Adolescents Living with HIV

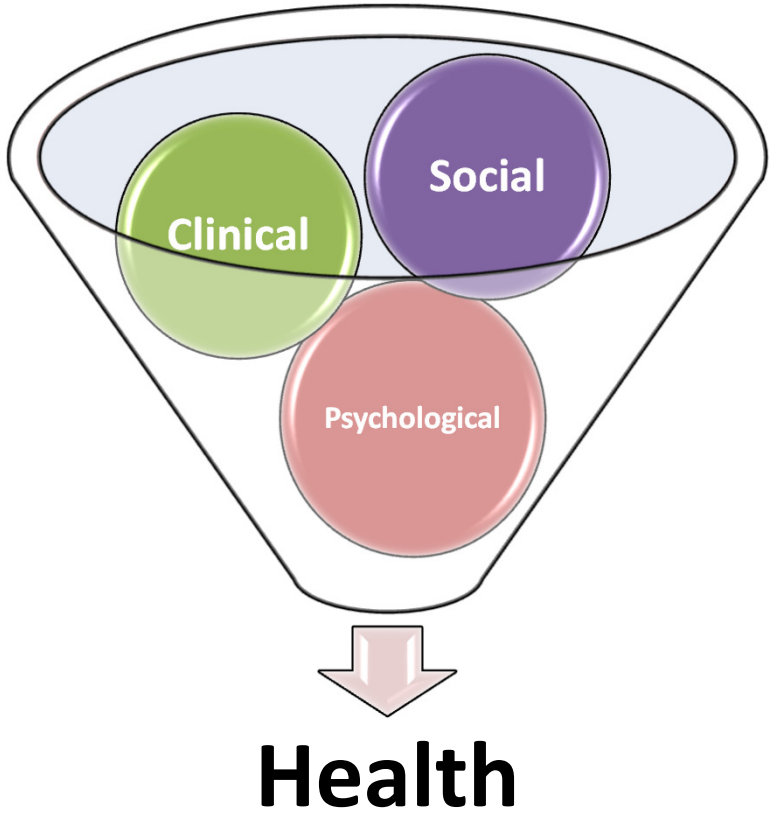
Dr Candice Fick

SA HIV Clinician's Society Symposium

9th May 2015

Child and Adolescent Health

- Complex interaction between environmental factors, social factors and clinical factors



Why Adolescent Health?

- 1 in 6 people in the world are adolescents:

  1.2 billion people are aged 10 to 19.
- Adolescent health previously largely neglected – assumed to be healthy.
  - Spectrum of health issues affecting adolescents: tobacco, alcohol and drug use, HIV, injuries, mental health, nutrition, sexual and reproductive health, and violence.
  - A number of behaviours which have a long term impact on health – such as substance use, smoking, sedentary lifestyle – begin in adolescence

WHO (2014). Adolescents: health risks and solutions [online]

Global statistics: Adolescent Health

- In 2012 an estimated 1.3 million adolescents died worldwide.
- The leading causes of death among adolescents worldwide in 2012 were:
  1) Road injury
  2) HIV
  3) Suicide
  4) Lower respiratory tract infections
  5) Interpersonal violence.

WHO (2012)

HIV in adolescence: A growing concern

- HIV-related deaths have more than tripled since 2000, making it the number 2 cause of mortality among adolescents. In contrast, in 2000 HIV was not even among the top 10 causes of death.

  (WHO 2012)

- Of the estimated 2.1 million adolescents aged 10–19 years living with HIV in 2012, 82% were in sub-Saharan Africa, and the majority of these (58%) were females.

  (Idele et al, 2014).

HIV and adolescence

According to 2010 ICAP data, youth (15 - 24 years) are:

- Least likely to attend HCT
- If not on ART:
  - More likely LTFU – 52% retention at 1 year post diagnosis,
- If on ART:
  - Twice as likely to be LTFU compared to 11–14 year olds, and
  - 1.6 times more likely to be LTFU than older adults

WHO (2011). *Retention in HIV Care*

Adolescents living with HIV

- An inhomogeneous group, consisting of perinatally infected adolescents as well as non-perinatally infected adolescents.
  - HIV Incidence: high in females aged 15 – 24 years
  - Greater background HIV prevalence in adolescents due to longer survival for children initiated on ART
- Clinical characteristics and needs may be very different
- Implications for prevention of transmission

Agwu & Fairlie (2013).
Shisana O et al. (2013).

