

CARING FOR PATIENTS WITH SERIOUS ILLNESS: HOW PALLIATIVE CARE CAN HELP

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DISCLOSURES

- I have no relationships with any industry pertaining to this presentation



LEARNING OBJECTIVES

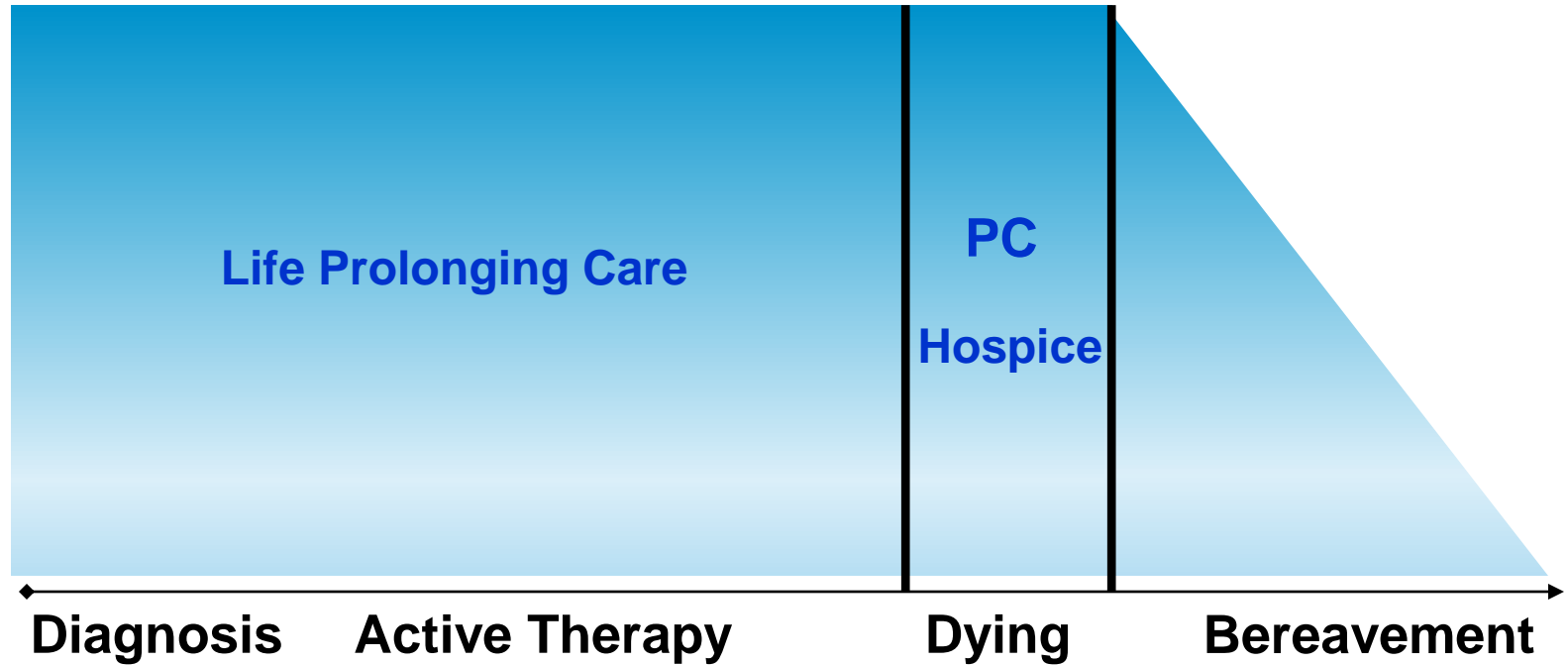
- Define palliative care (PC), and how it differs from the traditional hospice model
- Better understand how PC is beneficial for patients
- Gain skills in managing common symptoms encountered in PC patients
- Identify opportunities to improve care of patients and families with serious illness through the provision of prognostic data
- Learn who may benefit from PC referral and how to introduce the referral to the patient



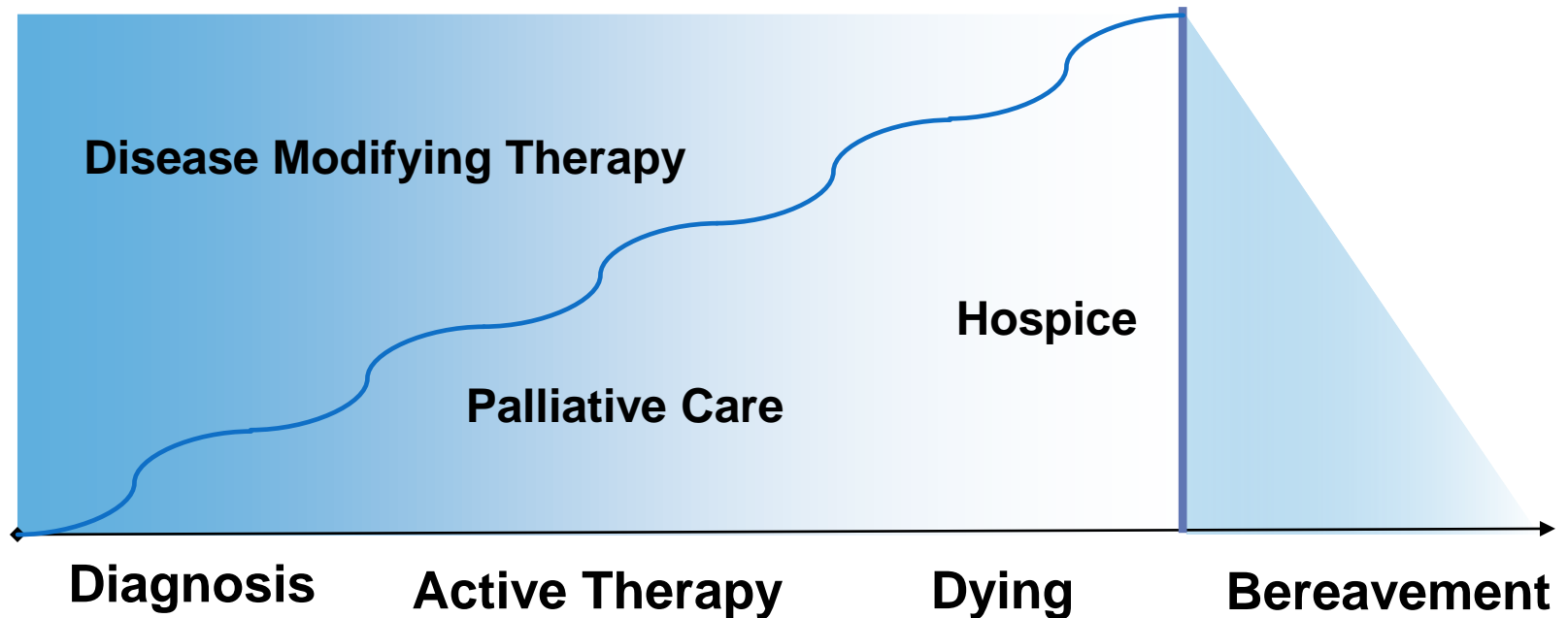
SUBSPECIALTY OF PALLIATIVE CARE

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis or prognosis. It is an extra layer of support to the patient's other clinicians.

