- airplane, hotel etc.; Paying bills/financial decisions
  - Confused with apathy
  - Gets overwhelmed
- Talking while cooking; walking while remembering or while holding an object
- Easily distracted by external noises

# Memory Changes

- Short-term recall
  - Information is there-can't pull it out
  - Does better with cues
  - Repetition helps
  - Not the memory changes associated with Alzheimer's disease

# Bradyphrenia

- Patients with *bradyphrenia* may describe or may manifest slowed thought processes, evidenced by increased latency of response.
  - Important to allow time to respond
  - Becomes an important issue in social situations
  - Awareness and compensatory plan is essential to keep engaged

# Language

- Word finding
  - Most commonly reported
  - Executive function
- Decreased spontaneous speech
- Decreased comprehension

# Visuospatial Functioning

- Trouble perceiving their environment
- Misperceptions
- Difficulties with directions
- Difficulties judging distances
- Later on - getting lost

How can the QI questionnaires help identify these subtle changes in your clinic setting?

Not just a registry anymore!

National Parkinson Foundation Patient Registry  
(Definitions & instructions on reverse; Use 888 for unknown)



|  |   |  |                             |
|--|---|--|-----------------------------|
| First name   | Last name   |  |                             |
| DOB  | SS/ HIN#  |  |                             |
| (MMDD/YYYY)  |   |  |                             |
| Clinician name   | Visit date  |  |                             |
| Person completing form   |   |  |                             |
| Sex  | 0=male; 1=female  | Zip code /province                       | 1=M.D.; 2=RN; 3=RA; 4=Other |
| Weight w/o shoes   | lbs, 999=not done   | kg                                       | 999=not done                |
| Height w/o shoes   | inches, 999=not done  | cm                                       | 999=not done                |
| Race & Ethnicity   | 1-6 (see below), 999=NA/abstain   | 1=Hispanic/Latino; 2=not; 999 NA/abstain |                             |
| Race codes: 1=Am. Indian; 2=Asian; 3=Pac. Islander; 4=Black/Afr. Am; 5=white; 6=Multiple |   |  |                             |
| Can patient stand unaided?   | 0=no; 1=yes   |  |                             |
| Living situation   | 1=at home; 2=skilled care; 3=other  |  |                             |
| Does pt. have regular care partner?  | 0=no; 1=yes, spouse/partner; 2=yes, other relative; 3=has paid caregiver; 4= other            |  |                             |
| If yes, did regular care partner come to visit?  | 0=pt. unaccompanied; 1=with regular care partner; 2=with other caregiver; 3=with other person |  |                             |

|   |                                 |
|---|---------------------------------|
| <b>PD DIAGNOSIS/STAGE</b>                 |                                 |
| Year of first onset of PD symptoms (YYYY) | Year of PD diagnosis (YYYY)     |
| Certainty of idiopathic PD dx             | 1= <50%; 2= 50-89%; 3= >=90%    |
| Rest tremor present?                      | 0=no; 1=yes                     |
| Does pt. have motor fluctuations?         | 0=no; 1=yes                     |
| If yes, medication effect at this visit?  | 1="on"; 2="off"; 3="in between" |
| Hoehn and Yahr stage at this visit        | 1-5; 999=not assessed           |

|  |                  |  |  |
|--|------------------|--|--|
| <b>COMORBID CONDITIONS</b>   |                  |  |  |
| CODES: 0=absent; 1=asymptomatic/minimal; 2=moderate; 3=severe; 4=very severe |                  |  |  |
| Heart problems   | Cancer           |  |  |
| Respiratory problems   | Arthritis        |  |  |
| Diabetes   | Other            |  |  |
| Other neurological disorder  | History of falls |  |  |
| Hospital admits  | Count: 999=NA    | In past year, admitted for:  |  |
| ER visits  | count: 999=NA    | <input type="checkbox"/> Injury <input type="checkbox"/> Infection <input type="checkbox"/> Pneumonia <input type="checkbox"/> AMS |  |

|                      |   |               |   |
|----------------------|---|---------------|---|
| <b>MEDICATIONS</b>   |   |               |   |
|                      | Before visit  | (current med) | After visit (new or continued med)                      |
| Any form of levodopa | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Dopamine agonist     | 0=no; 1=yes   |               | 0=no; 1=yes   |
| MAO-B inhibitor      | 0=no; 1=yes   |               | 0=no; 1=yes   |
| COMT inhibitor       | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Amantadine           | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Antidepressant med   | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Cognitive enhancers  | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Stimulants           | 0=no; 1=yes   |               | 0=no; 1=yes   |
| Antipsychotic meds   | 0=no; 1=Clozapil @ or Seroquel @; 2=Respirator; 3=other |               | 0=no; 1=Clozapil @ or Seroquel @; 2=Respirator; 3=other |
| Anticholinergic med  | 0=no; 1=yes   |               | 0=no; 1=yes   |

