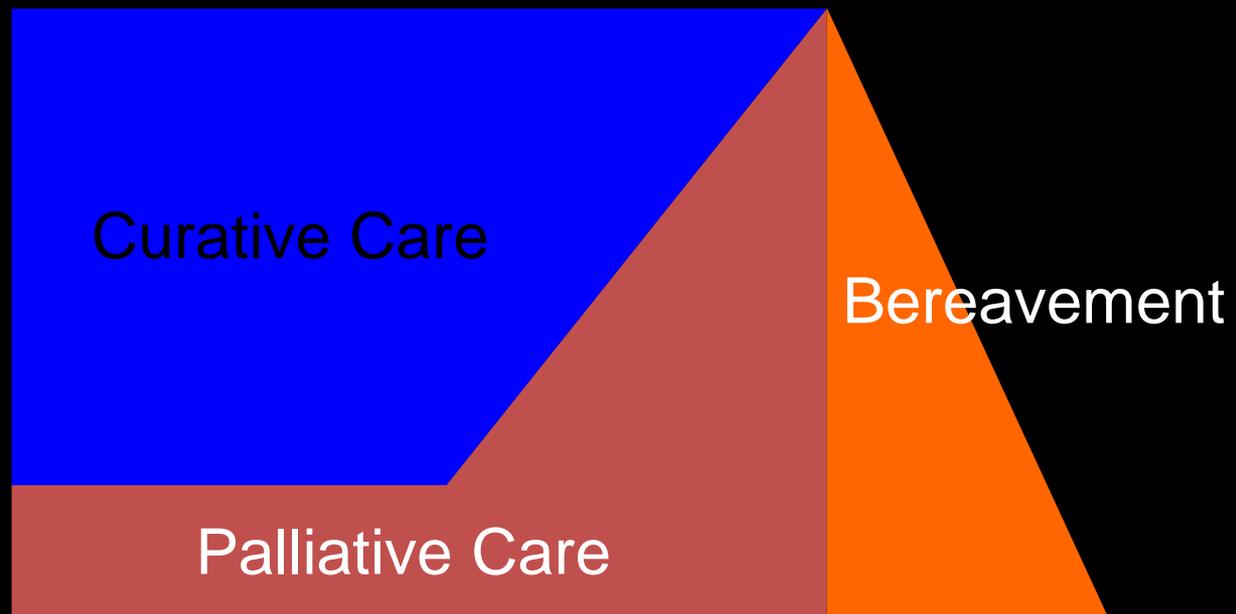


High Quality Cancer Care: The Role of Communication, Treatment Decision-Making, and Supportive Care

