Improving Quality of Life in Patients with Advanced Cancers

Alexi A. Wright, MD MPH
Dana-Farber Cancer Institute
Harvard Medical School

January 19, 2018

Overview

- End-of-life (EOL) care today
- Barriers to EOL discussions
- Evidence that EOL discussions improve care and outcomes.
- Approaches to talking with patients
- Early efforts to scale discussions

VOLUME 23 · NUMBER 13 · MAY 1 2005

JOURNAL OF CLINICAL ONCOLOGY

THE ART OF ONCOLOGY:
When the Tumor Is Not the Target

Necessary Collusion: Prognostic Communication With Advanced Cancer Patients

Paul R. Helft

From the Department of Medicine, Division of Hematology/Oncology, the Indiana University Center for Bioethics, and the Regenstrief Institute for Health Care, Indiana University School of Medicine, Indianapolis, IN.

Submitted June 20, 2004; accepted February 7, 2005.

Author's disclosures of potential conflicts of interest are found at the end of this article.

Address reprint requests to Paul R. Helft, Division of Hematology/Oncology, 535 Barnhill Dr, RT 473, Indianapolis, IN 46202; e-mail: phelft@iupui.edu.

0732-183X/05/2313-3146/$20.00

DOI: 10.1200/JCO.2005.07.003

INTROD

As a young oncologis
tling with many of th
in the practice of onc
trade-offs between ris
ous treatments, findi
to deal with the deva
tients' situations, and
communicate import
tients in ways that g
useful information, b
preserve some hope f
last issue on which I o

I have noticed th
wisdom holds that we
and honest prognost
tients at all times, in
do. So, I find myself e
communication abou
tients which, in a sens
facts to come out ove
presenting them up
other oncologists who
strategy. I do this be

Bioethics ISSN 0269-9702
Volume 17 Number 2 2003

'HITTING YOU OVER THE HEAD': ONCOLOGISTS' DISCLOSURE OF PROGNOSIS TO ADVANCED CANCER PATIENTS

ELISA J. GORDON A
CHRISTOPHER K. D

ABSTRACT

The disclosure of progno
recent concern given grea
decision-making in the U
process, American physici
information to such patie
all available treatment o
pies. Although not legally
is ethically justified becau
and enables patients to m
goals. To understand on

Collusion in doctor-patient communication about imminent death: an ethnographic study

Anne-Mei The, Tony Hak, Gerard Koëter, Gerrit van der Wal

See also *Education and debate* p 1400

Institute for Research in Extramural Medicine/Department of Social Medicine, Vrije Universiteit, Van der Boechorststraat 7, 1081 BT Amsterdam, Netherlands
Anne-Mei The *researcher*
Tony Hak *researcher*
Gerrit van der Wal *professor*

continued over

BMJ 2000;321:1376–81

bmj.com

An additional box covering atypical cases can be found on the BMJ's website

Abstract

Objective To discover and explore the factors that result in "false optimism about recovery" observed in patients with small cell lung cancer.
Design A qualitative observational (ethnographic) study in two stages over four years.
Setting Lung diseases ward and outpatient clinic in university hospital in the Netherlands.
Participants 35 patients with small cell lung cancer.
Results "False optimism about recovery" usually developed during the (first) course of chemotherapy and was most prevalent when the cancer could no longer be seen in the x ray pictures. This optimism tended to vanish when the tumour recurred, but it could develop again, though to a lesser extent, during further courses of chemotherapy. Patients gradually found out the facts about their poor prognosis, partly because of physical deterioration and partly through contact with fellow patients who were in a more advanced stage of the illness and were dying. "False optimism about recovery" was the result an association between doctors' activism and patients' adherence to the treatment calendar and to the "recovery plot," which allowed them not to acknowledge explicitly what they should and could know. The doctor did and did not want to pronounce a "death sentence" and the patient did and did not want to hear it.
Conclusion Solutions to the problem of collusion between doctor and patient require an active, patient oriented approach from the doctor. Perhaps solutions have to be found outside the doctor-patient relationship itself—for example, by involving "treatment brokers."

Introduction

Almost all patients with cancer want to know their diagnosis and most patients also want to be informed about the chance that they will be cured.[1] This does not imply that these patients want to hear the really bad news about their condition. Many patients, when they fear that their prognosis is rather poor, do not ask for precise information and do not hear it if it is provided by the doctor.[2 3] Our study started from the observation that, after their first course of chemotherapy virtually all patients with small cell lung cancer in a university hospital programme showed a "false optimism" about their recovery, in the sense that the patients' interpretations of their prognosis were

Photo courtesy New York Times: Sandomir R, A Story of Perseverance, March 12, 2014

Keating NL, Cancer 2010

Patients living with serious illness have many priorities in addition to living longer.

- Symptom management and quality of life
- Sense of control and completion
- Strengthening of relationships

Singer JAMA 1999; Steinhauser JAMA 2000; Heyland Palliative Medicine 2015

Gap Between What Patients *Want* and What They *Get*

Most people want to be at home and prefer comfort-focused care at the end of life, but often *not* the reality.

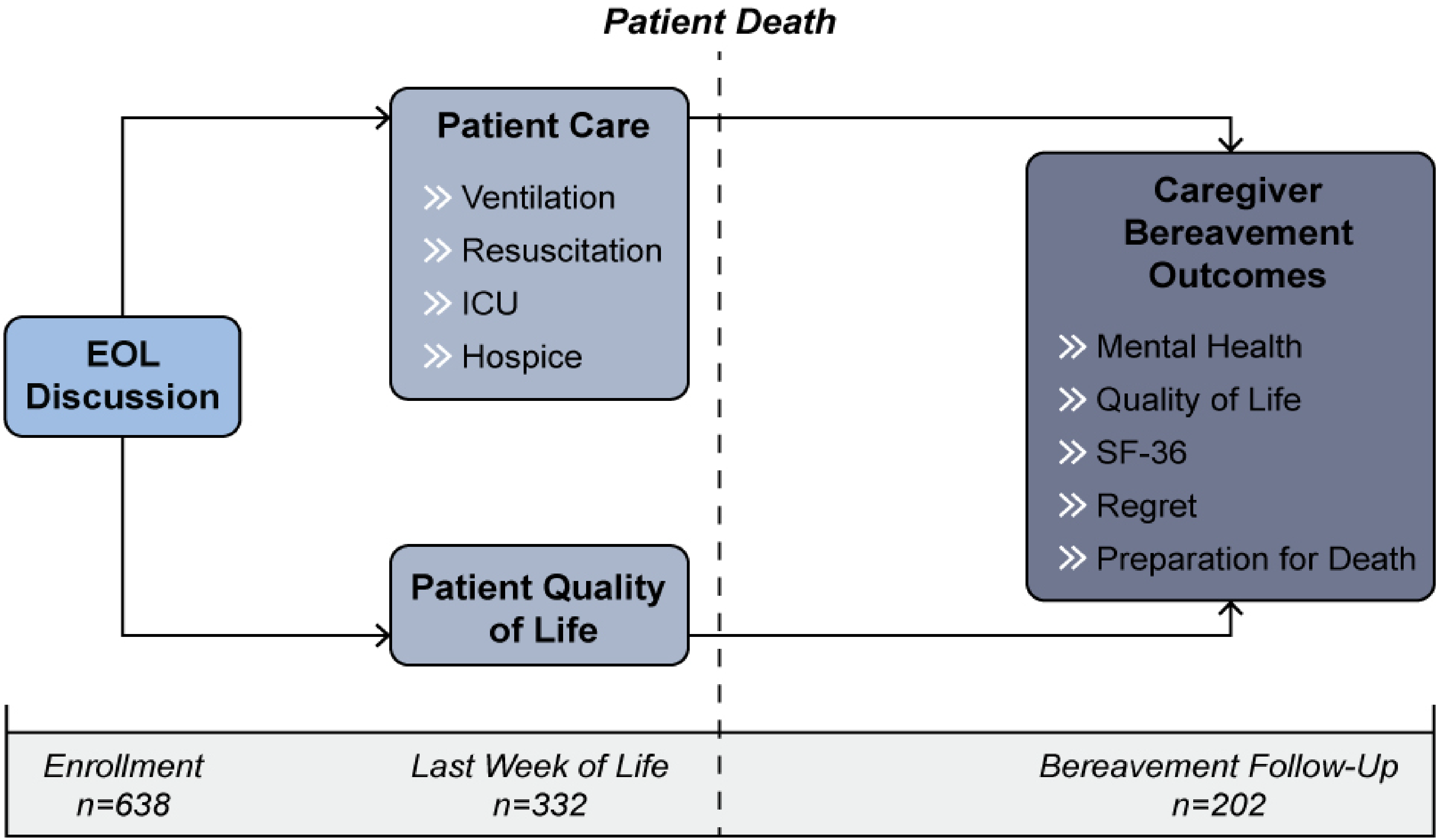
- 86% Medicare beneficiaries want to spend final days at home
- 25-39% die in an acute care hospital
- 70% are hospitalized in the last 90 days
- 29% receive intensive, hospital-based care in the last 30 days
- Many experience care transitions and very short hospice stays

