Guideline:
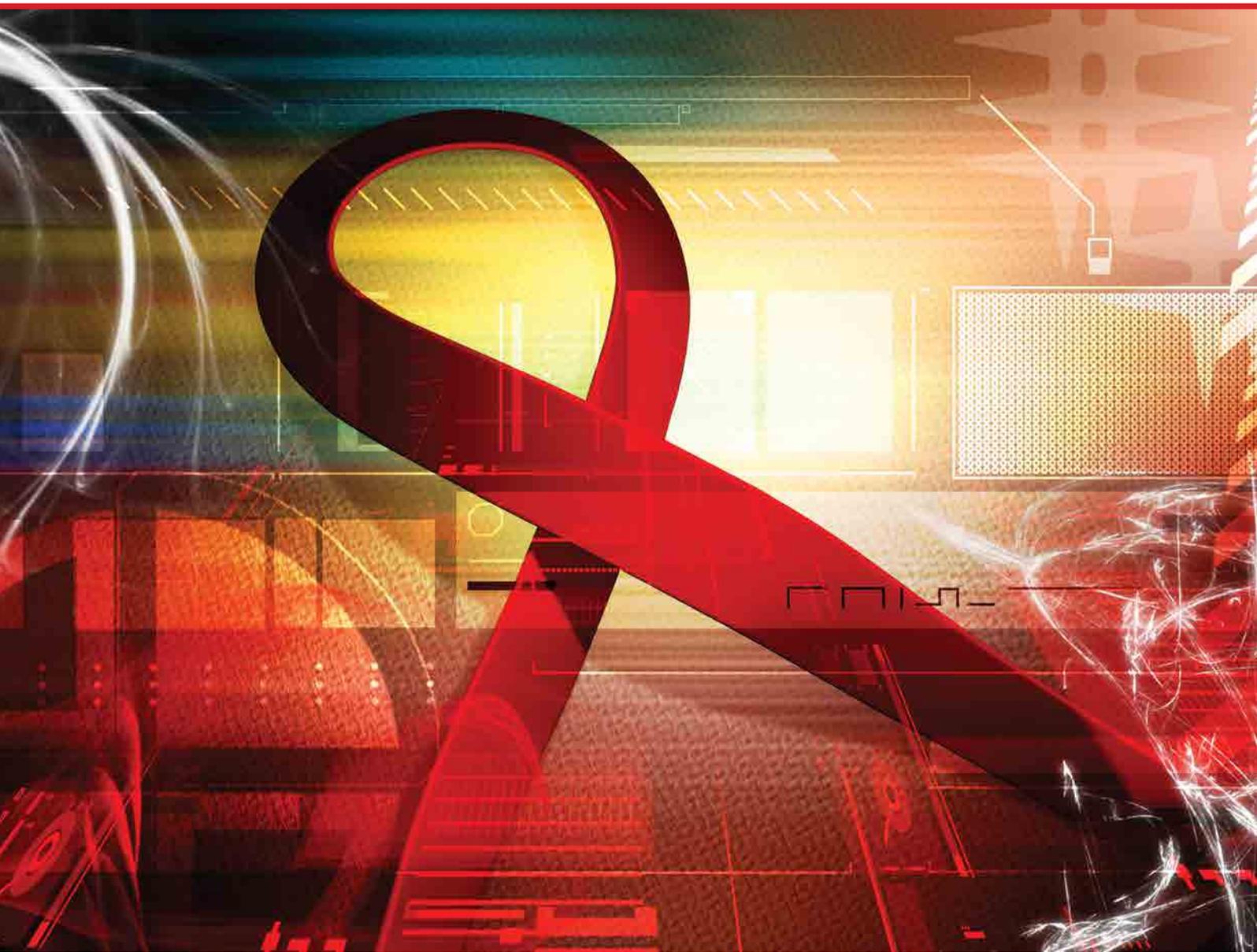# Adherence to antiretroviral therapy in adolescents and young adults
(expanded version)

Recommendations, resources and references

Guidelines for adherence to antiretroviral therapy in adolescents and young adults
A publication of the Southern African HIV Clinicians Society

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Ab	Antibody
ACT	Acceptance and commitment therapy
ADHD	Attention deficit hyperactivity disorder
Ag	Antigen
AIDS	Acquired immune deficiency syndrome
ALT	Alanine transaminase
ART	Antiretroviral therapy
ARV	Antiretroviral
AUDIT	Alcohol use disorders identification test
AYFS	Adolescent- and youth-friendly services
AYLHIV	Adolescent(s) and/or young adult(s) living with HIV
AZT	Zidovudine
CAGE-AID	Cutdown, annoyed, guilty, eye-opened – adapted to include drugs
CBO	Community-based organisation
CBT	Cognitive behavioural therapy
CCMD	Central Chronic Medicine Dispensing and Distribution Programme
CCG	Child care grant
CCr	Creatinine clearance rate
CD4	Cluster of differentiation 4 T-cell
CES-D	Centre for Epidemiological Studies Depression Scale
CHC	Community healthcare
CHW	Community health worker
CM	Cryptococcal meningitis
CPT	Cotrimoxazole preventive therapy
CrAg	Cryptococcal antigen
CRPD	Convention on the Rights of Persons with Disabilities
DoH	Department of Health
DRV	Darunavir
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
DUDIT	Drug use disorders identification test
EC	Emergency contraception
FBC	Full blood count
GAD	Generalised anxiety disorder
GBV	Gender-based violence
HANDs	HIV-associated neurocognitive disorders
Hb	Haemoglobin
HbsAg	Hepatitis B surface antigen
HCT	HIV counselling and testing
HIV	Human immunodeficiency virus
HIVAN	HIV-associated nephropathy
HPCSA	Health Professions Council of South Africa
HPV	Human papilloma virus
HSRC	Human Sciences Research Council
INH	Isoniazid
IPT	Isoniazid preventive therapy
IRIS	Immune reconstitution inflammatory syndrome
LGBTIQ	Lesbian, bisexual, gay, transgender, intersex or questioning

LPV/r	Lopinavir/ritonavir
MAC	*Mycobacterium avium* complex
MDR-TB	Multidrug-resitant tuberculosis
mHealth	Mobile health
MMC	Medical male circumcision
MND	Mild neurological disorder
MOU	Memorandum of understanding
MSM	Men who have sex with men
MTCT	Mother-to-child transmission of HIV
NCDs	Non-communicable diseases
NDoH	National Department of Health
NGO	Non-governmental organisation
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OI	Opportunistic infection
Pap	Papanicolaou test
PC-PTSD-5	Primary care post-traumatic stress disorder screening 5
PEP	Post-exposure prophylaxis
PHC	Primary healthcare
PHQ-9	Patient health questionnaire 9
PHQ-A	Patient health questionnaire for adolescents
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission of HIV
PrEP	Pre-exposure prophylaxis
PTSD	Post-traumatic stress disorder
PWID	People who inject drugs
RAL	Raltegravir
RCT	Randomised controlled trial
RIC	Retention in care
RSA	Republic of South Africa
SAD	Substance abuse disorders
SAHIVSoc	Southern African HIV Clinicians Society
SAMA	South African Medical Association
SANAC	South African National AIDS Council
SANC	South African Nursing Council
SASL	South African Sign Language
SMS	Short message service
SRH	Reproductive and sexual health
STI	Sexually transmitted infection
TB	Tuberculosis
TDF	Tenofovir
UN	United Nations
UNICEF	United Nations Children's Fund
US	United States
UTT	Universal test and treat
VL	Viral load
WHO	World Health Organization
WRHI	Wits Reproductive Health Institute
XDR-TB	Extensively drug-resistant tuberculosis

background

1. Background, definitions and context

In 2016 the South African Department of Health launched the *National Adherence Guidelines for Chronic Diseases (HIV, TB and NCDs)* in 2015.[1] The guidelines provided welcome direction for healthcare professionals supporting patients on treatment regimens.

Subsequent to the introduction of the Guidelines, a number of stakeholders came together with the aim of exploring the treatment adherence difficulties of HIV-positive adolescents in particular. These stakeholders acknowledged that adherence during the adolescent years represents a significant challenge and poses a considerable threat to healthy outcomes.

Given the multiplicity of factors that influence adherence and the complexity of adolescence as a developmental stage, stakeholders who participated in the forum called for a set of adolescent-specific guidelines, aligned to the National Guidelines. These would offer a more in-depth look at adherence during the adolescent years, thereby meeting the needs of healthcare providers in a package comprising a concise set of guidelines, supported by a lengthier version for background and more in-depth reading.

Two documents have been developed. The first (***Guidelines for adherence to antiretroviral therapy in adolescents and young adults***) provides a quick reference and summary of the main aspects related to supporting antiretroviral therapy adherence for HIV-positive adolescents and young adults. The second, expanded version (this document: ***Guidelines for adherence to antiretroviral therapy in adolescents and young adults (expanded version): Recommendations, resources and references***) provides more detail for those requiring additional background information, resources and references.

Both documents are aligned to several related National Department of Health HIV guidelines, including: *National Adherence Guidelines for HIV, TB and NCDs* (2016); *National Consolidated Guidelines for the Prevention of Mother-To-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults* (April 2015); and *Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases* (2016).

The guideline package reflects an appreciation that for most adolescents and young adults living with HIV (AYLHIV), understanding the commitment to the long-term nature of antiretroviral therapy (ART) is a difficult concept. This makes support one of the key aspects to helping youth become successful in maintaining ART adherence. The package provides direction on this and other aspects of adherence such as helping adolescents who are not familiar with what it means to take chronic medication and those who are facing the challenge of dealing with their diagnosis.

1.1 Definition of an adolescent – differentiating children from adolescents

Adolescence is defined as a time of both physiological and social transition to adulthood, during which individuals develop secondary sexual characteristics and take on increasing levels of independence and responsibility. The guidelines acknowledge that adolescence is a critical transition period characterised by tremendous and unique physical, biological, intellectual, behavioural, and emotional growth and changes. For this reason, it is especially important that the adolescent stage of development, and its potential impact on treatment adherence, is distinguished from treatment support for adults and children. Adolescents are not children, nor are they adults.

Most national and international guidelines define adolescents as individuals aged 10 - 19 years,[1,2] or 10 - 24 years;[3] and this period may be divided into early (10 - 14 years), middle (15 - 16 years) and late (17 - 19 years) adolescence. Aligned with the WHO definition,[3] these guidelines are intended to be applicable to AYLHIV aged 10 - 24 years.

1.2 Adherence and adolescents

Four overarching influences on adherence in adolescents are considered in the guidelines:

- *The individual themselves:* negotiating adolescence – a developmental stage during which normal striving for identity and independence from authority figures – may lead to difficulties aligning decisions and behaviour with adherence guidance.

- *Family, community and cultural structures*: caregiver availability; level of trust and openness for disclosure; and general support available.

- *Health services*: accessibility; level of youth-friendliness; confidentiality; stock-outs; and service delivery models (including counselling and support group availability).

- *Medication*: formulations; adverse side-effects; timing of doses; and supplier changes.

1.3 Addressing the context

In 2015, adolescents represented the fastest-growing age group of people living with HIV (PLHIV), accounting for 5.9% of the burden of HIV.[4] This underscores the need for greater understanding and suitable adaptation of HIV care and treatment services. Sustaining optimal ART adherence in AYLHIV has emerged as a major healthcare challenge, fundamentally due to regimen complexity and adherence efficacy.

Correlates exist between ART adherence among adolescents in low- and middle-income countries and: gender and knowledge of serostatus; influence of family structure; impact of onerous ART regimens; attitudes about medication; healthcare challenges; environmental factors, such as rural versus urban setting; and retention in care (RIC). Some studies cite being orphaned, loss of a caregiver, mental health challenges, changes in guardianship, and absence of parental and social support as adherence-related challenges. Others name lack of autonomy, reliance on caregivers to access care, compliance with clinic visits, collection of medication and adherence to dosing schedules.[4]

These are confounded by issues concerning disclosure, autonomy and maturity. Non-disclosure is often associated with negative health outcomes and is compounded if the disclosure (from a vertical infection) reveals the HIV status of the parent on whom the adolescent may depend, or to whom the surviving caregiver is connected. Emerging maturity, developing autonomy and independence, and normal experimentation associated with this developmental stage, all factor into these complexities.[4]

Great strides have been made in the field of paediatric HIV over the last 15 years and improvements in ART have enabled many adolescents to reach adulthood. However, many challenges with adolescent HIV treatment remain, and often place this age group at risk for failing their treatment. The treatment failure rates for adolescents with HIV are much higher than that of adults. Whereas the failure rate for adults ranges from 10% to 15% depending on location, failure rates for adolescents are reported to be as high as >50% in some studies.[5]

Differentiated models of care for this vulnerable youth population are called for, with a 50% reported increase in AIDS-related mortality, relative to a 30% decline in the general population.[6]

It is the purpose of these guidelines to provide practical guidance to support and improve adherence for adolescents and young adults.

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1. National Department of Health (NDoH). Adherence Guidelines for HIV, TB and NCDs. Pretoria, South Africa: NDoH, 2016.

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2. Clinical aspects of ART adherence in adolescents

2.1 Standardised monitoring for adolescents living with HIV

Table 1: Monitoring at initial diagnosis of HIV	
Monitoring	**Purpose**
Ensure that two rapid HIV tests have been done and are positive to confirm HIV diagnosis	Ensure that national testing algorithm has been followed
Document weight and height	Monitor growth and assess which ART regimen to start
WHO clinical staging	Assess eligibility for fast-tracking, although all HIV-positive youth are eligible for ART initiation
Screen for pregnancy and offer family planning	Access to family planning
Ask if planning to conceive	Counselling about need for suppressed VL if wanting to conceive
Screen for STIs	Treat STIs
Screen for TB symptoms and TB contacts	Identify TB/HIV co-infected; assess need for IPT
Screen for hepatitis B virus – HbsAg	Identify hepatitis B infection
CD4 count	Baseline CD4; need for CPT and cryptococcal Ag screening
CrAg screening if CD4 count <100 cells/µl	Prevention or early treatment of CM
CCr and urine dipstick test (if starting TDF)	Assess renal function before starting TDF
ALT (if starting NVP or on TB treatment)	Assess baseline liver function
FBC (if starting AZT)	Assess for anaemia, neutropaenia +/- thrombocytopaenia
Perform mental health screen	Assess for depression, suicidal ideation, non-consensual sexual violence and substance abuse

Ab – antibody; Ag – antigen; ALT – alanine transaminase; ART – antiretroviral therapy; CCr – creatinine clearance rate; CM – cryptococcal meningitis; CPT – cotrimoxazole preventive therapy; CrAg – cryptococcal antigen; FBC – full blood count; HbsAg – hepatitis B surface antigen; NVP – nevirapine; STIs – sexually transmitted infections; TB – tuberculosis; TDF – tenofovir; VL – viral load; WHO – World Health Organization.

If CD4 count is <100 cells/µl, then the following work-up should be done to exclude HIV-associated complications:
- Cryptococcal antigen (CrAg)
- TB BACTEC to screen for *Mycobacterium avium* complex (MAC), if clinically indicated
- Urine dipstick test and blood pressure to screen for HIV-associated nephropathy (HIVAN)
- Clinically exclude cardiomyopathy and encephalopathy.

Table 2: Monitoring at routine follow-up visits (on ART)				
Monitoring	**Month 3**	**Month 6**	**Month 12**	**Thereafter/ other**
CD4 count; assess eligibility for CPT			✗	Annually
VL testing		✗	✗	6-monthly if any issues, otherwise annually
Hb – if on AZT	✗	✗	✗	Annually
Creatinine – if on TDF	✗	✗	✗	Annually
Cholesterol and triglycerides – if on LPV/r	✗		✗	Annually
ALT – if on NVP				If symptomatic
Pap smear – if sexually active				Annually
TB contact and symptom screening; assess for eligibility for IPT	Every visit			
Assess side-effects	Every visit			
STI screen	Every visit			
Family planning; screen for pregnancy; discuss plans for future pregnancies; provide contraception	Every visit			
Mental health screen	Every visit			

ALT – alanine transaminase; AZT – zidovudine; CPT – cotrimoxazole preventive therapy; Hb – haemoglobin; IPT – isoniazid preventive therapy; LPV/r – lopinavir/ritonavir; NVP – nevirapine; Pap – Papanicolaou test; STI – sexually transmitted infection; TB – tuberculosis; TDF – tenofovir; VL – viral load.

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1. National Department of Health (NDoH). National TB Management Guidelines. Pretoria, South Africa: NDoH, 2014.

2. National Department of Health (NDoH). Adherence Guidelines for HIV, TB and NCDs. Pretoria, South Africa: NDoH, 2016.

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2.2   Universal test and treat

Universal test and treat (UTT) is a recommendation made in 2015 by the WHO to initiate ART in all HIV-positive patients irrespective of CD4 count.[1] This recommendation was put in place, based on a systematic review, with two important aims: (i) to prevent HIV-related morbidity through earlier initiation of ART; and (ii) to prevent sexual transmission of HIV by achieving and maintaining viral suppression. Importantly, none of the evidence reviewed included adolescents; recommendations were extrapolated from adult data, and do not take into account the unique adherence and RIC challenges affecting adolescents. The adolescent recommendations have been aligned to the adult guidelines to simplify programming and increase ART coverage.[1]

UTT policy was adopted by South Africa and came into effect on 1 September 2016. Accordingly, the criteria for initiation of adolescents on ART are currently as follows:

- All HIV-positive adolescents are eligible for ART, irrespective of CD4 count.[1]

- Adolescents with a CD4 count <350 cells/µl or WHO stage 3 or 4 are a priority for initiation.[1]

- Fast-tracking (initiating within 1 week of diagnosis/ becoming eligible):[2]
  - CD4 count ≤200 cells/µl
  - WHO stage 4
  - Multidrug-resistant (MDR-) or extensively drug-resistant (XDR-) tuberculosis (TB).

However, **all adolescents must be assessed on an individual level** and timing of ART initiation planned according to clinical and psychosocial factors. **If an adolescent is eligible for fast-tracking, then initiation must not be delayed for psychosocial reasons, but any concerns must be addressed immediately to improve adherence.** If there is any doubt concerning the timing of initiation in adolescents, then it is advisable to consult an expert.

Clinical indications for initiation delay

Table 3: Clinical indications for initiation delay[2]	
TB, excluding meningitis	• CD4 count <50 cells/µl: Initiate after 2 weeks once symptoms improve and treatment is tolerated • CD4 count >50 cells/µl: Initiate 2 - 8 weeks after initiation of TB treatment
TB meningitis	Delay initiation for 4 - 6 weeks
Cryptococcal meningitis	Delay initiation for 4 - 6 weeks
CrAg-positive, no meningitis	Delay initiation for 2 weeks
ART – antiretroviral therapy; CrAg – cryptococcal antigen; TB – tuberculosis.	

Delays for clinical indications (Table 3) may be necessary to decrease the likelihood of severe complications associated with immune reconstitution inflammatory syndrome (IRIS).

Psychosocial indications for initiation delay

Disclosure to the adolescent

- WHO recommends full disclosure by age 10 - 13 years.

- Full disclosure is a continuous process that involves naming the illness as HIV and educating the adolescent about the disease and treatment.

- Full disclosure is vital to adherence as it gives the adolescent a clear reason for daily treatment.

- Circumstances around disclosure are likely to differ depending on the adolescent's age; e.g. a younger adolescent brought to the clinic by a caregiver is likely to be more clinically and immunologically compromised and will require urgent ART initiation while disclosure is progressed.

Disclosure to a family member/treatment supporter

- In many cases, adolescents (particularly older members of this age group) may come in for testing alone and be diagnosed with HIV.

- These may be vertically infected adolescents who have not been diagnosed or to whom disclosure has not taken place, but many will be horizontally infected.

- These adolescents may not be willing to disclose to a family member or friend; however, disclosure should be encouraged so that they have support at home to assist with adherence and RIC.

- Non-disclosure should not be a reason to deny ART; but if disclosure can be facilitated, then consider delaying initiation of ART until disclosure has been done and the adolescent has support.

Support

- Adolescents are usually old enough to comprehend the diagnosis and know how to take their treatment, **but** they require support at home.

- However, many vertically infected adolescents may be less mature or have neurocognitive impairment and may have substantial difficulty understanding their diagnosis and remembering to take medication; this needs to be recognised and support optimised.

- Support does not have to originate from a family or household member; additional sources such as family friends and community-based organisations (CBOs) should be explored and offered.

References

1. World Health Organization (WHO). Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Geneva, Switzerland: WHO, 2015. http://www.who.int/hiv/pub/guidelines/earlyrelease-arv/en/ (accessed 1 October 2016).

2. National Department of Health (NDoH). National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. Pretoria, South Africa: NDoH, 2015.

2.3 Differentiated service delivery for all adolescents and young adults

- Differentiated service delivery (DSD) is a patient-centred approach to patient care that simplifies and adapts HIV services across the treatment cascade according to differing needs. The approach aims to offer less intensive services to those who are stable on ART, thereby releasing resources to patients who require more intensive care and follow-up.

