Growing up with HIV – the paediatric legacy for HIV adult services

Dr Caroline Foster, part 2 of 2
2 Populations with PaHIV?

• **18+ yrs**: survived preHAART
  • Slower progressors
  • Mono-dual therapy
  • Less but toxic ART exposure
  • More viraemia
  • Family bereavement

• **<18 yrs**: +/- rapid progression but survived
  • Less viraemia but >ART exposure
  • Physical disability + HIV + adolescence
  • 28% of 12-18yrs olds significant neurodevelopmental issues
Time of change:

Downside: Increases in

- Challenging behaviours
- Disaffection with school
- Risk taking – drugs, alcohol etc.
- Pregnancy & STD’s
- Depression
- Self harm

Upside: opportunities for

↑ Friends
↑ Relationships
↑ Freedom
↑ Creativity: music, clothes, dance
↑ Developing identity, sexuality and control
↑ Excitement and fun often without responsibility
UK 15 year olds:

- 25% smoke regularly
- 50% drink weekly
- 35% have used drugs
- 10% girls self harmed last year
- 35% sexually active
Greater rate of risky behaviours in youth with chronic conditions

- current smoking 1.32 (1.13, 1.54)
- illegal drugs 1.49 (1.15, 1.92)
- early sexual debut 1.33 (1.03, 1.72)
- eating disorder 1.44 (1.26, 1.74)
- antisocial acts 1.48 (1.26, 1.74)
- attempted suicide 2.24 (1.55, 3.24)

- more likely to report 3 or > 4 simultaneous behaviours

*JC Suris et al, 2007 J Begent CHIVA 2010*
Prefrontal cortex maturation - 3rd decade

- Embarrassed by parents section
- Ability to remember the lyrics to offensive hip hop song...
- Have no idea...
- Cars, cars, cars, cars, and... oh, yeah, girls...
- Girls are suddenly fascinating section
- Ability to listen to extremely loud base tracks
- School Work (smallest section of the brain)

Anatomy of a Teenager's Brain
Impact of HIV throughout brain development?

• Spectrum: Infantile encephalopathy (hypertonic diplegia)
  Abubaker et al 2008
  Expressive speech delay
  Behavioural difficulties
  Increased psychiatric morbidity
  Poor executive functioning
  Eur J Paediatr Neurol. 2008

• Complex potential aetiology: HIV
  Chronic inflammation,
  Previous CNS infections,
  Complex psychosocial/family circumstances,
  ARVs and in utero drug exposure
  Malnutrition
• 154 PaHIV median age 19.5yrs.
• 18% psychiatric diagnosis: depression>psychosis> anxiety
• Median age psychiatric diagnosis 18yrs
• 37% psychological diagnoses: anxiety, depression, self harm, risk behaviours
• Associated with lower current median CD4 count
Mortality amongst HIV-infected young people following transition to adult care: Fish et al HIV Med in press

- 11 deaths reported Sept 2003 - March 2011
- 9 black African, 6 female, 9 born abroad
- median age: transfer: 17 yrs (15-21), death: 21 yrs (17-24)
- Causes of death: suicide (2)
  - end stage AIDS (3)
  - respiratory infections (2)
  - PML (1)
  - cerebral lymphoma (1)
  - ICH cerebral toxoplasmosis (1)
  - missing (1)
Immunology/virology

- **Transfer** - median CD4 count 120
  VL <50 in 2 pts
- **Death** - median CD4 count 27
  VL <50 in 2 pts

- **Resistance**: all had treatable virus in yr of death

Only 2 others ever had VL<50 recorded in adult care
9/11 mental health diagnosis
• 138 YP aged 12-24 on HAART
• 55% on ART 4 yrs+, 38% ever stopped
• Family and peer support felt most helpful for adherence (69%)
• Daily activities and simply forgetting identified as the main barrier (88%)
• Needing to keep diagnosis secret impacts on adherence (23%)
Financial Incentives and motivational interviewing for adolescents with advanced HIV disease; a pilot service
C Foster et al BHIVA 2012

Eligible:

- PaHIV age 16-25 years
- CD4 count ≤200
- Off ART despite multiple attempts to start
- Willing to start ART and to sign patient agreement

<table>
<thead>
<tr>
<th>Started ART</th>
<th>VL response &amp; attended for MI</th>
<th>Voucher value</th>
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<tr>
<td>Week 2</td>
<td>Fall in VL</td>
<td>£ 25</td>
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<tr>
<td>Week 4</td>
<td>Fall in VL</td>
<td>£ 25</td>
</tr>
<tr>
<td>Week 8-16</td>
<td>VL&lt;50</td>
<td>£ 50</td>
</tr>
<tr>
<td>3 months suppressed</td>
<td>Sustained VL&lt;50</td>
<td>£ 25</td>
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<tr>
<td>6 months suppressed</td>
<td>Sustained VL&lt;50</td>
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<tr>
<td>12 months suppressed</td>
<td>Sustained VL&lt;50</td>
<td>£ 50</td>
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<tr>
<td>Total</td>
<td></td>
<td>£ 200</td>
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Results

Median CD4 count start 30 (IQR 10-160)
- 9/11 ever achieved VL<50,
- 5 sustained at 1yr, 6 at last OPD
- CD4 median increment of 110 cells at 1 yr
- Cost £67 per 50 CD4 cells at 1 yr
  - £44 per 50 CD4 cells at last OPD
    - median 6/12 post IS
Cardiovascular Risk

