

The background is a solid blue color with a complex graphic overlay. It features several concentric circles and arcs of varying sizes and colors (white and light blue). A prominent feature is a large circular scale on the left side, with numerical markings from 150 to 260 in increments of 10. The scale is partially obscured by other circular elements. There are also several smaller circles and arcs scattered throughout the background, some with arrows indicating direction. The overall aesthetic is technical and scientific.

THE ROLE OF PALLIATIVE CARE IN TREATMENT OF PATIENTS WITH CHRONIC, INFECTIOUS DISEASE

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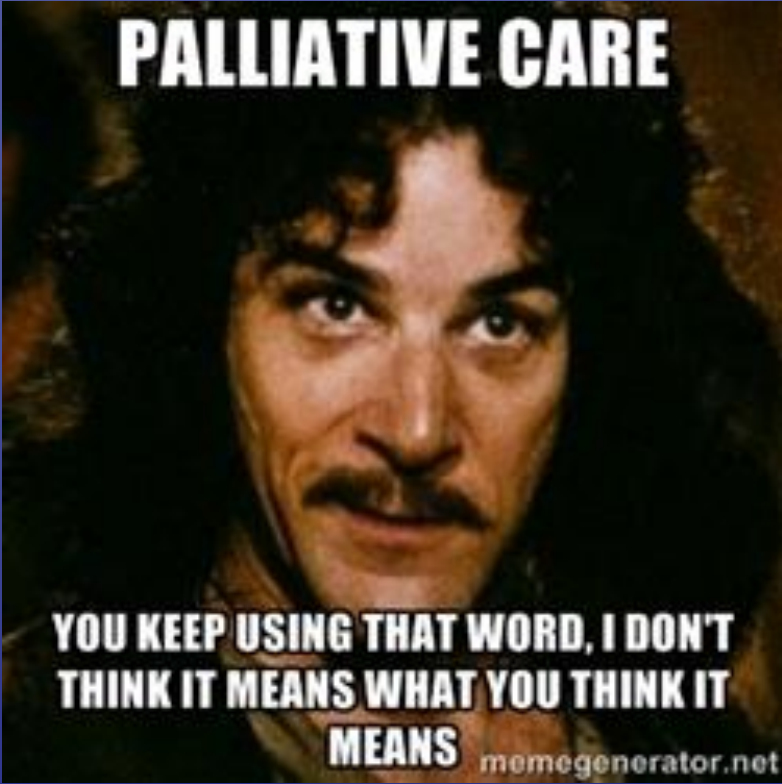
DIVISION CHIEF, PALLIATIVE AND SUPPORTIVE CARE

I HAVE NO COI OR DISCLOSURES



GOALS OF CARE

- Understand how palliative care practices are applied to all patients with chronic , infectious disease
- Recognize the role of ID providers in exploring the unmet palliative care needs of their patients
- Consider when a referral to a Palliative Care Specialist may be helpful
- Develop a skill set for advanced care planning



PALLIATIVE CARE

**YOU KEEP USING THAT WORD, I DON'T
THINK IT MEANS WHAT YOU THINK IT
MEANS**

memegenerator.net

THERE ARE MANY MISCONCEPTIONS ABOUT PALLIATIVE CARE

Traditional Palliative Care

Life-prolonging or curative treatment

Palliative care
to manage
symptoms and
improve quality
of life

Diagnosis

Death

HOSPICE CARE LOOKS LIKE THIS...

All hospice is palliative care, but not all palliative care is hospice.



WHY DO PHYSICIANS AND NURSES AVOID PALLIATIVE CARE EARLY IN THE COURSE OF A DISEASE?

“Offering palliative care ... is a challenge for the team and family because it is perceived as ‘giving up hope’ for recovery or cure.”

This occurs because the term palliative care is often used by health care providers as synonymous with end-of-life care...”

HOW DID DOCTORS AND NURSES DEFINE PALLIATIVE CARE?

