The HIV journey from paediatric to adult services

Dr Tomás Campbell, Consultant Clinical Psychologist
Psychology & Health Team, Newham NHS, East London Foundation Trust

Tomas.campbell@eastlondon.nhs.uk

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Definition

"a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems"

Department of Health, UK (2006)
Before the advent of HAART children were not expected to live beyond childhood and as a result they were often unprepared and under-informed about HIV.

Thankfully, HAART has changed the entire context but HIV disclosure is still a huge issue and affects the transition context.

Parents/carers are also adapting to the new developmental needs and may find them a challenge – anxiety about relinquishing control.
Issues like sexuality and sexual behaviour are usually a challenge.

Services were also unprepared to deal with the complexities of delivering appropriate care to young people who had new and perhaps unexpected developmental needs.

HIV stigma affects the transition and needs to be addressed in a straightforward way.
Approaches to Transition (1)

- Transition of young people from paediatric to adult services should be a process **NOT** an event.
- Research indicates that planned transition results in better clinical outcomes for the young person.
- The planning process should help the young person acquire skills to help them self-manage.
- Parents/carers are an essential component to the success of the transition process.
- Healthcare teams may also need to adapt and change to reflect the changed needs of the young person.
Approaches to Transition (2)

- The transition process is not just about transitioning young people from paediatric/family to adult healthcare services.
- We aim to equip young people with skills, confidence and understanding to live successful adult lives whilst living with HIV.
- We think this aim is best achieved by facilitated group work in which HIV is normalised and talked about in a straightforward way.
- We also create an environment in which HIV+ young people can learn from one another.
The Looking Forward Project

- Multidisciplinary approach hosted by Specialist Nurse and Psychologists
- Established in 2004
- 3 times per year during school holidays
- 12 years or over, MUST BE AWARE OF THEIR HIV DIAGNOSIS
- Held at a local church hall – non-clinical environment, good transport links
- Lunch at a local popular restaurant
- £15 voucher for a national store when complete the day
Participant characteristics

- All participants are of African origin and were infected vertically.
- Many children live in non-traditional family structures, i.e. adopted, living with relatives, etc.
- Most families have other pressing issues, e.g. housing, immigration.
- Many children also have additional educational needs.
- Their experience of HIV is surrounded by secrecy and fear.
Content of the Looking Forward Days

- What is HIV, what it does, viral load, CD4 count
- Medication – what it does, why take it, their thoughts and feelings about it
- Puberty, sex, relationships, sexual health, pregnancy
- How HIV is managed in their family
- Cultural difficulties
- Future goals
- Stress and anxiety management
- Communicating with healthcare workers
- Identifying and addressing stigma
- Talking to your HIV health carers
Approaches

Topics have been addressed using:

- Drama
- Quizzes
- Games
- Discussion groups
- Role play
Evaluation process and methodology (1)

- Each event is evaluated using a questionnaire
  - Mixture of quantitative and qualitative items
  - Quantitative items are measured using a 5 point Likert scale
  - Qualitative items are completed in their own words

- The tool focuses on:
  - Information about HIV
  - Emotional responses to status
  - Relationship with family and healthcare providers
  - Medication
  - The future

- Data was pooled from 2007 - 2009
  - 8 events in total
  - 97 episodes of attendance
Evaluation process and methodology (2)

- We have also conducted a qualitative study about the factors which facilitate attendance
- Focus groups about what worked/didn’t work
- Consultation event with older participants to check that LfD still meeting their needs (or not) and explore new topics for consideration
Results

Have you attended a looking forward day before?
Results: The Looking Forward Day(s) answered some thoughts or questions I had about HIV

- **HIV info, sex, safer sex, condom use, STIs**
  - ‘The most important thing I have learned today is that there are different types of HIV and more ways to keep safe’
  - ‘I liked learning about condoms (my sister told me that when you have HIV and having sex that you must use specially made condoms’

- **Fertility**
  - ‘I learned about pregnancy and how you can prevent your child from developing the virus’
Having this information makes me feel that I can deal better with having HIV. If so, how?