|   |              |  |   |
|---|--------------|--|---|
| <b>PATIENT DATA</b>                     |              |  |   |
|   | Before visit | (current treatment)  | After visit (new or continued treatment)                    |
| Physical therapy                        |              | 0=no; 1,2=yes  | 0=no; 1=yes   |
| Occupational therapy                    |              | 0=no; 1,2=yes  | 0=no; 1=yes   |
| Speech therapy                          |              | 0=no; 1,2=yes  | 0=no; 1=yes   |
| Exercise program                        |              | hours per week; 0=no program                                       | hours per week; 0=no program                                |
| Social worker/ counseling               |              | 0=no; 1,2=yes  | 0=no; 1=yes   |
| Mental health tx or referral            |              | 0=no; 1,2=yes, tx  | 0=no; 1=yes, tx; 2=yes, refer for tests                     |
| Deep Brain Stimulation                  |              | 0=no; 1=uni; 2=bilateral   | 0=no change; 1=Refer for eval                               |
| If yes, month/yr of most recent surgery |              | Targets: STN <input type="checkbox"/> Gpi <input type="checkbox"/> | PPN <input type="checkbox"/> Other <input type="checkbox"/> |

|  |  |
|--|--|
| <b>CLINICAL CONDITION/OUTCOMES</b>                         |  |
| <b>Timed up &amp; go test (TUG)</b>                        |  |
| Without pushing off  | 5-30 in whole seconds; 30=unable to do; 999=not tested |
| If unable without pushing off, then pushing off from chair | 5-30 in whole seconds; 30=unable to do; 999=not tested |
| If unable without assist device, then using cane or walker | 5-30 in whole seconds; 30=unable to do; 999=not tested |
| <b>Cognition</b>   |  |
| Immediate 5 word recall                                    | 0-5 words; 999=not tested                              |
| Verbal fluency (animal list)                               | # of words; 999=not tested                             |
| Delayed 5 word recall                                      | 0-5 words; 999=not tested                              |

|  |   |
|--|---|
| <b>PDQ39 (report subscale scores only)</b> |   |
| Who completed form?                        | 1=patient; 2=pt. & caregiver; 3=caregiver               |
| Mobility (max. possible=40)                | sum, 999=NA Lit. avg. range: 16-26 This study IQR: 3-21 |
| ADL (max. possible=24)                     | sum, 999=NA Lit. avg. range: 8-14 This study IQR: 2-11  |
| Emotional well-being (max. possible=24)    | sum, 999=NA Lit. avg. range: 7-10 This study IQR: 2-9   |
| Stigma (max. possible=16)                  | sum, 999=NA Lit. avg. range: 4-6 This study IQR: 0-4    |
| Social support (max. possible=16)          | sum, 999=NA Lit. avg. range: 2-3 This study IQR: 0-2    |
| Cognition (max. possible=16)               | sum, 999=NA Lit. avg. range: 5-8 This study IQR: 2-6    |
| Communication (max. possible=12)           | sum, 999=NA Lit. avg. range: 2-4 This study IQR: 0-5    |
| Pain (max. possible=12)                    | sum, 999=NA Lit. avg. range: 5-6 This study IQR: 2-6    |

|   |                     |
|---|---------------------|
| <b>MCSI (Care partner burden)</b>               |                     |
| Physical strain (max. possible=12)              | sum, 999=not tested |
| Social constraints (max. possible=16)           | sum, 999=not tested |
| Financial strain (max. possible=8)              | sum, 999=not tested |
| Time constraints (max. possible=8)              | sum, 999=not tested |
| Interpersonal strain (max. possible=20)         | sum, 999=not tested |
| Elder demanding/ manipulative (max. possible=8) | sum, 999=not tested |

|                              |  |
|------------------------------|--|
| <b>COMMENTS/FLEX SPACE</b>   |  |
| Approx. minutes to complete: |  |

