Palliative Care and End of Life Care for Persons Living with HIV-
Beyond the 95-95-95…
A Fourth 95
Person Centred Care

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Introduction

- Antiretroviral Therapy has transformed HIV to a chronic disease
- However as we live and age with HIV, what does the future look like?
- Continued Viral Load monitoring
- Screening for TB and other opportunistic infections
- Chronic Diseases of Lifestyle
- PAP smears
- PSA screening
- Other Cancer screening

What is missing?

- What other symptoms do PLWH experience?
- Memorial Symptom Assessment Scale-Short Form
- Using a 7 day recall of 32 items
- 28 Physical

The prevalence and burden of pain and other symptoms among South Africans attending HAART clinics

Lindsay Farrant, Liz Gwyther, Natalya Dinat, Keletso Mmoledi, Ntombi Hatta, Richard Harding

Table 1. Prevalence and high burden/high frequency of symptoms among 385 participants over a 7-day period

Symptom	Prevalence *N* (%)	High burden*\high frequency† *N* (%)
Feeling sad	249 (64.68)	120 (48.19)†
Feeling irritable	239 (62.08)	143 (60.01)†
Numbness/tingling in hands/feet	235 (61.04)	146 (62.39)
Worrying	235 (61.04)	132 (55.93)†
Sexual interest/activity problems	200 (51.95)	136 (68.27)
Pain	197 (51.17)	116 (59.19)
'I don't look like myself'	188 (48.83)	144 (71.28)
Feeling nervous	156 (40.52)	83 (53.20)†
Lack of energy	155 (40.26)	76 (49.03)
Sweats	150 (38.96)	87 (58.39)
Weight loss	150 (38.96)	95 (64.19)
Feeling bloated	147 (38.98)	73 (49.66)
Feeling drowsy	139 (36.10)	59 (42.76)
Changes in skin	136 (35.32)	70 (51.47)
Difficulty concentrating	131 (34.03)	63 (48.09)
Constipation	121 (31.43)	56 (46.28)
Itching	116 (30.13)	59 (50.87)
Lack of appetite	100 (25.97)	59 (59.00)
Cough	98 (25.45)	32 (32.65)

THE HIGHWAY HOSPICE
We Care

Global Perspective

- Globally 38 million people living with HIV
- 28 million receive treatment regularly
- 680 000 deaths due to Advanced HIV (WHO-2020)

Advanced HIV disease and health related suffering- exploring the unmet need of palliative care

Ajay Rangaraj[1], Stephen Connor[2], Richard Harding[2,3], Clarice Pinto[1], Lastone Chitembo[1], Nathan Ford[1]