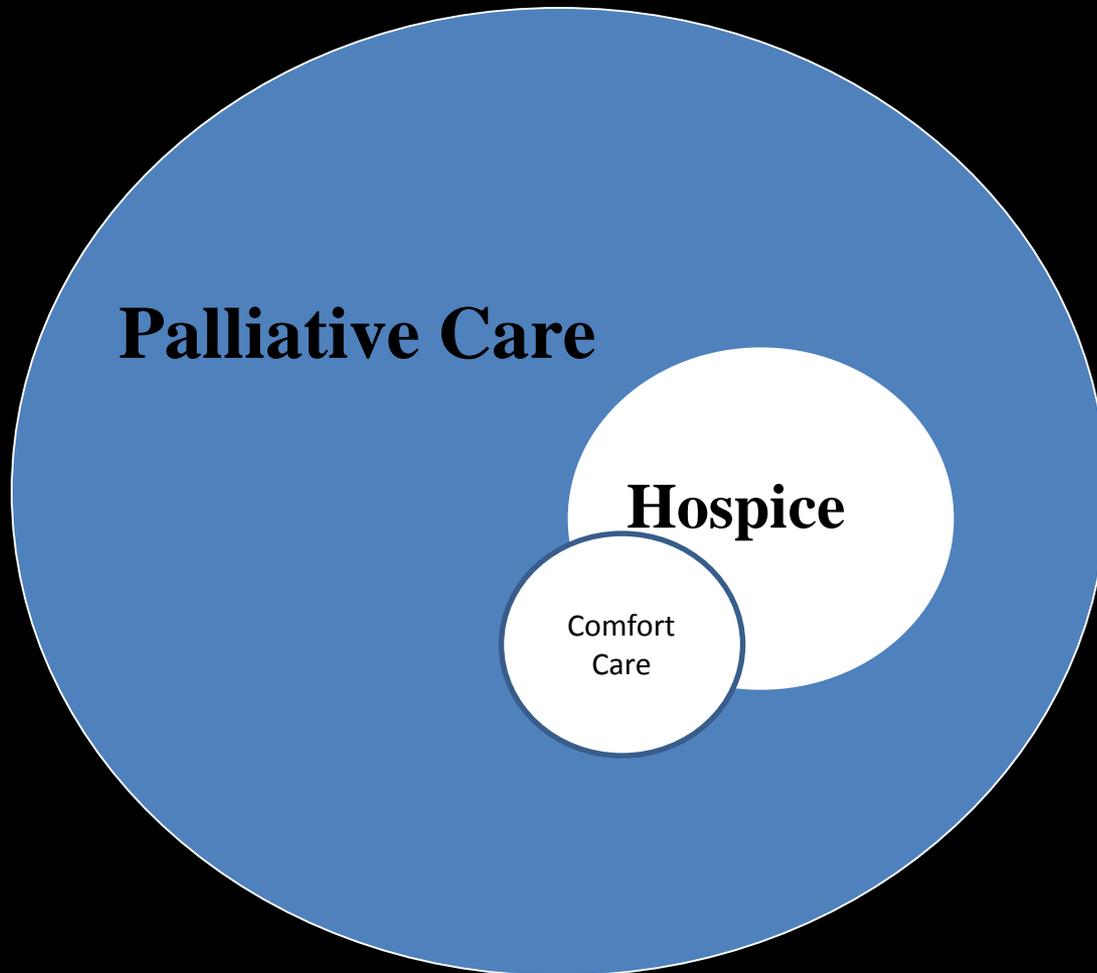
Arif Kamal MD, MBA, MHS
Duke University

Integrating Palliative Care into Serious Illness Care



“curing sometimes, caring always”

Palliative Care & Hospice



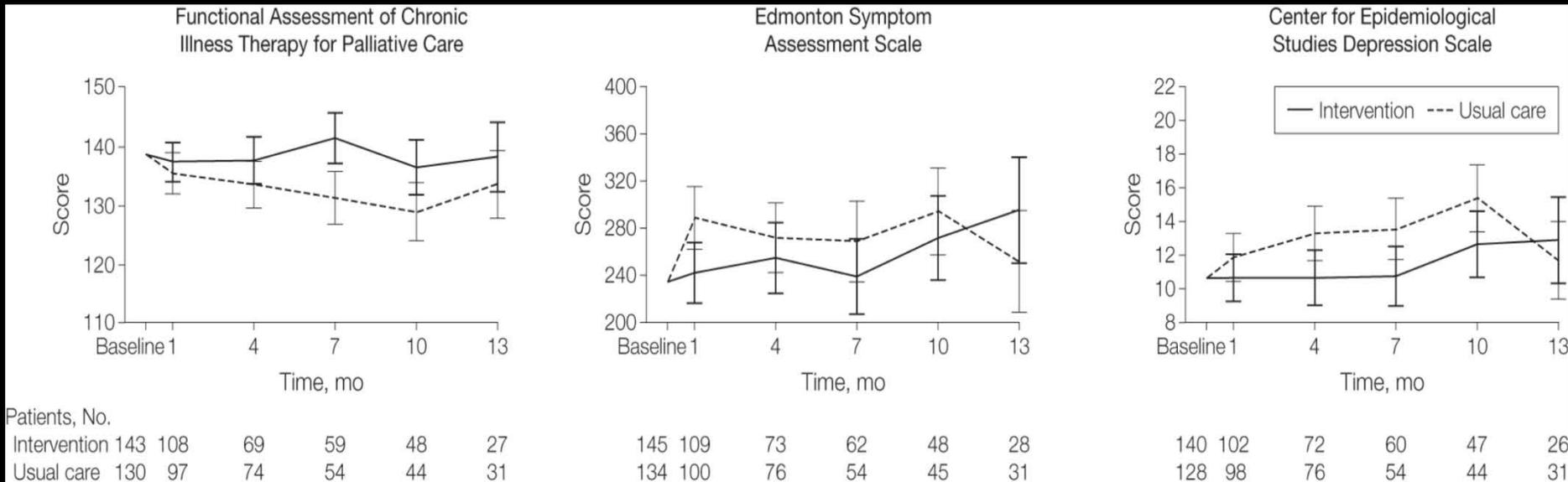
Why is this distinction important?