HIV Incidence 2012 by age and sex

Age groups (years)	Sex	HIV incidence % (95% CI)	Estimated number of new infections (95% CI)
2+	**Total**	**1.07 (0.87–1.27)**	**469,000 (381,000–557,000)**
	Male	0.71 (0.57–0.85)	151,000 (121,000–181,000)
	Female	1.46 (1.18–1.84)	318,000 (257,000–401,000)
2–14	**Total**	**0.25 (0.21–0.29)**	**29,000 (24,000–34,000)**
	Male	No incident cases found	
	Female	0.49 (0.39–0.59)	29,000 (23,000–35,000)
15–24	**Total**	**1.49 (1.21–1.88)**	**139,000 (113,000–175,000)**
	Male	0.55 (0.45–0.65)	26,000 (21,000–31,000)
	Female	2.54 (2.04–3.04)	113,000 (91,000–135,000)
25+	**Total**	**1.41 (1.15–1.67)**	**300,000 (245,000–355,000)**
	Male	1.21 (0.97–1.45)	145,000 (116,000–174,000)
	Female	2.28 (1.84–2.74)	251,000 (203,000–302,000)

A quarter of all new HIV infections in this age group
Incidence 4 times higher in females than in males 15-24y

Emergence of perinatally HIV-infected Adolescents

Slide Source: Dr H Moultrie, 2013.

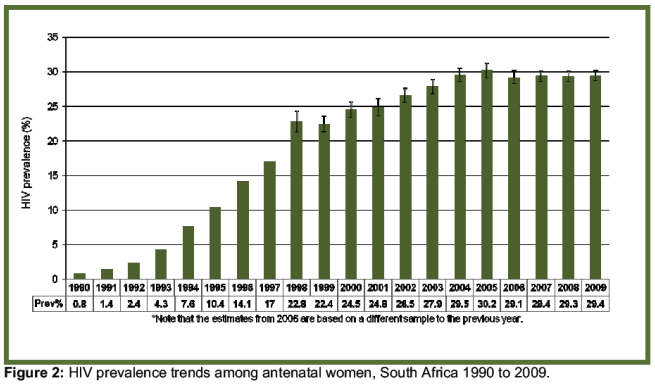


Figure 2: HIV prevalence trends among antenatal women, South Africa 1990 to 2009.

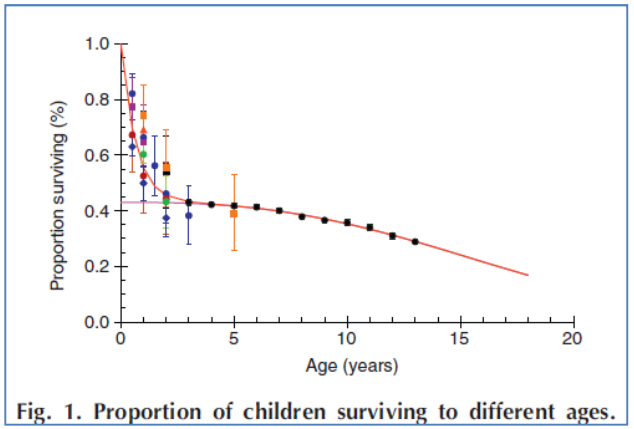
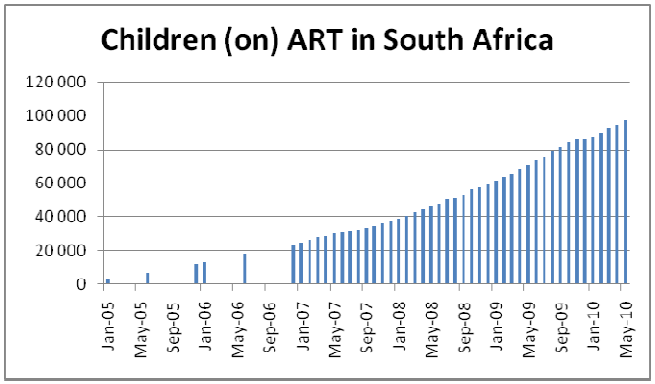
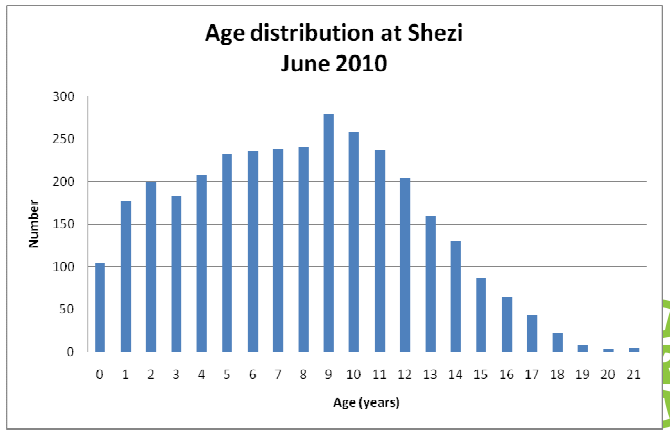


