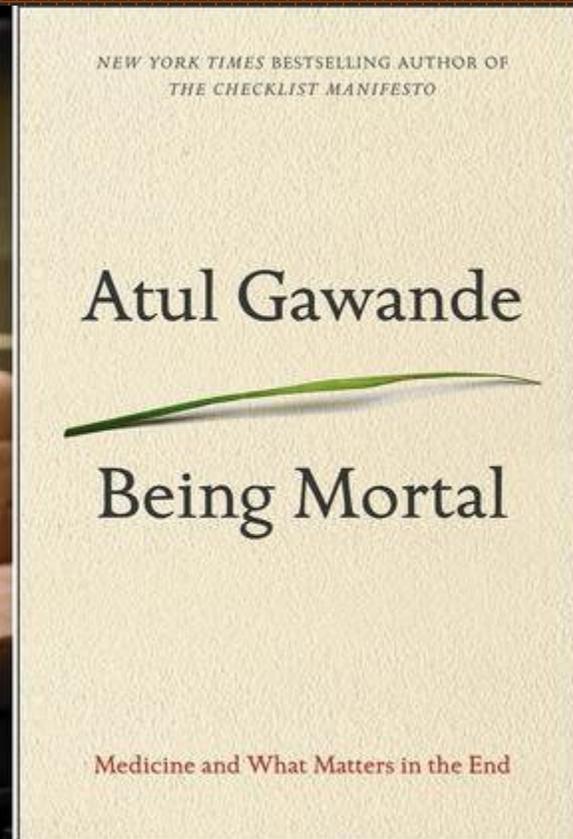
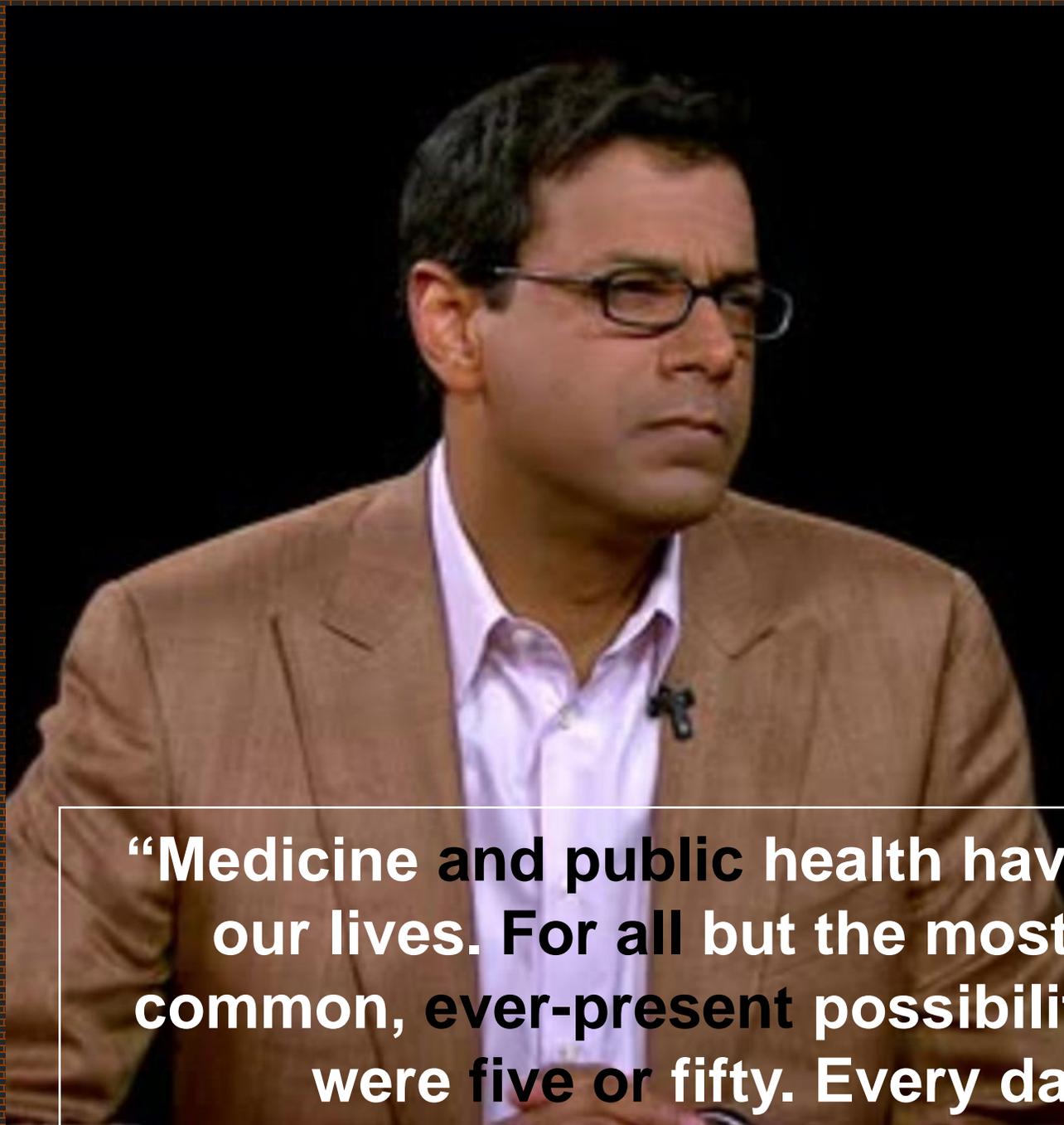


