

End of Life Care in Patients with TB

Dawn Gross MD, PhD, FAAHPM
ANX Hospice Medical Director
Palliative Care Service, UCSF

Heather Isaacs, M.Div., BCC
UCSF Health and Mettle Health

October 24, 2024

What comes to mind when the “H” word is uttered?

nothing more to do

death

morphine

incurable

goodbye

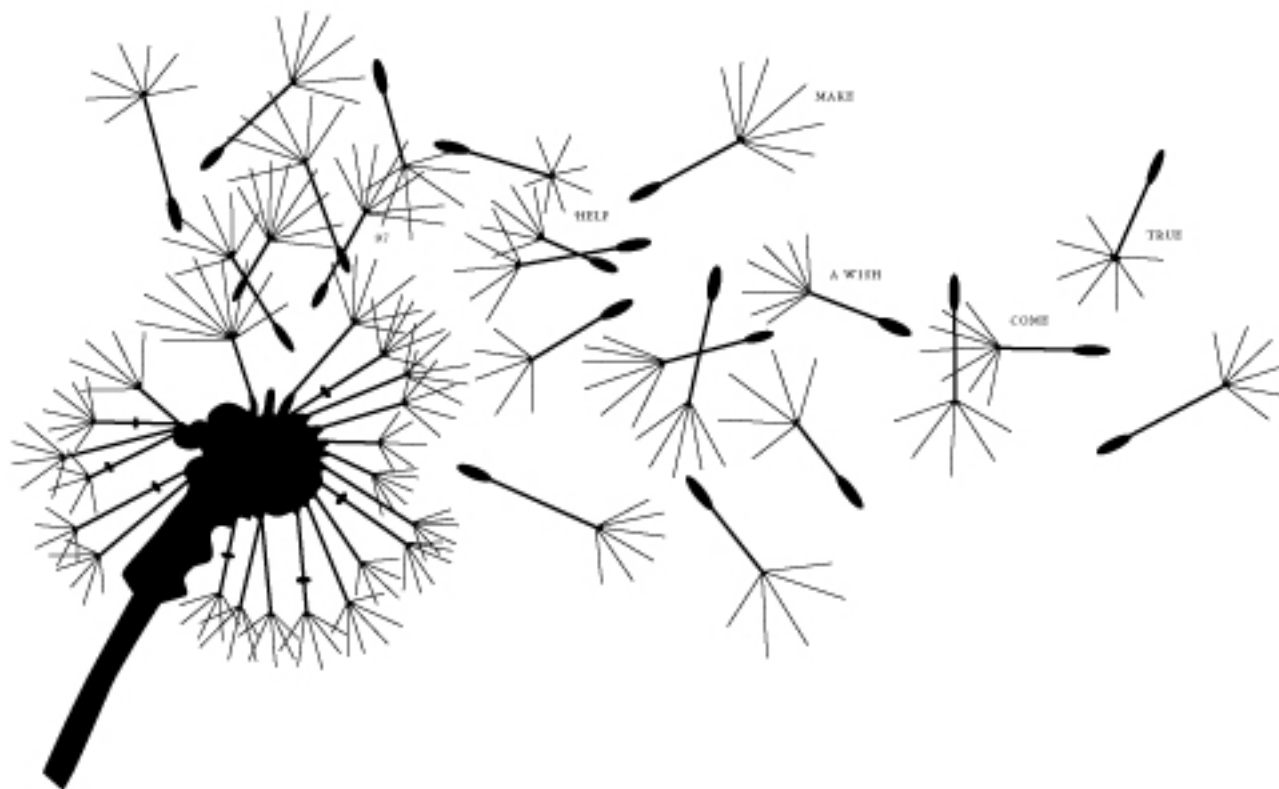
sadness

hopelessness

palliative care

hospice





Hospice vs. Palliative Medicine

Fundamentally, it is a difference in payment model



Hospice vs. Palliative Medicine

∞ 5 team members required

∞ 5 team members aspired

Spiritual Care: Who, What, Why, & How

- * Chaplaincy as an evolving discipline of professionalized spiritual care
- * Chaplains as members of the interdisciplinary team and bridges to the community (e.g. clergy, spiritual leaders)
- * Spiritual Care as part of the care we can all provide: Generalist vs. Specialist model
- * Addressing “Total Pain” (Dame Cicely Saunders)

Spiritual Care:

- * Care for Self—How do you honor your spirit? Connect to a sense of what is most important/sacred/true? How do you know yourself as part of something larger than yourself? How do you nurture that relationship via spiritual or religious practices? Art? Nature? Rituals? Community?
- * Care for Others—Interpathy: “Describes a caregiver’s capacity to enter into another’s narrative, cultural, and symbolic world—their meaning-making system.”
- * Includes on-going curiosity about their story, to not assume shared experience or values, to be willing to constantly learn and adjust, as needed, to acknowledge and be responsible for implicit biases as well as systemic causes to “Total Pain.”