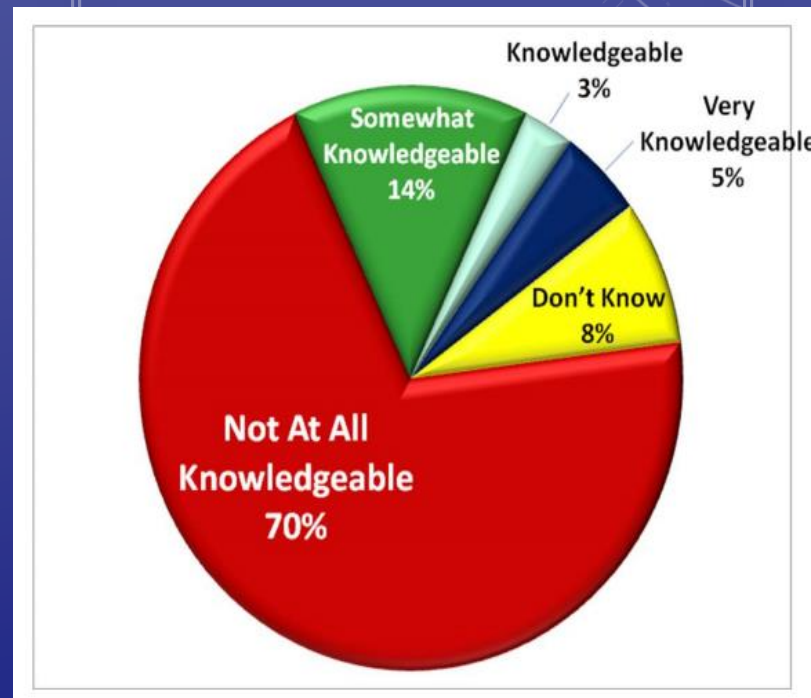
“Comfort care during one’s last few weeks or days of life to allow patients to pass in comfort and dignity”

“Make a patient’s remainder of life comfortable and pleasant, without side effects of treatment, no aggressive measures are taken. “

“The goal is to keep a patient comfortable and out of intensive medical treatment. The goal is not to cure but to treat their symptoms”

“Palliative care is helping families to give them comfort and options for what to do at their loved one’s end of life”

WHAT DO PATIENTS SAY ABOUT PALLIATIVE CARE?



SPECIALTY PALLIATIVE CARE CAN BE BETTER DEFINED LIKE THIS...

Palliative care is *specialized medical care* for people with *serious illnesses*. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve *quality of life* for both the patient and the family.

Specialty palliative care is provided by a *team* of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an *extra layer of support*. It is appropriate *at any age and at any stage* in a serious illness and can be provided along with curative treatment.

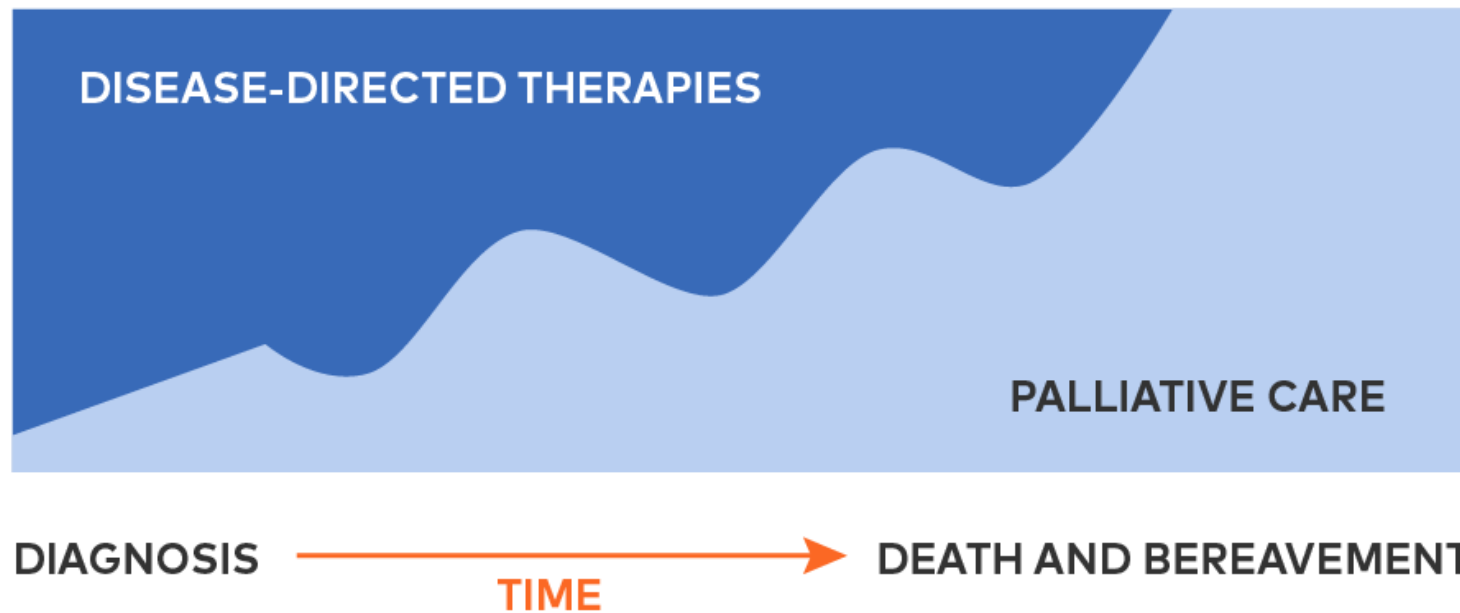
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PALLIATIVE CARE LOOKS LIKE THIS

Patients receive palliative care throughout the course of serious illness, and *at the same time as* disease treatment.



