Expanding palliative care beyond oncology

KARL TECHNAU

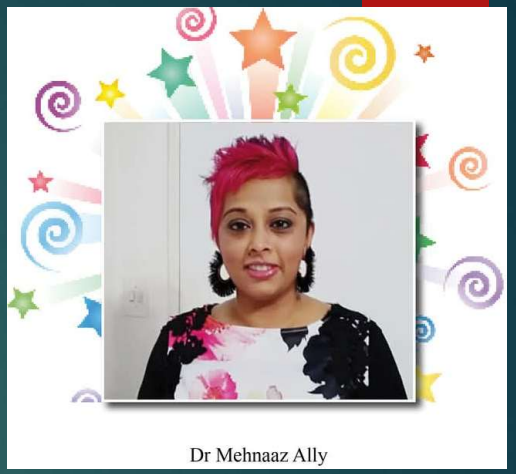
27TH JULY 2025

WITS UPTO SPAED CONFERENCE

25 - 27 July 2025
The Wanderers Club, Johannesburg

In loving memory of…

Dr Mehnaaz Ally



Celebrate! Her and You

Slow down

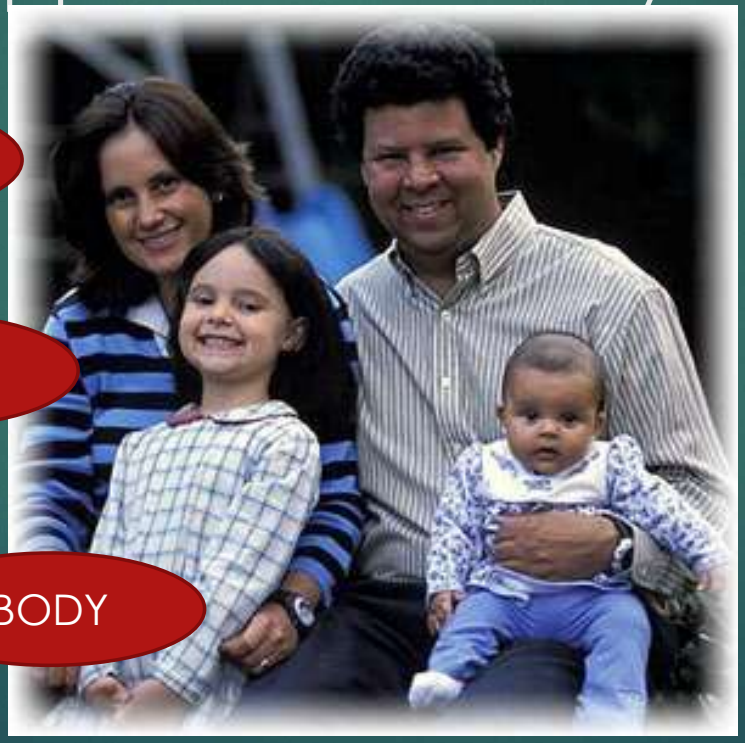
- Loss, Achievements
- Daily work

Palliative care beyond oncology

What is palliative care?

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

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.



SPIRIT

MIND

BODY

FAMILY

What is it?

A speciality?

A calling for a few people in medicine who feel that way inclined?

Touchy feely part of medicine?

A survival strategy?

An example outside of oncology

Ten steps of palliative care for children with SAM

Ten steps

The WHO Ten Steps[2]

Step 1: Treat/prevent hypoglycaemia

Step 2: Treat/prevent hypothermia

Step 3: Treat/prevent dehydration

Step 4: Correct electrolyte imbalance

Step 5: Treat infection

Step 6: Correct micronutrient deficiencies

Step 7: Start cautious feeding

Step 8: Rebuild wasted tissues

Step 9: Stimulation, play and loving care

Step 10: Preparation for follow-up after discharge

Mortality in SAM

We now know that most malnutrition related deaths occur in the first few days of treatment and are mainly due to the following 5 conditions:[1]

- HYPOGLYCAEMIA
- HYPOTHERMIA
- MISMANAGEMENT OF DEHYDRATION
- MISSED INFECTIONS
- SEVERE ANAEMIA

This brief was written by Susan Strasser, Nurse Training Coordinator, Health Systems Trust, Initiative for Sub-District Support, Professor David Sanders (UWC), Dr. David McCoy (ISDS), Dr. Thandi Puoane (UWC) and Dr. Mickey Chopra (UWC).