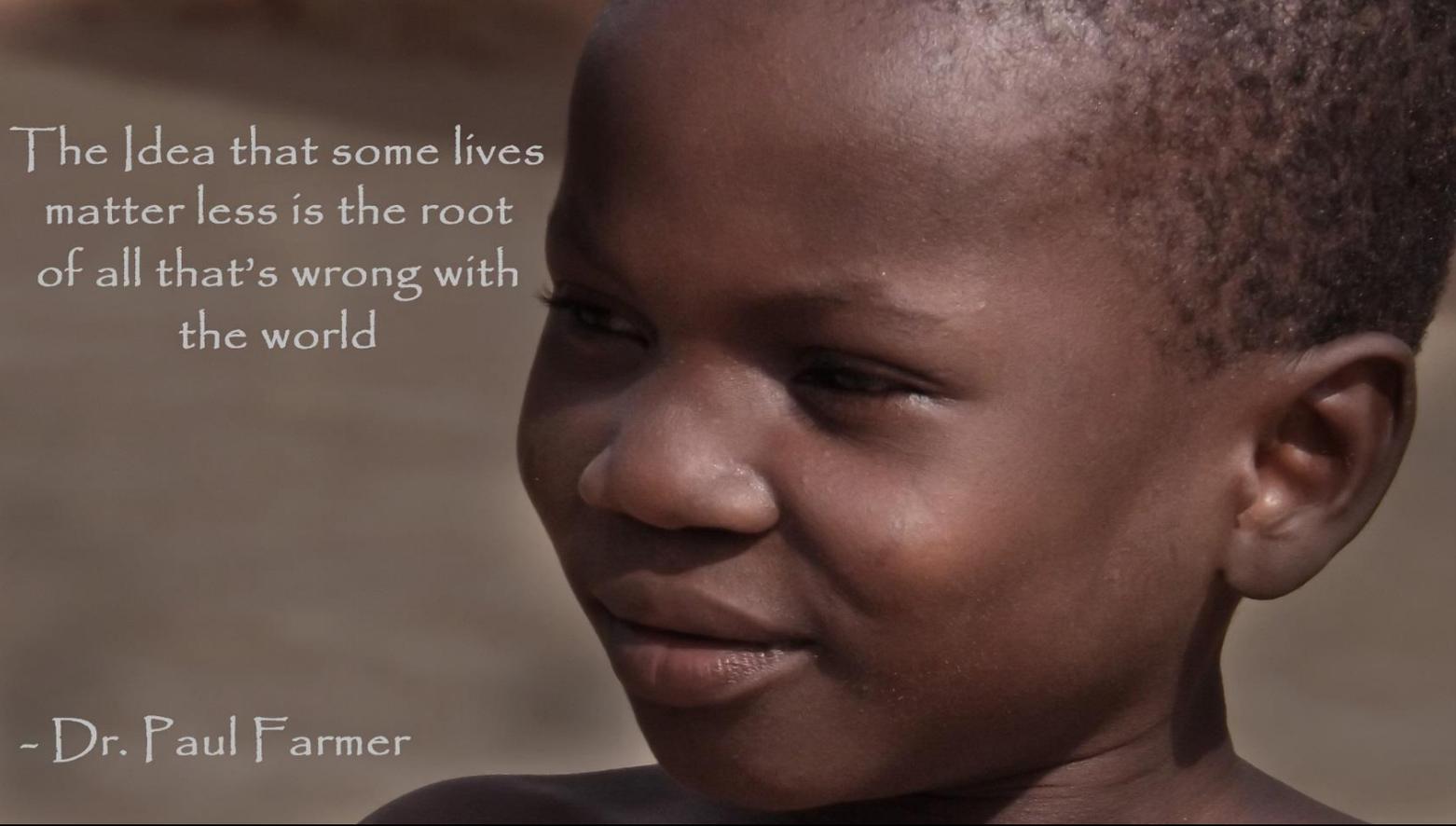
HIV, SOUTH AFRICA and PALLIATIVE CARE in 2018.

Dr Dave Spencer Johannesburg SA HIV Clinicians Society Conference October 2018

**THE GOAL OF
HIV-PALLIATIVE CARE
IS THE RELIEF
OF SUFFERING**



“Medicine and public health have transformed the trajectory of our lives. For all but the most recent history, death was a common, ever-present possibility. It didn’t matter whether you were five or fifty. Every day was a roll of the dice.”



The Idea that some lives
matter less is the root
of all that's wrong with
the world

- Dr. Paul Farmer



- More than 25.5 million people who died in 2015 i.e. 45% of the 56.2 million deaths recorded worldwide, experienced serious health-related suffering.
- **Of these, more than 80% of the people who died were from the developing world and the vast majority lacked access to palliative care and pain relief.**
- Of the 298.5 metric tonnes of morphine-equivalent opioid distributed in the world per year, only 0.1 metric tonne is distributed to low-income countries.

Knaut FM, Farmer P, et al. Lancet 2018; 391: 1391-454

HIV palliative care: *What is it? why do we need it?*

McCarthy K. NICD 2018

The holistic care of persons and their families when a person's disease is no longer responsive to curative treatment

Neither hastens nor postpones death

Provides relief from distressing symptoms, including pain

Integrates the psychological and spiritual aspects of care

What is Palliative Care?

Palliative care is a multidisciplinary approach to the holistic care and support of patients and families facing a life-threatening illness. Its aim is to improve quality of life while maintaining dignity from diagnosis to death. For children, the spectrum of illness includes life-limiting conditions that may progress to death or may be severely disabling. Palliative care should be available to all patients *as needed, from birth until death*, and should be accessible at all levels of the health care service. Palliative care cuts across all health programs in the delivery of services.

National Policy Framework and Strategy Policy on Palliative Care, 2017-2022. Department of Health. South Africa, 23 March, 2017

Offers support to help the family cope during a persons illness and during their bereavement

