



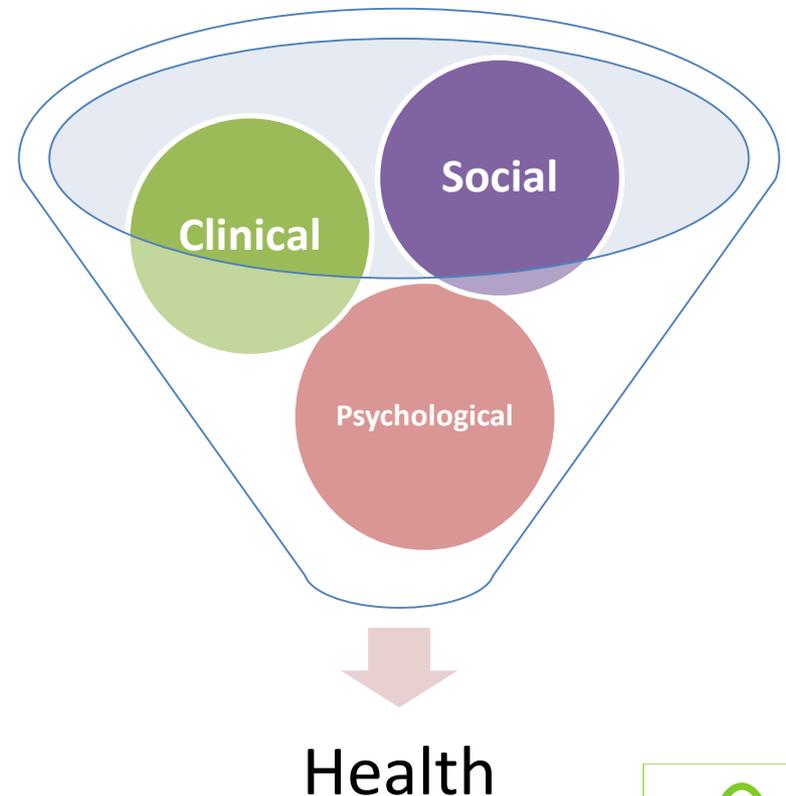
# Adolescents Living with HIV: Mental Health and Disclosure

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# Background: The Handbook and the Toolkit

- “Working with adolescents living with HIV: A handbook for healthcare providers” was developed through collaboration between Wits RHI and the Southern African HIV Clinician’s Society
- Deals with the holistic management of adolescents living with HIV
- Serves as a general reference for much of the content of the presentation
- The Toolkit is a summarised quick reference of the Handbook.



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

PART	SECTION	CHAPTER
	<b>INTRODUCTION</b>	
<b>PART A</b> Clinical management of adolescents living with HIV	<b>SECTION 1</b> 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
	<b>SECTION 2</b> Consultation, screening and history-taking	4. The consultation 5. Clinical management: history-taking, screening and examination
	<b>SECTION 3</b> 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
	<b>SECTION 4</b> Management of opportunistic infections and other HIV-related conditions	12. Tuberculosis 13. Cryptococcal disease 14. Other opportunistic infections 15. HIV-associated conditions (non-infectious)
	<b>SECTION 5</b> Sexual and reproductive health	16. Sexual and reproductive health 17. Pregnancy and adolescents living with HIV 18. Prevention for adolescents
<b>PART B</b> Management of the psychosocial wellbeing and mental health of adolescents living with HIV	<b>SECTION 6</b> Psychosocial wellbeing	19. Psychosocial support and communication 20. Adherence 21. Disclosure 22. Transition 23. Support groups for adolescents
	<b>SECTION 7</b> 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

# The Adolescent Challenge

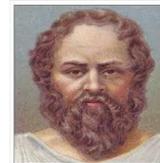
“I would there were no age between ten and three-and-twenty, or that youth would sleep out the rest; for there is nothing in the between but getting wenches with child, wronging the ancients, stealing, fighting.”

