
Falling Through the Gap: Transitioning Adolescents with HIV from Paediatric to Adult Care in Rural South Africa

A Palliative Care Perspective

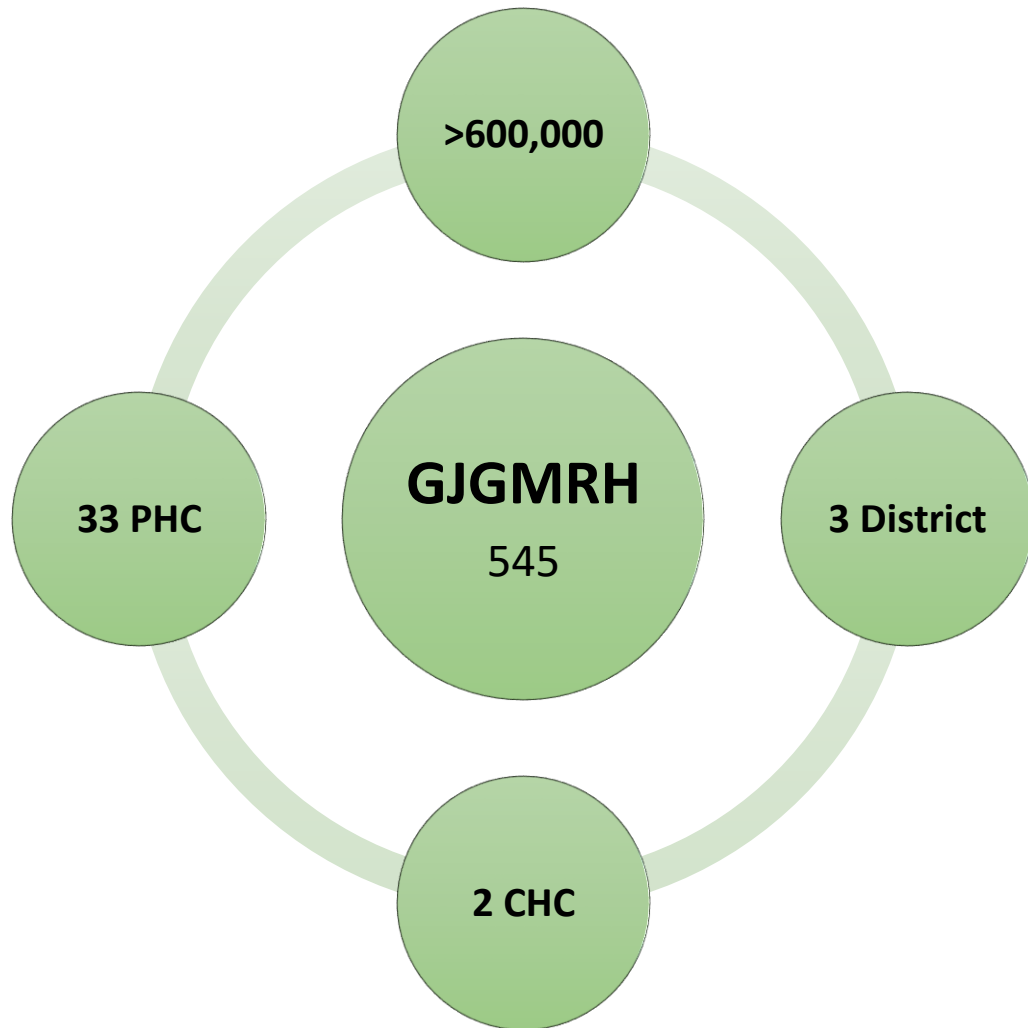


Dr Jivanesh Chetty

Senior Medical Officer

GJGMRH – HAST Unit

General Justice Gizenga Mpanza Regional Hospital





Services offered at General Justice Gizenga Mpanza Regional Hospital

Accident and emergency care

Ante-natal clinic

Arv clinic

Breast care clinic

CT Scan

Dermatology clinic

Diabetic clinic

Diagnostic imaging

Dental clinic

ECG services

Enchocardiography

Endocrine clinic

ENT clinic

General medical & surgical outpatients

HCT

Medical, surgical and paediatric inpatient care

Obstetrics and gynaecology

Occupational therapy

