

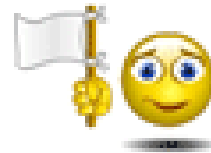


Adolescents Living with HIV

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Conflicts of Interest

No relevant conflicts of interest to declare



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Your Experiences & Concerns?



- Do you have dedicated adolescent clinics?
- When & how do you transition patients?
- When do parents stop accompanying patients?
- Does the patient have a say?
- How important are the other patients attending their clinic?
- What problems with adolescents have you experienced?



A question from one of our adolescents:

**“IS THE SMELL FROM MY ARMS
BECAUSE OF THE DRUGS OR BECAUSE
OF HIV?”**

Case Presentation 1

- 14 year old Mark, middle of a busy clinic
- Mother very worried about disclosure
- ‘He is very clever’
- ‘Don’t worry mom we don’t have to talk about it...’ OR
- ‘We need to talk about it, but we can do it next time...’

Case Presentation 2

- 18 year old Nadia
- Started ART at age 7
- VL has been fully suppressed throughout
- CD4 was 854 (29%) 6 months ago
- Now it is 650 (30%)

- She is worried about the drop in CD4 count!

Case Presentation 3

- 16 year old Mary
 - unaccompanied
- Tearful, contemplating suicide:
 - Upset with her family for not acknowledging her HIV status.
- 2 years earlier: found out about HIV status when reading her hospital file
- Admitted 2 weeks ago and retested:
 - Her father did not acknowledge or show any emotion when the result was mentioned

Case Presentation 4

- 18yr old girl, on ART since 2006.
- CD4 Nadir = 2 (0.98%), VL = 35 000 initially
- Since then fully suppressed, CD4 = 588 (30.3%)
- Disclosure 4 years ago
- She asks you whether there is any chance she could stop ART for a month:
 - Going on holiday with friends...
 - If they see the bottles she will be put on the spot.
 - “My friends tell me everything... I feel bad because I haven’t told them my status.”
 - “What if they change and reject me?”
 - “How should I tell them?”

Case Presentation 5

- 19 year old boy reports that his 16 year old girlfriend is pregnant
 - She is HIV-negative
- He is HIV-positive (MTCT) and fully suppressed on ART since 8 years
- The girls father wants to speak to us

Case Presentation 6

- 17 year old female
 - HIV-infected perinatally
 - Presented January 2005 (8y):
 - WHO 1
 - CD4 198 (11.9%)
 - ART started May 2005 (d4T, 3TC, EFV)
 - February 2008: CD4 562 (27.4%), virally suppressed

BUT...

Case Presentation 6

Date	Jul 08	Aug 08	Dec 08	Mar 09	Oct 09	Feb 10	May 10	Oct 10	Feb 11
Age	12y4m	12y5m	12y7m	12y11	13y6	13y10	14y1	14y7	14y10
CD4 #	261			198		247	205	221	224
CD4%	14			14.6		14.5	12.9	12.47	17.72
VL	15000	150	37000	18000	25	1800	1200	46888	1577

August 2008: no ART resistance detected

March 2011: changed to ABC, TDF, LPV/r

Socially:

- Lives with Aunt
- Mother looks after her ill grandmother
- Disclosure at 12½ years

Case Presentation 6

Date	Oct 11	April 12	June 12	Sep 12	Nov 12	May 12
CD4#		167	214		228	130
CD4%		11.9	15.8			11.2
VL	188	4130	11958	154122	1347	124293