- If one thinks palliative care and hospice are the same thing, and that a patient has to be imminently dying before they qualify for service, then symptoms may not be addressed until it's too late.

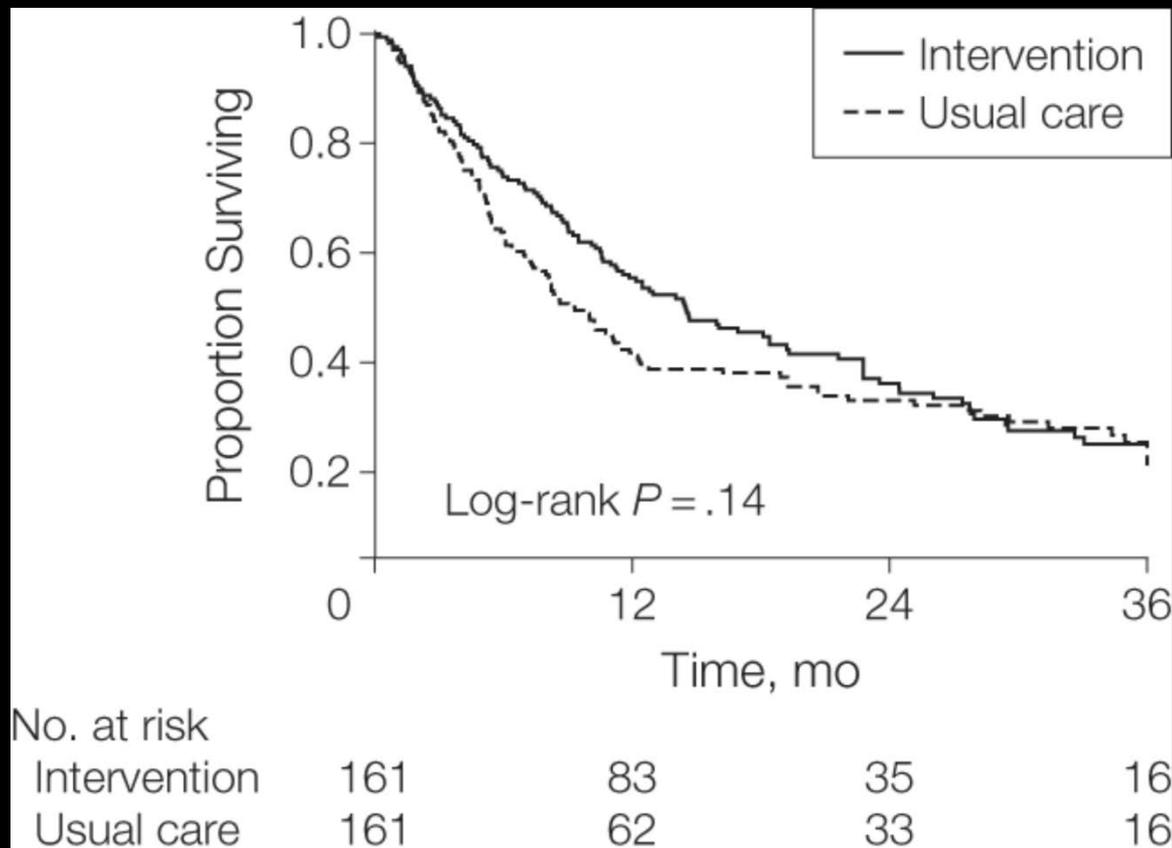
Palliative care ≠ hospice ≠ nothing we can do ≠ death

- ~~“There’s nothing more we can do....”~~
- “We may not be able to cure you, but there is ALWAYS something we can do!”