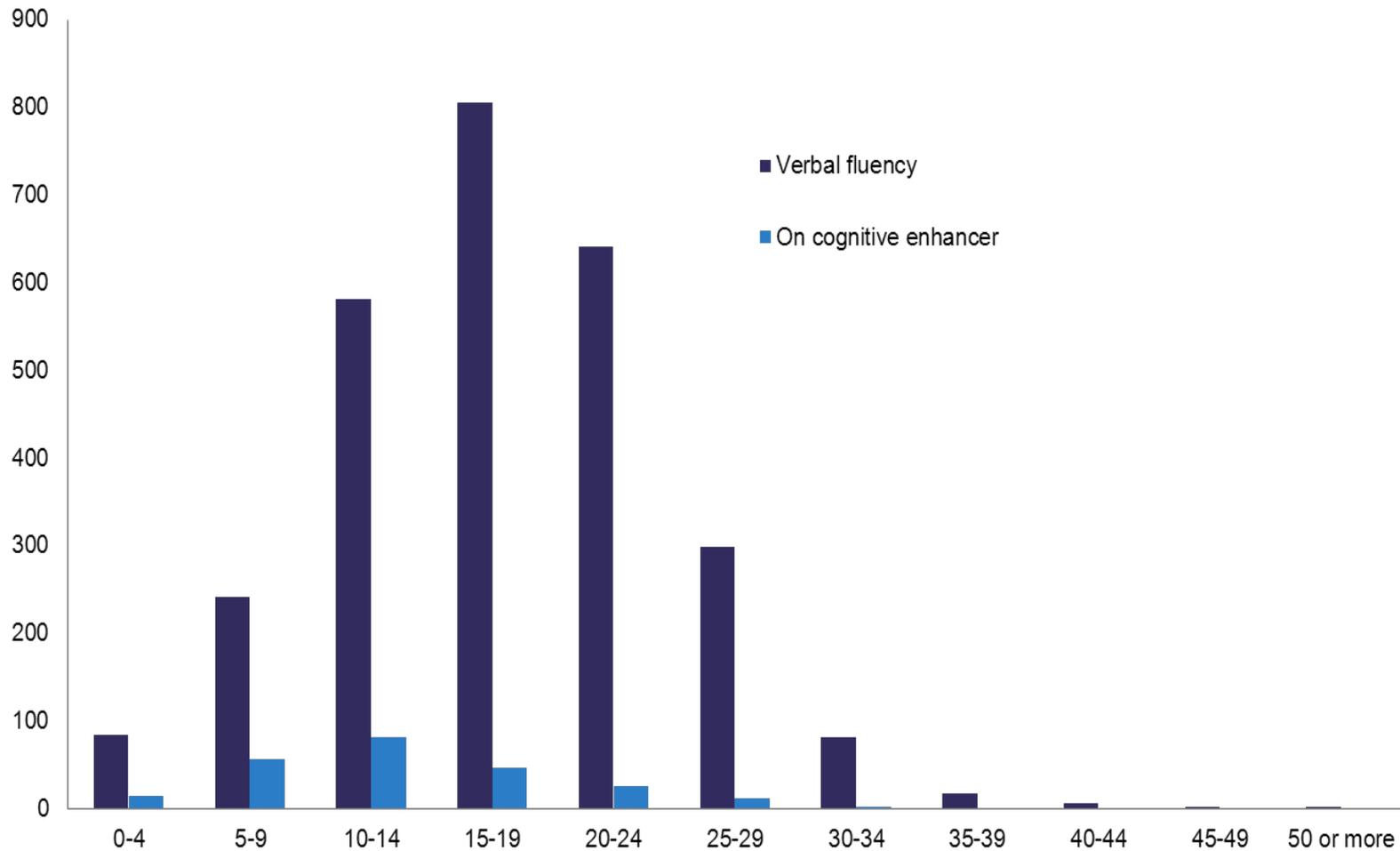


# Contribution in PDQ-39 by TUG, Word recall/fluency and Co- morbidities

|                        | <u>Alone</u> | <u>After control for other variables</u> |
|------------------------|--------------|--|
| TUG:                   | 23.0%        | 5.3%                                     |
| Immediate word recall: | 6.6%         | 0.4%                                     |
| Word Fluency:          | 8.4%         | 0.4%                                     |
| Comorbidities:         | 14.0%        | 4.0%                                     |