Operating theatre

Ophthalmology clinic

Orthopedic outpatient clinic

Paediatric asthma/cardiac & neurology clinic

Psychiatric Department

Physiotherapy

PMTCT

Psychology

Social Worker

Specialist medical clinic

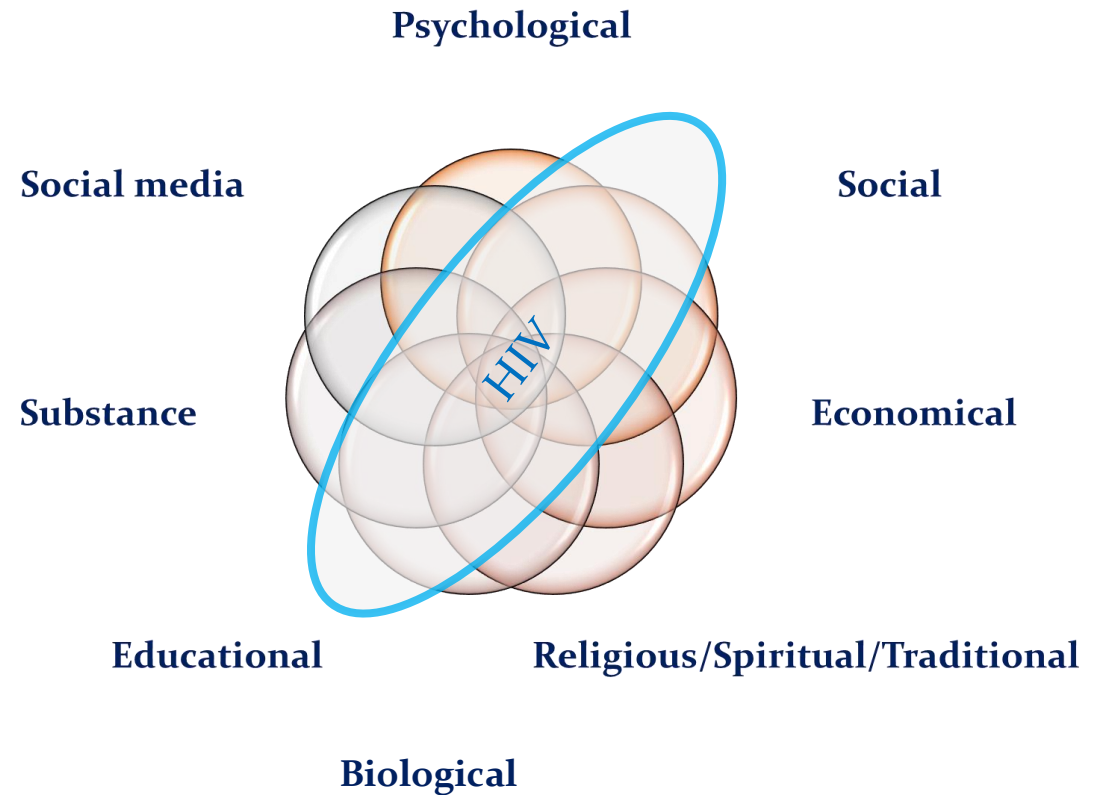
Speech and hearing & audiology services

Thutuzela care centre (crisis centre)

Urology

Adolescence

- Unstable and vulnerable period in an individual's life involving developmental changes that go beyond biological maturation.
- HIV adds layers of complexity to this transitional period that need to be proactively addressed in order to circumvent negative health outcomes.
- Managing the adolescent optimally requires the concerted efforts of several role players with an aligned agenda.