Case Baby OM

- 17 Months old boy
- Family:
  - Mother (brought him in)
  - Three siblings - 5yr old, 10yr old (lives elsewhere), 23 year old with one child
    - 5 year old
- Father abandoned the family

- 5 people in household (1 room shack)
- Outside toilet, public tap
- No birth certificates, no grant access
- Not SA citizens

- During this admission
  - 23 year old daughter looked after the own child and other sibling (both 5 years old)

Birth and Obstetric History

- Mother booked at 24 weeks
- Diagnosed HIV positive
- Started ART
- Born at term 3200g, normal Apgars
- No admissions
- RTHB – complete until 14 weeks, missed 6,9,12 moths visits
- AT 14 weeks WAZ 0-> -2, HAZ 0
- Breastfed for 12 days
- Very poor circumstances
- Development:
  - Walked at 12 months
  - Regression, only sitting

Initial presentation

- Swollen hands and feet
  - Three week Hx
  - Initially treated by a local clinician as allergy
- Peeling skin
- Loss of weight

Heilskov, S., Vestergaard, C., Deleuran, M.S. (2017). Defining and Assessing Skin Changes in Severe Acute Malnutrition (SAM). In: Preedy, V., Patel, V. (eds) Handbook of Famine, Starvation, and Nutrient Deprivation. Springer, Cham. https://doi.org/10.1007/978-3-319-40007-5_12-1

Ten steps

The WHO Ten Steps[2]

Step 1: Treat/prevent hypoglycaemia	Step 6: Correct micronutrient deficiencies
Step 2: Treat/prevent hypothermia	Step 7: Start cautious feeding
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Summary

- 1 – Impeccable Assessment
- 2 - Warmth
- 3 - Access
- 4 - Pain
- 5 - Presence
- 6 - Family
- 7 – Medical Team
- 8 – Post “ICU” syndrome
- 9 - Post admission
- 10 - Bereavement

HIV disease in infants

- Why do you have HIV, my child?
- Severe spiritual suffering
  - Guilt
  - Anger
  - Frustration
  - Fear

The hardest part of treating a baby with HIV is treating the mother's broken heart

Considerations

- Careful communication
- Support post diagnosis of the child
- Maternal care/Family care
- Prevent maternal illness and family disintegration
- Mindful of bereavement
- Cervical cancer and

HPV awareness

AIDS and Behavior
https://doi.org/10.1007/s10461-025-04760-5

ORIGINAL PAPER

Care for the Caregiver: How Caregiver Mortality Affects Treatment Outcomes—An Observational Cohort Study

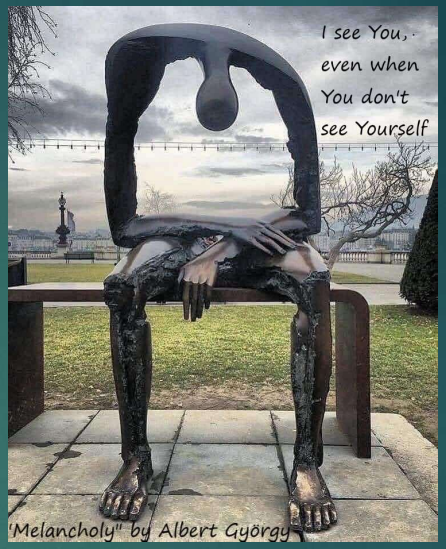
Josephine Keal[1] · Nicola van Dongen[1] · Thalia Ferreria[1] · Gillian Sorour[1] · Karl-Günter Technau[1]

Accepted: 5 May 2025

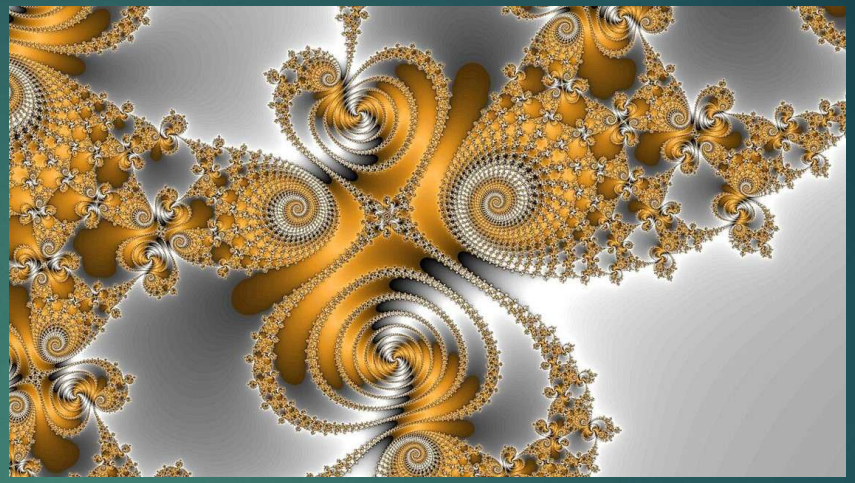
Table 1 Ages of caregiver and children and relation to clinic entry in cases with caregiver death

	All	Mother	Father	Other
Total	119	100	18	1
Median age of child (years) at time of death (IQR)	6.9 (3.5–11.7) N=95	6.1 (3.1–10.3) N=81	10.6 (5.113.5) N=13	12.7 N=1
Median age of caregiver (years) at time of death (IQR)	35.3 (30.241.7) N=77	35.2 (29.939.2) N=66	43.2 (32.752.1) N=10	65.4 N=1
Death in relation to entry into clinic N (%)				
After entry	66 (69)	57 (70)	8 (62)	1 (100%)
Same year as entry	10 (11)	8 (10)	2 (15)	0
Before entry	19 (20)	16 (20)	3 (23)	0
Unknown	24 (20)	19 (20)	5 (28)	0
Year of death N (%)				
2005 and earlier	2 (2)	2 (2)	0	0
2006–2010	13 (11)	13 (13)	0	0
2011–2015	23 (19)	19 (19)	4 (22)	0
2016–2021	54 (45)	44 (44)	9 (50)	1 (100)
Unknown	27 (23)	22 (22)	5 (28)	0

IQR Inter-quartile range



What is suffering?