- To build a patient-centred DSD model, it is necessary to define and cluster: the core needs of the patient population (e.g. adult or adolescent), other defining population characteristics (e.g. MSM, sex worker), their clinical characteristics (e.g. stable or unstable), and their context (e.g. urban or rural).

- The WHO identified four clinical types of PLHIV to illustrate the diversity of clinical needs: patients presenting well, patients presenting with advanced disease, stable patients, and unstable patients – each requiring different care packages.

- Once the population has been defined, the following four questions need to be answered for clinical consultations and ART refill collection (Table 4): *Visit frequency*: When is care provided?; *Location*: Where is care provided?; *Provider*: Who is providing care?; *Service package*: What care or services are provided?

Table 4: Four questions regarding differentiated care	
When?	*Depending on the situation:* Monthly; Every 2 months; Every 3 months; Every 6 months
Where?	HIV clinic; Hospital; Clinic; NGO; CBO; Home
Who?	Physician; Nurse; Pharmacist; Community health workers; Parent/guardian; Family; Adherence support counsellor; Treatment buddy
What?	ART initiation; Refills; Clinical monitoring; Adherence support; Laboratory tests; Opportunistic infections; Psychosocial support

ART – antiretroviral therapy; CBO – community-based organisation; NGO – non-governmental organisation.

Differentiated care – relevance for adolescents and young adults and adherence

Adolescents have a lifetime of ART management ahead. Sustained adherence, often from early childhood through adolescence into adulthood, is essential to reduce the risk of morbidity and mortality.

To date, focus has been placed on DSD models for adult patients who are stable on ART. Adolescent outcomes studies report sub-optimal adherence and poorer outcomes than their adult counterparts. Access to DSD options that strive to support routine life-paths for AYLHIV should be considered as soon

Table 3: Key considerations for differentiated ART delivery for clinically stable adolescents

Eligibility for adolescents: Same as WHO recommendation for adults (at least one year on ART, no adverse drug reactions that require more frequent clinical monitoring, no current illnesses including mental health conditions, a good understanding of lifelong adherence and evidence of treatment success (two consecutive VL measurements of <1 000 copies/ml) and access to psychosocial support.

	ART refill	**Clinical consultation**	**Psychosocial support**
When?	3-6-monthly[§±ξ]	3-6 monthly[§±ξ]	1-6 monthly
Where?	Primary healthcare/out-of-facility	Primary healthcare/outreach from primary healthcare	Primary healthcare/out-of-facility/ virtual environment
Who?	Lay provider*	Nurse*	Lay provider/Peers
What?	ART refill Referral check Adherence check	• Adolescent clinical consultation • Mental health assessment • Laboratory testing: VL annually; or if not available, then CD4 count 6-monthly • Re-script: Cover period between clinical consultations	• Peer group environment • Referral check • Onward disclosure support

ART – antiretroviral therapy; AYA – adolescent/young adult; AYLHIV – adolescents and youth living with HIV; MH – mental health; PHC – primary healthcare; SMS – short message service; SRH – sexual and reproductive health; VL – viral load; WHO – World Health Organization.

§ If adolescents are away at school extending ART refills to accommodate school terms should be given priority.
± In general do not need to be clinically reviewed more than twice a year.
ξ If possible, adolescent friendly service hours (late afternoon and/or Saturdays) could be considered.
* Adolescent-friendly orientation should be considered.

Source: World Health Organization; 2017. Key considerations for differentiated antiretroviral therapy delivery for specific population: children, adolescents, pregnant and breastfeeding women and key populations.

as feasible after treatment initiation, including: limited time in health facilities, uninterrupted school attendance, increased time with peers, etc.

> **Need to know more?** See Annexure 1 for links to further information regarding differentiated care.

WHO guidance for differentiated ART delivery for adolescents

The WHO suggested the following:
- WHO eligibility criteria for DSD for stable adults also apply to adolescents.
- Adolescent DSD models should engage parents/caregivers to provide a support structure while fostering independence.
- DSD for adolescents requires consideration of building blocks (*when*, *where*, *who* and *what*?) for clinical review, ART refill, plus psychosocial support. The appropriate suggested building blocks for stable adolescents are described in Table 5.

2.4 ART service-delivery building blocks

ART maintenance – first year on ART (initiation to second viral load)

Below are key points for the initiation and first year of ART, together with a summary of service-delivery building blocks (Table 6):

Key points
- HIV care as close to home as possible.
- Treatment for all irrespective of CD4 count.
- Rapid ART initiation – defined for the purposes of these guidelines as within 7 days of diagnosis – with two ART preparation sessions from HIV diagnosis to the day of initiation (ideally aligned with these dates, not requiring additional clinic visits).
- Aligned ART refill and clinical review visits.
- Psychosocial support in the form of support group participation can also be aligned or provided separately at community level.
- Youth-orientated service provision to the extent that the context allows – i.e. adolescent-/youth-oriented staff and AYLHIV hours or allocated space within the clinic.
- Frequency of clinic visits kept to the minimum. Where AYLHIV are struggling with illness, adherence or social environment issues, clinician/counsellor/pharmacy consideration should be given to whether increasing visit frequency is desirable or whether intensified support can be provided without increasing visit frequency.

ART maintenance – from second year on ART onwards (after second viral load)

Below are key points for ART maintenance from the second year on ART, together with a summary of service-delivery building blocks (Table 7):

Key points
- Simplify ongoing access to HIV care as far as possible to support long-term adherence.
- Prioritise a reduced frequency of HIV-care-related visits, with longer periods between ART refills, quick pick-up and psychosocial support services as close to home as possible.
- Clinical reviews do not need to take place at every ART refill visit. Consider de-linking ART refill collection and psychosocial support from clinical review visits.

2.5 Moving between stable and unstable classifications

AYLHIV patients are on ART for life. During the period of adolescence and young adulthood there are likely to be periods of instability, possibly requiring multiple transfers between stable and unstable categorisations. This needs to be managed smoothly with the participation of the AYLHIV, and with as little disruption to their life as possible. The points below summarise the management of moving between stable and unstable classifications.

Stable to unstable
- Criteria include: high VL, acutely unwell, pregnant, high-risk psychosocial issue(s) requiring attention, or missed appointment for more than 30 days with missed doses.
- The patient does not necessarily have to be taken out of their existing service-delivery model, but could have additional/intensified clinical or psychosocial visits added. This is especially relevant where removing AYLHIV from a strong peer-support environment may prove harmful.

Unstable to stable
- Requires a VL <1 000 copies/ml and management of clinical or psychosocial issues
- Requires continual assessment to ensure the patient does not remain in the unstable category unnecessarily with increased visit frequency and longer visits. This can be demotivating and lead to a break down of trust in the healthcare system.

Table 6: Service-delivery building blocks: ART maintenance for first year on ART (initiation to second viral load)

	Stable at initiation *Defined as: clinically well, CD4 >200 cells/µl, no high-risk psychosocial concerns*		Unstable at initiation *Defined as: clinically unwell, CD4 <200 cells/µl, high-risk psychosocial concerns*	
	Clinical review + ART refill	**Psychosocial support**	**Clinical review + ART refill**	**Psychosocial support[§]**
When? (visit frequency)	m0, m1, m3, m6, m7, m9, m12, m13*	1 - 3-monthly	Monthly[†]	1 - 3-monthly
Where? (visit location)	PHC facility	PHC facility or in community	PHC facility/specialised paediatric service (if available)[‡]	PHC facility or in community
Who? (service provider)	• Nurse • Lay HCW	• Lay HCW • CBO worker	• Nurse (with access to expert clinical support if needed) • Lay HCW	• Lay HCW • CBO worker • Social worker • Community psychologist
What? (service package)	• Clinical examination: 1m, 3m, 7m and 13m, specifically checking for IRIS or any side-effects • VL: 6m, 12m[¶] • VL results: 7m, 13m • CD4 count: 12m • TB screen: at each visit • SRH screening e.g. FP, STIs: at each clinical examination visit • MH screening (see Section 5.2): 1m, 7m, 13m • Risk factors (substance abuse/IPV etc.): at each visit • Requires any additional support (e.g. CCG for child): as needed **Notes:** If any concerns, then move to unstable group. Include three ART preparation sessions (pre-start, at ART start and m1) and MH screening. If necessary, include nurse assessment at ART start, m6/7 and m12/13; m13 includes stability assessment.	• Stability assessment • Post-ART-initiation one-on-one adherence support session: 1m • Peer-support-group environment	• Include all in 'stable' package **plus**: • If OI or clinically unstable: monthly clinical examinations until clinically stable (resolved TB, etc.) • VL: same as stable patients, but if VL >1 000 copies/ml, then step-up adherence and repeat VL after 3 months • Additional blood test monitoring: as indicated, e.g. ALT if on TB treatment • Track appointments and pharmacy refill, if possible • Psychologist/psychiatrist assessment: as applicable	• Peer-support environment • One-on-one adherence and other support counselling including: • 1m for post-ART-initiation session • Every month until m6 if there are psychosocial concerns requiring additional support • Three enhanced adherence sessions if VL>1 000 copies/ml • Social services support
Appropriate service-delivery model examples	• Youth clubs (see Section 7) • Facility care plus attendance at community/facility support group		• Facility care plus attendance at community/facility support group	

ALT – alanine transaminase; ART – antiretroviral therapy; AYLHIV – adolescents and young adults living with HIV; CBO – community-based organisation; CCG – child care grant; DSD – differentiated service delivery; FP – family planning; HCW – healthcare worker; IPV – intimate partner violence; IRIS – immune reconstitution inflammatory syndrome; m – month(s); MH – mental health; OI – opportunistic infection; PHC – primary healthcare; SRH – sexual and reproductive health; STIs – sexually transmitted infections; TB – tuberculosis.

* Where a facility has the capacity to recall AYLHIV with high VLs effectively, it is possible to schedule visit frequency as follows: ART start, m3 and 3-monthly thereafter, recalling any AYLHIV with a high VL immediately for repeat consultation.

† Consider the reason(s) for instability and whether visit frequency can be reduced throughout the first year. Provided that AYLHIV consent has been obtained, prioritise caregiver involvement.

‡ Specialised paediatric services must be utilised for complicated clinical cases, e.g.: TB, psychiatric complications or multi-treatment.

§ Prioritise access to a support-group environment. If this is not available in the community, then consider starting a group within the facility (see Section 3.1).

¶ For VL visits, give the patient the laboratory form at the previous visit. This is a quick visit for blood tests only, unless any concerns are raised. A full visit is conducted at the next visit when the VL results are available.

Table 7: Service-delivery building blocks: ART maintenance from second year on ART (after second viral load)					
	Stable on ART *Defined as: on ART for 12 months; two consecutive VLs <1 000 copies/ml, no acute illness, side-effects or psychosocial issues requiring more regular clinical follow-up*			**Unstable on ART** *Defined as: not stable*	
	Clinical review	**ART refill**	**Psychosocial support**	**Clinical review + ART refill**	**Psychosocial support†**
When? (visit frequency)	6-monthly	3-monthly	1 - 3-monthly	1 - 3-monthly*	1 - 3-monthly
Where? (visit location)	PHC or mobile outreach from PHC	PHC or in community	PHC or in community	PHC/specialised paediatric service (if available)‡	PHC or in community
Who? (service provider)	• Nurse	• Lay HCW • CBO worker • Private provider	• Lay HCW • CBO worker	• Nurse (with access to expert clinical support if needed) • Lay HCW	• Lay HCW • CBO worker • Social worker • Community psychologist
What? (service package)	• Clinical examination: annually • TB screen: each visit • SRH screening: each visit • MH screening for risk factors (substance abuse/IPV etc.): each visit • VL and CD4: annually§ • VL and CD4 results and annual check-up to coincide • Any additional support (e.g. CCG for child): as needed	• ART refill • Adherence check • Referral check	• Peer-support-group environment • Adherence check • Referral check	• Include all in 'stable' package **plus**: • If OI or clinically unstable: monthly clinical examinations until clinically stable (resolved TB, etc.) • If clinically stable: 6-monthly examinations • VL as opposite, but if VL >1 000 copies/ml, then step-up adherence and repeat VL after 3 months • Additional blood test monitoring as indicated, e.g. ALT if on TB treatment • Track appointments and pharmacy refill, if possible • Psychologist/psychiatrist assessment: as applicable • Assess whether possible to move to stable management: every visit	• Peer-support environment‡ • One-on-one adherence and other support counselling including: • Every month if there are psychosocial concerns requiring additional support • Three enhanced adherence sessions if VL>1 000 copies/ml • Social services support
Appropriate service-delivery model examples	Youth clubs Saturday or after-school-hours clinic for AYLHIV Community-/clinic-provided fast ART pick-up and support groups			Adolescent treatment failure intervention (see Section 2.6) Youth clubs plus intensified clinical/adherence support	

ALT – alanine transaminase; ART – antiretroviral therapy; AYLHIV – adolescents and young adults living with HIV; CBO – community-based organisation; CCG – child care grant; DSD – differentiated service delivery; FP – family planning; HCW – healthcare worker; IPV – intimate partner violence; IRIS – immune reconstitution inflammatory syndrome; MH – mental health; OI – opportunistic infection; PHC – primary healthcare; SRH – sexual and reproductive health; STIs – sexually transmitted infections; TB – tuberculosis.

* At the discretion of the clinician, dependent on the reason for instability, with a continued focus on reducing frequency to support adherence as soon as possible.
† Prioritise access to a support-group environment. If this not available in the community, then consider starting a group within the facility (refer to Section 3.1).
‡ Specialised paediatric services are only to be utilised for complicated clinical/psych cases. Where these require infrequent clinical follow-up, ART refills should be de-linked and provided at PHC level in between specialised facility visits.
§ For VL visits, give the patient the laboratory form at the previous visit. This is a quick visit for blood tests only, unless any concerns are raised. A full visit is conducted at the next visit when the VL results are available.

2.6 Treatment failure intervention: Programmatic and clinical guidelines

Great strides have been made in the field of paediatric HIV over the last 15 years. Improvements in ART have enabled many adolescents to reach adulthood and achieve their goals. However, many challenges with adolescent HIV treatment remain, and often place this age group at risk for failing their treatment. These include: fewer antiretrovirals (ARVs) available for adolescents; side-effects of existing ARVs for adolescents; ARV dosing complexities; and many psychosocial issues surrounding the administration of life-long medication and maintaining long-term adherence. It is therefore unsurprising that the treatment failure rate for adolescents with HIV is much higher than in adults. Whereas the failure rate for adults ranges from 10% to 15% depending on location, failure rates for adolescents are reported to be as high as >50% in some studies.[1]

What is paediatric HIV treatment failure?

Treatment failure in adolescents with HIV can be categorised as *virological failure* (high viral load (VL)), *immunological failure* (low CD4 count), *clinical failure* (development of opportunistic infections and other illnesses), or a combination of the three.[2]

> **Virological failure:** In South Africa, virological failure in AYLHIV is defined as two VLs >1 000 HIV RNA copies/ml on two consecutive occasions 2 months apart.

Causes and consequences of HIV treatment failure in adolescents and young adults

For most patients with treatment failure, the cause is *secondary* ARV failure due to **poor adherence**. First-line ART must be taken >95% of the time to achieve virological suppression, which **equates to missing only two or three doses of ARVs per month.** This is difficult to achieve and is the major reason for the high treatment failure rate among adolescents.

Causes and consequences of poor adherence are summarised in Table 8.

Table 8: Causes and consequences of poor adherence in adolescents and young adults

Patient-related causes	Health-system-related causes
• Treatment fatigue • Influence of peers • Unwell/unstable/varying caregiver • No treatment supporter • Food insecurity • Disclosure issues • Stigma • Alcohol abuse • Mental illness (patient or caregiver) • Unstable home life • Multiple barriers	• Complicated treatment regimens • Poor palatability of drugs • Poor HIV education • Lack of treatment drugs available • Stock-outs of ARVs • Poor patient support and tracing

Development of resistance due to poor adherence:

Poor adherence → High VL → Development of resistant mutations → ARVs no longer effective
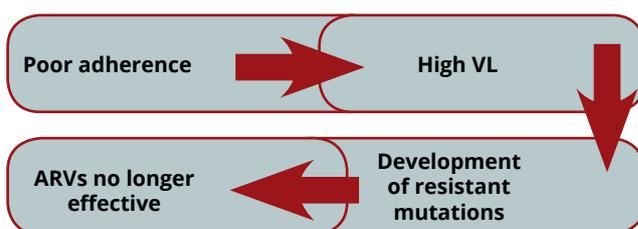
ARVs – antiretrovirals; RIC – retention in care; VL – viral load.

Unfortunately, once resistance has developed to a specific ARV, it will no longer be effective and the adolescent will need to switch to an alternative ARV regimen – either second- or third-line depending on the current failing regimen – adherence to which can be even more difficult and may cause additional side-effects. Moreover, *cross-resistance* may develop to other drugs within the same ARV class, particularly the non-nucleoside reverse transcriptase inhibitors (NNRTIs).

Programmatic information on starting an adolescent HIV treatment failure programme

Components needed to start an adolescent HIV treatment failure programme

Table 9 summarises programmatic aspects of an adolescent treatment failure programme. While some are mandatory for a successful programme, others are not essential; and components will depend on the resources available. Each component is labelled as 'required' or 'recommended' as a guide for devising a programme.

Table 9: Components recommended/required to start an adolescent HIV treatment failure programme		
Component	**Required or Recommended?**	**Description**
DoH and clinic support	Required	Before establishing a treatment failure programme, it is important to gather support and buy-in from key DoH representatives and clinic personnel. Discussions with DoH officials, facility managers and others will be necessary to gain consent. Once obtained, it can be helpful to inform the full staff complement about the programme.
Dedicated, youth-friendly space for the programme	Recommended	While a space to see patients is obviously a necessary component, having a *dedicated space* to provide adolescent treatment failure services can be beneficial – with adolescent-oriented medical equipment, materials and supplies, and the provision of 'youth-friendly' posters, pamphlets and books. This space can also be used to hold support groups. It is recognised, however, that many clinics are extremely short of space and it may not be practical to have a room allocated solely to adolescents; consultations and adherence counselling can be performed adequately within the existing clinic set-up.
Flagging system for high VLs	Required	It is imperative to establish a system to **flag high VLs** – without this it will be difficult to know which adolescents are failing treatment and require enrolment into the programme. The following is required to implement a flagging system: • A designated person (clerk, nurse, doctor, etc.) to follow up VL results for returning patients (ideally, on a weekly basis). • A notification system to alert the clinician if the VL is high (e.g. marking the patient folder with a visible identifier, such as a star or circle). • A referral system to schedule high VL patients to attend the programme.
Adolescent adherence tools	Required	As poor adherence is the main cause of treatment failure, **good adherence counselling is the most important intervention** in an adolescent treatment failure programme. Comprehensive adherence documents are available that provide step-by-step guidance for counselling adolescents about adherence to ARVs.
Adolescent 'champions' and a passionate healthcare team	Recommended	An adolescent programme will be much more successful if the people involved have a genuine interest in caring for adolescents. Such 'adolescent champions' take the lead in scheduling adolescent patients and overseeing the day-to-day organisation of the programme. Responsibilities include: • **Doctor:** oversee organisation of programme activities (daily clinic, support clubs); provide clinical care to patients; teach adherence modules to patients; send, follow up and interpret laboratory results including genotypes; complete programme patient data forms; provide guidance and mentorship to programme nurses and counsellors; oversee scheduling of patients and follow up patients LTFU. • **Nurse:** provide clinical care to patients and refer to the programme doctor (if available) with any questions; teach the programme adherence modules to patients; draw blood samples for laboratory testing; schedule patients for clinic and follow-up if patients are LTFU; complete programme patient data forms. • **Counsellor:** facilitate programme support group meetings; assist doctor and nurse with scheduling of patients; assist with overall patient flow in the clinic; assist doctor and nurse with translation (if needed).
Support groups	Recommended	• Support groups can be a powerful way for people to learn about HIV and troubleshoot problems related to ART administration. Led by a facilitator, these 30 - 40-minute structured sessions enable adolescents to share their ART experiences and learn from one another. Specific discussion topics include alcohol and drug use, dating, contraception, ARVs and school attendance, among others. During a productive support group, the participants do most of the talking among themselves, with the facilitator speaking only infrequently to clarify misconceptions. If possible, these sessions should be held before the individual follow-up appointments.
Adolescent-focused services	Recommended	• Complicating factors in treating adolescents with HIV include complex psychosocial dynamics, peer pressure, school responsibilities and navigating sexual issues. As such, adolescents require specific support services to help them through these turbulent years. Interventions such as the adolescent support groups can be helpful in providing additional assistance. Also, scheduling adolescents to come for their clinic appointments on the same day (essentially creating 'adolescent clinic days') can aid in increasing peer support and education.
ART – antiretroviral therapy; ARVs – antiretrovirals; DoH – Department of Health; LTFU – lost to follow-up; VL – viral load.		