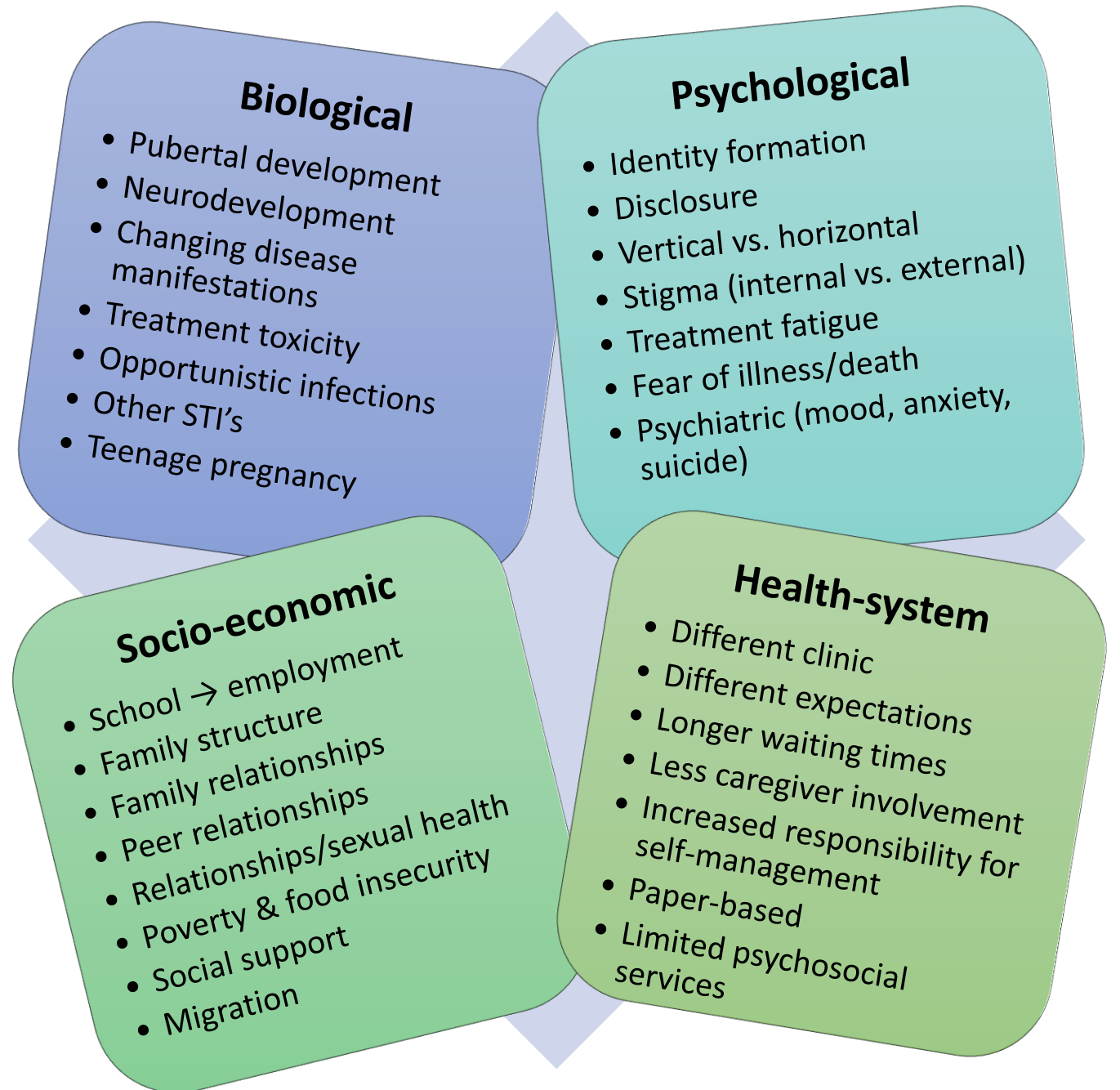
Biological Changes in Adolescence

Organ system	Key maturation
Reproductive/endocrine	HPG-axis activation → puberty, gonadal maturation and secondary sexual characteristics
Neurological	Continued brain maturation, particularly prefrontal cortex and its connections → executive function, impulse control and decision-making, risk assessment continue developing
Musculoskeletal	Rapid bone growth, increased bone mineralisation and muscle development; growth plates remain open
Cardiovascular	Heart size and cardiovascular capacity increase with body growth; changes in blood pressure and autonomic regulation occur
Respiratory	Lung growth and increasing airway dimensions; pulmonary function increases with body size and maturation
Immune	Immune function continues to mature, although much of the immune system is already functional in childhood
Renal	Kidney growth and maturation of renal function continue toward adult capacity
Hepatic/metabolic	Increasing metabolic capacity and changes in body composition and hormone metabolism
Skin	Increased sebaceous/sweat gland activity → acne, body odour and changes in skin/hair
Gastrointestinal	Growth of the GI tract and changing nutritional/metabolic requirements

Impact of HIV on the Developing Adolescent

Normal adolescent process	Impact of HIV
Growth spurt	Chronic HIV inflammation, recurrent infections and malnutrition can cause stunting, wasting and reduced height velocity.
Puberty	Perinatally acquired HIV is associated with delayed pubertal onset and delayed peak height velocity, particularly when HIV was advanced or ART was initiated late.
Bone development	Poor growth, delayed puberty, nutritional deficiencies and chronic HIV may impair bone mineralisation and peak bone mass acquisition.
Neurodevelopment	Long-standing HIV, particularly if inadequately controlled, can contribute to neurocognitive and developmental difficulties, affecting, intellect, learning, reasoning, decision-making, impulse control and self-management.
Energy/metabolism	Chronic infection increases metabolic demands; poor nutrition and treatment effects can further disrupt normal growth and body composition.
Overall maturation	HIV can create a mismatch between chronological age and biological/developmental maturity, which is highly relevant when deciding readiness for adult care.

HIV destabilizes adolescence further



The Impact of Perinatally acquired HIV



- Lifelong medication exposure
- Treatment fatigue
- Previous treatment failure
- Resistance
- Neurodevelopmental consequences
- Chronic comorbidities
- Repeated hospitalisation
- Complex disclosure histories
- Caregiver dependency
- Orphanhood or unstable caregiving
- Stigma & discrimination

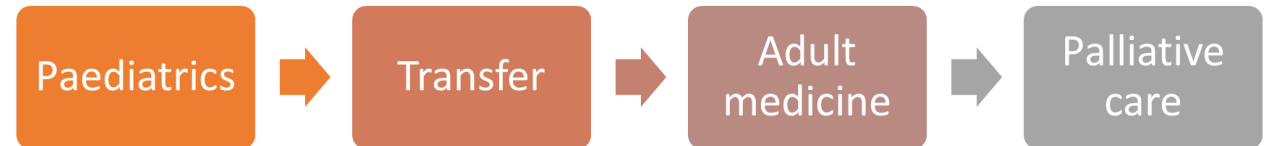
Transfer to Adult Medicine in SA

- Historically, SA HIV practice has used 12–13 years as the threshold for transfer to adult HIV care.
- For other chronic conditions, there is flexibility as to WHEN to transition, depending on disease complexity and after considering the child to be developmentally, clinically and psychosocially ready.
 - Type 1 DM
 - Congenital Heart Disease
 - Cancer
 - Epilepsy/Neurological conditions
 - Cystic fibrosis
 - Renal disease/transplant

Transfer vs. Transition

Transfer: *Administrative event*

- “You are now 12; go to the adult clinic.”