Less well documented than in adults but HIV +/- ART:

- Hypercholesterolaemia 10-86%
  hypertriglyceridaemia 13-67%
  insulin resistance in 7-52% [Hazra at al 2009]
- Increased carotid artery intima-media thickness.
- Increased hsCRP [Ross et al Atherosclerosis. 2010]
- High prevalence of thrombophilic abnormalities. [Pontrelli et al AIDS 2010]
- Treatment interruptions, Abacavir use…..
• 19% of children and 9% of young adults had stage I hypertension
• 24% of children and 14% of young adults had cholesterol > 5.0 mmol/l
• 32% children overweight/obese

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>BMI definition</th>
<th>Children (%)</th>
<th>Young Adults (%)</th>
<th>P=</th>
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<tbody>
<tr>
<td>Obese</td>
<td>BMI &gt; 98th c or &gt;30</td>
<td>16</td>
<td>4</td>
<td>P=0.006</td>
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<tr>
<td>Overweight</td>
<td>BMI 91st-98th c or 25-30</td>
<td>16</td>
<td>16</td>
<td></td>
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<tr>
<td>Underweight</td>
<td>BMI &lt;2nd c or &lt;20</td>
<td>5</td>
<td>20</td>
<td>P=0.001</td>
</tr>
</tbody>
</table>
Education and Peer support

- Puberty
- Aware diagnosis - routes of transmission
- Negotiating relationships
- Safe sex and condom use
- Contraception
- PEPSE/ECP
- Criminalisation and the law
- Pregnancy planning
**Accidents and it**

With thanks to all the young people who worked on this leaflet and gave their time and advice.

**The facts**

**What can happen if a condom splits or falls off?**

1. A girl can get pregnant – this is less likely if she takes the “morning after pill” as soon as possible – within 3 days. Your clinic calls the morning after pill the **Emergency contraceptive pill**.

2. HIV can be spread from person to person – this is much less likely if your boyfriend/girlfriend takes special anti-HIV medicines after a condom accident. Your clinic calls this medicine **PEP. Post Exposure Prophylaxis**.

If you are taking anti-HIV medicines you probably need a double dose of the morning after pill – talk to your clinic/GP/A&E/Pharmacy.

**PEP- what’s this?**

This is anti-HIV medicine that can be given to people who are not infected with HIV to PREVENT them getting it after they have been in a risky situation such as a condom breaking if their partner has HIV.

**PEP- why would my boyfriend/girlfriend need it?**

If a condom breaks, slips off or you have forgotten to use one, this means your girlfriend or boyfriend is at risk of getting HIV.
Negotiating Relationships with HIV

- Disclosure: who and when and where and how?
- Transient relationships and confidentiality
- Fear of transmission
- Fear of criminalisation
- Fear of future - family and MTCT

Most are VERY responsible but stigma and secrecy unchanged by HAART
- 51 pts; median age 20 yrs (IQR 18-21)
- 77% females, 62% males reported being sexually active.
- Median age first sex 16yrs
- Median lifetime sexual partners was 3.5 (range 1-40).
- 5 reported non-consensual sex (4 females, 1 male).
- 7/33 STI
- 11 pregnancies in 8 patients, 1 father.
- 18/24 cervical smear - 5 abnormalities

Body and Soul CHIVA 2011

- n= 50, median age 17
- Median age coitarche 14 yrs, 5/50 non consensual sex
Reproductive Health in PaHIV

- Low rates of MTCT (0-3%)
- Complex case management
- Long term outcome for infants born to mothers with lifelong exposure to HIV and ARVs - unknown eg mitochondria
- Questions: Fertility-male and female, reproductive desires,
36 pregnancies in 27/172 (16%) women
- Median age 18 yrs (range 14-29)
- 75% unplanned, 61% disclosed status
- Outcomes: Miscarriage 14%, TOP 25%, live births 61%
- At delivery; Two thirds VL <50 c/ml
- 5/21 infants delivered prematurely
- 1/21 infected infant
- 67% social service support, 2/21 infants fostered
Research questions - sibling matched, large numbers, longterm follow up -
“AALPHI” Ali Judd MRC

- Transition: do different models have different outcomes?
- Adherence: RCT trials of interventions, sustainability, role of VS and “buddys”
- CNS: HAART as neuroprotection?
- CVS: prevention and paediatric lipid management
- Reproductive: HPV vaccination, cervical smears, fertility, offspring
Perinatal v Horizontally acquired HIV

- Multigenerational illness- young carers
- Chronic ill health in childhood- delayed puberty, growth, cognition/education
- Complicated ARV need- MDR
- Longterm S/E HIV and ARVs + future?
- Negotiating first (and every) relationships/SI with an STI
- Stigma and secrecy
- Immigration, poverty, employment
Prescribing HAART is the easy part
Rebels or conformists?
• The patients and staff of the Family and 900 clinics
• Sarah Fidler, Susan McDonald, Sarah Ayers, Graham Frize, Nina Lenton, Linda Greene, John Walsh, Adam Croucher
• Hermione Lyall, Sam Walters, Gareth Tudor Williams, Alasdair Bamford, Diane Melvin, Jo Dodge
• Edward Cairns, Tsitsi Chawatama, Michael James, Ruth Fish, Ellen Dwyer