[1]World Health Organization, Geneva

[2]Worldwide Hospice Palliative Care Alliance, UK

[3]Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation

Cancer and HIV

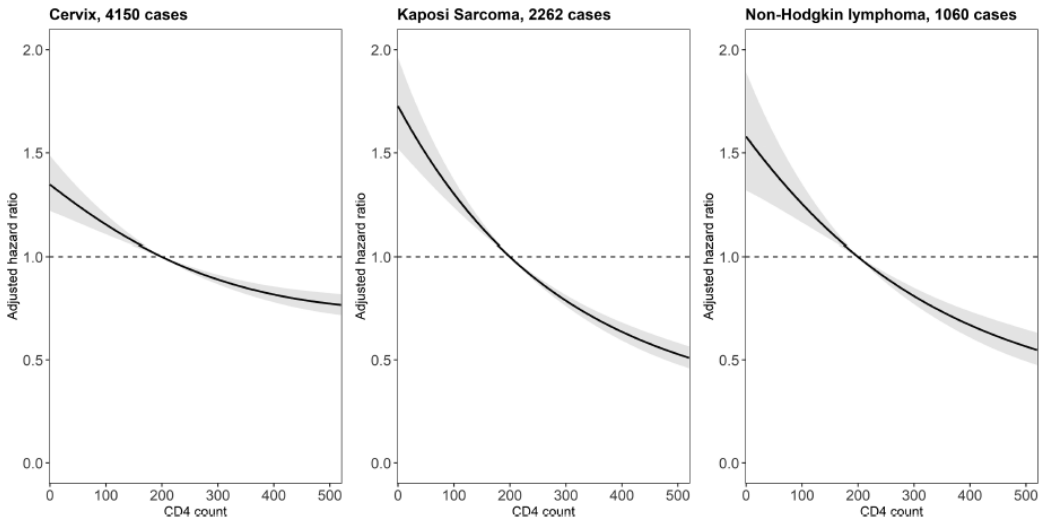


Figure 1. Adjusted hazard ratios (solid lines) with 95% confidence intervals (gray area) for the incidence of AIDS-defining cancers, comparing a grid of CD4 cell counts with the reference value of 200 cells/μL. The models are adjusted for sex, age, calendar year, and diagnosis of other cancers.

- Data from the SAM Study
  - National Health Laboratory Service (NHLS)
  - National Cancer Registry (NCR)
- PLWH 3 532 266
- Patient with Cancer 15 078

* Under-reporting of cancer

Age and Cancer Incidence in 5.2 Million People With Human Immunodeficiency Virus (HIV): The South African HIV Cancer Match Study

Yann Ruffieux,[1] Mazvita Muchengeti,[2,3] Victor Olago,[2] Tafadzwa Dhokotera,[1,2,4,5,6] Julia Bohlius,[1,4,5] Matthias Egger,[1,7,8] and Eliane Rohner[1]

Infection Related Cancer

- Oncoviruses
- Patients with lower CD4 counts are at greater risk
- Cancer related to infectious agents
- Cancer not related to infectious agents

Table 1. Categorization of Infection-Related Cancers

Infection	Cancer	ICD-10 Codes
AIDS-defining cancers		
Human papillomavirus	Cervical	C53
Human herpesvirus 8	Kaposi sarcoma	C46
Epstein-Barr virus	Non-Hodgkin lymphoma	C82-C85
Non–AIDS-defining cancers		
Human papillomavirus	Anal	C21
	Head and neck	Various[a]
	Penile	C60
	Vaginal	C52
	Vulvar	C51
Epstein-Barr virus	Hodgkin's lymphoma	C81
	Nasopharyngeal	C11
HIV[b]	Conjunctival	C69.0
Hepatitis B and C	Liver and bile duct	C22–24
Helicobacter pylori	Stomach	C16
Schistosomiasis	Bladder	C66, C67

Abbreviations: HIV, human immunodeficiency virus; ICD-10, International Classification of Diseases, 10th revision.

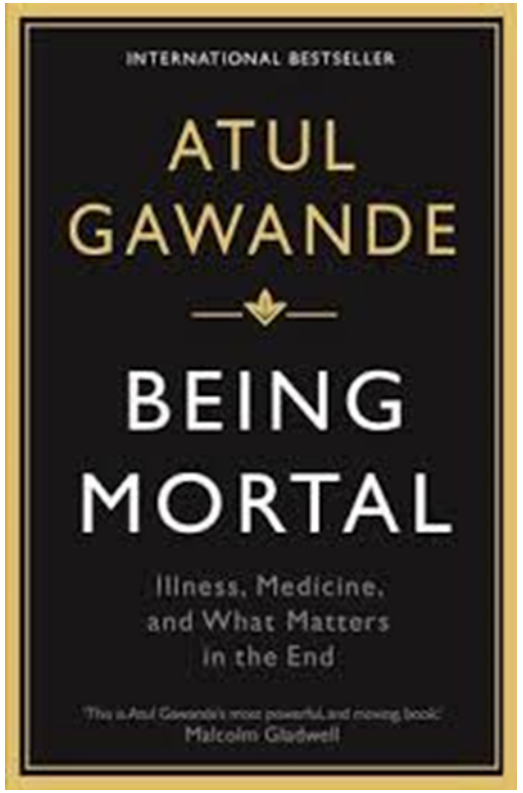
[a]Base of tongue (C01), lingual tonsil (C02.4), palatine tonsil (C09.0–09.9), oropharynx (C10.2–10.9), pharynx NOS (C14.0), Waldeyer's ring (C14.2).
[b]HIV infection is an established risk factor for conjunctival cancer but an association with other oncogenic viruses remains controversial.

