

Concurrent Palliative Care through the Cancer Continuum

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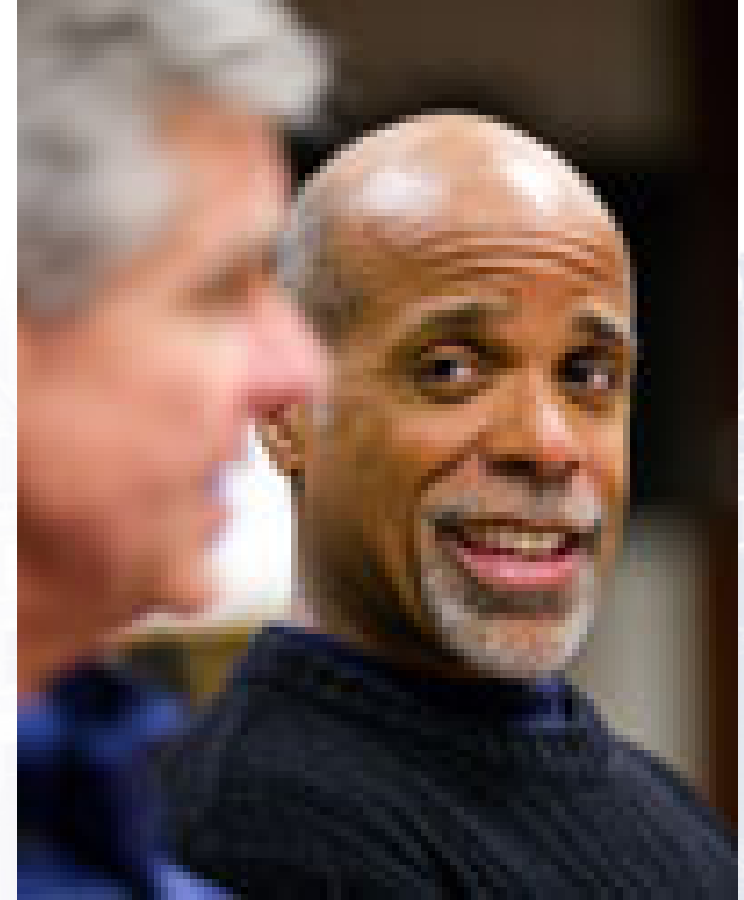
Learning Objectives

1. Improve knowledge of the comprehensive nature of palliative care and symptom management.
2. Enhance appreciation for a multidisciplinary team approach to patient care, particularly for the terminal patient.
3. Understand the importance of all health care professionals in contributing to the care plan of the terminal patient.
4. Understand the value of early introduction of palliative care in combination with other treatments during the cancer continuum.

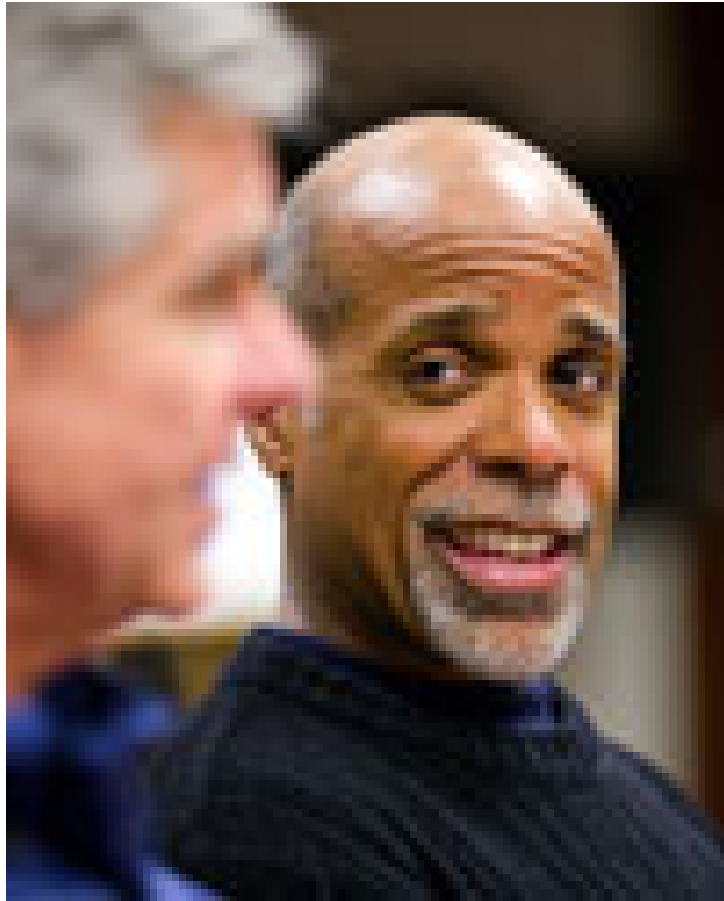
Case: Bob

What healthcare options exist?

- Bob is a 72 y/o man with diabetes, hypertension and stage 4 colon cancer
- He had a hemi-colectomy with positive nodes three years ago
- He has a seizure at work and is diagnosed with new metastasis in his liver, bone and brain
- His daughter moves him from South Carolina to her home for “treatment.”



What healthcare options exist?



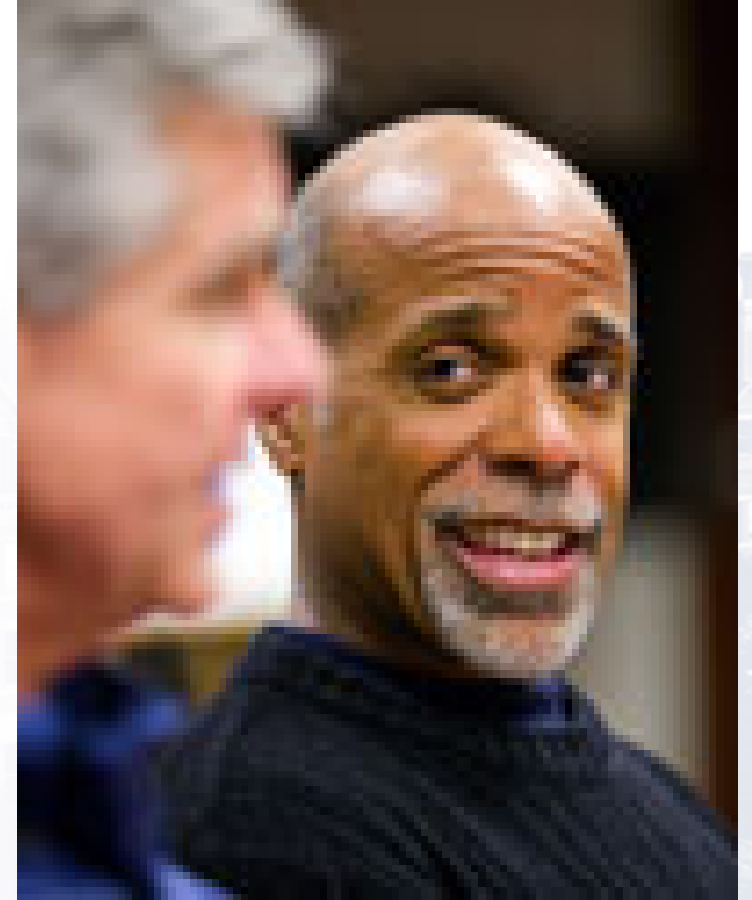
Cyberknife?
Whole brain radiation?
Palliative Chemo?
Immuno-therapy?
Palliative Care?
Hospice?

