Managing HIV in people with cognitive deficit

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Overview

• Potential causes of cognitive impairment
• HIV-related neurocognitive impairment
• Assessing and managing HAND
• Case studies
• 5 top tips for HCPs working with someone with neurocognitive impairment
What can cause cognitive impairment?
‘The pathogenesis pachyderm’

neurotransmitter depletion
oxidative stress
inflammation
apoptosis
mitochondrial DNA
excitotoxicity
multiple sclerosis

ALZHEIMER’S DISEASE
ALS
STROKE
EPILEPSY
PARKINSON DISEASE

Vladimir Hachinski Stroke. 2007;38:1396
What can cause cognitive impairment?

- Moving away from idea of ‘age’ to ‘health’ of brain (which tends to decline with age!)
- Drug use
- Alcohol
- Cholesterol
- Pain
- Alzheimer’s
- Parkinson’s
- ADHD
- Syphilis
- Hepatitis
- Cardiac problems
- Hypoxia
- Vascular dementia
- CO poisoning
- Multiple Sclerosis
- Liver problems
- Medication
- Toxins exposure
- Sleep apnoea
- Encephalitis
- Delirium
- Anxiety
- Psychosis
- Depression
- Fatigue
- Smoking
- Stroke
- Motor-neurone disease
- Vitamin deficiencies
- Concussion
- Head injury
- Epilepsy
- Intellectual disability...
- And, for some people, HIV and/or ARVs...
HIV related neurocognitive impairment

• **3 levels of disturbance** *(Antinori et al., 2007)*
  1. Asymptomatic neurocognitive impairment: no difficulties, own insight
  2. Mild neurocognitive disorder: difficulties complex tasks, others notice
  3. HIV-associated dementia: require support w/ ADLs (rarer post-HART)

• **Differential diagnosis** - ‘Secondary HAND’
  - *ART related* = sudden onset, restored following ARV change
  - *Other dementias* (e.g. Alzheimer's = greater memory difficulties, Vascular = stepped decline, Lewy-bodies = hallucinations etc.)
  - *Depression* = greater difficulty with timed tasks, more tired in morning c.f. neurological tire over the day
  - *Anxiety* = episodic memory and executive function but not verbal fluency or psychomotor speed
  - *Older age* = natural decline, use appropriate age-related norms, difficulties above and beyond episodic memory
HIV-related neurocognitive impairment

- **HIV-Associated Neurocognitive Disorders (HAND) (Rackstraw, 2011)**
  - $H_1$: HIV brought inside the brain by immune system cells sets up inflammation in the brain (‘Trojan Horse’)
  - $H_2$: HIV infection sets up brain cells to be permanently more vulnerable to conventional risk factors

- **HIV risk factors**
  - Nadir CD4 <200, non-concordance w/ ARV, co-infection, older, substance use

- **Common deficits (‘sub cortical’ profile)**
  - Affects: processing speed; episodic memory; attention/working memory; executive function; visuo-perception; verbal fluency
  - **BUT** increasingly getting ‘mixed’ and ‘cortical’ profiles too...
What are the rates of HAND? A good question with a variable answer!

‘Sceptics’ vs. ‘enthusiasts’ – Dr Lewis Haddow

Prevalence estimates of HAND vary depending on population studied, sample/exclusions criteria, ARVs, criteria/definition used, neuropsych tests and norms used, etc.

Wide ranges e.g. from 74% of ‘complaining patients’ (Simioni et al., 2010), to HIV-negative controls having higher rates of NCI than HIV+ patients (Crum-Cianflone et al., 2013).
Assessing & Managing HAND/NCI

- **Detection**: client and/or friends/family noticing sustained cognitive impairment (memory, problem solving, language etc.), possibly in relation to effects of HIV and/or medication, or detected in screening.

- **Assessment**: clinic interview and neuropsychometric testing; aim is to identify client’s neurocognitive profile (strengths and weaknesses), and whether this deviates from pre-morbid state, and if so, why.
  - **Motivation**: does client wish to complete tests, fatigue effects
  - **Cognitions**: insight, beliefs about cognitive ability, anxiety +/- or depression
  - **Behaviours**: performance on tests, test behaviours
  - **Systems**: who is concerned? Individual? Family? Friends? HIV team?