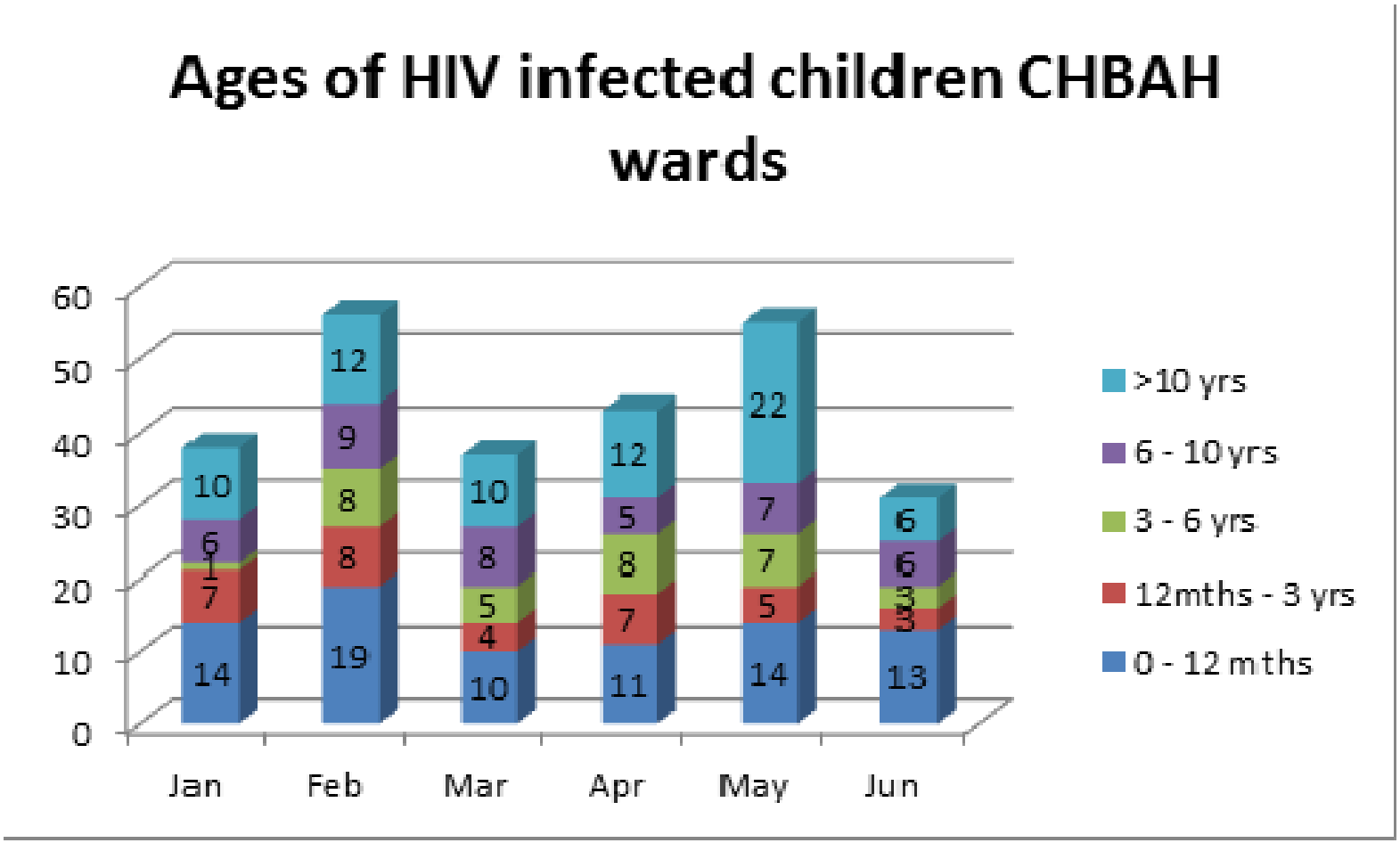
Fig. 1. Proportion of children surviving to different ages.

Ferrand, AIDS (2009)