TRADITIONAL MODEL OF CARE AT THE END OF LIFE



PALLIATIVE CARE FOR QUALITY OF LIFE “UPSTREAM”



WHAT PALLIATIVE CARE IS...

- ✔ Excellent, evidence-based medical treatment
- ✔ Vigorous care of pain and symptoms throughout illness
- ✔ Care that patients want *at the same time* as efforts to cure or prolong life

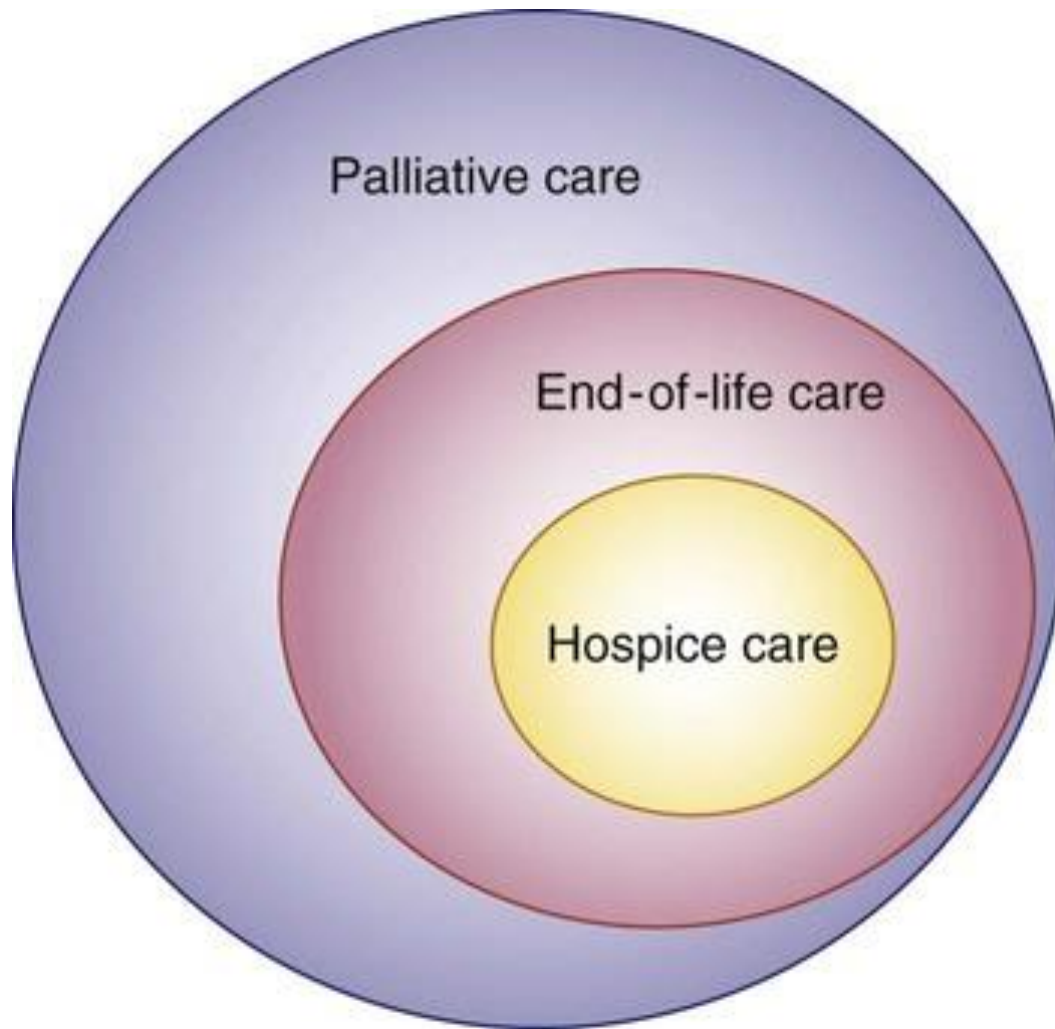
What palliative care is not...

- ✔ Not “giving up” on a patient
- ✔ Not in place of curative or life-prolonging care
- ✔ Not the same as hospice



HOSPICE VS. PALLIATIVE CARE

| | Hospice | Palliative Care (includes Hospice) |
|------------------|---|--|
| Timing | Less than 6 month prognosis if disease runs it's expected course | Can occur at any stage of serious illness |
| Treatment | Focus is on comfort rather than aggressive disease-directed therapy | Care integrates disease-directed therapies with attention to quality of life and advance care planning |
| Location | Mainly provided in the home (relies upon the family caregiver and visiting hospice team). May also be provided in skilled nursing facility or hospice house | Often provided as outpatient or inpatient consultations |



DEMAND FOR IMPROVED CARE: WHAT PATIENTS AND FAMILIES WANT

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

A 59 year old woman with metastatic cancer
presents to her internist



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JULIE



- 59 year-old nurse with metastatic lung cancer
- Married with 3 college-aged children
- Receiving chemotherapy
- Complains of back pain



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PAIN AND SYMPTOM ASSESSMENT

- Pain is deep, aching in her back and right hip
- She is taking 2 tabs of 5 mg oxycodone/ 325 mg acetaminophen every 4 hours
- Pain intensity 8/10 with 50% relief from current opioid regimen that lasts 2 hours
- Unable to sleep or function normally
- Normal neurologic exam, spinal MRI negative for cord compression but shows L4 bony metastases



QUESTION 1

- What is the next best step in managing her pain?
 - A) Add Diclofenac 50 mg PO TID to current regimen
 - B) Recommend further imaging prior to medication changes
 - C) Stop the oxycodone/acetaminophen and start a 100 mcg/hr transdermal Fentanyl patch
 - D) Add sustained-release morphine 30 mg PO q12h to current regimen