Palliative care in addition to usual oncology care allowed improved quality of life, fewer symptoms, and less depression. Bakitas M, et al. Project ENABLE. JAMA 2009

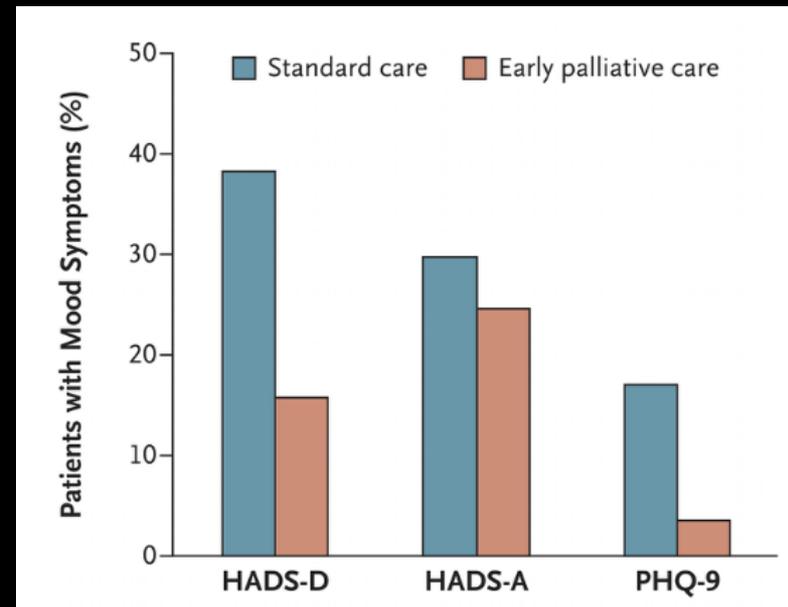
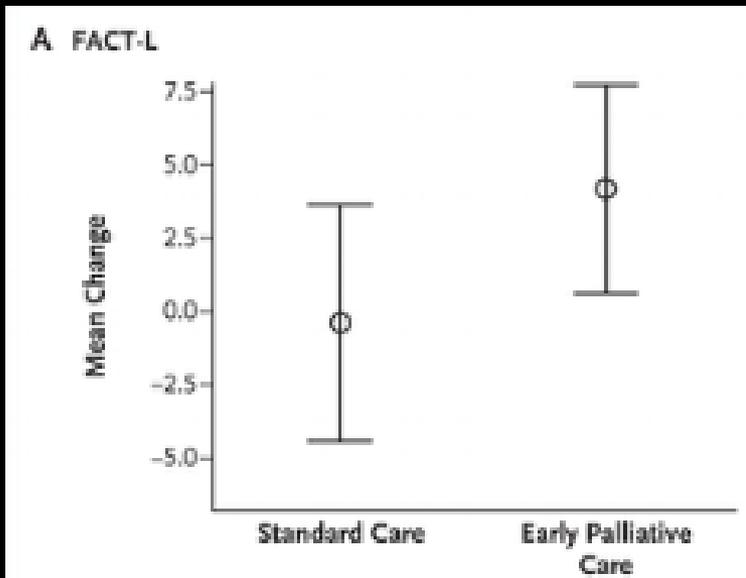


Palliative care in addition to usual oncology care allowed improved lifespan. Bakitas M, et al. Project ENABLE. JAMA 2009



Palliative care in addition to usual oncology care allowed lung cancer patients to have much better quality of life (FACT) and less anxiety and depression.

