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marking World AIDS Day

QUEEN ELIZABETH II CONFERENCE CENTRE
LONDON

Evolving Models of HIV Care for the 21st Century

British HIV Association BHIVA

Multi-professional working in practice

London, 27.11.14

'Complex issues of the late presenter'

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Promoting excellence in psychology

Talk overview

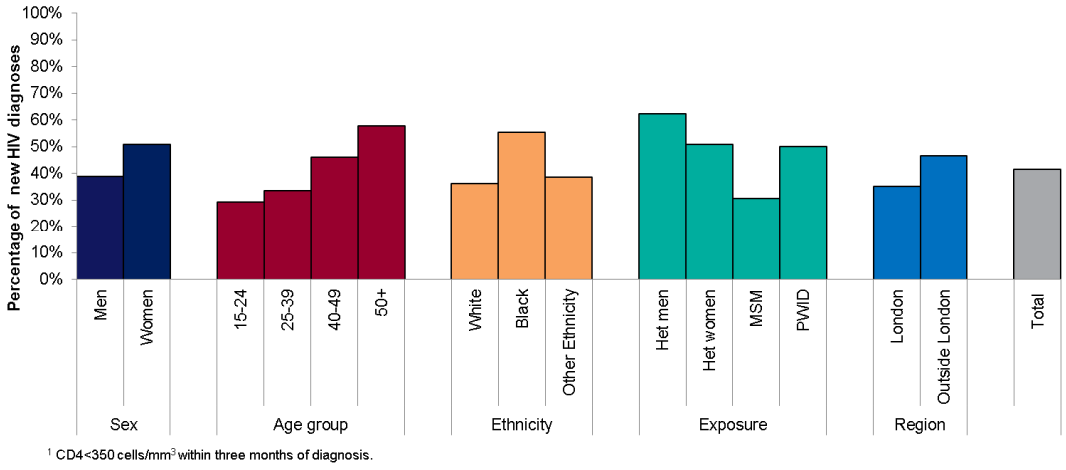
- Defining late medically
- Why being 'late' matters
- Defining late psychologically
- Those who knew their status *c.f.* those who didn't
- Rehabilitation
- What we need to be changing

Defining 'late presenter': a medical perspective

- **Late presentation**: persons presenting for care with a **CD4 count below 350** cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count.
- **Presentation with advanced HIV disease**: persons presenting for care with a **CD4 count below 200** cells/μL or presenting with an AIDS-defining event, regardless of the CD4 cell count
- Antinori *et al.* (2011). Late presentation of HIV infection: a consensus definition. *HIV Medicine*, *12*, 61-64.
- Of the 6,000 new HIV+ diagnoses made in 2013, **42%** (2,500) diagnosed with CD4<350: **24%** (1430) = CD4<200 (PHE, 2014).

Who is 'late'?

Proportion adults diagnosed with CD4 <350 in UK in 2013[1] (PHE, 2014)



[1] CD4<350 cells/mm^3 within three months of diagnosis.

Why it matters: a medical perspective

- Those diagnosed HIV+ late (CD4 <350) have **10x** increased risk of death in 1st year of diagnosis *c.f.* those diagnosed early (PHE 2014).
- **81%** of the 2,000 AIDS-related deaths in England and Wales over past 10 years were attributable to late diagnosis (PHE 2013).
- Premorbid and comorbid opportunistic infections, HIV-associated symptoms (e.g. weight loss, diarrhoea, fatigue) and other difficulties (especially Hep B/C, mental health, substance use) can complicate **ARV effectiveness** and/or **adherence** (Battegay *et al.* 2008).
- Immune Reconstitution Inflammatory Syndrome (**IRIS**): immune system begins to recover but then responds to other infections with inflammatory response which makes symptoms worse (Battegay *et al.*)

Why it matters: public health and financial perspectives

- More infectious if high viral load, more likely to infect others.
- Medical care **$27K-$62K** more expensive tracked **over first 8 years** comparing CD4 <200 *vs* >500 (Fleishman *et al.* 2010).
- Annual estimated cost for starting first line ARVs £12,812 if CD4 <200 vs. £10,478 CD4 >200 :**18% difference**. (Beck *et al.*, 2011).
- Direct medical costs over 15 years when CD4 <350 **twice** >350 inc. inpatient care and non-HIV drug costs.(Krentz & Gill, 2012).
- **Loss of productivity** to social economic system if ill: not working, not caring for others, and/or claiming benefits.

Defining 'late presenter': a psychological perspective

Language: what was the last thing you were late for?
What emotions, thoughts, images come to mind when you think of being late? How do you expect others to react?

Psychological models

- Having a HIV test is a **behaviour**. It will be driven by your **thoughts**, **feelings** and physical **body** (aka 'hot cross bun').
- Decision making models relevant e.g. **Health Belief Model**.
- **Benefits** to knowing your HIV status have to outweigh **barriers**.
- **You tell us**: what are disadvantages to knowing you are HIV+?