Which part of you relieves it?

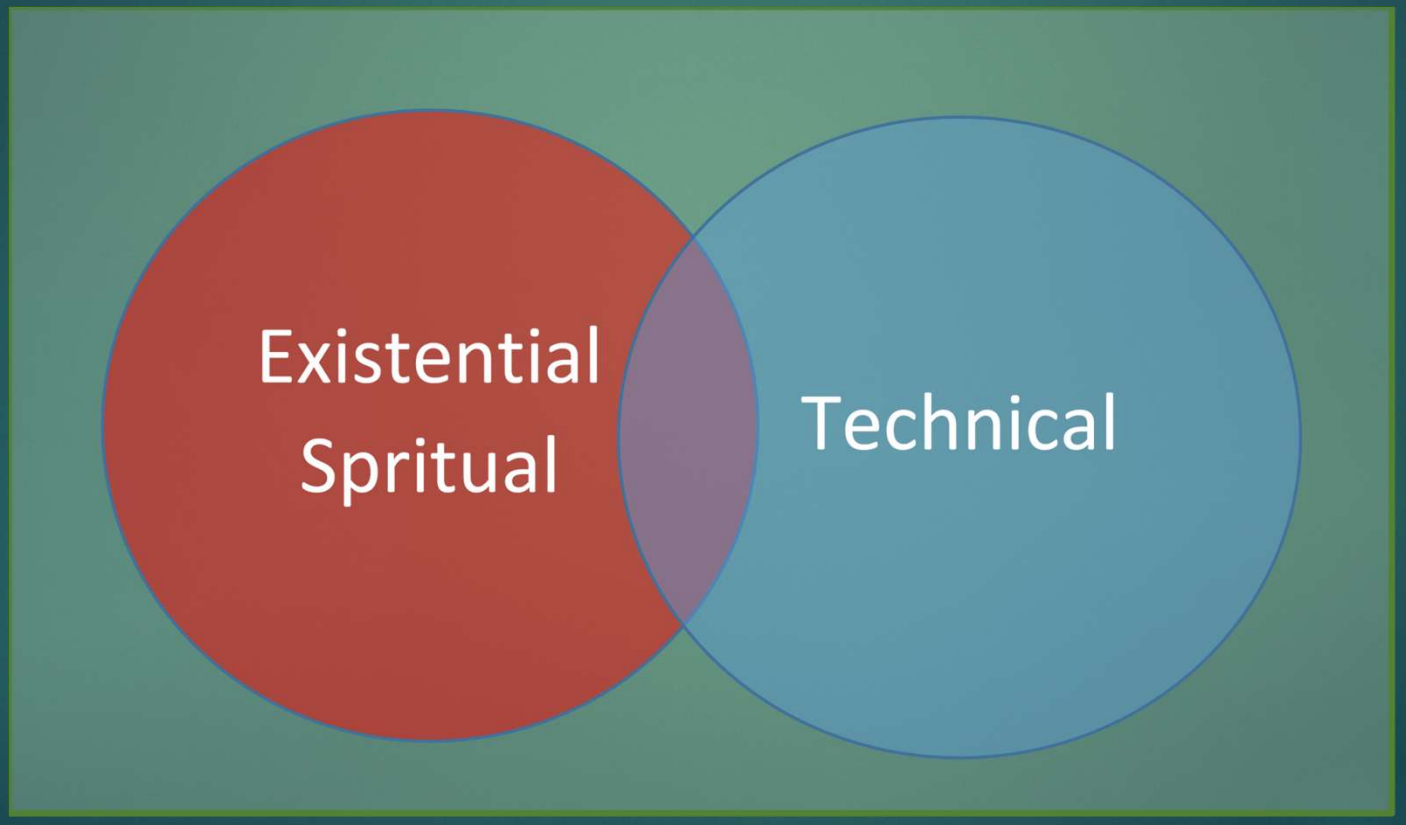
SPECIAL ARTICLE

THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE

ERIC J. CASSEL, M.D.

Abstract The question of suffering and its relation to organic illness has rarely been addressed in the medical literature. This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself. (N Engl J Med. 1982; 306:639-45.)