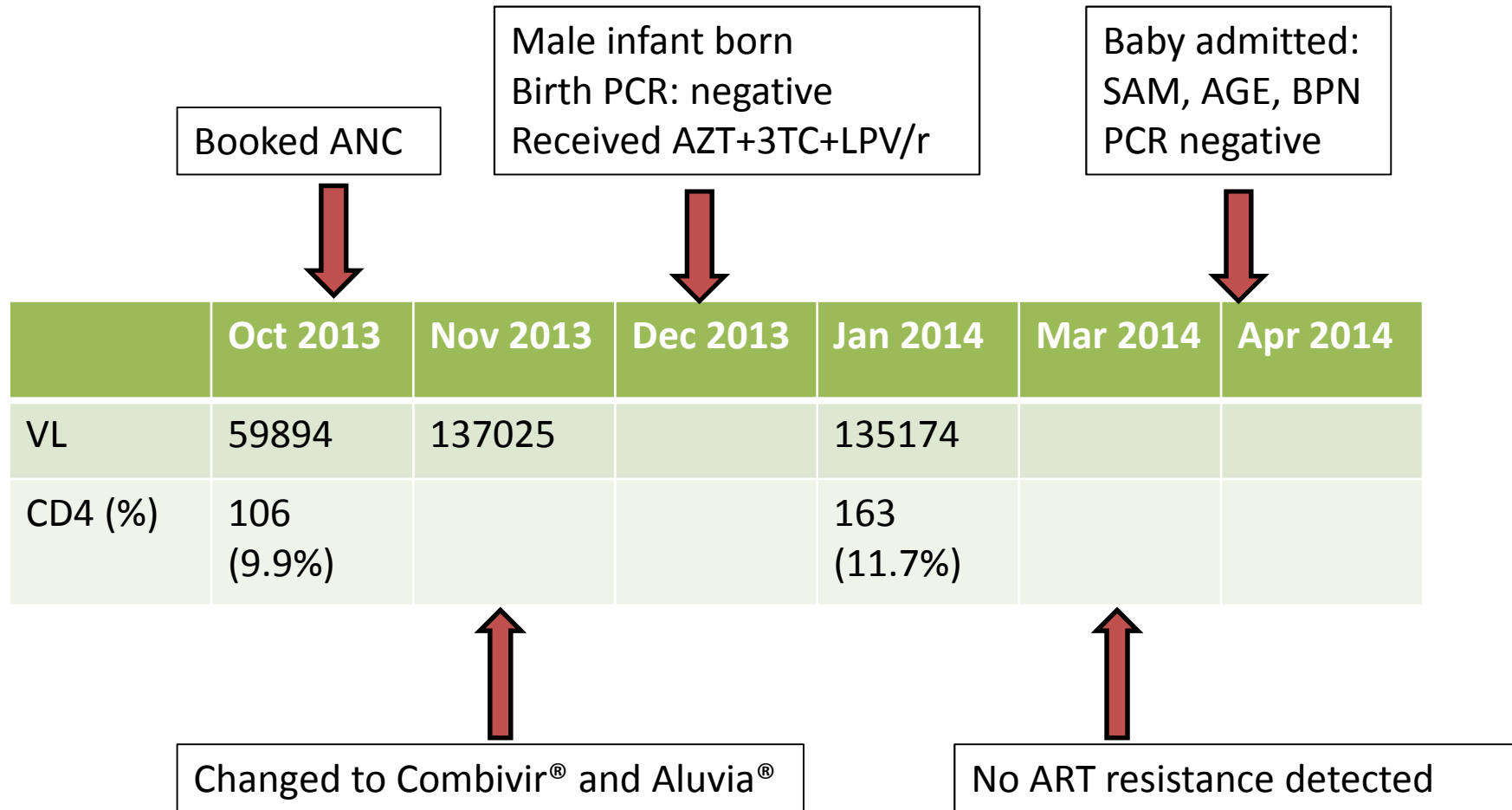
- Remained clinically well
- Struggled with LPV/r 200/50, so changed to 100/25
- Ongoing adherence concerns & missed appointments

Case Presentation 6

July 2013

- LMP April 2013
- Pregnant, but refuses to consider TOP
- SFH = 16cm
- No ART for 2-3 months
 - Told by her sister that it could to be harmful to her baby!!