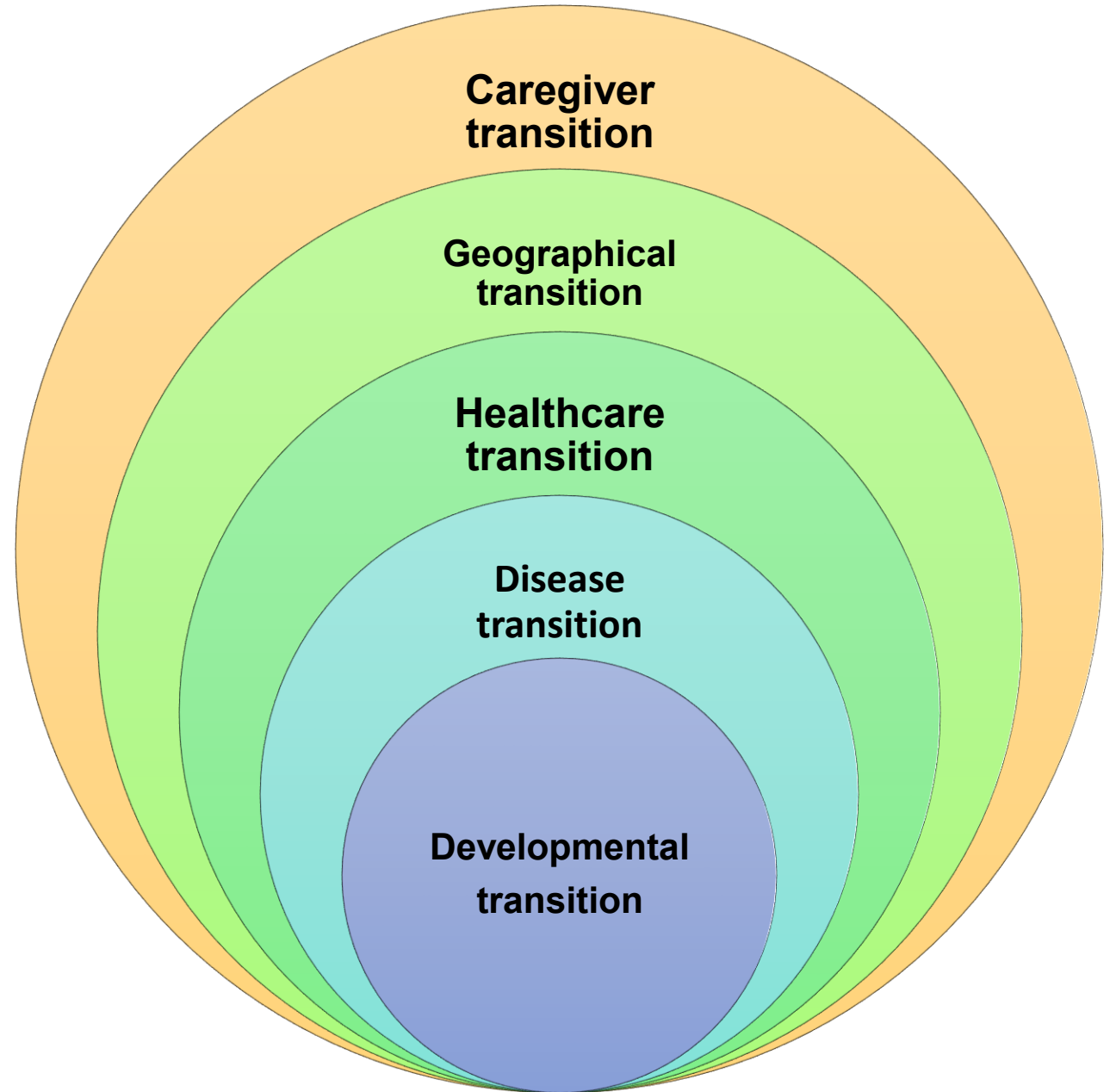


Transition: *Developmental + clinical + psychosocial process*

- knowledge of one's illness
- medication self-management
- appointment management
- disclosure skills
- health literacy
- decision-making
- navigating the health system
- sexual/reproductive health knowledge
- psychosocial independence
- advance care planning where appropriate

Transition is multi-dimensional

Adolescents experience several layers of transition, often simultaneously, which adds to the instability of an already vulnerable life period.



Consequences of Improper Transition

Poor preparation

Poor understanding of illness

Poor adherence / missed appointments

Loss to follow-up

Virological failure / recurrent OI

Advanced disease

Hospitalisation

Increased symptom burden

Late palliative-care referral

Potentially avoidable suffering

Long-term morbidity

Premature death

Evidence gap for adolescent transition in SA

► PLoS One. 2020 Oct 27;15(10):e0240918. doi: [10.1371/journal.pone.0240918](https://doi.org/10.1371/journal.pone.0240918) 

Transition from pediatric to adult care for adolescents living with HIV in South Africa: A natural experiment and survival analysis

[Brian C Zanoni](#)^{1,2,3,*}, [Moherndran Archary](#)⁴, [Thobekile Sibaya](#)⁴, [Nicholas Musinguzi](#)⁵, [Jessica E Haberer](#)^{2,3}

Editor: Joel Msafiri Francis⁶

- Poor retention in those transitioned at age 12 vs. those who remained in paediatric care (49% vs 92%, $p < 0.001$).
- 1 year + long-term viral suppression comparable.
- Combined outcome of retention and viral suppression was significantly worse among those transferred at age 12.

Review Article

Transition of adolescents from paediatric to adult HIV care in South Africa: A policy review

Charné Petinger, Talitha Crowley, Brian van Wyk

Received: 22 Oct. 2024; **Accepted:** 05 Dec. 2024; **Published:** 02 Apr. 2025

Copyright: © 2025. The Author(s). Licensee: AOSIS.