Collaborating with Hospice

- * Your warm hand-off to the hospice team, when possible, can be an essential part of helping build trust with new hospice team, establish continuity of care, provide TB-specific education, when needed, and honor your specific relationship to patient and family.
- * When a patient transitions to hospice care, it is not a sign of “failure” or “giving up” on a person. It can be an opportunity to recognize the need for increased focus on quality of life and pain/symptom management as well as support for families, including caregiver support and bereavement.
- * Empowering patients and families to know their rights and options regarding hospice (e.g. NHPCO, www.medicare.gov/care-compare)

Making Space for Grief as a Professional Caregiver

- * Recognizing the impact patients have on our lives: cultivating opportunities to grieve and memorialize our patients with our work community and in our own personal lives, how do we ritualize letting go, releasing our part in another person's story?
- * We all need support at different times in life. We may be in a season of our own personal loss while caring for others and/or a patient situation may mirror a relationship or loss in our lives that can reactivate our grief.
- * Lack of institutional commitment or personal resources to access support
- * Mitigating risk of compassion fatigue
- * Protective aspects of developing meditation/mindfulness/prayer practice

Hospice vs. Palliative Medicine

∞ 5 team members required

∞ 5 team members aspired

∞ Physician certification of terminal diagnosis

∞ Any point in time of life-altering illness

∞ Bereavement care

∞ Capitated payment

∞ Fee-for-Service



Wit



SPIKES

- * Set up
- * Perception
- * Invitation
- * Knowledge
- * Emotion
- * Summary

Set up

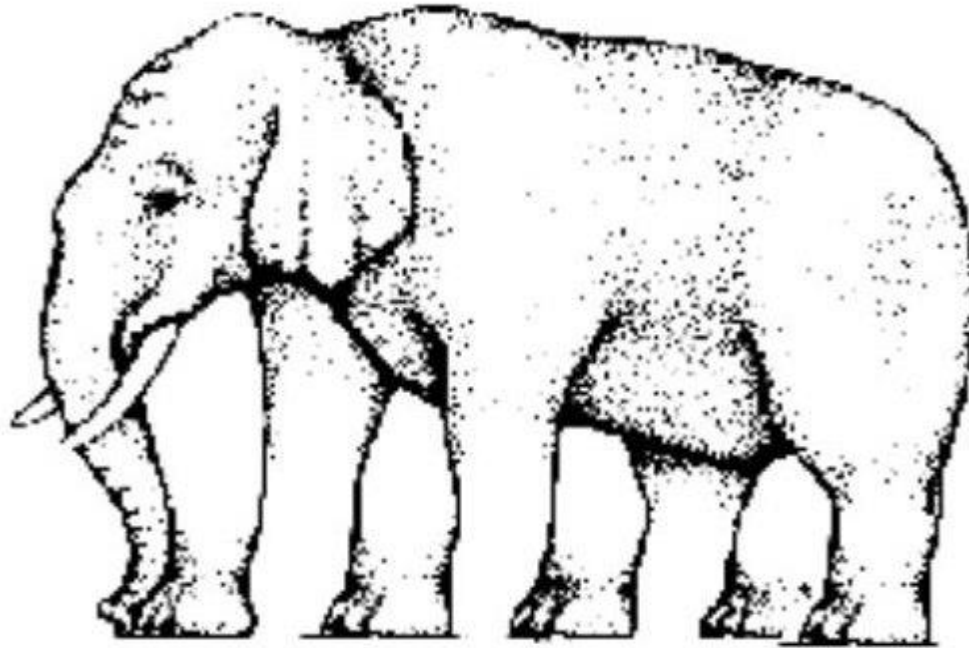


Have a Seat



Bruera et al *Nature Rev Clin Onc* 2007
Swayden et al *Pt Educ and Counsel* 2011

Perception



How many legs does this elephant have?

Invitation



Knowledge



Ask-tell-Ask



Addressing Emotions



Addressing Emotions



- #1 Fear of destroying hope
- #2 Dealing with emotion
- #3 Time

Baile et al *The Oncologist* 2000



Addressing Emotions

- * Name
- * Understand
- * Respect
- * Support
- * Explore

You have cancer.



You have TB.



...an insidious
infection...



Insidious...
insidious means
treacherous



Shall I
continue?



Name



I can see this is
upsetting news
for you.

Name



The medications will inevitably have some side effects.

You will need to use infection precautions.



We will be relying on
your resolve to
withstand some of the
more pernicious side
effects... isolation...



I can't imagine how
difficult this must
be to hear.

Understand



I am so moved by
your commitment
to your students...

Respect



*I will do my best to make
sure you have what you
need.*

Support





I see you biting your lip. Can you share what you are thinking?

Explore



Summary



Acknowledgement



Debrief



Take Home

- * Take time to set up family meetings
- * Language matters
- * Let patient/family do the talking
- * Discover what people *wish/want/need*
- * The Hospice team is here for YOU