Adolescent HIV: Transition to Adult Care

Brian Zanoni MD, MPH
Instructor, Harvard Medical School
Assistant in Medicine, Massachusetts General Hospital Global Health

Note: all photographs obtained with written consent/assent and used with permission
### South African Adolescent Continuum of Care

<table>
<thead>
<tr>
<th>Category</th>
<th>South Africa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Infected</td>
<td>867 283</td>
</tr>
<tr>
<td>On ART</td>
<td>124 070</td>
</tr>
<tr>
<td>Retained</td>
<td>102 481</td>
</tr>
<tr>
<td>Virally Suppressed</td>
<td>83 010</td>
</tr>
</tbody>
</table>

#### Notes:
Approaching Wave of Perinatally HIV-infected Adolescents in South Africa

Zanoni, BMJ Global Health, 2016
Adolescent Outcomes After Transition

• USA cohort
  o 20% lost to follow up by age 22 after transition by age 21
  o Higher viral failure in perinatally-infected adolescents compared to behaviorally-infected adolescents

• UK cohort
  o 16 to 20 year olds in adult care had higher mortality than 13 to 15 year olds in pediatric care

• Canada
  o 25% lost to follow up after transition
Adolescent Outcomes

- Large cohort of from Kenya, Mozambique, Tanzania, and Rwanda
  - Adolescents were 60% more likely to be lost to follow up than adults after ART initiation

- Bulawayo, Zimbabwe
  - Older adolescents more likely to be lost to follow up than younger adolescents

- Western Cape, South Africa
  - 81% Successful transfer
    - 72% Transferred at ages 10 to 14 years old
  - Adolescents 15 - 19 years old at transfer had higher virologic failure than those 10 to 14 years old

- Adolescent-friendly services
  - Mixed results
    - Khayelitsha – MSF – high retention 94% among stable adolescents
    - Pre-post implementation in Kenya – no difference in retention or viral suppression
    - Retrospective study in KZN – improved retention and viral suppression
Adolescents who transferred to adult clinic in KZN:

“[Coming to clinic] was not a nice experience, coming with adults. Those moms there shouting, ‘Don't jump the queue!’ Long queues, [you] sit there for a long time. My friends were not even there. It was boring. I started to hate coming to clinic.”
Barriers and Facilitators to Transition Care

**Barriers**
- Lack of infrastructure
  - Lack of guidelines
  - Human resources
- Poor communication
- Stigma
- Disclosure

**Facilitators**
- Adolescent-friendly services
  - Adolescent clinics
- Clear transition protocols
When to Transition

- No clear consensus
- Age
  - Range: 12 to 24+
  - Most commonly in sub-Saharan Africa after age 15
- Clinical
  - Weight - Fixed dose combination ART
  - Pregnancy
  - ART Resistance or Viral Failure
- Maturity
  - After disclosure
- Education
  - Completing matric
Models of Transition

• **Standard Model**: Transition from pediatric clinic to adult clinic

• **Generalist Model**: Same clinician cares for both children and adults

• **Integrated Model**: Adolescent care integrated to family centered approach (PMTCT)

• **Youth-friendly Model**: Adolescent clinics prior to transition to adult clinic
  - Dedicated self-management skills development
  - Adherence support
  - Retention efforts
  - Transition planning
Transition to Adult Care

Standard Model: The Pass and Catch

The Adolescent

Pediatric clinic

Adult clinic
Pediatric Care: The Pass

• Pediatric clinicians unwilling to let go
  o Poor adherence by adolescent
  o Second-line treatment
  o Medication dosing
  o Psychosocial issues
  o Disclosure / stigma
  o High patient to clinician ratio in adult clinic (dehumanized / overburdened)
  o Lack of guidelines / communication between providers
Adolescents: The Ball

• Responsibility for own health and disease management
  o Maturity
  o Self-esteem
  o Neurocognitive or mental health problems
  o Health problems: chronic lung disease
  o Resistance and second-line treatment
  o Delayed puberty / stunting / malnutrition

• Loss of relationships with peers and clinicians

• Physically and emotional uncomfortable
Adult Care: The Catch

• Lack of support services
  o Disclosure support
  o Adherence support groups
  o Psychosocial support

• Lack of training / guidelines

• Medication dosing

• Overcrowding
The Generalist Model

- Disclosure
- Adherence support
- Psychosocial support
- Medical independence
- Self-esteem
Adolescent-friendly Services