Barnato, Medical Care 2007; Teno JAMA 2013; Silveira, NEJM 2010

Bitter Pill or Better Medicine?

- Question 1: Is there an association between EOL discussions and patients' mental health and/or psychiatric disorders?
- Question 2: Are EOL discussions associated with less aggressive medical care near death?

Coping with Cancer: Study Schema



Patient Death

EOL Discussion

Patient Care

- Ventilation
- Resuscitation
- ICU
- Hospice

Patient Quality of Life

Caregiver Bereavement Outcomes

- Mental Health
- Quality of Life
- SF-36
- Regret
- Preparation for Death

Enrollment
n=638

Last Week of Life
n=332

Bereavement Follow-Up
n=202

EOL Discussions: No Evidence of Distress

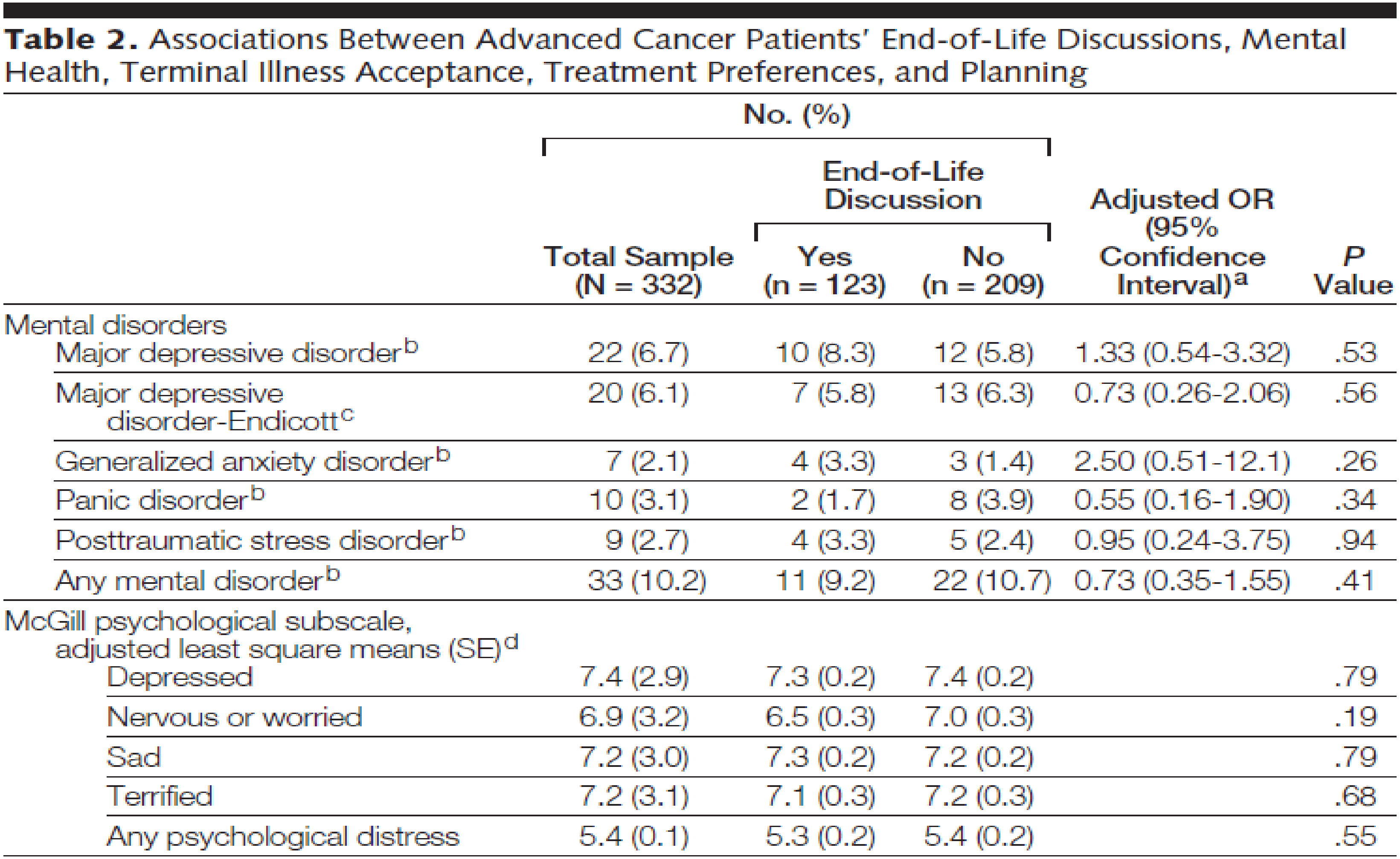


Table 2. Associations Between Advanced Cancer Patients' End-of-Life Discussions, Mental Health, Terminal Illness Acceptance, Treatment Preferences, and Planning

	No. (%)				
		End-of-Life Discussion			
	Total Sample (N = 332)	Yes (n = 123)	No (n = 209)	Adjusted OR (95% Confidence Interval)[a]	*P* Value
Mental disorders					
Major depressive disorder[b]	22 (6.7)	10 (8.3)	12 (5.8)	1.33 (0.54-3.32)	.53
Major depressive disorder-Endicott[c]	20 (6.1)	7 (5.8)	13 (6.3)	0.73 (0.26-2.06)	.56
Generalized anxiety disorder[b]	7 (2.1)	4 (3.3)	3 (1.4)	2.50 (0.51-12.1)	.26
Panic disorder[b]	10 (3.1)	2 (1.7)	8 (3.9)	0.55 (0.16-1.90)	.34
Posttraumatic stress disorder[b]	9 (2.7)	4 (3.3)	5 (2.4)	0.95 (0.24-3.75)	.94
Any mental disorder[b]	33 (10.2)	11 (9.2)	22 (10.7)	0.73 (0.35-1.55)	.41
McGill psychological subscale, adjusted least square means (SE)[d]					
Depressed	7.4 (2.9)	7.3 (0.2)	7.4 (0.2)		.79
Nervous or worried	6.9 (3.2)	6.5 (0.3)	7.0 (0.3)		.19
Sad	7.2 (3.0)	7.3 (0.2)	7.2 (0.2)		.79
Terrified	7.2 (3.1)	7.1 (0.3)	7.2 (0.3)		.68
Any psychological distress	5.4 (0.1)	5.3 (0.2)	5.4 (0.2)		.55