Offers support to help persons live as actively as possible until death

Affirms life and regards dying as a normal process

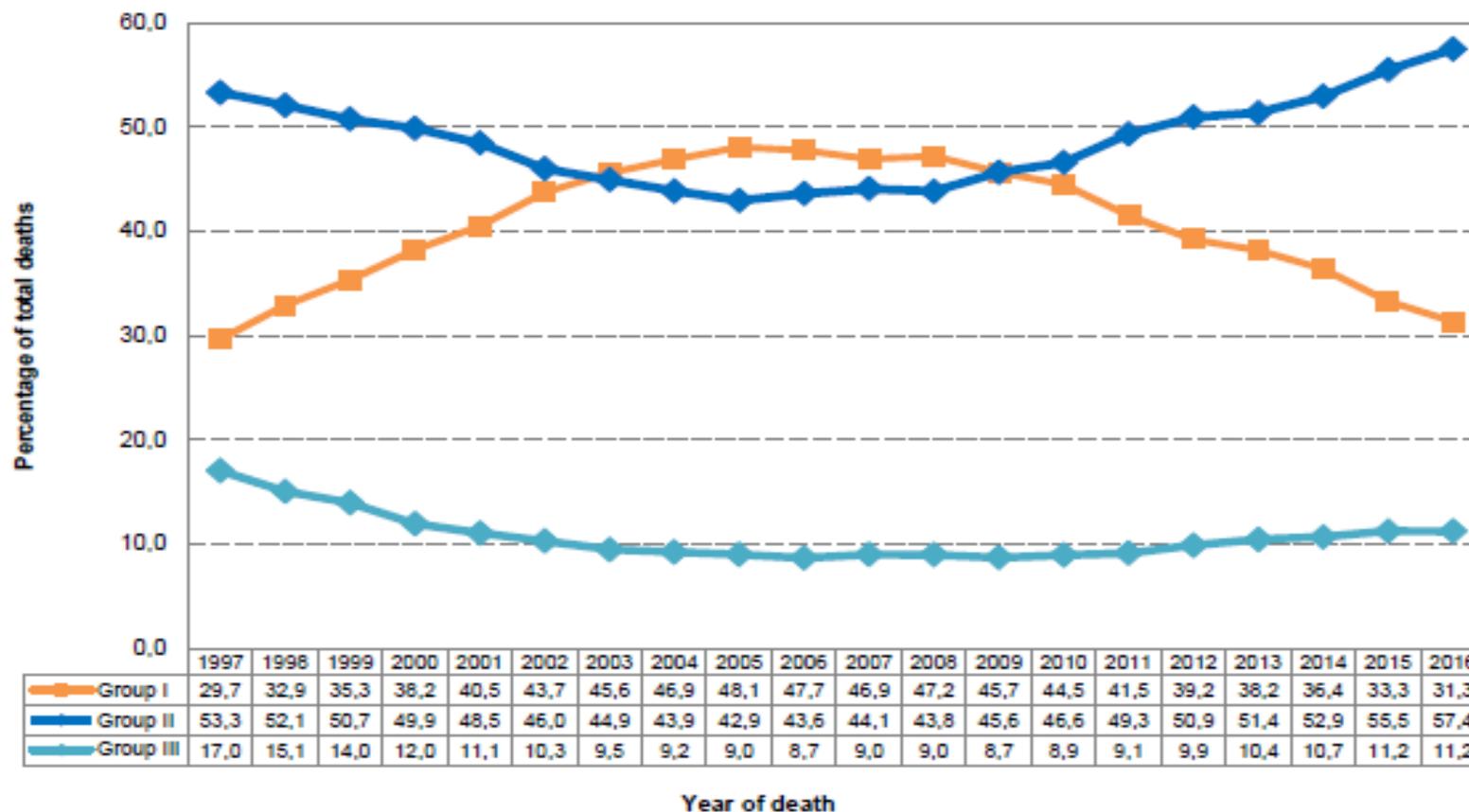
<http://www.who.int/hiv/topics/palliative/PalliativeCare/en/>

HIV palliative care

What is it? why do we need it?

McCarthy K. NICD 2018

- The proportion of deaths by group by year, 1997-2016 according to category (**Category 1, orange=communicable disease**; **Category 2, dark blue=non-communicable disease**; **Category 3=non-natural death**)



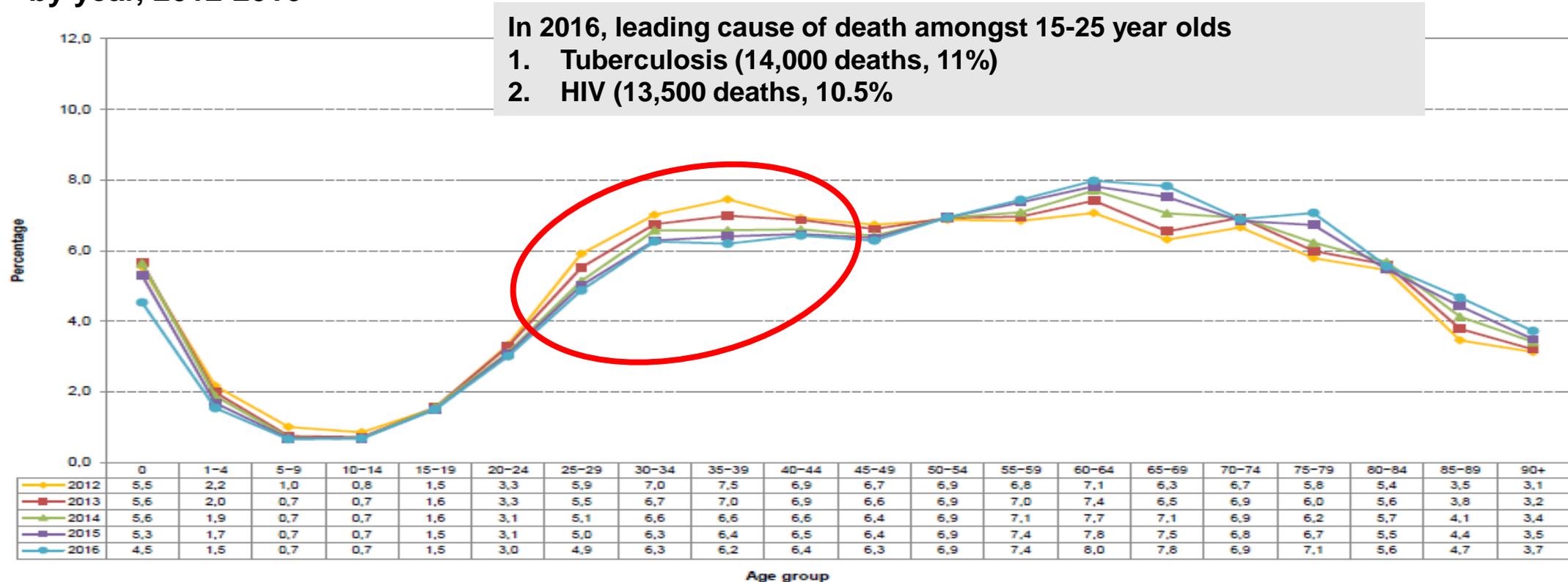
*Mortality and causes of death in RSA – findings from death notifications. StatsSA P0309.3

HIV palliative care

What is it? why do we need it?