Justification for Palliative Care

- Palliative Care (Balfour Mount)- derived from the Latin word

  Pallium- to cloak

- I have learnt many things in Medical School…but Mortality was not one of them.
  - Atul Gawande
- Modern Palliative Care -1967
- Part of Universal Health Coverage (UHC)
- Universal Health Coverage: All individuals and communities receive health services they need without suffering financial hardship. It includes the full spectrum of essential quality health services from health promotion, prevention, treatment, rehabilitation and **palliative care**



What is Palliative Care?

WHO Definition of Palliative Care 2002

- Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Components of Palliative Care 1

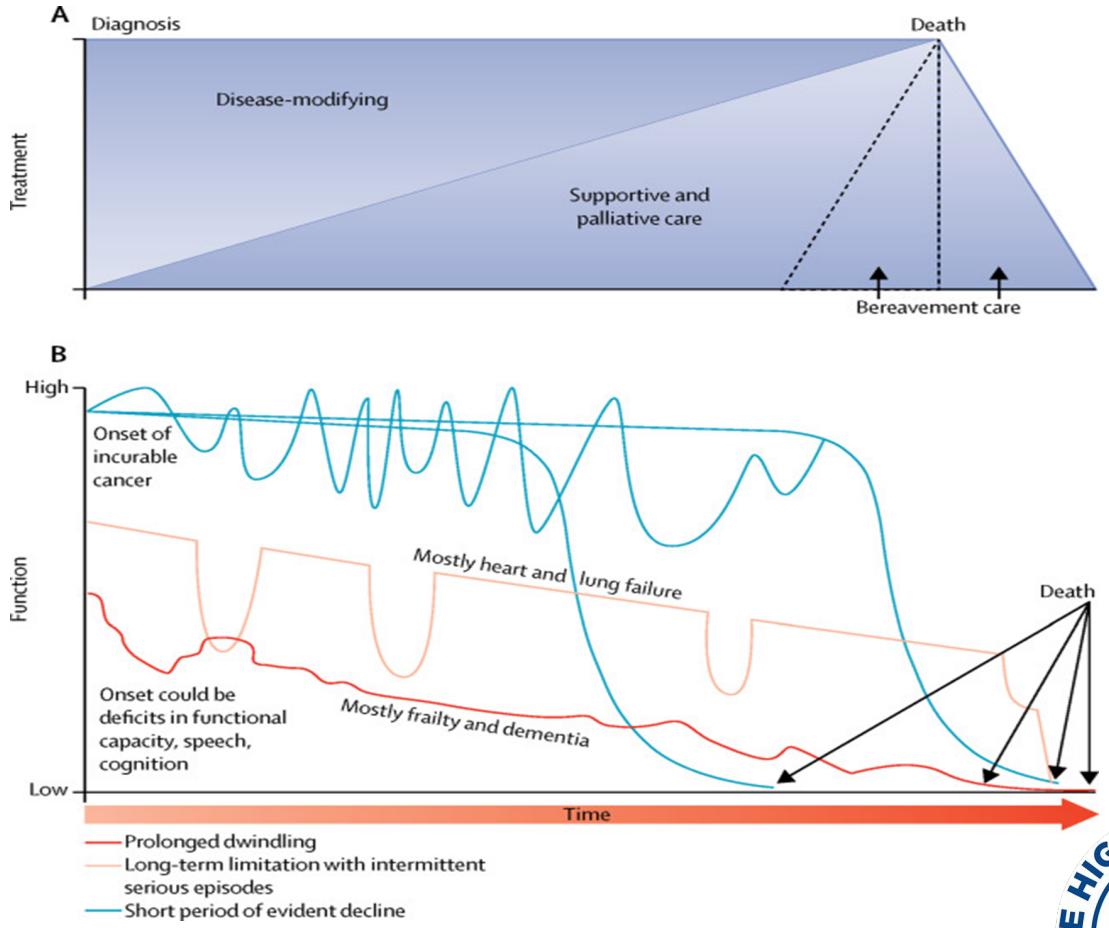
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;