Reducing anxiety
- “By not going to bed thinking why have I got HIV”
- “By now knowing I am not alone and people feel the exact same as I do”
- “Not feeling alone”

Increasing coping mechanisms and strategies
- “It helps me to be more aware and how I can handle/ deal with it”
- “By talking to people for example mum, dad or doctors”
- “More confident to express my feelings about HIV”
- “Because I know that there are people I can go to about it”

Information about HIV
- “Because I know I can control it, even though there isn’t a cure I know I can cope with it”
- “Because now that I know more about it I know how to control my actions”
- “I know how HIV can be transmitted to others and know I feel like it’s not much of a big deal”
After the Looking Forward Day(s) I feel less sad about having HIV
After the Looking Forward Day(s) I feel less angry about having HIV
After the Looking Forward Day(s) I feel less worried about having HIV
Talking to Family

I feel able to talk to someone in my family about coming to Looking Forward day(s)

I find it easy to talk to my family about HIV

- Most tend to say that HIV isn’t talked about openly in their families, some avoid talking about it so as not to upset their parents. There is a desire to protect their families.
Talking to Professionals and taking Medication

- After coming to Looking Forward Day(s) I feel more comfortable talking to the doctor or nurse about my HIV

- I feel more okay about taking my medication after coming to Looking Forward Day(s)
  - They generally express mixed feelings about medication – daily reminder of diagnosis, interference with social life
What we have talked about today makes me feel more optimistic about my future

“I look forward. I feel insecure but I am ok with it’.

“Well, I have made a lot of friends and I have hope for the future”

“Live for the moment, take nothing for granted in life”
Has being HIV+ had any good effects on your life? If so, what were they?

- **Support**
  “I’ve been able to meet others, like me and been able to talk about things I considered and questioned”
  “Meeting new people and learning a subject that’s hidden away”
  “No longer feel alone’
  ‘I like that we are all positive – we understand each other more’
  ‘It’s a place where you speak openly’.

- **Special treatment**
  “Being able to miss school in the morning to go to the clinic in the morning”
  “We get special treatment e.g. Nandos”
  “Attending Body & Soul”

- **Appreciate what you have**
  “It’s made me think about being healthy and keeping fit”
  “It has made me a stronger person”
  “It has made me appreciate life and what I have”
  “Live a healthier life”

- **It’s hard having HIV**
  “No, because there are things like rules to do in order to have safe sex and in order to not catch HIV”
  “Having it was something not nice. But it nice to know that people do have it”
  ‘No, it’s just normal to me’
Sex, relationships, and secrets

Keeping the diagnosis a secret
- “Just taking them and having to take them somewhere (stressed tone). You have to remember to carry them. When I visit my sister my meds are quite big. It’s OK now but in the future I suppose I might have to find someone and someone might find out. What will they think of me?”

Relationships are complicated
- “…it made me consider what I would do if I was in a relationship. Would I tell them? I suppose not. Keep it cool because you don’t want to bring up the situation. Learn to trust them, love them. Eventually it comes out in the open. Take time. You just can’t tell them. Your condition is a secret because you need to learn to trust them. If you just fall out there’s no point telling them then the relationship is over”
- “What’s the point of having a relationship. If you do tell them they won’t want you, if you don’t tell them and then they find out they will leave you. There is never a right time to say so there is no point in starting anything”

An ongoing sense of stigma
- “On World Aids Day someone was collecting money. My teacher said that they would give to cancer or something else but not HIV. How is that meant to make me feel?”
- “I have defended HIV so much in class my teacher and friends started to suspect something so now I have to just keep quiet”
Young peoples’ experiences of stigma

- **HIV stigma and young people in the UK** There is little literature on the impact of HIV-related stigma on young people in the UK but the context in which young HIV+ people are developing and maturing is one in which HIV-stigma is a reality and is expressed in many ways. Levels of HIV-stigma may be highest in African communities from which most young HIV+ people originate. HIV stigma may have complex and negative effects on HIV+ people (e.g. poorer social support, poorer mental health, disclosure difficulties, lower adherence to ARVs and HIV stigma can be a barrier to accessing health care).

- **Methods** A pilot study was conducted with 21 HIV+ young people with the aim of exploring experiences of stigma in this group. Participants completed a stigma questionnaire, which was adapted from a validated stigma questionnaire comprising 2 components: enacted stigma refers to experiences of stigmatising actions: perceived stigma captures the effect on perception of self. Participants subsequently participated in a one-day intervention designed to equip them with some knowledge and skills to counter HIV stigma.