McCarthy K. NICD 2018

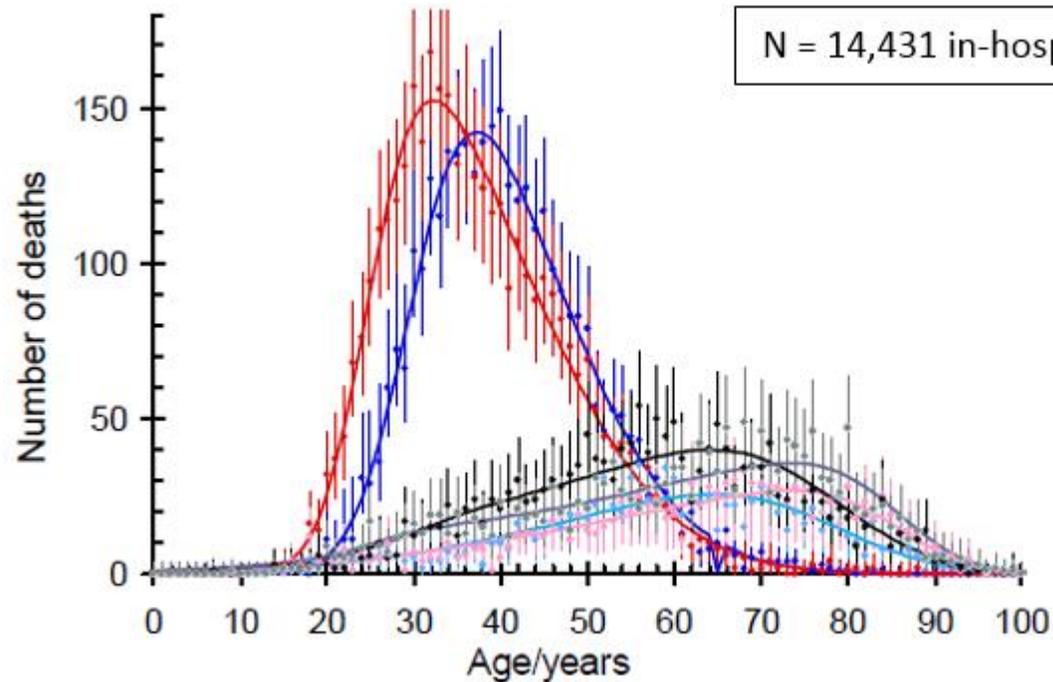
The proportion of deaths amongst persons in 5-year age categories as a percentage of total annual deaths, by year, 2012-2016



*Mortality and causes of death in RSA – findings from death notifications. StatsSA P0309.3

HIV palliative care: *What is it? why do we need it?*

The Number of Deaths by Age and HIV-status of Men and Women Admitted to the Chris Hani Baragwanath Hospital, Soweto, 2006-2009



Red: HIV-infected women;
Pink: HIV-uninfected women;
Blue: HIV-infected men;
Light blue: HIV-uninfected men;
Black: HIV-status unknown (males);
Grey: HIV-status unknown (women).

Black A, Kriel J, Mitchley M, Williams B. The burden of HIV in a Public Hospital in Johannesburg, South Africa. (2015) arXiv:1412.2788. Available at <https://arxiv.org/pdf/1512.04781.pdf>.

% of Patients with a Confirmed Infectious Disease Diagnosis (n=741)

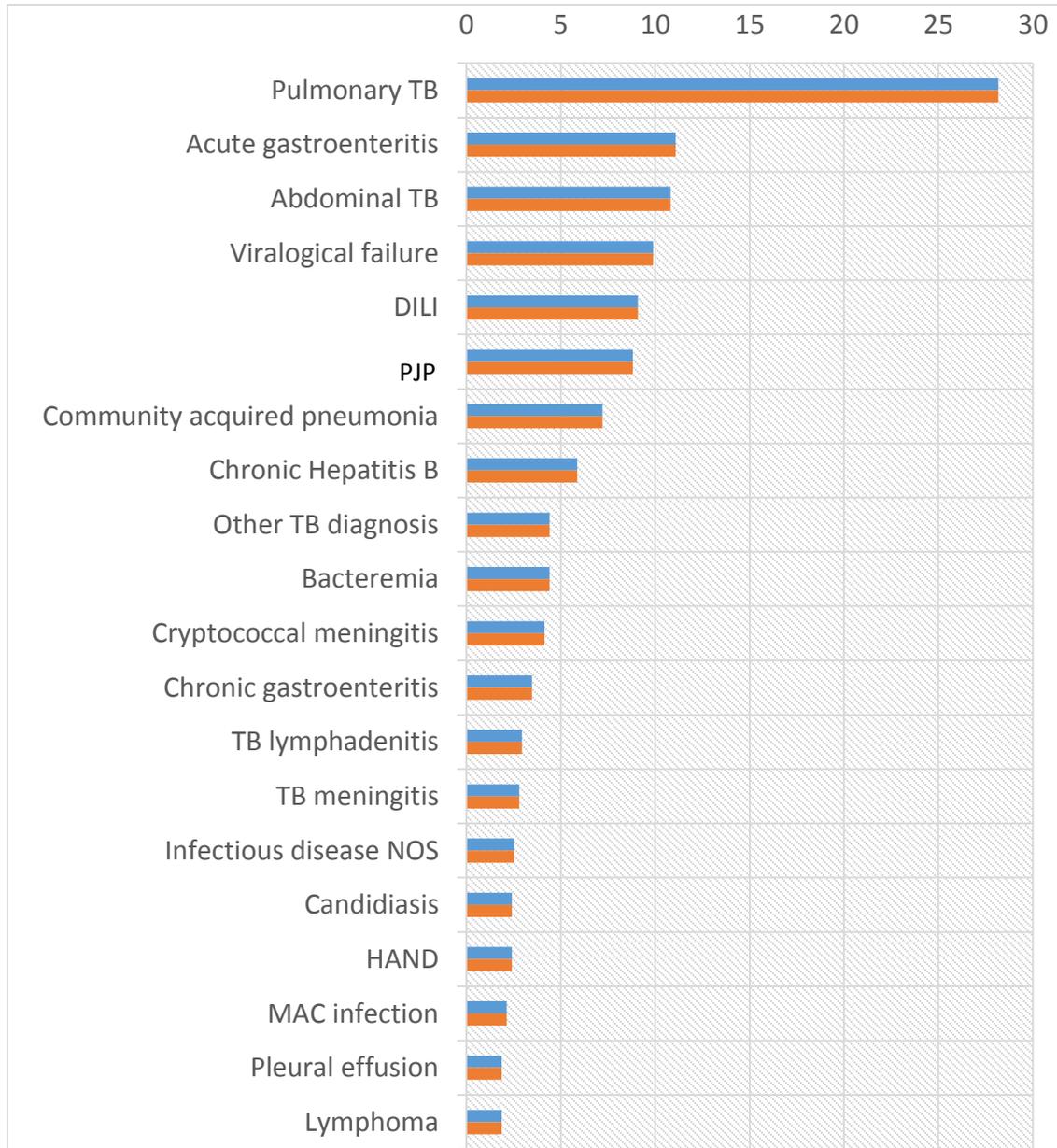


Figure. Medical Diagnoses of a Six-Month Review of In-Patient Infectious Disease Consultations at the Helen Joseph Hospital, Johannesburg, 2015-2016

93% of consultations assessed on the ID Service of the Helen Joseph Hospital were HIV-infected people. Most were South Africans.