Case Presentation 6



Defaulted clinic visits since May 2015

Issues Raised

- Disclosure & Parental Guilt
- Teenage pregnancy
- ? Infected partner(s)
- ? Resistant virus
- Failed/missed opportunities for FP
- Management of babies born to mothers with virological failure
- Transition to adult ART regimens & clinics

Issues Raised

- Orphaned
- Child-headed households
- Bereavement
- Mental Health problems
- Long term medical concerns:
 - School difficulties
 - Behavioural problems
 - Short stature, etc.
- HCW-related issues

And OTHERS....

What is the role of the HCW?

- The conflict between parenting...
- And an adult – adult relationship...



Definitions (WHO)

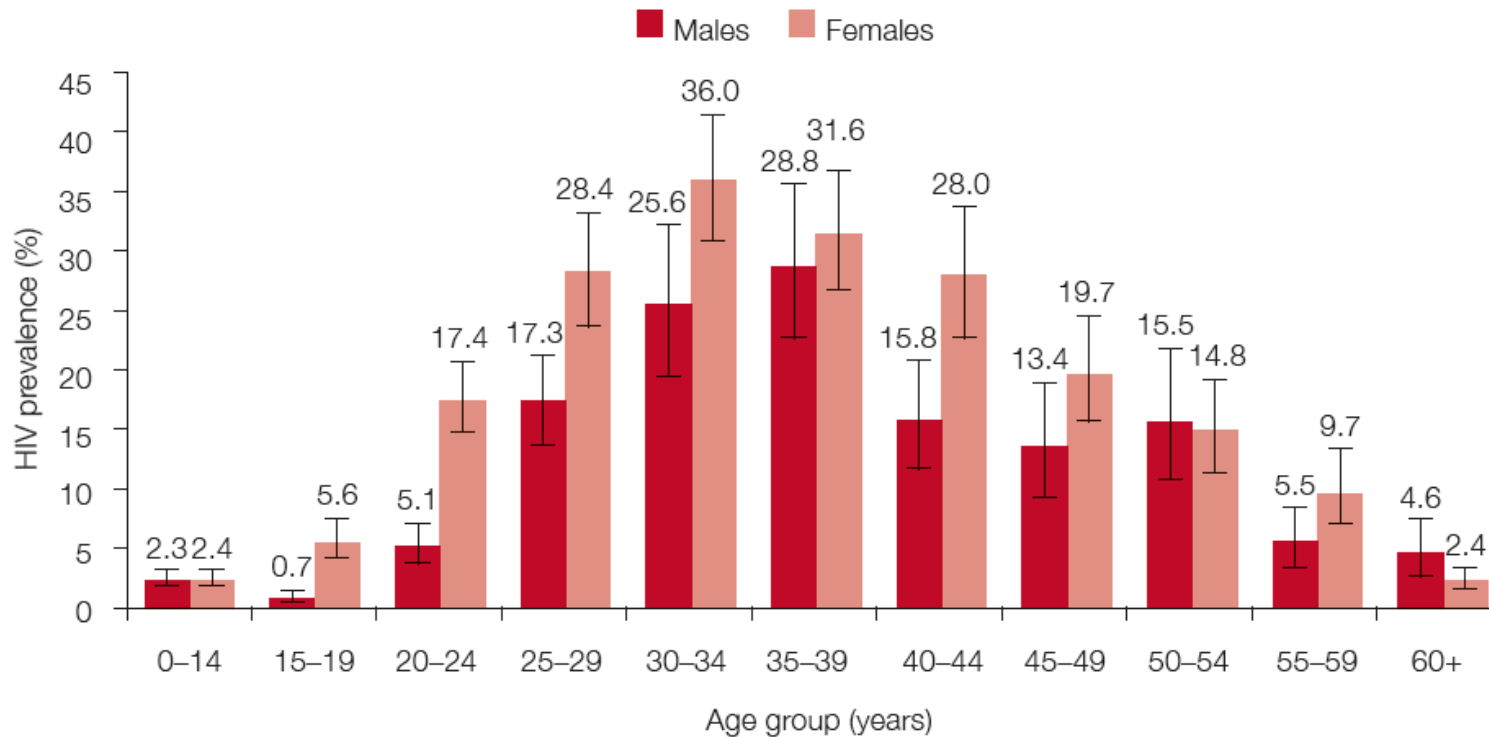
- Child < 10 yrs
- Adolescent 10 – 19yrs
- Adult > 19yrs

- For the purposes of ART treatment –
Adolescents <15 yrs or <40kgs follow the
paediatric regimens

How common is HIV in adolescence?