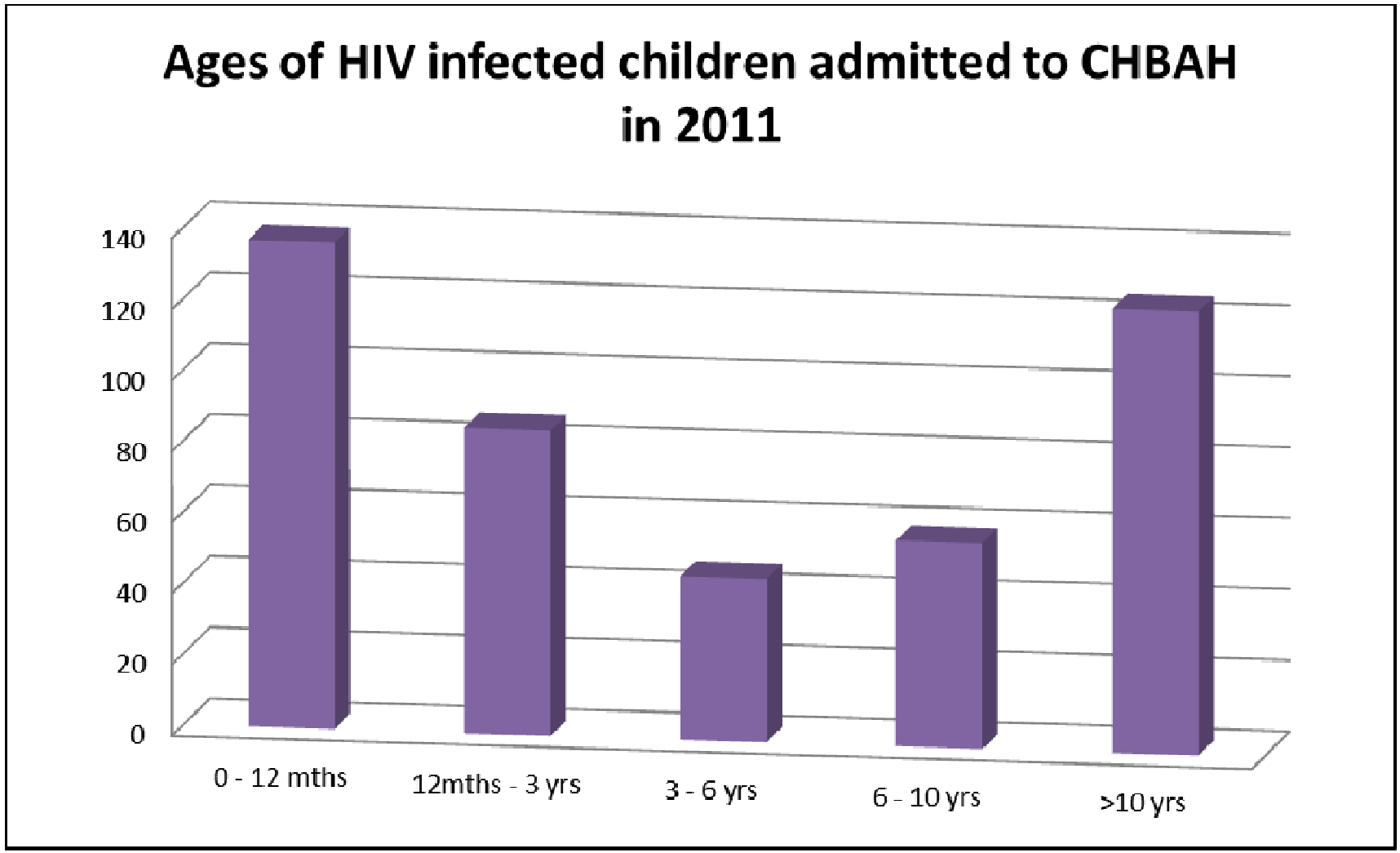




Ages of HIV infected children CHBAH wards



Unpublished data – HSCC 2011



Unpublished data – HSCC 2011

Concerns for adolescents living with HIV

- Higher rate of loss to follow-up
- Lower viral suppression rates – implications for HIV transmission as well as patient care
- Adolescence is a high risk time for mental health problems – may be compounded by being HIV positive
- Undergoing psychological, physical and cognitive changes associated with adolescence.

Nachega et al. (2009), ICAP (2010), WHO (2011).

Additional concerns for PHIA

- May be highly treatment exposed – implications for ART management, treatment side effects and comorbidities
- May have been undiagnosed, and thus may present with marked immune suppression.
- Disclosure to the adolescent is necessary. Disclosure by the adolescent may become necessary.
- Developmental delays may occur:
  - Neurocognitive
  - Sexual
  - Stunting and being small for age

Effects on normal growth and development may be ameliorated by early initiation of ART

Diaz et al. (2006), Colton et al (2012)

Considerations: Medical challenges of ALHIV (PHIA)

CF3

- Long term exposure to ART – side effects
  - Lipodystrophy, dyslipidaemias, gynaecomastia, renal and bone effects
- Long term exposure to the virus
  - Growth, puberty, development (including neurodevelopment), possible increased risk of malignancy
- Co-morbidities
  - Bronchiectasis, non-communicable diseases
- Effects of treatment fatigue and changing autonomy on adherence to treatment