— *William Shakespeare, The Winter's Tale*



“Our youth now love luxury. They have bad manners, contempt for authority; they show disrespect for their elders and love chatter in place of exercise; they no longer rise when elders enter the room; they contradict their parents, chatter before company; gobble up their food and tyrannize their teachers.”

— *Socrates*



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# Consider...

“To be left alone on the tightrope of youth unknowing is to experience the excruciating beauty of full freedom and the threat of eternal indecision. Few, if any, survive their teens. Most surrender to the vague but murderous pressure of adult conformity. It becomes a constant battle with the superior forces of maturity.”

– *Maya Angelou*



# The global picture: 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 infections, and
  - 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.

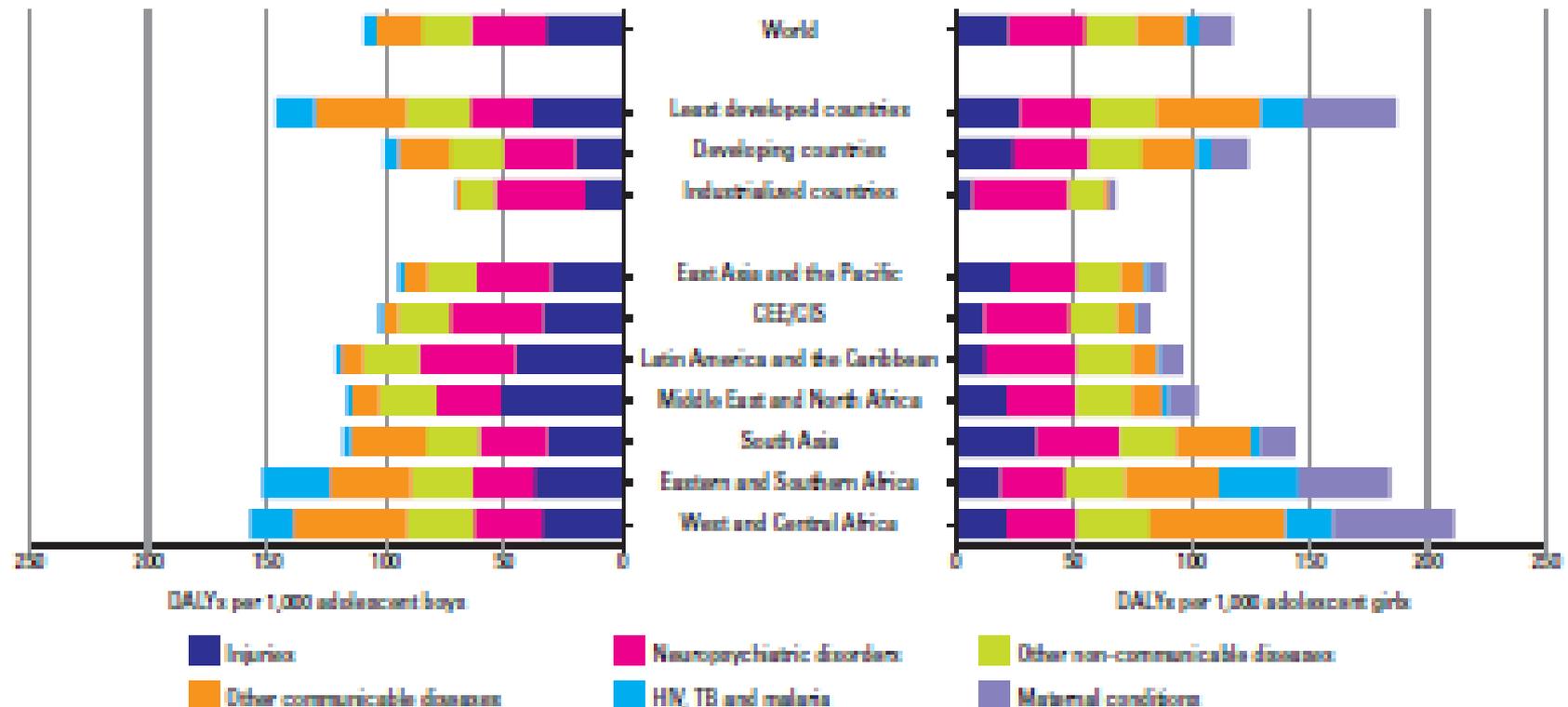
*(Idele et al, JAIDS supplement 2014).*



**FIGURE 4.1**

## Injuries and neuropsychiatric disorders are major causes of mortality and morbidity among adolescents in all regions

Major causes of disease burden in disability-adjusted life years (DALYs) per 1,000 adolescents 10–19 years old, by region and by sex