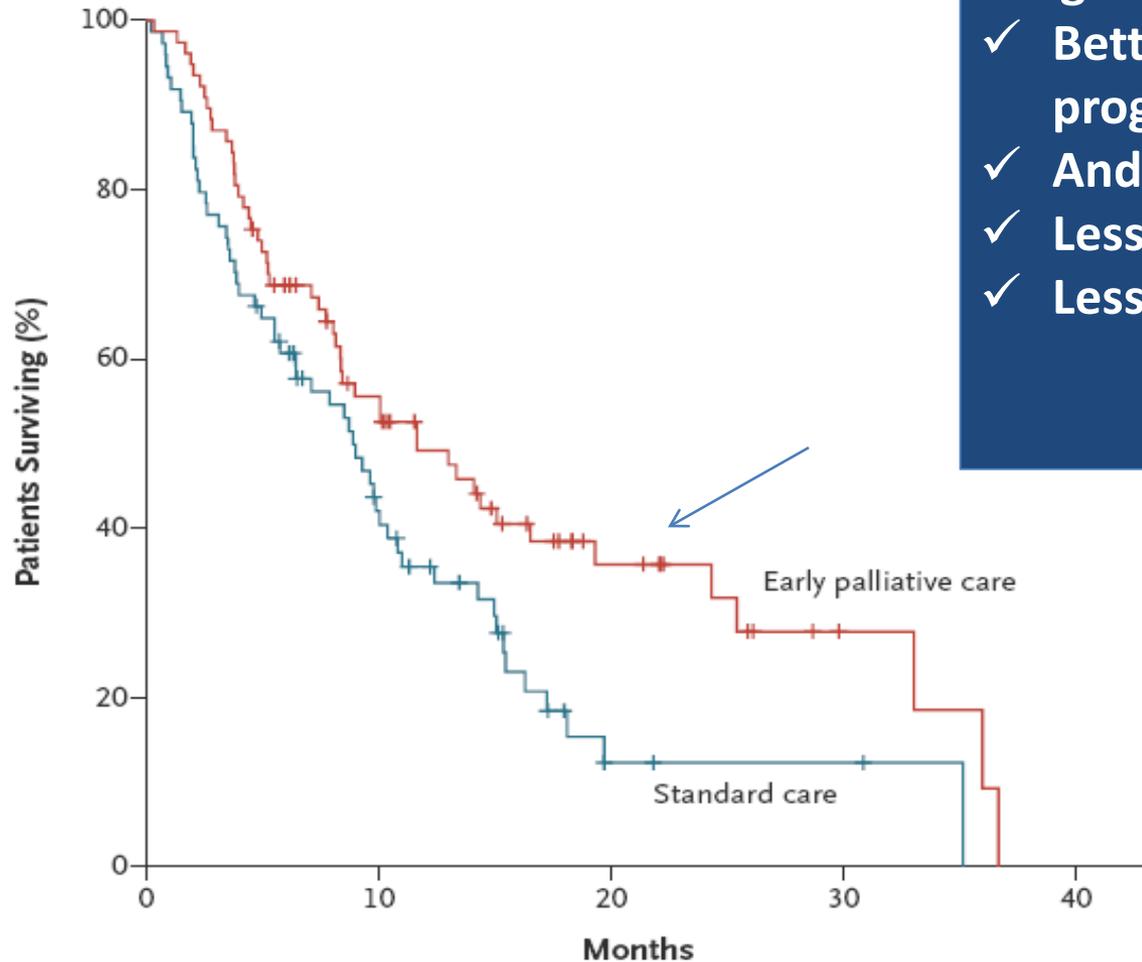
Temel J, et al. NEJM 2010; Temel J, et al, JCO 2011



Possibly increased survival

Longer and better survival

- ✓ Better understanding of prognosis
- ✓ And goals of care
- ✓ Less IV chemo in last 60 days
- ✓ Less aggressive end of life care



