

# Neurocognitive Symptoms in PLWH

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# Objectives

- What do people worry about?
- What do their partners worry about?
- What's the 'truth'?





He took hold of his wife's head

Tried to lift it off, to put it on





# Screening Principles

- Wilson and Jungner
  - the condition should be an important health problem
  - there should be an accepted treatment
  - there should be a suitable test
  - the natural history of the condition should be understood

# Issues

- Symptoms don't always predict NCI
- Tests aren't very good
- Natural history not understood
- No clear intervention that helps



# Natural History

- A large proportion of HAND does not appear to have major impact on everyday function
  - falling into ANI in Frascati criteria
- May be a risk of deterioration and some reports show risk of subsequent impairment with mild NC disorder (MND) inpatients with ANI at baseline
- Link with depression may affect ‘progression’
  - thus change from ANI to MND can be mood congruent



# Challenges

- Norms
  - old
  - don't reflect our population
- Circularity of screening research
  - populations
  - mood

# Jack (Lewis) Says....

Widespread implementation of screening for HIV associated neurocognitive disorders is premature, on the basis of available evidence



# Symptoms

- Important because they guide clinical decisions around investigation and treatment
  - but often they do not identify patients at risk of neurological disease
- Even if symptoms are only weakly correlated with cognitive impairment they are often highly important to the patient
- Other reasons may affect the validity of self reported scales
  - psychiatric problems
  - excessive substance use
  - other reversible cause affecting daily functioning



# PLWH

- May perceive a decline in function that's not present, because of depression or anxiety
- May be worried or hypervigilant about symptoms
- May state decline in function as they think the clinician or researcher wants to hear it
- May be secondary gain by reporting it
- Measuring instruments may lack validity and fail to measure what they purport to

# Symptoms

- Subcortical vs. cortical
- Motor vs. memory
- Self vs. others

# Symptoms

- Life, drugs, alcohol
- HIV, treated or otherwise
- Something else.....

# Symptoms

- Mood
- Personality change
- Multitasking
- Remembering things

# Symptoms

- **Mood**
  - **cause or symptom?**
- Personality change
- Multitasking
- Remembering things

# What Symptoms?

- General cognitive symptoms may be the main driver of patients coming to the attention of clinicians:
  - memory
  - concentration
  - reasoning
  - attention
- Patients' own causal attributions of functional decline (cognitive or physical) are inconsistent with objective neuropsychological assessments of function



# Evidence

- CIPHER Group
- 5 European countries
- Determine factors associated with self-reported decline in ADL and cognitive impairment symptoms
- Computerised as well as pen and paper tests
  - cognitive function in five domains
  - psychosocial factors
  - clinical parameters

# Evidence

- 448 completed the assessments (approx 46y, 84% male, 87% white)
- 96 (21.4%) reported decline in ADLs and attributed this to cognitive difficulties
- Declining ADLs and increased frequency of cognitive symptoms were both associated with worse cognitive performance on testing

# Evidence

- A number of factors were found to be associated with self reported decline in ADLs:
  - speed/reaction time
  - attention/working memory
- Several other factors were also associated with a decline in ADLs:
  - ability to afford basic needs most of the time or some of the time
  - depressive symptoms
  - anxiety symptoms
  - longer time since HIV diagnosis (median time 10 years)

# Evidence

- A number of factors were found to be associated with self reported decline in ADLs:
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- Several other factors were also associated with a decline in ADLs:
  - ability to afford basic needs most of the time or some of the time
  - depressive sx
  - anxiety sx
  - longer time since HIV diagnosis (median time 10 years)
- Participants in London were more likely to report a decline in everyday function due to cognitive problems than those in any of the other 3 sites ( $p=0.0042$ )

# Evidence

- In longitudinal studies of HIV associated cognitive impairment:
  - other factors driving self reported decline could mimic progressive decline in the absence of true cognitive change
- Work
  - 50% reported problems in CHARTER
  - 10% of functionally unimpaired patients had difficulties with work in CIPHER report