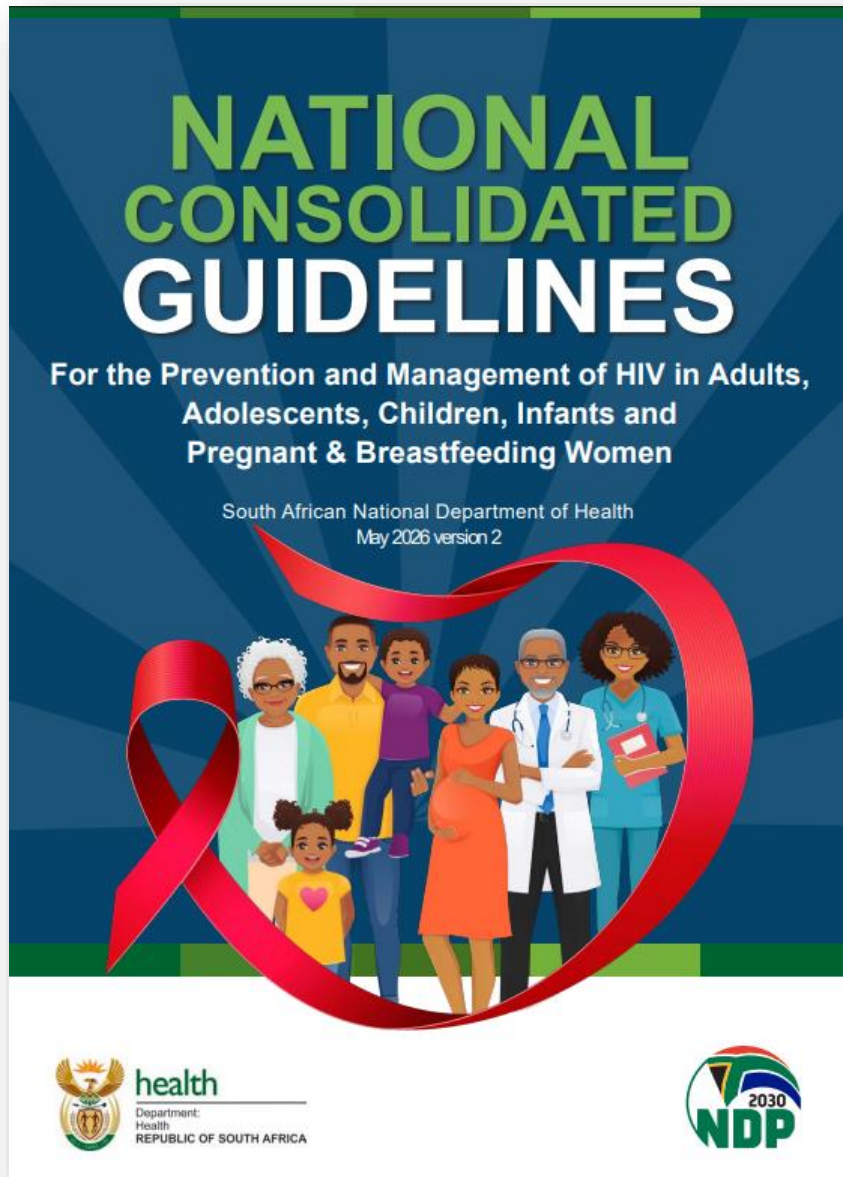
This is an Open Access article distributed under the terms of the **Creative Commons Attribution License**, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

- Access to highly active cART has allowed children to survive into adolescence, but older adolescents (15–19 years) have poorer retention and viral suppression than younger adolescents, coinciding with the post-transition period.
- Of the 8 policies reviewed, South African national and provincial guidance largely focuses on the clinical timing of transfer and ART regimen changes, rather than transition as a structured psychosocial and developmental process.

BMJ Open Qualitative situational analysis of palliative care for adolescents with cancer and HIV in South Africa: healthcare worker perceptions

Nothando Ngwenya,¹ Julia Ambler,² Moherndran Archary³

- Palliative-care pathways were unclear, inconsistent and poorly coordinated.
- HIV was often not viewed as requiring palliative care in the ART era, despite persistent symptom burden and chronic illness.
- Rural settings faced additional challenges, including poverty, long travel distances, limited specialist services and difficulty accessing pain medication.



The guideline provides a strong framework for continuity of HIV care, but a potential gap remains in explicitly integrating structured paediatric-to-adult transition and palliative-care needs into this pathway.

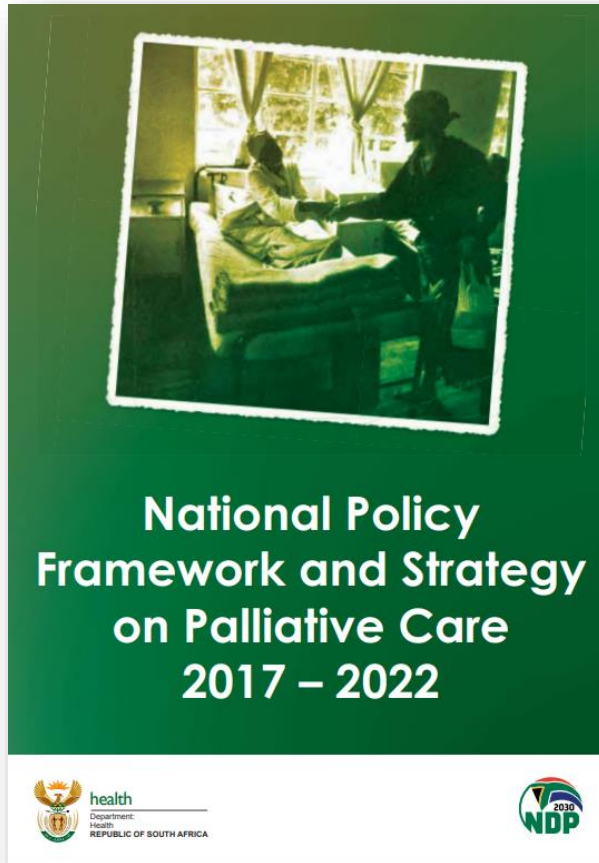
MANAGEMENT OF TUBERCULOSIS IN CHILDREN AND ADOLESCENTS

A Clinical Guideline
for the Diagnosis and Treatment
of Drug-susceptible TB in
Children and Adolescents
in South Africa

September 2024



- TB/HIV must be managed as an integrated package of care, rather than as separate diseases.
- Transition planning for adolescents with HIV/TB must preserve clinical continuity, adherence support, psychosocial care and confidentiality, while recognising the additional treatment burden of TB.



- Palliative care is an essential component of healthcare, rather than an end-of-life or hospice-only service.
- Applies across the entire disease trajectory, including chronic conditions such as HIV and TB, and should begin early – not when curative treatment fails.
- Equitable access
- Integrated into primary healthcare at clinic, community and home-based levels of care.
- Support for families and caregivers.
- Seamless continuum of care and MDT collaboration rather than disease-specific silos.