- What does Bob want?
- What does his Daughter want?
- Are these the same?

Case: Bob

What healthcare options exist?

- Patient referred for whole brain XRT near his home in SC, and seen in palliative clinic where a hospice referral is given.
 - He has some nausea & headache
- Daughter seeking second opinion.
- Does not get along with Dad's girl-friend who endorses hospice:
 - "It helped so much with my first husband"
- Daughter angry that Bob wasn't followed "properly" after first surgery years ago.



What is Palliative Care?

- **Specialized medical care for patients with serious illness.**
 - “Any age; any stage”
 - Can be combined with life-prolonging treatment or can be the sole focus of care (Hospice).
- **Physical, psychological, spiritual, and practical burdens of illness addressed.**
- **Goals: Added Layer of Support**
 - Control pain and other suffering
 - Assist with decision-making/advance care planning
 - Enhance quality of life for patient & family

Definition: Clinical Practice Guidelines for Quality Palliative Care

- Palliative care is

“Patient and family-centered care that optimizes quality of life (QOL) by anticipating, preventing, and treating suffering.”

National Consensus Project for Quality Palliative Care
www.nationalconsensusproject.org

Stats: Patients with Cancer

Last 30 days of life in the US:

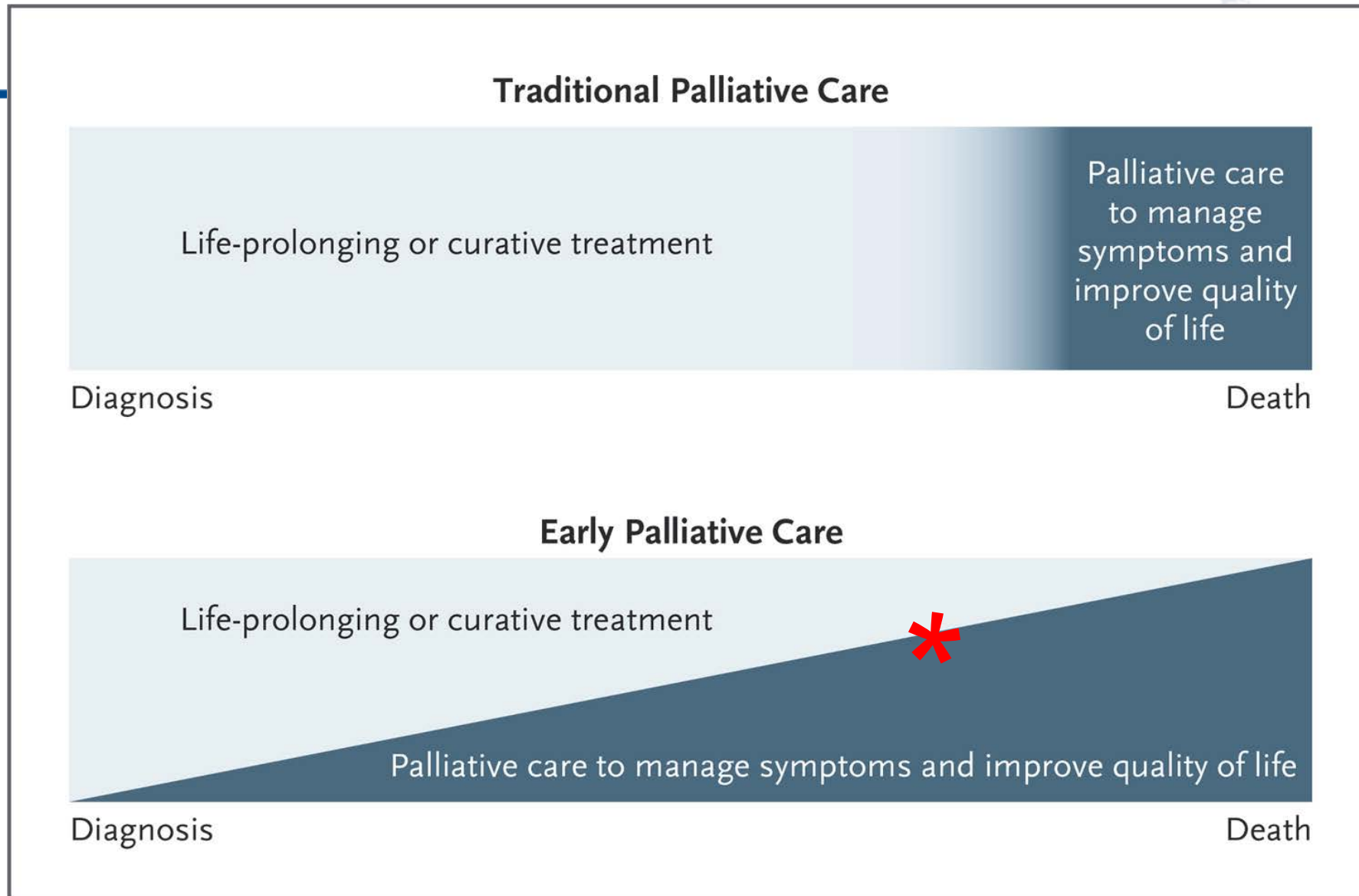
- 22% of patients die in acute hospitals
- 25% have 1+ ICU admission
- 12% receive 1+ chemotherapy course

However, family interviews of those who have died link better quality care to:

- Earlier hospice enrollment
- Avoidance of the ICU
- Death someplace other than the hospital

JAMA. 2016;315(3):272-283

Traditional vs. Trajectory view of Palliative



What is the evidence to support Palliative care and Concurrent Oncology Care?



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The Study Which Started it All!!!