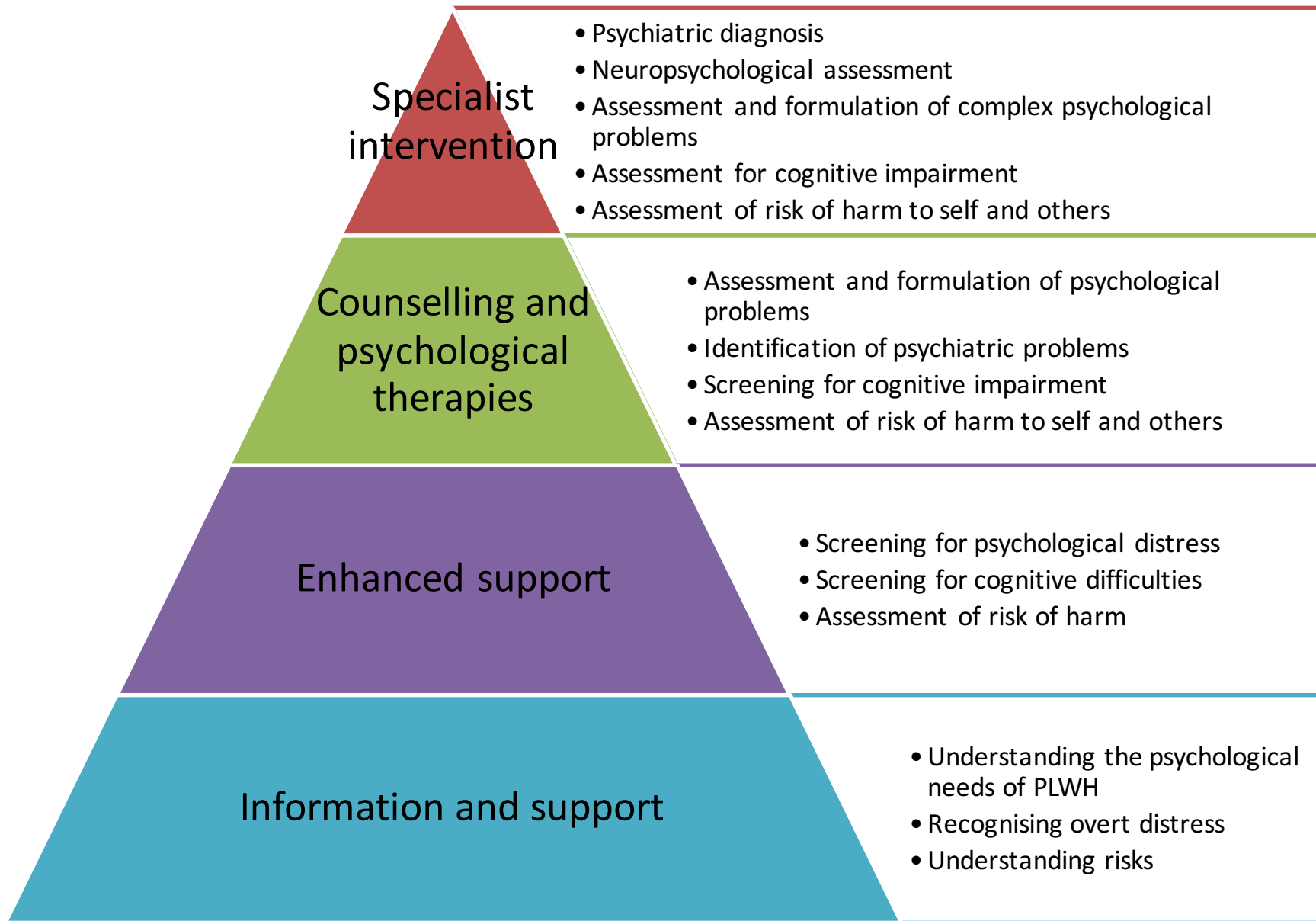
# Recommendations

- Awareness
  - health care professional and patient
- Approaches to screening
- Brief intervention and education
- Practical support
- Referral pathways



# Guidelines for Integrated Care in HIV

- PLWH should be given the opportunity to discuss their psychological wellbeing *with the professionals providing their health and social care*
- All PLWH *should be assessed* for the appropriate level of psychological support to meet their needs
- PLWH should be provided with access to care according to a *stepped care model*

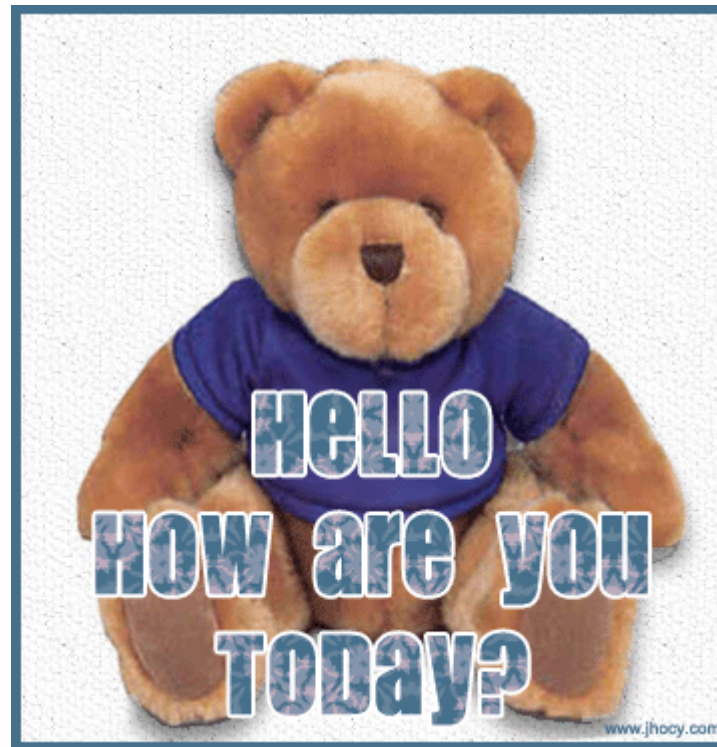


# Summary

- What do people worry about?
- What do their partners worry about?
- What's the 'truth'?