Monitoring and evaluation tools

Table 10 lists indicators that can be used to monitor an adolescent HIV treatment failure programme.

Table 10: Adolescent HIV treatment failure programme – monthly data collection indicators*
• Number of patients enrolled in programme (this month and total)
• Change in enrolment from previous month (absolute number and % change)
• Number of patients aged 0 - 5 years (this month and total)
• Number of patients aged 5 - 14 years (this month and total)
• Number of patients aged 14 - 19 years (this month and total)
• Average age of patients in programme (years)
• Number of missed appointments (% of total appointments)
• Number of patients on first-line ARVs
• Number of patients on second-line ARVs
• Number of patients on third-line ARVs
• Number of resistance tests completed (this month and total)
• Number of patients changed to second-line ARVs (this month and total)
• Number of patients changed to third-line ARVs (this month and total)
• Number of patients started on DRV (this month and total)
• Number of patients started on RAL (this month and total)
• Number of patients diagnosed with TB (this month and total)
• Number of patients diagnosed with other co-morbidity (this month and total)
• Number of VLs performed (this month and total)
• Number of patients with VL<1 000 copies/ml (this month and total)
• Number of patients with VL>1 000 copies/ml (this month and total)
• Number of patients with change in caregiver
ARVs – antiretrovirals; DRV – darunavir; RAL – raltegravir; TB – tuberculosis; VL – viral load.
*Applicable dependent on available resources, e.g. there may not be access to third-line ARVs or genotypes.

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3. Adherence counselling

3.1 Adherence counselling

Adherence counselling is a crucial aspect of the ongoing support system necessary for adolescents who are found to be HIV-positive, and those who are about to start, or are already receiving ART. This section focuses on the psychosocial aspects of adherence counselling, centred on support groups and disclosure.

What is a support group?

A support group is a gathering of individuals at set time intervals to provide non-material, social help for particular shared burdensome concerns or experiences such as bereavement or coping with a chronic medical condition.[1] Members with the same issues come together to share coping strategies and moral support, to feel more empowered or for a sense of oneness. Such support groups can be facilitated by professionals such as a social worker, psychologist, religious official or healthcare worker. In some instances they are peer-led.

Adolescent support groups

A support group for HIV-positive adolescents aims to provide a platform for these individuals to meet and share the psychosocial and emotional burden of living with HIV and the journey of ART.[1] This burden is additional to other physical, behavioural and socio-economic changes commonly associated with normal adolescent development. Issues that may necessitate the need for support groups include: ART adherence; disclosure to family members, partners and friends; relationships; body growth and development; and sexual and reproductive health (SRH).[2] In a societal context, in which stigma concerning HIV/AIDS persists, it is difficult for an HIV-positive adolescent to open up about their health condition or to trust others with their health information. Adolescents can, however, learn a great deal from each other through peer support and role modelling.[1]

Why adolescent support and not adherence group, if HIV/AIDS-related?

Adherence support groups for HIV-positive adults are usually facilitated on condition that members have a supressed VL. Such adults are considered to be clinically stable and adhering well to their ART regimens. In adolescents, however, ART adherence proves to be more challenging due to numerous social and behavioural dynamics; consequently they present fluctuating VLs, necessitating *adherence* counselling. Adolescents are grouped into support groups according to age, after initially identifying individual disclosure status.

Who facilitates the support groups?

In healthcare facilities, adolescent support groups can be facilitated by counsellors, nurses, health promoters, psychologists, social workers or peer educators.[2]

Which topics are covered in the support groups?

Common topics relevant to AYLHIV are summarised in Table 11. Health and development issues during the adolescent ages affect health later in adult life, hence the importance of equipping adolescents with life skills.

Table 11: Common support group topics relevant to adolescents and young adults living with HIV[2]	
• TB	• Stigma
• Treatment and adherence	• Disclosure
• You and your body'	• Stress and mental health
• Positive sexuality	• Substance abuse
• Contraception and conception	• Self-esteem
• STIs	• Bullying
• Teen pregnancy	• Gender and respect
• PMTCT	• Relationships and communication
• OIs	• Nutrition
• MMC	• Transition to adult or independent care

MMC – medical male circumcision; OIs – opportunistic infections; PMTCT – prevention of mother-to-child transmission of HIV; STIs – sexually transmitted infections; TB – tuberculosis.

Support group outcomes

In addition to providing a platform for HIV-positive adolescents to support one another socially and emotionally, support groups also serve as a form of group adherence counselling. Most HIV-positive adolescents who attend support groups are encouraged knowing that they are not alone in the ART journey. The support group setting is structured in a manner to give adolescents a chance to engage in topics they are not comfortable discussing with their parents, caregivers, family members, partners or friends. With the main objective of providing adherence counselling, most adolescents who attend are likely to see an improvement in their VLs.

How to initiate support groups in healthcare facilities[1,2]

- Adolescents targeted for support groups (those on ART, as well as newly diagnosed patients) must be scheduled on a common date to collect their ART from the healthcare facility.

- The support group, prior to ART collection, should be scheduled early morning or in the afternoon, so as not to interfere with school schedules.

- It is important to find out the disclosure status of each adolescent in one-on-one sessions *before* they join a support group, to prevent accidental disclosure.

- Engagement with guardians of AYLHIV aged ≥10 years in necessary, in order to support them to complete full disclosure.

- Sessions should occur at least once a month or at every clinic visit corresponding with ART collection. Decide on the frequency, day and time of support groups in collaboration with the adolescent support group participants.

- The healthcare facility must set aside a specific 'adolescent- and youth-friendly (AYFS) clinic day' each week to avoid mixing adolescents with adults.

- Adolescents value confidentiality greatly, therefore it is important to run the support groups in secure spaces and have the same facilitator(s) each time.

- The facilitator must be trained or mentored by a professional on conducting adolescent support groups and using appropriate support group tools.

- Each support group session must engage between eight and 12 AYLHIV.

- Each session should focus on one topic and last an average of 45 minutes.

- The facilitator must select topics based on suggestions from support group members.

Disclosure

Disclosure is discussed in greater depth in Section 4. In brief, in the context of AYLHIV, 'disclosure' concerns informing the individual of their HIV-positive status at an appropriate time when they have reached a sufficient level of mental and cognitive maturity.[3] Some children are found to be HIV-positive when they are still minors and are initiated on ART with the support of guardians. Such children may grow up being forced/reminded on a daily basis to take their ART without fully understanding the reasons therefore. It is advised that full disclosure to such children takes place, i.e. that they are informed of their HIV-positive status, by the time they reach the adolescent stage (age 10 years or earlier if the child presents adequate mental and cognitive maturity).

Benefits of disclosure for adolescents

Benefits of informing adolescents of their HIV-positive status in an appropriate manor:

- Encourages daily responsibility of taking ART with minimum supervision

- Good responsibility with taking ART improves the likelihood of achieving VL suppression

- Opportunity to join a support group with other fully disclosed AYLHIV and benefit from information, support and a sense of belonging

- With proper support and counselling, a reduction in risk behaviour such as unprotected sexual intercourse, thereby reducing the spread of HIV/AIDS

- Easier access to support from parents/ caregivers.

Who plays a role in disclosure?

The following individuals play a role in disclosure:
- the caregiver (guardian/parent)

- the AYLHIV

- the healthcare provider/worker (counsellor, social worker, doctor or nurse) based at the facility.

The healthcare provider must support both caregiver and adolescent during the disclosure journey; but it is ultimately the caregiver who should disclose fully to the AYLHIV when full disclosure stage is reached.

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3.2 Involvement of caregivers in adherence

The Children's Act

The Children's Act (No. 38 of 2005)[1] enables a child aged ≥12 years with sufficient emotional and mental maturity to comprehend the risks and benefits of treatment to consent to HIV testing and treatment without guardian consent. Children and adolescents should be empowered and supported in a manner that does not breach their privacy to disclose their involvement in HIV testing, treatment and adherence clubs. Consent should be sought from the adolescent for caregiver involvement.

In the context of modern changes to traditional family structures, poverty, unemployment or the loss of one or both parents to illness, the current definition of a caregiver extends to include those responsible for the day-to-day needs of a young person: a legal guardian, parent, grandparent, aunt, uncle, older sibling or even a member of the young person's community.

Involvement of caregivers of adolescents

The adherence pyramid[2] (Fig. 1) provides a framework to address adherence and the need for long-term sustainability. According to the pyramid, the family structure is influential at every stage and the healthcare provider should ensure that there is a basic foundation for adherence to be achieved.
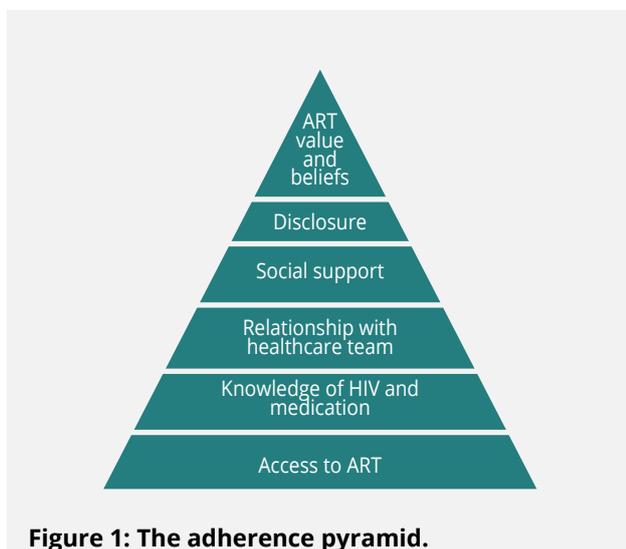
Figure 1: The adherence pyramid.

Successful adherence in adolescents is determined by many factors, including those relating to the caregiver. In infancy, the child is solely dependent on their caregiver for their treatment; but as they get older, it would appear that the caregiver leaves greater responsibility to the adolescent, regardless of their emotional and cognitive maturity and disclosure status. The specific ways in which caregivers and families are involved in their adolescent's adherence and how they affect adherence levels, have received limited attention. One author noted that, 'as the epidemic has unfolded, the early focus on individuals has become inadequate: families live with HIV, not just individuals ... yet intervention models continually focus on medical and psychosocial interventions for individuals.'[3] In other words, healthcare providers need to place more emphasis on involving the caregiver and other family members in the adherence process. This needs to start from initiation of treatment, and applies to the disclosure process.

The three main barriers to disclosure of HIV status to adolescents have been identified as: local norms that deter caregivers from communicating with their children about sexuality; fear of HIV stigma; and an underlying presumption that adolescents would not understand the consequences of an HIV diagnosis on their lives and relationships.[4] As a result of stigma, adolescents and their families end up living in a 'conspiracy of silence' and shame associated with the HIV illness.[5] One of the disturbing consequences of stigma is that families of AYLHIV become withdrawn, socially isolated and emotionally cut off from available community support systems. Fear of stigma and lack of disclosure skills and knowledge have been cited by guardians as the major reason for non-disclosure of HIV status to adolescents.

Grover *et al.*[6] assert that stigma breeds fear, anger, remorse, psychological pain and blame, which lead to denial and non-disclosure by parents, 'even in cases where illness is evident in their adolescents infected by HIV'. In instances where the adolescent would not have been informed of their diagnosis or status, it is difficult for them to make informed decisions regarding their sexual actions and related life choices.[5] There is also emerging evidence that if AYLHIV do not receive adequate counselling and guidance, they are more likely to engage in early sexual debuts, unprotected, transactional or intergenerational sex, sexual and gender-based violence (GBV), substance abuse and other risks.[7] Those AYLHIV receiving ARVs are likely to 'rebel' and not adhere to their treatment regimens.[8]

These guidelines recommend equipping caregivers of AYLHIV with the skills and knowledge to inform/disclose their own and the adolescent's HIV status, incrementally in accordance with the adolescent's age, cognitive skills and emotional maturity. Integrated, focused, structured, practical and standardised strategies for engaging and involving parents in adolescent care and RIC will avoid variations and inconsistencies. Formulation and utilisation of an adolescent- and youth-friendly adherence model is important – something equivalent to the Kidz Alive Model (Kidz Adherence) formulated by Zoë-Life.[9] Adolescents who have been informed of their HIV status should be provided with ongoing support to prevent disclosure negatively affecting their psychological and social wellbeing. Furthermore, efforts should be made to explore the potential role

of trusted family members in contributing to the disclosure process – refer to Section 4.

Adolescent-caregiver relationship

Adolescence is a transitional period for both child and parent/caregiver. It involves individual and family changes that can, at times, disrupt family relationships. By improving communication, understanding independence and developing better problem-solving skills, families can work together to minimise disagreements and restore a good level of harmony in the family structure.

Communication

Open, effective communication from the caregiver benefits not only the child, but every member of the family: it serves to strengthen the child-caregiver relationship, serves as a show of respect, boosts self-esteem, and allows the child to reciprocate with open communication. On the other hand, communication that is ineffective or negative can lead children to believe that they are unimportant, unheard or misunderstood. Such children may also come to see their caregivers as unhelpful and untrustworthy.

Strong family relationships help children develop self-esteem, resist peer pressure, and act responsibly when making decisions about drugs, violence and sexual intercourse. Effective parent-child communication is a cornerstone of strong and healthy family structures. In the era of HIV/AIDS, caregivers must learn ways to communicate more effectively with youth. How and what they communicate about body image, peer pressure, puberty, reproduction, sexuality, love and intimacy can make a significant difference in the health and wellbeing of their children.

It may be difficult for young people to navigate and process all the information that they are able to access from various sources such as television and the internet. Through willingness to engage in open and honest communication about issues such as sex and puberty, guardians can ensure that adolescents gain access to information that is correct, as they grow towards adulthood.

Independence

There is a misconception that because adolescents require independence, they no longer need their caregivers. Young people do need to know that they have the love and support of their caregivers. They may otherwise seek this elsewhere, which sometimes means engaging in risk behaviour to feel accepted. For example, a young person who feels unsupported

and unloved in the family may become involved in a group where substance abuse is encouraged, or engage in unprotected sex. During adolescence, the part of the brain that encourages exploration and experimentation is quite well developed, but the part that processes danger and risk, is not. This means that while it is natural for young people to want to explore and experiment, they may not think about consequences.

It is important that caregivers understand that wanting more independence is a normal part of adolescent development. As this quest for independence can cause conflict between child and caregiver, it is important to encourage rules and self-discipline. Caregivers should be encouraged to involve adolescents in making the rules, and there must be agreement in terms of the consequences if they are broken. It must also be remembered that rules need to change as the young person grows up; the rules for a child of 10 years will be different for a young person of 16 years.

Values – beliefs about what is right or wrong – are learned by experiences within the family structure. Although the questioning of adult values is a normal development process critical to adolescents developing their own values, caregivers continue to shape young people's morals throughout adolescence and into adulthood.

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4. Disclosure

4.1 Disclosure to vertically infected adolescents

Participation of parents/caregivers

Disclosure of HIV status to adolescents is generally regarded as a key component of disease management and has been related to improved treatment adherence and psychological adjustment.[1] However, a significant number of youth reach adolescence without knowing their HIV-positive status.

There are many reasons for this. From the parent/caregiver's perspective, telling a child that s/he is HIV-positive creates considerable discomfort and anxiety. This can be related to cultural taboos surrounding sex and sexuality, fears that the adolescent will disclose indiscriminately to others resulting in stigmatisation, guilt for having transmitted the disease, concerns regarding blame and negative psychological reactions. In response, parent/caregivers often give non-HIV-related reasons for healthcare visits and medication regimens; e.g. the adolescent may be told that the treatment is for TB rather than ART for HIV. These obstacles strongly suggest the need to address the concerns of parent/caregivers before embarking on the disclosure process.

Parent/caregiver participation in disclosure is in the best interests of the adolescent. Thus, working with a reluctant parent/caregiver is often a starting point for supporting an adolescent who is not aware of their HIV status. Key to the process is to help parents/caregivers recognise that status disclosure is a necessary step towards positive health outcomes. Healthcare providers generally see their role as being supportive and educational. In accordance with this, the national *Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases*[2] recommend that the parent/caregiver should be the one to disclose to the adolescent. In preparation for this, healthcare providers can empower parents/caregivers with knowledge and skills and help them to view disclosure as an important aspect of responsible parenting.

A number of disclosure-related initiatives build parental support and education into the programmes (e.g. The Disclosure Talk Tool[3]). The national paediatric and adolescent disclosure guidelines[2] go a long way towards providing guidance and there are now a variety of disclosure tools available (see mini disclosure 'Flipster' – Annexure 1).[3,4]

Timing of disclosure

It is generally recognised that the disclosure process should begin as early as possible with partial disclosure at around 4 years of age. Children of a young age can be given information about their health in a way they understand. For example, they are often told that they need to visit the clinic regularly and take medication because there is a 'germ' in their blood. As the child develops and their level of understanding about illness changes, more information may be given as the process moves towards full disclosure, or naming the 'germ' or virus as HIV.

The guidelines recommend full disclosure to the child by the age of 10 years.[2] Postponing disclosure beyond this creates a number of difficulties. Adolescence is a time of significant physical, emotional, cognitive and social change, with each developmental stage – early (age 10 - 14 years), middle (15 - 16 years) and late (17 - 19 years) adolescence – heralded by different challenges. Delaying HIV status disclosure increases the likelihood of complications in normal developmental tasks. For example, identity formation – a key developmental task in early to middle adolescence – can be disrupted when young people experience a loss in their sense of self after disclosure. During middle adolescence, tasks pertaining to sexuality can be disrupted by the young person's realisation of having a stigmatised and sexually transmissible illness. In late adolescence, the process of career choice may be affected, leading young people to make negative assumptions about their future.

Starting the disclosure process early and in a way that takes into account the child's emotional and cognitive maturity, facilitates adjustment to news of a positive HIV status; whereas late disclosure can have implications for psychological functioning and other behavioural outcomes. One example is the damaging effect on the trust in the adolescent-parent/caregiver relationship, at a time when support and guidance is most needed. Research also suggests that in addition to the stage of partial disclosure, there is often a stage of 'suspicion' when the AYLHIV suspects their status but is denied the opportunity to have this confirmed. In this scenario, suspicion and non-disclosure collide at the expense of the AYLHIV.

Mental health considerations

Mental health issues frequently arise in the context of disclosure, with fears that revealing HIV status to an adolescent can lead to psychological damage. The WHO suggests that psychological benefits outweigh any negative short-term effects. Despite the immediate reaction to learning their status, young people who are told earlier rather than later, appear to have better emotional health than their non-disclosed counterparts: higher self-esteem, fewer symptoms of depression, enhanced coping skills and better ability to obtain social support. Furthermore,

many of the benefits of disclosure are health-related, including better treatment adherence, good clinical outcomes and more responsible sexual behaviour.[5]

Post-disclosure support

Many of these outcomes are contingent on post-disclosure support. Disclosure is not a one-off conversation but an ongoing process to address the emerging needs of AYLHIV as they negotiate adolescence. Post-disclosure approaches should be factored into the disclosure package, in the form of one-on-one counselling or referral to an adolescent support group (see Flipster Tool for support groups (Annexure 1) and *Working with adolescents living with HIV: A handbook for healthcare providers*[4]). Both have clear advantages: post-disclosure counselling provides a psycho-educational opportunity for discussion around ART, the meaning of VL, viral suppression and resistance; while support groups bring AYLHIV together to discuss issues brought to the fore by an HIV-positive status (e.g. disclosing to an intimate partner).

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4.2   Disclosure to horizontally infected adolescents

Horizontal acquisition of HIV

When approaching HCT in adolescents who are horizontally infected, it is important to understand how they might have acquired HIV, as this will influence approaches to disclosure and the potential impact on ART adherence. Horizontally infected adolescents acquire HIV either through:

- sexual transmission: consensual, coerced or through sexual exploitation

- parenteral transmission: sharing injecting equipment, traditional practices (scarification, circumcision and female genital mutilation) or unsafe surgical procedures, injections and blood transfusions.

While the majority of adolescents contract HIV through unprotected heterosexual sex, it must not be assumed that this is consensual. There is increasing evidence that sexual coercion is fairly common in young people and leads to high-risk sexual behaviour,[1] and it is important that healthcare workers do not assume consent or express judgment. Exploring aspects of coercion (forced sex, exchanged money and gifts, compliments or persistence and threats) will enable an understanding of the risks that negatively affect adherence. When handled well, such conversations can be empowering and validating for adolescents. Building a rapport with adolescents is a critical part of engaging them in healthcare, and enables treatment and adherence skills and strategies to be explored in a respectful manner.

It is important that the likely mechanisms of HIV acquisition are explored during counselling for HIV testing, to enable the healthcare worker to provide information, support and referral tailored to the adolescent's needs. An adolescent who has acquired HIV through coercion or exploitation is likely to need more intensive counselling and referral into specialist support services than an adolescent who has acquired HIV through consensual sex. Understanding these differences will enable adherence and disclosure counselling to be tailored after a positive HIV diagnosis has been given.