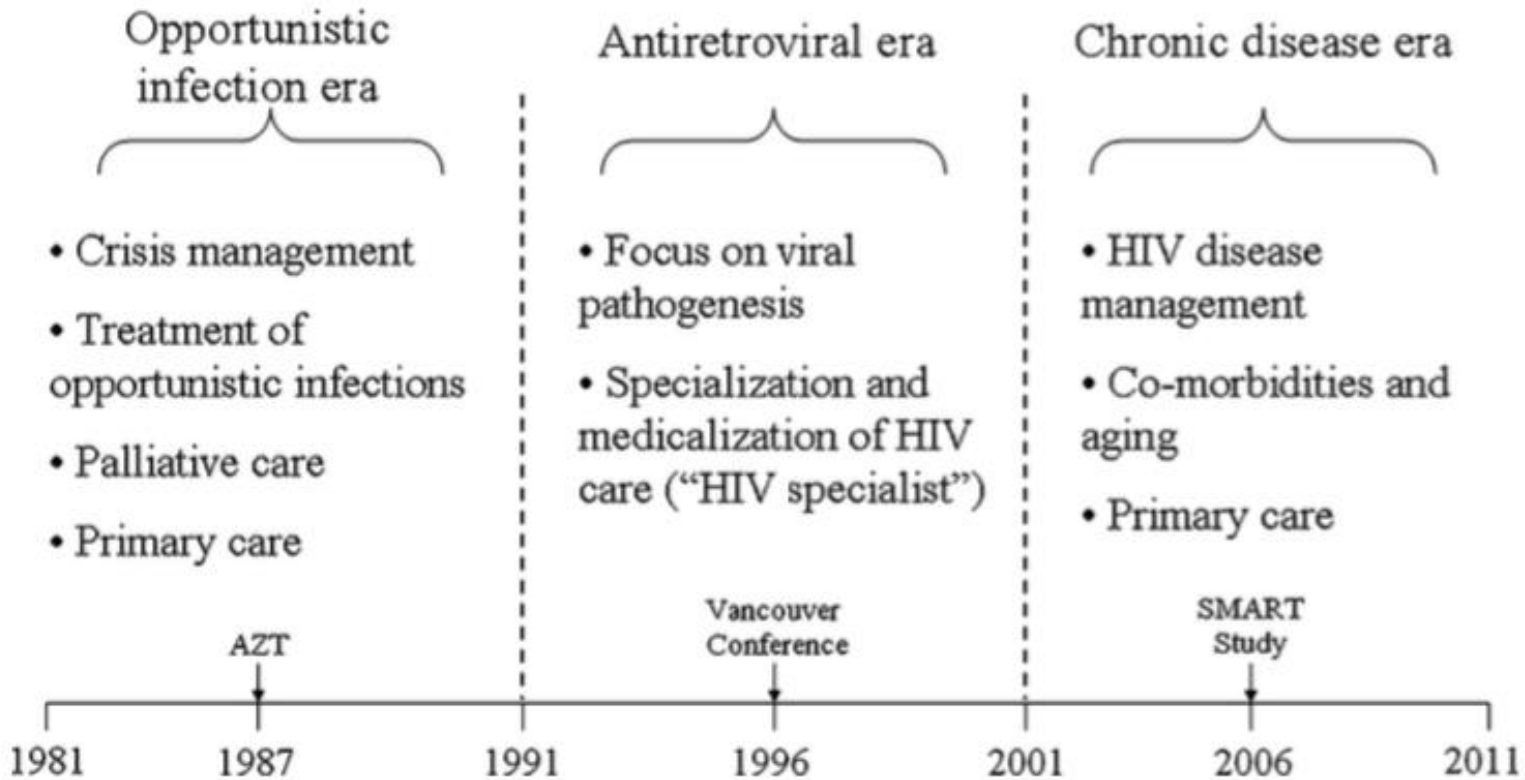


FIGURE 1. The HIV/AIDS epidemic: major clinical themes over 3 distinct eras, 1981–2011.