- Paediatric HIV prevalence 1-4% and ↓^{ing}

Figure II: HIV prevalence by sex and age, South Africa 2012

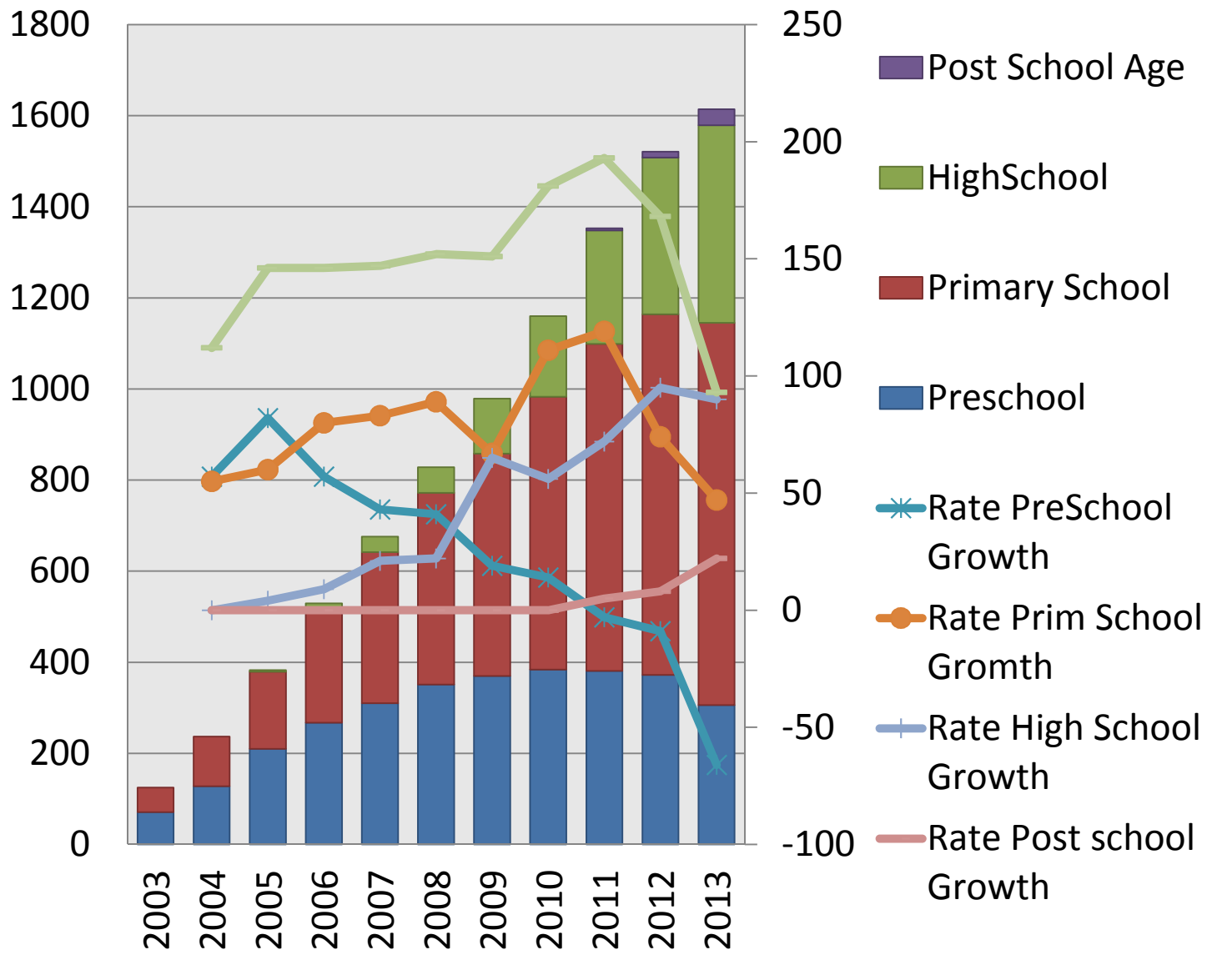


South African National
 HIV Prevalence, Incidence and
 Behaviour Survey, 2012

Adolescents at RMMCH



Active Population at RMMCH



- Progressively fewer new patients
- Majority of new patients older than 3 yrs
- Many cases of “NEWLY DIAGNOSED” adolescents
- Adolescent age groups increasing
- \pm 50% of our clinic attendees > 10 years

- 100-150 adolescents (7-8% of currently active population) are in immediate need of:
 - Transition to adult services
 - Reproductive health services
 - Career and education planning

RMMCH ALHIV

- Total number of pregnancies: 28
 - 4 currently pregnant
 - 5 with second pregnancies
 - 1 with third pregnancy
- TOPs: 7
- Miscarriages: 1
- Live Births: 16
- Transmissions: 1
 - likely recently acquired maternal infection, mother not perinatally infected, no PMTCT

Adolescents living with HIV

Table 1. Differences between Adolescents by Transmission Routes

Perinatally Infected	Behaviorally Infected
More likely to be in advanced stages of HIV	Earlier stages of HIV
More likely to have OIs	Fewer OIs
More likely to not be on first-line drugs and in need of complex ART regimens	Less likely to need ART and resistance to ART less likely
More obstacles to achieving self-management and autonomy	Less likely to experience obstacles to achieving self-management and autonomy
More physical and developmental delays	Less likely to have physical and developmental delays
Higher risks of complications during pregnancy	Lower number of complications during pregnancy
Higher mortality rates	Long-term chronic disease outlook
May not know HIV status though may have been in treatment	May experience more adherence challenges
More likely to have experienced multiples losses related to HIV (parents, siblings, etc.)	More likely to have denial and fear of HIV