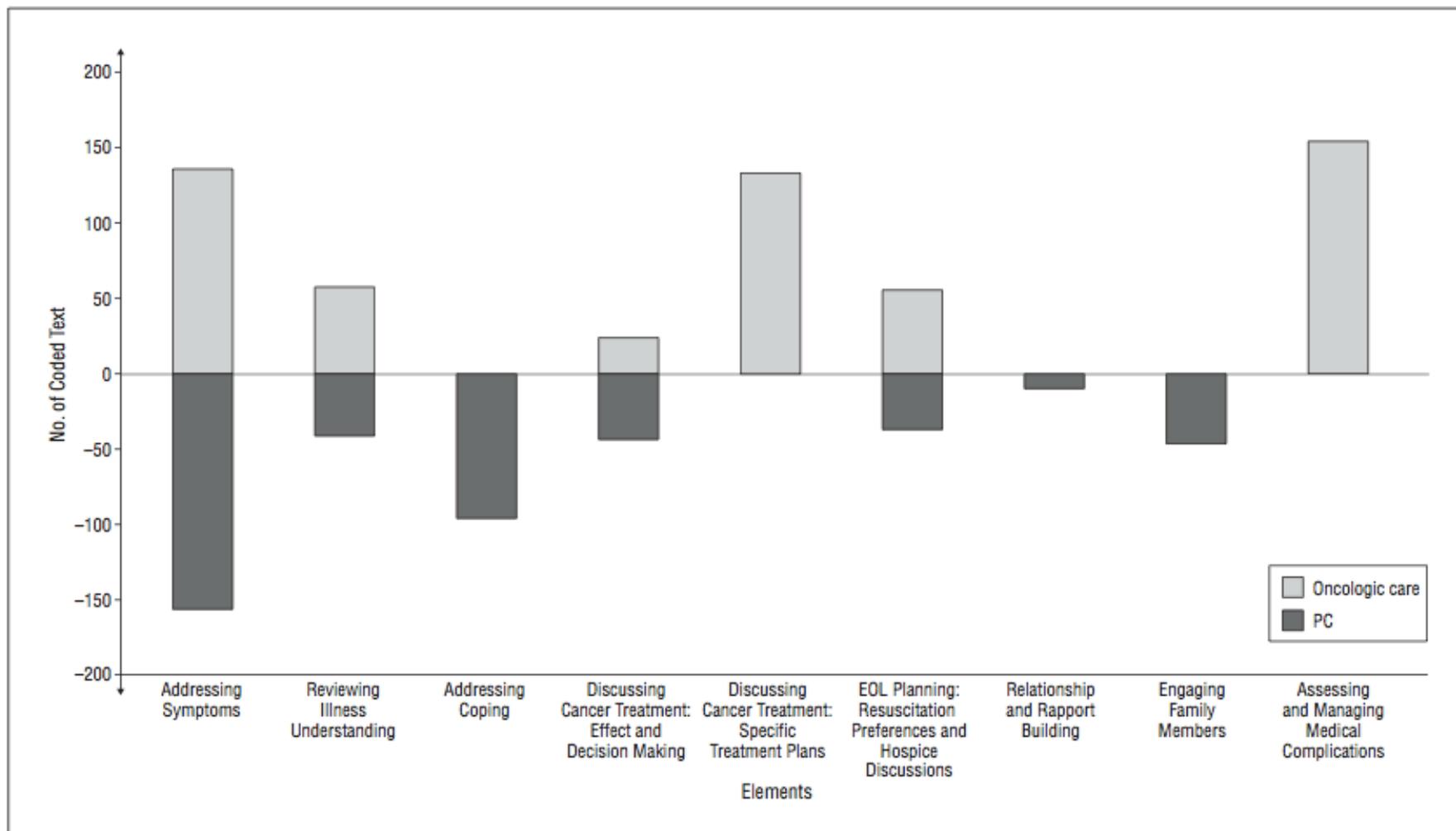


Figure 2. Elements of palliative care (PC) vs oncologic care visits at clinical turning points. EOL indicates end of life.