Many were diagnosed with ≥ 1 active infectious disease and/or comorbid disease.

Richards L. M.Med Thesis, Dept. Internal Medicine, Wits University. September 2018

Foundational tools for ethical problems

The meaning of personhood

The recognition of a person's dignity means that we need to do as much as we can to support all aspects of their personhood



Foundational tools for ethical problems

The meaning of personhood

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Foundational tools for ethical problems

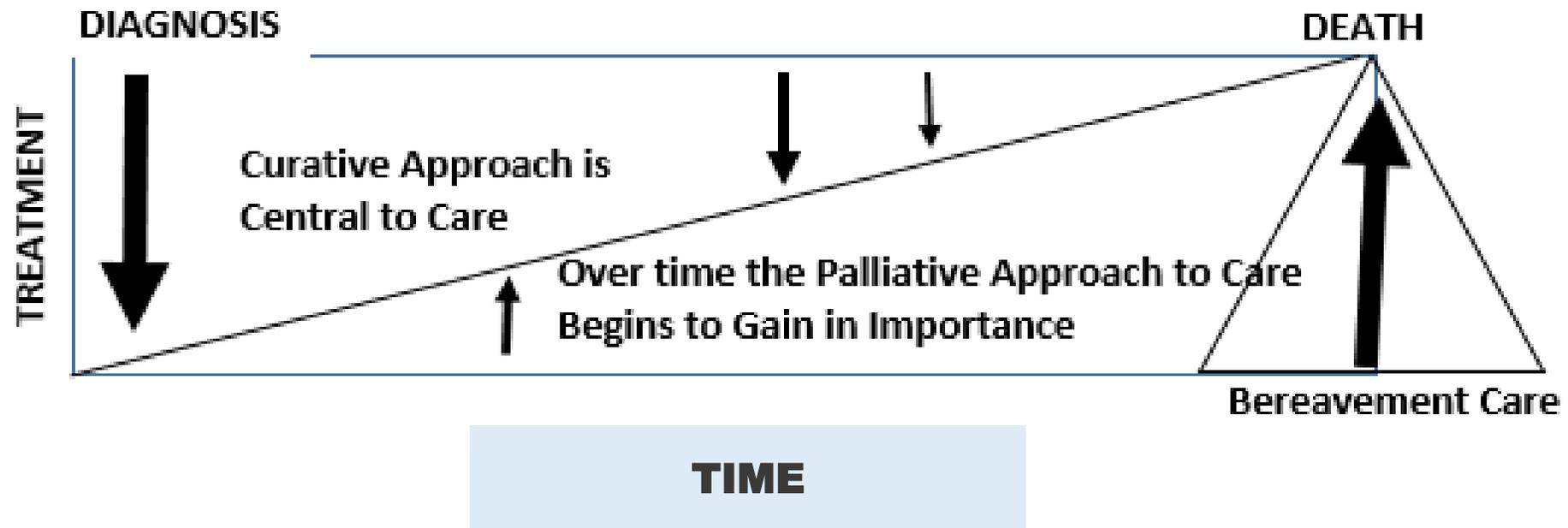
The meaning of personhood

The recognition of persons dignity means that we need to do as much as we can to support all aspects of their personhood



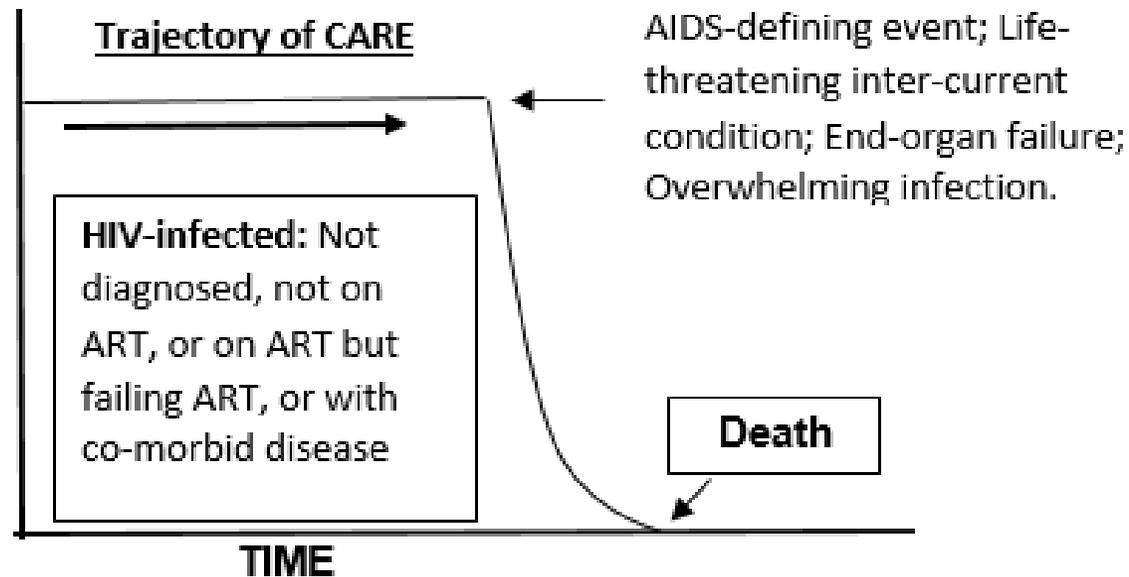
MODELS OF HIV-PALLIATIVE CARE
South African Public and Private Sector 2018

Current Concept of Palliative Care: From Diagnosis to Bereavement¹



3.1 No Formal Palliative Care Provided

Figure 3. The HIV-Infected Patient, No Palliative Care



Legend: This model is adapted from original sources^{12, 13}

Lunney JR. et al. Patterns of Functional Decline at the End of Life. JAMA 2003; 289: 2387-92

Gawande A. Being Mortal. Cpt. 2 pg 25. Things Fall Apart. Wellcome Collection. 183 Eustace Rd., London. NW1 2BE. Published in 2014