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

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

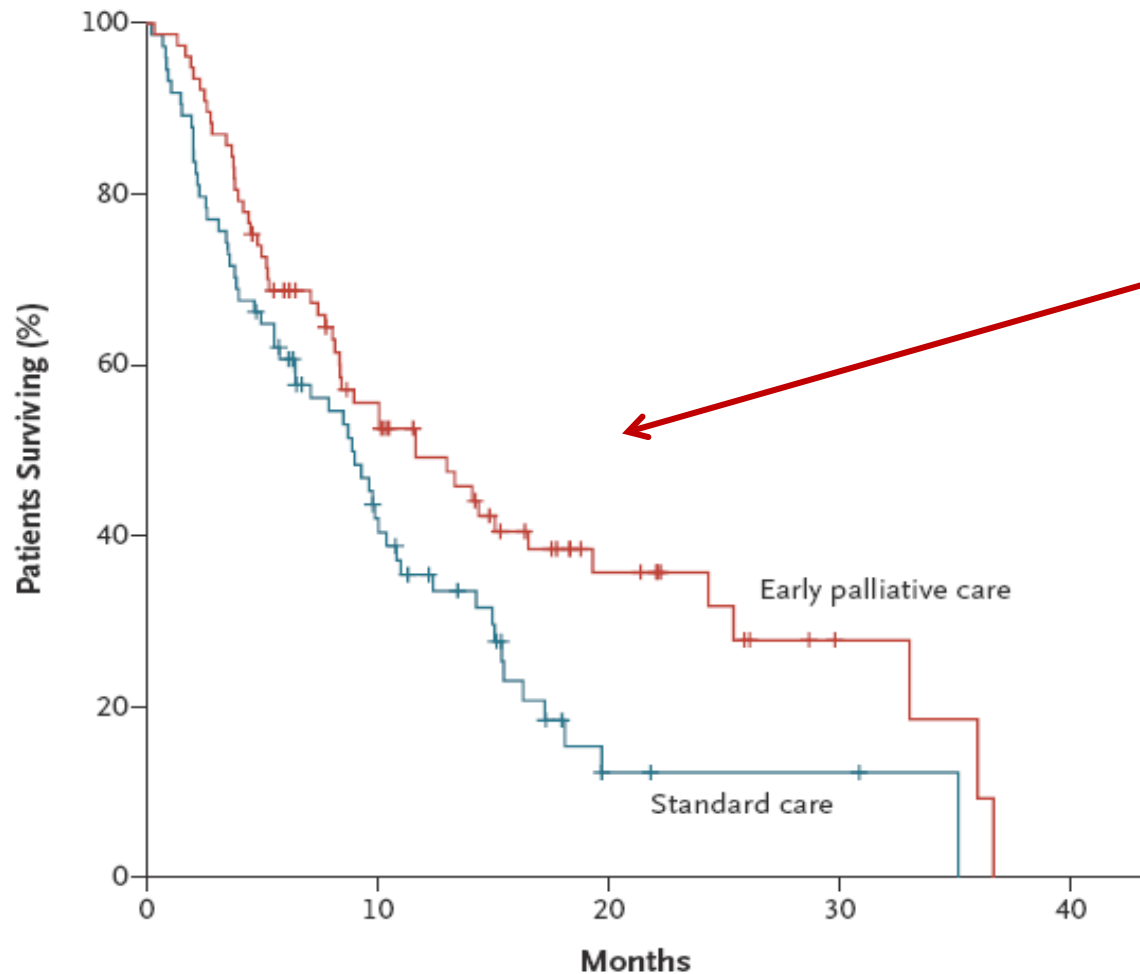
Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
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Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas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

ABSTRACT

- Better symptom control
- Improved quality of life
- Longer life
- Less costs

Palliative care + Standard care = 3 months longer life! than Standard care alone

Temel J, et al. NEJM 2010



Longer and better survival

- ✓ **Better understanding of prognosis →**
- ✓ **Less IV chemo in last 60 days**
- ✓ **Less aggressive care at the end of life**
- ✓ **More and longer use of hospice**
- ✓ **\$2000 per person savings to insurers and society**
(Greer, et al. J Clin Oncol 30, 2012)



Table 3 Health Care Utilization by Patients With Non–Small-Cell Lung Cancer Who Received Standard Care or Integrated Care

	Standard Care	Standard Care + Palliative Care	P Value
Received aggressive end-of-life care	54%	33%	.05
Resuscitation preference recorded	28%	53%	.05
Duration of hospice care	4 days	11 days	.09

Data from Temel JS et al. N Engl J Med. 2010.[20]

People who use hospice may live longer.

Matched cohort study: hospice use or not. 4493 Medicare patients, 2095 (47%) received hospice care for at least one day, 1999	
Disease	Added survival
CHF	+ 81 days, P = 0.0540
Lung cancer	+ 39 days, P < 0.0001
Pancreatic cancer	+ 21 days, P = 0.0102
Colon cancer	+ 33 days, P = 0.0792
Breast	+ 12 days, P = 0.6136
Prostate	+ 4 days, P = 0.8266



More Data!!!

Recommendation: Concurrent palliative care “should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”

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JOURNAL OF CLINICAL ONCOLOGY

ASCO SPECIAL ARTICLE

Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update

Betty R. Ferrell, Jennifer S. Temel, Sarah Temin, Erin R. Alesi, Tracy A. Balboni, Ethan M. Basch, Janice I. Finn, Judith A. Paice, Jeffrey M. Peppercorn, Tanyanika Phillips, Ellen L. Stovall, † Camilla Zimmermann, and Thomas J. Smith

9 RCTs, 1 quasi-experimental trial, and 5 secondary analysis from the RCTs in 2012 PCO



**The Integration of Palliative Care into Standard Oncology
Care: American Society of Clinical Oncology Clinical
Practice Guideline Update**

**THE INTEGRATION OF PALLIATIVE CARE INTO STANDARD ONCOLOGY CARE:
AMERICAN SOCIETY OF CLINICAL ONCOLOGY CLINICAL PRACTICE GUIDELINE UPDATE**

Clinical Question	Recommendation	Evidence Rating
What is the most effective way to care for patients with advanced cancers' symptoms (palliative care services in addition to usual care, compared with usual care alone)?	Patients with advanced cancer should be referred to interdisciplinary palliative care teams (consultation) that provide inpatient and outpatient care early in the course of disease, alongside active treatment of their cancer.	Type: evidence based, benefits outweighs harms Evidence quality: intermediate Strength of recommendation: strong
What are the most practical models of palliative care? Who should deliver palliative care (external consultation, internal consultations with palliative care practitioners in the oncology practice, or performed by the oncologist him- or herself)?	Palliative care for patients with advanced cancer should be delivered through interdisciplinary palliative care teams, with consultation available in both outpatient and inpatient settings.	Type: evidence based, benefits outweigh harms Evidence quality: intermediate Strength of recommendation: moderate
How is palliative care in oncology defined or conceptualized?	Patients with advanced cancer should receive palliative care services, which may include a referral to a palliative care provider. Essential components of palliative care include:	Type: informal consensus Evidence quality: intermediate Strength of recommendation: moderate
	Rapport and relationship building with patient and family caregivers	
	Symptom, distress, and functional status management (e.g., pain, dyspnea, fatigue, sleep disturbance, mood, nausea, or constipation)	
	Exploration of understanding and education about illness and prognosis	

**THE INTEGRATION OF PALLIATIVE CARE INTO STANDARD ONCOLOGY CARE:
AMERICAN SOCIETY OF CLINICAL ONCOLOGY CLINICAL PRACTICE GUIDELINE UPDATE**