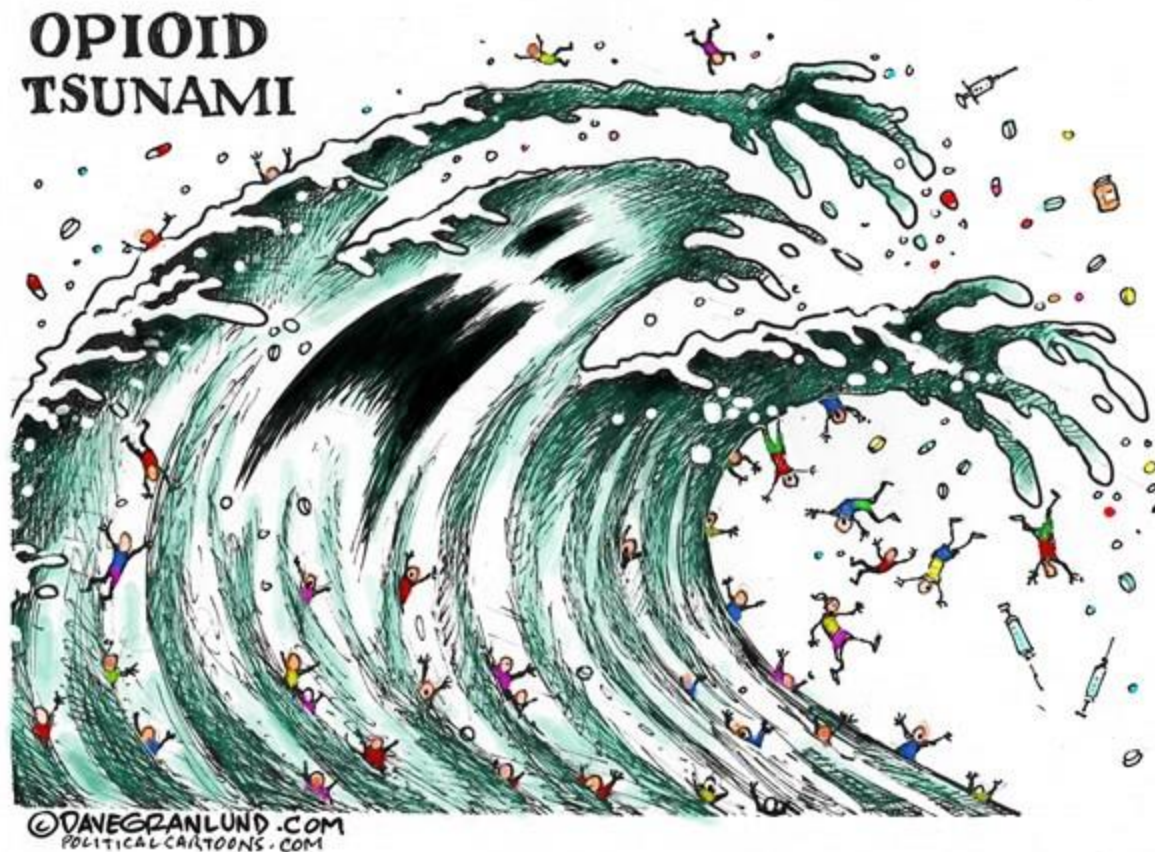
PROVIDE SUSTAINED PAIN RELIEF FOR CONSTANT CANCER PAIN

KEY POINT

Since she is using short acting
opioids around the clock,
add a sustained-release opioid



MANAGING CANCER PAIN IN THE OPIOID EPIDEMIC ERA



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WHICH LONG-ACTING AGENT?

- Long-acting opioids
 - Consider route of administration
 - Cost
 - Availability
 - Efficacy
 - Contraindications



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CALCULATE THE SUSTAINED-RELEASE DOSE USING 24H TOTAL OF SHORT-ACTING OPIOID

- Each tablet of 5 mg/325 mg has 5 mg oxycodone
- $5 \text{ mg} \times 2 \text{ tablets} = 10 \text{ mg/dose}$
- Every 4 hours = 6 doses/24 hours
- $10 \text{ mg} \times 6 \text{ doses} = 60 \text{ mg oxycodone/24 hour}$



USE THE EQUI-ANALGESIC TABLE WHEN SWITCHING TO ANOTHER OPIOID

| Opioid | Oral | IV |
|---------------|-------------|-----------|
| Morphine | 30 mg | 10 mg |
| Oxycodone | 20 mg | N/A |
| Hydromorphone | 7.5 mg | 1.5 mg |

Morphine 50 mg/24 hours orally = Fentanyl patch 25 mcg/hour



EQUI-ANALGESIC DOSE CALCULATION: WHEN CONVERTING FROM OXYCODONE TO MORPHINE

From equi-analgesic chart:

20 mg oxycodone = 30 mg oral morphine

If the patient, for example, was taking 60 mg of oxycodone in 24 hours:

20 mg oxycodone = 60 mg oxycodone

30 mg oral morphine x mg oral morphine

x = 90 mg oral morphine/24 hours



NEW DOSE MUST ACCOUNT FOR INCOMPLETE CROSS TOLERANCE

A patient who is tolerant to the effect and side effects of one opioid may not be equally tolerant to the effects and side effects of another opioid



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DECREASE DOSE OF NEW DRUG FOR INCOMPLETE CROSS TOLERANCE

- Decrease equi-analgesic dose by ~25-50% because of incomplete cross tolerance
- In the example, 90 mg oral morphine – 30 mg = 60 mg oral morphine/24 hours
- New dose: **30 mg sustained-release morphine PO Q12h**



PROVIDE A SHORT-ACTING OPIOID FOR BREAK THROUGH PAIN

- Use 10-20% of the total opioid dose every 3 hours PRN
- Use adjuvants such as NSAIDs around the clock for improved pain control
- Avoid using combination preparations (e.g. oxycodone 5 mg/acetaminophen 325 mg) for breakthrough dosing
 - Can lead to overdosing of acetaminophen
- Prevent opioid-induced constipation



EXCELLENT CANCER PAIN MANAGEMENT OFTEN REQUIRES OPIOIDS PLUS ADJUVANTS

- Pain regimen prescribed:
 - Morphine sustained-release 30 mg PO every 12 hours
 - Morphine immediate-release 7.5-15 mg PO every 3 hours PRN pain
 - Ibuprofen 600 mg PO every 8 hours scheduled
 - Zoledronic acid monthly
 - Omeprazole prophylaxis
 - Bowel regimen



PATIENTS ASK FOR PROGNOSTIC INFORMATION

- Today Julie asks you about what to expect as her illness progresses
- You aren't sure of her prognosis or what exactly she is asking
- You tell her that you will get more information from her oncologist and discuss prognosis at her next visit



QUESTION 2

- When estimating patient's survival, physicians often:
 - A) Underestimate prognosis drastically
 - B) Underestimate prognosis slightly
 - C) Are fairly accurate
 - D) Overestimate prognosis slightly
 - E) Overestimate prognosis drastically



PHYSICIANS STRUGGLE TO DETERMINE PROGNOSIS

- As the duration of physician-patient relationship increases and time since last contact decreases, prognostic accuracy decreases
- Physicians in the upper quartile of practice experience are most accurate