Figure 4. Palliative Care During Periods of Need

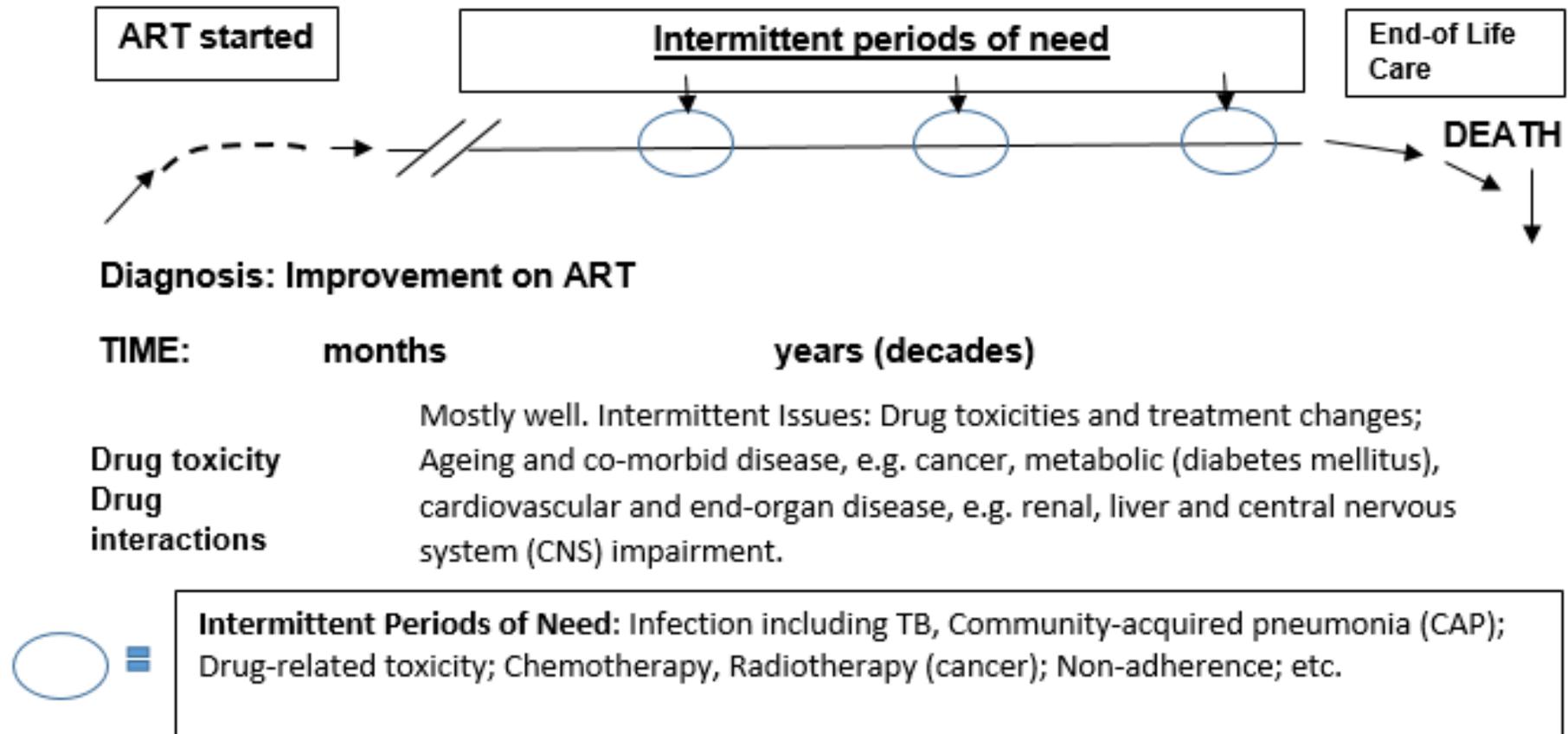
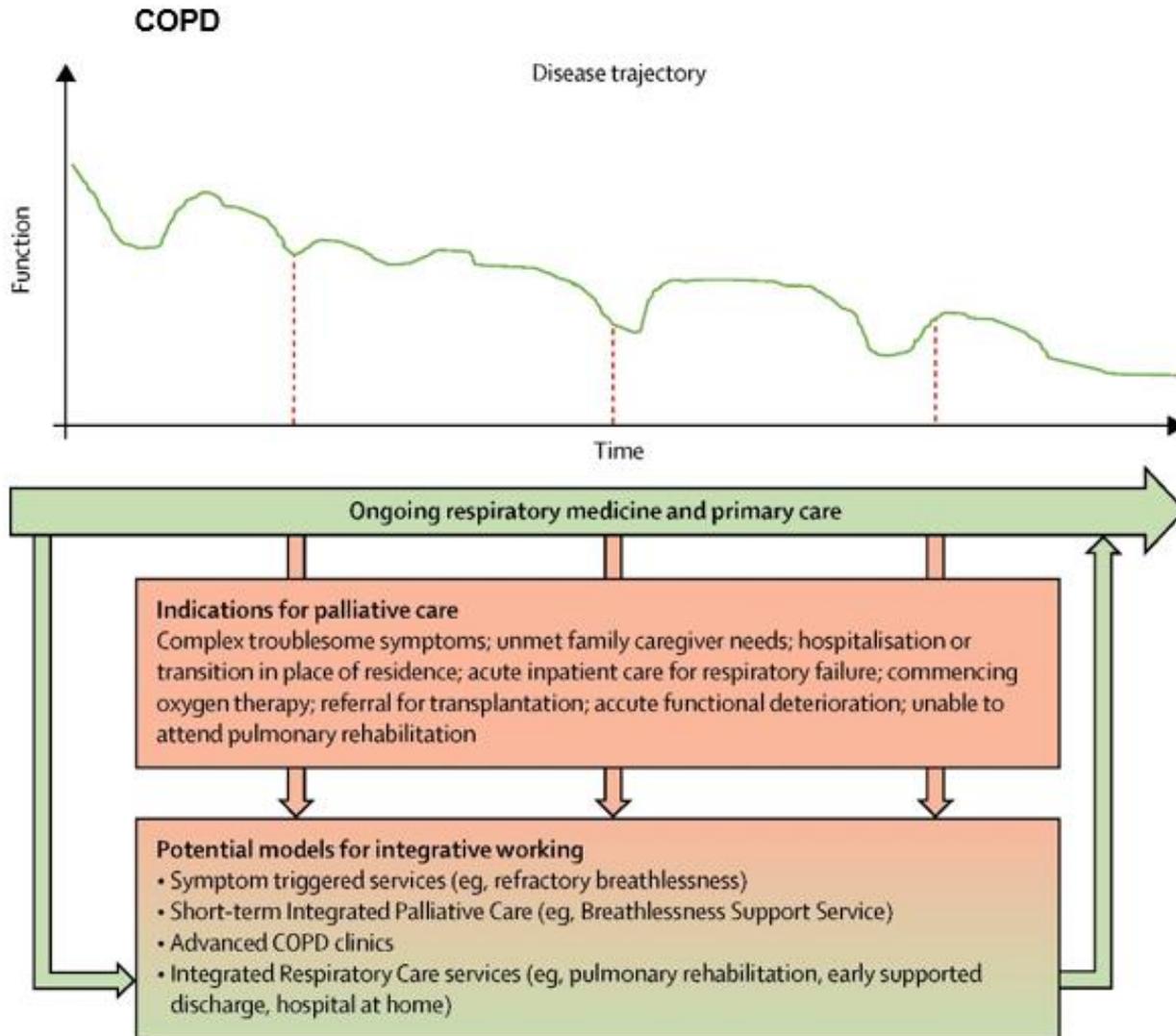


Figure 5. Integrated Palliative Care for People with Progressive Co-Morbid Disease, e.g. Chronic Obstructive Pulmonary Disease (COPD)¹⁹



MODELS OF CARE:

The Slowly Progressive Loss of Wellbeing.