Note: Neuropsychiatric disorders include depression, bipolar disorder, anxiety/panic disorders (including post-traumatic stress disorder and obsessive-compulsive disorder), psychotic disorders (including schizophrenia), seizure disorders (including epilepsy and Parkinson's disease) and alcohol and drug-use disorders.

Disability-adjusted life years (DALYs) are a summary measure combining years of life lost because of premature mortality (YLLs) and years lost because of disability (YLDs) for incident cases of the disease or injury. One DALY represents the loss of the equivalent of one year of full health. Population data are for the year 2008. The data have been recalculated according to UNICEF regional classification.

Source: WHO, *The Global Burden of Disease: 2008 update*, 2009, and United Nations Department of Economic and Social Affairs, Population Division, *World Population Prospects: The 2010 revision*, CD-ROM edition, 2011.

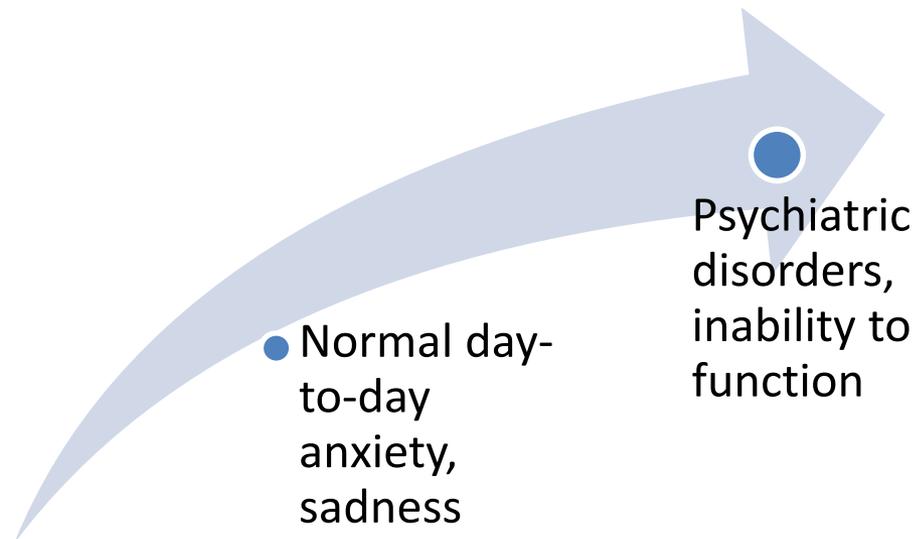
- “The statistics expose some largely neglected issues in adolescent health: mental health problems, suicide, alcohol use, road injuries and other unintentional injuries, interpersonal violence and war.”