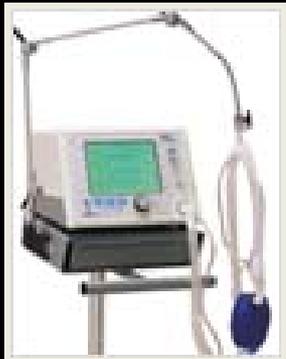
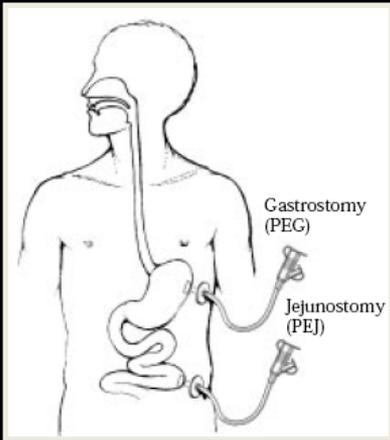
100 years of medical advancement

Causes of Death Comparison				
Rank	Cause of Death in 1900	Percentage	Cause of death 1994	Percentage
1	Influenza, pneumonia	11.8%	Heart disease	25.7%
2	Tuberculosis	11.3%	Cancer	20%
3	Gastritis, Enteritis	8.8%	Strokes	6%
4	Heart disease	8.0%	Chronic Pulmonary Obstructive Disease	4.5%
5	Strokes	6.2%	Accidents/trauma	3.4%
	All others		All others	

Death in Hospitals

- **98%** of Medicare decedents spent *at least some time* in a hospital in the year before death
- 15-55% of Medicare decedents had *at least one* stay in an ICU in the 6 months before death

PROGRESS



The Problem - Communication

Biggest Concerns for Patients with Serious Illness

%Biggest/ One of Biggest Concerns

Doctors might not provide all of the treatment options or choices available	58%
Doctors might not talk and share information with each other	55%
Doctors might not choose the best treatment option for a seriously ill patient's medical condition	54%
Patients with serious illness and their families leave a doctor's office or hospital feeling unsure about what they are supposed to do when they get home	51%
Patients with serious illness and their families do not have enough control over their treatment options	51%
Doctors do not spend enough time talking with and listening to patients and their families	50%

Logistics

Finances

Survivorship

Diagnosis

Treatments

LOTS TO TALK ABOUT

Prognosis

Clinical Trials

End of Life Care

Caregiving

ENGAGEMENT

=

ASKING QUESTIONS

CHEMOTHERAPISTS

NEGOTIATION

Conflict

- We want what's best for our patients
 - Yet sometimes attempts to convey bad news go awry
 - They may feel like we have a different agenda than theirs, and that we're not entirely "on their side"
 - Emotional aspects of a situation may be too much to bare
- Heels get "dug in," and stubbornness ensues
 - Fear of retaliation, litigation
 - Inappropriately aggressive care is rendered
- Staff morale suffers, moral distress occurs
 - "Why are we flogging this patient?"

HOPE/WORRY

Myth: Most people survive codes

1578

THE NEW ENGLAND JOURNAL OF MEDICINE

June 13, 1996

SPECIAL ARTICLE

CARDIOPULMONARY RESUSCITATION ON TELEVISION

Miracles and Misinformation

SUSAN J. DIEM, M.D., M.P.H., JOHN D. LANTOS, M.D., AND JAMES A. TULSKY, M.D.

Abstract *Background.* Responsible, shared decision making on the part of physicians and patients about the potential use of cardiopulmonary resuscitation (CPR) requires patients who are educated about the procedure's risks and benefits. Television is an important source of information about CPR for patients. We analyzed how three popular television programs depict CPR.

Methods. We watched all the episodes of the television programs *ER* and *Chicago Hope* during the 1994–1995 viewing season and 50 consecutive episodes of

and 18 on *Rescue 911*. In the majority of cases, cardiac arrest was caused by trauma; only 28 percent were due to primary cardiac causes. Sixty-five percent of the cardiac arrests occurred in children, teenagers, or young adults. Seventy-five percent of the patients survived the immediate arrest, and 67 percent appeared to have survived to hospital discharge.