Chu C, Selwyn PA. An epidemic in the evolution: the need for new models of HIV care in the chronic disease era. *J Urban Health*,

“ In the HAART era, the false dichotomy of curative vs palliative care for patients with HIV/AIDS must be supplanted by a more integrated model to provide comprehensive care for patients with advanced HIV disease and their families. ”

Selwyn PA, Forstein M. Overcoming the False Dichotomy of Curative vs Palliative Care for Late-Stage HIV/AIDS"Let Me Live the Way I Want to Live, Until I Can't". *JAMA*. 2003;290(6):806–814.
doi:10.1001/jama.290.6.806

WHAT IS IN THE PALLIATIVE CARE SPECIALIST'S SYRINGE?

- Symptom management
- Prognostication
- Information Preferences
- Communication skills that work to match treatments with a patient's values and goals
- Care that integrates psychological and spiritual aspects of care



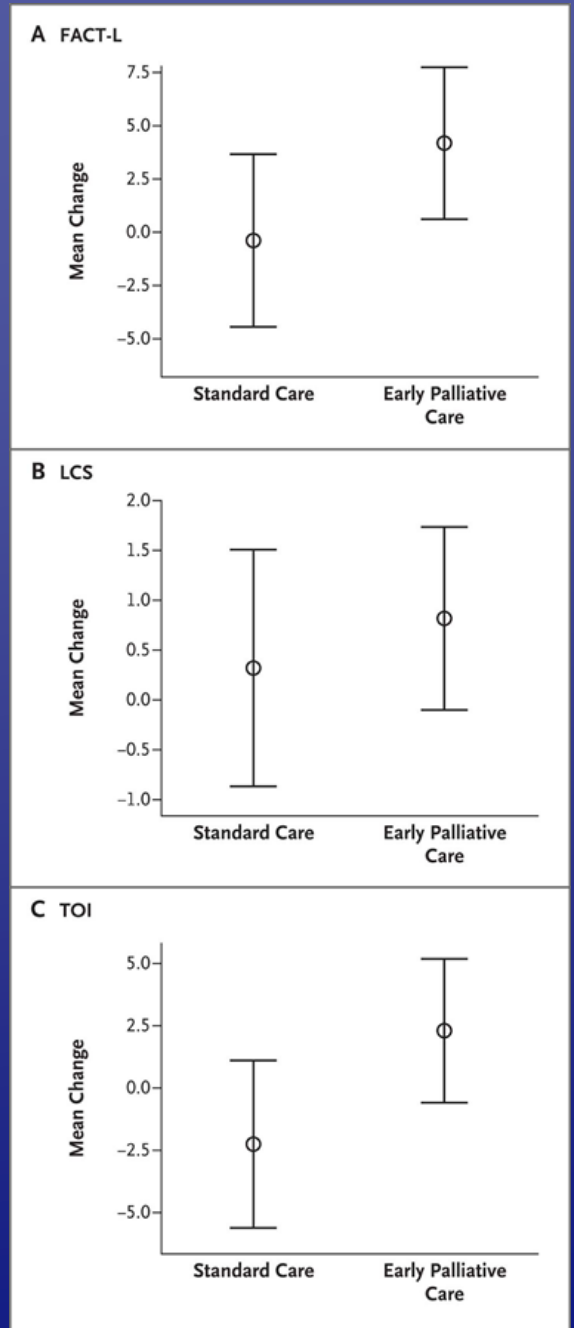
BUT MIGHT ADDING A PALLIATIVE CARE SPECIALIST MAKE A BAD THING WORSE?

- take away hope ?
- increase stress?
- create a self fulfilling prophecy?
- worsen outcomes or increase mortality?