Wright AA, et al., JAMA, 2008

EOL Discussions: Preferences and Planning

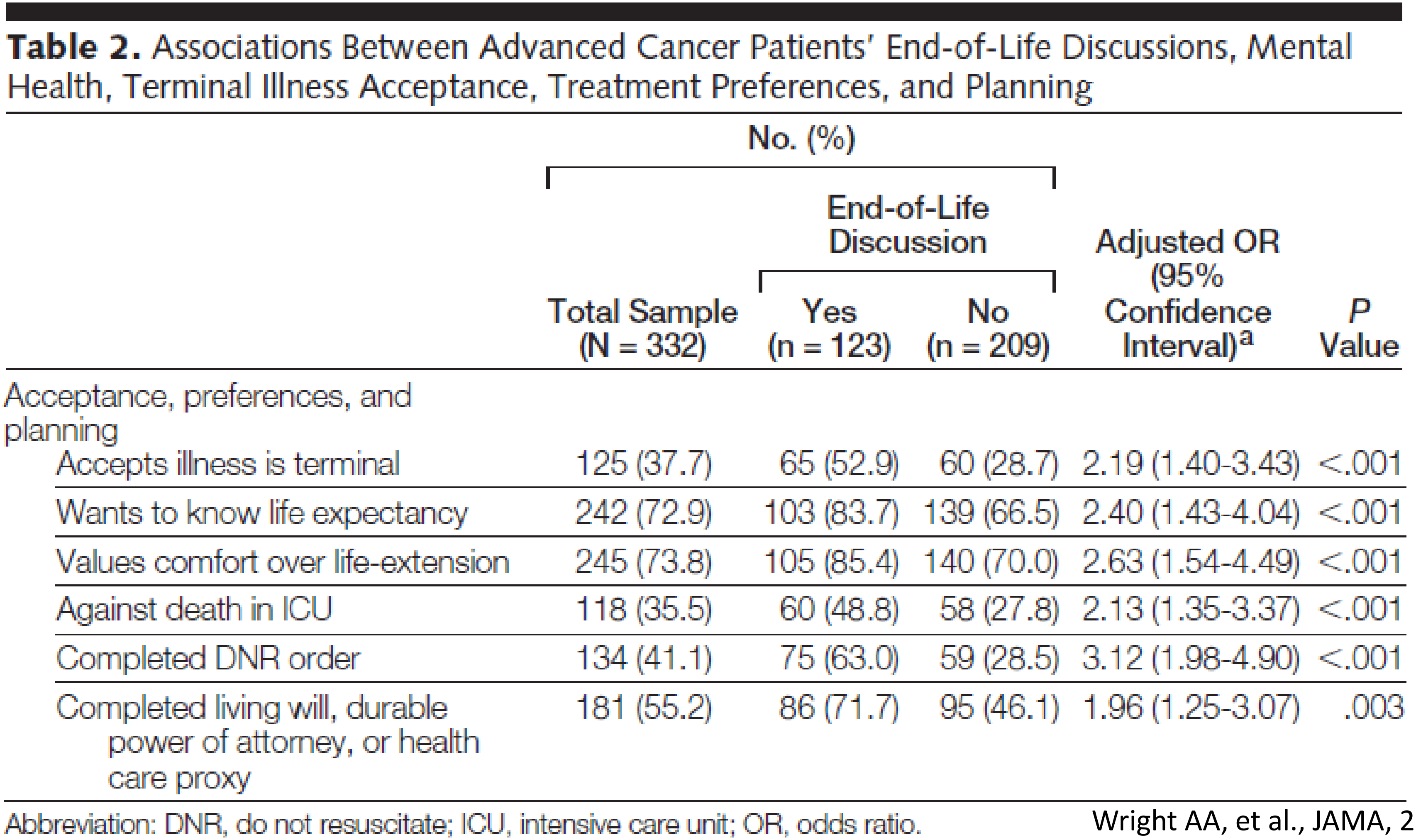


Table 2. Associations Between Advanced Cancer Patients' End-of-Life Discussions, Mental Health, Terminal Illness Acceptance, Treatment Preferences, and Planning

	No. (%)				
		End-of-Life Discussion			
	Total Sample (N = 332)	Yes (n = 123)	No (n = 209)	Adjusted OR (95% Confidence Interval)[a]	*P* Value
Acceptance, preferences, and planning					
Accepts illness is terminal	125 (37.7)	65 (52.9)	60 (28.7)	2.19 (1.40-3.43)	<.001
Wants to know life expectancy	242 (72.9)	103 (83.7)	139 (66.5)	2.40 (1.43-4.04)	<.001
Values comfort over life-extension	245 (73.8)	105 (85.4)	140 (70.0)	2.63 (1.54-4.49)	<.001
Against death in ICU	118 (35.5)	60 (48.8)	58 (27.8)	2.13 (1.35-3.37)	<.001
Completed DNR order	134 (41.1)	75 (63.0)	59 (28.5)	3.12 (1.98-4.90)	<.001
Completed living will, durable power of attorney, or health care proxy	181 (55.2)	86 (71.7)	95 (46.1)	1.96 (1.25-3.07)	.003

Abbreviation: DNR, do not resuscitate; ICU, intensive care unit; OR, odds ratio.