Conclusions. The survival rates in our study are significantly higher than the most optimistic survival rates in the medical literature, and the portrayal of CPR on tele-

Table 4. Outcomes of In-Hospital Pulseless Cardiac Arrests by First Documented Pulseless Arrest Rhythm*

	No. (%) of Patients							
	VF or Pulseless VT		Asystole		PEA		Unknown Rhythm	
	Pediatric (n = 120)	Adult (n = 8361)	Pediatric (n = 350)	Adult (n = 13 024)	Pediatric (n = 213)	Adult (n = 11 963)	Pediatric (n = 197)	Adult (n = 3554)
Any ROSC	80 (66.7)	5629 (67.3)	184 (52.6)	5858 (45.0)	123 (57.7)	6270 (52.4)	137 (69.5)	2062 (58.0)
ROSC >20 min	74 (61.7)	5185 (62.0)	157 (44.9)	4997 (38.4)	108 (50.7)	5135 (42.9)	120 (60.9)	1866 (52.5)
Survival to discharge	35 (29.2)	3013 (36.0)	78 (22.3)	1379 (10.6)	57 (26.8)	1340 (11.2)	66 (33.5)	753 (21.2)
Neurological outcome								
Good	22 (62.9)	2268 (75.3)	43 (55.1)	841 (61.0)	36 (63.2)	834 (62.2)	35 (53.0)	447 (59.4)
Poor	1 (2.9)	264 (8.8)	16 (20.5)	243 (17.6)	13 (22.8)	222 (16.6)	11 (16.7)	111 (14.7)
Unknown	12 (34.3)	481 (16.0)	19 (24.4)	295 (21.4)	8 (14.0)	284 (21.2)	20 (30.3)	195 (25.9)

Abbreviations: PEA, pulseless electrical activity; ROSC, return of spontaneous circulation; VF, ventricular fibrillation; VT, ventricular tachycardia.

*First documented pulseless rhythm (VF or pulseless VT, asystole, PEA, and unknown) was defined as the first electrocardiographic rhythm documented at the time the patient became pulseless. Good neurological outcome was prospectively defined as cerebral performance category (CPC) 1 or 2 for adults; the comparable pediatric CPC (PCPC) of 1, 2, or 3 for children on hospital discharge; or no change from baseline CPC or PCPC.

What Do Patients with Serious Illness 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

- And, as death nears:
 - Preparation
 - **Completion**

Singer et al. *JAMA* 1999;281(2):163-168

Steinhauser et al. *Ann Intern Med* 2000;132(10):825-32

What Do Family Caregivers Want?

475 family members, 1-2 years after bereavement:

- Loved one's wishes honored
- Inclusion in decision processes
- Support and assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

CONVERSATION

WHOSE STORY?

SILENCE

PERMISSION

WE'RE IN A DIFFERENT PLACE

I WORRY/WISH

An Algorithm

- Setting
- Perception
- Invitation
- Knowledge
- Emotion
- Summarize / Strategize

How to start

- “Ask-Tell-Ask”
 - Always a good way to start a difficult conversation
- “What have your doctors told you about what’s going on now?”
 - The patient’s response will guide you as to where to go next
 - Might be, “This is just a setback, and I’m getting chemo again next week
 - OR, “I’m getting weaker, and I’m worried about what this means for the future...”
- “Tell me a little more about that...”

Some tips and tricks

- Ask-tell-ask – *Cancer, 2005*
- “Tell me more” – *Cancer, 2005*
- Demonstrating empathy
 - “I wish...” – *Annals of Int Med, 2001*
- “Hope for the best, while preparing for other possibilities” - *Annals of Int Med, 2003*

DISCUSSION/QUESTIONS

SCENARIO 1

BREAKING UP IS HARD TO DO

SCENARIO 2

BREAKING BAD (NEWS)

SCENARIO 3

DIVINE INTERVENTION