Key populations

There is increasing focus on the needs of key adolescent populations including: sex workers, MSM, transgender people and people who inject drugs (PWID). This extends to adolescents with increased vulnerabilities: those who are homeless, sexually abused or exploited, or in correctional institutions or care homes. Non-judgmental engagement, as described above, will empower the sharing of such sensitive information. It may be helpful to reflect on the challenges many people face in HIV disclosure: fears around rejection, violence, judgment and blame are common anxieties for key populations.

Disclosure of HIV status to an adolescent

As described earlier and elsewhere, adolescence covers a range of physical and neuro-developmental stages. It is therefore critical to take into consideration both the physical age of the adolescent and their cognitive/developmental abilities, as understanding the levels of skills and competencies of each adolescent enables adherence and disclosure information to be tailored to their needs and abilities.

Horizontally infected adolescents are more commonly involved in the HCT process – where consent is generally sought from the guardian – than those who are vertically

infected. The advantage of including the adolescent in the counselling process is that their engagement is sought from the outset. It enables the health provider and adolescent to explore reasons for testing, existing knowledge, values, myths and fears, and seeks informed consent for HIV testing to take place.

For younger adolescents (age 10 – 14 years), a guardian may also be included in the counselling and consent process, but it is important to recognise the needs of the adolescent in this to enhance their engagement and provide a level of control over health decision-making. Identifying local support systems that can assist the adolescent and their family (e.g. support groups in clinics or the community) and linking into these early on will provide support and learning opportunities beyond clinical consultations.

For older adolescents (age 15 - 19 years), a guardian may also attend the consultation, but it may also be that they attend alone, or with a partner. Critical to this process is to understand who the adolescent wishes to have present during the consultation. It may be that the guardian remains for some of the discussions, but is then asked to wait outside while the conversation continues without them. Preparing guardians for this at the beginning of the session enables the adolescent to plan what they wish to share and when, and the guardians are made aware that a planned private conversation is going to occur without them.

Ultimately, engaging horizontally infected adolescents in their HIV diagnosis and treatment from the outset enables linkages to adherence clubs and other support groups (where available) to be introduced early, and support around beneficial (onward) disclosure of diagnosis to be provided.

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4.3 Disclosure to friends, family and intimate partners

Disclosure allows the adolescent to live in an open and trusting social context, and increases the amount of emotional and practical support the adolescent can receive.[1] For these reasons, disclosure is seen as an essential part of adherence.[2] However, disclosure is ultimately the choice of the adolescent, and cannot be forced or implemented without their consent.[3] It is vital that the adolescent feels in control over the disclosure of their HIV status.[4]

Building strong support systems among family, friends and partners is essential to all adolescents, as some may not be mature enough to manage treatment and care commitments on their own. Many adolescents are facing uncertain futures in South Africa, with low rates of completion of basic education and high rates of unemployment. These anxieties are commonly worsened by fears around long-term health and the impact that living with HIV will have, including on opportunities to live well and long, to secure work, to have long-term relationships and begin a family. These are therefore of particular relevance to adolescents receiving ART, who may resist discussing or sharing their HIV diagnosis. Inadequate support can leave adolescents feeling isolated and excluded, and can impact negatively on their ability and desire to adhere to ART and to achieve their life goals.

Disclosure of an HIV-positive status can be frightening and emotional for the adolescent; and is often avoided out of fear of the reactions of others. Although discourses regarding HIV are changing in current South African society, there are still moderate levels of stigma attached to HIV infection, which often manifest as internalised stigma that the patient themselves experience.[5] Despite these fears, most people to whom patients disclose are supportive,[5] and healthcare workers should try to gain a realistic sense of the level of support, trust and understanding in the adolescent's primary relationships. This will assist in understanding how realistic fears of stigmatisation may be. It is important to bear in mind that adolescents may have very legitimate concerns about isolation, abandonment and even abuse.[4]

Beneficial disclosure

The healthcare worker must make it clear to the adolescent that there are many good reasons to disclose their status to important individuals in their lives: e.g. not having to hide their status or medication contributes to ease of adherence; and psychological benefits include a reduction in stress, anxiety, guilt and isolation. Disclosure allows others to act as a support for the patient: reminding them about appointments and taking their medication, and collecting treatment or communicating with facilities when the patient is too ill to do so.[6] The support structures also serve to strengthen relationships and increase psychosocial support,[4] which contributes to the patient's emotional and psychological well-being. These are linked to better physical health and higher rates of adherence.

That said, disclosure should be encouraged with sensitivity and understanding. It is important to gain a clear idea of what barriers to disclosure exist, considering that these will differ for each person and the disclosure process should be specific to each individual's unique challenges and situation.

There are useful tools that can assist in facilitating discussions with both individuals and groups around beneficial disclosure.[7] In planning disclosure, it is helpful to ask the patient a few basic questions:

Useful questions to explore regarding disclosure:

- **Who?** Identify trusted people to whom it would be helpful to disclose, and explore with the patient reasons why they wish to disclose to those particular people.[4]

- **Why?** Do they wish to disclose due to their own anxiety, a need for support, or prevention of onward transmission? What are the potential benefits of disclosing to this person?

- **When?** Assist the patient to think of appropriate times to disclose – when they would be undisturbed, and when the person to whom they want to disclose would be open and amenable to listening.

- **How?** What are they planning to say, and how much detail will they include? Role-playing and practising can be helpful.

- **Risks?** What are the potential risks of disclosing – are they at risk of violence, abandonment or stigmatisation? What could be done to reduce the potential risks?

- **Support?** To whom can the person turn for support – before, during, or after the disclosure? To whom can the person talk about their experience of disclosure? Referral to a support group?

Role-playing can assist the patient to imagine negative and positive reactions to disclosure, and their own responses to those reactions. It is helpful to discuss possible questions which the adolescent may be asked about the disease, and to provide the adolescent with the information needed to address these.[8]

Following disclosure, a follow-up visit can be useful to offer support and help the adolescent reflect on the process.[8] They can also be referred to a support group, if not already done, and encouraged to make use of supportive people in their lives.[4]

Telling family members and friends

Very often, parents will already be aware of the adolescent's status, but if not, these would usually be the first people to whom disclosure should be encouraged. Parental support has been correlated positively with increased ART adherence;[9] the exception to this being when parents are clearly abusive or neglectful and disclosure would put the adolescent at risk. Any indications of such a situation should be taken seriously, and where possible, disclosure to any parental figure who the adolescent trusts (e.g. grandparent or close relative) should be facilitated.

Disclosure to peers may be easier for some adolescents, as associated fears of judgement and stigmatisation may be fewer than in their relationships with adults. However, these risks still exist, especially if peers in turn disclose to others, or if the patient is already subjected to bullying or social rejection. The possible benefits of disclosing to friends should be explored with the patient; and disclosure should only be encouraged if it will increase the safety and comfort of the adolescent.

Telling an intimate partner

Disclosure to friends and family can occur whenever the adolescent is ready; but if the adolescent is sexually active, there are real and pressing reasons to consider disclosing to sexual partners. Legal issues come into play here – refer to Section 4.4.

Intimate partner violence, or fear thereof, is often a consideration.[10] Adolescents should not be pressured into disclosing their HIV-positive status as this can put them at risk of abuse – discretion should be used to ensure that the patient is not placed in danger.[11] Disclosure should only occur when it is in the best interests of those concerned; and in the case of adolescent minors, the best interests of the child are paramount.[3]

Whether or not the adolescent discloses to their partner, it is important to ensure that they understand the process of HIV transmission and the ways they can prevent it, as well as the principles of protection against STIs and pregnancy. Following disclosure to a partner, HCT should be arranged for the partner.[4]

Disclosure to, and treatment of adolescents who have been horizontally infected may also be necessary. General disclosure guidelines can be followed as appropriate.[12] In the event of treating an adolescent couple simultaneously (more likely with older adolescents), procedures will depend on the results of the test:

- If both partners are HIV-positive, and both consent to their partner knowing their status, they can be counselled together on risk reduction, healthy living and safe-sex practices. If the relationship is supportive and stable, then partners can act as social support for one another.

- If the couple is sero-discordant, and the health-care provider has their consent to disclose to them when they are together, it is important to ensure that the process is managed sensitively and allowance is made for a range of experiences on behalf of both partners. It is important to ensure that both partners understand what 'sero-discordant' means and the implications thereof.

Going forward, both partners will have different responsibilities to ensure adherence and avoid infection of the HIV-negative partner.

Depending on the nature of the relationship, intimate partners can be a source of support and understanding for AYLHIV, or the impact of the diagnosis can lead to conflict, isolation or abuse. Because adolescents often do not have deep or long-term relationships, and may/may not maintain a relationship following a positive HIV diagnosis, it is important to assess both partners' plans for the future of their relationship. AYLHIV should not feel judged in terms of their behaviour in their relationship, nor pressured into continuing their relationship – adherence is more likely if parties feel accepted.

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4.4 Legal aspects of disclosure

South Africa has committed, and is legally obligated, to ensure that appropriate disclosure is an 'integrated component of child and adolescent HIV management'.[1] Recent legislation fully recognises the rights of children and adolescents to participate in decisions affecting their healthcare and to clarify their right to privacy and disclosure of their HIV status. It is therefore the duty and responsibility of all healthcare providers to ensure that the legal and ethical rights of child and adolescent disclosure are practised, according to the following laws and guidelines (Table 12):

Legal and ethical considerations in working with children and adolescents

Best interests of the child

The best interests of the child are paramount in every matter concerning the child. In all matters concerning the care, protection and wellbeing of a child, including disclosure, the best interest standard must be applied.

Research has consistently found that it is in the best interests of the child or adolescent to disclose their HIV status to them. All healthcare providers and those working with children and adolescents must encourage and assist guardians with the process of this disclosure. If, however, the guardians refuse to disclose to the child or adolescent, then the healthcare provider should work with them, allaying their fears until they are ready to do so. It is important that disclosure is not delayed for too long.

The right to confidentiality, privacy and sensitivity in health services

All children and adolescents have the right to confidentiality; meaning that information on the child's health status, or the health status of the child's guardian(s) or family member(s), must be kept confidential by the healthcare provider; except when maintaining such confidentiality is not in the best interests of the child. If the healthcare worker decides that it is in the best interests to breach confidentiality, s/he should talk to the child before doing so, and explain why it is in their best interests.

Despite section 133 of the Children's Act[4] declaring that all information regarding a child or adolescent's HIV status must be kept confidential, ethical issues can arise, especially in the case of a positive HIV test result in a child younger than 12 years. Children aged <12 years cannot consent to treatment, but can refuse to disclose test results to a guardian. In this case, the healthcare provider should encourage and assist the patient to disclose to their guardian.

Table 12: Laws and guidelines governing legal and ethical rights of child and adolescent disclosure	
Law/Guideline	**Description**
Constitution of the Republic of South Africa (Act 108 of 1996)[2]	• Promotes human dignity, equality and freedom; including PLHIV. The Bill of Rights declares: • Everyone in South Africa has the right to equality (section 9); meaning that no person may unfairly discriminate against another person on 16 listed grounds, including disability. • Everyone has inherent dignity and has the right to have this protected (section 10). • Everyone has the right to privacy (section 14); meaning personal information is confidential and no one has the right to disclose this information without your consent. However, this law does not protect the confidentiality of deceased persons.
	Addresses the issue of medical confidentiality without expressly mentioning HIV/AIDS. This Act prohibits disclosure without consent and thus protects all patient information, including information relating to a person's health status, treatment or their stay in a healthcare facility, as confidential (section 14(1)). It further adds that no person may disclose any information relating to another person's health status, treatment or stay in a healthcare facility, unless: the person gives written permission to do so, a court order or a law requires the disclosure, or non-disclosure of the information represents a serious threat to public health (section 14(2)).
Children's Act 38 of 2005[4]	Introduces new principles relating to the role of children, primary caregivers, healthcare providers and others working with children in making decisions about the healthcare of children and adolescents. Section 133 states that information on a child's HIV status must be kept confidential.
National Patients' Rights Charter[5]	Sets out the rights and duties of patients who attend government clinics and hospitals, including partaking in decisions about treatment, confidentiality and privacy about medical treatment, and informed consent to medical treatment.
NDoH Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases[1]	Aim to assist all stakeholders involved in the disclosure process in empowering and equipping children and adolescents to be actively involved in the management of their chronic disease.
Health Professions Council of South Africa (HPCSA) Ethical Guidelines for Good Practice with Regard to HIV (2007)[6]	Form an integral part of the standards of professional conduct and are based on international best practice: • With regards to confidentiality, it is required that the test results of HIV-positive patients are treated with the highest possible level of confidentiality. Therefore, confidentiality regarding a patient's HIV status extends to other healthcare practitioners and will require that patient's consent unless the disclosure is clinically indicated. The decision to disclose information relating to the HIV status of a patient must always be done in consultation with the aforementioned patient. • In terms of partner disclosure, healthcare providers should always encourage their HIV-positive patients to disclose their status to their sexual partners. In the case of adolescents, this should be done cautiously, as at this age many sexual relationships are quite casual or new. These guidelines also state that, 'if the patient refuses consent, the healthcare practitioner should use discretion when deciding whether or not to disclose the HIV status to the patient's sexual partner, [always] taking into account the possible risk of HIV infection to the sexual partner and the risks to the patient (e.g. through violence) that may follow such disclosure'.[6] However, the HPCSA first recommends that the healthcare provider must: i. counsel the patient on the importance of disclosing to her/his sexual partner(s) and on taking other measures to prevent HIV transmission ii. provide support to the patient to make the disclosure iii. consider other measures to prevent infection, and counsel the patient on the healthcare practitioner's ethical obligation to disclose such information iv. choose whether or not to disclose the patient's HIV status to the sexual partner, if the patient still refuses to do so, ensuring that any such intentions are communicated to the patient before enacting them v. follow up with the patient and their partner(s) after disclosure on the part of the healthcare provider, to assess any resulting adverse consequences or violence for the patient, and to intervene appropriately if necessary.
Guidelines of the South African Medical Association (SAMA) and South African Nursing Council (SANC)	State that doctors and nurses must respect a patient's right to confidentiality by keeping their medical information confidential.
PLHIV – people living with HIV.	

Third-party disclosure with children and adolescents

According to the Children's Act No. 38 of 2005,[4] the following people may consent to disclose a child or adolescent's HIV status to a third party when it is in the best interests of the child:

- the guardian or designated protection organisation (if the patient is aged <12 years or has no capacity to consent)

- the chief executive officer of the healthcare facility (if the patient has no guardian)

- the healthcare team can disclose to each other (if it is related to providing the patient with the best possible healthcare)

- the court of law (if the magistrate deems it).

The rights of children and adolescents who have disabilities in the context of disclosure

According to the United Nations Convention on the Rights of Persons with Disabilities article 7:[7]

- All children with disabilities must enjoy the same fundamental human and freedom rights as other children, such as: physical accessibility to all facilities; accessibility to HIV treatment and other HIV- and disclosure-related services; and referral to appropriate healthcare services.

- In all actions concerning children with disabilities, the best interests of the child must be a primary consideration.

- Children with disabilities should be allowed to express their views freely on all matters affecting them.

- The views of a child with disabilities must be given due weight in accordance with their age and maturity:

  – Children with physical disabilities but with normal cognitive or emotional development should receive disclosure services within the normal facility setting and processes.

  – Children with cognitive or emotional problems relating to their disability should be referred to a social worker, psychologist or specialist service for disclosure and ongoing support.

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5. Mental health

5.1 Mental health and adherence in adolescents

Mental health disorders – 'clinically significant behavioural or psychological impairment(s) of an individual's normal cognitive, emotional or behaviour functioning, associated with present distress and caused by physiological or psychological factors'[1] – commonly start in adolescents between 11 and 18 years of age, with depression and anxiety contributing the largest burden in this age group. Negative health and social outcomes include, *inter alia*, adolescent pregnancy, school dropout and substance abuse. Despite recognition of the lifelong impact of mental health disorders, these receive relatively little attention in adolescents, and are frequently under-diagnosed and -treated, as routine screening is seldom conducted as a standard aspect of care. Within families, under-reporting is common with mental health difficulties often attributed to normal adolescent development.

From the perspective of HIV care, treatment and support, the detection of mental health issues is of particular importance. While attention is frequently focused on promoting adherence to the treatment regimen, neurocognitive and mental health disorders *can* and *do* play a significant role in health outcomes. Vertically infected adolescents present with particularly high rates of emotional, behavioural and psychiatric disorders, exceeding rates in the general population and in other high-risk groups.

Across chronic illnesses, adolescents find adherence to medication challenging; and this is often exacerbated by mental illness. In the context of HIV, the impact of mental health on treatment adherence is a serious concern: poor adherence increases the risk of HIV treatment failure and drug resistance, progressively limiting future ART options and increasing the likelihood of poor outcomes.

Major depressive disorder (MDD) is most usually associated with HIV and has been widely linked to poor adherence and increased mortality. Even at subclinical levels, depressive symptoms have been found to disrupt adherence. Also relevant are: anxiety disorders, including generalised anxiety disorder (GAD), panic disorder and PTSD; substance abuse disorder (SAD), attention deficit hyperactivity disorder (ADHD) and impairments in cognitive function. The presence of psychotic symptoms (e.g. hallucinations and delirium) and mania do not occur among HIV-positive adolescents as frequently as in adults, and an adolescent presenting with a psychotic psychiatric disorder requires thorough investigation. Establishing cause can be challenging, since a number of disorders can present with psychotic symptoms including severe mood disturbances, ARV-related psychosis and substance use.

The presence of more than one mental health problem is also not unusual; e.g. depression with co-morbid substance abuse. Substance abuse – the consumption and misuse of various dependence-forming substances such as alcohol, cannabis, cocaine, heroin, methamphetamines and nyaope – has serious, multifaceted and devastating health impacts on HIV-positive adolescents including lower treatment adherence, increased sexual risk behaviour, ARV regimen interference, incomplete viral suppression and disease progression.[9] Substance abuse is on the increase in South Africa: the average age of substance dependence is 12 years, and the age at which adolescents are starting to abuse substances is decreasing.[10] There is also a trend towards more addictive substances and poly-substance abuse (e.g. concurrent use of methamphetamines ('*tik*') and cannabis ('*dagga*')).[10] It is therefore crucial to ensure adherence by linking key adolescent populations to programmes for early detection and management – discussed further in Section 5.2.

The roots of mental health disorders are many and varied and include: the impact of HIV on the brain; social determinants of health, including poverty; and psychosocial stressors related to living with HIV, such as multiple loss, stigma and family instability. The influence of different stressors, particularly those perceived as severe, has implications for adherence: for every stressor reported by a patient, the likelihood of missing medication increases by over 30%. There also needs to be cognizance of the impact of traumatic experiences on young people. Childhood sexual and physical abuse can give rise to mental health problems that will in turn negatively influence treatment adherence.

Impairments in cognitive function – attention, memory, producing and understanding language, learning, reasoning, problem-solving and decision-making – also take a toll on health outcomes in AYLHIV. Milder forms of neurocognitive disturbance are recognised in HIV-positive children and adolescents, including milder forms of the HIV-associated neurocognitive disorders (HANDs) seen in adults. These are often overlooked, but can have implications for functioning at various levels including academic performance. Although initiation on ART improves cognitive functioning, particularly if treatment is started early, AYLHIV may present with deficits in specific areas, such as executive function, that may have implications for health literacy and adherence as they move towards taking more responsibility for their healthcare.

The National Mental Health Policy Framework and Strategic Plan (2013 – 2020)[11] states that mental health should be integrated into all aspects of healthcare, and must target certain vulnerable groups including children and adolescents and PLHIV. In a similar vein, the *Child and Adolescent Mental Health Policy Guidelines (2013)*[12] assert that all front-line providers should be able to recognise and manage mental

health issues in these populations. Early detection of mental health problems, appropriate referral and effective intervention can do much to improve the health outcomes of AYLHIV.

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5.2 Mental health and substance abuse screening and assessment

Screening refers to a process of gaining a broad range of information about the mental state of a patient to determine whether they need referral or care. Comprehensive psychometric assessment of mental health disorders can be conducted by a psychologist, if available. If not, healthcare workers can conduct screenings regularly to identify markers of mental health difficulties and refer as necessary.

Early identification of mental health and substance abuse problems leads to quicker intervention, and this can encourage positive treatment outcomes, as risky behaviours may be curbed. It is also important to determine when mental health and substance use occur co-morbidly.[1]

Healthcare providers can take several actions to assess mental health needs in AYLHIV and refer them to appropriate resources.[2] Five important aspects of this process are outlined below:

1. Conducting a mental state exam

2. Collecting a thorough history and collateral information

3. Pre-screening

4. Screening to identify and refer suspected cases

5. Following up with those who screen positive and/or are referred.

Conducting a mental state exam

This is an assessment of the patient based on their presentation at a clinical visit. The characteristics listed in Table 13 should be assessed, looking for any abnormalities or changes in the adolescent which may be indicative of a change in mental health. Note that no aspect of the mental state exam can be used as conclusive proof of a diagnosis.

