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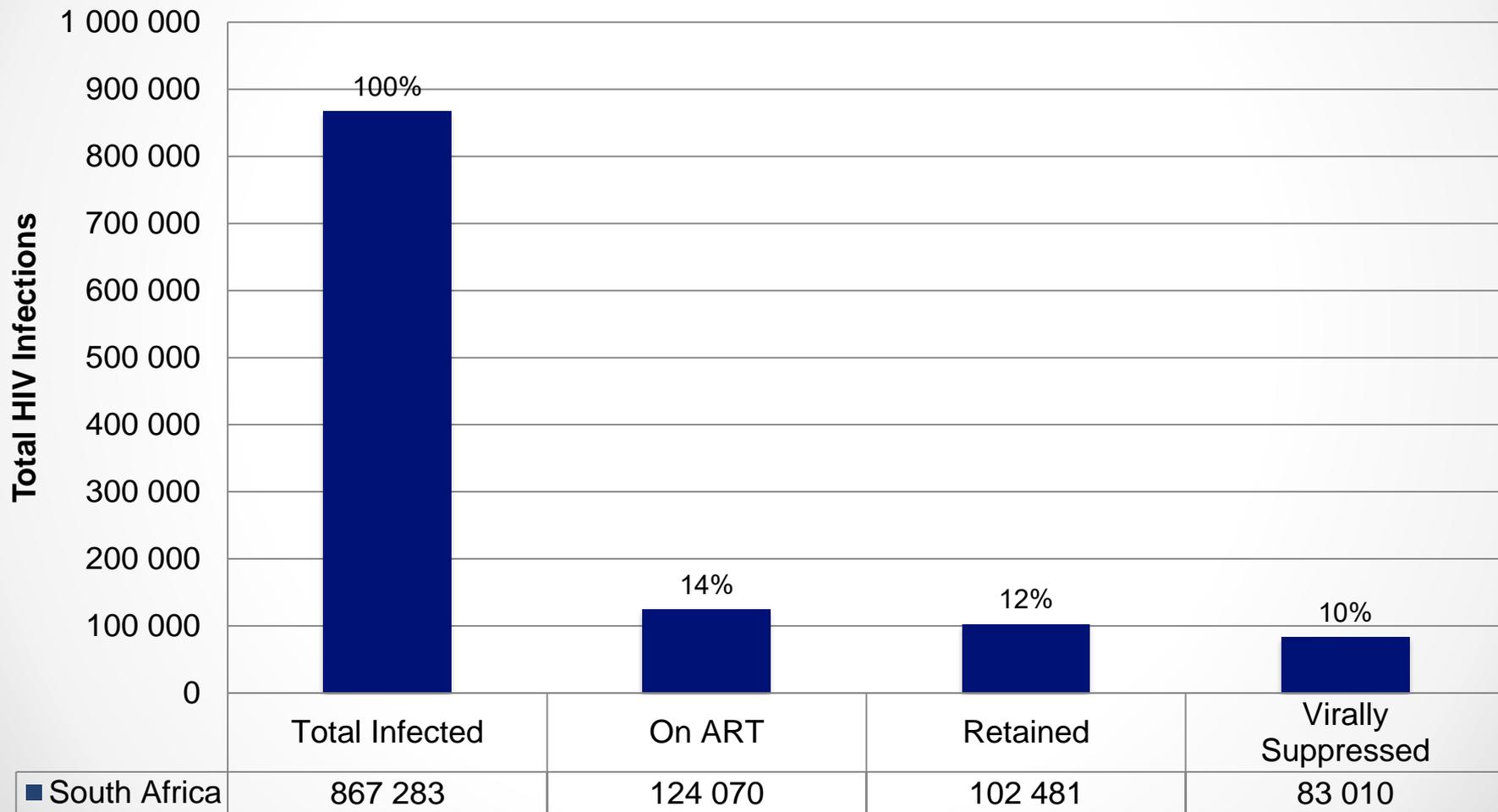
Adolescent HIV: Transition to Adult Care