Slide 14

CF3 New slide, check all content and if refs/rev required

Candice Fick, 2015/05/06

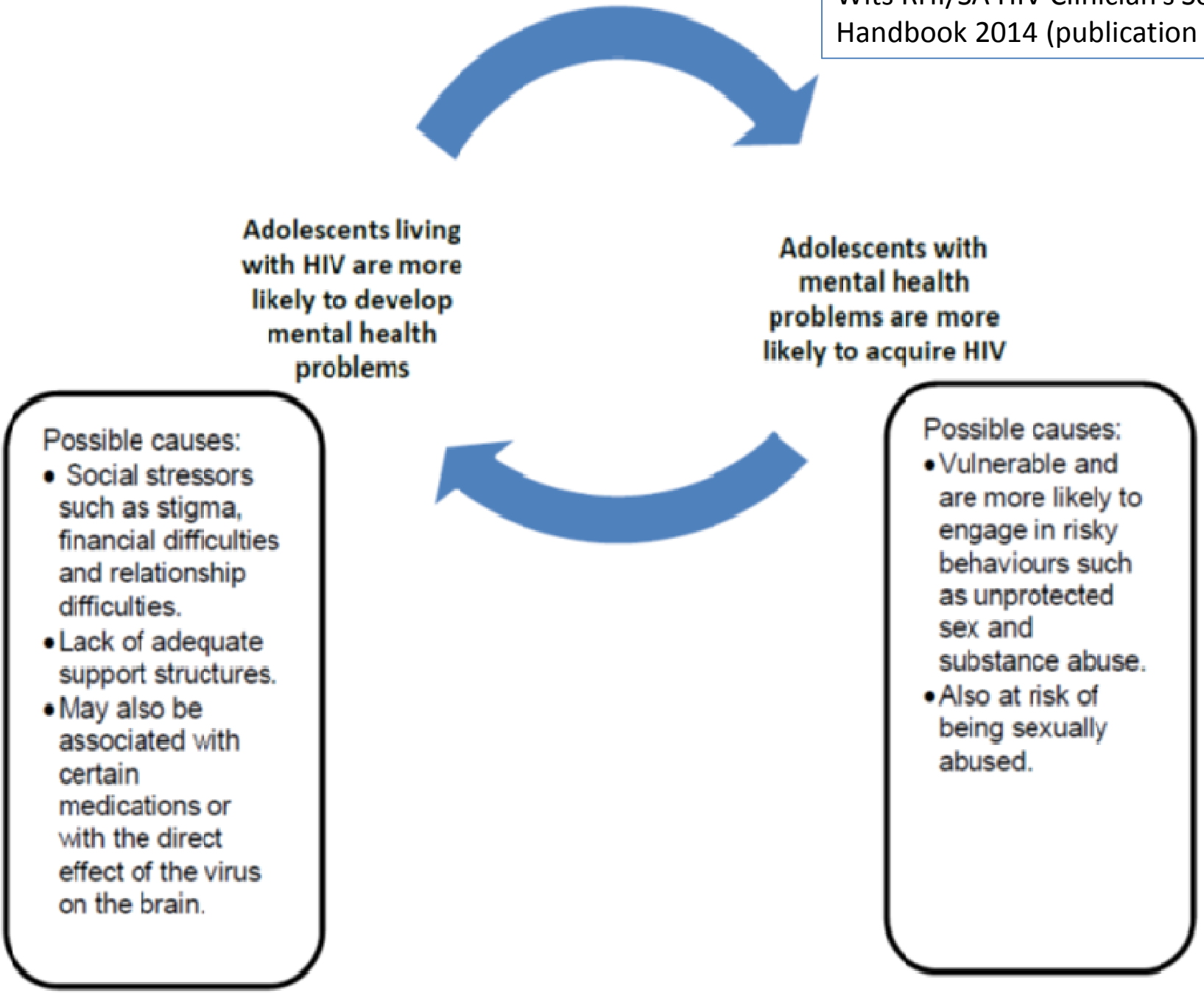
Considerations: Psychosocial challenges for ALHIV

- Have to deal with HIV diagnosis:
  - Stigma and discrimination
  - Issues related to disclosure
  - May have had multiple loss, orphanhood
  - Chronic illness, may have comorbidities
  - Treatment adherence
- Have to deal with adolescence:
  - Peer pressure
  - Desire to “fit in”
  - Striving for autonomy
  - Physical, emotional and cognitive changes

Many of these adolescents are OVCs

- May be single or double orphans (especially perinatally infected)
- May be shifted between different caregivers
- Lack of support structures
- Vulnerable group – at risk of abuse, transactional or intergenerational sex
- Financial implications of regular clinic attendance
- Child-headed households

Wits RHI/SA HIV Clinician's Society Handbook 2014 (publication pending)



Summary of the situation

- High incidence of HIV in adolescence, (particularly in girls aged 15 – 24 years)
- Ageing cohort of perinatally infected children, many of whom may be highly treatment experienced
- May be difficult to manage medically based on the past medical history and psychosocial circumstances
- Often require psychosocial support in terms of living with HIV as well as the challenges of adolescence
- An adolescent focus is needed to provide holistic care, both for the purposes of treatment and for preventing transmission of HIV

What is needed?