Wright AA, et al., JAMA, 2008

EOL Discussions: Less Aggressive Care

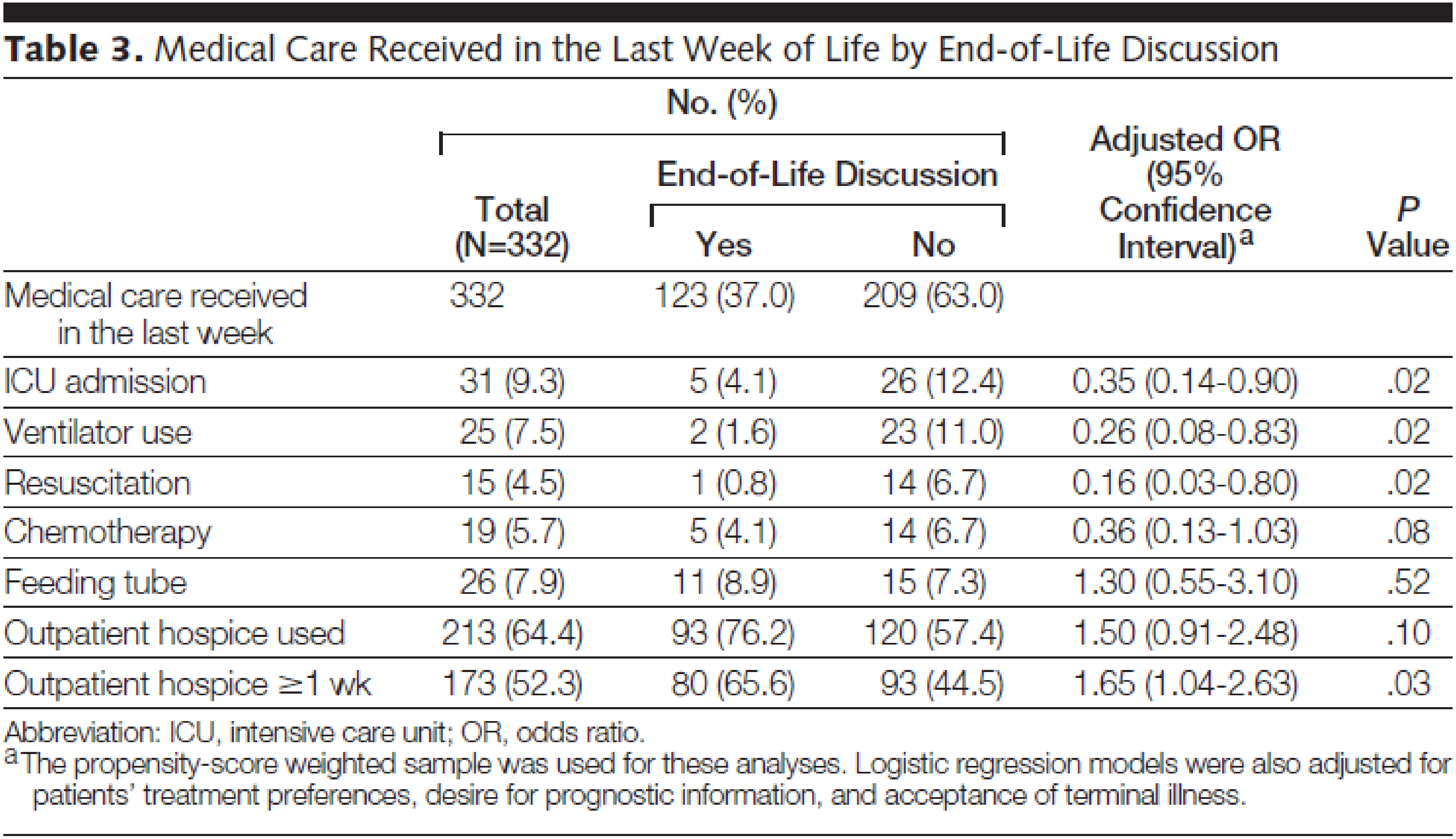


Table 3. Medical Care Received in the Last Week of Life by End-of-Life Discussion

	No. (%)			Adjusted OR (95% Confidence Interval)[a]	*P* Value
		End-of-Life Discussion			
	Total (N=332)	Yes	No		
Medical care received in the last week	332	123 (37.0)	209 (63.0)		
ICU admission	31 (9.3)	5 (4.1)	26 (12.4)	0.35 (0.14-0.90)	.02
Ventilator use	25 (7.5)	2 (1.6)	23 (11.0)	0.26 (0.08-0.83)	.02
Resuscitation	15 (4.5)	1 (0.8)	14 (6.7)	0.16 (0.03-0.80)	.02
Chemotherapy	19 (5.7)	5 (4.1)	14 (6.7)	0.36 (0.13-1.03)	.08
Feeding tube	26 (7.9)	11 (8.9)	15 (7.3)	1.30 (0.55-3.10)	.52
Outpatient hospice used	213 (64.4)	93 (76.2)	120 (57.4)	1.50 (0.91-2.48)	.10
Outpatient hospice ≥1 wk	173 (52.3)	80 (65.6)	93 (44.5)	1.65 (1.04-2.63)	.03

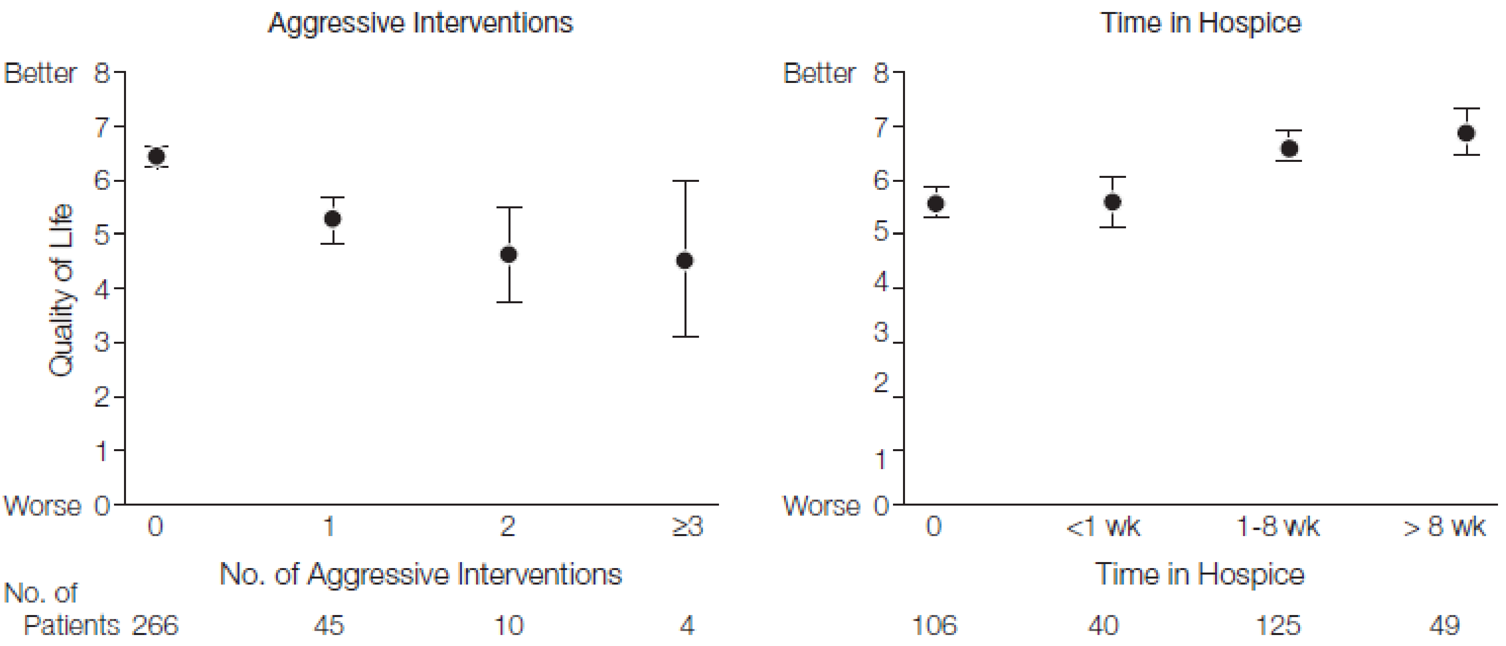
Abbreviation: ICU, intensive care unit; OR, odds ratio.

[a] The propensity-score weighted sample was used for these analyses. Logistic regression models were also adjusted for patients' treatment preferences, desire for prognostic information, and acceptance of terminal illness.

Wright AA, et al., JAMA, 2008

Timing of Hospice Referral Matters

Figure. Relationship Between Quality of Life and End-of-Life Care



Results are adjusted for illness severity, as measured by Karnofsky score and survival. Caregivers were asked, "In your opinion, how would you rate the overall quality of the patient's death or last week of life?" Response items were arranged on a Likert scale from 0 "worst possible" to 10 "best possible." The hospice statistical scores were $F = 4.04_3$, $P < .001$. Interventions included ventilation, resuscitation, chemotherapy, or feeding tube ($F = 3.61_3$; $P = .01$). Error bars represent 95% confidence intervals.

