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Mortality amongst HIV-infected young people following transition to adult care: an HIV Young Persons Network (HYPNet) audit.

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Background

- Increasing numbers of young adults transitioning from paediatric to adult care - outcomes unreported in the UK
- Annual prospective follow up in paediatric care in UK/Ireland in CHIPS cohort ceases at transfer to adult care
- By March 2011 CHIPS cohort: 305/1603 were in adult care
Age* of children including those transferred to adult care by year, 1996-2011

*Age is taken to be age at start of the year, or age at presentation if child presented during that year. Note: Data are for all children and young people in CHIPS (excluding those who have died or who are lost to follow-up) as well as young people in CHIPS who have transferred to adult care (assuming no deaths or losses to follow-up in adult care).
Methods

- A proforma disseminated via HYPNet to 15 participating adult HIV/voluntary sector services

- Identified cause of death and factors associated with mortality, including adherence, co-morbidity and mental health.

- Retrospective reporting of deaths in childhood acquired HIV up to 30.09.11

- Deaths were matched to the CHIPS database to ascertain clinical profile at transfer to adult care
Results

- 11 deaths reported Sept 2003 - March 2011
- 9 black African, 6 female, 9 born abroad
- median age at transfer: 17 yrs (range 15-21)
- median age at death: 21 yrs (range 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)
Results -VL/CD4

Death: CD4 median 27 cells/ul (range 0-630), 9/11 CD4 <200
2 had VL<50; suicide CD4 630, LRTI bronchiectasis CD4 270

Transition: CD4 median 120 cells/ul (range 0-651),
7/11 with CD4 <200, 2 had VL<50.

Resistance: 8/11 had any ART resistance
1 with triple class, two 4 class resistance
however all had potentially suppressive regimens available.
Adherence

- 9/11 had a history of poor adherence in paediatrics, 4/11 ever achieved VL<50 in adult care

- All those with poor adherence were offered multiple modes of support including: specialist and community nurses, health advisors, psychology

- 3 had gastrostomies to aid adherence

- 9/11 attended peer support.
Psychosocial

- Psychiatric Diagnoses: Depression (6), Psychosis (2), eating disorder (1)

- 4 lived with parents, 3 fostered/adopted, 4 lived alone.

- 6 in education, 1 employed, 4 unemployed.

- 6 ever involved with social services: 2 youth offending

- Drug use (4) never smoked (6) sexually active (6)
## Results - Statistics

### Mortality rates by age group (per 100 person years) from 2006-10*

<table>
<thead>
<tr>
<th>Age</th>
<th>Person years</th>
<th>Deaths</th>
<th>Mortality rate /100 person yrs (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;17</td>
<td>1746</td>
<td>5</td>
<td>0.29 (0.12 - 0.69)</td>
</tr>
<tr>
<td>&gt;17</td>
<td>1253</td>
<td>8*</td>
<td>0.64 (0.32 – 1.28)</td>
</tr>
</tbody>
</table>

### Poisson regression analysis

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>n</th>
<th>Mortality rate /100 person yrs (95% CI)</th>
<th>IRR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>13-15</td>
<td>3</td>
<td>0.22 (0.07-0.67)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>16-20 pre transition</td>
<td>2</td>
<td>0.30 (0.07-1.22)</td>
<td>1.39</td>
<td>0.21-8.3</td>
</tr>
<tr>
<td>16-20 post transition</td>
<td>4</td>
<td>0.63 (0.24-1.67)</td>
<td>2.87</td>
<td>0.64-12.8</td>
</tr>
<tr>
<td>21+</td>
<td>4</td>
<td>1.2 (0.45-3.2)</td>
<td>5.49</td>
<td>1.2-24.5</td>
</tr>
</tbody>
</table>
Conclusion

• Small number of deaths from selected clinics (15/~45)
• Due to AIDS diseases cf adult populations
• Associated with poor adherence in paediatric care
• High burden of mental health disorders

Planning

• UK Register of HIV Seroconverters
• Flagged to ONS/NHS Information Centre mortality data
• AALPHI - Adolescent and Adults Living with Perinatal HIV Cohort
• Novel adherence interventions - P85, P225
Acknowledgements

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