More secrecy regarding disclosure	More likely to be misinformed on HIV
Struggling with issues of related to engaging in intimacy, sexuality, and sexual identity	May distrust clinical facilities
May have heightened concerns about pregnancy and starting families	Lack of belief in clinical treatment to prevent vertical HIV transmission
More likely to have support from family/caregiver and health provider	More likely to lack familial, clinical, and social supports

Source: Gibson and Garcia (2009), HIV Transitional Care Working Group (2011).

GUIDELINE ON HIV DISCLOSURE COUNSELLING FOR CHILDREN UP TO 12 YEARS OF AGE

Key findings

A comprehensive review of the literature, undertaken to find evidence to support recommendations, reached the following conclusions:

Disclosure to children of their own HIV status

- There is evidence of health benefit (e.g. reduced risk of death) and little evidence of psychological or emotional harm from disclosure of HIV status to HIV-positive children. Immediate emotional reactions dissipate with time and respond to programme interventions.
- Disclosure of diagnosis, as described by published researchers and by practitioners, is not an isolated event but rather a step in the process of adjustment by the child, caregivers, and the community to an illness and the life challenges that it poses.

Disclosure to children of their parent's or caregivers' HIV status

- There is evidence of benefit to health for HIV-positive and HIV-negative children of HIV-positive caregivers if the caregiver discloses to them.
- The concerns of some caregivers that disclosure leads to increased behavioural problems in children and decreases the quality of the relationship are not supported by children's reports about their reactions to disclosure of their caregivers' HIV status. Even by parents' reports, anticipating and preparing for the understandable initial emotional reactions can improve the child's responses, and responses improve with time.