Wright AA, et al., JAMA, 2008

Higher Health Costs Associated with Worse Patient Quality of Life Near Death

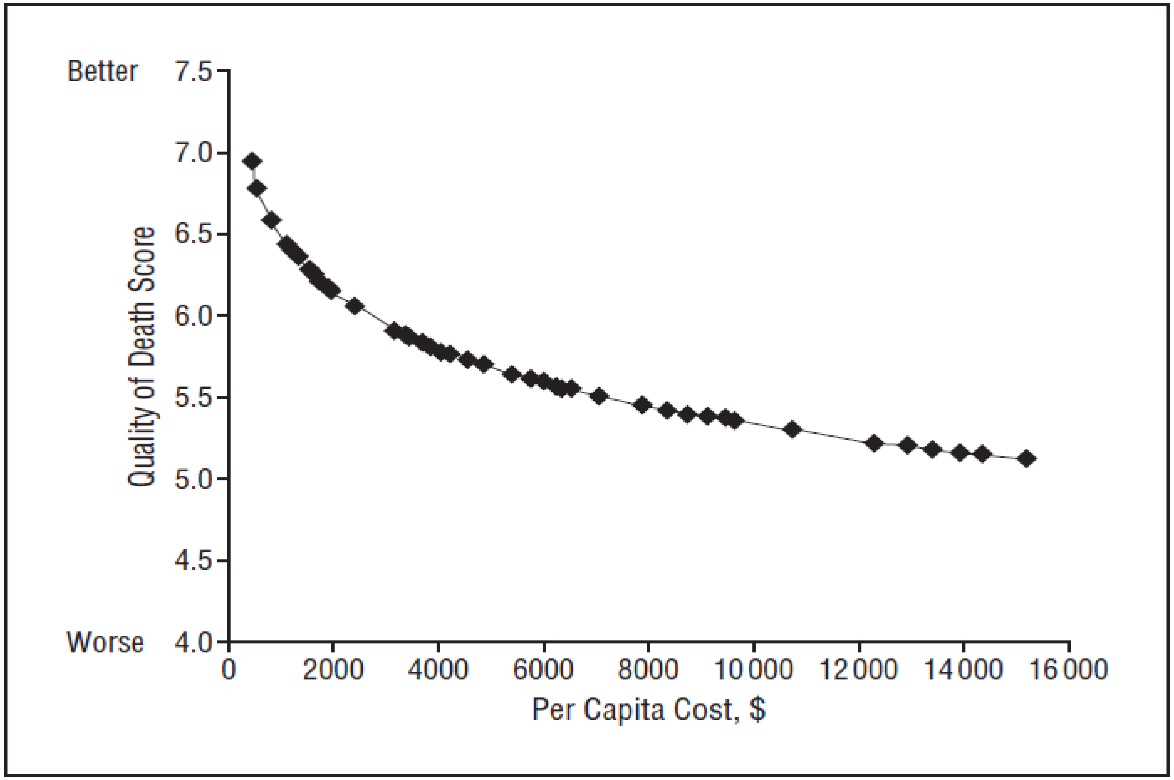


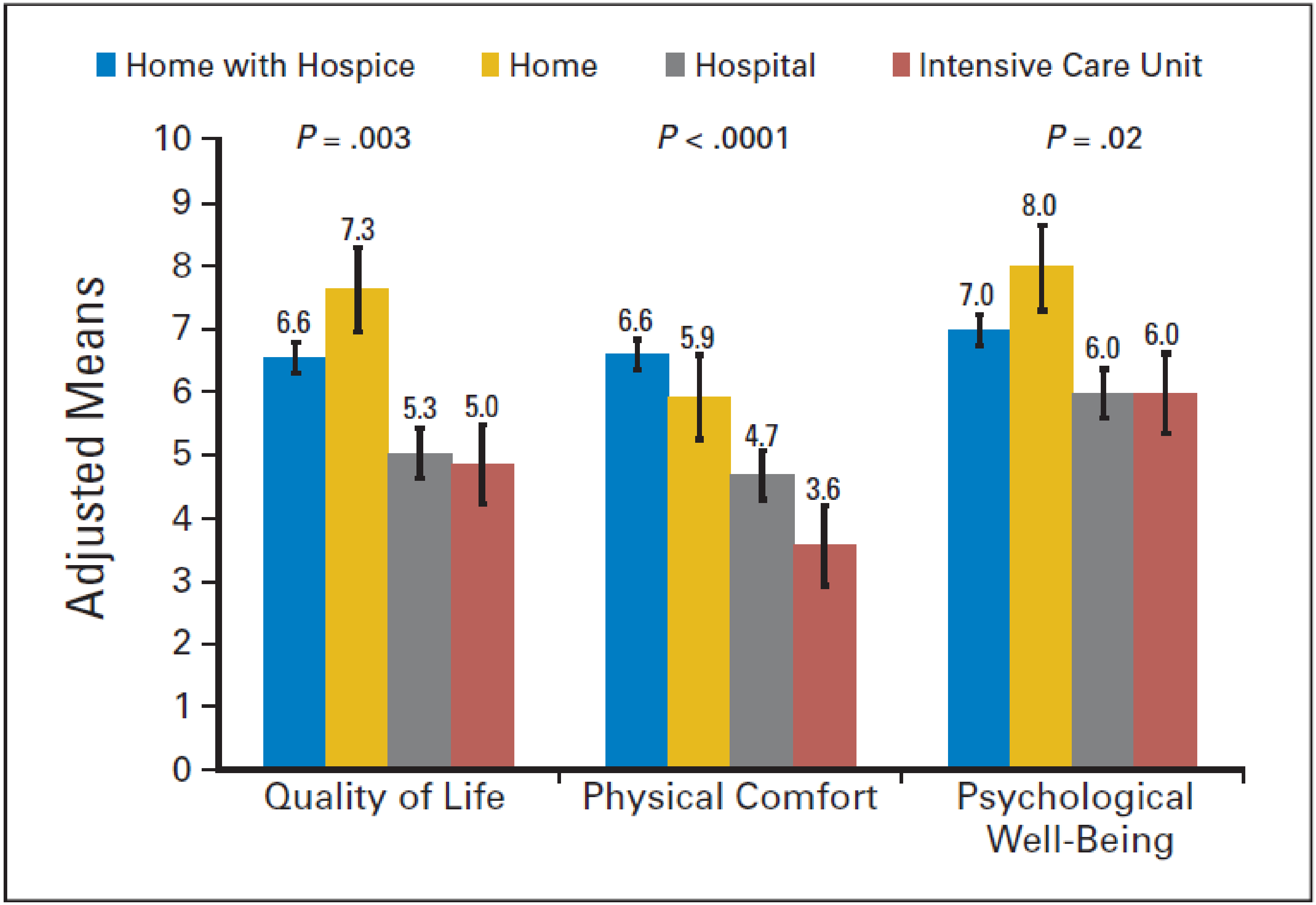
Figure. Association between cost and quality of death in the final week of life (adjusted *P*=.006). Age, sex, education status, survival time, race/ethnicity, and source of report were controlled for in the adjusted analysis of per capita cost predicting quality of death in the deceased cohort (n=316).

Zhang B, et al., Arch Intern Med, 2009

Cascading Effects of End-of-Life Care

- Bereaved caregivers of patients who received aggressive care:
  - Worse quality of life (SF36: self-reported health)
  - Less prepared for death
  - More regret
  - Higher odds SCID-criteria for MDD

Patients’ EOL Experiences by Place of Death



Wright AA, et al. J Clin Oncol, 2010

Terminal Hospitalizations: Increased Odds of Psychiatric Disorders in Bereaved Caregivers