COPD
Renal failure
CVD
Frailty
End-Stage AIDS

Maddocks M, Lovell N, Booth S, Man W D-C, Higginson IJ. Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. *Lancet* 2017; 390: 988-1002.

PALLIATIVE CARE: LIMITED RESOURCES

ASSESSING NEED

“Any attempt at prognostication that does not address whether the patient has had an adequate trial of ART would be ill-informed and inaccurate.” (Merlin J, et al. 2018)

THE LAZARUS EFFECT

Mortality Indicators: Assessment Tools

Karnofsky Score: 0-100 [0=dead, 100 = alive and well]

- ❑ $\leq 60\%$ = consider for hospice/ home support
- ❑ $< 50\%$ = needs hospice/home support

The Support and Palliative Care Tools (SPICT™).

- ❑ **General indicators: ≥ 2 indicators**
- ❑ **Clinical indicators: ≥ 1 indicator**

The Veterans Aging Cohort Study (VACS) Index.

- ❑ **A scoring system that utilizes 7 clinical/laboratory areas of interest**

Estimated Life Expectancy of $< 6m$ (USA)

DO PLWH ON ART EXPERIENCE GREATER PAIN THAN THEIR UNINFECTED PEERS?

THE POPPY STUDY: Observational, cross-sectional study from the UK

Three arms: % experiencing pain in the preceding month and at the time of assessment?

N=699 ≥50yr PLWH

N=374 ≤49yr PLWH

N=304 >50 yr HIV-ve

RESULTS: Pain in Past Month

Older PLWH: n = 473/667, 70.0%
Younger PLWH: n = 224/357, 62.7%
Older, uninfected: n = 188/295, 63.7%

P = 0.03

PLUS

- More days off work
- Depression
- Poor quality of life
- Greater functional impairment

RESULTS: Current Pain

Older PLWH: n = 330, 48.8%
Younger PLWH: n = 134, 37.5%
Older, uninfected: n = 116, 39.3%

P = 0.0007

CHRONIC PAIN CONTROL IN HIV

“Of all treatment modalities reviewed, the best evidence for pain reduction averages roughly 30% in about half of treated patients, and these pain reductions do not always occur with concurrent improvement in function.

These results suggest that none of the most commonly prescribed treatment regimens are, by themselves, sufficient to eliminate pain

and have a major effect on physical and emotional function in most patients with chronic pain.”

CHRONIC PAIN IN HIV: IDSA GUIDELINES

“HIGH LEVEL, STRONG QUALITY EVIDENCE”

- Any ‘new pain’ in a patient with previously controlled pain **needs fresh re-assessment**
- **Acetaminophen and NSAIDs are the first-line agents** for the treatment of musculoskeletal pain in persons living with HIV
- **Topical capsaicin** is indicated for **chronic HIV-associated peripheral neuropathy** in conjunction with additional analgesics and supportive therapies and adequate viral control
- **Screen all with chronic pain syndromes for depression**, i.e. direct questioning, via a depression questionnaire and/or through a psychiatric referral.

CHRONIC PAIN IN HIV: IDSA GUIDELINES

“MEDIUM LEVEL, STRONG QUALITY EVIDENCE”

- The re-evaluation of pain among those with a **‘changing experience of pain’**
- The **‘immediate/early’ commencement of ART** in those with a sensory polyneuropathy believed to be caused by HIV infection
- **Gabapentin, with dose escalation up to a maximum of 2400mg daily po in divided doses, is recommended as the first-line oral treatment of chronic HIV-associated neuropathic pain** (the authors note that somnolence occurs in 80% and can be problematic). The serotonin-noradrenaline reuptake inhibitors, tricyclic antidepressants and pregabalin received only weak or moderate support.
- Despite the absence of RCTs in HIV-related pain syndromes, **Alpha-lipoic acid (ALA) received support for neuropathic pain treatment** in view of its confirmed role in diabetic neuropathy, a condition that also targets the peripheral nerves.
- **Opioid analgesics are not indicated for first-line control of neuropathic pain or chronic pain syndromes.** Tramadol, a combination opioid, i.e. a serotonin + noradrenaline reuptake inhibitor + a μ -opioid agonist, received support, however, for use in several non-cancer pain syndromes including osteoarthritis, fibromyalgia and the neuropathic pain syndromes.³⁶

HIV, Cancer and Palliative Care in Southern Africa

How can the HIV-infected cancer patient be better served?

- **Prevention**

- Tobacco use control
- Hepatitis B vaccination
- Hepatitis C serology and access to directly-acting antivirals (DAAs)
- Human papillomavirus (HPV) vaccination
- Cervical and anal Pap smears
- **The early introduction of ART.** Uncontrolled plasma (HIV) viral load is associated with the increased risk of malignancy in the HIV-infected.^{68, 69}

- **Baseline determination of HIV status of every cancer patient.** Survival of the HIV/cancer patient requires access to ART and long-term suppression of HIV.^{70, 71}

- **Linkage to care.** The ethos of this care is holistic, i.e. oncology, HIV-caregivers and the palliative care team work together in the support of the patient.

- **Collaboration is needed between Oncology/ Radiotherapy and the disciplines of HIV/Infectious Diseases and Palliative Care.** Cancer care in SA must be sensitive to the needs of the HIV-infected, and closer collaboration between HIV, palliative care physicians and oncology/radiotherapy specialists must take place if weak links in healthcare delivery are to be strengthened. ARV drugs and regimens are constantly changing, drug-drug interactions and toxicities are common, and secondary infection with opportunistic microbes frequently occur. A team approach is required to improve survival outcome in this group of patients.

