Mass General Brigham

Management at End of Life

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Learning Objectives

Review historical roles of psychiatrists in end of life care and present landscape of integrating psychiatrists into end of life care.

Be able to identify trajectories of individuals at end of life.

Reflect on opportunities for greater connection between psychiatrists and patients at end of life

Psychiatry at End of Life

Disclosure/Reflexivity

No Disclosures

I am on a journey to understand how my social position as a white, cisgender man raised in a Jewish middle-class family and partnered to a white queer woman has shaped the lens through which I view the world. I completed my medical education at a public university in Kentucky where I became exposed to end of life care predominantly through hospice and inpatient palliative care, with little integration with psychiatry. My interest in caring for psychiatrically ill patients at end of life stems from the recognition of the difficulties in accessing psychiatric care across the lifespan and a desire to serve this particularly vulnerable population. In light of this, I practice predominantly in palliative medicine as a psychiatrist appointed through the department of medicine.

“I say to people who care for people who are dying, if you really love that person and want to help them, be with them when their end comes close. Sit with them – you don’t even have to talk. You don’t have to do anything but really be there with them.”

–Elisabeth Kubler-Ross

In the end
I want my heart
to be covered
in stretch marks.

Andrea Gibson

“Palliative medicine and psychiatry are natural allies yet have not leveraged their intrinsic affinity to optimize patient care. The two fields share a deep concern with the broad human experience-physical, psychosocial, and spiritual—of suffering, how people cope with the intrinsic aspect of life, and how they can be helped. Both fields utilize a broad array of treatments to ameliorate suffering. Both fields are concerned centrally with emotions and the connection between psychic and physical experience.”

–J. Andrew Billings & Susan Block

Psychiatric Expertise Is Needed At End Of Life

- Psychiatric distress is common in serious illness[1,2].
  - Approximately 40% of individuals with life-limiting illnesses experience clinically significant mood and anxiety symptoms.
  - Delirium at EoL is common, impacting ~75% of patients prior to death
  - Psychiatric comorbidity associated with poor QoL, lower functioning and higher physical symptom burden
- Mental health comorbidity associated with increased utilization of palliative care[1].
- Addressing psychological and psychiatric aspects of care is a core palliative care domain[3].
- Minority of palliative care providers feel adequately prepared to address these forms of distress[4,5]

1. Sadowska, K., Fong, T., Horning, D. R., McAteer, S., Ekwebelem, M. I., Demetres, M., ... & Shalev, D. (2023). Psychiatric Comorbidities and Outcomes in Palliative and End-of-Life Care: A Systematic Review. *Journal of Pain and Symptom Management*.
2. Marcantonio, E. R. (2011). Delirium. *Annals of internal medicine*, *154*(11), ITC6-1.
3. Betty R. Ferrell, Martha L. Twaddle, Amy Melnick, and Diane E. Meier.National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition.Journal of Palliative Medicine.Dec 2018.1684-1689.
4. Lee, W., Chang, S., DiGiacomo, M. *et al.* Caring for depression in the dying is complex and challenging – survey of palliative physicians. *BMC Palliat Care* **21**, 11 (2022).
5. Patterson, K. R., Croom, A. R., Teverovsky, E. G., & Arnold, R. (2014). Current state of psychiatric involvement on palliative care consult services: results of a national survey. *Journal of pain and symptom management*, *47*(6), 1019-1027.

Addressing Psychiatric Distress Is Structurally Challenging

Insufficient Availability

Scarcity of geriatric psychiatrists in general; High case load for c/l psychiatrists

- High volume forces psychiatrists into consultant/initial recommendation providers

Challenges in Establishing Outpatient Care

Tenuous health/comorbid appts can make in person appointments challenging; minimizing visits when on hospice

- What modifications are needed to the therapeutic frame?

Perceived Psychiatrist Lack of Interest

Belief that psychiatrists don't want to care for dying patients, traditional psychiatric lens might not be appropriate, availability of other support services

- What exposure to end of life care was part of your training?

Sitting with the Dying Is Hard Work

Emotionally intense, vulnerable and humbling. It isn't for everyone, and that's ok.