Twin obligations of medical practice



Expanding palliative care

- Founded in a philosophy of non-separateness
- Holistic assessment
- Identification of what is truly causing suffering

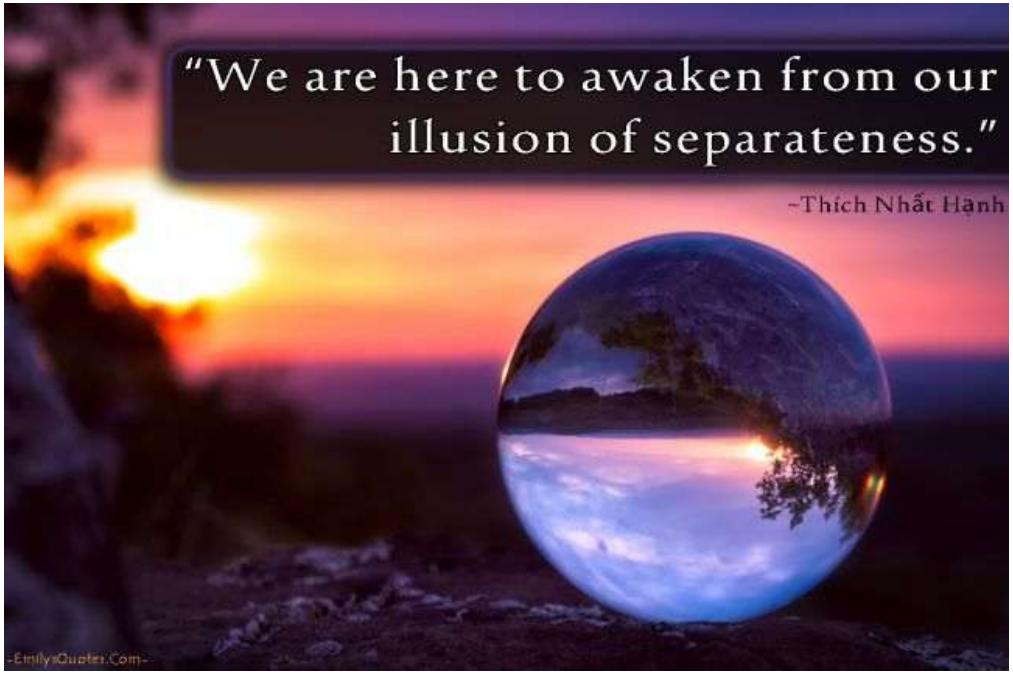


Figure 1: Genogram for PJM. Green lines indicate close relationships while red lines indicate conflictual relationships. Striped black line indicates relationship characterised by occasional abuse. Dotted black lines indicate non-familial, non-romantic outside relationships.