- *WHO (2014) Adolescent Health Epidemiology [online]*



# Mental health for adolescents

- Mental health exists on a continuum, from every day anxiety to the extreme of mental illness
- Adolescence is a dynamic time with many changes occurring. It may be difficult to identify the emerging signs of mental health problems



# Mental health problems in adolescents

- Common mental health problems affecting adolescents include:
  - Depression
  - Alcohol and Substance use/abuse
  - Trauma and PTSD
  - Anxiety
- Additional concerns for adolescents living with HIV:
  - Neurocognitive disorders
  - Link (?) with ADHD



# Protective factors vs. Risk factors

Domain	Risk factors	Protective factors
<b>Biological</b>	<ul style="list-style-type: none"> <li>• HIV infection</li> <li>• Congenital malformations</li> <li>• Genetic tendency to psychiatric disorder</li> <li>• Malnutrition</li> <li>• Other illness</li> </ul>	<ul style="list-style-type: none"> <li>• Age-appropriate physical development</li> <li>• Good physical health</li> </ul>
<b>Psychological</b>	<ul style="list-style-type: none"> <li>• Psychiatric disorder</li> <li>• Maladaptive personality traits</li> <li>• Effects of emotional and sexual abuse, and neglect</li> <li>• Self-stigma</li> <li>• Orphanhood</li> </ul>	<ul style="list-style-type: none"> <li>• Ability to learn from experiences (resilience)</li> <li>• Good self-esteem</li> <li>• High level of problem-solving ability</li> <li>• Effective social skills</li> <li>• Supportive peer group</li> <li>• Supportive parent/caregiver</li> </ul>
<b>Social: Family</b>	<ul style="list-style-type: none"> <li>• No family</li> <li>• Deceased parents</li> <li>• Divorced parents</li> <li>• Family conflict and domestic violence</li> <li>• Poor family management</li> <li>• Poor family discipline</li> </ul>	<ul style="list-style-type: none"> <li>• Secure family attachment</li> <li>• Opportunity for positive involvement in family</li> <li>• Safe family relationships</li> <li>• Fair discipline practices</li> </ul>
<b>Social: School</b>	<ul style="list-style-type: none"> <li>• Academic failure</li> <li>• Learning disability</li> <li>• Poor commitment to schooling</li> <li>• Inadequate/inappropriate educational provision</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunities for involvement in school activities</li> <li>• Supportive and safe school environment</li> </ul>
<b>Social: Community</b>	<ul style="list-style-type: none"> <li>• Community disorganisation</li> <li>• Exposure to violence</li> <li>• Effects of discrimination</li> <li>• Poverty</li> <li>• Mobility/access/transport</li> <li>• Transition/urbanisation</li> <li>• Transactional or intergenerational sex</li> </ul>	<ul style="list-style-type: none"> <li>• Connectedness to community</li> <li>• Opportunities for constructive use of leisure</li> <li>• Safe environment</li> <li>• Positive role models</li> <li>• Legislation that is favourable to development</li> <li>• Appropriate gender equity norms</li> </ul>

Adapted from : DOH (2012) Policy guidelines: Child and Adolescent Mental Health.



# Considerations: Adolescents living with HIV

- 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





**Adolescents living with HIV are more likely to develop mental health problems**

**Adolescents with mental health problems are more likely to acquire HIV**

Possible causes:

- Social stressors such as stigma, financial difficulties and relationship difficulties.
- Lack of adequate support structures.
- May also be associated with certain medications or with the direct effect of the virus on the brain.



Possible causes:

- Vulnerable and are more likely to engage in risky behaviours such as unprotected sex and substance abuse.
- Also at risk of being sexually abused.

# Identifying adolescents with mental health problems

- *At every visit ask:* How are things in your life at present? How have things been since you were last at the clinic/in the last month?

If problems are identified, ask how the patient copes with them, who they have to support them and if they feel the problem is manageable for them.

- Specific questioning will be directed by the adolescent's response
- Feeling overwhelmed, hopeless or feeling unsupported indicate a need for further questioning, counselling and support.
- Red flags: marked deterioration in function, suicide ideation, no/poor response to previous interventions



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# Depression

- Common in adolescents living with HIV
- Is a risk factor for suicide.
- May be missed as the adolescent may present differently than an adult with depression.
- Clinical features of depression(2 week period):
  - EITHER: Depressed mood, most of the day. (*Adolescents may appear irritable or angry*).
  - OR Inability to take pleasure or enjoy things.
  - ASSOCIATED WITH: appetite/weight changes, sleep disturbances, negative thinking or guilty thoughts, suicidal thoughts, low energy, psychomotor slowing/agitation.
- Refer if concerned, medication may be required.