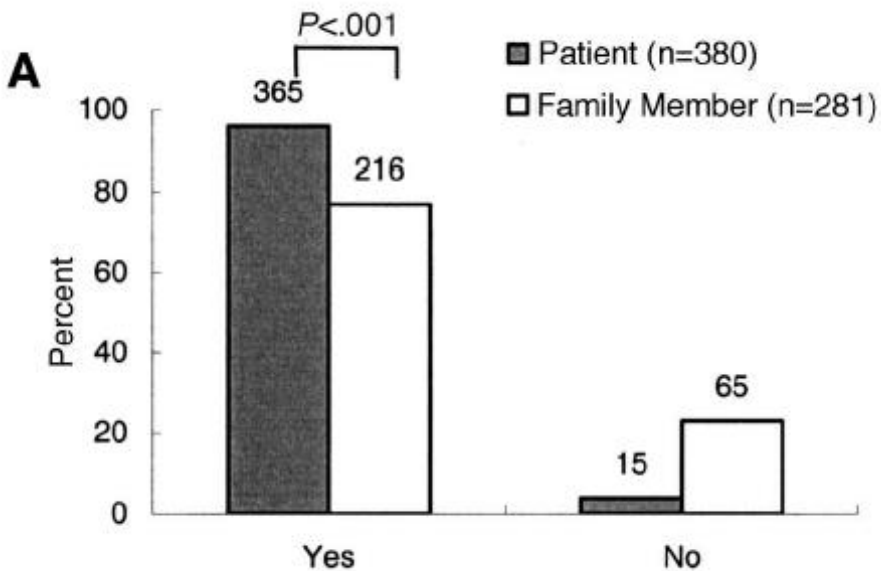


CLINICIANS ARE AMBIVALENT ABOUT MAKING PROGNOSTIC DISCLOSURES

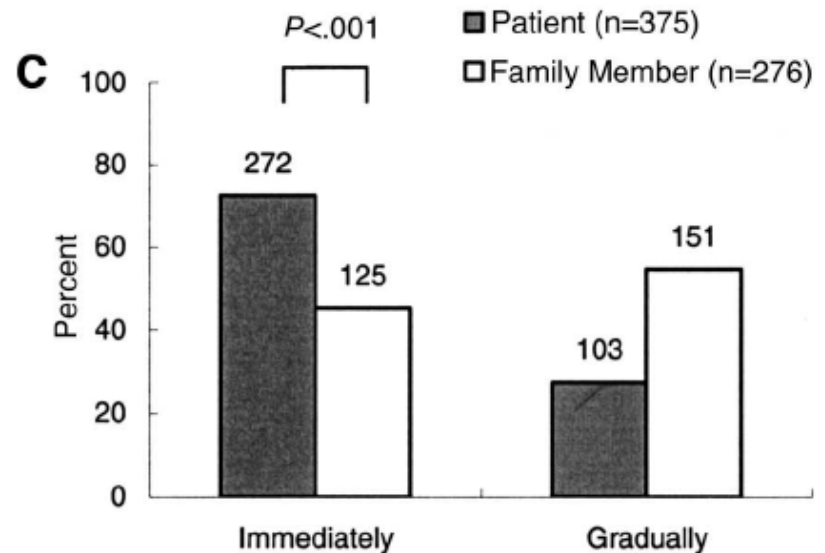
- Julie's oncologist thinks she has a life expectancy of 9-12 months
- He expects she will slowly dwindle over the next 6-9 months
- Her cancer has not responded to the first 2 lines of chemotherapy
- You worry that telling Julie will make her give up and maybe die sooner



PATIENTS WITH ADVANCED CANCER WANT TO KNOW PROGNOSIS, EARLY IN THE COURSE OF ILLNESS



Do you want to be informed the truth?



When is the appropriate time to be informed the truth?

DISCUSSING PROGNOSIS CHANGES TREATMENT DECISIONS

- Patients who expected 6 month survival are 2.5 times more likely to choose and receive life-extending therapy, but did not have longer survival
- Patient understanding of 10% chance of dying in 6 months led to less aggressive treatment decisions

DISCUSSIONS OF PROGNOSIS IMPROVE OUTCOMES

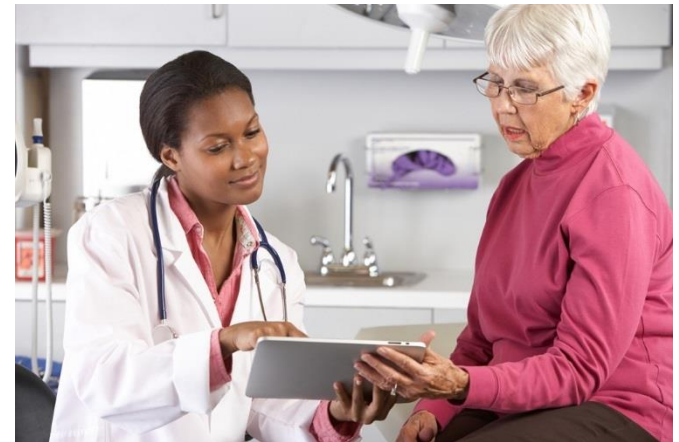
In Coping with Cancer study, 37% of patients reported having prognosis discussion at baseline

- These patients had lower use of aggressive treatments, better quality of life (QOL), and longer hospice stays
- Not associated with more worry or depression
- Family after-death interviews showed better psychological coping, self-reported health, and overall QOL for those with conversations as compared to those without