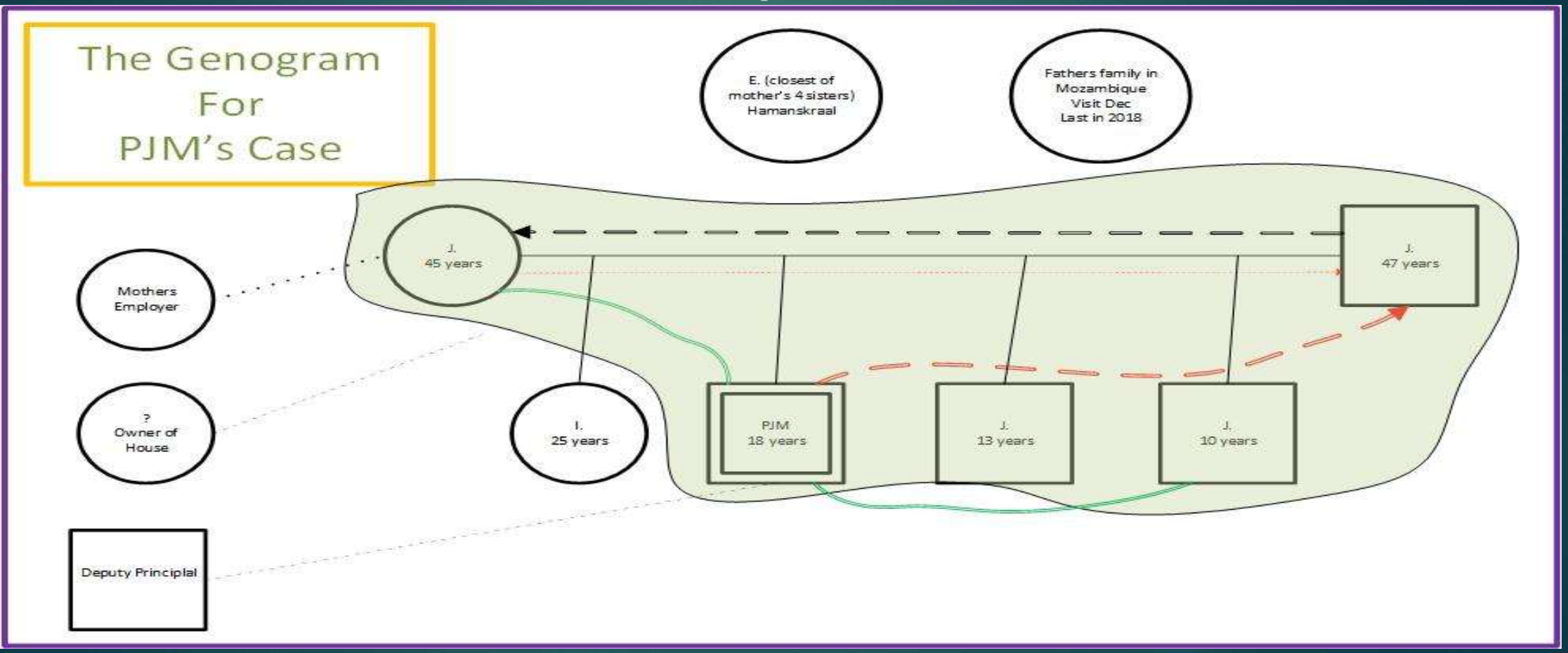
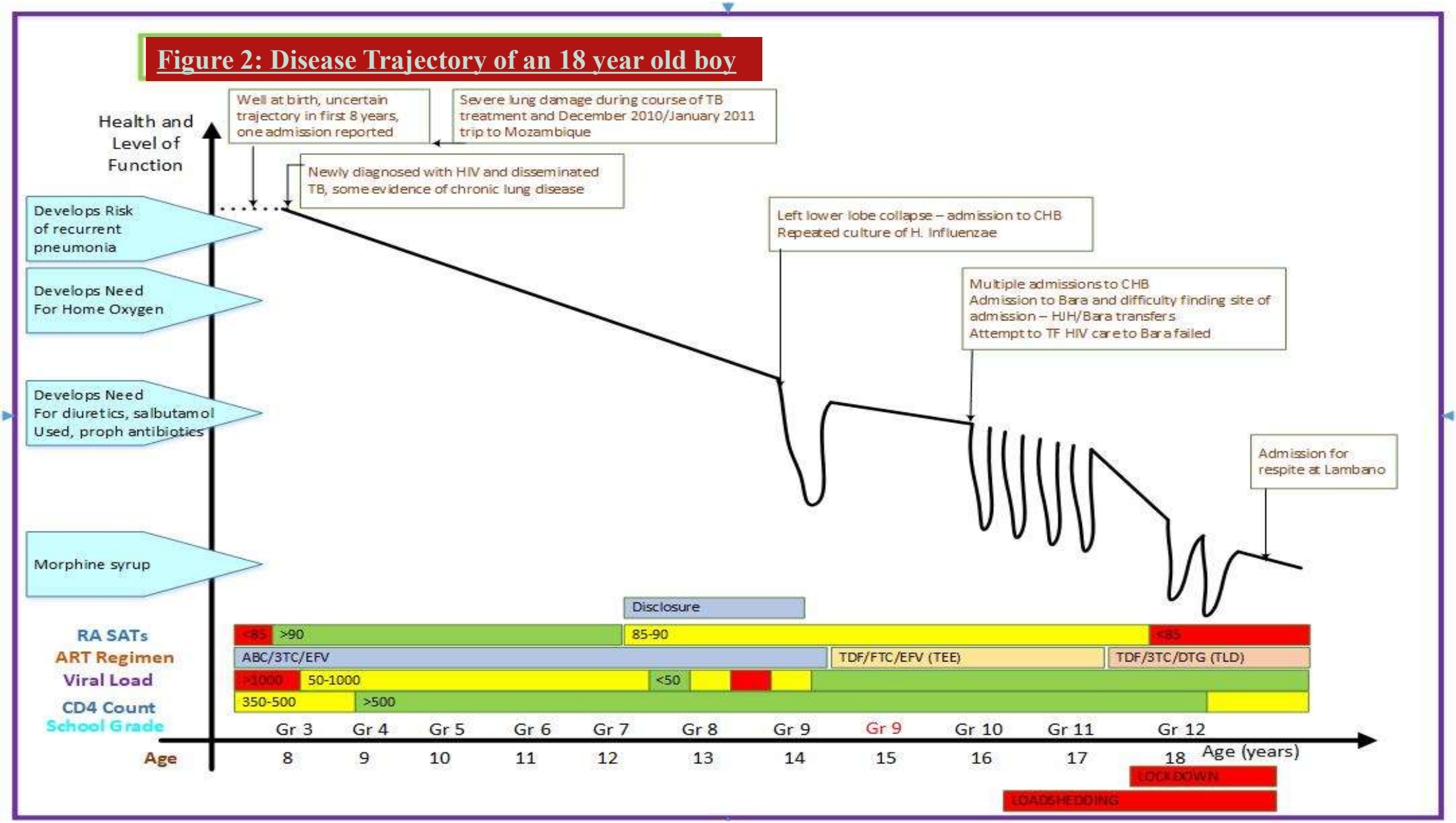