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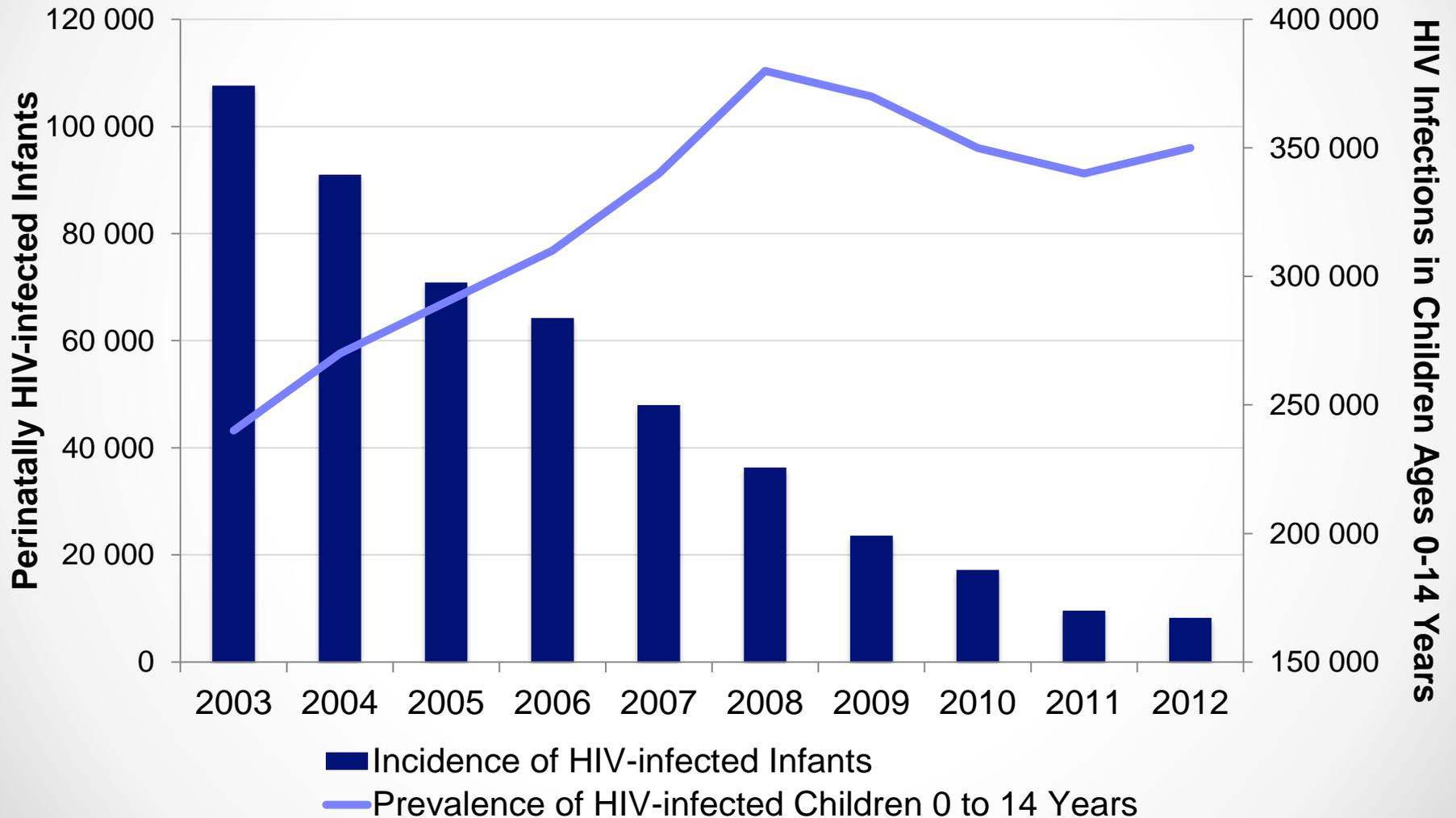
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South African Adolescent Continuum of Care