EARLY PALLIATIVE CARE IN AN OUTPATIENT SETTING

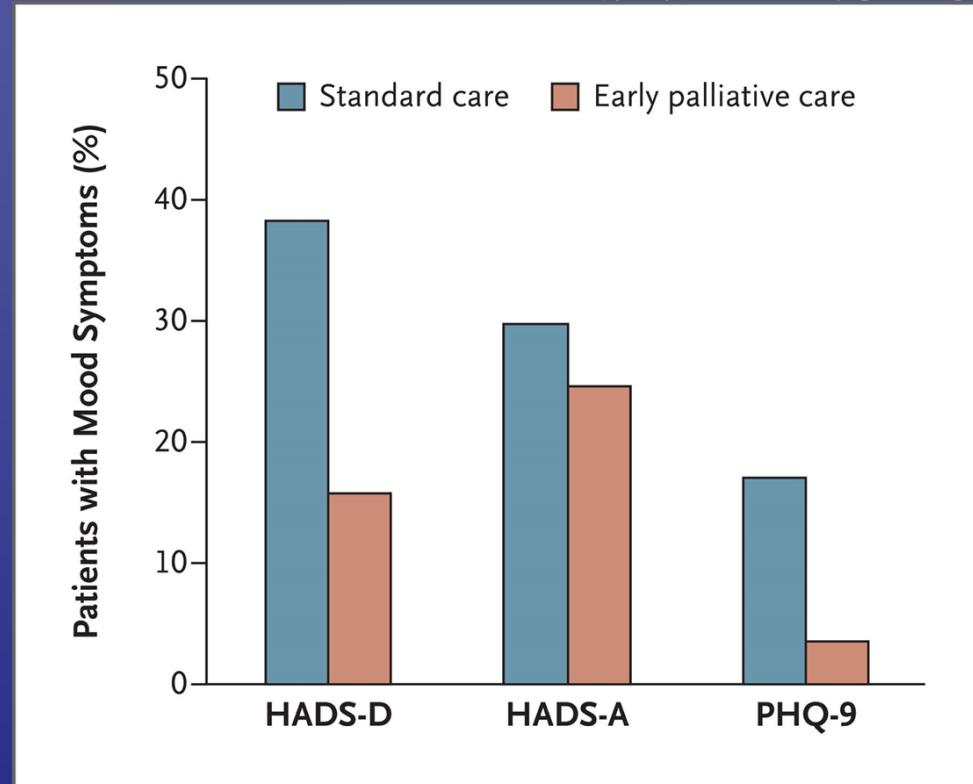
Massachusetts General Hospital piloted a RCT of 151 patients with newly diagnosed metastatic non-small-cell lung cancer to receive either early palliative care (EPC) integrated with standard oncologic care or SOC alone.

EPC group trended toward better quality of life scores on Functional Assessment of Cancer Therapy-Lung scales



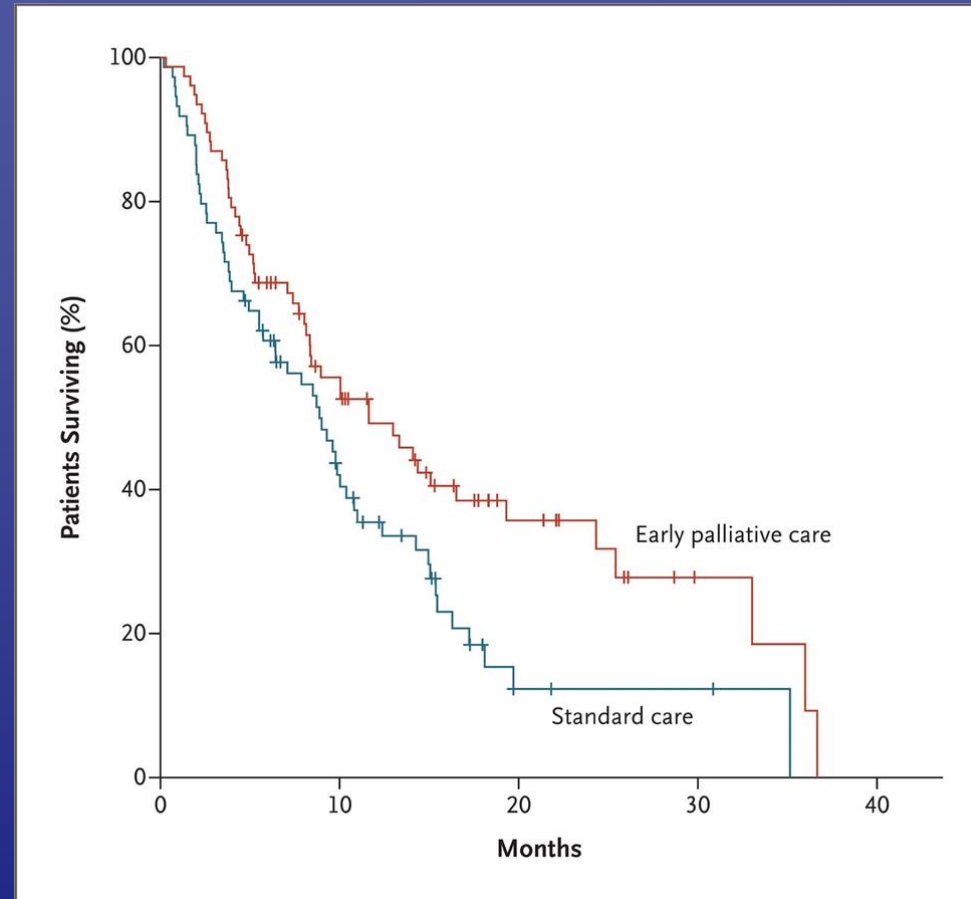
EARLY PALLIATIVE CARE IN AN OUTPATIENT SETTING

- Hospital Depression Scale and the PHQ-9 Scale for major depression were significantly lower ($p < .05$)



EARLY PALLIATIVE CARE IN AN OUTPATIENT SETTING

- Median estimates of survival
- 9.8 months in the entire sample (151 patients)
- 11.6 months in the group assigned to early palliative care (77 patients)
- 8.9 months in the standard care group (74 patients) (P=0.02 with the use of the log-rank test).