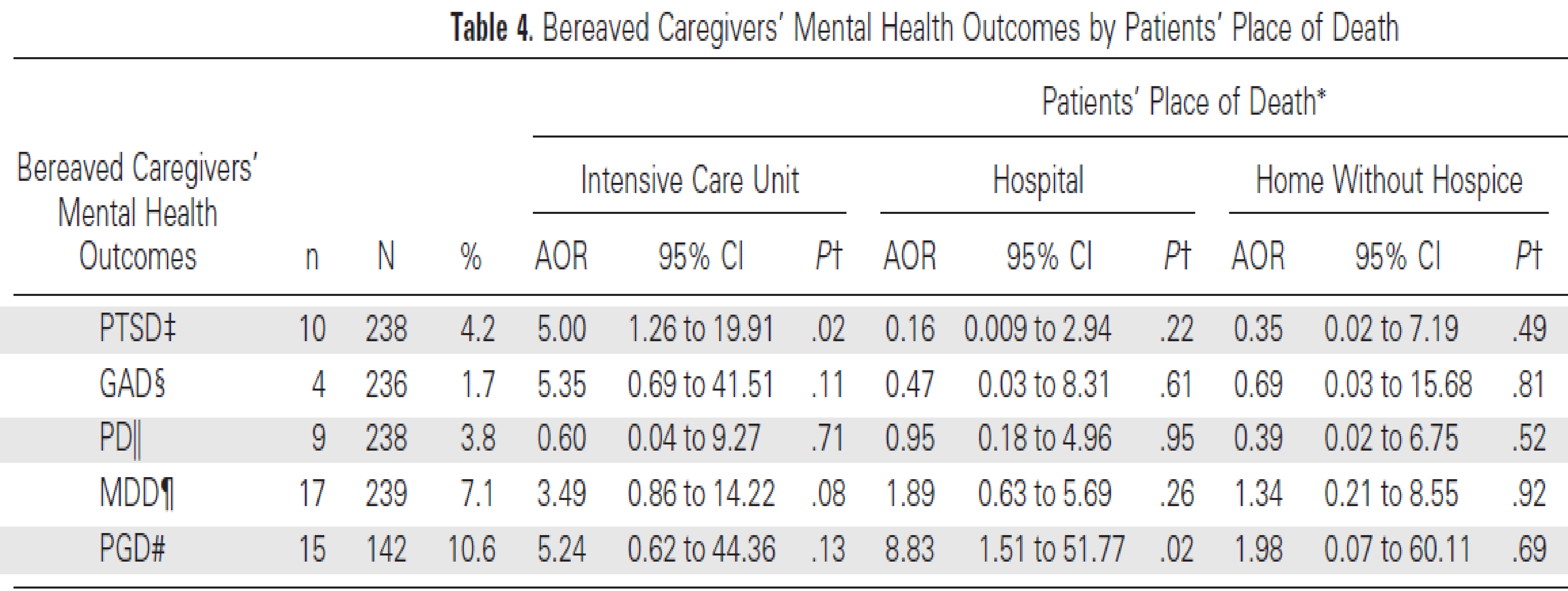


Table 4. Bereaved Caregivers' Mental Health Outcomes by Patients' Place of Death

Bereaved Caregivers' Mental Health Outcomes	n	N	%	Patients' Place of Death*								
				Intensive Care Unit			Hospital			Home Without Hospice		
				AOR	95% CI	*P*†	AOR	95% CI	*P*†	AOR	95% CI	*P*†
PTSD‡	10	238	4.2	5.00	1.26 to 19.91	.02	0.16	0.009 to 2.94	.22	0.35	0.02 to 7.19	.49
GAD§	4	236	1.7	5.35	0.69 to 41.51	.11	0.47	0.03 to 8.31	.61	0.69	0.03 to 15.68	.81
PD‖	9	238	3.8	0.60	0.04 to 9.27	.71	0.95	0.18 to 4.96	.95	0.39	0.02 to 6.75	.52
MDD¶	17	239	7.1	3.49	0.86 to 14.22	.08	1.89	0.63 to 5.69	.26	1.34	0.21 to 8.55	.92
PGD#	15	142	10.6	5.24	0.62 to 44.36	.13	8.83	1.51 to 51.77	.02	1.98	0.07 to 60.11	.69

Wright AA, et al. J Clin Oncol, 2010

Intensive, Hospital-Based Care is Often Harmful

- For patients:
  - Lower quality of life
  - Greater physical and psychological distress

- For bereaved caregivers:
  - More major depression
  - More PTSD
  - More regret
  - Worse quality of life

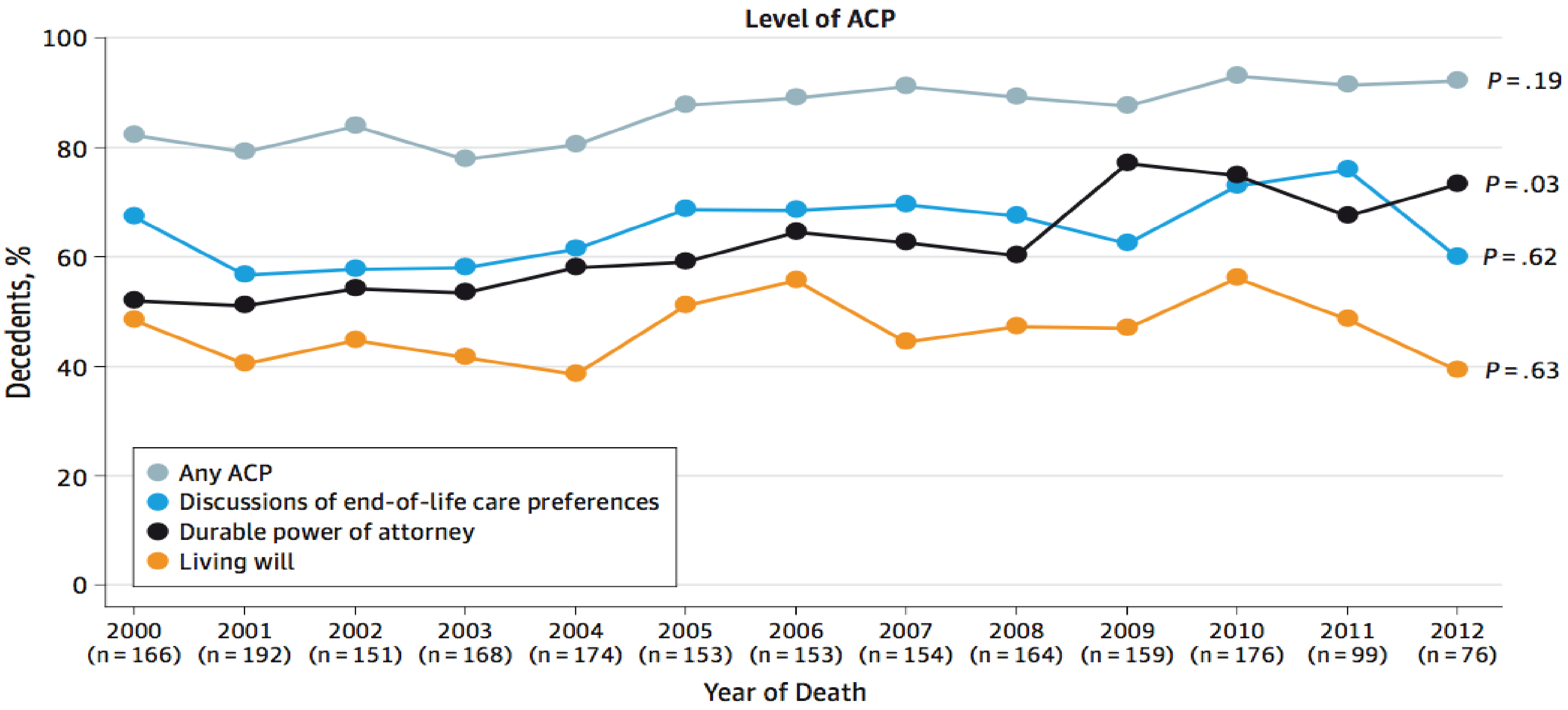
Conversations are Infrequent, Late, and Limited

- *Infrequent*
  - <1/3 of patients with end-stage diagnoses reported end-of-life (EOL) discussion with clinicians
- *Late*
  - In patients with advanced cancer, first EOL discussion 33 days before death
  - 55% of initial EOL discussions occurred in hospital
- *Limited*
  - Conversations often fail to address key elements

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008

Little Improvement Over Time

Figure 1. Adjusted Yearly Percentages of Advance Care Planning (ACP) and Subtypes Over Time