The late presenter who **did not know** they were HIV+…

- Now adjusting to the news - normal psychological adjustment processes *c.f.* early diagnosis, plus may have questions like…
- **Am I going to die?** - may be in very poor health, this is now their first personal association with HIV. ***Honesty with prognosis and examples of recovery.***
- **How did I get it?** - source of infection may be harder to ascertain: longer time period (memory for events poorer, longer time period for multiple risk factors to occur over) or client may be from 'low risk' demographic group. ***Move from 'how/who/why' to 'what next' for best health.***
- **What about my… (ex)partner(s)/child(ren)?** - may have been longer period of others being at risk (and with higher viral load) and guilt from this if others infected. ***Test others whilst working to reduce hindsight bias.***
- **Why did no one pick it up?** - trust in healthcare may be shattered - was HIV missed/misdiagnosed? ***Signpost to PALS, what can we do differently?***

The late presenter who **knew** (or suspected) they were HIV+…

- *Possible reasons they may not have (re)engaged in healthcare*:
- **Fear** - of confirmation of result, of stigma, of judgment from the healthcare system - ***what can we do to reduce anxiety?***
- **Disbelief** - aka 'denial' - not wishing to believe you're HIV+, or not feeling able to cope with a diagnosis at a previous life-stage - ***why able/want/need to now?***
- **Depression** - fatalism, nihilism, hopelessness - not believing you can be helped or not believing you deserve to be helped - weakens drive to seek help - ***how can we improve knowledge, self esteem and instil hope?***
- '**Cured**' - belief you have been cured (e.g. faith healing, alternative medicines) - ***what does re-diagnosis mean to the belief system?***
- **Access** - not been able to access treatment (e.g. not available where previously lived, or too dangerous/costly) - ***how can we make this easier/safer?***

What is Rehabilitation?

- Interventions to maintain and improve an individual's functioning
- Multi-disciplinary – inc. physiotherapists, occupational therapists, speech and language therapists, and psychologists, alongside medical and nursing staff
- Any setting – hospital, clinic or community settings
- Indicated following a specific HIV related illness, or where there has been a gradual decline in function
- Reduces length of hospital stay and helps prevent unnecessary admission to hospital

Common Late Presenting Illnesses with Rehab Needs

- PCP (Pneumocystis pneumonia)
- Lymphoma
- TB (Tuberculosis)
- Cerebral toxoplasmosis
- PML (Progressive Multifocal Leukoencephalopathy)
- HAND (HIV Associated Neurocognitive Disorder)
- Deconditioning/weight loss

Rehabilitation Issues

- Am I dying or living?
- The lower the nadir, the longer the recovery
- Late presentation = co-morbidities = rehabilitation needs
- Ageing factors

Rehab: Evidence & Access

Evidence

- Cochrane reviews (2004/2010) aerobic exercise and progressive resistive exercise – safe and effective
- O'Brien *et al.* (2014). Evidence informed recommendations for rehab with older adults living with HIV: a knowledge synthesis

Access

- Form links with Therapy Department at local hospital
- Single point of referral
- Refer back to GP

What should we be changing?

- **Earlier diagnosis, practical & psychological barriers**: will be different for different risk-groups (reviews, Enrico *et al.*, 2007; Mukolo *et al.* 2013):
  - routine HIV testing in health settings where 'high-risk' individuals attend
  - HIV testing services in non-medical settings (including home)
  - partner notification schemes
  - peer-led projects to encourage high-risk individuals to attend for testing
  - **fear and stigma** of testing and/or of becoming HIV+: those who 'preferred not to know' have double risk late testing than 'okay knowing'
  - **self risk-appraisal:** if perceive self to be low risk (demographically or because trust in '-ve' status of high risk partner) less likely to present

What should we be changing?

- **Care models**: given the inherent physical and psychological issues for 'late presenters', a **separate** or **enhanced care pathway** is likely to be needed, which has a MDT **rehab** interface.
- E.g. rehab class and psychology pathway at C&W
- Mocroft *et al.* (2013): need timely referral after testing HIV+ and improved retention in care strategies when DNA/Cx.

People, *not* CD4 counts

"Having been found to be positive at almost seventy years old was a massive shock but once it had sunk in I did feel somewhat let down that nobody had suggested it before, despite the otherwise wonderful care I had received."

Alan, 70, Ch4 News.

E-Module for Evidence-Informed Rehabilitation

- Canadian Working Group on HIV and Rehabilitation
  www.hivandrehab.ca

- Comprehensive electronic resource
- Includes sections on Ageing and Concurrent Health Conditions and cognitive rehabilitation

- http://www.hivandrehab.ca/EN/information/care_providers/documents/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf

E-MODULE FOR EVIDENCE-INFORMED HIV REHABILITATION

(E-Module)

2014

Key documents

- Antinori *et al.* (2011). Late presentation of HIV infection: a consensus definition. *HIV Medicine*, *12*, 61-64.
- Battegay et a. (2008). Antiretroviral therapy of late presenters with advanced HIV disease. *Journal of Antimicrobial Chemotherapy, 62, 41–44*
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- Cochrane Database Syst Rev. (2010). Aerobic exercise interventions for adults living with HIV/AIDS.
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- PHE (2013). HIV in the United Kingdom 2013 Report.
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