Clinical Question	Recommendation	Evidence Rating
	<p>Clarification of treatment goals</p> <p>Assessment and support of coping needs (e.g., provision of dignity therapy)</p> <p>Assistance with medical decision making</p> <p>Coordination with other care providers</p> <p>Provision of referrals to other care providers as indicated</p> <p>For newly diagnosed patients with advanced cancer, the Expert Panel suggests early palliative care involvement, starting early in the diagnosis process and ideally within 8 weeks of diagnosis.</p>	
<p>How can palliative care services relate in practice to other existing or emerging supportive care services (including nurse navigation, lay navigation, community and home health care, geriatric oncology, psycho-oncology, and pain services)?</p>	<p>Among patients with cancer with high symptom burden and/or unmet physical or psychosocial needs, outpatient programs of cancer care should provide and use dedicated resources (palliative care clinicians) to deliver palliative care services to complement existing program tools.</p>	<p>Type: informal consensus, benefits outweigh harms Evidence quality: intermediate Strength of recommendation: moderate</p>
<p>Which interventions are helpful for family caregivers?</p>	<p>For patients with early or advanced cancer for whom family caregivers will provide care in outpatient, home, or community settings, nurses, social workers, or other providers may initiate caregiver-tailored palliative care support, which could include telephone coaching, education, referrals, and face-to-face meetings. For family caregivers who may live in rural areas and/or are unable to travel to clinic and/or longer distances, telephone support may be offered.</p>	<p>Type: evidence based Evidence quality: low Strength of recommendation: weak</p>

Common causes of suffering in seriously ill:

- Pain
- Dyspnea
- Nausea/vomiting
- Weakness & fatigue
- Insomnia
- Anorexia +/- cachexia
- Incontinence
- Constipation
- Agitation/Delirium
- Anxiety
- Depression
- Sense of well-being
- Uncertainty about future
- Fear of disability
- Fear of death
- Hopelessness
- Remorse
- Loneliness
- Loss of
 - Meaning/Role
 - Control
 - Dignity
 - Autonomy

What exactly does a palliative provider do???

Comprehensive Palliative Assessment:



1. Create rapport and build relationships with patient and family
 - Coordinate care with others teams and manage transitions across settings
 - Provide continuity (a comfort measure?)
2. Symptom assessment
 - Broad view of symptom in 4 domains:
 - 1) Physical
 - 2) Social
 - 3) Emotional
 - 4) Spiritual/existential
 - Use Standardized assessment tools: ESAS, MSAS, etc

What exactly does a palliative provider do???

Comprehensive Palliative Assessment:

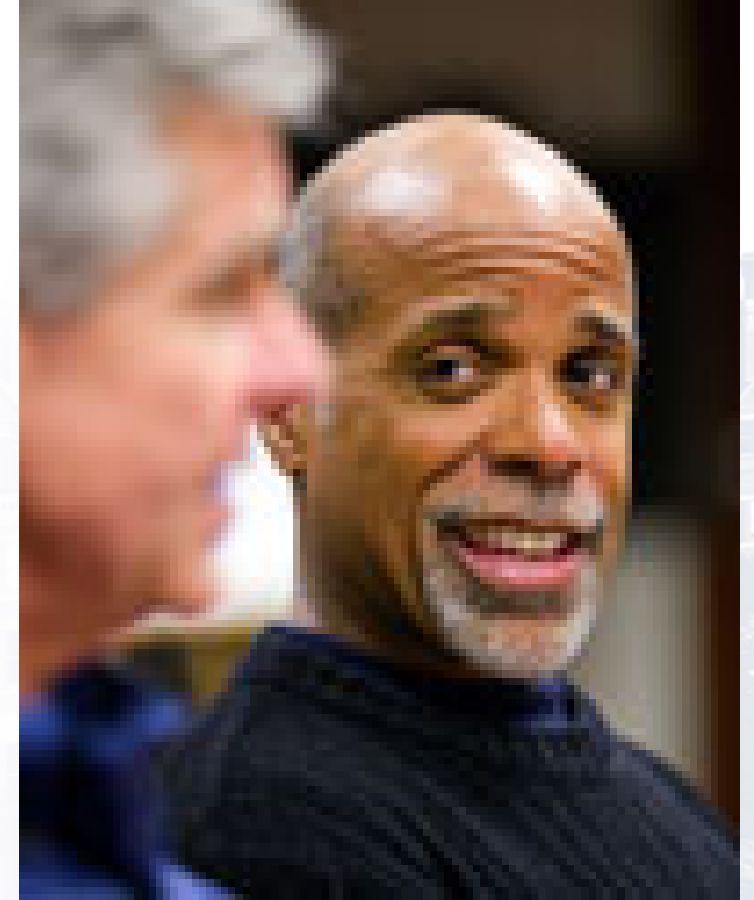


3. Evaluate illness understanding and provide prognostic education
4. Assess awareness of treatment focus/goals
5. Assess care preferences & assist with medical decisions
 - Facilitate advance care planning
6. Evaluate social and economic resources/needs of patient and caregivers
7. Assess and augment coping

Case: Bob

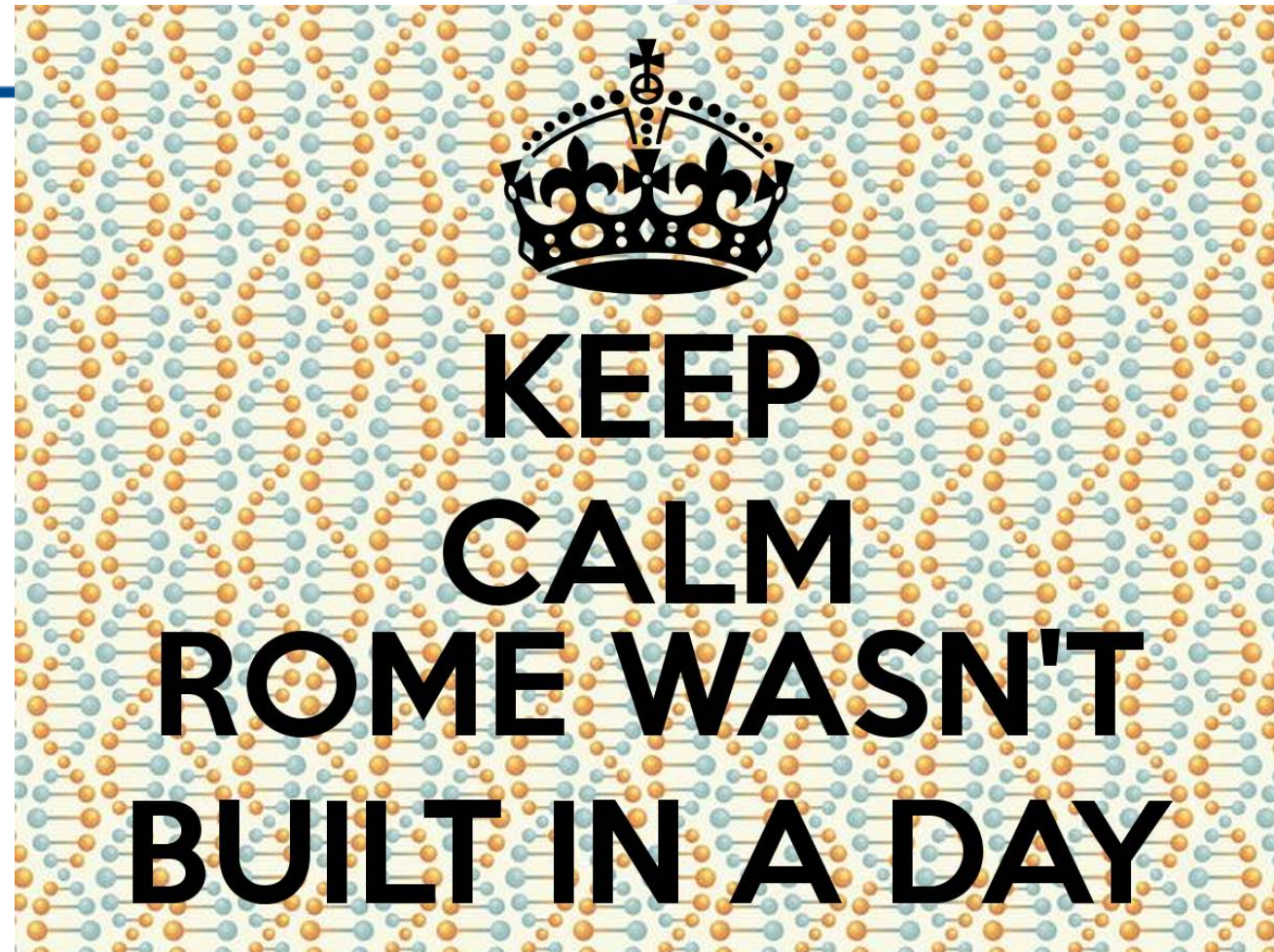
What healthcare options exist?