# Anxiety

- The adolescent may report feeling anxious, and may be able to identify the source of their anxiety.
- The presenting complaint may be of physical symptoms, which may be especially concerning for chronically unwell patients (or those who perceive themselves so).
- An important area for inquiry is if the adolescent feels they are able to cope with their anxiety, as well as if their anxiety is affecting their daily functioning.



# Anxiety

- Symptoms to look out for:
  - Physical (nausea, abnormal heartbeat, reported breathing disturbance, insomnia),
  - Cognitive (difficulty concentrating, overwhelming fear, panic disproportional to the cause)
  - Behavioural (social withdrawal, avoidance, restlessness)
- Also remember the possibility of associated substance use/abuse



# Trauma/PTSD

- Common in adolescents living with HIV.
- Caused by exposure to a traumatic event, usually involving threatened or actual death, harm or injury (to self or others).
- Symptoms may occur soon after the event or be delayed.
- Symptoms include:
  - Hyper-arousal
  - Avoidance
  - Intrusive recollections/memories of the event



# Alcohol and substance abuse

- Often co-morbid with other mental health problems (depression, anxiety, PTSD)
- Concern for effects on ART adherence
- May be a risk factor for risky sexual behaviour or place adolescents at risk of violence
- Certain substances may interact with ART
  - *Alcohol*: theoretically may increase ABC levels
  - *Benzodiazepines*: midazolam, clonazepam, alprazolam  
Increased sedation may occur with PI use
  - *Cannibus*: May reduce serum PI levels
  - *MDMA and Amphetamines*: Ritonavir may increase levels and cause toxicity

New York State Department of Health AIDS  
Institute (2008).



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# Neurocognitive effects of HIV

- Perinatally infected adolescents may have been diagnosed with HIV encephalopathy in infancy, with residual effects to varying degrees.
- Later effects of the virus may result in HIV-associated Neurocognitive Disorders (HAND) and HIV associated Dementia (HAD) similarly to adults.
- Milder forms of HAND may be difficult to pick up clinically. It should be considered for adolescents who present with schooling difficulties

All are WHO IV conditions, related to direct effects of the HIV virus on the CNS.



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# Clinical features of neurocognitive disorders

- Adolescents with neurocognitive disorders may be slower at processing information.
- Effects may be seen in concentration, attention, memory, learning and higher level functioning such as planning, judgement and organisation.
- There may be abnormal motor skills or sensory perception.
- School difficulty and learning problems may arise as a result of these effects.

There are no screens validated for identifying neurocognitive disorders in this age group. It is advisable to regularly enquire about school performance, and to take a careful history where these are reported.

Management consists of ART (ensuring viral suppression) rehabilitation, and appropriate schooling.



# Referral

- Suicidal, high risk for self-harm
- Risk of harming others
- Need for psychiatric drugs not available at facility level
- Need for psychological/psychiatric intervention not available at facility level
- Acute psychiatric presentation – no previous history (NB: screen for common medical causes)
- Suspected delirium
- Marked effect on function
- Poor response to intervention



# Suicide:

- Adolescence is considered a period of high risk for suicide – regular suicidal screening has been advocated as a routine part of adolescent healthcare
- In one report on local suicide data, adolescents aged 10 – 19 years formed 9.92% of suicide cases
  - 8.35% in age group 15 – 19 years
  - 1.57% in age group 10 – 14 years
- Mental disorders or substance abuse have been associated with more than 90% of suicides

Rosen et al (2004), Shilubane et al. (2013), Donson (2008)



# Results from the National Youth Risk Behaviour Surveys

- Percentage of South African adolescents who had seriously considered and made a plan to commit suicide:
  - 2002: 18%
  - 2008: 19%
- Percentage of South African Adolescents who have attempted suicide at least once: 18.5%
- Usually, suicide ideation preceded the attempt. Occasionally it was impulsive
- Suicide attempts more common in females (19.5% vs 17.3%)
- (Possibility that males more likely to use lethal methods)

Shilubane et al. (2013).