Narang, JAMA Oncology, 2015

Little Improvement Over Time

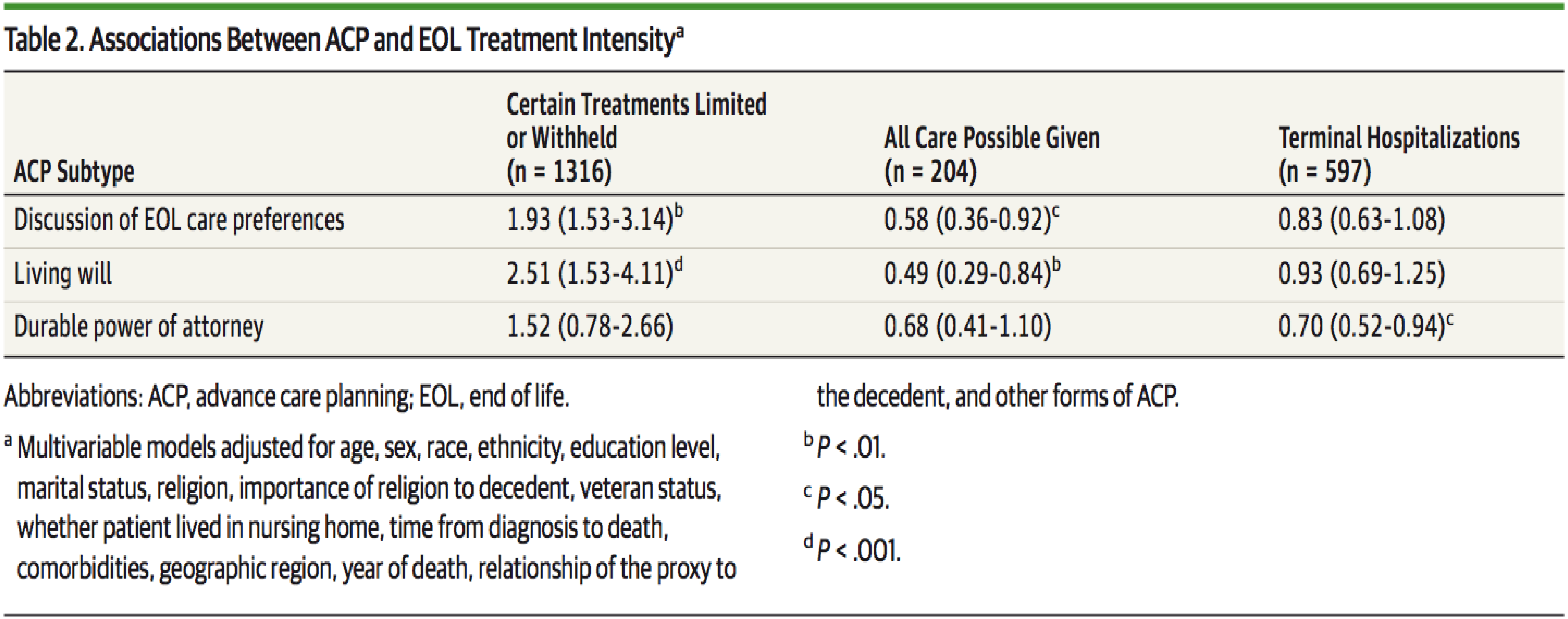


Table 2. Associations Between ACP and EOL Treatment Intensity[a]

ACP Subtype	Certain Treatments Limited or Withheld (n = 1316)	All Care Possible Given (n = 204)	Terminal Hospitalizations (n = 597)
Discussion of EOL care preferences	1.93 (1.53-3.14)[b]	0.58 (0.36-0.92)[c]	0.83 (0.63-1.08)
Living will	2.51 (1.53-4.11)[d]	0.49 (0.29-0.84)[b]	0.93 (0.69-1.25)
Durable power of attorney	1.52 (0.78-2.66)	0.68 (0.41-1.10)	0.70 (0.52-0.94)[c]

Abbreviations: ACP, advance care planning; EOL, end of life.

[a] Multivariable models adjusted for age, sex, race, ethnicity, education level, marital status, religion, importance of religion to decedent, veteran status, whether patient lived in nursing home, time from diagnosis to death, comorbidities, geographic region, year of death, relationship of the proxy to the decedent, and other forms of ACP.

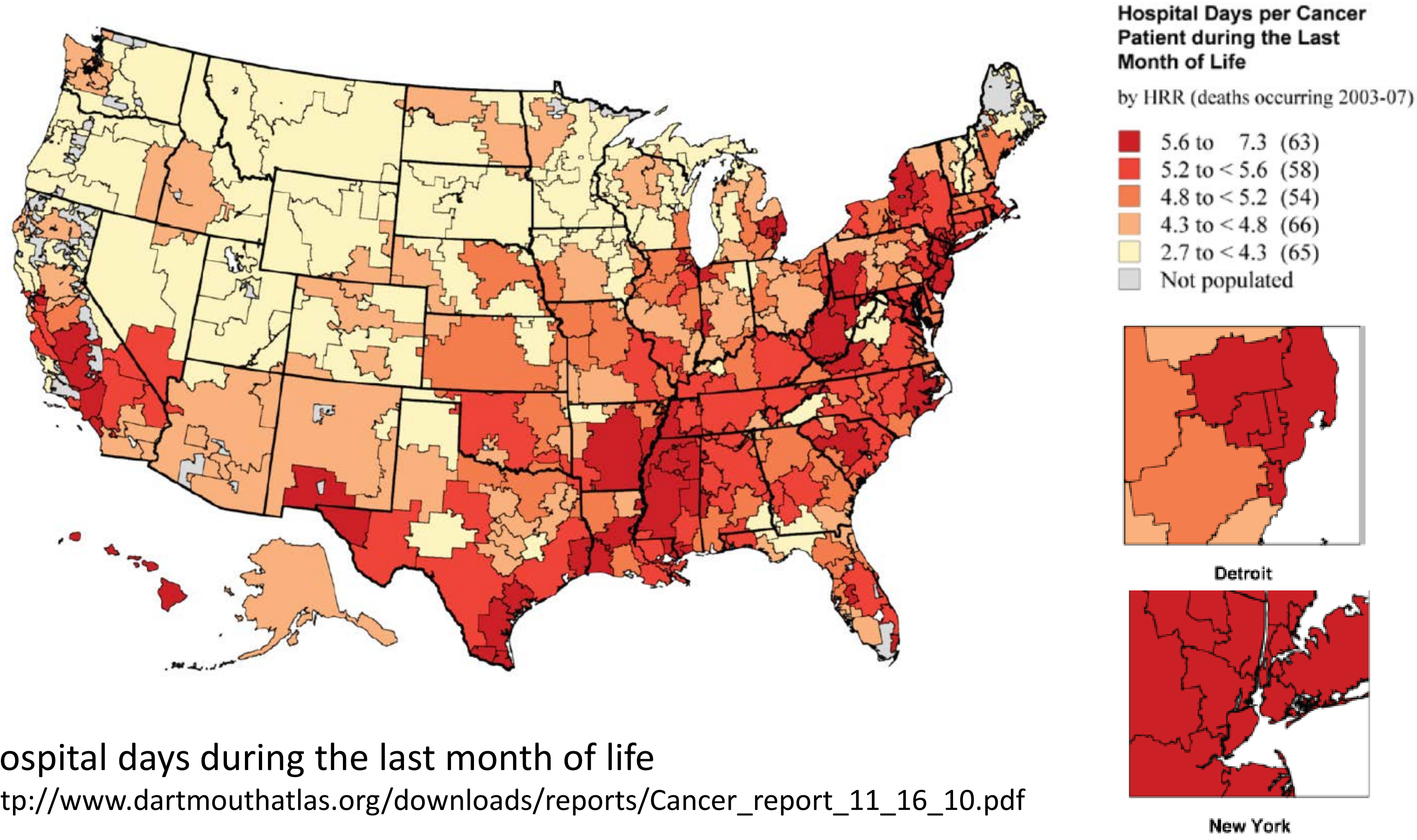
[b] $P < .01$.

[c] $P < .05$.

[d] $P < .001$.