Approaching Wave of Perinatally HIV-infected Adolescents in South Africa



Adolescent Outcomes After Transition

- USA cohort
 - 20% lost to follow up by age 22 after transition by age 21
 - Higher viral failure in perinatally-infected adolescents compared to behaviorally-infected adolescents
- UK cohort
 - 16 to 20 year olds in adult care had higher mortality than 13 to 15 year olds in pediatric care
- Canada
 - 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

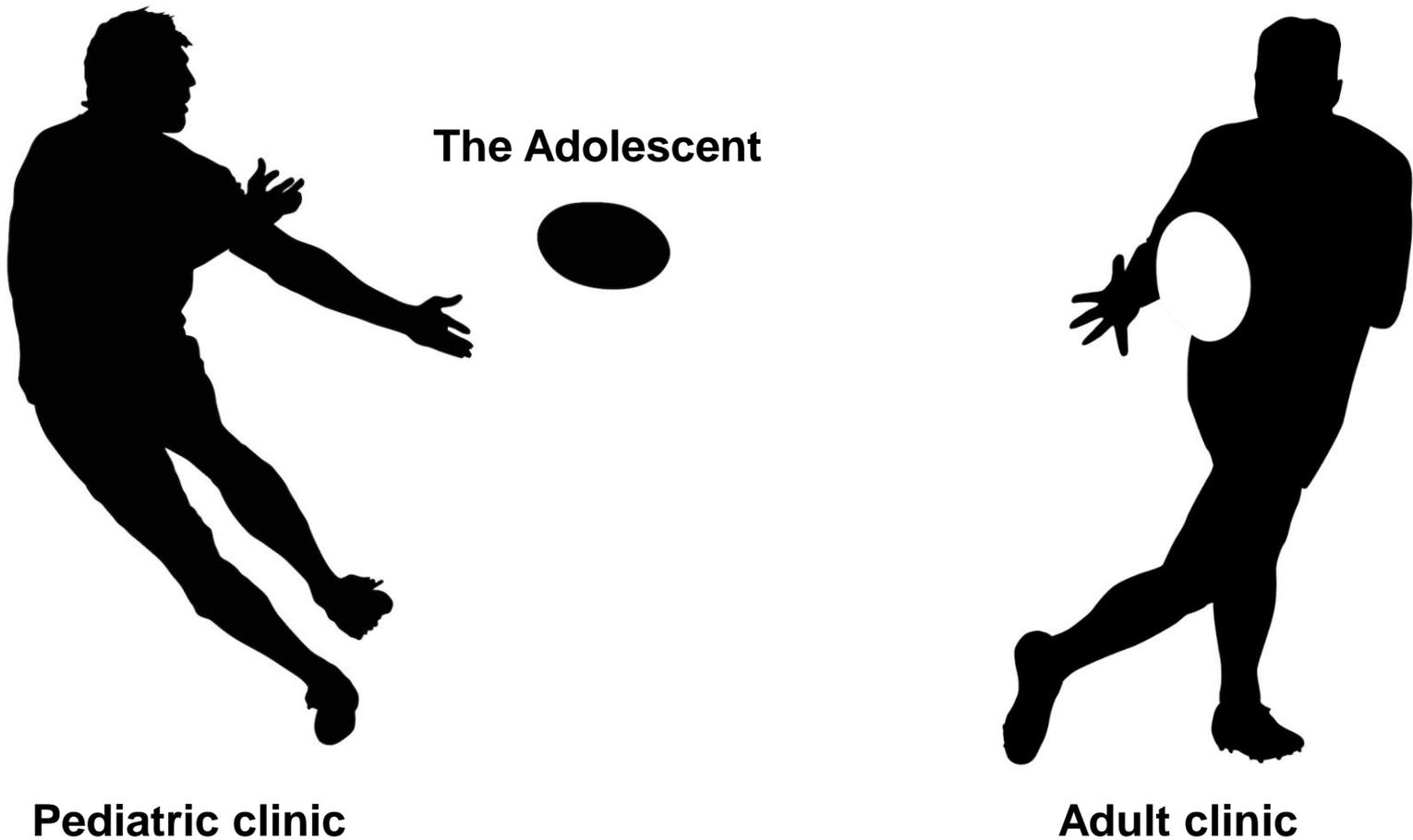
- No clear consensus
- Age
 - Range: 12 to 24+
 - Most commonly in sub-Saharan Africa after age 15
- Clinical
 - Weight - Fixed dose combination ART
 - Pregnancy
 - ART Resistance or Viral Failure
- Maturity
 - After disclosure
- Education
 - Completing matric