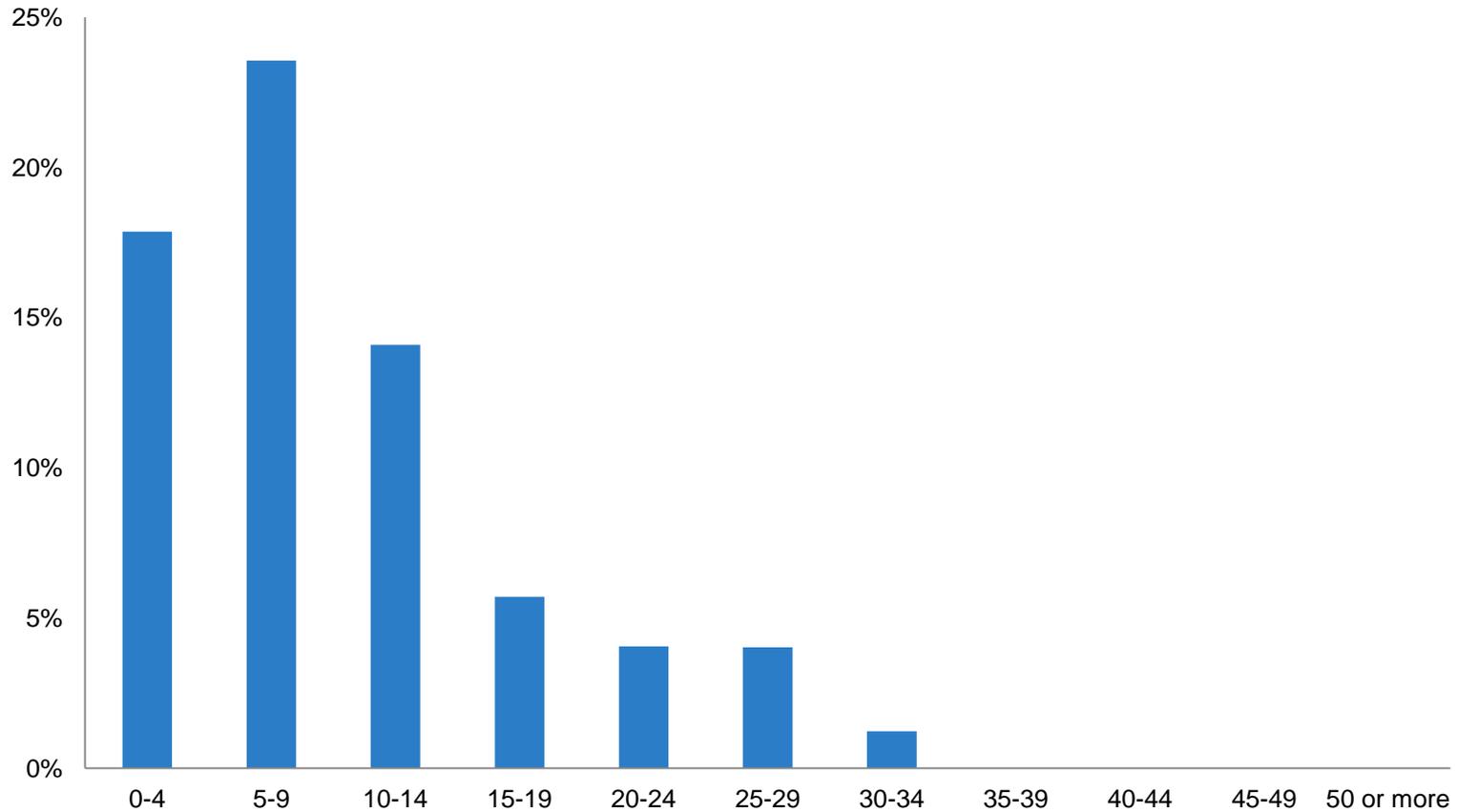
Implication: Maintaining mobility is a critical issue

# Verbal fluency and cognitive enhancer status



# Proportion of Cognitive Enhancer Use

## Cognitive enhancer status by verbal fluency



# New Criteria for MCI in PD

- **Diagnosis of Parkinson's disease as based on the UK PD Brain Bank**
- **Gradual decline, in the context of established PD, in cognitive ability reported by either the patient or informant, or observed by the clinician**
- **Cognitive deficits on either formal neuropsychological testing or a scale of global cognitive abilities**
- **Cognitive deficits are not sufficient to interfere significantly with functional independence, although subtle difficulties on complex functional tasks may be present**

(Litvan et al., Movement Disorders, Vol. 27, No. 3, 2012)

# Abbreviated Assessment for MCI (Level I)

- Impairment on a scale of global cognitive abilities validated for use in PD or  
Impairment on at least *two* tests, when a limited battery of neuropsychological tests is performed (i.e., the battery includes less than two tests within each of the five cognitive domains, or less than five cognitive domains are assessed)

(Litvan et al., Movement Disorders, Vol. 27, No. 3, 2012)

# Comprehensive Assessment of MCI (Level II)

- Neuropsychological testing that includes two tests within each of the five cognitive domains (i.e., attention and working memory, executive, language, memory, and visuospatial)
- Impairment on at least two neuropsychological tests, represented by either two impaired tests in one cognitive domain or one impaired test in two different cognitive domains
- Impairment on neuropsychological tests may be demonstrated by:
  - Performance approximately 1 to 2 SDs below appropriate norms or
  - Significant decline demonstrated on serial cognitive testing or
  - Significant decline from estimated premorbid levels