PROGNOSTIC AWARENESS : THE PATIENT'S CAPACITY TO UNDERSTAND THE LIKELY DISEASE TRAJECTORY AND PROGNOSIS

With deeper prognostic awareness patients can

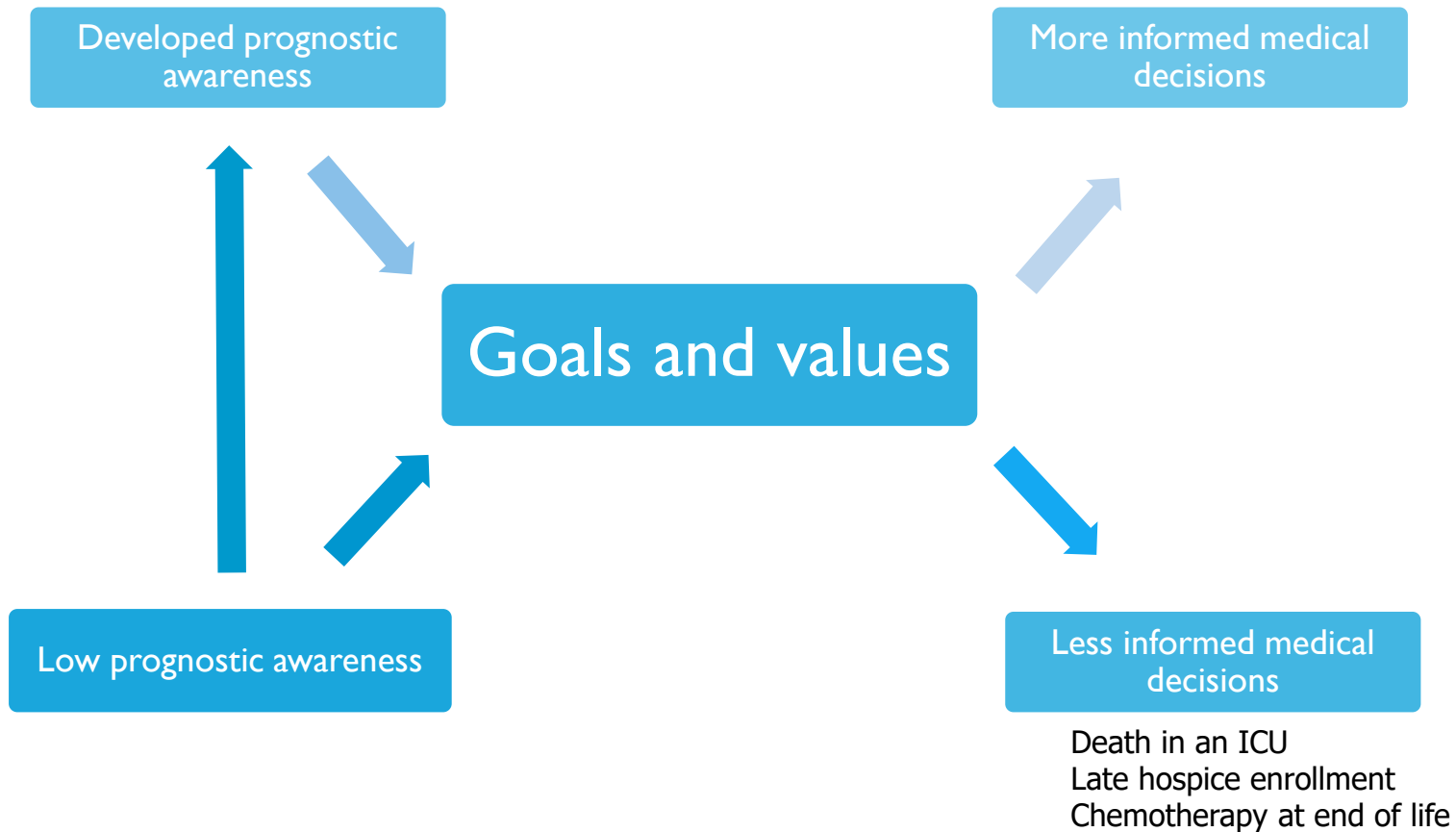
- Weigh burdens and benefits of treatment
- Have more meaningful discussions of their goals and values
- Match treatment decisions to goals and values



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DEEPENING PROGNOSTIC AWARENESS IS A PROCESS THAT ENABLES MORE INFORMED DECISIONS



Patient expertise

Clinician expertise

**Goals and
Values**

**Prognosis and
medical
options**

Clinician role

Make a recommendation



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PROVIDE PROGNOSTIC INFORMATION TO HELP PATIENTS MAKE INFORMED DECISIONS

- Patients can ask for two different types of prognostic information
 - “How much time do I have left?”
 - “What’s going to happen to me with this illness?”
 - Both kinds of information tell the patient something about prognosis
 - But we will answer the questions differently



EXPERTS USE SPECIFIC SKILLS TO ADDRESS PATIENT AMBIVALENCE

- ASK-TELL-ASK
 - Assess what patients really want to know
 - Why is the patient asking?
 - What information are they looking for?
 - Permission that there are no right answers here
 - Avoids giving too much information
 - Allows honest discussion at the level the patient needs



SOME PATIENTS WANT TO KNOW LIFE EXPECTANCY

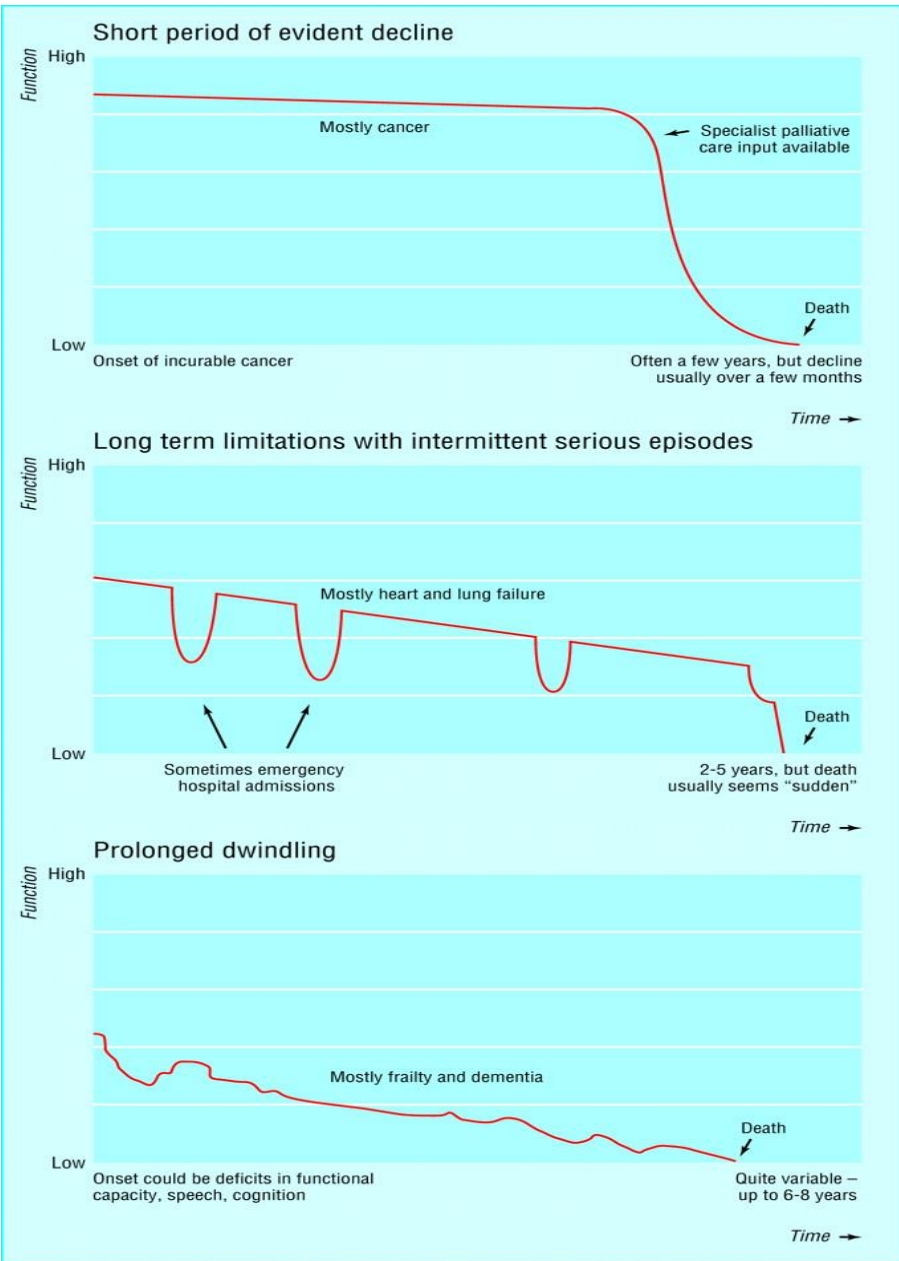
- Use a standard method to provide prognostic information about length of time the person has to live
 - Days to weeks
 - Weeks to months
 - Months to years