Table 13: Mental state exam – assessment characteristics	
Aspects to note	**Description**
Physical appearance	Age, grooming, clothes, cleanliness, bruising, scars
Behaviour	Eye contact, co-operation, interaction
Mood	-
Thinking	-
Speech and language	Volume, rate, fluency, language skill
Attention, concentration and memory	Can sometimes be observed from simple interaction (e.g. grooming, eye contact, fluency of speech), but it may be necessary to probe further or ask about certain aspects, such as mood and memory.
Questions to ask	• 'How are things in your life at present?' • 'How have things been in your life since you were last at the clinic/in the last month?' • 'How are you coping?'

History-taking and collateral information

This encompasses information about the patient's life, obtained from others and from the patient themselves. History-taking can include the questions on official clinic stationery, but can also include a more detailed history of particular factors which have affected the patient's life. For example, when a patient has a history of trauma, it may be useful to understand what these traumas comprised and when they occurred (without re-traumatising the patient, and as far as the patient

Table 14: Examples of pre-screening questions	Every day	Most of the time (5 - 6 days/week)	Sometimes (3 - 4 days/week)	Not much (1 - 2 days/ week)	Never
How often do you feel sad?					
(If ≥3 - 4 days/week, then screen for depression and suicide)					
How often do you feel worried?					
(If ≥3 - 4 days/week, then screen for anxiety)					
First screen: Have you ever had a bad experience where you were scared that you or someone you love would be seriously hurt or killed? (Every further visit, please adapt: Since your last visit …)	Yes	No			
(If yes, then screen for trauma)					
Do you drink alcohol or use drugs?	Yes	No			
(If yes, then screen for substance abuse)					

is willing to disclose). History-taking is most thorough upon initial contact with the patient, but specific history-taking may have to occur subsequently if events occur during the course of treatment, or past events in the patient's history come to light.

Collateral information includes any information gained from sources other than the patient: other healthcare professionals, friends, family members, teachers, support group members, etc. It is important that confidentiality of the patient's status is not broken without the patient's consent. No one should be compelled to provide confidential information. Specific checking with external sources should only be done with the patient's consent, as it is important to maintain a trusting alliance with the patient. The only exception to this is when the patient's safety is at risk.
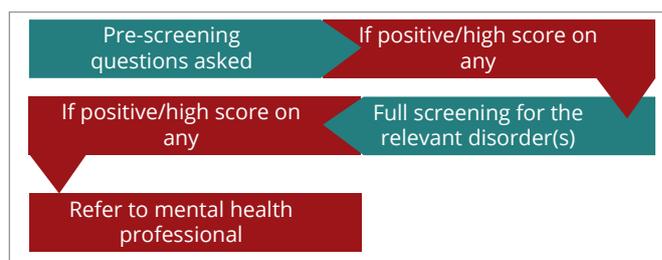
Pre-screening

In primary care facilities, resources are often not sufficiently available (in terms of time, materials or staff) for full screenings to be conducted at every visit – and adolescents will often not have the time or interest to engage fully with extensive screenings, especially if they do not feel they are relevant. On this basis, it is suggested that a two-stage screening process is conducted: (i) pre-screening, and (ii) if necessary, full screening based on the results of pre-screening.

Basic pre-screening questions (Table 14) can be used to indicate the usefulness of conducting a full screening for any disorder. One question is asked for every disorder assessed (i.e. one question for anxiety, one question for trauma, etc.). This means that full screening does not need to be conducted at every visit, as this would be time-consuming and inefficient for both healthcare provider and patient; but if pre-screening questions are asked at every

visit, then there is still a consistent process in place for monitoring mental health.

Screening for disorders

Potential disorders indicated by the pre-screening should then be assessed with a validated screening tool (Fig. 2 and Tables 15 and 16). Such tools do not have the purpose of providing a diagnosis; their aim is to ascertain whether sufficient symptoms of a disorder exist to necessitate mental healthcare. Full screenings can give a broad overview of the symptoms the patient is currently experiencing, and the patient's score can indicate whether referral to a counsellor, social worker, psychologist or psychiatrist is necessary.

Figure 2: Process of pre- and full screening for mental health disorders.

It may be possible for the adolescent to complete the screening in written form, but this may prove costly in terms of materials and difficult for some adolescents, especially those who are younger adolescents or whose first language is not English. Thus, it is acceptable for the clinician to administer the screening verbally and to complete the responses. Translation may be necessary, but every effort should be made to ensure the accuracy of translation in order to preserve the validity of the screening tool.

Table 15: Mental health assessment tool for referral

These questions are not intended as a diagnostic tool, but can be asked by the healthcare provider to assess the need for referral to a mental health professional. Referral should be made if any of the 'often' boxes are ticked.

1. Do you worry a lot about things and find the worry just won't go away?

Never	Once or twice	Often

2. Do you find that you have difficulty paying attention or concentrating on what people say to you at school or at home?

Never	Once or twice	Often

3. Do you ever use alcohol to relax, feel better about yourself or fit in? (If yes, ask Q4)

Never	Once or twice	Often

4. Has the use of alcohol or drugs meant that you haven't been able to do things that are expected of you at school or in the family?

Never	Once or twice	Often

5. Do you ever feel worthless, hopeless, feel that you let people down all the time or are not a good person?

Never	Once or twice	Often

6. Have you ever had thoughts, plans or actions about suicide or self-harm?

Never	Once or twice	Often

7. Have you ever experienced or witnessed an event that caused you to feel intense fear, helplessness or horror? Do you think or dream about what happened and seem unable to put it out of your mind?

Yes	No

8. Sometimes when they are alone, people hear voices, see things or smell things and they don't quite know where these things come from. Has this ever happened to you?

Never	Once or twice	Often

Screening tools that can be used to assess for mental health concerns are listed in Table 16. All are freely available electronically and are designed for use in PHC facilities. Screening tools other than those mentioned here can be used, but it should be ensured that these tools are thoroughly researched and validated (if not in a South African population, then in several different cultural settings). Choice of screening tool used is at the discretion of the facility, manager and healthcare worker. What is imperative is that there is a screening tool readily available in the facility for each disorder.

In addition to the formal screening, clinical observation can assist in identifying possible markers of mental illness. It is advisable to use these observations in combination with screening to perform assessments.

Follow-up

Once patients are referred to mental health professionals, ensure that it is clear to them that they are still patients of yours and that the referral provides additional support rather than a replacement of care. For adherence to be maintained, the adolescent should still feel supported in the ART process. Mental healthcare should be a way to address issues that may have a negative impact on adherence, and thus bolster the patient's coping skills and adherence. When the patient is referred, ensure you have a date set for a follow-up appointment. In the follow-up visit, conduct full screenings for the concern(s) that presented before referral. If/when you see a significant recovery, you can go back to pre-screening at every visit and follow the process as before.

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Table 16: Screening for mental health disorders

Disorder	Description	Signs	Screening tools
Depression	Depression sometimes manifests differently in adolescents to the way it is seen in adults.	While it is important to be on the lookout for sad and tearful behaviour, the following signs may also indicate depression in adolescents:[3] • angry, irritable or reckless behaviour • school-related problems such as a drop in marks, social withdrawal, stopping activities they used to enjoy • negative thinking and hopelessness • physical symptoms like headaches, fatigue, changes in sleep patterns, significant weight loss or weight gain • difficulty or interruption in adhering to medication • self-harm, suicidal thoughts, suicide attempts • substance abuse.	• **PHQ-9:** Patient Health Questionnaire - 9-item questionnaire - Takes ~2 minutes to complete and score - Available at: http://www.cqaimh.org/pdf/tool_phq9.pdf • **PHQ-A:** Patient Health Questionnaire for Adolescents - PHQ-9 modified for adolescents - Available at: http://www.uacap.org/uploads/3/2/5/0/3250432/phq-a.pdf • **CES-D:** Centre for Epidemiological Studies Depression Scale – Widely-used, 20-item questionnaire – Available at: http://idacc.healthbase.info/questionnaires.html
Suicide	Whenever screening for depression is performed, suicide screening should also be conducted. The period immediately after an HIV diagnosis is high risk for suicide, necessitating screening for suicide as part of the post-test counselling process. Adolescents can be asked directly whether they are having any thoughts about killing themselves, and any plans in this regard.[4] Asking directly does not create suicidal thoughts, so it is not risky. If a patient is suicidal, then it is important to be able to speak calmly and openly about their thoughts and feelings.	Examples of suicide screening questions: '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? • Are you currently thinking of killing yourself? An answer of 'yes' to any of these questions should lead to an urgent referral to a psychologist or similar mental health professional. An indication of current intent to commit suicide, with a plan of how to do so, should lead to immediate hospitalisation and psychiatric care.	
Trauma	Trauma symptoms can manifest in various ways. Depending on the patient and the nature of the trauma, discussing trauma may in itself bring out trauma symptoms.[3] Speaking about traumatic events should be done with care and sensitivity, and the adolescent should not be pushed to speak about anything they do not want to share.	In addition to the symptoms of PTSD or Acute Stress Disorder as found in the DSM-5, it should be noted that adolescents who have been exposed to trauma may:[3] • use substances • engage in abusive or violent relationships • attempt to intervene in assaults or crimes • act out aggressively or support aggression[5] • behave fearfully or appear nervous • self-harm • be unable to function at school and home as they did before.	• **PC-PTSD-5:** Primacy Care Post-Traumatic Stress Disorder Screening - 5-item questionnaire - Fast and easy to administer - Available at: http://www.integration.samhsa.gov/clinical-practice/pc-ptsd.pdf – A version has been developed for DSM-5 (PC-PTSD-5) and is being validated • **PCL-5:** PTSD Checklist - 20-item questionnaire - Updated for the DSM-5 - Available at: https://sharepoint.washington.edu/uwpsychiatry/SPIRIT/Evaluation/Documents/pcl-5.pdf

Disorder	Description	Signs	Screening tools

Anxiety	Anxiety or worry may be related to the adolescent's illness, parent/caregiver, school, home or environment. It is expected that some anxiety will be present, especially following diagnosis. Anxiety becomes a concern when it significantly affects the adolescent's functioning at school or in relationships with family and friends. Because anxiety may also be a cause or a result of substance abuse, it is advisable to be on the lookout for any signs and symptoms of substance abuse.[3]	Physical anxiety symptoms:
		• lack of appetite
		• tremulousness
		• sweating
		• racing heart
		• difficulty breathing
		• headaches
		• difficulty falling asleep
		• increase in skin conditions, e.g. eczema
		• restlessness
		• difficulty concentrating
		
		Psychosocial symptoms:
		• changes in schoolwork
		• fearfulness
		• insecurity
		• changes in sleeping or eating patterns
		• behavioural changes
		• subjective feeling of being stressed or overwhelmed.
			• **GAD-7:** General Anxiety Disorder Screen
			  – 7-item questionnaire
			  – Takes ~5 minutes to complete
			  – Available at: http://www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf

Substance use	Assessing substance use may be challenging, as adolescents are sometimes reluctant or evasive about discussing the topic. It may be useful to discuss the patient's friends' substance-related behaviours, as a way of understanding their own substance-related behaviours in relation to this. Collateral information is often useful in this regard; however, confidentiality should not be breached,[4] as a lack of trust will have a negative impact on the relationship between patient and healthcare provider, and potentially on adherence.	Possible indicators of substance use/abuse/dependency:[5]
		• Changes in behaviour or mood (low energy, agitated, fidgeting, slurred speech)
		• Changes in eating or sleeping patterns
		• Physical signs of drug use (injection marks, skin infection, injuries, unkempt appearance, red eyes, shaking, dilated pupils)
		• Requesting prescriptions for non-prescribed medication
		• Changes in personality, e.g. aggression, defiance, withdrawal, secretiveness
		• Financial difficulties or crime-related legal problems
		• Difficulties in carrying out usual responsibilities (e.g. school, duties at home)
		• Changes in healthcare behaviours and adherence.
			• **AUDIT:** Alcohol Use Disorders Identification Test
			  - 10-item questionnaire
			  - Alcohol use
			  - Designed for primary care providers
			  - Available at: https://www.drugabuse.gov/sites/default/files/files/AUDIT.pdf
			• **DUDIT:** Drug Use Disorders Identification Test
			  - 11-item questionnaire
			  - Drug use
			  - Not as widely validated as AUDIT
			  - Available at: http://www.emcdda.europa.eu/best-practice/eib/dudit
			• **CAGE-AID** Cutdown, Annoyed, Guilty, Eye-opened Adapted to Include Drugs
			  - 4-item questionnaire
			  - Can be completed in 1 minute
			  - Available at: http://www.integration.samhsa.gov/images/res/CAGEAID.pdf

5.3 Counselling intervention and referral

Consequent to a limited number of mental health counselling services and referral points in South Africa, healthcare providers – such as doctors, nurses, and social and auxiliary workers – frequently have to administer counselling and support themselves.[1] Many studies[2,3] and recent national guidelines[4] recommend cognitive behavioural therapy (CBT) combined with ART adherence counselling to reduce depression and psychosocial stress. However, CBT provision requires skilled mental healthcare providers, who are hugely under-resourced in public health settings. Task-shifting is recommended in low-resource contexts: this requires training and supervision of non-specialist healthcare workers by the limited number of available specialist mental health professionals.[5]

Antidepressants, alone or in combination with other treatments, may be efficacious; and in terms of counselling interventions, individual and group psycho-education and group interpersonal therapy may be most effective as part of a stepped-care treatment programme.[5,6] Brief psycho-education alone does seem to reduce non-adherence and encourage compliance with medication regimens, and has favourable results for mental state and social functioning.[7]

Psycho-education[8] is an evidence-based psycho-therapeutic intervention for patients with mental health problems and their families. It involves education on the nature of the illness, its treatment, coping and management strategies (e.g. breathing exercises for anxiety, ways to share personal difficulties with key family members or caregivers), and the skills required to prevent poor adherence and prognosis. Although, psycho-education does include elements of CBT, it is easily and effectively delivered by unskilled mental healthcare providers and is thus an essential counselling intervention.

Referral

Despite limited referral sites, some adolescents will require referral and it is important to collate information regarding referral and support resources within the catchment area of the relevant facility. Referral systems and networks need to be established, ensuring that referral processes are youth-friendly. This includes: making contact with the referral personnel, referring to a named provider where possible; and giving clear directions on how to access the service. It is preferable to accompany the adolescent to the referral point, wherever possible.[1]

Recommended mental healthcare referral sites where adolescents can be provided with psycho-therapy and medication:

• Community mental health clinics

• Hospital psychology departments

• University psychology services for external patients/psychological assessment centres

• NGOs and CBOs in the community.

When referring adolescent patients, it is important to include information on:

• presenting complaint

• reason for the referral

• current mental state

• current physical condition

• current medication

• history of any relevant behaviour.

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Table 17: Management plan for specific common mental health disorders*	
Disorder	**Recommended intervention by healthcare provider**
Depression	• Basic counselling • Check for alcohol and substance abuse • Review physical and mental health history • Always screen for suicidal ideation and assess the risk • Refer to a psychologist for psychotherapy as required (if resource is available) • Consider medical management: recommended only for severe depression symptoms (in combination with counselling or psychotherapy) and for a minimum of 90 days once initiated • Consider referral for admission if the patient is showing signs of self-harm, suicide or violence towards others
Anxiety	• Symptoms may be managed through psychosocial counselling and support strategies (relaxation, coping mechanisms for anxiety, reassurance and communication with school/employers) • Assess for alcohol and other substance abuse • Review physical and mental health history • Refer to a psychologist for psychotherapy as required (if resource is available) • Consider medical management: antidepressants; may need tranquilisers • Refer for specialist care, where available, if the patient is unresponsive to interventions and their functioning is impaired
Trauma	• Contain and support the traumatised adolescent by identifying feelings, support people and counselling • Containment involves normalising the patient's feelings and symptoms by reassuring them that their feelings are normal and to be expected after a traumatic event • Check for alcohol and other substance abuse • Refer to a psychologist or mental healthcare provider for therapy as required (if resource is available) • Consider medical management: tranquilisers or antidepressants, based on the clinical picture

Suicidal risk	• Explore suicidal statements further, as well as reasons for wanting to die
	• Review the risk: is this person low-, medium- or high-risk?
	  - Be kind, empathetic and non-judgmental when assessing the risk for suicide, but remain objective
	  - If the patient suffers from mental illness or is currently engaging in substance abuse, this automatically increases their risk
	  - If there are additional specialised resources, such as access to a psychologist or mental health professional, then refer the adolescent for further screening and intervention
	• Contract a safety plan
	  - Draw up a suicide-prevention contract with the suicidal adolescent – a contract that contains an agreement with the suicidal patient not to commit suicide
	  - Discuss the legal requirement to which a healthcare provider is bound and that confidentiality may need to be broken if a minor is in danger: this must be reported to parents
	• Make a relevant referral
	  - Psychologist or other mental health professional
	  - NGO or CBO
	  - Hospitalisation if the patient is high-risk

Substance abuse	• Review physical and mental health history • Provide psycho-education and counselling on risk reduction, behaviour change and the potential negative health effects of substance abuse • Work together with family, schools, employers, where possible: set goals and boundaries and agree on consequences if the patient fails to keep the terms of agreement (work these out in a mutually agreed 'contract' with the adolescent) • Refer to more specialised assistance, where possible (e.g. websites and help lines for the South African National Council on Alcoholism (SANCA), Alcoholics Anonymous, Narcotics Anonymous), as substance addiction in adolescents is challenging • Provide ongoing support and follow-up at every visit.
* Adapted from *Working with Adolescents with HIV: A Handbook for HealthCare Providers*[1]	

6. Adolescent- and youth-friendly services (AYFS)

6.1 Barriers to adolescents acessing health services

Young people in South Africa face many life-changing challenges such as adolescent pregnancy, high-risk sexual practices, GBV, drug and alcohol abuse, poverty, having to head households and many other social ills that can have serious implications for their future. The continuing burdens of HIV and other STIs add to the challenges that threaten young people's goals and roles in the community and society at large.

A great deal has been written about the significant barriers that young people face in accessing health services – specifically SRH at public health facilities, despite facing greater reproductive health risks than adults. These barriers (Table 18) can potentially affect service utilisation, support, RIC and adherence to treatment, and can have a detrimental impact on health outcomes. Many studies in developed and developing countries have confirmed that most of the changes needed to render health services youth-friendly are attitudinal and not structural.

Table 18: Barriers to adolescents using healthcare services
• Clinic operating hours
• Location and distance from home or school and cost of transportation
• Clinic environment is uncomfortable/not adolescent-friendly
• Lack of dedicated space for adolescents
• No waiting area or long waiting times
• No adolescent- or youth-specific care
• No educational material that speaks to adolescents
• Different appointment dates for different services
• Confidentiality or privacy concerns
• Shortage of staff trained on the provision of AYFS
• Unfriendly, judgmental or questioning staff attitudes towards young people
• Lack of policies and knowledge to support young people
• Lack of support and adolescent-specific referrals
• Stigma and discrimination by others
• Difficulty communicating and expressing themselves to healthcare providers
• Experiences of mental health or violence.
AYFS – adolescent- and youth-friendly services.

6.2 Key components of adolescent- and youth-friendly services

This section provides information on clinical AYFS for providers who deliver healthcare to adolescents and youth. Confidentiality, respectful treatment, integrated services and easy access are all widely recognised as important components of appropriate clinical AYFS. The focus in this section is on essential aspects of these components that may be little known to providers. This information may challenge users to reflect on their personal knowledge, attitudes and behaviours, as well as on the protocols and practices in use at their clinic.

Table 19 summarises key components of AYFS that are especially important to specific groups, including younger or older youth; pregnant and parenting adolescents; LGBTIQ adolescents; sexual assault survivors; and HIV-positive youth.

