

# Living Longer, Living Better: Improving Mental Fitness for People Over 50 Living with HIV at Ryan White Clinic

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Barbara Duarte Esgalhado, PhD has no relevant financial interests to disclose.

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# Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Be able to distinguish between functional and performance-based measures of cognition.
2. Be able to Identify comorbidities that can affect PLWH cognitively mediated functional abilities.
3. Be able to define what adaptive and compensatory strategies are and their role in supporting PLWH as they age.

# Introduction

- Of the more than half a million clients served by the Ryan White HIV/AIDS Program (RW), 46.8 percent are aged 50 years and older.
- At UPMC's RW clinic, 63% of our clients are over the age of 50 and many are reporting challenges with memory and executive functioning.
- We developed a model to identify and address neuropsychological challenges for clients aged 50 and older.

# Background

- Early management of HIV care focused on disease-specific measures like viral load and CD4 count.
- As the population of older people living with HIV increases, a shift in approach is needed.
- HIV infection and its treatment as a complex chronic condition **interacting** with aging changes, co-existing conditions, and the treatments for those conditions.

[Aging with HIV: Responding to an emerging challenge | National Institute on Aging \(nih.gov\)](#)

# HIV and Central Nervous System (CNS)

Antiretroviral therapy (ART) adherence has resulted in:

- Viral suppression, good immune function, and decrease in opportunistic infections **AND**
- Improvements in neurocognitive decline from high virus burden and opportunistic infections in the central nervous system, including the incident of HIV-associated dementia (Nabha et al. 2013)

# HIV-Associated Neurocognitive Disorder

- Central nervous system (CNS) remains a “reservoir” for HIV with neurons being affected at moment of acute infection.
- While combination ART has resulted in virologic control in the plasma, the virus can still breakthrough to the central nervous system due to limited ART drug exposure (Nabha et al., 2013).
- Most severe forms of HIV-associated dementia have dramatically decreased, but milder forms of HAND cognitive challenge **have increased and are estimated at about 40%**.
- HAND important to address because it interferes in daily functioning and reduces quality of life.
- In severe forms, HAND can contribute to increased mortality due to ART nonadherence.

# Mental Health Assessment (MHA)

- We annually administer a mental health assessment (MHA) composed of evidence-based diagnostic tools for depression (PHQ-9), anxiety (GAD-7), post-traumatic stress disorder (PC-PTSD-5), and an inventory of tobacco, alcohol, and non-prescription drug use.
- Last year, we added the ECog (“Everyday Cognition”) to the MHA, an instrument used to assess **cognitively mediated functional abilities** in older adults.



# Everyday Cognition (ECog)

- Several **performance-based cognitive screening** instruments are already used in clinical settings to screen for dementia like the Mini Mental Status Examination (MMSE) and the Montreal Cognitive Assessment (MOCA).
- ECog's focus is on **functional abilities**.
- Includes **caregiver and/or informant** ratings of everyday cognition and functional abilities.
- Problems in daily function and everyday cognition frequently occur in neurodegenerative diseases of aging, **and**
- Can predict who will more rapidly decline and possibly struggle with dementia.
- Provide us with more information on whether an individual needs **additional support or a higher level of care**.

# ECog-12 vs Ecog Original

- Both cover 6 cognitive domains: Everyday Memory, Everyday Language, Everyday Visuospatial Abilities, Everyday Planning, Everyday Organization, and Everyday Divided Attention.
- Research has examined internal and external validity of both versions and found both equally valid assessments (Farias et al., 2011).

# ECog-12 vs Ecog Original 2

## ECog-12

- 12 items to answer.
- Good measure of global cognition.
- Domain specific mean and overall mean is 1.5.

## ECog Original

- 39 items to answer.
- Preferable if you want to track functional abilities over time.
- Domain specific mean and overall mean is 1.3.

# Everyday Cognition (ECOGG-12): Questions 1-6

For patients 50\* years and older. Compared to (5)\* years ago, has there been any change in...

1 Better or no change 2 Questionable/occasionally worse 3 Consistently a little worse

4 Consistently much worse 5 Don't know

## Memory

- |   |           |
|---|-----------|
| 1. Remembering where you placed objects.            | 1 2 3 4 5 |
| 2. Remembering the current date or day of the week. | 1 2 3 4 5 |

## Language

- |   |           |
|---|-----------|
| 3. Communicating thoughts in a conversation.        | 1 2 3 4 5 |
| 4. Understanding spoken directions or instructions. | 1 2 3 4 5 |

## Visual-spatial and Perceptual Abilities

- |  |           |
|--|-----------|
| 5. Reading a map and helping with directions when someone else is driving. | 1 2 3 4 5 |
| 6. Finding your way around a house visited many times.                     | 1 2 3 4 5 |

