Adolescent transition to adult care: what do we know and research priorities

High-Resource Perspective On Adolescent Transition and Research Priorities
Ali Judd
Outline

1. What is transition?
2. Who is transitioning?
3. What are health outcomes after transition?
4. What transition interventions work?
5. What do we need to know?

Photo credit: UNAIDS/W.Triyasakda
1 - What is transition?
Purposeful planned movement of children with special health care needs from child to adult-centred care.

Blum 1993

Specialist paediatric

→ adolescent / transition clinic

→ adult care

Completely integrated care
POLICY STATEMENT

Transitioning HIV-Infected Youth Into Adult Health Care

Transition from children’s to adults’ services for young people using health or social care services

NICE guideline
Published: 24 February 2016
nice.org.uk/guidance/ng43
INDEPENDENT LIFE
LEAVING HOME AND STANDING ON YOUR OWN TWO FEET:

www.ncb.org.uk/LifeLinks
Key issues for transition

• Greater personal autonomy, less parental influence

• Depends on being aware of diagnosis
  – Stigma of HIV and family makes this difficult
  “Children of school age should be told their HIV positive status: younger children should be told incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure” (WHO 2011)
2 - Who is transitioning?
## UNAIDS 2015 HIV data, globally

<table>
<thead>
<tr>
<th>Description</th>
<th>Global total</th>
<th>Female</th>
<th>Male</th>
<th>sub-Saharan Africa % of Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated number of 10-19 year olds living with HIV</td>
<td>1,800,000</td>
<td>1,000,000</td>
<td>800,000</td>
<td>80%</td>
</tr>
<tr>
<td>Estimated number of 15-19 year olds newly infected with HIV</td>
<td>250,000</td>
<td>165,000</td>
<td>85,000</td>
<td>77%</td>
</tr>
<tr>
<td>Estimated number of 10-19 year olds dying of AIDS-related causes</td>
<td>40,000</td>
<td></td>
<td></td>
<td>87%</td>
</tr>
</tbody>
</table>

Source: UNAIDS 2015 HIV and AIDS estimates
About half of adolescents living with HIV are in just six countries: South Africa, Nigeria, Kenya, India, Mozambique and Tanzania.

How many people with perinatal HIV are in Europe?

<table>
<thead>
<tr>
<th>Category</th>
<th>Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;100</td>
<td>Austria, Belgium, Denmark, France, Netherlands, Romania, Sweden, Switzerland, UK, Spain, Portugal, Ireland, Greece, Italy</td>
</tr>
<tr>
<td>100-&lt;500</td>
<td>Russia, Poland, Ukraine, Latvia, Estonia, Lithuania, Finland</td>
</tr>
<tr>
<td>500-&lt;1,000</td>
<td>Russia, Poland, Ukraine, Latvia, Estonia, Lithuania, Finland</td>
</tr>
<tr>
<td>1,000-&lt;2,000</td>
<td>Russia, Poland, Ukraine, Latvia, Estonia, Lithuania, Finland</td>
</tr>
<tr>
<td>2,000-&lt;4,000</td>
<td>Russia, Poland, Ukraine, Latvia, Estonia, Lithuania, Finland</td>
</tr>
<tr>
<td>No paediatric</td>
<td></td>
</tr>
<tr>
<td>Not in EuroCoord</td>
<td></td>
</tr>
</tbody>
</table>

Age of UK/Irish patients with HIV acquired in childhood, 1996-2015

- Presented to care 10-15 years ago
- Transitioning now
- Already transitioned

<table>
<thead>
<tr>
<th>Year</th>
<th>3-5</th>
<th>1-4</th>
<th>&lt;1</th>
<th>10-14</th>
<th>5-9</th>
<th>15-19</th>
<th>20+</th>
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<tbody>
<tr>
<td>1996</td>
<td>334</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>457</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>624</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>816</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>1077</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>1274</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>1438</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>1550</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>1629</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>1657</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

N= 334 457 624 816 1077 1274 1438 1550 1629 1657
3 – What are health outcomes after transition?

Outcomes after transition:
- Retention in care
- Adherence/ viral load
- CD4
- death

Adolescent health outcomes:
- Psychosocial
- Cognition
- Sexual health
- Etc.
Retention in care after transition

- 50 adolescents in paediatric care in Baltimore

Ryscavage et al, AIDS Care 2016

Behavourally-acquired HIV

Perinatally-acquired HIV

Pre-transition linked to care

Retained at 12 months
Post-transition outcomes, UK
(Collins et al P_82)

• Linkage of 2 UK datasets: paediatric ↔ adult
• N=271 adults with perinatal HIV in both
  – Median follow-up in paed care 12 yrs [IQR 6, 16]
  – Median follow-up in adult care = 3 yrs [IQR 1, 6]
• Factors affecting CD4 after transition
  – CD4 slope stable pre-transfer, and declined post-transfer, after adjustment for other variables
  – Females had lower CD4s overall
  – No effect of changing hospitals at transfer
Problems of measuring health outcomes after transition

- Problems with measuring when transition occurred, different outcomes
- Small sample sizes, confounding
- Lack of detail on intervention
- Lack of comparison groups
- Lack of long-term health outcomes
Are paediatric and adult cohort data within countries linked?