- Bob is seen by his new Oncologist
- He is most worried about his nausea & new abdominal pains.
- He identifies his girl-friend as his health care surrogate.
- He misses the Church where he is a Deacon.
- He says he doesn't enjoy living with his daughter, who "is smothering me with loving kindness."
- Referrals?



Who is on the Palliative Team? Multiple “touches”

- Physician
 - Nurse Practitioner
 - Physicians Assistant
 - Social Worker
 - RN Coordinator
 - Pharmacist
 - Chaplain
 - Volunteers
 - Anyone who gets you through the day
-
- Inpatient teams – follow in/out of ICU
 - Outpatient clinics – continuity over time
 - Home Care / Long-term care



Traditional vs Interdisciplinary

- Traditional Medical model
 - Disease focused
 - Often misses non-physical assessment
 - Care is episodic & may be uncoordinated and fragmented
- Interdisciplinary Medical model
 - Patient and family focused
 - Coordinated care is paramount
 - Interdisciplinary team is a cornerstone**



Bob is seen by the outpatient palliative team, including the Chaplain and NP, and makes an appointment with private a financial counselor recommended by the Social Worker

Tips of the Trade

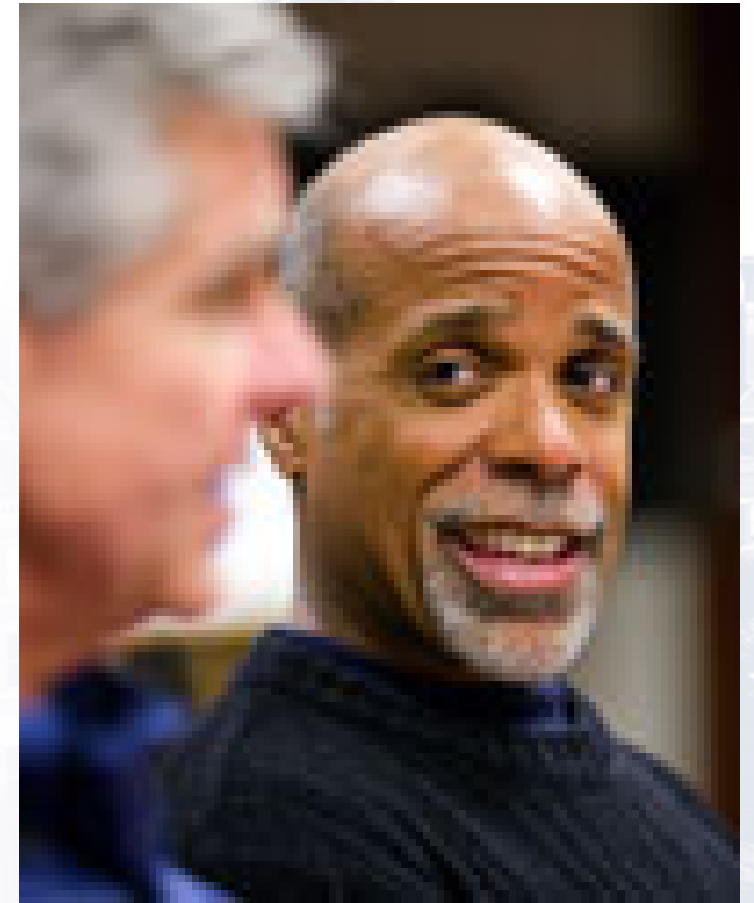


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Case: Bob

What healthcare options exist?

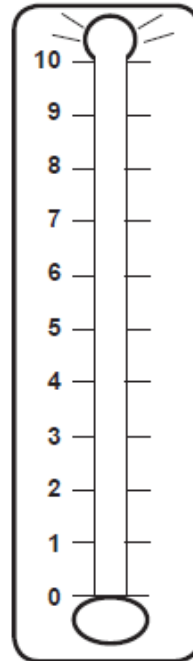
- “The Hair-dresser Effect”
- How do we assess for palliative needs?
- Who should do the assessment?
- How many have Patient Navigators?
- How many have RN Coordinators?
- How many have Social Workers?
- How many have Community Health Partners?
- How many have Pain Specialists?
- How many have Lymphedema and Beauty?



NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST

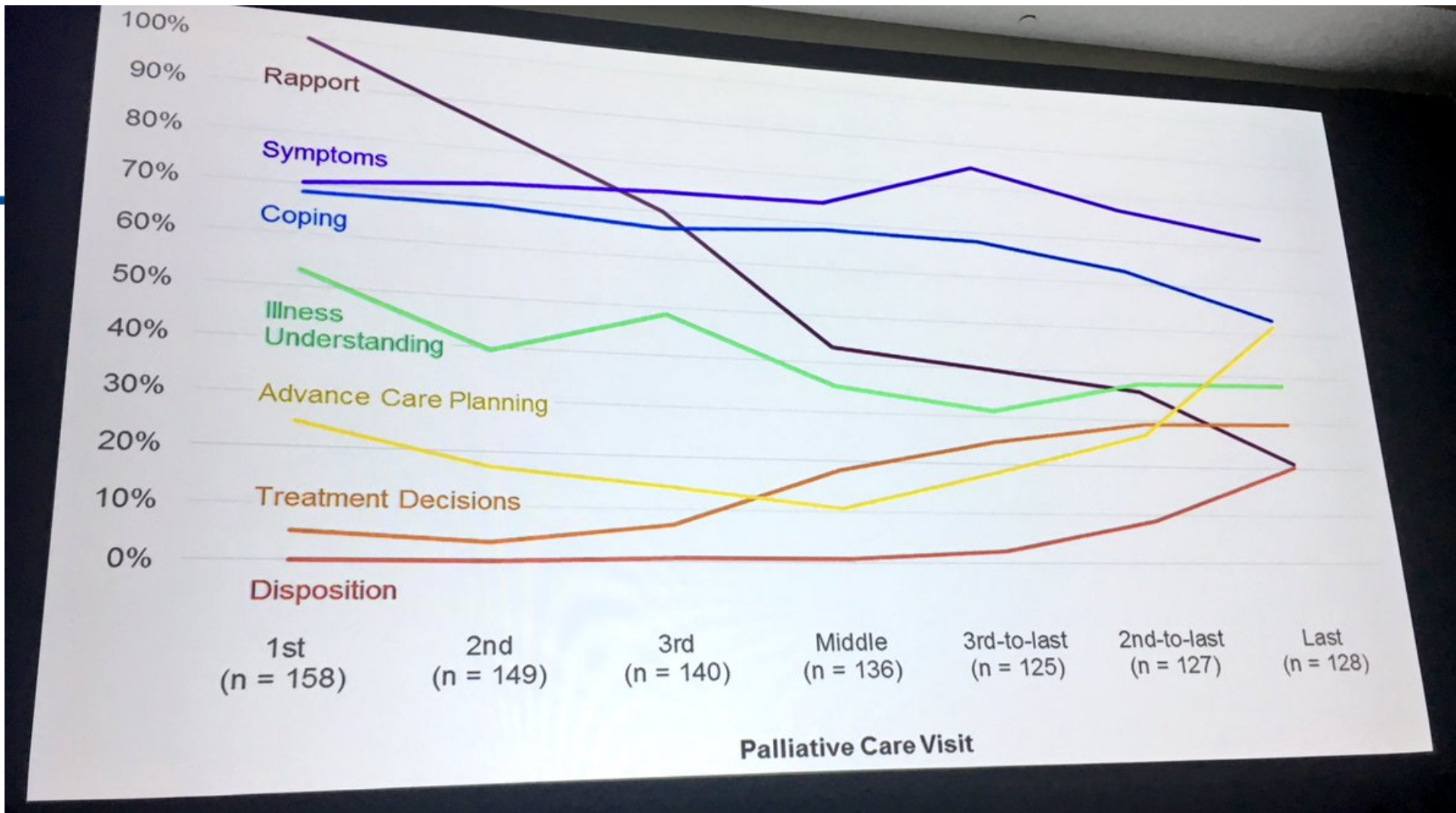
Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

- | YES | NO | <u>Practical Problems</u> | YES | NO | <u>Physical Problems</u> |
|--------------------------|--------------------------|--------------------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care | <input type="checkbox"/> | <input type="checkbox"/> | Appearance |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing | <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial | <input type="checkbox"/> | <input type="checkbox"/> | Breathing |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school | <input type="checkbox"/> | <input type="checkbox"/> | Constipation |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner | <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears | <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry | <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/religious concerns</u> | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

Other Problems: _____

Use
systematic
assessment
tools



Hoerger, M., Temel, J. S., Jackson, V. A., Park, E. R., Pirl, W. F., El-Jawahri, A., Gallagher, E. R., Hagan, T., Jacobsen, J., Perry, L. M., & Greer, J. A. (2017, March). Defining the elements of early palliative care (PC) that are associated with patient-reported outcomes (PROs) and the delivery of end-of-life (EOL) care. Paper presented at the annual meeting of the Palliative and Supportive Care in Oncology Symposium, San Diego, CA.

Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
 - Prognosis
 - Goals of treatment
 - Suffering
 - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
 - Within families
 - Between staff and families
 - Among treatment teams
- Assistance in addressing cases of near futility

1. How do you like to get medical information?
2. What is your understanding of your medical situation?
3. What is important to you?
4. What are you hoping for?
5. Do you have an advance directive or living will?

- Opioids 101
- Adjuvants 101
- Breaking bad news
- Prognostic disclosures
- Goals of Care discussions

Medications are the easy part!

[Quill TE, Abernethy AP.](#) Generalist plus specialist palliative care--creating a more sustainable model [N Engl J Med.](#) 2013 Mar 28;368(13):1173-5. doi: 10.1056/NEJMp1215620. Epub 2013 Mar 6.



Can't Oncologists do it all?

Maybe. Palliative concentrates on **COPING**, disease awareness, and helping the family.