# The suicidal adolescent

- Suicide is complex, with many cultural and socioeconomic factors playing a role, and is more likely in the event of crisis
- Suicidal ideation occurs frequently, but this is not necessarily an indication of acute risk
- **HOWEVER**, any verbalisation of suicidal intent should always be taken seriously
- Management depends on the assessed risk



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# Screening for suicide ideation

- Suicidal screen may include :
  - In the past month did you wish you were dead?
  - Did you want to hurt yourself?
  - Did you think of killing yourself?
  - Did you think of a way to kill yourself?
  - Did you try and kill yourself?

*(Mini International Psychiatric Interview for Adolescents)*

Sheehan D et al. (2004), Lecrubier et al. (1997)



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# Assessment of suicidal risk

SAD PERSONS scale	
S	Sex: Male is at higher risk (1 if male; 0 if female)
A	Age: Extremes of age at higher risk (1 if < 20 or > 44)
D	Depression: higher risk (1 if depression is present)
P	Previous attempt: Past attempts higher risk (1 if present)
E	Ethanol/Alcohol/Substance abuse (1 if present)
R	Rational thinking loss: (1 if present)
S	Social Supports Lacking: higher risk (1 if present)
O	Organised Plan: (1 if plan is made and lethal)
N	No Spouse: (1 if divorced, widowed, separated, or single)
S	Sickness: higher risk (1 if chronic, debilitating & severe)

Patterson et al, (1983)

# Usefulness of the SAD PERSONS Scale

- All HIV + adolescents will automatically be scored with 3 points if this is applied (4 if male)
- Does not take protective factors into account, or the lethality of the plan
- Has not been shown to be good at predicting suicide attempts, but is useful to remind the healthcare provider of important risk factors
- Best to consider each case on its individual circumstances



# Management according to risk

RISK LEVEL	RISK/PROTECTIVE FACTOR	SUICIDALITY	POSSIBLE INTERVENTIONS
<b>High</b>	Psychiatric diagnoses with severe symptoms or acute precipitating event; protective factors not relevant	Potentially lethal suicide attempt or persistent ideation with strong intent or suicide rehearsal	Admission generally indicated unless a significant change reduces risk. Suicide precautions
<b>Moderate</b>	Multiple risk factors, few protective factors	Suicidal ideation with plan, but no intent or behavior	Admission may be necessary depending on risk factors. Develop crisis plan. Give emergency/crisis numbers
<b>Low</b>	Modifiable risk factors, strong protective factors	Thoughts of death, no plan, intent or behavior	Outpatient referral, symptom reduction. Give emergency/crisis numbers

*Appendix to: Wits RHI/SA HIV  
Clinician's Society Handbook 2014  
(publication pending)*





# Disclosure

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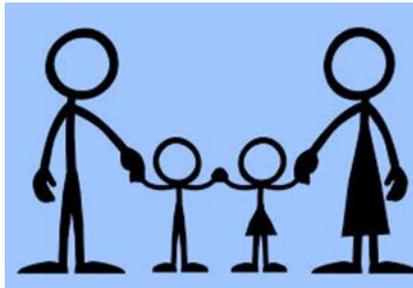
- Disclosure of the HIV diagnosis is necessary as children age
- Disclosure may:
  - Improve adherence to treatment
  - Improve clinical outcomes
  - Encourage adolescents to take more responsibility and participate in their healthcare
  - Improve access to support
  - Improve retention in care

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



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



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



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# 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).



# 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



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# 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



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# 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.



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THANK YOU