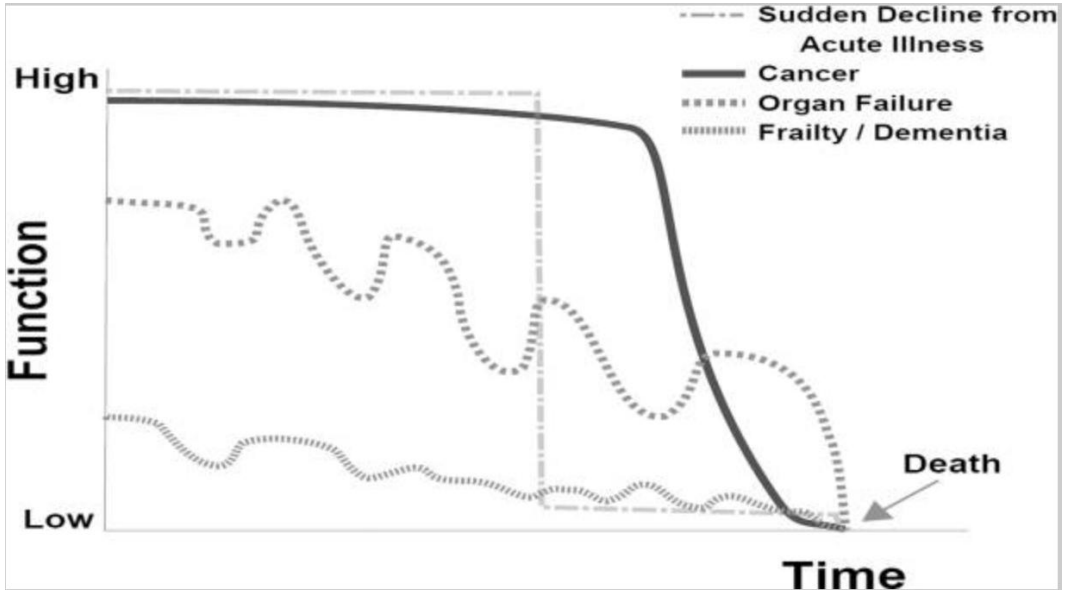
Patterson, K. R., Croom, A. R., Teverovsky, E. G., & Arnold, R. (2014). Current state of psychiatric involvement on palliative care consult services: results of a national survey. *Journal of pain and symptom management*, *47*(6), 1019-1027.

The Form That Distress Takes Changes As Death Approaches

- Clear depressive and anxiety symptoms may be more prominent earlier in the disease course
- Distress may take the form of existential dread or fear
- The loss of control and disconnection from meaning may present as demoralization
  - 43% of sampled palliative care patients at DFCI reported moderate-severe demoralization
- Symptoms and presentation shift as disease burden changes
- Physicality of dying may make psychiatric and psychological interventions challenging
- Opportunities to think outside the box

What Does End Of Life Look Like?

- There are varying trajectories to and through end of life[1]



- The Transitional Phase—marked by increase in symptoms and *transition* to being bedbound
  - More confusion, somnolence
  - Weakness
  - Loss of appetite, cessation of eating drinking
  - Falls
  - Incontinence
  - A felt sense that things are changing
  - *The Rally*

1. Sager, Z., Catlin, C., Connors, H., Farrell, T., Teaster, P., & Moye, J. (2019). Making end-of-life care decisions for older adults subject to guardianship. *The elder law journal*, *27*(1), 1.

Dying Is Hard Work[1]

- Individuals can survive 1-2 weeks without water, food
- Cessation of eating/drinking is an important milestone to watch for
- Draw the distinction between laboring and suffering
- Dying marked by significant changes—body temperature, skin color, breathing changes, etc

Manifestations of Active Dying

- Changes in skin temperature, moisture
- Breathing changes—tachypnea, irregular patterns, periods of apnea, *ahhh* exhales
- Changes in appearance--noticeable sinking, color changes, mouth drooping/gaping, skin mottling
- Agitation/restlessness
- An awareness that things are ending

1. Abrahm, J. L. (2015). *A physician's guide to pain and symptom management in cancer patients*. JHU Press.

What Is My Role Here?