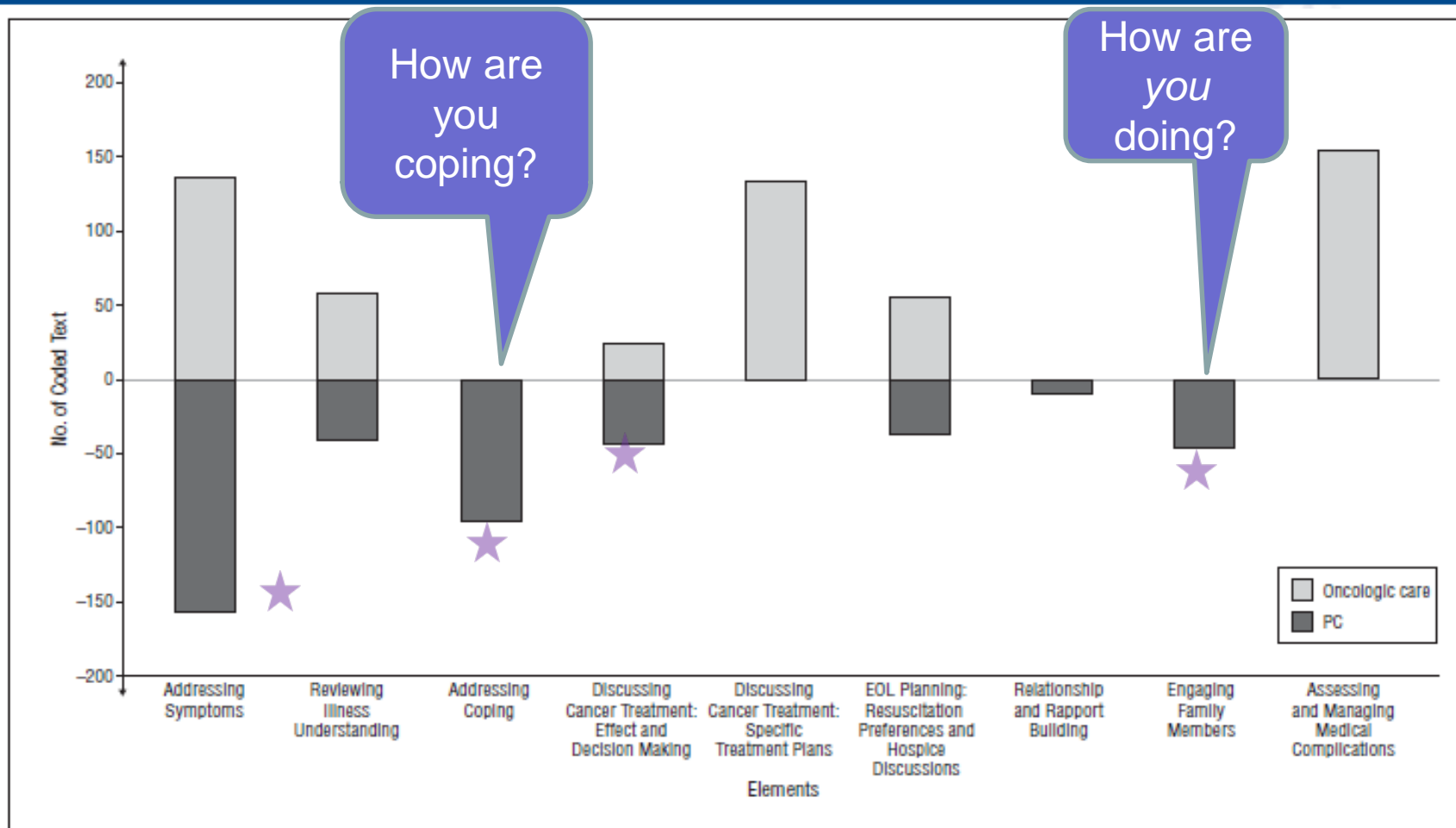


Figure 2. Elements of palliative care (PC) vs oncologic care visits at clinical turning points. EOL indicates end of life.

Advance Care Planning in the Clinics/Admission:

Be straightforward, calm, routine, positive

Social History:

- *“Do you smoke or drink alcohol? What do you do for a living?”*
- *Do you have a **living will, advance directive** or other healthcare wishes I should honor & respect when caring for you?”*

Surrogate: *“If sickness ever makes it such that you cannot speak to me, who should I call who knows you best, and can speak on your behalf?”*

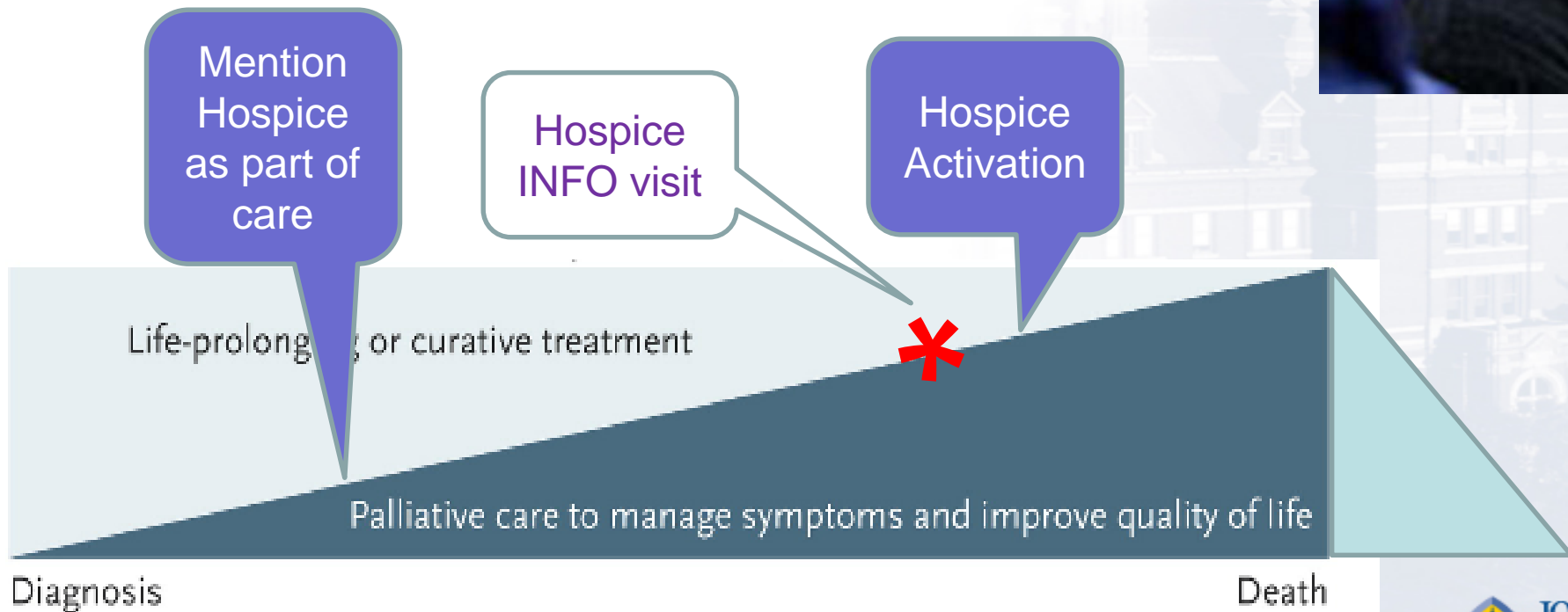
Values & Goals Assessment:

- *“I want to help you achieve what you want out of your health care, and I have some questions to ask:”*
- *“What makes life worth living?
What if you could no longer do these things?”*
- *“What are your most important hopes?
What are your biggest fears about your health?”*
- *“Would there be any circumstances under which you would find life not worth living?”*
- *“In terms of your treatments, what are your thoughts about balancing quality of life with length of life in terms of your treatments?”*

How Do We Normalize the Hospice Discussion?

Make it routine, with equal weight as other options.

- “What is your understanding of Hospice services?”
- “There is a company which is paid for by your insurance and can come to your house and provide...”

