21st Annual Conference of the National HIV Nurses Association (NHIVNA)

27–28 June 2019 · Manchester Conference Centre
Challenges of getting people on treatment

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Declaration of interests relating to this presentation

• None
Plan for session

• Explore reasons why people are not on ARVs

• Look at some strategies to support people to start or re-start ARVs

• Outline our role as nurses in addressing the complexities of getting people on ARVs
ZERO DISCRIMINATION

PARIS DECLARATION
1 December 2014

FAST-TRACK CITIES: ENDING THE AIDS EPIDEMIC
Cities Achieving 90-90-90 Targets by 2020

THE TREATMENT TARGET

- 90% diagnosed
- 90% on treatment
- 90% virally suppressed

ZERO DISCRIMINATION
Figure 1: Continuum of HIV care, UK: 2017

- People living with HIV: 100%
- People diagnosed with HIV: 92%
- On treatment: 90%
- Virally suppressed: 87%

UNAIDS 90:90:90 target:
- People living with HIV: 100%
- People diagnosed with HIV: 90%
- On treatment: 81%
- Virally suppressed: 73%

Progress towards ending the HIV epidemic in the United Kingdom: 2018 report
Audit of those not on ARVs in Brighton, June 2019

21 not on ARVs

- 5 elite controllers and 1 had HIV 2
- 15 had declined

- 3 LTNP of which 2 were symptomatic
- 12 declined for other reasons

- 4 felt better off treatment
- 3 using alternative therapies
- 3 insecure housing
- 2 significant mental health issues

Overall 7/15 expressed concerns about side effects
### Side effects

#### Key messages for patients

- Many side effects are short term and most can be managed
- Modern ARVs have a better side effect profile
- We have a lot of ARVs to choose from
- Long term side effects are less common and are monitored for
- Direct to online patient resources such as aidsmap, i-base and myHIV
- Involve Peer Mentors where available
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Common-sense origins of HAART Necessity and Concerns

**NECESSITY**

Doubts about personal need for HAART associated with:

- Perceiving oneself to be in relatively good physical health ($r = -0.24, p<0.005$)
- Higher CD4 count ($r = -0.18, p<0.03$)
- Longer time since HIV diagnosis ($r = -0.32, p<0.001$)
- Scepticism about efficacy of HAART ($r = 0.58, p<0.001$)
- Negative attitudes towards medicines in general

(General harm ($r = -0.26, p<0.005$), general overuse ($r = -0.30, p<0.001$))

**CONCERNS**

HAART-Concerns associated with:

- Perceived sensitivity to adverse effects from medicines ($r = 0.38, p<0.001$)
- Perception that medicines in general are harmful ($r = 0.42, p<0.001$) and over-prescribed ($r = 0.28, p<0.001$)
- Depression (HADS) ($r = 0.46, p<0.001$)
- Anxiety (HADS) ($r = 0.47, p<0.001$)

NOT associated with depression, anxiety, VL or disease classification (asymptomatic/symptomatic/AIDS)

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Insecure housing

- ARVs not a priority
- Often nowhere to store tablets
- Food restrictions can be a limiting factor
- Financially insecure
- Drug and alcohol issues can co-exist
Case Management

• Keeping individuals engaged in HIV care
• Individualised care plans working with their priorities
Assessing need/priorities

We would like to know about your worries and concerns today. Please circle a number on the thermometer below and tick any boxes that are relevant to you.

**PRACTICAL PROBLEMS**
- Housing
- Financial
- Benefits
- Immigration
- Employment
- Childcare
- Transport

**PSYCHOLOGICAL PROBLEMS**
- Loneliness or isolation
- Depressions or sadness
- Worries about the future
- Difficulty accepting your diagnosis
- Concerns about stigma/confidentiality

**SOCIAL PROBLEMS**
- Relationships (family, friends, partner)
- Difficulty telling others about your diagnosis

**SPIRITUAL/RELIGIOUS ISSUES**
- Questioning beliefs and values
- Conflicts between faith and HIV

**MEDICATION PROBLEMS**
- Side effects of medication
- Difficulty remembering medication

**OTHER**

10 Many Worries

0 No Worries
Case Management

• Keeping individuals engaged in HIV care
• Individualised care plans working with their priorities
• Build relationships with housing and outreach services
• Focus on getting people off the streets where possible
• Flexible approach to follow-up and ARV supplies
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Prevalence of Mental Health Conditions
Royal Sussex County Hospital