SOME PATIENTS WANT TO KNOW WHAT THE FUTURE WILL BE LIKE

- Patients do not know what it looks like to be ill and eventually die from a terminal illness
- They are often surprised that the decline is slow
- They want us to tell them what the illness trajectory will look like





ILLNESS TRAJECTORIES

DELIVER PROGNOSTIC INFORMATION USING A HOPE/WORRY STATEMENT

- Patients want to know that we **hope** they will do well

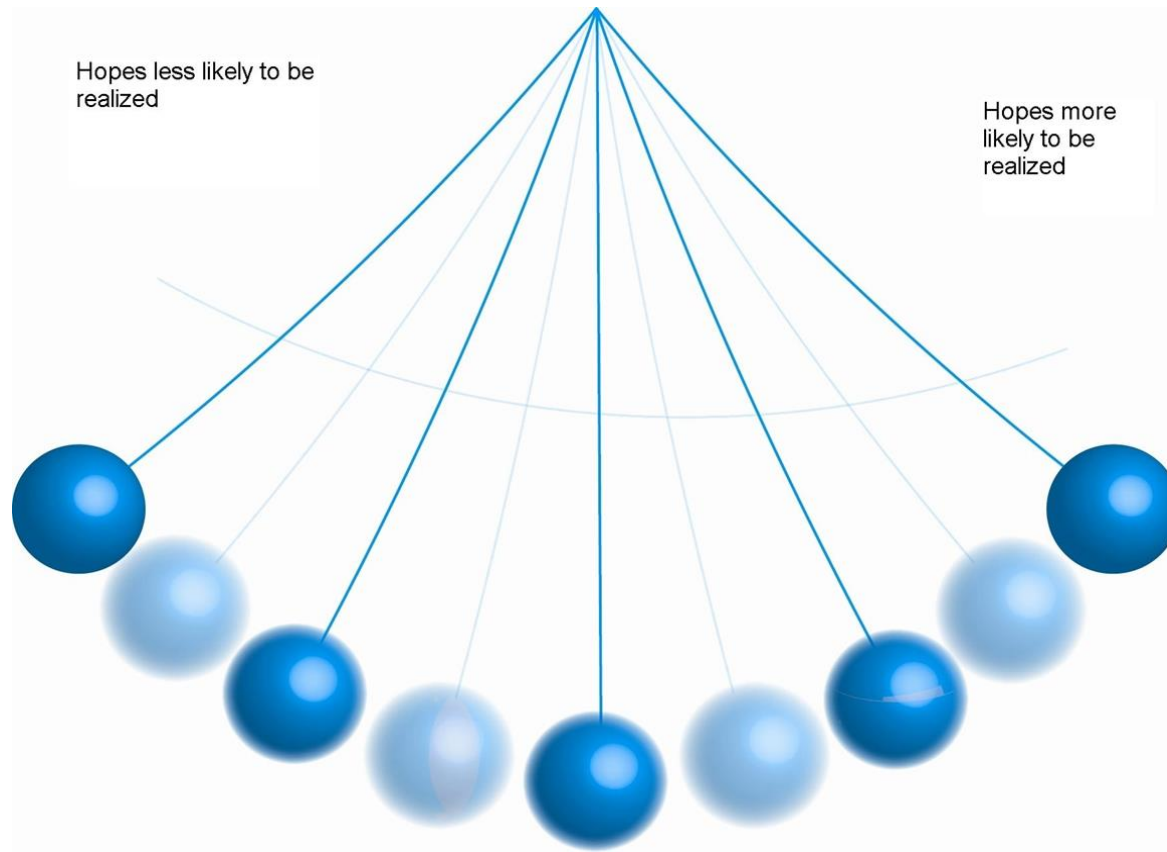
Function: “I hear you’re **hoping** to _____ and I **worry** the decline we have seen is going to continue.”

Time: “I hear you’re **hoping** for _____ and I **worry** something serious may happen in the next few (weeks/months/years).”

