Forget me not: providing care for people living with HIV and dementia
(What does the future hold for our elderly HIV patients?)

Dr Simon Rackstraw FRCP
Medical Director, Mildmay Hospital, London
Consultant HIV Physician, Bartshealth NHS Trust, London

Annual new HIV and AIDS diagnoses and deaths: UK, 1981-2012

Attributes of late* HIV diagnosis, UK 2012

* CD4 <350 cells/mm³ within three months of diagnosis
CDC definition of HIV encephalopathy (dementia)

- Clinical findings of disabling cognitive or motor dysfunction interfering with occupation or activities of daily living, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings.

- Methods to rule out such concurrent illness and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.

1987 Revision of the CDC Surveillance Case definition for Acquired Immunodeficiency syndrome
Changing epidemiology rising prevalence of HIV dementia

Due to improved survival rates, the cumulative prevalence of HIV dementia has risen

"Frascati" definition of HIV Associated Neurocognitive Disorder (HAND)

<table>
<thead>
<tr>
<th></th>
<th>No Pre-existing Cause</th>
<th>Delirium Absent</th>
<th>Acquired Impairment in ≥ 2 Cognitive Abilities</th>
<th>Interferes with Daily Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asymptomatic Neurocognitive Impairment (ANI)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (&gt;1SD)</td>
<td>No</td>
</tr>
<tr>
<td>Mild Neurocognitive Disorder (MND)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (&gt;1SD)</td>
<td>Mild</td>
</tr>
<tr>
<td>HIV-Associated Dementia (HAD)</td>
<td>Yes</td>
<td>Yes</td>
<td>Marked (&gt;2SD)</td>
<td>Marked</td>
</tr>
</tbody>
</table>

Cognitive domains: attention-information processing, language, abstraction-executive, complex perceptual motor skills, memory, including learning and recall, simple motor skills or sensory perceptual abilities
CNS HIV AntiRetroviral Therapy Effects Research Project, Years 2003-2007


Cognitive impairment in UK MSM

Clinical features of HAND: functional impairment

- Activities of daily living
  - Medication adherence\(^1\)
  - Driving (2–3 times as likely to fail tests)\(^2\)
  - Household finances
  - Meal preparation
- Vocational functioning\(^3\)
  - 5 times more likely to complain of job performance problems
  - Twice as likely to be unemployed


Projected numbers with dementia in UK

Figure B: Projected increases in the number of people with dementia in the UK, by age group (2012–2051)

Alzheimer’s Society. Dementia in the UK – Update (2014)
Alzheimer’s disease

- First report of a combination of Alzheimer’s disease and HIV related cognitive impairment in the same patient.


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**Table 1** Summary of neurocognition, neuroimaging, neuropathology, and pathophysiology of brain disturbances in HIV and Alzheimer’s disease

<table>
<thead>
<tr>
<th></th>
<th>HIV</th>
<th>Alzheimer’s disease</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurocognitive</td>
<td>Psychomotor slowing</td>
<td>Primary amnestic disturbance</td>
<td>Memory disturbances</td>
</tr>
<tr>
<td>manifestations</td>
<td>Executive dysfunction</td>
<td>Anoma</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Selective cognitive impairments</td>
<td>Global cognitive dysfunction</td>
<td></td>
</tr>
<tr>
<td>Cerebral volumetric</td>
<td>Early declines in basal ganglia and frontal lobe volumes</td>
<td>Greater cortical atrophy and ventricular enlargement</td>
<td>Early white matter changes</td>
</tr>
<tr>
<td>changes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
New comorbidities in the era of HAART

- Cardiovascular disease¹,²,³,⁴
- Diabetes mellitus & insulin resistance⁴
- Cancer⁵
- Osteopenia & osteoporosis⁶,⁷
- Liver failure⁸
- Kidney failure⁹
- Cognitive decline & dementia¹⁰
- Frailty¹¹

¹⁰ McCutchan et al. HIV suppression by HAART preserves cognitive function in advanced, immune-reconstituted AIDS patients. AIDS. 2007 May 1;21(9):1109-17.

Ageing and HIV

Symptoms and comorbidities in older adults with HIV infection

Prevalence of geriatric syndromes

• 155 participants with a median age of 57 (interquartile range: 54–62)
• 94% were men.

Decrease in function in ageing HIV+ patients


Ongoing care needs in the era of HAART

- “As people live longer with HAART, there is a rising number of HIV-positive people over 50 years old. They are more likely to have poorer psychological health related to a greater likelihood of comorbid conditions and economic hardship, and of being more severely affected by HIV-related stigma.”
- “There has been a shift from acute mental health problems associated with dying to chronic complex problems associated with living.”
- “The health of some HIV-positive people does not improve with HAART and some may die. Because of the optimism associated with HAART, failure to respond to the therapy may lead to a profound feeling of failure.”