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Table 19: Key components of adolescent- and youth-friendly services		
Component	**Description**	**Recommendations**

Confidentiality	Sensitive healthcare issues must be kept in strict confidence between adolescent and provider. The imperative need to guard the adolescent's confidentiality extends to every member of staff, including receptionists, cleaners, CHWs, etc.	• Ensure staff have a clear understanding of laws on informed consent and confidentiality with regard to:
		  - contraceptive services
		  - STI testing and treatment
		  - HIV testing and treatment
		  - substance abuse treatment
		  - mental healthcare.
		• Train **all** clinic staff about the importance of guarding adolescents' confidentiality. Ensure staff understand how sensitive youth may be to any incident of carelessness with regard to their medical record, name, test results and/or the reason they are seeking care.
		• Emphasise the protections of confidentiality to the patient and explain the limits of confidentiality as a matter of caring rather than of law; e.g. *'I hope you would discuss things like feeling suicidal or being abused with me because these are really serious and I would want to help you and get others to help you, too.'*
		• When accompanied to the clinic by a parent or caregiver, always ensure to have counselling time **alone** with the adolescent. Experts suggest explaining to parents that this is necessary to ensure that the adolescent has no unaddressed health problems or concerns; and that it is **as important** to guard the adolescent's confidentiality as to guard the caregiver's.
		• Be willing to treat unaccompanied minors.
		• Remember that some populations of youth need **extra assurances** of confidentiality:
		  - **HIV-positive youth**: especially with regard to HIV status. They are often fearful of being rejected by family and friends if their status becomes known.
		  - **Older youth**: For older adolescent females, this may relate to their increasing autonomy from the family. For older adolescent males, this may relate more to their need to conceal vulnerability from their peers than from caregivers.
		  - **LGBTIQ:** especially regarding sexual orientation or gender identity. They may be put in considerable danger by being deliberately or accidentally 'outed'.
		  - **Pregnant and parenting adolescents:** These young women are already under considerable stress and may discontinue or delay care if confidentiality is not assured.

Privacy	Adolescents are very sensitive to privacy and confidentiality; concerns about a lack thereof will discourage use of health services.	• Managers must work with service providers and support staff to ensure both **visual and auditory privacy** in the facility, given prevailing resource constraints.

Respectful treatment	Adolescents are particularly sensitive to rude, judgmental or overbearing attitudes and behaviours on the part of adults. These that can cause them to: leave the clinic before they receive the necessary care; fail to comply with treatment requirements (such as taking medicine on time); and/or refuse or forget follow-up care.	• Ensure that every staff member – from clinicians to receptionists – receives training in adolescent development and in treating youth respectfully. Retrain anyone who treats adolescents and young adults with less dignity and respect than is shown to older patients.
		• Schedule slightly longer visits with adolescents than adults so youth have time to ask questions and obtain answers; just because an issue is not clinically significant **does not** mean it is not important to the youth who is asking about it.
		• Train all clinicians in how to raise sensitive issues, such as SRH, condom and contraceptive use, substance use, interpersonal violence, and mental health.
		• Treat every adolescent as a whole person and with dignity: involve them in their own health management, as independence is increasingly important at this life stage.
		• Always ask whether the adolescent wants a chaperone present during an examination.
		• Explain the reason for a particular test and what is involved. Be gentle when performing the test – whether a pelvic exam, testicular exam, drawing blood, or any other procedure that may make adolescents feel uncomfortable, wary or fearful.
		• Some populations of youth are particularly sensitive to disrespectful treatment:
		  - **Pregnant and parenting adolescents:** often have fears about being examined, the pain of delivery, having a secure place to live with the baby, being a good parent, and finishing school, among others.
		  - **LGBTIQ youth** can be upset by heterosexist assumptions. Train all clinicians with regard to sexual orientation so that they know to **avoid**:
		    - saying that an adolescent who has acknowledged being LGBTIQ is 'just going through a phase'
		    - confusing sexual orientation with sexual behaviours
		    - stigmatising an adolescent's sexual orientation
		    - associating sexual orientation with risk or safety regarding STIs or pregnancy, domestic violence, or any other issue that youth may face.
		  - **HIV-positive youth:** may be overwhelmed when first diagnosed with fears about the future, dying, maintaining relationships, establishing intimacy, abandonment, stigmatisation, and taking a lot of medication. Patience, positivity and a non-judgmental approach are particularly important to ensure they continue with the healthcare they need.
		  - **Youth who are survivors of sexual or physical assault** are particularly vulnerable due to the traumatic event(s) they have endured: young women may blame themselves; young men may question their own masculinity. Respectful treatment is imperative.

Component	Description	Recommendations
Integrated care services	Allow youth to obtain different services in a single location; a 'one-stop shop'.	• Establish protocols to remember to ask about risk-taking behaviours, including unprotected sex, substance use and violence, and issues such as depression, suicidal thoughts and violence victimisation. • Ensure staff members understand that some adolescents (e.g. adolescent parents, those in foster care, street children) exhibit higher rates of risk-taking behaviour than other adolescents. Set up strong referral systems, co-locate services, and/or establish collaborative partnerships with agencies who serve these youth. • Develop links with school-based health clinics, which are especially effective in serving adolescents but are often unable to provide contraceptive and family planning services. • Ensure continuity of care by making every effort to ensure that adolescents see the same counsellor and/or clinicians at every appointment. • Advertise the clinic's services widely. If youth know that the clinic offers primary as well as care for more sensitive issues such as SRH, STIs, substance abuse and mental health, then they can come in for care related to a sensitive issue without worrying that others will know why they are in the clinic. • Adolescents often have difficulty negotiating complex medical systems: schedule referral appointments for them and ensure that they know exactly where and when to go. Give them clear directions, assurances of continuing confidentiality. Knowledge can help lessen their anxiety so they will be more likely to keep the referral appointment. • Before an adolescent leaves the clinic, provide a slip of paper with their correctly spelled diagnosis and medications, if any. • Integrated care is especially important to some populations of youth: • **Young men** may be particularly drawn to integrated services that allow them to seek care for sensitive issues without exposing their vulnerability. • **Pregnant adolescents** need more than just prenatal care. They need to know that their clinician cares as much about them as about the fetus they carry. They often need assistance to get publicly funded health insurance and social services. • **LGBTIQ youth** have the same physical and psychosocial needs as their heterosexual peers and need the same comprehensive services. • **HIV-positive youth** need co-ordinated care that provides a range of services, including case management, comprehensive medical care and psychosocial support. • **Sexual assault survivors** need immediate prophylaxis for HIV. Women of reproductive age need immediate emergency contraception (EC) to prevent pregnancy. Youth need clear, gentle explanations of why the medications are important; and to be treated gently and respectfully during the examination.
Easy access to health services	Access issues may include: lack of transportation; difficulties making appointments; not knowing where to go; hours and days when services are available; and requirements to return for follow-up.	• Offer flexible hours for adolescents: appointments in the afternoons and on weekends. At the same time, accept walk-in appointments during those afternoons and weekend hours that have been set aside, especially for youth.
Promoting equity to health services	Important consideration for all health service provision. Recognising that some adolescents will need additional support/services to enable them to access healthcare should be part of routine planning and delivery.	• Analyse current service access – does it enable all adolescents to access services (e.g. wheelchair access, flexible hours, tailored sessions for key populations)? • Take steps to ensure that every adolescent receives the assistance they need to access services (including advertising services, promoting confidentiality policy, etc.).

Component	Description	Recommendations
SRH services	Education and counselling, contraceptive services, STI/HIV testing and treatment, prenatal services, discuss pregnancy management services, and fertility counselling and treatment.	• Use a standardised form for noting sexual history. It is critically important to obtain a sexual history from **every** patient using standardised forms. This will help to ensure that clinicians can adequately and appropriately address each patient's sexual risk. • Offer adolescent females a wide array of hormonal contraceptive methods. Do not hesitate to offer intrauterine contraception and implants. A patient cannot make an informed choice unless she knows the benefits and drawbacks of all her contraceptive options. At the same time, advise her of the importance of using condoms for additional protection against pregnancy in the first seven days after she has begun her chosen method of hormonal contraception. • Offer all patients an HIV test including pre- and post-test counselling and linkage to appropriate care. • Advise all adolescent and young adult female patients about the importance of using dual protection, regardless of their sexual orientation. Most sexually active young women are able to use hormonal contraception to prevent pregnancy. All sexually active youth – male and female – should use condoms or dental dams at every act of sex, to prevent or lessen the risk of infection with STIs, including HIV. • **Do not** require a pelvic exam before prescribing or dispensing hormonal contraception to adolescents. Also be sure that young women know, in advance, when a pelvic exam will not be necessary and when it will be needed. • **Do not** require a pregnancy test before offering EC. A pregnancy test is entirely unnecessary before a young woman uses EC because the medication will not harm an established pregnancy and will have **no** effect if the woman taking it is already pregnant. Remember that EC is **entirely safe** for adolescent women. • For purposes of partner notification, be sure to ask about sexual partners: in the previous two weeks to one month (for herpes and most bacterial infections); in the past two months (for chlamydia and gonorrhoea); and in the past year (for HIV).

Supportive management	Basis for the delivery of quality healthcare services.	• Facility and district managers need to commit to improving services for adolescents in their community and provide guidance, support and supervision to their teams to enable quality improvements. Managers must:
		  - be conversant with the principles of AYFS and commit to building services for this population
		  - provide support and supervision to their healthcare team to secure buy-in to AYFS
		  - provide tools and resources needed to deliver high-quality AYFS
		  - receive support and supervision to assist service development and delivery.

AYFS – adolescent- and youth-friendly services; CHWs – community health workers; ECs – emergency contraception; LGBTIQ – lesbian, gay, bisexual, transgender, intersex or questioning; STI – sexually transmitted infection; SRH – sexual and reproductive health.

Table 20: Supporting and encouraging adolescent participation[5,6]	
Approach	It is useful to understand the importance of youth participation in terms of three main relationships between services, programmes, policy-makers and adolescents. All those involved with adolescents should:[6] • work with and for adolescents as beneficiaries • engage with adolescents as partners • support adolescents to take initiatives and to serve as leaders. This approach focuses on acknowledging and mobilising the value, strengths, contributions and talents of adolescents rather than concentrating solely on their needs or challenges.
Practical measures	Practical measures to encourage adolescent participation in the consultation:[5] • Involve the patient in the care process through education and provide opportunity for questions and discussion • Maintain mutual respect in interactions • Be encouraging and positive • Display patience and encourage patients to speak for themselves • Involve parents/caregivers where appropriate.
Health system interaction	Adolescent participation concerns not only the interaction between the patient and the health worker, but their interaction within the facility and other aspects of the health system. Examples of strengthening facility-based adolescent participation include: • Having adolescent representation on clinic advisory boards • Adolescent involvement in clinic-based activities such as support groups.

6.3 Encouraging adolescent participation in healthcare

Awareness of the right of adolescents to participate in decision-making is a crucial component of providing AYFS. Participation of children and adolescents in their healthcare is enshrined within the UN Convention on the Rights of the Child, ratified by South Africa in 1995,[1-3] and the Children's Act of 2010.[2] When focussing on HIV healthcare, this encompasses providing AYLHIV with the knowledge and opportunity to discuss their health status, take ownership of their health management, and to raise concerns and queries with health providers in a collaborative and constructive manner. While increasing participation is a goal in and of itself, it is important to recognise the potential benefits of increasing adolescent participation for clinical outcomes such as RIC.[4]

Not only is adolescent participation essential to promoting a rights-based and youth-friendly approach to the care of adolescents, but it is an essential step to preparing adolescents for their eventual transition into adult-oriented services.[5] Table 20 summarises the approach, practical measures and interactions to encourage adolescent participation.

References

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7. Youth clubs

7.1 The youth club model for adolescents

Worldwide, more than 2 million adolescents aged 10 - 19 years are HIV-positive.[1] South African youth aged 15 - 24 years have an HIV prevalence of 7%,[2] with young women at particular risk, as an estimated 2 363 in this age group become infected every week.[3] Differentiated models of care for this vulnerable youth population remain limited, with a 50% reported increase in AIDS-related mortality, relative to a 30% decline in the general population.[1]

Included in the National Adherence Guidelines as an 'additional recommended intervention',[4] the youth club care (YCC) model (summarised in Table 21)

Table 21: Basis of the youth club model	
Description	• Group-based HIV-management approach that provides integrated clinical care and psychosocial support to improve adherence and RIC of AYLHIV • Provides AYLHIV access to HIV clinical management, contraceptives, ART refills (pre-packed ART refills are distributed at the YCC), routine health screenings and psychosocial support in one visit
Club size	• YCCs are closed groups of 15 - 20 HIV-positive adolescents/youth aged 12 - 24 years.
Club composition	• Each YCC has a mix of pre-ART, newly initiated, virally suppressed and non-virally suppressed members – to encourage peer learning and motivation across the different categories • Members grouped into three age categories: 12 - 15 years, 16 - 19 years and 20 - 24 years to ensure age- and stage-appropriate interaction • If the facility does not have a large population of HIV-positive adolescents, then separate groups for adolescents (12 - 19 years) and young adults (20 - 24 years) can be formed • YCC members are further grouped according to mode of transmission (perinatal and horizontal) to ensure that the psychosocial needs of each group are catered to accordingly
Inclusion criteria for enrolment of AYLHIV	• Age 12 - 24 years • Has received full disclosure regarding HIV status and comprehends HIV status • Sufficiently mature to be taking own ART • Completed acceptance and commitment therapy (ACT) for adolescents or equivalent ART initiation counselling • AYLHIV with unsuppressed VLs (>400 copies/ml) are included, provided that they are otherwise clinically and psychologically stable
Exclusion criteria	• Known mental and cognitive disabilities • Other chronic co-morbidities or clinical complexities
Frequency and duration	• YCCs meet monthly (every 4 weeks) for the first 12 months, to encourage social cohesion and a strong peer support network, and to ensure sound HIV clinical management of newly initiated and non-virally suppressed members • After 12 months, YCC members can chose to meet monthly or once every 2 months (8 weeks); by this stage, most YCC members would be virally suppressed and therefore eligible for 2-month ART refills • The duration of each YCC visit is between 1 and 2 hours
Facilitation	• YCC visits are facilitated by a lay counsellor and supported by a clinician

Meeting types	• Four types of YCC visits require preparation in advance to ensure smooth running and avoid time-wasting:
	  - routine
	  - blood
	  - clinical
	  - scripting

Screening conducted by the YCC counsellor	• Weight, symptoms, TB, contraception, STIs, nutrition and psychosocial state • YCC members who screen positive are referred to the YCC clinician
YCC discussion topics*	• Interactive and participatory discussions related to youth-specific issues are facilitated by the YCC counsellor. • Discussion topics:* - Welcome to your YCC; Adherence; Disclosure; Stress and coping skills; Me, myself and I; My future; Sex, sexuality and gender; Healthy, unhealthy and abusive relationships; Communication within relationships; Puberty (adolescents)/Negotiating safe sex (youth); Teen pregnancy (adolescents)/Contraceptives and being a young parent (youth) • Various tools from which counsellors can choose will be provided for subsequent YCC visits • The YCC clinician fast-tracks YCC members for HIV clinical management, contraceptives or any other clinical needs on the meeting day
Fundamental benefits to YCC members and the facility	• Improved RIC and adherence outcomes • Reduced waiting time by pre-packing ART refills for members weighing >40 kg or on an adult dose • Reduced frequency of clinic visits by integrating psychosocial support with HIV clinical management, contraception and ART refill • Supports transition from adolescent and youth to adult care (each YCC naturally transitions into an adult adherence club) • Platform from which to offer AYFS by using existing facility resources.

AFYS – adolescent- and youth-friendly services; ART – antiretroviral therapy; RIC – retention in care; STIs – sexually transmitted infections; TB – tuberculosis; YCC – youth club (youth club care); VLs – viral loads.
*As provided by the Wits RHI, University of the Witwatersrand, Johannesburg, South Africa.

has proven to be an effective group-management approach to providing integrated clinical and psychosocial care that supports adherence and RIC in this vulnerable group. Furthermore, the YCC model supports effective transition from adolescent to youth to adult care, as youth clubs naturally evolve into adult clubs, ensuring continuity of care.

The YCC model aims to improve ART initiation and adherence among pre-ART, newly initiated and ART-stable adolescents and youth aged 12 - 24 years. YCC members are grouped into closed clubs of 15 - 20 members according to age and mode of transmission (perinatal or horizontal).

References

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8. Vulnerable populations

8.1 HIV and disability

An estimated 650 million people (10% of the world's population) have a disability. A bidirectional relationship exists between HIV and disability: HIV is a risk factor for disability including neurocognitive impairment, hearing loss and physical disability; while persons with sensory, hearing, physical or intellectual disability are at significant risk of HIV infection and its associated poor outcomes.[1] Yet the relationship between HIV and disability has not received due attention, and the impact of the AIDS epidemic is largely unrecognised among both disability and AIDS outreach and advocacy groups.

Persons with disability face ongoing challenges with disclosure and in accessing HIV counselling and treatment services. Reasons for this include:

- Disabled persons are stigmatised and may not seek medical assistance.

- Healthcare workers are not trained to work with persons with disabilities, may lack knowledge about disability issues, or have misinformed attitudes towards such persons. Healthcare workers often feel overwhelmed and unsettled when confronted by a person with a disability.

- Services offered at clinics, hospitals and other locations may be physically inaccessible, lack South African Sign Language (SASL) interpreters or fail to provide information in alternative formats such as Braille, audio or easy-to-understand language.

- Confidentiality for persons with disabilities during HCT may be compromised, for example, by the need for a personal assistant or SASL interpreter to be present.

- In settings with limited ART and PEP, persons with disabilities may be considered low priority for treatment.

- Health professionals may not pay enough attention to the potential for negative drug interactions between ART and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with co-morbid health conditions such as depression.

Recommendations

- Establish age-, gender-, culture- and language-appropriate HIV-prevention programmes and provide HIV information in tailored formats for people from different disability groups, e.g.: radio campaigns will not reach individuals who are deaf or those who are hard of hearing; billboard and print campaigns will not reach those who are visually impaired; AIDS messages that convey too much information, or that use euphemisms for AIDS and safer sex may be confusing to individuals with intellectual disability.

- Include training on the rights of persons with disabilities for professionals working in the area of HIV.

- Provide adequate HIV training and support for personal assistants, SASL interpreters and others who support persons with disabilities.

Disability and adherence

Refer to Section 4.4 for a discussion on the rights of children and adolescents who have disabilities in the context of disclosure.

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8.2 Supporting pregnant adolescents on ART

An overwhelming majority of the estimated 1.4 million women living with HIV who give birth every year reside in sub-Saharan Africa. Although ART adherence is necessary to ensure good health for all PLHIV, it is particularly critical for pregnant and breastfeeding women in order to prevent maternal disease progression and reduce MTCT. Compared with their older counterparts, pregnant AYLHIV have poorer outcomes at a number of steps along the HIV care continuum, including an increased risk of MTCT and poorer maternal and infant health outcomes.

A South African study examining maternal and infant health outcomes among 956 pregnant AYLHIV aged <24 years in the Eastern Cape found that these women were less aware of their HIV status at booking than older women, and more likely to be diagnosed with HIV at a later gestational age.[1] Furthermore, these women exhibited a substantially longer median time between booking and ART initiation during pregnancy, and had an increased likelihood of not receiving ART by delivery, maternal mortality, stillbirth and MTCT.[1] The increased risk of MTCT in infants of adolescent mothers (<20 years old) was corroborated by a study comparing self-reported characteristics of 19 093 mothers in KwaZulu-Natal.[2]

Adequate adherence to ART remains a focus area for many pregnant and postpartum women;[3] and even without pregnancy as a consideration, adolescents in southern Africa have poorer ART adherence rates and virological outcomes than adults.[4] Accordingly,

ART adherence presents a significant challenge for pregnant AYLHIV. Studies examining age as a variable in ART adherence in pregnancy have consistently found a negative association with younger age (<20 or <25 years old).[5-9] It should be noted that these studies did not examine disaggregated data between young women with perinatally versus sexually acquired HIV.

Regardless, it is clear that pregnant AYLHIV require better care and services in order to support ART adherence and good health through pregnancy and the post-partum period.

Recommendations

- Refer to the South African *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT), and the Management of HIV in Children, Adolescents and Adults*,[10] with particular attention to:
    - Section 4.4: Preparation of HIV-positive pregnant women
    - Section 5: Adherence, psychosocial care and support
    - Section 6.1: ART in pregnant and breastfeeding women.

- Extra care must be taken to provide non-discriminatory support to AYLHIV receiving ART and who test positive for pregnancy, given the poorer outcomes for this vulnerable population. They must be given non-judgmental, appropriate information and support to allow them to make choices regarding pregnancy and be content with the options available to them.

- Pregnant adolescents and young women should receive holistic care, with care taken to enquire about social circumstances, emotional and financial support at home/work/school, and GBV.

- Pregnant adolescents of unknown HIV status should be offered HCT, with linkages to prevention, treatment and care.

- For all adolescents and young women in the care of HIV services: a sexual history should be taken, effective contraception offered at each clinic visit, and pregnancy testing offered as appropriate.

- Adherence support should be offered to all pregnant adolescents receiving ART.

References

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8.3   Key populations

Adolescents are defined as a vulnerable population because they are particularly vulnerable to HIV infection in certain situations or contexts, i.e. they are not affected uniformly across all countries and epidemics. Key populations are defined as groups who, due to specific higher-risk behaviours, are at increased risk of HIV irrespective of the epidemic type or local context. Adolescents in key populations – those who are injecting drug users (IDU), sex workers, men who have sex with men (MSM), and members of the lesbian, gay, bisexual, transgender, intersex and questioning (LGBTIQ) community – therefore require special consideration in relation to adherence, as they are vulnerable on various levels.