# Everyday Cognition (ECog-12): Questions 7-12

## **Executive Functioning: Planning**

7. Anticipating weather changes and planning accordingly (i.e., bring a coat or umbrella). 1 2 3 4 5
8. Thinking ahead. 1 2 3 4 5

## **Executive Functioning: Organization**

9. Keeping living and workspace organized. 1 2 3 4 5
10. Balancing the checkbook without error. 1 2 3 4 5

## **Executive Functioning: Divided Attention**

11. Doing two things at once. 1 2 3 4 5
12. Cooking or working and talking at the same time. 1 2 3 4 5

# ECog-12 vs ECog Original: Language

## ECog-12: Language

1. Communicating thoughts in a conversation.
2. Understanding spoken directions or instructions.

## ECog (Original): Language

1. Verbally giving instructions to others.
2. Following a story in a book.
3. Understanding the point of what other people are trying to say.
4. Describing a program watched on TV.
5. Understanding spoken directions or instructions.
6. Forgetting the names of objects.
7. Finding the right words to use in a conversation.
8. Remembering the meaning of common words.
9. Communicating thoughts in a conversation.

# ECog-12 vs ECog Original: Executive Functioning

## ECog-12: Executive Functioning: Organization

1. Keeping living and workspace organized.
2. Balancing the checkbook without error.

## ECog (Original): Executive Functioning: Organization

1. Keeping living and workspace organized.
2. Balancing the checkbook without error.
3. Keeping financial records organized.
4. Prioritizing tasks by importance.
5. Using an organized strategy to manage a medication strategy.
6. Keeping mail and papers organized.

# Modifications to ECog-12 for PLWH

- Lowered the age of screening to **age 50 and above**.
- Lowered the length of comparison time for people to compare themselves to their previous baseline to **5 years**.

Example:

Please rate your ability to perform certain everyday tasks **NOW, as compared with your ability to do these same tasks 5 years ago.**

In other words, try to remember how you were doing **5 years ago** and indicate any change you have noticed.



# PACT: Preliminary Findings

- 106/948 or 11.18% scored with functional challenges in at least one domain.
- 44/106 or 41.51% who scored in at least one domain: **Memory or Executive Functioning: Organization.**
- 62/106 or 58.49% who scored in 2 or more domains: **Memory, Language, Executive Functioning: Organization, Executive Functioning: Planning.**
- 95/106 or 89.62% scored with **mild to severe depression** as assessed by PHQ-9.

# Comorbidity: Depression

- Depression “dulls” or impedes cognitive functioning, especially memory, language, and executive functioning.
- Assess and treat depression and re-evaluate cognitively mediated functional abilities.
- Psychotherapeutic treatment that looks at the whole person, including social and economic factors, level of physical health, impact of HIV diagnosis, how they live and how they want to live.
- Symptom management for depression, anxiety, and residual posttraumatic stress disorder.
- May include medication, short or long term.
- Needs to extend beyond symptom management.

# Follow Up: Having a Conversation

- All assessments are just a beginning.
- Follow up consultation to get to know the whole person and for clarification, verification, and contextualization of functional challenges.
- Medical and/or neurological evaluations, if haven't been done and are warranted.
- Identify and address co-morbidities, including cardiovascular disease, diabetes, sleep challenges, depression, anxiety, posttraumatic stress disorder, etc.
- Distribute caregiver/informant version, if hasn't been already completed.
- Explore options, including referrals for comprehensive neuropsychological assessment and/or neurological occupational therapy (neuro-ot).
- Integrate it into psychotherapeutic treatment.

# Keep Doing but Do Differently: Adaptive/Compensatory Strategies

- Adjustments and adaptations that can be made to help people learn how **not to stop doing** but to learn how **to do differently**.
- While a neuro-occupational therapist (neuro-ot) can assess and work with clients in a specific and thorough manner, **we can all support** this type of learning.

## Examples:

- Organize a grocery list by alphabet (e.g., A=Apples, B=Butter, C=Corn, etc.).
- Summarize a paragraph aloud after reading it.
- Break down a big task into several, smaller ones and check off each one when completed.

# Living Longer, Living Better: Improving Mental Fitness

- Maintain a healthy, meaningful, and purposeful lifestyle
- Nutrition
- Exercise
- Good sleep hygiene
- Intellectual stimulation
- Social interaction, mutual support, **interdependence**
- Keep growing, adjusting, adapting, imagining
- Keep asking: What do I want to be when I grow up?

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# References

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[Aging with HIV: Responding to an emerging challenge | National Institute on Aging \(nih.gov\)](#)

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