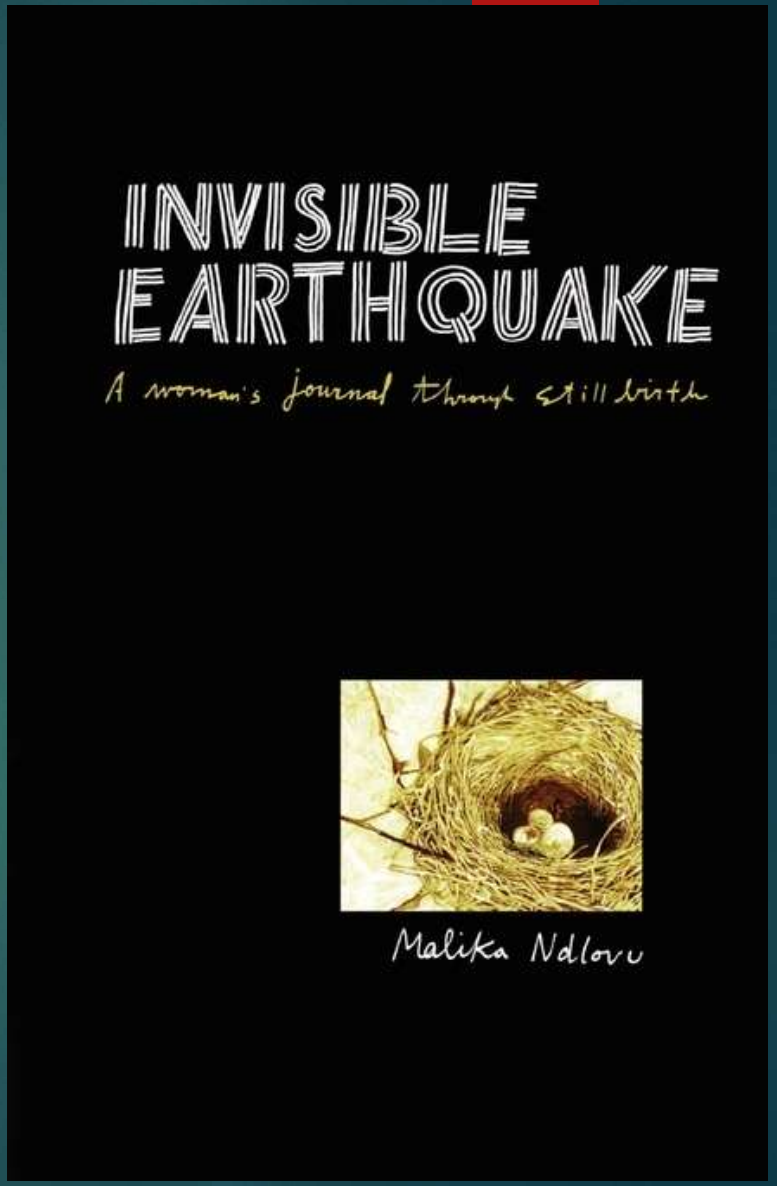