Disclosure

Start
early

Disclosure of HIV status is not a one-time event, but rather a process, involving ongoing discussions about the disease as the child matures cognitively, emotionally, and sexually.

Reinforce

Aim for
8-9 yrs

Sexual Health

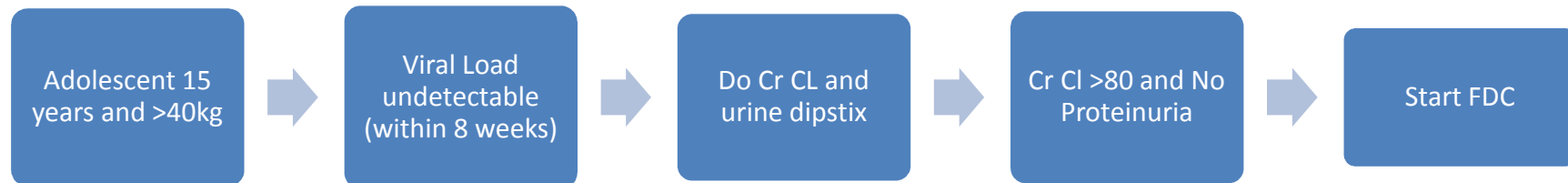
- Often delayed onset of puberty
- Age of sexual debut of perinatally infected adolescents is unknown
- Low knowledge of sexual transmission
- Unrealised need to provide risk-reduction counselling to perinatally infected adolescents
- ?Optimal contraception

- How best (for 'paediatricians') to do all of this?

'Interventions'

- Emphasis on a set of interventions together with disclosure
 - Adolescent focused readiness counselling and peer-support groups to improve adherence
 - Adherence team developed with monthly reporting
 - Introduction of child psychiatrist into the team in recognition of potentially severe psychiatric morbidity
- Improved data capturing of transfers and investigation of “loss to follow-up”
- Allocation of adolescent only clinic time proportional to the percentage in the clinic

Transition from paediatric ART regimens to adolescent/adult regimens



- Adolescents with an undetectable VL and no side-effects on ABC + 3TC + EFV, can remain on the same regimen until the patient becomes eligible for the TDF + FTC + EFV (FDC) at 15 years old and weighing > 40kg
- When an adolescent with an undetectable viral load (within the last 8 weeks) reaches 15 years and 40kg, a Creatinine Clearance (Cr Cl) and urine dipstix should be performed
- If the Cr Cl is >80 and no proteinuria on urine dipstix, then the patient can be switched to the FDC (TDF + FTC + EFV)
- If the Cr Cl is <80 or > 1+ Proteinuria on urine dipstix then refer to an expert for advice before switching.



Evolution of PMTCT



Date	PMTCT Guidelines
2002 to Feb 2008	Intrapartum maternal and infant single dose nevirapine
2004	ART available, threshold for initiation CD4 < 200 cells/mm ³
February 2008	Maternal AZT from 28 weeks. Infant AZT for 1-4 weeks depending on duration of maternal AZT. Single dose nevirapine intrapartum and for infants.
April 2010	AZT from 14 weeks gestation with single dose nevirapine and TDF+FTC intrapartum. Increase CD4 threshold for ART to 350 cells/mm ³ . Infant nevirapine for at least 6 weeks, throughout breastfeeding if no maternal ART
April 2013	Efavirenz-based FDC for prophylaxis and treatment for all pregnant and breastfeeding women. Discontinue FDC post breastfeeding if CD4 > 350 cells/mm ³ and WHO clinical stage I/II. Infant nevirapine for at least 6 weeks depending on duration of maternal ART.
January 2015	Option B+: cART for all pregnant and breastfeeding women to continue lifelong Infants receive 6-12 weeks prophylaxis- NVP or NVP & AZT depending on circumstances

Laboratory information system data demonstrate successful implementation of the prevention of mother-to-child transmission programme in South Africa