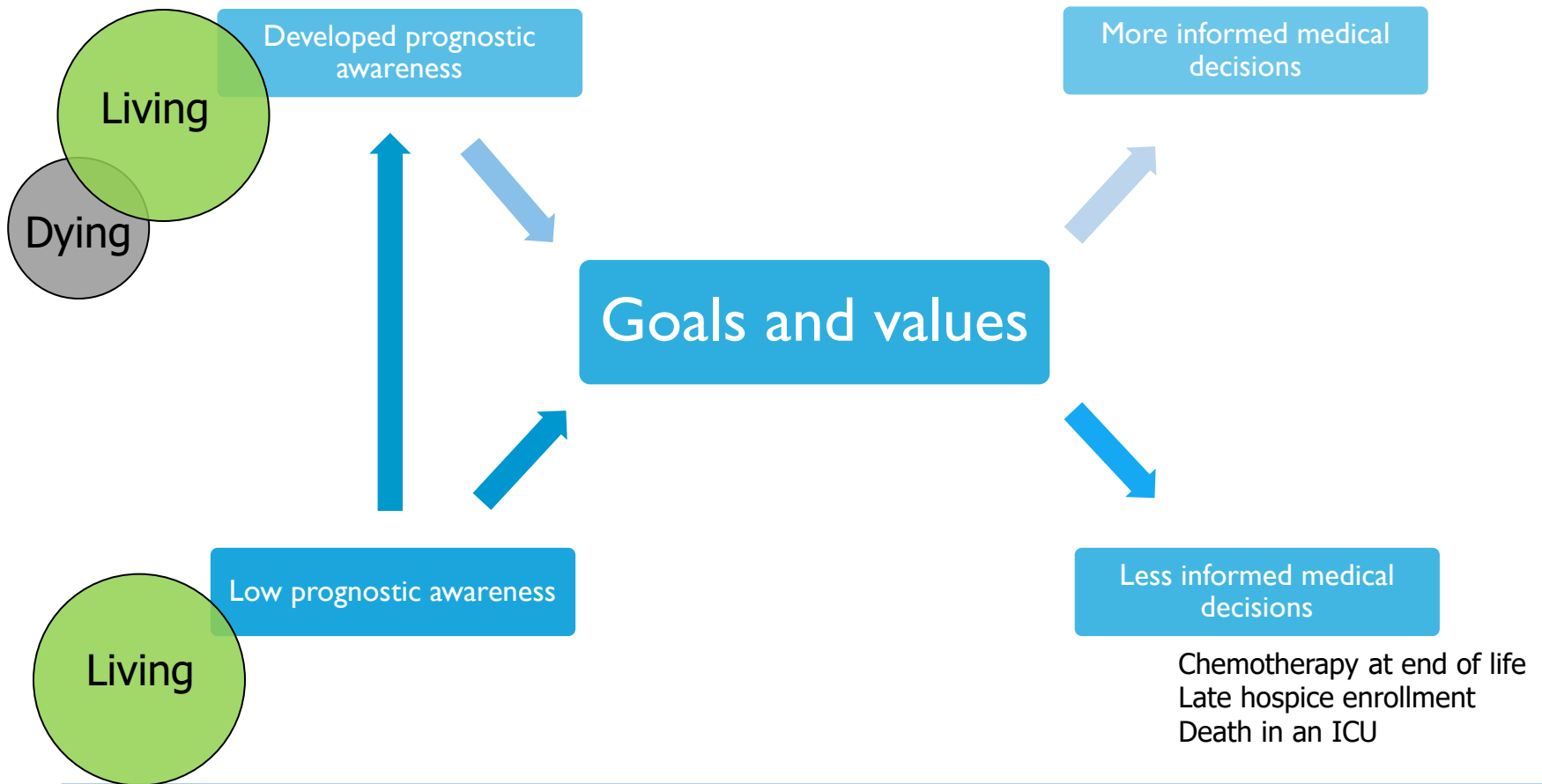
- Acknowledges uncertainty
- Aligns with the patient
- Allow clinician to be honest about prognosis



MOST PATIENTS SWING BETWEEN EXPRESSIONS OF HOPE AND REALISM



WHEN PATIENTS CAN ACKNOWLEDGE BOTH REALITIES, THEY CAN INCORPORATE THEM INTO DECISION MAKING



HONEST INFORMATION PRECIPITATES EMOTION

Prognostic information



Emotion

Sadness, anger, or disbelief



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EMOTIONS SHOULD BE EXPECTED- THE KEY IS WHAT YOU SAY NEXT

- Clinicians often struggle with what to say next
 - Common Pitfalls to Avoid:
 - Reassurance about clinical possibilities
 - Offer unhelpful treatments
 - Retreat into medical details
 - Take back what was said



RESPONDING TO EMOTION

- **Allow for silence**
- You should be talking <50% of the time
- Resist the urge to prematurely provide reassurance

McDonagh. Crit Care Med. 2004 Jul;32(7):1484-8.



EMPATHY IMPACTS PATIENTS' RESPONSES TO SERIOUS NEWS



LANGUAGE FOR RESPONDING TO EMOTION

- **Name the Emotion**

- “You seem devastated to hear this.”
- “It sounds like you’re feeling really shocked.”

- **Make a Connecting Statement**

- This expresses that you recognize that what the patient is feeling is a result of the information received.
- “I can tell this isn't what you were expecting to hear.”
- “I can imagine how scary this must be.”



LANGUAGE FOR RESPONDING TO EMOTION

- **Align with the patient**
 - “I really wish things were different.”
 - “This sucks.”

- We want to show that we’re trying to understand what the patient is going through, but can never truly know their experience
 - Would NOT recommend saying: “I know what you’re feeling,” or directly comparing their situation to your own



ALIGNING WITH THE PATIENT



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QUESTION 3

- When the clinician takes time to express empathy during a visit, by how much is the visit lengthened?
 - A) 20 seconds
 - B) 1 minute
 - C) 5 minutes
 - D) 15 minutes
 - E) Not at all



WHAT HAPPENS WHEN EMPATHY IS EXPRESSED?

- Patient trust in their clinician increases
- Minimal time added to encounter

- Butow et al. *Psychooncology*. 2002
- McDonagh et al. *Crit Care Med*. 2004
- Pollak et al. *J Clin Onc* 2007



PARTNER WITH PATIENTS ON HOPING FOR THINGS THAT ARE LIKELY ATTAINABLE

■ I HOPE....

- Focus on things that can be controlled
- *“I am hoping that we can get you feeling better so you can spend good time with your son.”*



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JULIE'S NEXT APPOINTMENT

- She is accompanied by her husband
- You assess what information would be helpful to hear. She wants information about her likely illness trajectory and survival
- You inform her that likely survival is on the order of months and that, at some point, she will become weaker and may spend most of her time in bed
- She had read this on the internet and is not surprised but her husband becomes angry stating, “I just think we should be hopeful!”



CASE CONTINUED

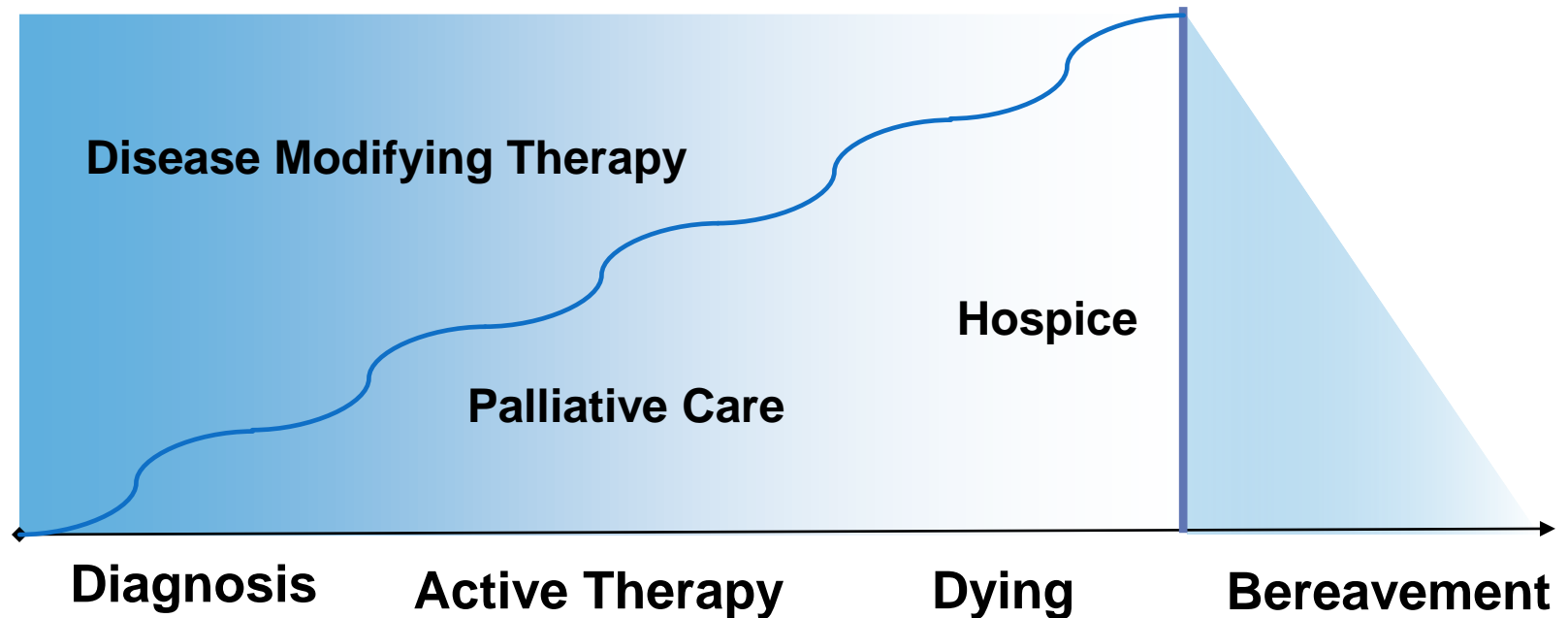
- Julie has had a difficult few weeks with a new diagnosis of spinal cord compression from a metastasis in her lumbar spine. She is undergoing radiation and despite treatment with opioids, her pain is very difficult to manage. You are not sure what to do next and wonder who could help you and the oncologist treat Julie's symptoms
- You're wondering if palliative care or hospice would be helpful...