- Education for healthcare providers on adolescent health and health concerns
- Reinforce the need for HCT in adolescents
- Focus on relevant adolescent concerns in HIV management: developmental delays, disclosure, non-adherence
- Consolidated guidelines on HIV management
- Age-specific data and monitoring
- Integrated Adolescent and Youth Friendly services

Disclosure to children and adolescents

Disclosure

- Disclosure of the HIV diagnosis is necessary as children age
- Disclosure may:
  - Improve adherence to treatment
  - Improve clinical outcomes
  - Encourage adolescents to take more responsibility and participate in their healthcare
  - Improve access to support
  - Improve retention in care

WHO (2011), Arrivé et al. (2012), Vreeman et al (2013).

- No link to poorer quality of life post disclosure
- No link to increased risk of adverse mental health outcomes

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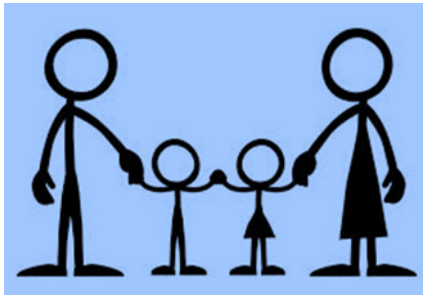

Mellins et al. (2002), Menon et al (2007), Butler et al. (2009).

LF1

A few suggestions

Lee Fairlie, 2014/09/18

Caregiver concerns

- Caregivers may delay or avoid disclosure. Reasons may include:
  - Feeling the child is “too young”
  - Fear the child will not be able to keep confidentiality
  - Feeling the child will not be able to understand the implications
  - Double-burden of stigma (for both adolescent and family)
  - Fear that the child will not cope psychologically with the information
  - Fear of resentment from the child, or guilt feelings that the child is HIV positive
  - Difficulty discussing the topic of HIV

Mburu G et al. (2014), Vreeman et al (2010), Mahloko et al. (2012).

LF2

Disclosure

- There is no “right age” for disclosure

  (WHO recommendation: before the age of 12 years)
- It is not a once-off process – ongoing education is necessary, and the child may have new questions or concerns as they grow older and as their circumstances change
- It is based on a foundation of health education, at an appropriate level for the child’s developmental level
- Disclosure is best done by the caregiver or trusted family member, facilitated by the healthcare provider as necessary
- Disclosure is never urgent
- Requires a degree of preparation for the caregiver, as well as for the child. This may include counselling, formation of caregiver support groups and education for the caregiver

Slide 24

LF2 Have just made the text bigger

Lee Fairlie, 2014/09/18

Preparation for disclosure

Occurs prior to readiness in preparation for full disclosure.

- Health education for the child:
  - basic concepts of health, illness, health-seeking
  - concept of an immune system
  - concept of a “germ”

- Education and support to the caregiver:
  - Support and educate on the need for disclosure
  - Discuss benefits and potential challenges
  - Reinforce understanding of HIV, strengthen ability to answer questions

Disclosure

- Ideally done by the caregiver or close family member – the situation needs to be assessed on an individual basis
- Disclosure should be clear and developmentally appropriate
- Preferably done in a safe and familiar environment, with privacy
- Best done at a time when the child is well
- Disclosure tools may/may not be used
- Caregiver should be advised that the disclosure should be an ongoing discussion, and is not closed after full disclosure has occurred

Post disclosure support

- Important to identify potential issues arising from disclosure
- Ongoing, as new issues may arise with time
- Provide opportunity for questions
- May include one-on-one follow-up, support groups for both caregiver and child, or check-ins.

Background: The Handbook and the Toolkit

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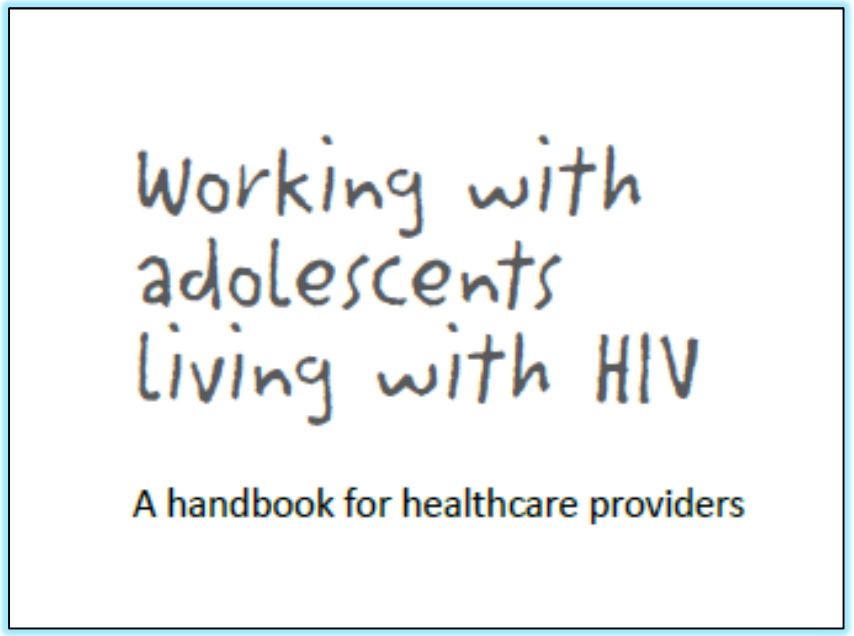
- "Working with adolescents living with HIV: A handbook for healthcare providers" was developed through collaboration between Wits RHI and the SA HIV Clinician's Society
- Deals with the holistic management of adolescents living with HIV
  - Part A – Clinical
  - Part B – Psychosocial and Mental Health
- The Toolkit is a summarised quick reference of the Handbook.