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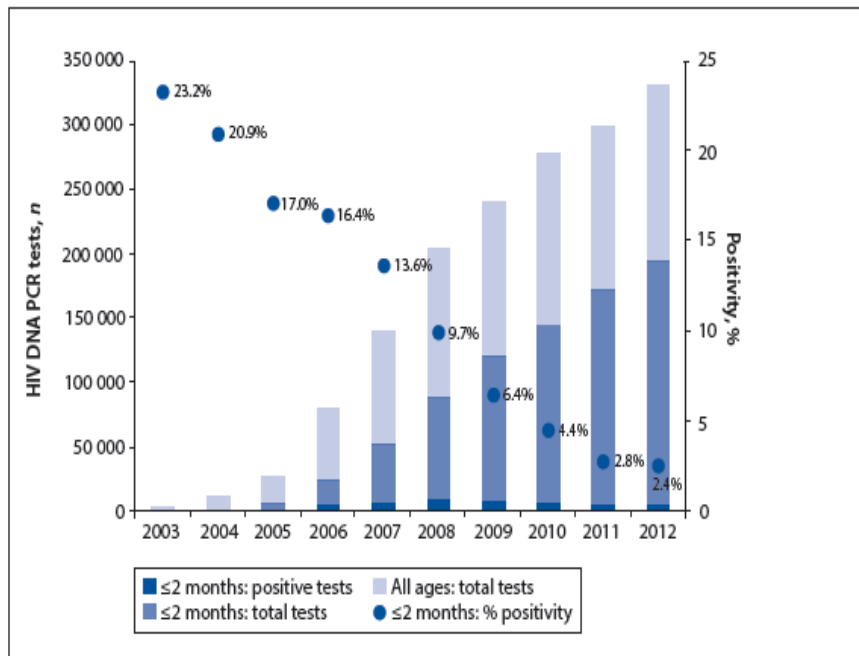


Fig. 1. Early vertical transmission in infants ≤2 months of age in South Africa. Illustration of the rapid scale-up of polymerase chain reaction (PCR) testing nationally with marked reduction in early vertical transmission of HIV over a decade. (KwaZulu-Natal data missing from 2003 to 2005.)