G Green and R Smith. The psychosocial and health care needs of HIV-positive people in the United Kingdom following HAART: a review. HIV Medicine (2004), 5 (Suppl. 1),1–4
HIV and Aging

- Hopelessness
- Isolation
- Cognitive impairment
- Poor self care
- Behavioural disturbance
- Poor medication adherence
- Diminished self efficacy
- Social disenfranchisement

- Mental illness:
  - Major depression
  - Bipolar disorder
  - Schizophrenia
  - Personality disorder
  - Substance abuse
  - Demoralisation
  - Poor coping skills

- Compromised immune function
- Inflammatory illness
- Diabetes
- Cardiac Disease

Adapted from Hammond and Treisman, 2008

Psychosocial response

- Uncertainty: disability, not death?
- Double diagnoses
- Impact of stigma & discrimination
- Interaction of physical, psychological, and social

Attitudes to long term care

Would residential homes or places for the long-term sick have the expertise to be able to look after an older person with HIV?

52-year-old gay man from Cardiff

I fear hugely going into a home, or getting so frail or ill and I have to be looked after by a paid care agency in my own home, i.e. I fear the attitudes towards HIV that I may find and ignorance from care staff. One of our HIV charity trustees died last year and a private care agency actually refused to provide him with care at home when he was dying of cancer… they did not want to come into contact with his bodily fluids … and if I get dementia … I may not be able to fight this disrespect and stigma or educate them on my care.

57-year-old white heterosexual woman from Cornwall


Mildmay Hospital
Ageing cohort at the Mildmay

- In year 2005/2006 21% of admissions to Mildmay were 50 years or older
- In the most recent year 2013/2014 37.3% of admissions to Mildmay were 50 years or older
- Current distribution of ages gives a median age of admission of 47

Mildmay Mission hospital admission trends

- Increasing age of patients
- Increasing neurological disability
- Increasing amount of comorbidities
- Increasing numbers of patients loss to follow
- New neurological syndromes i.e CD8 lymphocytosis, CSF escape
Measuring rehabilitation outcomes - Comparison of Admission and Discharge scores (NPDS & HoNOS-ABI combined)

Rackstraw et al. A preliminary investigation of the use of a ‘basket’ of outcome measures within a rehabilitation service for adults diagnosed with HIV-related neurological disorders. Abstract 5.8, 10th AIDS Impact Conference, Santa Fe, USA; September, 2011.

Identification and interventions

Treatment of cerebrovascular risk factors

An active lifestyle is associated with better neurocognitive functioning in adults living with HIV infection

Parinya L. Fazeli, Steven Paul Woullert, Robert K. Huenion, Anjka Umlauf, Marni Gauris, Debra Rosario, Rosanne C. Moore, Igor Grant, and David J. Moore - the HNRP Group

Abstract: Studies of healthy adults show that engagement in physical, social, and mental activities is associated with better neurocognitive functioning. Given the prevalence and real-world impact of HIV-associated neurocognitive disorders (HANDs), the present study examined the association between neurocognitive scores and self-reported proxies for physical exercise, social activity, and mental activity (landmark activities). Landmark activities are defined as those with a 4-year window of engagement (January 1990 to December 1993) among the HIV-infected participants. A significant number of neurocognitive and neuropsychological tests were administered to these participants. Results revealed that an increased number of landmark activities were associated with better global neurocognitive performance as well as a lower prevalence of HAND. These cross-sectional findings suggest that an active engagement in life may behove neurocognitive functioning, perhaps by enhancing cognitive and/or brain reserve. Future studies should utilize neuromapping, methodological data, and intervention approaches to conduct cause-effect relationships and uncover the neural mechanisms behind physical, social, and mental stimulation and neurocognitive impairment via cognitive training intervention strategies. Keywords: Cognitive reserve, NeuroAIDS, Cognitive impairment, Promotive factors

Introduction

Infection with HIV continues to negatively impact the central nervous system through effective combination antiretroviral therapy (cART) that has improved survival rates (Huenion et al., 2011). Although the prevalence of HIV-associated neurocognitive disorders (HAND) that underlies commonly intuitive and real-world functioning are observed in about half of HIV-infected adults (Huenion et al., 2010). With the increased longevity of HIV-infected individuals (Duks and Phillips 2009) and the potential combined effect of HIV and aging on neurocognitive changes (Huenion et al., 2011), there is a significant need to examine factors that may help this high-risk population to potentially avoid, or delay the onset of neurocognitive impairment. Successful cognitive aging occurs in a subset of persons living with HIV and is correlated with better everyday functioning (Maher et al., 2011), so reducing factors that may further sap the neurocognitive reserve of older adults is critical. Among both HIV-infected and uninfected adults, research to date has shown that higher education, better socioeconomic status, a more cognitively challenging occupation, and a higher number of landmark activities are all related to better HAND scores and lower neurocognitive impairment.

Brain Training That Works

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BrainHQ is a brain training system built and tested by an international team of over 100 top neuroscientists and other brain experts. The exercises aren’t just “scientifically designed”—more than 70 published papers (and...