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



Pediatric Care: The Pass

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



Adolescents: The Ball

- Responsibility for own health and disease management
 - Maturity
 - Self-esteem
 - Neurocognitive or mental health problems
 - Health problems: chronic lung disease
 - Resistance and second-line treatment
 - Delayed puberty / stunting / malnutrition
- Loss of relationships with peers and clinicians
- Physically and emotional uncomfortable



Adult Care: The Catch

- Lack of support services
 - Disclosure support
 - Adherence support groups
 - 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

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

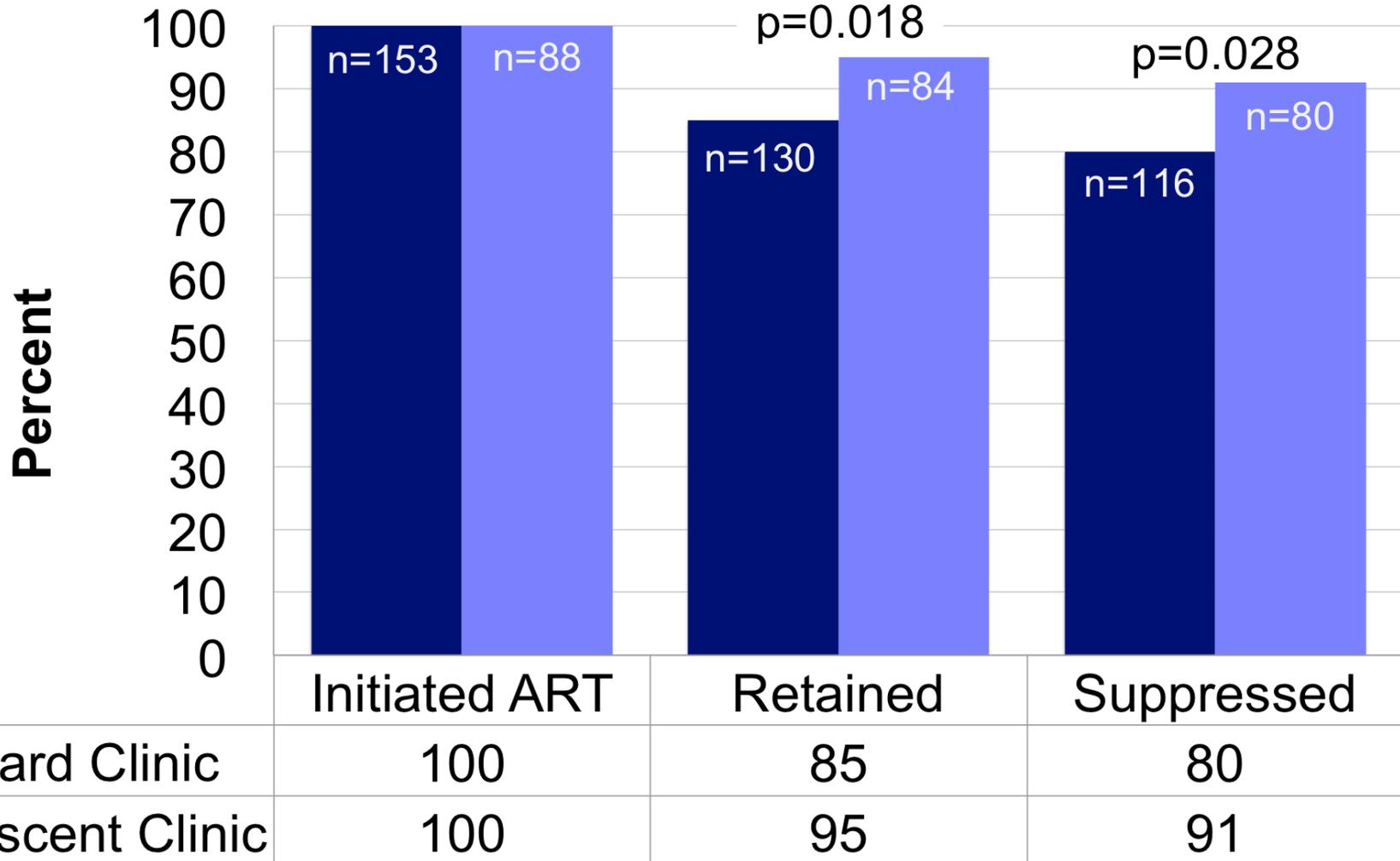
Demographics

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

Overall Outcomes

- Retention 89% (214/241)
- Viral suppression 84% (196/233)

Higher Retention and Viral Suppression with Adolescent Clinic



Higher Retention in Adolescent Clinic

	Unadjusted OR (p-value)	Adjusted* OR (p-value)
Adolescent Clinic vs. Standard Clinic	3.7 (0.019)	8.5 (0.002)

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

Higher Viral Suppression in Adolescent Clinic

	Unadjusted OR (p-value)	Adjusted* OR (p-value)
Adolescent Clinic vs. Standard Clinic	2.5 (0.031)	3.8 (0.005)