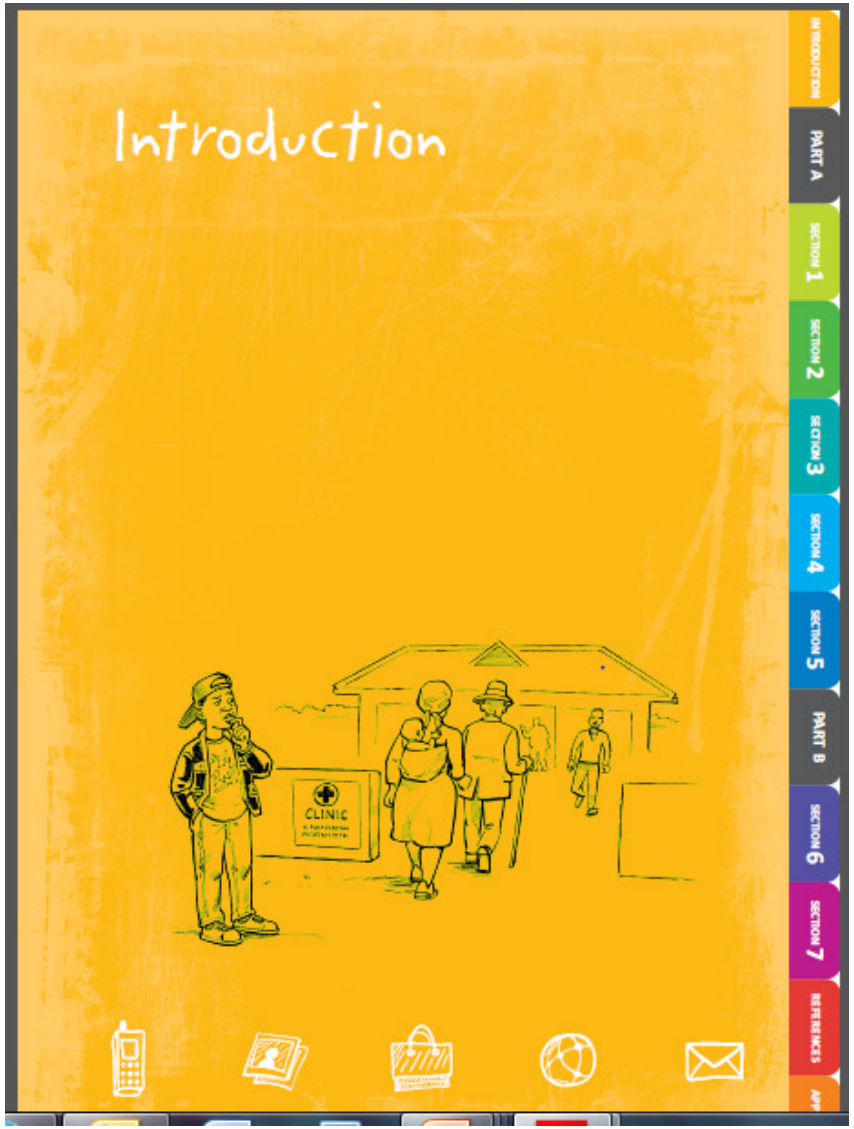


Slide 28

CF1 This slide is really to explain the heading of the topic I was asked to present...not sure how appropriate this is or where it should actually fit in.
Candice Fick, 2014/09/17

Working with adolescents living with HIV: A handbook for healthcare providers

PART	SECTION	CHAPTER
	INTRODUCTION	
PART A Clinical management of adolescents living with HIV	SECTION 1 An introduction to working with adolescents	1. Adolescent-friendly services 2. Adolescents living with HIV: who are they? 3. Development and maturation of adolescents living with HIV
	SECTION 2 Consultation, screening and history-taking	4. The consultation 5. Clinical management: history-taking, screening and examination
	SECTION 3 Continuum of care: HCT and ART	6. HIV counselling, testing and linkages to care 7. Preparing for ART: the initial assessment 8. ART initiation 9. Follow-up and monitoring of clients on ART 10. Adverse events and drug reactions to ARVs 11. Managing virological failure and changing treatment regimens
	SECTION 4 Management of opportunistic infections and other HIV-related conditions	12.Tuberculosis 13. Cryptococcal disease 14. Other opportunistic infections 15. HIV-associated conditions (non-infectious)
	SECTION 5 Sexual and reproductive health	16. Sexual and reproductive health 17. Pregnancy and adolescents living with HIV 18. Prevention for adolescents
PART B Management of the psychosocial wellbeing and mental health of adolescents living with HIV	SECTION 6 Psychosocial wellbeing	19. Psychosocial support and communication 20. Adherence 21. Disclosure 22. Transition 23. Support groups for adolescents
	SECTION 7 Mental health	24. Mental health and HIV in adolescence 25. Management of common mental health conditions in adolescents living with HIV 26. Neurocognitive effects of HIV