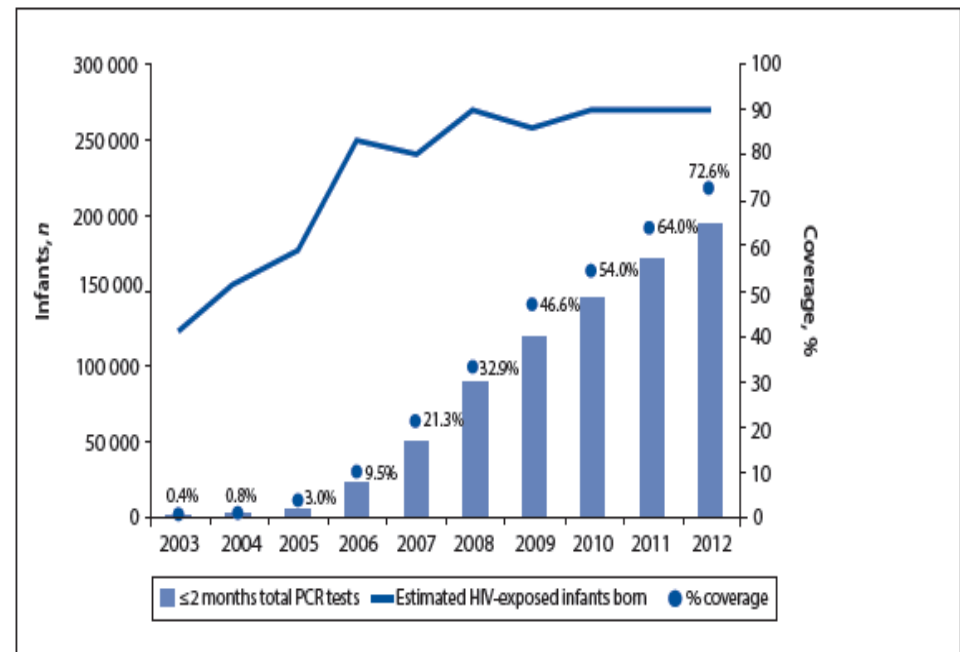


Fig. 2. Early infant diagnosis coverage: estimated number of HIV-exposed infants born in South Africa who access polymerase chain reaction (PCR) testing at ≤2 months of age. (KwaZulu-Natal data missing from 2003 to 2005.)

What to do in children and adolescents failing cART

- US longitudinal cohort comparing continuing failing cART, switch to new ART, stopping ART and drug-sparing regimen:
 - VF occurred in 939/2373 (40%) children
 - After 12 months: children switching to new cART (16%) had a non-significant increase in CD4% from baseline, (0.59 PP) (95% CI:-1.01 to 2.19), not different from those continuing failing cART (71%) (-0.64 PP, p=0.15) or switching to a drug-sparing regimen (5%) (1.40 PP, p=0.64)
- Children discontinuing all ART (7%) experienced significant CD4% decline -3.18 PP (95% CI: -5.25 to -1.11) compared to those initiating new cART (p=0.04)
- All treatment strategies except discontinuing ART yielded significant mean decreases in \log_{10} VL by 12 months; the new cART group having the largest drop (-1.15 \log_{10} VL)
- Similar study being conducted with leDEA South African Data

Challenges of Success: Children growing up with HIV

- ALHIV face this transition with clinical, social, and structural complexities of longstanding HIV infection
- Health and developmental problems:
 - Opportunistic infections e.g. recurrent infections, TB
 - Malignancies
 - Chronic diseases e.g. CLD, growth failure, CVS
 - Neuro-cognitive complications e.g. HIV encephalopathy, learning difficulties, behavioral problems
- Psychosocial issues
 - SES
 - Orphanhood
 - Delayed disclosure



ART Adherence in Adolescence

- Optimal adherence to ART is crucial to achieve immunologic recovery, improve survival, and decrease morbidity.
- Suboptimal adherence results in;
 - inadequate drug exposure
 - increases the likelihood of VF and resistance
 - limits future therapeutic options
 - leads to clinical progression of disease
- Maintaining adherence to dosage and regimen requirements is challenging for many ALHIV

Current tools to measure adherence are inadequate

HCWs not able to identify pts who may or may not adhere to ART

Direct and objective measures

- Directly observed treatment (DOT)
- Therapeutic drug monitoring (TDM)
- Biomarkers (VL, Hair Samples)
- Medication Event Monitoring System (MEMS)

Indirect measures

- Pharmacy records
- Self-report
- Pill count
- Visual analogue scale
- Pill identification test

Interventions to improve adherence

Medication-related barriers

- Reduced pill burden (OD dosing, FDC)
- Palatable formulations
- Management of side effects
- Anti-nausea, anti-diarrheal agents
- Change timing of dosing
- Regimen change

Patient-related factors

- Disclosure
- Bereavement and trauma counseling
- Treatment of concurrent mental illness
- Intensive HIV and ART education

Structural Barriers

- Address barriers such as transportation, child care, clinic hours
- Education of clinic staff
- Address stigma and discrimination

Behavioural interventions

- Motivational interviewing
- Counseling, support groups
- Life skills education
- Parental/caregiver involvement
- Buddy systems
- Adherence clubs
- Peer motivators/educators
- Activity triggers (e.g. meals)
- Calendars
- Technological interventions
- Pill boxes
- Directly observed therapy
- Anti-stigma campaigns

ANY
QUESTIONS
?

Conclusion

- Emerging and Increasing Issue
- Many similarities with Adult & Paediatric HIV
 - But, some Different & Novel Issues
- Listen more, talk less!
- Be innovative!