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
 - Wait in long queues and do not return to school
 - Academics suffer
- Only attend clinic for blood draws
 - Have limited time with clinicians, counselors, support services
 - 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.”

16 year old female in adolescent clinic

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 staid 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.

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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
 - Decreases school absenteeism
 - Allows for adolescent to be more involved in healthcare
 - Provides peer support
 - Strengthens bonds with healthcare team
 - Increases retention in care
 - Increases viral suppression
 - 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

Modified Social-ecological Model of Adolescent and Young Adult Readiness to Transitions (SMART) Model

Preexisting factors

Objective factors less amenable to intervention

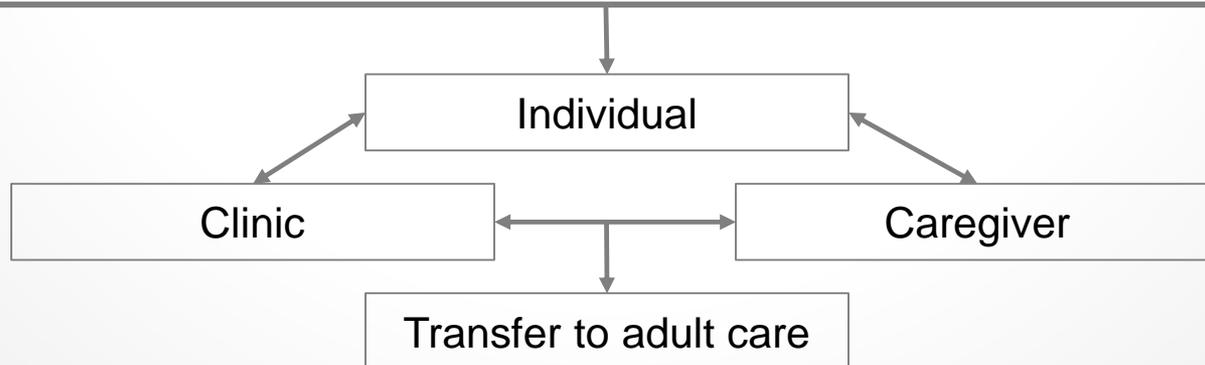
- Sociodemographic
- Clinical (CD4, HIV RNA, TB, weight)
- Neurocognition and mental health
- Structural (transportation, appointment time)

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



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

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