Example from KZN
## Standard vs. Adolescent Clinic

<table>
<thead>
<tr>
<th></th>
<th>Standard Clinic</th>
<th>Adolescent Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>First patients</td>
<td>April 2007</td>
<td>March 2009</td>
</tr>
<tr>
<td>Clinic dates</td>
<td>Weekdays</td>
<td>Saturdays</td>
</tr>
<tr>
<td>Medication collection</td>
<td>On campus pharmacy</td>
<td>Pre-packaged</td>
</tr>
<tr>
<td>Lab draws available</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Meal provided</td>
<td>None</td>
<td>Lunch</td>
</tr>
<tr>
<td>Additional activities</td>
<td>Individual counseling</td>
<td>Individual or group counseling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sports, music, dancing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Career counseling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transition preparations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Various social activities</td>
</tr>
<tr>
<td>Staff</td>
<td>1 physician, 3 counselors</td>
<td>Don McKenzie Hospital, Botha's Hill</td>
</tr>
<tr>
<td>Facilities</td>
<td>Don McKenzie Hospital, Botha's Hill</td>
<td></td>
</tr>
</tbody>
</table>
### Demographics

<table>
<thead>
<tr>
<th></th>
<th>Standard Clinic (n=153)</th>
<th>Adolescent Clinic (n=88)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent male (n)</td>
<td>53% (80)</td>
<td>43% (38)</td>
<td>0.181</td>
</tr>
<tr>
<td>Median age at ART initiation (IQR)</td>
<td>9.7 (7.5-12.0)</td>
<td>11.2 (9.4-12.8)</td>
<td>0.002</td>
</tr>
<tr>
<td>Median pre-ART CD4 (IQR)</td>
<td>211 (110 – 353)</td>
<td>94 (35- 220)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Median months on ART (IQR)</td>
<td>74 (58-92)</td>
<td>80 (57-98)</td>
<td>0.246</td>
</tr>
<tr>
<td>Percent initial ART: NNRTI (n)</td>
<td>95% (145)</td>
<td>100% (88)</td>
<td>0.029</td>
</tr>
<tr>
<td>Percent current ART: PI (n)</td>
<td>32% (35)</td>
<td>16% (14)</td>
<td>0.245</td>
</tr>
<tr>
<td>Percent history of tuberculosis (n)</td>
<td>54% (83)</td>
<td>48% (42)</td>
<td>0.351</td>
</tr>
</tbody>
</table>
Overall Outcomes

• Retention 89% (214/241)
• Viral suppression 84% (196/233)
Higher Retention and Viral Suppression with Adolescent Clinic

<table>
<thead>
<tr>
<th></th>
<th>Standard Clinic</th>
<th>Adolescent Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiated ART</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Retained</td>
<td>85</td>
<td>95</td>
</tr>
<tr>
<td>Suppressed</td>
<td>80</td>
<td>91</td>
</tr>
</tbody>
</table>
### Higher Retention in Adolescent Clinic

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Unadjusted OR (p-value)</th>
<th>Adjusted* OR (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescent Clinic vs. Standard Clinic</td>
<td>3.7 (0.019)</td>
<td>8.5 (0.002)</td>
</tr>
</tbody>
</table>

*Adjusting for: age at ART initiation, sex, months on ART, pre-ART CD4, TB history

### Higher Viral Suppression in Adolescent Clinic

<table>
<thead>
<tr>
<th>Comparison</th>
<th>Unadjusted OR (p-value)</th>
<th>Adjusted* OR (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescent Clinic vs. Standard Clinic</td>
<td>2.5 (0.031)</td>
<td>3.8 (0.005)</td>
</tr>
</tbody>
</table>
How can having clinic on a Saturday improve outcomes?
Student’s Paradox

• Conflict between academic needs with health needs
• Adolescents miss school frequently to attend clinic
  o Wait in long queues and do not return to school
  o Academics suffer
• Only attend clinic for blood draws
  o Have limited time with clinicians, counselors, support services
  o Adherence and mental health suffer
• Both do not disclose to friends and create excuses for when they attend clinic, creating conflict and anxiety
Standard Clinic: Impact on School

Caregiver: “She’s been doing well [in school] but last year was her first time failing her grade. She made an excuse that the teacher was saying she missed school so much when she has to come [to the clinic] for her pills and blood.”

Caregiver: “…each time she needs to come to clinic that means she is going to be late for school [be]cause she start[s] at the clinic first, then go[es] to school. It becomes a norm and known to other kids that each month she is going to be late cause she starts at the clinic. Even when they don't know why, but they notice [that] there is something she is doing at the clinic. That somehow has some effect on the child.”
Adolescent: I used to come here first thing in the morning in my uniform and they serve me first and I go home, leave my pills, get a taxi, and go to school a bit late; and my friends used to ask me why I’m late? I used to lie and say I was not feeling well and stared at the clinic. I hated doing that. Sometimes I just don’t go to school after collecting my pills.