- Depression: 33% of PLHIV nationally, 19% in the general population
- Anxiety: 25% of PLHIV nationally, 15% in the general population
- Sleep Disorder: 15% in PLHIV nationally
- Personality disorder: 3%
- Bipolar: 2%
- Eating disorder: 3%
- PTSD: 5%
- Psychosis: 1%

Positive Voices Survey 2017
Integrated care

- Work in partnership with mental health services
- Professionals Meetings / Case Conferences
- Identify the patient’s priorities
Screen all patients using PHQ4. If PHQ 4 score is > 4 do both a GAD7 and PHQ 9

<table>
<thead>
<tr>
<th>GAD-7 score</th>
<th>Anxiety Severity</th>
<th>Proposed Treatment Actions</th>
<th>Depression Severity</th>
<th>PHQ-9 score</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 4</td>
<td>Mild</td>
<td>None</td>
<td>None/ Minimal</td>
<td>0 - 4</td>
</tr>
<tr>
<td>5 - 9</td>
<td>Moderate</td>
<td>Watchful waiting; repeat GAD-7 and PHQ 9</td>
<td>Mild</td>
<td>5 - 9</td>
</tr>
</tbody>
</table>
| 10 - 14     | Moderately severe| 1. Onward referral for further evaluation and assessment to GP OR  
2. Self referral to health and well-being service https://www.brightonandhovewellbeing.org/  
AND relevant referral for practical support such as THT, Housing, Peer Support, Mind out, Headspace, LGBT helpline AND consider referral to HIV Community Specialist team for support or mental health input.  
www.nhs.uk/oneyou for generic stress, anxiety, sleep  
Online apps: https://www.mindcharity.co.uk/advice-information/how-to-look-after-your-mental-health/apps-for-wellbeing-and-mental-health/  
Also see mental resource sheet in Lawson nurses file. | Moderate           | 10 - 14       |
| 15 - 21     | Severe           | Active treatment psychotherapy and/or pharmacotherapy by GP………………………OR  
If HIV related refer to SPNT.HIVMHREF@nhs.net and encrypt or password protect the letter  
What is HIV related?  
When HIV is the cause of the anxiety / depression or the anxiety/depression is likely to compromise stable HIV infection. | Moderately severe or Severe | 15 - 19       | 20 - 27    |
Keeping people engaged with treatment and care
ARV use in people not engaged with care

Lost to follow-up data 2014-2016, Brighton

PHE National data 2017

Progress towards ending the HIV epidemic in the United Kingdom: 2018 report
Risk Factors for poor attendance

- **General Risk factors**
  - Younger age
  - Diagnosed with HIV for longer
  - Having children
  - Female
  - Telling family about HIV status
  - Not getting help when sick in bed
  - Not having money for basic needs
  - Drug/alcohol dependency

- **Missed 1 or more appt /year**
  - Poorer recent health
  - Symptoms of neurocognitive impairment,
  - Depression
  - Having complex needs (HARS 3)
  - HIV-related hospitalisation
  - Uncertainty about being in charge of life

- **Absence of 1 year or more**
  - Not being registered with a GP
  - Not being a homeowner
  - Not feeling listened to by the nurse
  - Less educated
  - Recreational drug use

Howarth, A. Apea, V. Michie, S et al 2017
Principles for sustaining retention in care

1. Proactive DNA management approach
2. Identify who is at risk of disengaging
   o Review frequency of appointments
   o Individualised care planning
     • Community bloods / yearly attendance
     • Incentives for reduced attendance
   o Consider alternative venues to see patients
   o Engaged with any healthcare
3. Consider our responses when people return to care
4. Keep the door open for people to return
The forgotten few: the challenge of opting out of ART

Pauline Jelliman, 20th Annual Conference of NHIVNA, Brighton 2018
Patient right to refuse treatment

Quality statement 7: Supporting patient choice

“Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported”

https://www.nice.org.uk/guidance/qs15/chapter/quality-statement-7-supporting-patient-choice
Conclusion

• We need to balance respect for people’s decisions to refuse treatment with tackling any barriers that may help them to start or restart.

• But, we also need to remember that for some people not taking ARVs is *their* quality of life.