- Data held together
- Linkage in progress
- Linkage possible
- Linkage not possible
- Not known
- No paediatric
- Not in EuroCoord
Adolescent health outcomes

Key findings from some of the posters at this Workshop:

• Occasional missed doses are difficult to voice in the context of VL<50 (P_26 Bernays et al)

• Similar proportions of young adults with and without perinatal HIV reached milestones (P_76 Mellins et al)

• Over one in four young adults with perinatal HIV reported missed doses in last 3 days; 73% relied on a family member to help them take their ART (P_80 Judd et al)

• Similar prevalence of lifetime sex in young adults with and without perinatal HIV (P_81 Le Prevost et al)

• Infants of women with perinatal HIV may be at higher risk of low birth weight vs. other HIV+ women (P_90 Jao et al)
4 – What transition interventions work?
Interventions to improve
  – retention in care
  – adherence (viral load)
Which services improve retention?

- Primary outcome = ≥2 visits ≥90 days apart within 12 months

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>Ref.</th>
<th>Yes</th>
<th>Ref.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth-friendly waiting area</td>
<td>4.76 (2.85–7.96)</td>
<td>2.47 (1.11–5.52)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Email and/or text messages</td>
<td>2.08 (1.28–3.37)</td>
<td>1.07 (0.50–2.28)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening clinic hours</td>
<td>2.08 (1.28–3.37)</td>
<td>1.94 (1.13–3.33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Next available routine visit</td>
<td>0.29 (0.19–0.45)</td>
<td>0.75 (0.36–1.58)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providers with adolescent training</td>
<td>3.24 (2.10–4.98)</td>
<td>1.98 (1.01–3.86)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Lee et al, AIDS Pat Care STDs 2016, 30: 170-7
Can we pay adolescents to adhere?

• Financial incentives + motivational interviewing in 11 young people with perinatal HIV and very poor adherence

<table>
<thead>
<tr>
<th>Started ART</th>
<th>VL response and attended for MI</th>
<th>Voucher value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 2</td>
<td>Fall in VL</td>
<td>£ 25</td>
</tr>
<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>
</tr>
<tr>
<td>6 months suppressed</td>
<td>Sustained VL &lt;50</td>
<td>£ 25</td>
</tr>
<tr>
<td>12 months suppressed</td>
<td>Sustained VL &lt;50</td>
<td>£ 50</td>
</tr>
<tr>
<td>Total</td>
<td>VL suppression for 12 months</td>
<td>£ 200</td>
</tr>
</tbody>
</table>

Baseline: none had VL<50c/ml
12 months: 5 had VL<50c/ml
24 months: 6 had VL<50c/ml

Foster C et al, AIDS Pat Care STDs 2014, 27:28-32
What do young people think?

• Meta-synthesis of 18 qualitative studies on transition, covering 368 young people

• Common themes across diseases:
  – facing changes in significant relationships
  – moving from a familiar to an unknown ward culture
  – being prepared for transfer
  – achieving responsibility

CHIVA “Treat me like this”

• Young people were asked about:
  – how adult clinics differed
    “More people your age”
    “It can feel uncomfortable and awkward”
    “Doctors rely on you to look after yourself”
  – how clinics can support transition
    “People should be asked first if they are ready to move on to the adult clinic”
    “Transferring to an adult clinic with a friend, where possible, can be helpful”

• Four small RCTs included – none in HIV
  – “overall certainty of this evidence is low”
• 9 relevant reviews of adolescent transition
  – Diabetes, mental health, spina bifida etc.
  – “… all highlighted the lack of rigorously evaluated interventions”

Campbell et al, Transition of care for adolescents from paediatric services to adult health services, Cochrane Database of Systematic Reviews 2016
Problems of evaluating transition interventions

• Problems with designing interventions:
  – What is “standard of care” for a comparison?
  – Small numbers of patients for many conditions
  – Transferability and generalisability of findings

• Transition being a relatively recent concept

• Much of the evidence is likely to come from observational studies
5 – What do we need to know?
Longer term clinical outcomes

Who has better/worse outcomes?

How important is transition readiness?

What about education, employment?

What aspects of care are effective for which populations?

What are the different models in adult care?
Economic, qualitative, advocacy

- Learning from patient experiences
- Learning from family members and clinic staff
- Cost-effectiveness of transition care
- Youth engagement in design, analysis, dissemination
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