Figure 2: Disease Trajectory of an 18 year old boy



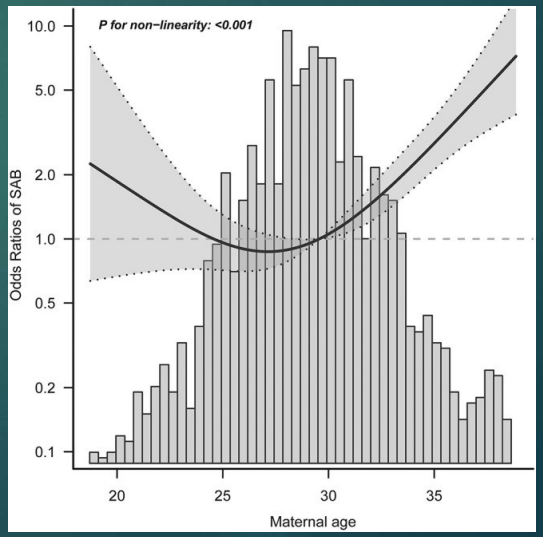
Pregnancy Loss and Neonatal Deaths



Broad topic of grief/loss associated with pregnancy

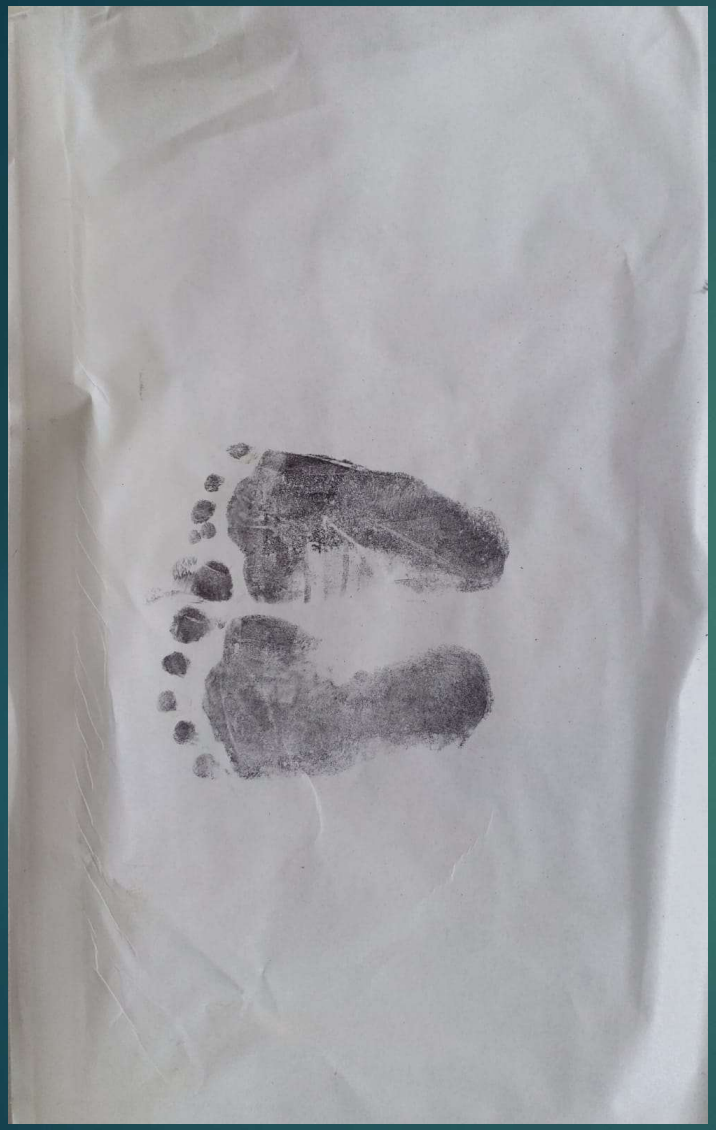
- Termination (intended) of pregnancy
  - High rates of unintended pregnancy 121 mio annually worldwide
  - High rates of TOP (60%) in unintended pregnancy
  - High rate of unsafe TOP (45% globally – 75% Sub-Saharan Africa)
  - Access to TOP complicated by many factors – social/stigma/legal/socio-economic
- Still birth – higher risk with young adolescents – still higher with older adolescents

- Miscarriage
- Ectopic pregnancy
- Neonatal and Previous child deaths



Issues in our setting

- Our settings are busy
  - Little time to spend with each case
  - Structured resources – psychology and social work – limited availability
- Culture of stoicism/moving on/being strong
- Many cases are not addressed adequately
  - Activities during admission – timeframe too short
  - No follow-up as clinical units and family's lives too busy
  - No chance for any memory/grief work
- Viscous cycle towards next pregnancy and whole experience of motherhood
- Please consider careful history
  - Past pregnancies and losses
  - Child losses
  - Disenfranchised grief – many varieties



THE PALLIATIVE CARE TEAM AT RAHIMA MOOSA INVITE YOU TO OUR SUPPORT GROUP FOR PARENTS WHO HAVE HAD STILLBORN BABIES.

WE WILL BE MAKING

MEMORY BOXES

PLEASE BRING ALONG ANY PRECIOUS ITEMS YOU HAVE: SCANS, CLOTHING, FOOTPRINTS, DRAWINGS OR LETTERS THAT YOU OR YOUR OLDER CHILDREN HAVE DONE.

AT 11H30 ON SATURDAY, 2 DECEMBER '23
IN THE NURSES' RESIDENCE HALL

WE WILL PROVIDE BOXES, ALL THE STATIONERY NEEDED TO CREATE YOUR BOX AS WELL AS FUNDS TOWARDS TRANSPORT.
LIGHT REFRESHMENTS WILL BE SERVED.

Honouring life together

RSVP:SR MERLYN GLASS ON +27 82 853 7113


Bostik
Prestik

Cervical Cancer

Case

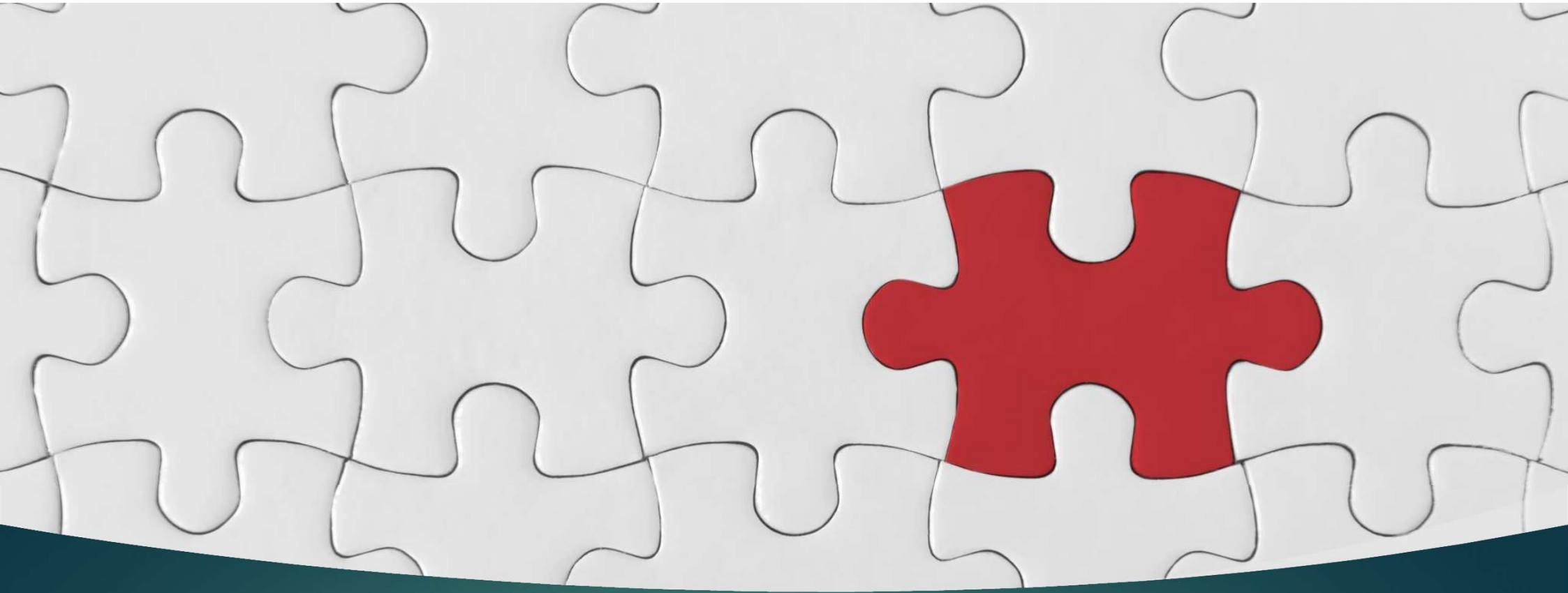
- 34 year old woman P3 G3
  - oldest child is 18 years old
  - Youngest child is 18 month old
- Providing palliative care due to advanced Ca Cx
- Living with HIV, on ART
- Lack of South African documentation – limited treatment options
- Attended in hospital by uncle, husband
- Arranged to travel back to home country to spend her last weeks with her children
- Many "what if questions"
  - What if she had had access to immunization?
  - What if she did not have such early sexual debut, poor socio-economic status?
  - What if cervical screening was better incorporated into obstetric care?