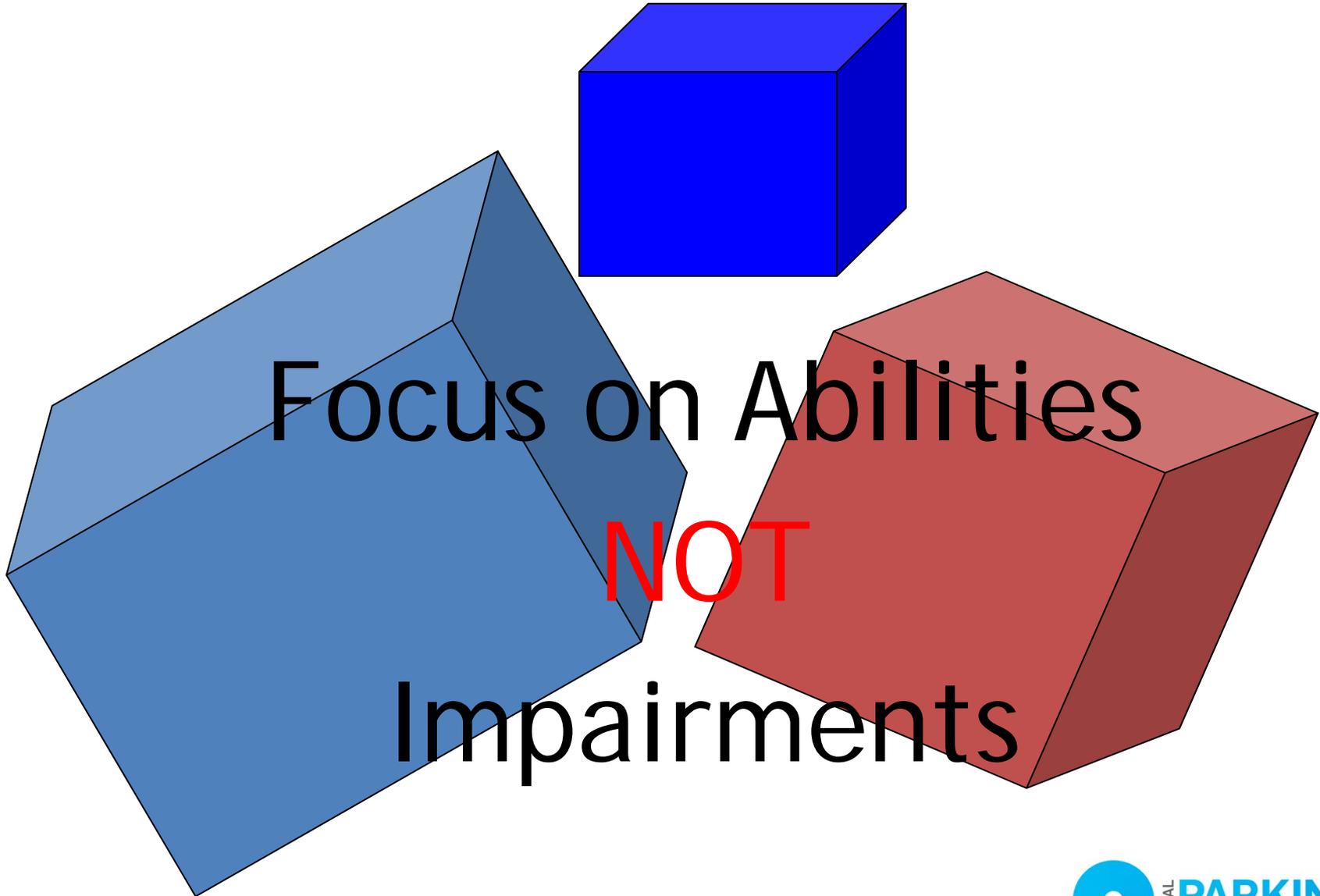
(Litvan et al., Movement Disorders, Vol. 27, No. 3, 2012)

# The Top 5 Ways to Maintain Your Brain

- Stay Mentally Active
- Stay Physically Active
- Maintain a Sense of Social Engagement
- Control Risk Factors for Diseases of the Heart and the Brain
- If Cognitive Problems Start, Use Compensatory Strategies

# Developing Networks of Care





Focus on Abilities

NOT

Impairments

# PARKINSON'S DISEASE CENTER AND MOVEMENT DISORDERS CLINIC

**BCM**  
Baylor College of Medicine

**Thank you!**