The Evidence Highlights...

- Structured transition matters is clinically relevant.
- A policy gap exists.
- The importance of Palliative Care integration cannot be understated.

The Transition Journey



Childhood

- Parent/caregiver-driven care



Early adolescence

- Developing autonomy



Older adolescence

- Increasing independence + psychosocial vulnerability



Young adulthood

- Adult responsibility for chronic illness

Palliative Care

For an adolescent with HIV/TB it can mean:



Physical

- Pain
- Breathlessness
- Nausea
- Fatigue
- Treatment adverse effects
- Symptom burden



Psychological

- Anxiety
- Fear
- Uncertainty
- Treatment fatigue



Social

- School
- Employment
- Poverty
- Caregiver burden
- Relationships



Spiritual/existential

- Meaning
- Hope
- Identity
- Fears about the future



Family

- Communication
- Disclosure
- Caregiver support
- Bereavement

Palliative Care

The Rural South African Context

Patient-level

- Poverty
- Food insecurity
- Transport costs
- School/work commitments
- Treatment fatigue
- Stigma
- Migration
- Unstable housing

Family/community

- Orphanhood
- Grandparent caregivers
- Non-nuclear caregivers
- Shuffling caregivers
- Caregiver illness
- Disclosure difficulties
- Traditional beliefs
- Community stigma

Health-system

- Shortage of specialists
- Paediatric/adult service separation
- Fragmented records
- Referral delays
- Limited adolescent-friendly services
- Limited mental-health services
- Limited specialist palliative care
- Medicine availability
- Laboratory access
- Long distances

Continuity

- The patient may move geographically before they move clinically.
- Rural village → PHC/Mobile clinic → school → district hospital → regional hospital.
- The health system may see these as separate encounters.
- The young person experiences them as *one illness*.

What does the adolescent with HIV need?

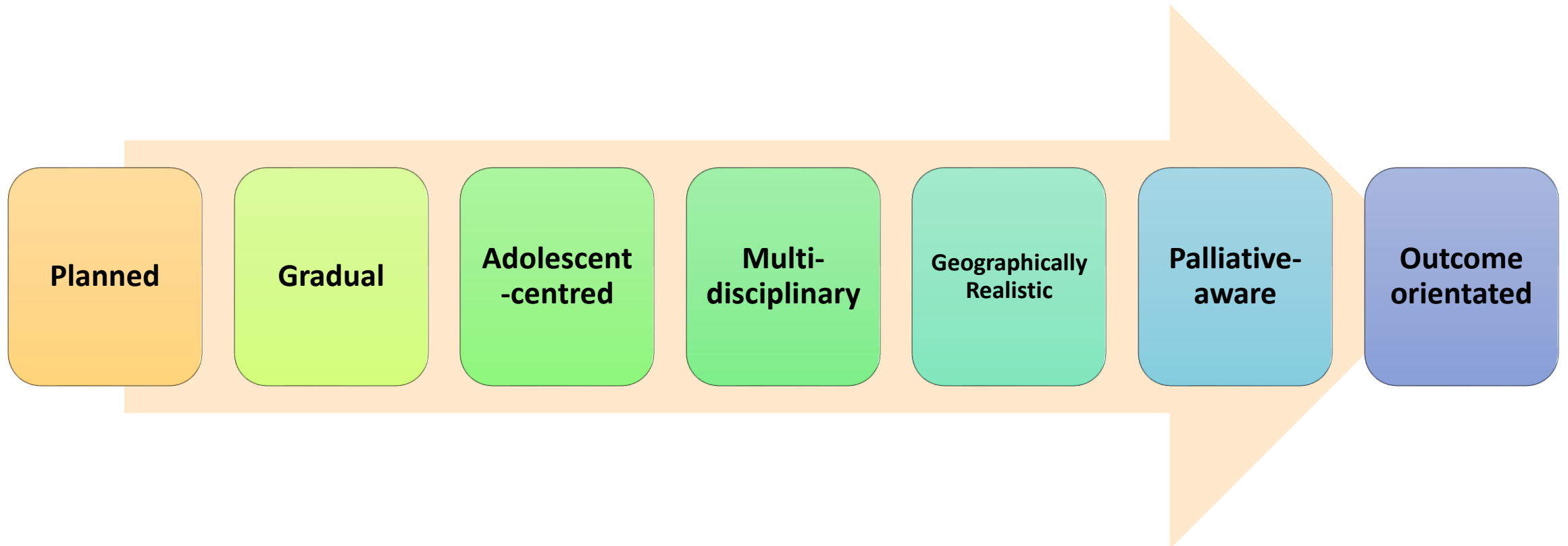
*Instead of designing the service around the clinic, **design it around the patient.***

Need	Paediatric service	Transition	Adult service
<i>Clinical</i>	Disease management	Shared care	Adult management
<i>Medication</i>	Caregiver-assisted	Self-management training	Self-management
<i>Psychosocial</i>	Family-centred	Increasing autonomy	Young-adult focused
<i>Disclosure</i>	Supported	Skills development	Independent
<i>Palliative</i>	Integrated		
<i>Records</i>	Paediatric file	Transfer summary	Adult record
<i>Caregiver</i>	Central	Gradual reduction	As appropriate

The Bottom Line

~~“When should this child be transferred?”~~

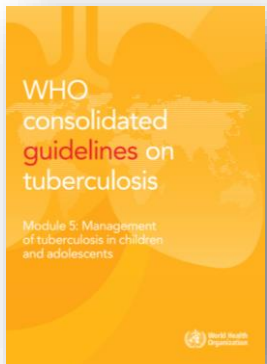
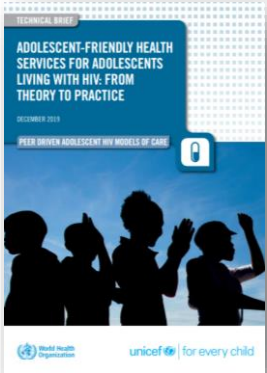
“What does this young person need to safely become an adult?”