PART A:

Clinical management of adolescents living with HIV

OVERVIEW

Also see chapter 1

6. HIV counselling, testing and linkages to care

Adolescents identified through HIV counselling and testing (HCT) may be either perinatally infected (and previously undiagnosed, with the possibility of having advanced complications of HIV) or non-perinatally infected.

HCT may be done as a result of provider-initiated counselling and testing (PICT) or as client-initiated counselling and testing (CICT), also known as voluntary counselling and testing (VCT).[1,2]

- *PICT* refers to the healthcare provider offering HIV testing to all clients as part of routine medical care. PICT is especially important for clients attending antenatal and postnatal care, tuberculosis (TB) and STI management, contraception and fertility planning and medical male circumcision (MMC).[1]
- *CICT* refers to the client requesting an HIV test from an HIV testing site.

6.1 HCT client's rights

When working with adolescents, any HCT (whether PICT or CICT) should follow the five Cs: consent, counselling, confidentiality, correct results and connection to care (Box 7).[4,5] Testing for HIV should be made available and accessible to all adolescents.

Box 7: HCT and adolescents: the 'five Cs'

- Informed consent is required. No coercion should take place.
- Pre- and post-test counselling conducted by a suitably trained healthcare provider should be provided to all clients.
- **Confidentiality** must be ensured.
- **Correct results** refers to the provision of quality healthcare, including quality assurance of the testing process.
- **Connection to care** refers to the availability of well-established and easy-to-navigate referral mechanisms.

6.2 The HCT process

The HCT process extends from pre-test counselling to client linkage to care, as presented in Figure 2.

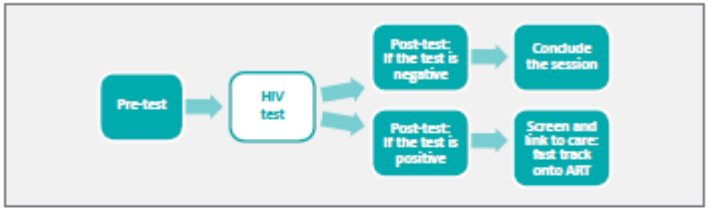


Figure 2: The HCT process

(i) Pre-test counselling[2,3]

Where feasible, it is recommended that group information sessions are conducted for clients who require HCT. Thereafter, targeted individualised counselling may be offered to address individual concerns.4 This is useful where large numbers of clients present for testing, such as at antenatal care. Group testing should be tailored to available resources and clinic function.

Adolescents presenting for HIV testing may have different levels of knowledge about HIV and the testing process. Some may have had an HIV test before. The counselling process should be tailored to the knowledge of the adolescent being tested, using clear and understandable language.

The checklist in Box 9 is designed to ensure that all necessary information is provided for informed consent.

Box 9: Checklist for pre-test counselling

- ✓ Emphasise that the HCT process, the results and everything discussed during counselling will remain confidential. Be honest and explain to the client that other staff in the facility may have access to the information on a need-to-know basis.
- ✓ Discuss the client's reason for wanting an HIV test and any questions/issues that may arise.
- ✓ Explore the implications of testing and knowing one's status, the benefits and possible people with whom they could share this information.
- ✓ Provide basic HIV information on modes of HIV transmission, risks and risk reduction, and treatment options available.
- ✓ Provide SRH information including safer sex practices, contraception and dual protection with condoms, STI signs, symptoms and where to get treatment.
- ✓ Explain the test procedure and processes.
- ✓ Ask what a potential 'HIV-negative' and 'HIV-positive' test result would mean for the adolescent.
- ✓ Emphasise that if the test result is positive there are ways to support the adolescent to live a meaningful and fulfilling life.
- ✓ Explain the 'window period'.
- ✓ Discuss the adolescent's support system: at home, school and/or a trusted adult. If there is no one, direct the adolescent to support services in the facility or community.
- ✓ Ask if there are any questions and provide youth-friendly information to take away and read.
- ✓ Obtain informed consent (verbal or written) and note in patient's file/record.

Acknowledgements

- Dr Lee Fairlie
- Dr Harry Moultrie
- Melanie Pleaner

THANK YOU