What do these examples illustrate?

- Many opportunities within paediatrics
- Bereavement care of families and children outside of paediatrics
- Many opportunities to prevent
  - Pain
  - Disease progression
  - Spiritual suffering

You may ask:

- Is this not too much to ask?
- How do you separate your emotions from your work?
- Where are the boundaries?



Who is the final part of the puzzle? Who else needs palliative care, or in other words, holistic recognition?

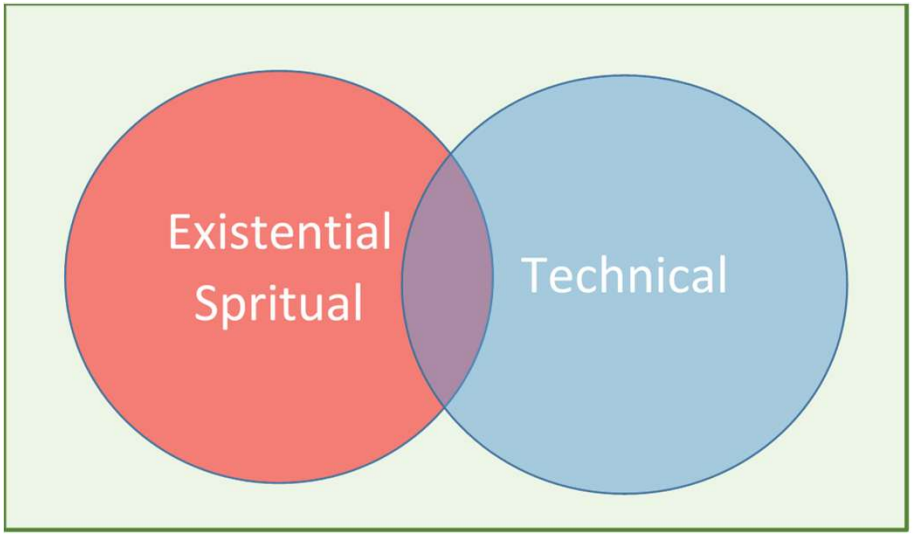
You

Our reality in the field

- Constant bombardment of facts and impressions
- Constant trauma
  - Emotional
  - Administrative
  - Physical
- Very little opportunity to process
- Culture of stoicism
- Most unequal society

A survival tool?

- Why would it help us to survive by going deeper into other peoples' and our own pain?
- Pretending to not have a broken heart is much harder than acknowledging a broken heart



Our job is a duality

FUNDAMENTALLY SPIRITUAL AND TECHNICAL

Why is palliative care an aide to survival?

- When you care about a fellow human being
- You celebrate existence
- You honour and do what you intrinsically know is the right thing.
- It restores not only their hope but yours too.

How do we expand palliative care to beyond oncology

- Existentially
  - We listen to our heart – acknowledge and accept who and what we are
  - We open our eyes and focus on what is before us, not the whole world, just what is in front of us and we allow ourselves to respond
- Technically
  - Pain monitoring
  - Advanced care planning
  - Parental/family care incorporation
  - Spiritual assessment

A last word on children and students

- Let us not fall into the illusion that we are the only doctors and teachers in the room
- Explore what your patients teach you
- Explore what your students teach you

Acknowledgements

- The organisers
- My mentors
- My patients
- My children
- My wife and family
- AI

Celebrate! Her and You