- **Management**: start ARV if not on; switch ARVs; reduce other risk factors; memory strategies/neuro-rehab (compensation > restoration). Initial assessment can become base-line for further assessment if change suspected.
Assessing Cognitive Impairments

• Functional assessments: tasks relevant to person, completed by occupational therapists in ward, clinic or community
• Identify abnormal performance, analyse steps of task and where difficulties present
• Working and managing finances
• Walking and talking
Managing Cognitive Impairments

- Neuro-rehabilitation
- Memory service and community rehab teams
- Early intervention as per NICE guidelines
  - Risk factors eg smoking
- Health Promotion is everybody’s business
FHIVA Case Study 1

Shaun Watson
Community Clinical Nurse Specialist
(HIV)
History

• Harry (67) HIV positive since 1999, lives with his partner, George (84) for 50 years.
• Taking Kivexa, Nevirapine, Septrin.
• History of AF, vascular dementia, no PMH to note
• Admitted to ward with AF and acopia. Discharged after one week with care package (not assessed) 2 visits a day.
• Referred to community CNS by HIV clinic CNS to assess adherence and general home situation.
• Called Harry and explained the referral and arranged visit
On Assessment

• Home spotless, well stocked with food. Partner unsure why carer’s are there to clean and shop as he does it all.
• Harry’s medication in bedside drawer, looks in order able to tell community CNS what he takes daily
• George mentions that he has vascular dementia too
• Both see different GP practices, discuss moving to same one.
• George & Harry have no family or friends, fiercely independent.
2\textsuperscript{nd} visit

- No Nevirapine, 4 boxes of Kivexa. More ordered and CNS to collect
- Harry states he takes once a day only
- George says he has nothing to do with Harry’s medication. Concerned about Harry’s lack of motivation
- Called social services to raise concerns that care package was too much and asked visits only to prompt medications
Question One

What do you think is happening?

1. Historical old collection of Kivexa?
2. Patient overdosing on Nevirapine?
3. Nevirapine hidden around the flat?
4. It’s a mystery? (white!)
3rd Visit

• Harry has been known to take too many Nevirapine (noted some time ago by HIV clinic, not mentioned on referral)
• After much discussion - weekly blister packs issued and community CNS advised to remove all stock. Harry in agreement with this
• Email trail started between Consultant, Hospital pharmacy team, Clinic CNS team, community HIV CNS
• George complaining about social services package of care (embarrassed, too much) – called to reassess.
• Social services reassess and stop all services as Harry “appears to be managing and told us he didn’t need it”
4th Visit

- CNS called by Harry – no medications, (there should be 4 days left)
- At home – all medications gone, Harry insistent that only 3 days in the blister pack. Some extra Kixexa added to blister pack. Issued with another.
- Contacted GP and referred to DN’s (reluctant to see as no physical problems but ‘make a referral’).
- Tried to re-refer to social services (told it was too early) no other dementia services offered as Harry is deemed to be “too well”
5th Visit

• Harry still adamant that he takes medications once a day, no medications left in blister pack (2 days missing) Decanted to his own dosette box

• George asking for more support – discussed day care, Admiral Nurse involvement (declined)

• Call from GP to discuss the situation, he will ask DN to visit to assess. Seen for 2 visits with no new issues....then Harry is seen in HIV clinic (written and verbal reminders) and prescribed 2 months ART!
Question 2

What happened next?

1. Harry wasn’t allowed to collect his ART and was distressed
2. Harry collected his ART and handed it over to the community CNS at the next visit
3. George collected the ART and handed it over
4. Harry collected the ART and overdosed (white)
8th Visit

• When seen at home 22 Nevirapine and 18 Kivexa missing over 4 days, all medications removed. Assessed and reported to HIV team and to be monitored
• Harry in ED (distressed over lack of medication) and admitted to hospital – seen by psychiatric liaison team feels no depression, identified memory issues.
• Harry stated that he takes Nevirapine for pain and anxiety.
• DN service started (weekly to compliment community CNS) Added to email group.
• Now both men supported by GP and DN.
Learning points

1. **Holistic assessment**: before discharge would have identified partners dementia, level of need etc.

2. **Communication**: Talk, talk, talk! Note issues raised in e-mails and flag to prevent medications being supplied.

3. **Integrate**: involve GP and community services as soon as possible.

4. **Issues for the future**: as our patients age we are seeing issues that don’t fit neatly into any box so use resources that are available and communicate along the pathway.
FHIVA Case Study 2

Michelle Croston

Specialist Nurse
History

• Joe (36) HIV positive since 2006, lives alone with his dog.
• Informal care given by family.
• Long history of non adherence to treatment
• Supported by specialist nurse and clinical psychologist since diagnosis.
• Joe has an advance directive to facilitate his choice to not take ARV’s and outline his care preferences.
• Previous history of falls, fractured hip and shoulder. Admitted multiple times as a result of seizures.
• Regular virtual support provided and Joe attends hospital when required (refuses regular home visits).
Presented at clinic

• Called in for a ‘chat’, weight loss (piece of string holding up his pants), incontinent (using tea towel as continence aid), recent graze to his head and is unsure how it happened.