Exploring with patients what dying means and represents

- What fears, worries, unfinished business is present?
- What is it like to say the D word?
- Asking the individual what is helpful
- What would it mean to plan your death? What do you want it to look like?
- What do you want your obituary to say?

Honoring your Relationship

- How to do you continue to care for someone who cannot communicate by speaking?
- What is your role to the family?
- What changes are necessary to the therapeutic frame?
- How do you say goodbye?

Offering Therapeutic Presence

- How do I show up authentically for this person and family?
- What are the boundaries with physical touch?

Changing Medications Before They Are A Problem

- Avoiding discontinuation syndrome
- Anticipating loss of swallowing
- Thinking outside the box

What Is My Role After the Patient Has Died?

Differentiating mourning, grief, depression, prolonged grief

What Do I Say To Families?

- Condolences
- Validation
- Reminiscing
- Offer to option to listen while the bereaved process the loss
- Listening
- Answering questions about burial rituals

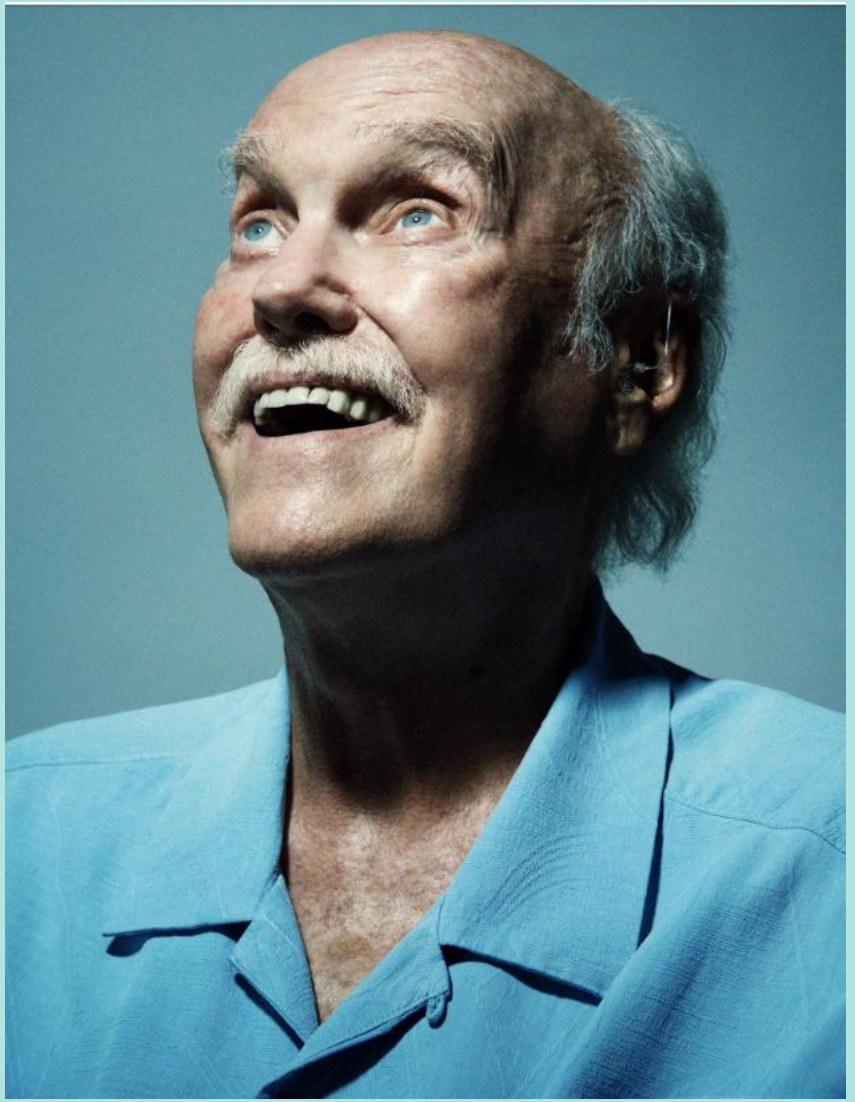
What Do I Say To Other Team Members?

- Opportunities to check in with colleagues
- Honoring the connection between clinician and patient

Death Represents An Opportunity To Connect With Living

We're All Just Walking Each Other Home

–Ram Dass

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