It is well established that HIV prevalence is higher among key populations than in the general population due to engagement in higher-risk behaviours. Legal and social issues also render these key populations more vulnerable; e.g. discriminatory laws and policies, such as the criminalisation of sex work, drug use, sexual orientation or gender identity, contribute to low levels of access to health services. PLHIV from key populations face stigma, exclusion, harassment and violence on two fronts: because of their HIV status, and because they are from a key population. Despite the number of new HIV infections occurring in these populations, they

often have the least access to prevention, treatment and care. While key populations are important to the dynamics of transmission, they are also key partners in the response to the epidemic.[1]

In 2014, the World Health Organization (WHO) produced consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations.[2] To effect adequate HIV services to these groups, the guidelines advocate that:

- The human rights of members of key populations must be protected

- Everyone has the right to access quality healthcare, free from discrimination

- Access to justice is particularly important for people from key populations

- Interventions to reduce the burden of HIV among key populations must be respectful and acceptable to recipients as well as appropriate and affordable for them

- People from key populations require accurate health and treatment information to enable their decision-making.

Yet, healthcare professionals often feel ill equipped to work with key populations. Their values systems and a lack of population-specific knowledge can generate a sense of helplessness and overwhelm. Providing health services that are available, accessible and acceptable to adolescent key populations requires additional effort as recommended below.

Recommendations

- Capacitation of healthcare providers can improve treatment adherence and RIC:
  - Provide values clarification workshops to counteract stigma and discrimination that may deter young people from accessing health services
  - Provide in-service training on counselling and supporting adherence among key populations.

- Tailoring interventions to the developmental needs of adolescents while respecting their need for independence is particularly important for groups engaged in behaviour frequently sanctioned by society.

- Provide speciality clinics/service sites that are easily accessible to vulnerable groups, e.g. clinics within brothels.

- Provide outreach services to access populations within their communities.

- Appoint peer educators and treatment navigators to enhance acceptability of services.

- Be aware of the range of needs that adolescents from key populations face in addition to healthcare needs. Referral to other service providers to address these needs may indirectly support adherence by promoting self-efficacy.

- Develop interventions to enhance community involvement among key populations – peer support is particularly important to sustain adherence, e.g. adherence support groups.

- Monitor and report incidences of violence against adolescents from key populations, and provide access to justice in collaboration with peer-led advocacy groups.

- Promote school-based GBV-prevention services and education, ensuring the inclusion of educators and caregivers.

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9. Working with communities

9.1 Community-based structures/organisations

In helping AYLHIV increase their adherence to ART, working with community structures is one of the pillars to strengthen support. A multisectoral approach contributes to successes in working with communities to address health and social issues: community mobilisation, stakeholder responses and leadership are part of the mindset required to help youth obtain appropriate support.

Effective community work is not only about starting up and supporting community interventions; it is about providing technical and skills capacity development. The need to benefit adolescent patients needs to be a conscious goal for any community development strategy, and for CBOs to integrate youth-friendly services into their day-to-day operations.

This section explores some of the important community structures that are well placed to assist in providing support to youth.

Understanding community structures

Structures vary in every community, but there are core services provided by a range of stakeholders. Some of these more formal stakeholders are the district and ward structures, and municipal and social sector structures (schools, clinics, hospitals and social services). Many of these stakeholders have been active in the community for some time, are manned by people known to or living in the community, and provide a valuable range of helpful services to families. Some of their activities may not be related or linked directly to ART, but considering the manner in which many things connect and intersect, they contribute to providing a broader support structure and extend valuable services from treatment facilities into the community.

CBOs are a key community structure, with many funded by donors or government departments to provide specific services focusing on specific indicators or targets (Table 22). Community outreach partnerships should be mindful of these influences and commitments.

People heading up small CBOs have an eclectic range of skills: some have achieved the qualification of child and youth care worker or have completed the accredited course to qualify as social auxiliary workers, some are volunteers, some are peer educators, and some are part of the Expanded Public Works Programme. Many have minimal formal qualifications – some have matric, some have challenges with numeracy and literacy skills – and some have developed skills (e.g. social workers). Working with so many varied levels of skills requires interventions to be tailored accordingly.

Table 22: CBOs – roles and examples of community services	
Examples of key CBO services	• Education: drop-in service for homework support; services linked to the local schools; and assistance accessing tertiary institutions • Basic services: assistance with identity documents, birth certificates and access to grants • Social support: distribution of food parcels; child protection; prevention of GBV • Healthcare: motivation for HCT and health screening; home-based care and community caregivers; antenatal care; assistance with TB, HIV and STIs. • Prevention strategies: implementation of comprehensive, evidence-based prevention strategies; encouraging responsible sexual behaviour (including condom use) • HIV education and support: Evidence- and skills-based, youth-specific HIV education and structured, time-limited, educationally sound support groups that are often evidence-based interventions.
Roles that CBOs are well situated to play with regard to ART	• Develop organisational skills in ART and general support of communities in ART care • Plan and implement follow-up and tracking of ART patients through regular home visits and clinic support • Manage and supervise CHWs • Strengthen linkages between the clinic and community structures • Train community healthcare workers to understand ART and adherence • Advocate for ART services, reduce stigma and promote basic human rights • Develop understandable information for healthcare workers to share with community members • Arrange community meetings to promote health services, including ART • Increase community support for patients receiving ART and those affected by HIV • Provide patient-centred treatment, support and home-based care • Provide access to counselling and services for patients receiving ARTs and their families • Monitor and ensure that referral systems are working • Create, manage, maintain or strengthen partnerships • Prepare partnership plans, and develop strategies and schedules • Monitor and review progress; align to stakeholder reporting systems.

ART – antiretroviral therapy; CHWs – community health workers; GBV – gender-based violence; HCT – HIV counselling and testing; STIs – sexually transmitted infections; TB – tuberculosis.

There are two main strategies recommended at community level:

• Providing structured psychosocial support groups encompassing prevention education and SRH
• Providing direct support to youth on ART with referral links to clinical services.

Historically there is some ambivalence between the community and clinical services, specifically with adolescents accessing services at the clinic.

Community-based structures sometimes struggle to help community members access the right care at clinics; there are often long queues and a lack of AYFS. Clinic structures often do not understand the way that the CBO and community-based interventions work, nor is there clarity on how best to foster the relationship to benefit the community, especially adolescent patients. In some areas, these relationships are well organised and structured, and in others, development and structure is still needed. Addressing core barriers by integrating the support proposed at the clinic as a partnership with community-based support will go a long way to strengthening the relationship between clinical and community-based healthcare.

Healthcare providers need to recognise the important role that community systems can play (Table 22). Once the clinic understands the community-based services in their area, and *vice versa*, a strategy can be developed that considers the unique characteristics of each community.

The importance of partnerships

Partnerships (Table 23) play a fundamental role in achieving some semblance of synergy between different parts of any community. Partnerships are often difficult to maintain without understanding how they work and benefit each partner. They need to be based on mutually agreed key roles and responsibilities, as well as protocols for communication, reporting and problem-solving. Partnerships are best structured when the partners begin collaboration from the start of a project; although when activities are based on enhancing adolescent healthcare at community level, partnerships are beneficial at any point.

Patient mapping and referrals

For most adolescents receiving ART, visits to the clinic are quarterly or sometimes monthly. In between these times, adolescents should have access to community-based support. The extensive variety of support activities from local stakeholder groups provides a stabilising influence for youth, especially when they are struggling with adherence and other challenges.

Some community and adolescent patient mapping will be necessary to enable community structures to identify youth closest to the relevant clinic and other services (Table 24). Some youth may be referred to community services from the local or regional hospital services. These referrals will need to be linked to community structures and the necessary referral systems need to be established to address this level of referral.

Table 23: Partnerships – definition, benefits, fundamental considerations and approach	
Working definition	Voluntary and collaborative relationships between various parties, both governmental and non-governmental, in which all participants agree to work together to achieve a common purpose or undertake a specific task and to share risks, responsibilities, resources, competencies and benefits.
Basic benefits	Access to people and places; new and good ideas; a helping hand; knowledge and skills; practical support; influences; and funding (sometimes).
Fundamental considerations for partnerships to operate optimally	• Partnerships are valuable in contributing to strengthening ART adherence in communities through strategies that develop the capacity of CBOs and community. • Using and strengthening existing partnerships is a key strategy to benefit community and clinic services. • Maintaining partnerships requires time and effort with clear roles and ongoing communication. • For CBOs, clear and simple communication strategies work best. • It is important to develop a simple MOU and written contracts to clarify roles and to keep to the brief of each partner's roles and responsibilities. • It is important to keep notes and document important decisions and agreements during meetings to maintain working partnerships.
Approach to establishing an integrated and effective community outreach strategy	1. Establish a co-ordinating body. 2. Establish the systems to deliver integrated treatment services. Co-ordinate joint planning to improve adherence. 3. Track and support patients receiving ART. 4. Intensify the search for ART-non-compliance patients for referral. 5. Intensify support to non-compliance patients once ART is restarted. 6. Monitor and evaluate the partnership.

Table 24: Guidance in linking youth to the closest community services
• Meeting of stakeholders (clinicians, clinic manager, nurses, CBO) to establish basic understanding of services and protocols
• Establish clear roles and responsibilities to clarify the disaggregation of work
• Mapping the adolescent patients to the CBO
• Working with the CBO to understand the roles and work they support
• Linking the youth to a CBO, working with the family and caregiver or child-headed household
• Setting up some basic training for the CBO to understand ART – this needs to consider low-literacy skills, basic checklists and reporting
• Establish and manage clear lines of communication
• Regular meetings and recording of progress.

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10. Stigma

10.1 HIV-related stigma and ART adherence in adolescents

The Human Sciences Research Council (HSRC) conducted a study in 2014 to explore how information on stigma and discrimination could be used to strengthen programmes and service delivery, and to measure levels of TB-related stigma experienced by PLHIV in South Africa. According to the resulting stigma index, stigma and discrimination towards PLHIV are widely recognised as barriers to prevention, the provision of adequate healthcare, adequate psychological and social support, and appropriate medical treatments in South Africa.[1]

Overall 36% of the study's respondents experienced some degree of **external stigma**, with respondents in the youngest age group (15 - 24 years) identified as a category experiencing such stigma to a considerable degree. It is evident that young people are vulnerable to stigma, and this requires urgent intervention. The report also noted persistent levels of **internal stigma**, highlighting the need to build confidence and esteem among PLHIV, and to offer support, skills and opportunities to address this.[1]

What is stigma?

Stigma refers to the process of devaluing or discrediting individuals in the eyes of others. Different types of stigma have been identified (Table 25).

Stigma develops over time in communities and does not occur in a vacuum. The process may occur as follows: differences (such as HIV status) are noted and labelled; these differences are assigned a negative attribute; a distinction is made between 'us' who do not have this negative attribute and 'them' who do; the person with the negative attribute is seen as having a lower status; and finally, this person is discriminated against. So stigma is socially created – this is a process shaped by individuals, institutions and the media over time. Stigma cannot be understood without considering the following factors: poverty, GBV, social inequality, local norms and attitudes.

Discrimination follows stigma, and is the unfair and unjust treatment of an individual based on their real or perceived HIV status. Stigma has a profound impact on individuals, communities and society: it results in a range of excluding behaviours towards people thought to be HIV-positive; it isolates, divides and breaks down communities; it undermines human rights; and it results in the internalisation of blame and shame.

Table 25: Types of stigma	
Type	**Description**

External stigma	• Apportioned by others to PLHIV; displayed through attitudes or actions aimed at PLHIV including insults, rejection, avoidance, intolerance, stereotyping, discrimination and physical violence.
	• Serves various psychological and social functions:
	  - At a psychological level, it enables people to distance themselves from those seen to be 'dangerous' or 'infectious' and falsely to deny their risk of infection, as a form of self- or community protection. This is a partial explanation for the obstinacy of stigma and why simply making testing and treatment available does not automatically eliminate it.
	  - At a social level, it tries to control human behaviour by excluding those who are seen as morally undesirable; it allows society to punish those who it believes could have avoided HIV infection; and it helps people to have power over PLHIV and keep resources for themselves.

Internal/ internalised stigma	• Occurs when PLHIV begin to believe negative things that those around them say or think. It can also be seen as thoughts and behaviours resulting from the person's own negative thoughts about themselves based on their HIV status. In addition, internal stigma can exist even if the person has not experienced actual acts of discrimination. This links to the idea of **anticipated stigma.** • An association between internal stigma and failure to disclose HIV status suggests that the internalisation of shame and blame, and beliefs in a 'spoiled' identity, and the resultant impact on disclosure, serve to protect PLHIV from further emotional harm.[2]
Anticipated stigma	• The anticipation or expectation that one will be treated differently or poorly because of the stigmatised identity of PLHIV as a group.
'Courtesy' stigma	• The stigmatisation a person perceives or experiences due to their association with a stigmatised individual or group.
'Super-stigmatisation'	• HIV-related stigma often happens together with other forms of social stigmatisation as a result of race-, gender- and class-based inequalities, engaging in sex work, having non-normative gender identities or sexualities, religious persecution, xenophobia, drug use, mental and/or physical disability, disease and so forth. This increases both the exclusion and devaluation of PLHIV, leading to double or multiple stigma.
PLHIV – people living with HIV.	

Stigma is not unique to HIV and has been seen in history in relation to other diseases such as syphilis and leprosy. There is no one explanation for stigma; rather, a number of different strands come together to explain why HIV is stigmatised:

- HIV can be fatal and thus causes fear.

- HIV was often associated with stigmatised behaviours such as sex work, drug use and homosexuality.

- HIV infection is seen as the result of choices made by an individual, so they are perceived as being to blame for being HIV-positive.

- It is believed that PLHIV have broken society's moral codes and they must be punished for their 'deviant' behaviour.

- In some communities, PLHIV are seen as a drain on limited resources.

Testing, disclosure, prevention, and care and support for PLHIV are widely promoted, but are challenged by stigma. Preventive methods such as condom use or discussing safer sex may be considered indications of HIV infection or immoral behaviours and are thus stigmatised. Available care and support may be accompanied by judgmental attitudes and isolating behaviour, which can result in PLHIV delaying care until absolutely necessary.

PLHIV and their families develop various strategies to cope with stigma. Decisions regarding disclosure depend on whether it would assist with coping strategy (by enabling access to care) or render the situation worse (through added stigma). Some cope by participating in networks of PLHIV, actively working in the field of HIV or confronting stigma in their communities. Others look for alternative explanations for HIV besides sexual transmission and seek comfort, often turning to religion or other beliefs.

Stigma mitigation

Stigma mitigation is complex. Perhaps the solution is to think of stigma work as occurring at multiple levels: at the level of person-to-person interactions; at the level of social processes; and at the structural level of policies and laws.

One recent example of a community intervention[3] was the South African National AIDS Council (SANAC)-supported process in three municipalities in the Eastern Cape (King Sabatha Dalindyebo, Nyandeni and Ingquza Hill). The process started with participatory workshops, where ideas about stigma approaches were discussed and communication resources to support these were developed. These included a logo and slogan to promote community mobilisation, and the training of community mobilisers.

Emphasis was placed on identifying cases of stigma and discrimination in focal communities, engaging via the following entry points: support groups, clinics, churches, families, taverns, taxi ranks and meetings with community members. A common format identified was institutionalised stigma and discrimination prominent in the systems and practices for managing HIV-positive patients, as well as practices in churches and community events. Local leaders – in particular, Chiefs and Headmen – and other stakeholders were engaged to share information about the initiative and to obtain support. Activities were reinforced by communication via folk media including songs and slogans, with mobilisers wearing branded caps and T-shirts and distributing stickers. Mobilisers addressed stigma and discrimination on a case-by-case basis and documented their experiences towards resolution.[3]

Addressing HIV stigma and ART adherence in adolescents

Cluver *et al.*[5,6] concede that stigma mitigation in adolescents is complex, but insist that this should be located in community interventions, including information provision, counselling, group desensitisation towards HIV, and contact with PLHIV. This latter aspect (contact with PLHIV) is complex: in order for adolescents to cope with their internalised stigma and given the real possibility of harm if they disclose to promote 'contact', they are taking a significant risk.

Building on available research, experience and literature, a suggested approach to address HIV stigma in adolescents is provided in Table 26.

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Table 26: Guidance for addressing HIV stigma and adolescent ART adherence*

Level	Guidance
Individual level	• One-on-one counselling, buttressed by group interventions with other AYLHIV, is essential to offer clear information, emotional support, adherence strategies and a focus on stigma. The emphasis on clear information is important because it offers AYLHIV opportunities to rebut myths and misconceptions that often underpin stigma, and to build their confidence in being able to understand and explain this information. Explicit mention of stigma is important to acknowledge that it is real and to make it possible for it to be spoken about and addressed. • Individual or group counselling on stigma should offer: • Information on what stigma is, focussing on external and internal stigma: origins, meanings, manifestations, consequences, and strategies to address both. • AYLHIV encouragement to speak out when they have experienced external stigma – whether at school, at home, in the community, or in a health setting. Examples of what external stigma looks like, need to be clearly described so that they are not overlooked. • Opportunities to process negative feelings AYLHIV may have internalised about being HIV-positive, and to develop a more positive self-attitude. Strategies to build self-esteem, and to deal with commonplace adolescent identity challenges, should be built into these strategies. • Opportunities to talk about sex, sexuality and gender, in a positive and affirming way, not only to normalise sexual changes, desires and practices, but to affirm the right of young people to explore their sexuality safely. Open talk regarding sexual activity and readiness, access to contraception, EC and pregnancy management (and PEP for partners) should be part of a comprehensive package of adolescent services. Acknowledging that adolescents exhibit sexuality that at some point may be acted upon is a key stigma-mitigation strategy. • Dissemination of existing and emerging information (on HIV stigma, but also on sexual health and HIV transmission) can occur via materials available in clinic waiting areas, as well as via the internet or social media platforms accessed by AYLHIV. These materials (multimedia, videos, brochures, youth-oriented smart phone apps and helplines) could also be used in one-on-one sessions or support groups. • Multimedia and video materials which tell the stories of other AYLHIV are a critical aspect of stigma mitigation, as they present positive role models who present messages of coping and hope, but do not gloss over the challenges of living with HIV.

Interpersonal level	• Creating opportunities for AYLHIV to engage with each other, either in person or through technology, is important: it offers a chance to hear other views and experiences, to work out ways to talk about HIV and ART that are successful in addressing stigma, and to deal with feelings of isolation and awkwardness. Both support group and peer-to-peer formats can be beneficial. Feelings of solidarity and the idea that collective agency can be built, are critical to addressing internal stigma.
	
	• Develop information sessions and counselling support for guardians of AYLHIV, to increase their knowledge and help them to talk to their children about issues around HIV, disclosure and SRH.
	
	  - AYLHIV and their caregivers, counsellors and health providers should be equipped with skills to address HIV disclosure, These can assist with stigma mitigation by addressing isolation and loneliness (noting that there is always risk in disclosure).
	
	  - AYLHIV must know their HIV status as a starting point.
	
	  - AYLHIV should be consulted about whether, why, when and how a disclosure should happen.
	
	  - Assistance with actual disclosure should be offered, and post-disclosure follow-up support provided.
	
	  - Regarding disclosure to a romantic or sexual partner: support should be offered to the partner; fears and anxieties allayed about HIV transmission; and transmission-prevention strategies offered.
	
	• Caregivers and health providers can be assisted to recognise negative self-talk and symptoms of depression, fatalism or suicidality in AYLHIV, and to report these to a mental health professional for appropriate intervention (counselling or medication).
	
	• Caregivers and health providers should be given information to recognise and address HIV stigma. Interventions in a community or school setting should be available to relevant adults: mediation, community meetings, and group sessions. These should include mention of what stigma is, the harms it causes and why it needs to be addressed.

Institutional level	• Thought should be given to the way institutional spaces and procedures are organised to offer privacy to AYLHIV: waiting times, waiting spaces, who knows the patient's status, and how documents are stored and marked. • Should adherence clubs for adolescents be established in the facility, these need to be appropriately discreet so that AYLHIV are not unfairly marked as HIV-positive to other patients. If these are set up in the community, those organising the clubs should be supported to run them and manage privacy and unintended disclosures. • Counsellors, support group leaders and where possible, caregivers, should be able to discuss sex, sexuality and gender in a neutral way with adolescents, utilising multimedia materials where necessary. A sex-positive approach is a stigma-mitigation strategy. • Teachers should be mentored to address stigma in the school system: They should integrate stigma in existing life-orientation curricula and be supported to implement HIV stigma-reduction in the school. This would increase knowledge around HIV and sexual health and ensure that teachers are confident to discuss HIV and stigma, foster non-judgmental attitudes and create a supportive classroom environment for AYLHIV.

AYLHIV – adolescents and youth living with HIV; EC – emergency contraception; PEP – post-exposure prophylaxis.