# Screening

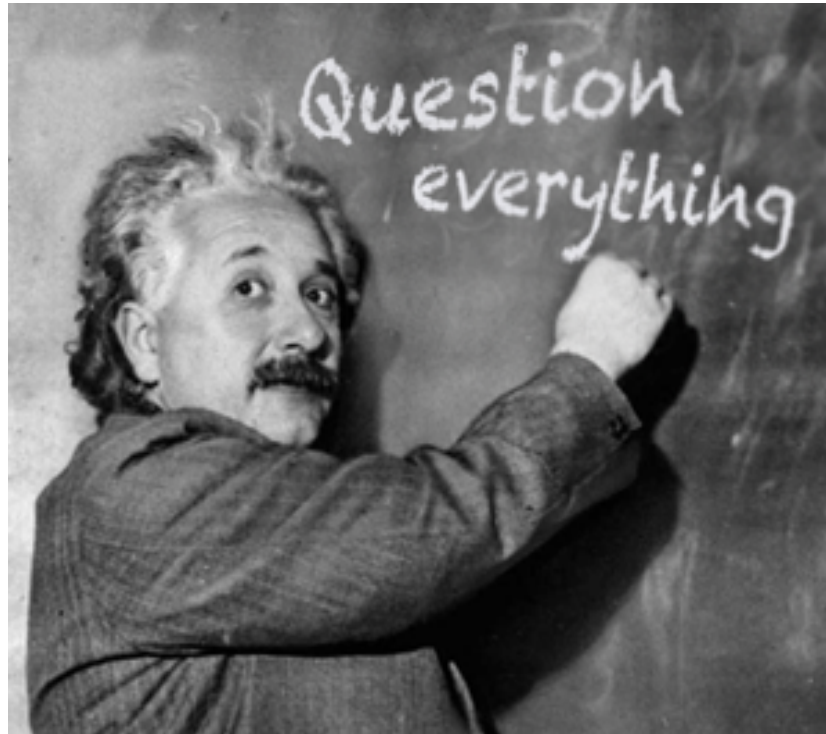
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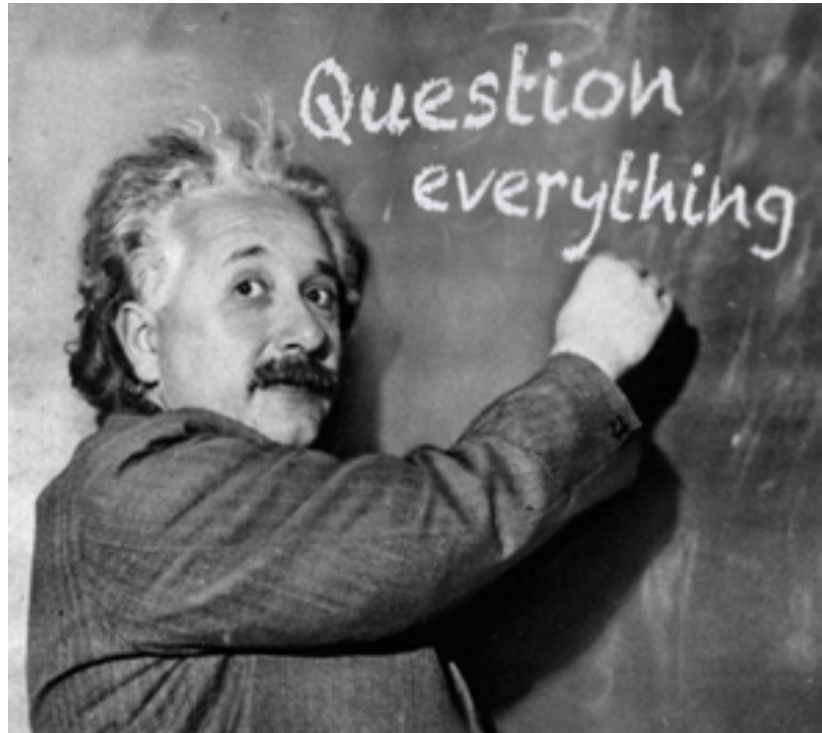


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**THANK YOU!**

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