PALLIATIVE CARE CREATES A SELF FULFILLING PROPHECY?

- *Changing the Culture Around End-of-Life Care in the Trauma Intensive Care Unit.* Mosenthal et al. J Trauma-Injury Infection and Critical Care 2008
- Rutgers New Jersey Medical School
- 10-20% of trauma patients in the ICU die
- Patients are young, previously healthy and without advanced directives
- Prognosis is unclear

Table 1 Palliative Care Intervention in Trauma ICU

Part I: On admission to the ICU (within 24 hrs)

- Bereavement/psychosocial support for patients and families within 24 h of admission to the SICU

- Interdisciplinary palliative care assessment within 24 h of admission

 - Prognosis

 - Advance directive

 - Pain and symptom

 - Family needs

Part II: Within 72 hours of admission to the ICU

- Interdisciplinary family meeting with physician and nurse

 - Communicate likely outcomes

 - Goals of care discussion

 - Assess family understanding

End-of-life care for the dying

- Palliative care order set

- Ventilator withdrawal guideline

Integration of palliative care performance into morbidity and mortality conferences and peer review

Table 5 Timing of Withdrawal and Withholding of Life Support

	Admission to DNR	DNR to Death	Admission to W/D (All)	Admission to W/D (Vent)	Admission to W/D (Pressors)
Baseline	20 (50.9)	3 (2.3)	11 (11.3)	12 (9.8)	10 (10.8)
Intervention	7 (10.2)	4 (10)	7 (11.9)	6 (7.3)	8 (13.4)

Mean days (standard deviation).

Table 6 LOS for Dying Patients

	Death (n)	Mortality	ICU LOS		Hospital LOS	
			Mean	Median	Mean	Median
Baseline (n = 286)	42	15%	7.6	3	14.4	3.5
Intervention (n = 366)	52	14%	6.1	1	6.5	1.5

LOS indicates length of stay.

THESE TRIALS HELPED CHANGE THE CULTURE AROUND PALLIATIVE CARE



**“Good news.
Your cholesterol has stayed the same,
but the research findings have changed.”**

HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?



HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?

- Primary palliative care refers to the basic skills and competencies required of all health care professionals.
- Secondary palliative care refers to the specialist clinicians and organizations that provide expert consultation and/or co-management. This may be inpatient, outpatient, or home.
- Tertiary palliative care refers to the academic medical centers where specialists practice, teach and conduct research.

HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?

1. PHYSICAL SYMPTOMS

NEEDS MET BY ID TEAM

- Basic Pain Management
- Basic management of non-pain symptoms
- Basic use of adjuvant pain relievers
- Equi-analgesic dose conversion

NEEDS MET BY PC TEAM

- Management of refractory pain
- Management of refractory non-pain symptoms
- Methadone for pain relief
- Concurrent serious illness and addiction

HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?

2. PSYCHOLOGICAL, SOCIAL, CULTURAL, SPIRITUAL ASPECTS OF CARE

NEEDS MET BY ID TEAM

- Basic management of depression/anxiety
- Exploration of psychosocial suffering
- Basic exploration of spiritual and religious views
- Basic exploratory family meeting

NEEDS MET BY PC TEAM

- Management of complex depression, anxiety, grief and existential distress
- Severe religion/spiritual suffering

HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?

3. SERIOUS ILLNESS COMMUNICATION ISSUES

NEEDS MET BY ID TEAM

- Explaining prognosis
- Exploring goals in light of prognosis
- Making recommendations about code status
- Seeking consensus among treating professionals
- Seeking consensus among the patient and family

NEEDS MET BY PC TEAM

- Complex medical decision making
- Dying patients who "want everything"
- Major conflict among family members
- Major conflict among treating teams
- Requests about assisted dying

HOW DOES PALLIATIVE CARE FIT INTO HIV CARE?