The Cannabinoid Drugs in the Palliative Management of HIV-Infected Patients

With regard to the role of cannabinoids in the palliative care of HIV-infected patients, several 'unknowns' remain, e.g.⁷²:

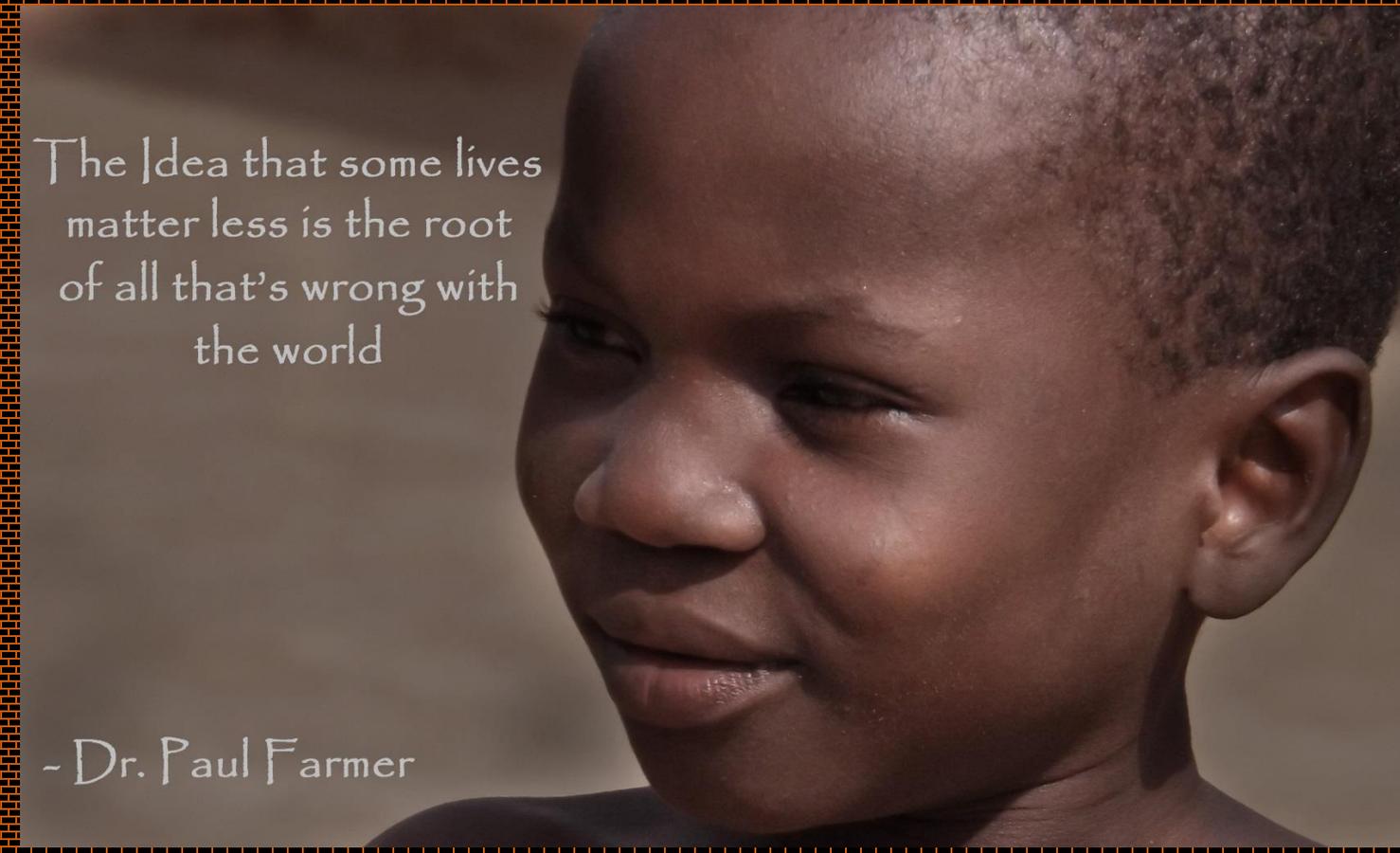
- **Indications for use of cannabinoids require urgent clarification**
- The **pharmacokinetics and pharmacodynamics of cannabinoids** in people **naïve to and those with prior exposure (to cannabinoids)** in the context of palliative care. Does this differ? Do the cannabinoid-exposed require a higher dosing of cannabis?
- **Drug-drug interactions** between the cannabinoids, ART and TB drugs have minimal/no data
- Which **route of administration** should be recommended: oral, inhaled (smoked)?

Cyr C, Arboleda MF, Kumar S, et al. Cannabis in palliative care: current challenges and practical recommendations. *Ann Palliat Med* 2018; doi.21037/apm.2018.06.04. View at <http://dx.doi.org/10.21037/apm.2018.06.04>



The Idea that some lives
matter less is the root
of all that's wrong with
the world

- Dr. Paul Farmer

A close-up portrait of a young child with dark skin, looking slightly to the left with a gentle expression. The background is a plain, light color.

More than 25.5 million people who died in 2015 i.e. 45% of the 56.2 million deaths recorded worldwide, **experienced serious health-related suffering.** Of these, more than 80% of the people who died were from the developing world and the vast majority lacked access to palliative care and pain relief. Of the 298.5 metric tonnes of morphine-equivalent opioid distributed in the world per year, only 0.1 metric tonne is distributed to low-income countries.

Knaul FM, Farmer P, et al. Lancet 2018; 391: 1391-454

On duty over Easter, I found Simone and his Mum had returned. He was conscious but very ill, a large mass in his mouth and cheek, which distorted his eye and made speech difficult.

I asked Simone's mother what she hoped that we could do. 'Nothing', she replied, 'but he asked to be brought to you.' I felt wretched; did Simone think that we had something special that would make him better?

Crouched beside his bed where he lay, we talked. Would he like some nice milk and porridge to make him strong? We would find something for his sore mouth and a syrup for his aching head.

On Easter Sunday I was walking down the long, main hospital corridor and found a procession slowly coming towards me from the children's ward. A nurse was pulling a trolley on which a small bundle lay, covered by a white cloth stitched with a red cross.

Behind the trolley came Simone's mother and stretching far behind, came 30 or more women from the wards, most with their sick children on their backs.

They were all singing. I stood aside as they passed, moved to tears.

Here was a hospital community sharing a mother's grief and supporting her in the difficult business of taking her little son's body home. The warmth and support that surrounded Simone's last few days showed how much can be done with little but hands, and hearts, and voices.