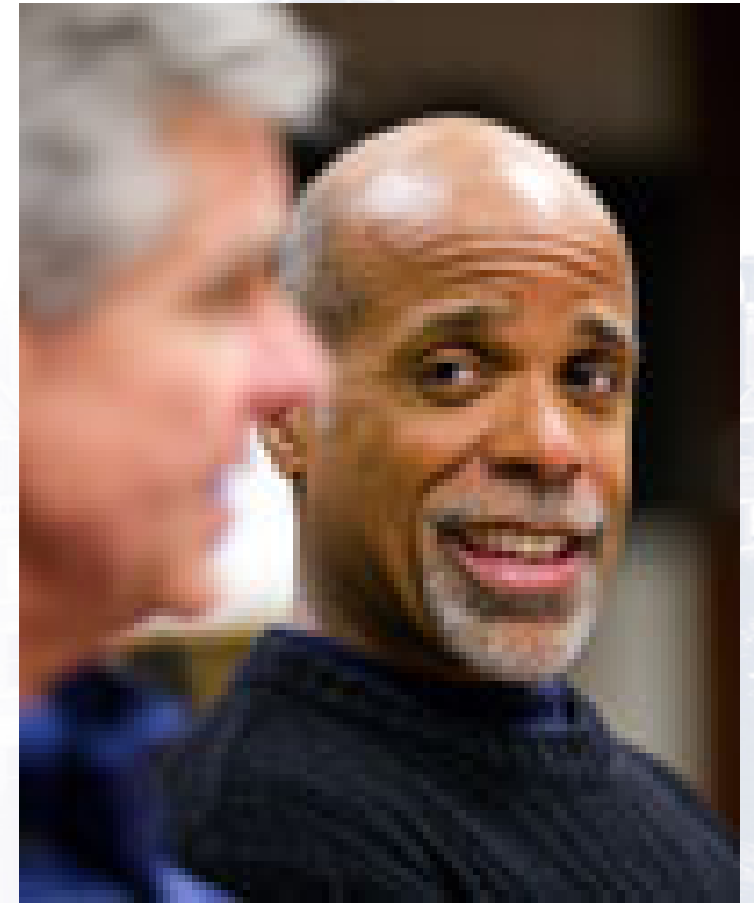


Case: Bob – 4 weeks later

What healthcare options exist?

- Worsening nausea and abdominal pain
- Unable to tolerate anything by mouth
- Dx: SBO and Peritoneal Carcinomatosis
- After 7 days of conservative measures, a venting PEG placed for comfort

- Do Bob and his Daughter have all the information needed for next steps?



Key to Palliative is Shared Decision Making

Do you have all the information to make a decision?

Information is key to informed consent

Does the patient know their prognosis?

The typical disease course?



Paternalism

Shared Decision Making

Autonomy

Can We Do Better? Ask!

- Oncologist: *“With the new abdominal pains, and these results on imaging, I am afraid his cancer is worse...”*
- Daughter: *“We just got the venting PEG! He is finally able to eat! That news will crush him. I don’t want him to give up Hope! He is so weak! Can’t he have more chemo?”*
- Oncologist: *“His hope is important to me too. Let’s wait and see. Let’s see if he is strong enough to do rehab.”*



Can We Do Better? Ask!

- Palliative: *“Can you help me understand what is most important to him right now? What he is most hoping to achieve?”*
- Daughter: *“Number one, is no pain or nausea, and number two is to go home and see his dogs. Number 3 is to sing with his Choir. We both know this is his last Thanksgiving.”*
- Palliative: *“Then I think we should focus on his goals, and work to get him home with services which can help him achieve what he wants.”*
 - *DNR optional*
 - *Consider brief hospice inpatient stay if available*



Empathy: Consider Saying:

- *“There must be something else you can do!”*
- *“Help me understand what you mean by that. Do you mean for more time, or less pain...?”*
- *“I wish we had better treatments for your cancer/illness.”*
 - Conveys reality of the situation without conveying false hope.
 - Consider OncoTalk training, which specifically addresses clinical trials discussions

Serious Illness Care Program and Conversation Guide Ariadne Labs

“Ariadne Labs is a joint center between Brigham and Women’s Hospital and the Harvard T.H. Chan School of Public Health”

<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>

Serious Illness Conversation Guide

CLINICIAN STEPS	CONVERSATION GUIDE
<input type="checkbox"/> Set up <ul style="list-style-type: none">• Thinking in advance• Is this okay?• Combined approach• Benefit for patient/family• No decisions today	Understanding What is your understanding now of where you are with your illness?
<input type="checkbox"/> Guide (right column)	Information preferences How much information about what is likely to be ahead with your illness would you like from me? <small>FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.</small>
<input type="checkbox"/> Summarize and confirm	Prognosis <i>Share prognosis, tailored to information preferences</i>
<input type="checkbox"/> Act <ul style="list-style-type: none">• Affirm commitment• Make recommendations to patient• Document conversation• Provide patient with Family Communication Guide	Goals If your health situation worsens, what are your most important goals?
	Fears / Worries What are your biggest fears and worries about the future with your health?
	Function What abilities are so critical to your life that you can’t imagine living without them?
	Trade-offs If you become sicker, how much are you willing to go through for the possibility of gaining more time?
	Family How much does your family know about your priorities and wishes? <small>(Suggest bringing family and/or health care agent to next visit to discuss together)</small>

Draft R4.2 12/10/13
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Serious Illness Conversation Guide

CLINICIAN STEPS

- Set up**
 - Thinking in advance
 - Is this okay?
 - Combined approach
 - Benefit for patient/family
 - No decisions today
- Guide** (right column)
- Summarize and confirm**

CONVERSATION GUIDE

Understanding

What is your understanding now of where you are with your illness?

Information preferences

How much information about what is likely to be ahead with your illness would you like from me?

FOR EXAMPLE:

Some patients like to know about time, others like to know what to expect, others like to know both.

“Would it be helpful to discuss prognosis?”

CPR “Yes” Patients

- ***“He is a fighter!”***

- ***“What are we fighting for?”***

- ***More time? More dignity? Less suffering?***

- ? ***Should we be moving away from battle imagery?***

Families need adequate understanding of prognosis to make decisions

→ Does Daughter have prognostic awareness?



What I Say

- Normalize the illness experience
 - *“Many people tell me....Do you feel the same?”*
- *“At this point, many people often ask about prognosis. Is this something you would like to discuss?”*

In Summary....



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Summary of Benefits of Early Palliative Care

Repeated Interactions over time lead to...

- Improved symptom control
- Lower rates of depression
- Improved overall quality of life
- Improved prognostic awareness
- Improved understanding of treatment plan/goals
 - When asked, most patients with metastatic cancer incorrectly say their cancer can be cured
 - May explain why those who receive early palliative care consultations are less likely to have chemotherapy near the end of life
- **Reduced hospital admissions & readmissions**

Does my patient need a palliative consult?

“Would I be surprised if this person died in the next year?”

- If the answer is “NO,” they need an advanced directive
- Primary team can accomplish this

Consider Palliative Consult:

- If you are having difficulty creating an advanced directive
- If you are having difficulty controlling symptoms
- If your patient takes up large amounts of your time wanting to talk about death, dying and their spiritual and existential angst.

Conclusions

1. Palliative care alongside usual care, with transition to hospice care when appropriate, is now the accepted best practice.
2. All the evidence suggests equal or better quality of life, fewer symptoms, equal or better survival, and less cost, with no harms.
3. Palliative care isn't scary... likely you or others in your office are already doing it and calling it "supportive care."

“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders

Nurse, Doctor, Social Worker and Writer

Founder of the Hospice Movement (1918-2005)



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Thank you for listening!



Questions?

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Key Resources

- ASCO Guideline on Integration of Palliative Care into Standard Oncology
www.asco.org/palliative-care-guideline
- ASCO Palliative Care Checklist
<https://www.asco.org/sites/new-www.asco.org/files/content-files/practice-and-guidelines/documents/2016-palliative-care-checklist.pdf>
- NCCN Distress Thermometer
https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf
- Ariadne Labs Serious Illness Care Program and Conversation Guide
<https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>