Components of Palliative Care 2

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Models of Palliative Care Integration

- Diagonal integration of curative care and palliative care
- Disease trajectories in Palliative Care



Why is Palliative Care important for PLWH?

- Symptom Burden
- Relief of pain and suffering
- Quality of Life

Palliative care guidelines for the management of HIV-infected people in South Africa

TABLE 1: Causes of death at post-mortem examination of 39 HIV-infected patients of the Charlotte Maxeke Johannesburg Academic Hospital, January–December 2009.[9]

Causes of death by category and/or organism†	All deaths (N = 39)		Pre-ART deaths (N = 14)		Early-ART deaths (N = 15)		Late-ART deaths (N = 10)	
	n	%	*n*	%	*n*	%	*n*	%
Mycobacterial	27.0	69	8	57	13	87	6	60
Bacterial	13.0	33	5	36	6	40	2	20
Fungal	8.2	21	3	21	4	27	1	10
Viral, not HIV	3.0	8	2	14	0	0	1	10
Neoplasm	10.0	26	3	21	3	20	4	40
Organ dysfunction‡	10.0	26	1	7	5	33	4	40
IRIS	11.0	28	-	-	11	73	-	-
Diagnosis unsuspected at death§	19.0	49	7	50	8	53	4	40
Unexplained	5.0	13	4	29	1	7	0	0

Source: Wong EB, Omar T, Setlhako GJ, et al. Causes of death on antiretroviral therapy: A post-mortem study from South Africa. PLoS One. 2012;7(10):e47542. https://doi.org/10.1371/journal.pone.0047542

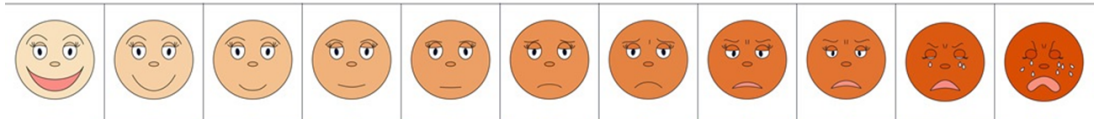
How to integrate Palliative Care into the continuum of care for PLWH?

- Screening
- Symptom Assessment
- Relief of pain and other distressing symptoms
- End of Life Care

Pain Management

- Pain Assessment
- World Health Organisation Analgesic Ladder
- Start low and go slow!
- Rules
  - By the mouth
  - By the clock
  - By the ladder

COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)



0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
No Pain	**Minor Pain**			**Moderate Pain**			**Severe Pain**			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt pain.			Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			



Surprise Question?

- <u>Definition of Hospice Care:</u>
- Would you be surprised if this patient would pass away in the next 6-12months?
- It is ‘’a specialized form of care designed to provide comfort, dignity and quality of life for individuals with a terminal illness, typically with a life expectancy of 6 months or less, who are no longer seeking curative treatment. It focuses on managing pain and symptoms, offering physical, emotional and spiritual support for both the patient and their family’’
- It is Palliative Care provided to the ‘’dying’’ patient, ie. a patient whose illness can no longer be treated for cure, is at an end stage and it is rapidly progressing toward death.