PALLIATIVE CARE

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis or prognosis. It is an extra layer of support to the patient's other clinicians.

PALLIATIVE CARE FOR QUALITY OF LIFE “UPSTREAM”



CASE CONTINUED

- Palliative care sounds, in theory, like it might be useful
- But is there any evidence that palliative care might change outcomes for your patient?



ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

RESULTS

Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (86% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; $P=0.03$). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, $P=0.01$). Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, $P=0.05$), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $P=0.02$).

CONCLUSIONS

Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

From Massachusetts General Hospital, Boston (J.S.T., J.A.G., A.M., E.R.G., V.A.J., C.M.D., J.J., W.F.P., J.A.B.); the State University of New York, Buffalo (S.A.); Adult Palliative Medicine, Department of Anesthesiology, Columbia University Medical Center, New York (C.D.B.); and Yale University, New Haven, CT (T.J.L.). Address reprint requests to Dr. Temel at Massachusetts General Hospital, 55 Fruit St., Yawkey 7B, Boston, MA 02114, or at jtemel@partners.org.

N Engl J Med 2010;363:733–42.
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Design: Randomized controlled trial of 151 patients

Comparing standard oncology care plus early referral to palliative care to standard oncology care

Population: patients with newly diagnosed metastatic non small cell lung cancer

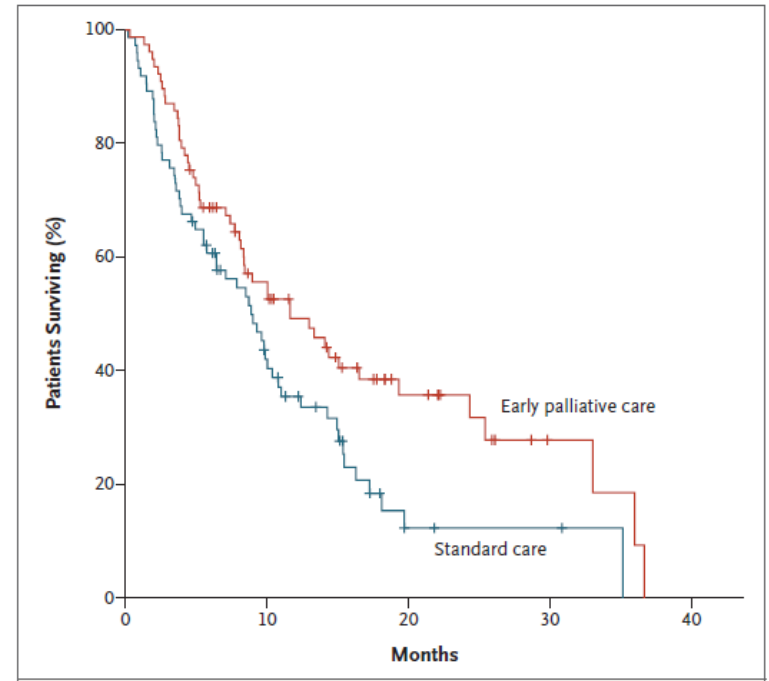
Intervention: At least monthly visits with the palliative care team

Primary outcomes: Quality of life

Secondary outcomes: Mood, end of life outcomes

EARLY PC FOR PTS WITH METASTATIC NSCLC ASSOCIATED WITH IMPROVED QOL, DECREASED DEPRESSION, AND IMPROVED SURVIVAL

| | Early Pall Care | Standard Care | Diff |
|--|-----------------|---------------|--------|
| Change in Quality of Life (TOI) | +2.3 | -2.3 | P=0.04 |
| Depression (PHQ-9) | 4% | 17% | P=0.04 |
| Survival | 11.6 mos | 8.9 mos | P=0.02 |
| IV Chemotherapy 60 DOD | 24% | 46% | P=0.01 |
| Utilization Trends | | | |
| Median inpatient days | 5.0d | 7.0d | 2.0d |
| Hospice admission <3 days prior to death | 3.0% | 14.7% | 11.7% |



PC WILL HELP PATIENTS LIVE BETTER WITH CANCER

- Julie returns to clinic. Her pain is worse despite treatment with short and long-acting opioids. She reports that her family is “breaking down.”
- You recommend referral to PC... “They can help us manage your symptoms and support you and your family through this illness.”
- Julie is surprised. She says, “Listen I know things aren’t great, but I am not ready for hospice. I’m not dying yet.”
- You respond, “You’re right, they will help you live better.”



ONCE REFERRED TO PC, MOST WISH IT HAD BEEN DONE EARLIER

- Half of bereaved family members felt that timing of referrals to palliative care was too late
- 87% of families reported that earlier cooperation of palliative care physicians with oncologists would be helpful

Morita, Journal of Clinical Oncology, 23(12), 588–2589, 2005.



IN SUMMARY: WE ALL CARE FOR THE SERIOUSLY ILL- OUR JOB AS HEALERS

- Aggressively treat suffering (physical, psychological, existential)
- Get to know the patient's goals and values
- Provide prognostic information to prepare the patient and family
- Avoid prolongation of dying
- Employ the assistance of a team and partner in this care
- Refer to palliative care when needed