- **Results** Participants were of African origin (12 females, 8 males), had been infected vertically and were aged between 12-21 years. Questionnaire responses showed mixed patterns in which there were marked gender differences: females had more experiences of stigmatised actions directed towards them than males (table 1).
Experiences of enacted stigma

<table>
<thead>
<tr>
<th></th>
<th>Males (n=8)</th>
<th>Females (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losing friends</td>
<td>12.5% (1)</td>
<td>31% (4)</td>
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<tr>
<td>Hassle/threatening</td>
<td>0</td>
<td>8% (1)</td>
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<tr>
<td>behaviour</td>
<td>Had to move house</td>
<td>0</td>
</tr>
<tr>
<td>Heard AIDS joke</td>
<td>12.5% (1)</td>
<td>39% (5)</td>
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<tr>
<td>Shut out by family members</td>
<td>0</td>
<td>16% (2)</td>
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Questionnaire responses showed mixed patterns in which there were marked gender differences: females had more experiences of stigmatised actions directed towards them than males (table 1).
Experiences of perceived stigma

- Table 2 shows that more females than males reported experiences of social rejection (43% vs. 20%) and social avoidance (17% vs. 12.5%), but feelings of shame amongst females and males were similar (30% vs. 25%).

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<thead>
<tr>
<th></th>
<th>Males (n=8)</th>
<th>Females (n=12)</th>
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</thead>
<tbody>
<tr>
<td>Avoidance dimension</td>
<td>12.5%</td>
<td>17%</td>
</tr>
<tr>
<td>Social rejection dimension</td>
<td>20%</td>
<td>43%</td>
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<tr>
<td>Shame dimension</td>
<td>29%</td>
<td>31%</td>
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<tr>
<td>Overall perceived HIV stigma</td>
<td>25%</td>
<td>30%</td>
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How many people in the family know you are HIV+?

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<thead>
<tr>
<th></th>
<th>None</th>
<th>A few</th>
<th>Most</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males (n=8)</td>
<td>12.5% (1)</td>
<td>37% (3)</td>
<td>37% (3)</td>
</tr>
<tr>
<td>Females (n=12)</td>
<td>0</td>
<td>76% (10)</td>
<td>15% (2)</td>
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Table 3 shows the data with regard to disclosure of the young person’s status in their family. There are clear gender differences with females reporting higher numbers than males about family members who are aware of their status.
How many of your friends know you are HIV+?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>A few</th>
<th>Most</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>37.5%</td>
<td>12.5%</td>
<td>37%</td>
</tr>
<tr>
<td>(n=8)</td>
<td>(3)</td>
<td>(1)</td>
<td>(3)</td>
</tr>
<tr>
<td>Females</td>
<td>8%</td>
<td>62%</td>
<td>31%</td>
</tr>
<tr>
<td>(n=12)</td>
<td>(1)</td>
<td>(8)</td>
<td>(4)</td>
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Table 4 shows that females had a higher number of friends than males who were aware of their status with females reporting that 93% of friends ("a few" to "most") compared with 40% of males using the same categories. Males were more likely to have friends who were completely unaware of their status.
Anti-stigma intervention

The workshop addressed types, meanings and effects of stigma to enable participants to identify stigma and equip them with skills to mediate the negative consequences. Participants explored how the effects altered self-image, relationships with others, disclosure and adherence to medication. We used a combination of group discussion, vignettes, drama and letter writing activities to explore types, meanings and effects of HIV stigma, and develop new skills to identify and effectively respond to perceived and enacted stigma.
Qualitative responses

“Basically its all about your mindset, if you believe you can get through it, you get through it. There’s medications for it for your whole life. We live in a good society with a lot of opportunities like medication, organisations that provide groups. You meet friends and go to your family who support you. It’s all about belief really” (Male, 19)

“My advice would be to carry on going and don’t give up no matter what people say about HIV and stuff because some of the stuff what they say, might not be true” (Male, 15)

“...you are not alone in this, there is always someone who wants to listen and who is probably going through the same situation as you so if you feel like you are alone, go to Dr’s and ask them ‘are there any support groups’ ‘is there any counsellors you can talk to’ ” (Female, 19)
Things we’ve found out

- The young people have few people to talk to or get support from regarding their diagnosis
- They clearly understood the necessity to keep their diagnosis a secret
- They are very nervous of sex and relationships
- “I asked my friends how they would feel if they knew someone with HIV to see how they might react if they knew about me”
Final comments

- Start young!
- Engage with the parents to reduce their anxieties and build trust
- Consider integrating LfD into wider programme of engaging with parents
- Bribe, persuade, encourage to maintain motivation
- Evaluate but tools require continual refinement
- Baseline measures?
- You will learn from them