• Contact next of kin, report he is not looking after himself, more argumentative, verbally abusive (more than usual) house is in a mess, dog faeces on the floor, refusing to let family in to the property if he is in a ‘bad ‘mood.

• Joe is receiving on average about 20 packages from Amazon a day.

• ‘Sacked’ his friends as they were boring. States he prefers his own company.
On the ward

• Difficult relationships with staff, disinhibited behavior and not engaging with care.
• Incontinent and refuses assistance with hygiene needs.
• Room quickly turned into ‘teenagers bedroom’, full of CD’s, DVD’s etc, Amazon packages continue to arrive!!
• Unsteady on his feet and has fallen twice and keeps sneaking off the ward for his nicotine fix.
• Decides he’s ‘had enough’, wants to go home, ‘not sure what all the fuss is about’.
Question One

What do you think is happening?

1. He is having a psychotic episode?
2. He has developed HIV related dementia?
3. He is having a mid life crisis?
4. Tricky, not sure? (white)
Consultant Review

• Urgent MRI scan requested which supported clinical diagnosis of dementia.
• Mental health team review, suggest he could also be psychotic and suggest mood stabilizer and antidepressants.
• Psychologist – brief neurocognitive assessment, identified executive functioning issues.
• Joe’s behavior became worse as did his desire to go home. Joe had an over exaggerated view of what he could ‘safely’ manage to do at home. Refused all care interventions. Refusing all medication and assaults member of staff.
• Emergency capacity assessment requested and the Deprivation of Liberties team become involved.
Care Home

• Qualified for continuing healthcare and transferred to care home (new DOLS assessment).
• Care home staff described him as ‘challenging’ and thought he was just ‘playing up’, moved him to the basement room.
• Decided to take ARV’s and wanted ‘out of the place’.
• Urgent transfer to alternative care home, tricky due to funding issues (new DOLS assessment).
• Improved significantly, 100% adherent to treatment, put on weight, loved the staff.
Re-Assessment & Funding

- DOLS assessment needed reviewing after 6 months. CHC funding also needed to be reviewed at the same time.
- MDT discussions, including Joe, felt he might not need as much support but there were still a number of concerns.
- Comprehensive assessment with myself and DOLS assessor around discharge, medication, etc. Very hard, emotive and felt this needed escalating to a judge to decide a longer term plan.
- Second assessment to be performed. Via the telephone!! Deemed to have capacity as was taking treatment
- CHC: he no longer met funding criteria (as he hadn’t died and was taking treatment) - Joe refused to pay for care.
What happened next?

1. Discharged home with family support
2. Discharged home with social services support
3. Referred to the court of protection for guidance
4. Something else? (white)
Home

• Went home, against advice, family at breaking point. I wasn’t able to get information from the DOLS team and they were unable to provide me with the assessments. Social worker closed the case.

• Within 2 months he was admitted four times, safeguarding team involved, more capacity assessments, by now Joe is a expert in all things capacity, refuses neurocognitive screening.

• Finally, Joe had a social worker who will work with him and understands his needs.

• Supported at home on an intensive care package, working towards supported housing.
Learning points

1. Capacity
2. Communication
3. Integrate
4. Issues for the future
5 top tips for HCPs working with someone with NCI

1. **Know about the cognitive impairment...**
   - Have it as an important alert on their file, so that everyone communicating with them knows/remembers each time they see or phone them.

2. **This about what you can do differently to help...**
   - E.g. Talk slower, have longer appointment time, avoid metaphors, special appointment reminder texts/calls/emails

3. **This about what they (the patient/client) can do differently to help...**
   - E.g. Record appointments on their phone, make notes for/during appointment, have friend/advocate with them in an appointment

4. **Beware of acquiescing...**
   - Their nods of head, ‘Yes/No...’ and understanding facial expression, but with no actual comprehension: most likely if we ask ‘closed’ questions:
     - ‘Do you understand?’ vs. ‘So I can check I’ve been clear, please can you say back to me what you’re going to do’?

5. **Be aware of any frustrations of your own...**
   - Remember it’s not the person’s fault they have NCI, they’re likely to be more frustrated than you, and maybe ashamed. Focus on their strengths!