4. CARE COORDINATION

NEEDS MET BY ID TEAM

- Coordinating care among specialists
- Clearly defining their role in patients care
- Managing transitions of hospice care
- Managing transitions out of the hospital

NEEDS MET BY PC TEAM

- Transitions to hospice if uncertainty exists
- Patient/family resistance to hospital discharge
- Conflict with providers

WHAT OTHER PATIENTS WITH CHRONIC, INFECTIOUS ILLNESSES MIGHT BENEFIT FROM PALLIATIVE CARE?

- HEPATITIS
- CHRONIC OSTEOMYELITIS
- SEPTIC, EMBOLIC DISEASE
- PATIENTS WITH RECURRENT INFECTIONS AFFECTING DIALYSIS CATHETERS, LVAD, IMPLANTED DEVICES

TO IMPROVE UTILIZATION CONSIDER A PALLIATIVE CARE CONSULT IF...

- The “surprise question”
- Frequent admissions
- Concurrent serious illness
- Admission prompted by difficult to control physical or psychological symptoms
- Complex care requirements (loss of independence, home support needed for antibiotics)
- Decline in function, feeding tolerance or unintended decline in weight

WHAT DO WE KNOW ABOUT THE PALLIATIVE CARE NEEDS OF PATIENTS WITH CHRONIC, INFECTIOUS DISEASES?

- NOT A LOT
- YET!!!

PALLIATIVE CARE SERVICES ARE UNDER UTILIZED IN THE HIV POPULATION

- **Retrospective cohort of HIV patients admitted to a large, urban safety net hospital**
- **367 patients identified. 28% of those patients died during admission**
- **Only 6% of sample received a palliative care consult at any time**
- **Only 6% of patients who died enrolled in hospice**
- **Of those that received a PC consult, 54% enrolled in hospice**
- **Hospice enrollees died 11 days after transition to hospice**
- **Only 8.7% of the patients had an advanced directive**

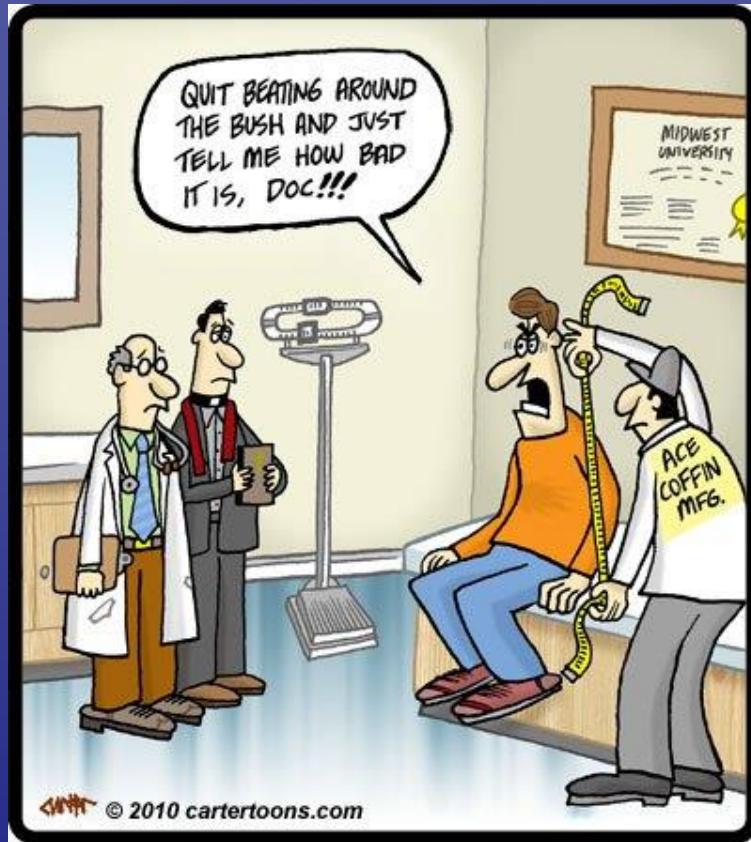
UNTREATED SYMPTOMS RESULT IN LESS ADHERENCE OR LACK OF INITIATION

- Prospective study of symptom burden, depression and adherence after starting HAART therapy
- High adherence leads to better symptom control
- Low adherence leads to poorer symptom control
- Patients who experience persistent symptoms while on HAART may begin to doubt their continued need for treatment and respond by missing doses.

The influence of symptom experiences and attributions on adherence to highly active anti-retroviral therapy (HAART): a six-month prospective, follow-up study *AIDS Care*, 2009 21(4)

WHAT DO WE KNOW ABOUT THE PALLIATIVE CARE NEEDS OF PATIENTS WITH CHRONIC, INFECTIOUS DISEASES?