Interviewer: Has that changed now?

Adolescent: Yes, I’m always present at school.

Interviewer: Has [the adolescent clinic] changed the way you feel about school?

Adolescent: Yes.

Interviewer: How?

Adolescent: Changed that I don’t have to think about lies anymore and think of things to say to my friends about my whereabouts.
Student’s Paradox

• Conflict between academic needs with health needs
• Adolescents miss school frequently to attend clinic
  o Wait in long queues and do not return to school
  o Academics suffer
• Only attend clinic for blood draws
  o Have limited time with clinicians, counselors, support services
  o Adherence and mental health suffer
• Both do not disclose to friends and create excuses for when they attend the clinic creating conflict and anxiety

Adolescent clinic solution: After school hours clinic
Adolescent Clinic Peer Support

- Everyone knows their HIV status
- Finally feel free and open to discuss concerns
- Can discuss HIV openly
Adolescent Clinic Peer Support

15 y.o. female in adolescent clinic:

“I enjoy very much when I come [to the adolescent clinic]…We enjoy each others company we talk about lot of things when we are together. We open and pour all out our issues and problems and come up with solutions.”

17 y.o. female in adolescent clinic:

“I like that fact that everyone is open. You feel free to share all you want to share you just enjoy to be around [peers.]”
Adolescent Clinic: A Place to Belong

16 y.o. Female in adolescent clinic:

“Since I joined [the adolescent clinic] this year, [I have] seen that I am not the only 16 year old who has HIV. All along since I found out about my [HIV] status, I was thinking it [was] written all over my back, that I have HIV. I was having that stigma; that everyone knows and they can see even when they are a mile away. But joining [the adolescent clinic] was nice, [I] met lot of people [names of clinic members, then names members of staff] everyone is just nice giving us advice about our lives…”
Adolescent Clinic: Connection with Staff

• More frequent visits
• Deeper connection to clinical staff

21 y.o. male attending adolescent clinic:

“[At the standard clinic] there was no one who had time to ask you what was going on in your life, they only asked you about your health, not how your life as a whole was going…[the adolescent clinic] helped me a lot because I could talk about anything with [names doctor and counselors].”
Summary

• Adolescent-friendly services
  o Decreases school absenteeism
  o Allows for adolescent to be more involved in healthcare
  o Provides peer support
  o Strengthens bonds with healthcare team
  o Increases retention in care
  o Increases viral suppression
  o Allows for preparation for transition
Steps for Transition: Got Transition

1. Transition policy
   - Develop policy, educate staff, inform patients and caregivers

2. Transition tracking and monitoring
   - Identify youth ready to transition and track progress

3. Transition readiness
   - Regularly assess readiness during visits

4. Transition planning
   - Prepare adolescent and caregiver
   - Communicate with adult provider

5. Transfer of care
   - Best when planned and stable

6. Transfer completion
   - Communication between providers, caregivers, and adolescent

www.gottransition.org
### Modified Social-ecological Model of Adolescent and Young Adult Readiness to Transitions (SMART) Model

#### Preexisting factors

*Objective factors less amenable to intervention*

- Sociodemographic
- Clinical (CD4, HIV RNA, TB, weight)
- Neurocognition and mental health
- Structural (transportation, appointment time)

#### Modifiable factors

*Subjective factors more amenable to intervention*

Components of individuals, caregivers, and clinic can be targeted/changed to help improve transition process

- Peer / social support
- Knowledge
- Self-efficacy
- Relationships
- Goals/motivation
- Maturity/disclosure

---

Graph adapted from: Schwartz, 2011
Successful Transition

- **Planning**
  - Pediatric clinicians
  - Adolescents
  - Caregivers
  - Adult clinicians

- **Communication**
  - Pediatric clinicians
  - Adolescents
  - Caregivers
  - Adult clinicians

- **Readiness assessment**
  - Pediatric clinicians
  - Adolescents
  - Caregivers
  - Adult clinicians

- **Future interventions**
  - Pediatric clinicians
  - Adolescents
  - Caregivers
  - Adult clinicians
Acknowledgements

South Africa
- Stephen Carpenter
- Mo Archary
- Tappie Cairns
- Nokuthula Buthulezi
- Thobekile Sibaya
- Patients and Staff at Don McKenzie Hospital

USA
- Jessica Haberer
- David Bangsberg
- Ken Mayer
- Bisola Ojikutu
- Sara Lammert

Funding: NIH T32 NAID AI 007433