Principles of End of Life Care

- Compassionate Presence
- Pain Assessment
- Sedation for Terminal Restlessness
- Feeding and Mouth Care
- Hydration
- Breathing changes
- Counsel family and caregivers
- Culture and rituals

What does Highway Hospice do?

- Homecare Team
- Inpatient Unit
- Psychosocial support
- Community based Adherence Support
- Interdisciplinary Team Meetings
- Education Unit



The History of Highway Hospice

- Greta Schoeman was a nurse from the United Kingdom
- She moved to South Africa in 1969
- She cared for her ailing dad at her home in Westville.
- It was then that she realized the need for specialized care and support for the dying patient and their carers
- She raised funds from the community to purchase the first building on this site, in 1984, to house 7 patients.
- In 1982, she established the oldest Hospice in KZN – The Highway Hospice



Highway Hospice Education Unit





- Beginnings and Endings Course
- Grief and Bereavement Support
- Journal Club

The Referral Process

- The patient may reach out to our admissions officer at Highway Hospice directly.
- If the patient is unable to speak for themselves we accept phone calls from the patient's next of kin provided that the patient has given consent.
- The patient must be aware of their diagnosis and prognosis, that they have been referred for Palliative Care and is accepting of Highway Hospice intervention.
  *We do not collude to lie to the patient.
- After the initial chat with our admissions officer, patients have to provide supporting clinical reports, a completed Highway Hospice referral form from their diagnosing, treating or referring doctor, confirming their diagnosis and prognosis, that they are at an end stage of their illness or in a terminal phase.

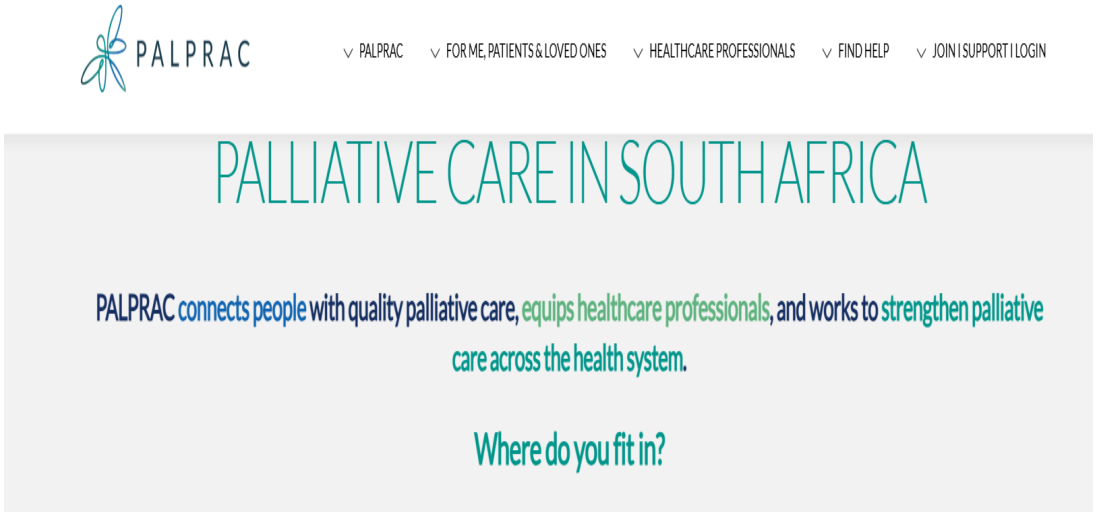
What do we want to know?

- Who?
- What?
- Why?
- When?
- Where?
- How?



Accreditation and Palliative Care Practitioners

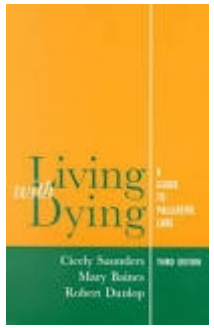




https://palprac.org/

You matter because you are you.
You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die.

Dame Cecily Saunders





THANK YOU!

THE HIGHWAY HOSPICE

—ASSOCIATION—

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