- Patient's have unmet palliative care needs
- Palliative care services are under utilized
- Patient's are less likely to have discussed advanced directives
- Multiple, controllable factors may result in poor compliance or lack of initiation of life prolonging therapies that may be addressed by attention to palliative care needs
- Trials are needed in this field



HOW CAN ADVANCED CARE PLANNING IMPROVE CARE?

- A conversation between a patient and their care team exploring what type of care they would want when or if they become seriously ill
- Allows patients to make informed choices that reflect their values, reduce suffering, enhance family well being and improve quality of life
- May include naming a surrogate, discussing code status, thinking about limits to care, talking about hospice

WHY TALK ABOUT ADVANCED CARE PLANNING? (ACP)

Most older adults want to talk about care at the end of life

Majority of older adults state a preference for dying at home

However, most people die in a hospital or at an institution

Conventional medical care at end of life is burdensome to patients and families and often associated with pain and suffering

Decisions about care at end of life are often made by a surrogate, who may not always know the wishes of the patient

ADVANCED CARE PLANNING DISCUSSIONS HELP MATCH GOALS AND VALUES TO TREATMENTS

Many patients and families may have personal, cultural, or spiritual reasons to choose aggressive medical care even when there is no expectation of longevity or improved quality of life

However, given the option many others would focus on relief of suffering and comfort even if it meant a shorter life

This is why it is important to have these conversations to make sure patients and families are receiving appropriate care consistent with their values

THERE ARE PERCEIVED BARRIERS TO ADVANCED CARE PLANNING

- Time
- Uncertainty
- Emotions
- Skills

ACP AND TIME BARRIER

Conversations about end of life care and advance care planning should not be rushed and busy clinicians have found it hard to fit into already packed clinical visits.

CMS now reimburses clinicians for having advance care planning conversations as well as for completing relevant advance directive documents

These conversations can be standalone or part of another encounter

ACP AND UNCERTAINTY BARRIER

Would you be surprised if this patient died within the next year?

- If your answer is no, you would not be surprised if they died, then it is appropriate to initiate conversations about end of life care

When major changes happen to chronically ill patients e.g.

- Progression of disease while receiving chemotherapy
- Referral for major procedures or surgery (tracheostomy, PEG tube insertion, coronary bypass surgery)
- Referral for organ transplant or replacement therapy (MCS, HD)
- Cognitive decline or functional impairment (loss of ADLs, fall with fracture)

ACP AND EMOTION BARRIER- TRY A NURSE STATEMENT

Name- You seem like you might be worried about this

Understand- I can't imagine how hard this is to think about

Respect- You have been doing a great job keeping up with all of these details

Support -We are going to continue to help with each step

Explore - Tell me more about what worries you

ACP AND SKILL BARRIER

Patients and their families want to have conversations about EOL care and expect honesty and kindness. These conversations can be difficult and require skills that can be acquired.

Resources to learn more include:

- Vital Talk: <http://vitaltalk.org/courses/>
- PalliTalk: <http://www.medicine.wisc.edu/hemonc/pallitalk>
- The Conversation Project: <https://theconversationproject.org/>
- [The Serious Illness Project](#)

REMAP: A TOOL TO USE FOR LATE ADVANCED CARE PLANNING

- Reframe
- Expect emotion
- Map the future
- Align with patient's goals
- Plan treatments

REFRAME

- Reframe why the status quo is not working
 - May need to first discuss serious news (e.g., scan results)
 - “Given this news, it seems like a good time to talk about what to do now”
 - “We’re in a different place”

EXPECT EMOTION

- Expect emotion and empathize
 - “It’s hard to deal with all this.”
 - “I can see why you’re really concerned about x”
 - “Tell me more about that “
 - “Is it okay for us to talk about what this means?”

MAP THE FUTURE

- Map the future
 - “Given this situation, what’s most important for you?”
 - “When you think about the future, are there things you want to do?”
 - “As you think toward the future, what concerns you?”

ALIGN



- Align with patient's values
 - “As I listen to you, it sounds like the most important things are x, y, z”

PLAN TREATMENTS

- Plan medical treatments that match patient values
 - “Here’s what I can do now that will help you do these important things. What do you think about this plan?”

TALK ABOUT SERVICES THAT WOULD HELP...BEFORE INTRODUCING HOSPICE

- “We’ve talked about wanting to conserve your energy for important things. One thing that can help us is having a nurse come to your house to can help us adjust your medicines so you don’t have to come in to clinic so often.”
- “The best way I have to do that is to call hospice, because they can provide this service for us, and more.”
- Expect emotion around the “hospice” word...

ADDRESSING GOALS OF CARE

- Reframe
- Expect emotion
- Map the future
- Align with patient's goals
- Plan treatments

THANK YOU