*See also: lessons learned from a study on adolescent girls living with HIV in urban Zambia.[7]

11. Transition overview

11.1 Transitioning from paediatric, to adolescent, to adult healthcare

The HIV-positive adolescent population comprises a mixed group of: (i) perinatally infected adolescents, who are now surviving into adulthood; and (ii) adolescents infected later in life, most of who were infected through unprotected sexual activity. Despite sharing common characteristics, these two populations are quite distinct with respect to their needs and challenges.

Transition is the **purposeful, planned** movement of children with special healthcare needs from child- to adult-centred healthcare (Fig. 3).

Figure 3: Transition from paediatric, to adolescent- and youth-friendly, to adult healthcare.[1]

General principles for effective transitioning addressed in these guidelines:[2]

- Individualise the approach used.

- Identify adult care providers who are willing to care for adolescents and young adults.

- Begin the transition process early and ensure communication between the paediatric, adolescent and adult care providers prior to and during transition.

- Include the primary caregiver in the transition plan, as they too have to adapt to the process of the adolescent taking charge of their own health management.

- Develop and follow individualised transition plans for the patient in the paediatric, adolescent and adult clinics. Plans should be flexible to meet the adolescent's evolving needs.

- Use a multidisciplinary transition team, which may include peers who are in the process of transitioning or have transitioned successfully.

- Address comprehensive care needs as part of the transition, including medical, psychosocial and financial aspects.

- Allow adolescents to express their opinions.

- Educate HIV care teams and staff about transitioning and about the specific needs of AYLHIV.

Common barriers to transition

Common barriers have been identified regarding transitioning adolescents with chronic diseases into adult care.[3,4] Many young patients experience worry and anxiety about transitioning and have a difficult time adjusting to the increased responsibility and expectations in an adult care setting.[5,6] Moreover, issues specific to AYLHIV may make the transition more difficult for this population than for adolescents with other chronic illnesses.[7]

The loss of stable and long-term relationships formed with their paediatric or adolescent healthcare team is likely to be a particular challenge for AYLHIV,[8] who may have lost family members and therefore regard care providers as their primary support system. Abrupt transition to an adult care setting without preparation may result in the patient withdrawing from medical care altogether owing to feelings of abandonment, which may further exacerbate perceptions of overall loss.[2]

The adolescent and youth age group refers to people between the ages of 10 and 24 years. In most settings, transitioning from paediatric to adolescent or adult care is expected around 10 - 12 years of age, with the exact timing of this transition varying from adolescent to adolescent. At this point, full disclosure of the child's condition should have occurred (prior to transition). In the same way, transitioning to adult care from adolescent and youth care can happen from the age of 18 years onwards (in settings where AYFS are provided), when the individual can begin to take advantage of decentralised adherence strategies, such as adherence clubs and the Central Chronic Medicine Dispensing and Distribution (CMDD) programme. This second transition should occur at a point at which the patient is ready (emotionally, mentally and physically) to transition to adult services, meaning that some patients may continue within AYFS past age 18 years. Readiness to transition can be evaluated using the sample tools and checklists in the resources listed at the end of this section.

Table 27 lists common challenges in transitioning AYLHIV, specific to both perinatally and behaviourally infected adolescents.[9-11]

Models of transition

Several models of transition are used within adolescent HIV care (Table 28). The model chosen should be determined by the patient group, available resources, clinical health mangers, health setting (systems, protocols and guidelines) and geographical setting. It is thought that there is no superior transition model and that the key to a successful transition is a flexible approach paced to the individual needs of the adolescent.[12]

Table 27: Challenges to successful transitioning of adolescents and young adults living with HIV[2]	
HIV-specific challenges (applicable to both perinatally infected adolescents and those infected later in life)	• Stigma of HIV infection, and for many AYLHIV, the additional stigma of LGBTIQ, substance use, teenage mothers • Increased need for mental health, substance use and psychosocial services in the HIV-positive population and the complexity of transitioning such services simultaneously • Lack of HIV-specific, youth-friendly antenatal services • Difficulty of disclosure to partners or others in their lives • For many AYLHIV, experience of multiple losses • Limited social support • Inability to identify with older patients in the adult clinic • Fear of illness progression and mortality • Lack of HIV providers with expertise to treat and care for this population
Challenges specific to perinatally infected adolescents	• Non-disclosure by caregiver – some patients may not have been told that they are HIV-positive • Loss of emotional support and sense of belonging – many have been lifelong patients in one clinical setting; transitioning may mirror earlier losses and bereavement experiences • Obstacles in achieving milestones – cognitive delay, excessive absence from school, lack of role models, perceptions that HIV could prevent them from living to adulthood or living a full, active and 'normal' life, physical stigma such as short stature, lipodystrophy, encephalopathy • Additional clinical issues related to lifelong HIV and ART exposure.
Challenges specific to adolescents infected later in life	• Difficulty disclosing to primary caregiver – one study found that one-third of youth do not disclose their HIV status to their maternal figure • Additional stigma of marginalised populations – LGBTIQ, substance users, teenage mothers • RIC after testing and diagnosis • Treatment literacy – no prior exposure to ARVs or treatment regimens • Psychological trauma related to acquiring HIV (e.g. history of sexual violence) • Limited time within AYFS for those acquiring HIV close to age 18 years.

ART – antiretroviral therapy; ARVs – antiretrovirals; AYLHIV – adolescents and youth living with HIV; LGBTIQ – lesbian, gay, bisexual, transgender, intersex or questioning; RIC – retention in care.

Table 28: Models of healthcare transition	
Model	Description
1: PHC – integration	In settings where HIV-positive adolescents are cared for by CHC or PHC centres, the transition to adult care can occur in an integrated manner. Care and treatment continue within the familiar setting, allowing the young person to take responsibility for their own health in stages, e.g. start to have consultations with the care teams on their own. The time period for this transition depends on each young person and their readiness to take on each new responsibility.
2: Specialist services – handing over	Transfer from paediatric directly to adult services is possible with a carefully planned and comprehensive transition programme. This can only work when both paediatric and adult providers fully understand the transition process and work together productively. This model may therefore be better suited to smaller centres and where transition from hospital- to PHC- or CHC-based care occurs. The adolescent should be involved comprehensively throughout the process.
3: Specialist services – separate youth clinic	Creating a separate, tailor-made 'youth clinic' allows AYLHIV to 'shape' the service and take responsibility for their own HIV-related needs, and provides the opportunity to interact with other AYLHIV. However, one challenge is the requirement for further transition into adult services in future. This model is also more resource-intensive and should be considered carefully before being adopted.

AYLHIV – adolescents and young adults living with HIV; CHC – community healthcare; PHC – primary healthcare.

Table 29: Prerequisites for a smooth transition

Prerequisite	Description
Preparation	Adequate preparation of the adolescent and primary caregiver (if applicable) for transition to the next level of service provision, whether AYFS or adult health services.
Disclosure	Refer to the section on disclosure below and Table 30. Child/adolescent disclosure should been completed before transition; if not, as soon as possible to avoid accidental disclosure when the adolescent is interacting with peers or health providers.
Training	Training of healthcare workers (professional, lay and support staff) to exhibit appropriate behaviour and attitudes in providing healthcare to adolescents and youth, in paediatric and AYFS.
Psychosocial support	Imperative for both child and primary caregiver, as the child must take charge of their own healthcare planning for transition. This may leave the primary caregiver feeling left out, and they may not understand the support required for the adolescent of take charge of their healthcare.
Individual transition plan	Should be developed and reviewed throughout the preparation for transition to the next level of healthcare. Although the general principles of transparency, support and multidisciplinary team approach apply, cognizance of individualisation is important for successful transition.
Multidisciplinary approach	If possible, the same team who have been working with the adolescent during the disclosure phase should facilitate the transition to AYFS. With older adolescents, it is advisable to have at least one member of the AYFS working to support the transition to adult health services.
Freedom of expression	Creation of a platform/space in which the adolescent can freely express themselves and communicate their concerns about their new environment, ongoing life changes and participate in decisions about their healthcare.
Familiarisation visits	Visits to the 'new' areas should happen before transition, to allow familiarisation with the environment and new team. Linking the adolescent to a peer who has successfully transitioned is of great value.
Age-appropriate services	It is important to provide age-appropriate healthcare services in line with the comprehensive healthcare package for young people. Health education should be provided on HIV, hygiene, development and changes during puberty, nutrition and SRH, together with resources such as contraceptives.
Referral linkages and support	The patient and primary caregiver (where appropriate) should be given information on how to access appropriate referral linkages and support systems in the different levels of care.
AYFS – adolescent- and youth-friendly services; SRH – sexual and reproductive health.	

PRACTICAL APPROACHES FOR TRANSITION

Communication at all stages of the process
- Start discussions about transition early.
- Engage parents and caregivers to support the adolescent in the transition process.
- Explain the transition process and its importance to the parent or caregiver and adolescent.
- Support the adolescent to develop a transition timeline.
- Ensure that an adolescent knows their HIV status before change of services – gradually explaining and progressively responding to their questions and concerns.

Transition is based on rights, readiness and responsibility
- The pace and timing of the transition process should be set by the adolescent and encouraged and supported by health provider and parent/caregiver.
- Discuss the importance of the adolescent developing independence and self-management with both the adolescent and with parent/caregiver.
- Ensure the adolescent has a good understanding of HIV, what the diagnosis means, importance of adherence, and how to stay healthy.
- Assist the adolescent to identify barriers (real or perceived) to the transition process and explore potential strategies to overcome barriers.
- Continually assess the readiness (emotional state, maturity) and willingness of the adolescent to assume responsibility for taking medication, making appointments, and actively engaging with health providers and services.

Close collaboration and communication between clinical settings
- Confirm that the adolescent can be accommodated by the receiving clinic (where possible).
- Arrange for the adolescent to visit the new receiving clinic, potentially through engagement with peer support groups, before transitioning.
- Arrange for transfer of patient records, including medical and psychological history as well as social background.
- Facilitate information sharing regarding particular challenges or needs of the adolescent, to ensure continuity of care.
- Inform the adolescent of available services at the receiving clinic, making introductions to health providers and peer support workers (where appropriate).
- A multidisciplinary approach to transition provides comprehensive support and may include health, psychological and social services.

Figure 4: Practical approaches for transitioning (source: WHO).[13]

Transition should be a gradual process of preparing and supporting adolescents to shift from dependence on caregivers to self-management and autonomy, and into more developmentally and medically appropriate care, always respecting their rights. Carefully planned transition recognises the evolving developmental, medical, emotional, educational and social needs of AYLHIV – which may vary according to the timing and mode of infection.[13]

Fig. 4 outlines practical approaches for transition recommended by the WHO.

Key point

All healthcare providers, regardless of specialty or location, should be skilled to manage the unique health needs of adolescents and young people.

Prerequisites for a smooth transition

These are summarised in Table 29.

Full disclosure of health status to the child

Age-appropriate disclosure should occur at the stages summarised in Table 30. It is important that the primary caregiver is part of the disclosure process. If the primary caregiver is not confident to disclose, then the attending health professional can support the primary caregiver after providing health education and counselling about the importance of disclosure for treatment adherence and RIC.

Support should be provided for disclosure to siblings and/or family members who live in the same household as the adolescent or young person. The disclosure process should also include an explanation of the roles of each of the team members.

Table 30: Age-appropriate disclosure	
Age	**Disclosure**
0 - 3 years	No disclosure
4 - 9 years	Partial disclosure
10 - 12 years	Full disclosure, depending on readiness
>12 years	If full disclosure has not been done and the adolescent has already begun to access AYFS, then this should be done at the earliest time possible.

Resources

- This section was adapted from Pathfinder's draft *Guidelines for Transition of Children, Adolescents and Young People in HIV Clinical Care and Treatment.*
- National Department of Health (NDoH). Disclosure Guidelines for Children and Adolescents in the Context of HIV, TB and Non-Communicable Diseases. Pretoria, South Africa: NDoH, 2016.

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12. Training considerations

12.1 Training in the management of adolescent adherence and retention in HIV care

Nurses demonstrate a multifaceted understanding[1] of matters related to adherence to long-term treatment; their knowledge, values and attitudes directly affect adherence. Nurses are often the first point of reference for the adolescent patient and other healthcare staff who provide services along the healthcare continuum. The minimum training considerations for nurses in the management of ART adherence in adolescents and retention in HIV care are briefly described below. Note that these descriptions are not limited to adolescent adherence to ART, and can be applied more broadly.

Clinical skills

- Basic nursing care including physical examination of patients (General Nursing, Midwifery, Community and Psychiatry)

- HIV Management – nurse-initiated management of antiretroviral therapy (NIMART)

- Integrated Management of Childhood Illnesses (IMCI) (optional/recommended)

- Contraceptive and fertility planning knowledge and application to adolescents

- Basic HIV counselling

- Dispensing of medicines.

Policy, guidelines and standard operating procedures

- Updated knowledge on country-specific policies, guidelines and standard operating procedures related to HIV linkage to care, treatment and care (mental health and psychosocial care included)

- An understanding of HIV, TB and NCDs medication and the mechanism of action and interaction

- Training/orientation in adherence and disclosure guidelines (AGL) and child and adolescent disclosure guidelines

- Relevant policies, guidelines and tool kits should be available for easy access and referral at implementation level.

Values clarification

- HCWs should have a clear understanding of the impact of values, culture, beliefs and societal norms on healthcare.

- Values clarification sessions provide an opportunity for HCWs to recognise situations where their own values are not in line with that of a patient, and how these may influence their attitudes and health service provision.

- Open and frank discussion about personal values and their impact should be done in a safe and confidential environment; HCWs should be reassured of their confidentiality and that their own values need not be changed. Rather, values clarification affords the opportunity to recognise that differences in values should not result in judgmental service provision.

- Care should be taken to ensure that group discussions on differing values do not negatively influence the teamwork that exists among facility members.

- Ultimately, HCWs need to resolve to balance their personal values with their professional responsibilities and their commitment to providing essential health services.

Knowledge and understanding of developmental stages of the adolescent

- HCWs providing services to AYLHIV should have a clear understanding of the psychological, physiological, cognitive and behavioural changes associated with the stages of adolescent development.[2]

Skills required when working with adolescents in healthcare

- Ability to administer adolescent counselling in relation to developmental stages

- Ability to tailor counselling approaches and content to different ages/stages and needs

- Employ a non-judgmental approach when engaging with adolescents; with particular emphasis on assumptions around risk behaviours/key populations and sexual coercion

- Ability to communicate with an adolescent and be an active listener

- Ability to perform a psychosocial assessment and identify when an adolescent has to be referred for specialist, ongoing and additional treatment services

- Ability to perform sexual-risk screening in a non-judgmental and safe manner that is not offensive to the young person

- Have a deep understanding of the adolescent and youth disclosure process and the psychosocial support required on a continuous basis

- Ability to identify the need for referral and be able to work with the multi- and interdisciplinary team.

Knowledge on positive living with HIV

- Ability to identify and remove all barriers that may contribute to non-adherence

- Ability to engage adolescents in support groups/ interventions that build self-esteem, knowledge and skills to manage HIV, ART, disclosure and aspects of their SRH.

Knowledge on the barriers that affect adherence

- Please refer to Sections 2.6 and 6.1.

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13. Adherence tools

13.1 Using technology to promote treatment adherence

Mobile technology and SMS reminders

Mobile phone penetration in South Africa is among the highest on the continent.[1] Over 70% of adolescents in lower socio-economic groups in the country have access to a mobile phone, and four out of five South African adolescents use mobile phones to access the internet, especially social media platforms.[2]

The development of interactive and economically viable adherence support options in the form of mobile technology using text messaging or short message service (SMS) interventions for supporting medication adherence among those living with chronic disease is promising. The WHO advises that mobile phone technology may be a convenient reminder mechanism to engage PLHIV in care.[1]

There have been ten RCTs examining the role of technology to improve ART adherence among adults in resource-limited settings. These studies used a variety of outcome measures to gauge adherence, and a number of the studies used electronic monitoring devices, such as MEMScap or Wisepill, in conjunction with SMS reminders. Six of these studies showed adherence benefit, with two showing biological benefit; i.e. an increase in viral suppression or CD4 count.[2-7] However, four showed no adherence or biological benefit.[8-11] Overall, a review of the literature of SMS interventions on health behaviour change identified that interactive messages, i.e. bidirectional messaging, and tailored messages can facilitate improved disease management.

Data on the use of mobile technology to support adolescent ART adherence are limited, particularly in resource-limited settings. A study from the U.S. examining the use of personalised daily text messages to promote adherence and retention among 25 AYLHIV (age 14 - 29 years) who had primarily acquired HIV sexually, found an increase in self-reported adherence, with no significant difference in biomarkers.[12]

Although an SMS reminders system holds promise as a relatively low-intensity intervention with potential for positive impact on medication adherence among adolescents on ART, further research with larger samples, objective measures of adherence, with a focus on biomarkers is warranted, together with research on these methods in sub-Saharan Africa.

Gamification

Gamification is a broad term used to encompass the process of using gaming elements to motivate and engage people in non-game contexts. Gamification in healthcare is a strategy to encourage self- motivation with regard to health.[13,14]

Game-based mobile health applications ('apps') are believed to exploit the urge to compete and achieve, using virtual prizes and levels to motivate users towards positive health outcomes. Mobile health apps are becoming popular in game-accustomed age groups. They may be useful in motivating individuals who find it hard to adhere to treatment schedules, particularly those with chronic conditions. In paediatric and adolescent populations, game-based approaches to adherence are primarily aimed at diabetic and asthmatic groups. Although there is little to suggest that this approach has been explored in the sub-Saharan African context, the use of game-based rewards could be considered when examining strategies to encourage treatment adherence in young people.[14]

Apps

The possibilities for HIV intervention have been expanded greatly with the advent of phones with more advanced functionality. The widespread use of apps holds the promise of delivering interactive and tailored services. This remains to be explored in the context of adolescent ART adherence, but two mHealth mobi-sites (mobile websites), B-Wise[15] and iLoveLife[16], are being used to explore the use of technology in behaviour-change communications and adherence.

The South African Ministry of Health (NDoH) launched B-Wise in 2015,[15] a mobile platform for communication between youth and health professionals. B-Wise provides reliable health information designed for youth and receives user feedback through surveys on their health service needs. All feedback is shared with the NDoH to be considered in policy and implementation decisions.

B-Wise is accessible on a wide range of feature- and smartphones. The mHealth platform addresses several health topics including HIV-risk behaviours, as well as mental health, nutrition and GBV. B-Wise is used by clubs and adherence support groups to link patients to health experts, increasing their chances of seeking care.

In July 2015, LoveLife launched iLoveLife.mobi,[16] a mobile platform in South Africa that uses an incentive-based point system or gamification to create behaviour change and promote adherence. Users receive points for taking health quizzes. The points give users a chance to win airtime. Although the site has not been developed for adherence specifically, it could be utilised by adherence clubs.

References

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annexure

Annexure 1: Links to resources

Note: This is not a comprehensive list of all resources, but represents tools and resources utilised and referred to in these guidelines.

Title	Link
Caregiver Support Groups	https://tulane.box.com/s/v91fqs9hmzrk0kzroifb9423pbw60bkl
Zoe-Life. Kidz Alive Resources: Talk Tool, 2015	http://zoe-life.co.za/kidzalive/#resources
Meyersfield, S. Support Clubs. Johannesburg, South Africa: Right to Care, 2014	hayley.ronald@righttocare.org for more info
Right to Care. Flipster Support Club tool. Johannesburg, South Africa, 2015	0713723550 for more info
Right to Care. Mini Disclosure Flipster Tool. Johannesburg, South Africa, 2016	0713723550 for more info
Zoe-Life. Kidz Alive Resources: Talk Tool, 2015	http://zoe-life.co.za/kidzalive/#resources
Fick C, Fairlie L et al. Working with adolescents living with HIV: handbook and toolkit for healthcare providers, WRHI/Southern African HIV Clinicians Society 2015	http://www.wrhi.ac.za/resources
I ACT documents (nationally mandated so this is made available by the training partner in the specific province. In Gauteng that is HPCA)	B-wise (www.bwisehealth.com)
Differentiated care	http://www.differentiatedcare.org/Portals/0/adam/Content/yS6M- GKB5EWs_uTBHk1C1Q/File/Decision%20Framework%20REPRINT%20web.pdf
	http://www.who.int/hiv/pub/meetingreports/hiv-differentiated-service-delivery-report/en/
Department of Health. Adherence Guidelines for HIV, TB and NCDs. Pretoria, South Africa: DOH, 2016	http://www.hst.org.za/publications/adherence-guidelines-hiv-tb-and-ncds
National Mental Health Policy Framework and Strategic Plan 2018-2020	https://www.health-e.org.za/wp-content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf
Child and Adolescent Mental Health Policy Guidelines, 2013	http://www.gov.za/sites/www.gov.za/files/childmentalhealth_0.pdf