Benchmarking International Recommendations



National Institutes
of Health



- Prep for transition early.
- Formal, individualized transition plan.
- Establish medical, psychosocial, cognitive and practical readiness.
- Ensure the adolescent understands their HIV history, medications and goals of care.
- MDT with a transition coordinator/contact person.
- Active communication between paediatric/adolescent and adult teams.
- Warm handover; not just a referral letter.
- Support after transfer and allow flexibility around missed appointments.
- Integrate with:
 - Mental health
 - Sexual/reproductive health
 - Psychosocial services
 - Housing
 - Support structures
 - Employment
 - Community-based care
- Accessible + acceptable + appropriate + equitable + effective.
- A successful transition should not require an adolescent to become geographically disconnected from care.

Putting the pieces together

Review Article

Transition of adolescents from paediatric to adult HIV care in South Africa: A policy review

Charné Petinger, Talitha Crowley, Brian van Wyk

Received: 22 Oct. 2024; Accepted: 05 Dec. 2024; Published: 02 Apr. 2025

Copyright: © 2025. The Author(s). Licensee: AOSIS.

This is an Open Access article distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

- Policy gap: South Africa has a transfer pathway; the international literature increasingly calls for a transition pathway.
- Can we adapt this international transition framework to the realities of HIV/TB and rural healthcare in South Africa?

Recommendations for South Africa

Recommendation 1 – NATIONAL FRAMEWORK

- Develop a national adolescent transition framework applicable across chronic diseases, not HIV alone.

Recommendation 2 – PALLIATIVE CARE INTEGRATION

- Embed palliative care into transition protocols.
- Symptom assessment + psychosocial support + goals-of-care conversations throughout transition.
- Incorporated into schooling syllabus.

Recommendation 3 – TRANSITION TOOL

- Develop a standardized transition readiness tool.

Recommendation 4 – PERTINENT HISTORY

- Relevant to chronic condition
- Comorbidities
- Psychosocial risks
- Educational needs
- Economic needs
- Nutritional needs
- Palliative needs
- Caregiver details
- Receiving facility

Recommendation 5 - PATHWAYS

- Optimize existing transition pathways.
- Expand pathways: Traditional healers, alternative medicine practitioners, Community leaders, Religious leaders, school teachers, taxi drivers.

Recommendation 6 – ELECTRONIC REFERRAL

- Optimize existing electronic systems or create new ones.

Recommendation 7 - TRAINING

- Train ALL levels of Healthcare Workers, caregivers, community leaders, traditional healers in basic paediatric/adolescent palliative care.

Recommendation 8 – MEASURE OUTCOMES

- Retention care
- Disease specific outcome's (VL, CD4, OI)
- Hospitalization
- Symptom burden
- Patient experience
- Caregiver experience
- HCW experience

A Contextualizing Case



Childhood

- Perinatally infected with HIV.
- Abandoned by alcoholic mother in early childhood.
- No paternal involvement.
- Maternal granny become primary CG.
- Family survived on 3 x CSG + 1 x SSG
- Struggled with viral suppression initially.
- Graded disclosure + regular & intense EAC (granny) + Adolescent Support Group (patient) → viral suppression 😊 at age 14.



Early Adolescence

- Changing social circles in school...
- Alcohol + cannabis...
- Jumped off of a bridge
- T12 burst fracture with paraplegia
- Intervention and intense rehab → walking unaided with mild-to-moderate residual paraparesis, pain-free, complete sphincter control, perform ADLs independently, returned to school 😊



Late Adolescence

- LTFU
- School dropout
- Alcohol + cannabis
- Unsafe + unprotected sex
- Pregnant, father unknown
- In a live-in relationship with an older man, undisclosed to
- Refuses ART...

Making It Make Sense

- The same patient who demonstrated successful engagement at 14 subsequently became disengaged from care as she approached adulthood.
- What changed?

DOMAIN 1 — Biological/clinical vulnerability

Complex clinical history

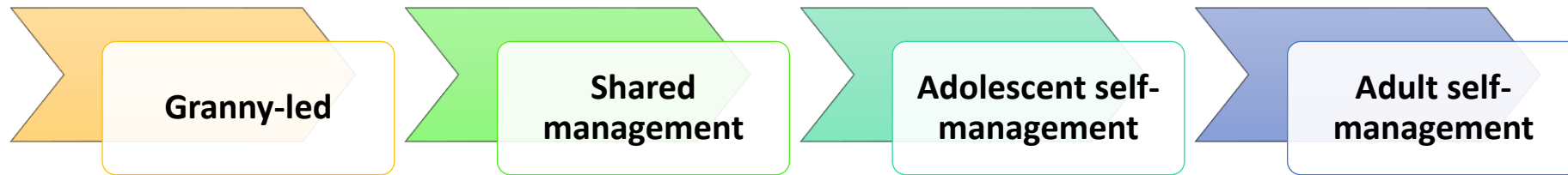
- Perinatally acquired HIV
- Prior difficulty achieving viral suppression
- Major neurological trauma
- Paraplegia/paraparesis
- Chronic pain history
- Prolonged rehabilitation
- High-risk pregnancy
- ART interruption, OI risk
- Unsafe sex practice

DOMAIN 2 — Psychosocial vulnerability

Accumulating vulnerability

- Maternal abandonment
- Absent father
- Dependence on grandmother
- Significant socioeconomic disadvantage
- Changing peer group
- Substance use
- School dropout
- Teenage pregnancy
- Older live-in partner ?power discordance
- Undisclosed relationship
- Loss of healthcare engagement

DOMAIN 3 — The caregiver transition



Did we deliberately transition the responsibility from grandmother → patient?

Or did we eventually reach a point where the grandmother was no longer sufficient to keep her engaged, but the patient had not yet developed the resources to manage independently?

DOMAIN 4 — Mental health & substance use

- History of serious self-harm
- Major physical disability
- Alcohol/cannabis use
- Later disengagement

Palliative Care

Although she received rehabilitation, rehabilitation of the body is not the same as rehabilitation of:

- Mind
- Identity
- Emotional well-being
- Relationships
- Adaptive coping mechanisms
- Chronic disease self-management

DOMAIN 5 — Sexual & reproductive health

- Unsafe/unprotected sex
 - Teen pregnancy
 - Unknown paternity
 - Older partner, undisclosed
 - ART refusal
- Did she genuinely receive adolescent-friendly, SRH services that addressed:
- Navigating disclosure in romantic relationships
 - Making sexual debut
 - Negotiating safe sex
 - Contraception needs
 - Family planning
 - GBV
 - STI
 - Cervical cancer

The Palliative Care Perspective

- This case is much more than an HIV transition case.
- There were palliative-care needs at several points in this patient's trajectory:

At neurotrauma

- pain
- loss of function
- psychological distress
- major disruption of identity and schooling
- dependence on others

During rehab

- adjustment to disability
- psychological support
- family support
- reintegration into school/community

Later adolescence

- substance use
- relationship difficulties
- reproductive health
- social vulnerability
- HIV treatment fatigue

Current situation

- untreated HIV
- teen pregnancy
- disengagement from care
- psychosocial vulnerability

Take-home messages

- ✓ Transfer ≠ Transition.
- ✓ Transition is not a single, static event in time, but a continuum of concerted efforts.
- ✓ HIV creates additional complexity to the already vulnerable adolescent.
- ✓ Vulnerability is unique, dynamic and cumulative and should, therefore, be managed in a similar, uniquely individualized manner.
- ✓ Rural, community and culture-specific factors magnify vulnerability.
- ✓ MDT means managing together, not managing in silos with the hope of achieving an aligned outcome.
- ✓ This is the point of the recommendations: an individualised, fluid transition framework spread across the continuum of a persons life course.
- ✓ Transitioning the young adolescent should be a structured and co-ordinated process that should intertwined with Palliative Care Principles.

References

- i. Petinger, C., Crowley, T. and van Wyk, B. (2025) 'Transition of adolescents from paediatric to adult HIV care in South Africa: A policy review', *Southern African Journal of HIV Medicine*, 26(1), a1674. doi:10.4102/sajhivmed.v26i1.1674.
- ii. Petinger, C., Crowley, T. and van Wyk, B. (2025) 'Health services' responses to transitioning adolescents to adult HIV care in South Africa', *African Journal of Primary Health Care & Family Medicine*, 17(1), a5060. doi:10.4102/phcfm.v17i1.5060.
- iii. Mwambenu, B., Ramoloko, V., Laubscher, R. and Feucht, U. (2022) 'Growth and the pubertal growth spurt in South African adolescents living with perinatally-acquired HIV infection', *PLoS ONE*, 17(1), e0262816. doi:10.1371/journal.pone.0262816.
- iv. National Institutes of Health (NIH) (2026) *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection: Adolescents and Young Adults with HIV*. Bethesda, MD: U.S. Department of Health and Human Services.
- v. National Institutes of Health (NIH) (2026) *Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV: Special Populations – Adolescents and Young Adults with HIV*. Bethesda, MD: U.S. Department of Health and Human Services.
- vi. Ngwenya, N., et al. (2019) 'A qualitative situational analysis of palliative care for adolescents and young adults with cancer and HIV in South Africa', *BMJ Open*, 9(1), e023225. doi:10.1136/bmjopen-2018-023225.
- vii. South African National Department of Health (2017) *National Policy Framework and Strategy on Palliative Care 2017–2022*. Pretoria: National Department of Health.
- viii. South African National Department of Health (2024) *Management of Tuberculosis in Children and Adolescents: Guideline*. Pretoria: National Department of Health.
- ix. South African National Department of Health (2026) *National Consolidated Guidelines for HIV Prevention, Testing, Treatment, Service Delivery and Monitoring*. Pretoria: National Department of Health.
- x. World Health Organization (WHO) (2015) *Global standards for quality health-care services for adolescents*. Geneva: World Health Organization.
- xi. World Health Organization (WHO) (2020) *Adolescent-friendly health services for adolescents living with HIV: From theory to practice*. Geneva: World Health Organization.
- xii. World Health Organization (WHO) (2020) *Palliative care*. Geneva: World Health Organization.
- xiii. World Health Organization (WHO) (2022) *WHO consolidated guidelines on tuberculosis: Module 5 – Management of tuberculosis in children and adolescents*. Geneva: World Health Organization.
- xiv. Zandoni, B.C., Archary, M., Sibaya, T., Musinguzi, N. and Haberer, J.E. (2020) 'Transition from pediatric to adult care for adolescents living with HIV in South Africa: A natural experiment and survival analysis', *PLoS ONE*, 15(10), e0240918. doi:10.1371/journal.pone.0240918.