Narang, JAMA Oncology, 2015

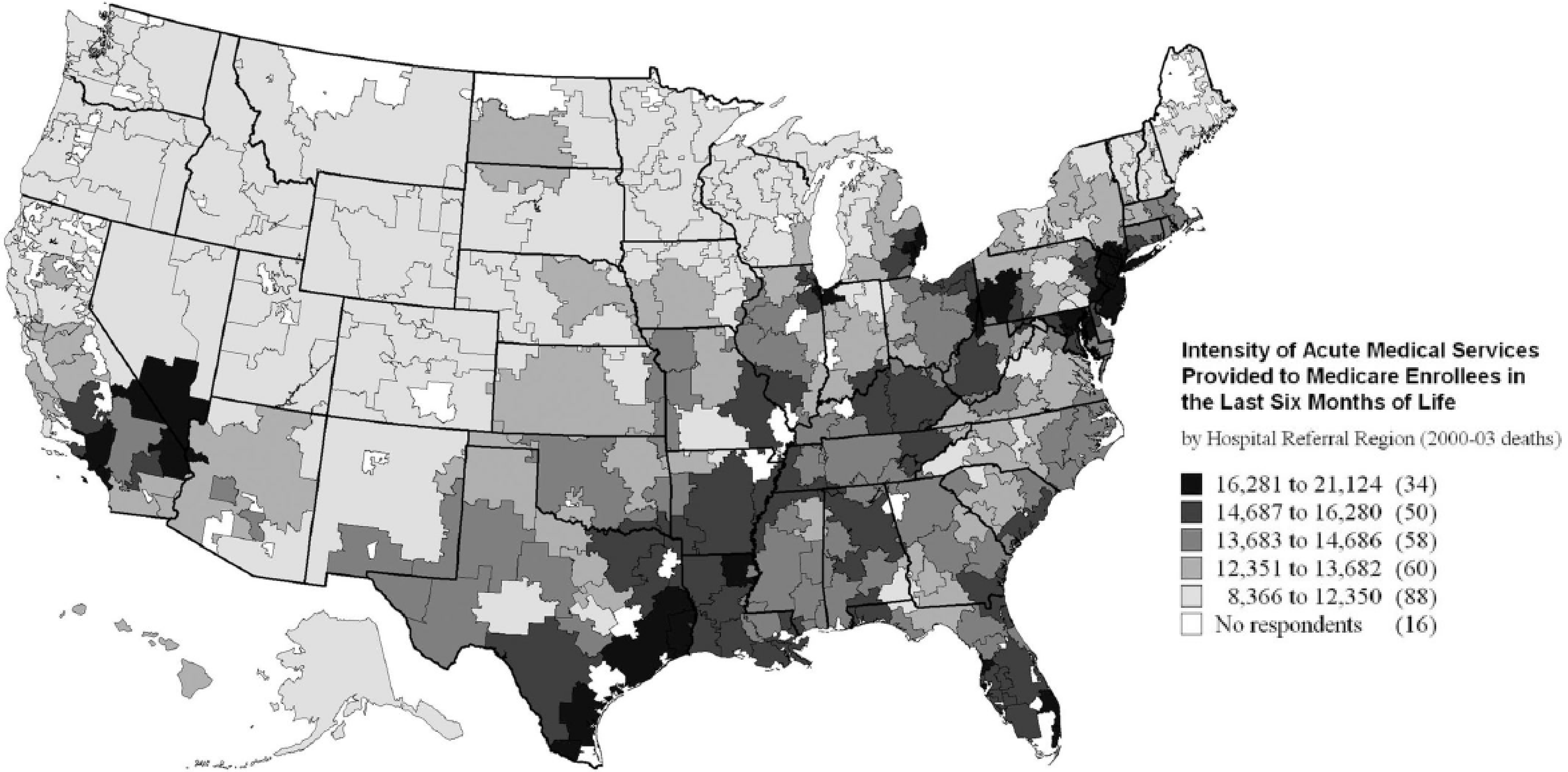
End-of-life Cancer Care Varies Widely



Hospital days during the last month of life

http://www.dartmouthatlas.org/downloads/reports/Cancer_report_11_16_10.pdf

End-of-Life Care: Insensitive to Patient Preferences?

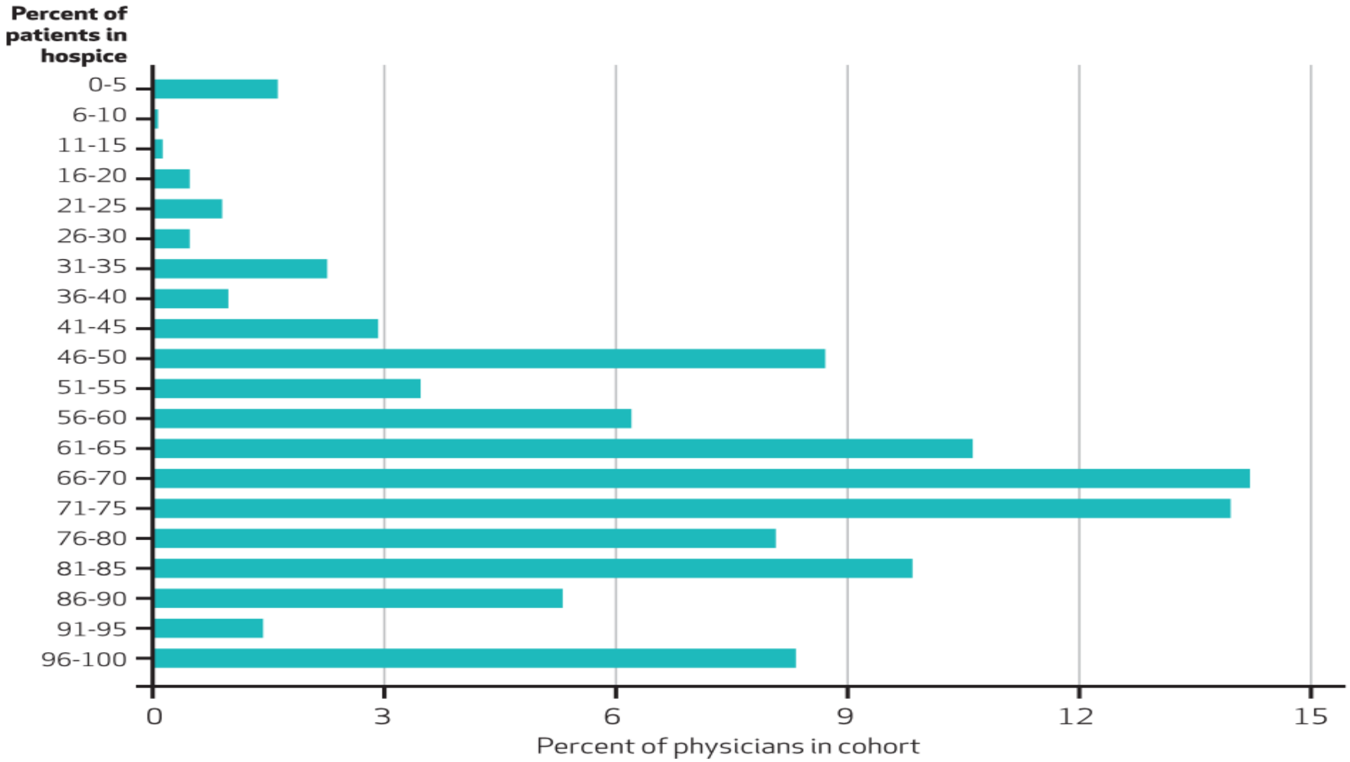


Barnato AE, et al. Med Care, 2007.

Physician Characteristics Strongly Predict Hospice Enrollment

EXHIBIT 1

Variation In The Percentage Of A Physician's Patients With Poor-Prognosis Cancer Enrolled In Hospice Before Death, 2006–11



Obermoyer Z, Health Affairs, 2015.

Physician Characteristics Strongly Predict Hospice Enrollment

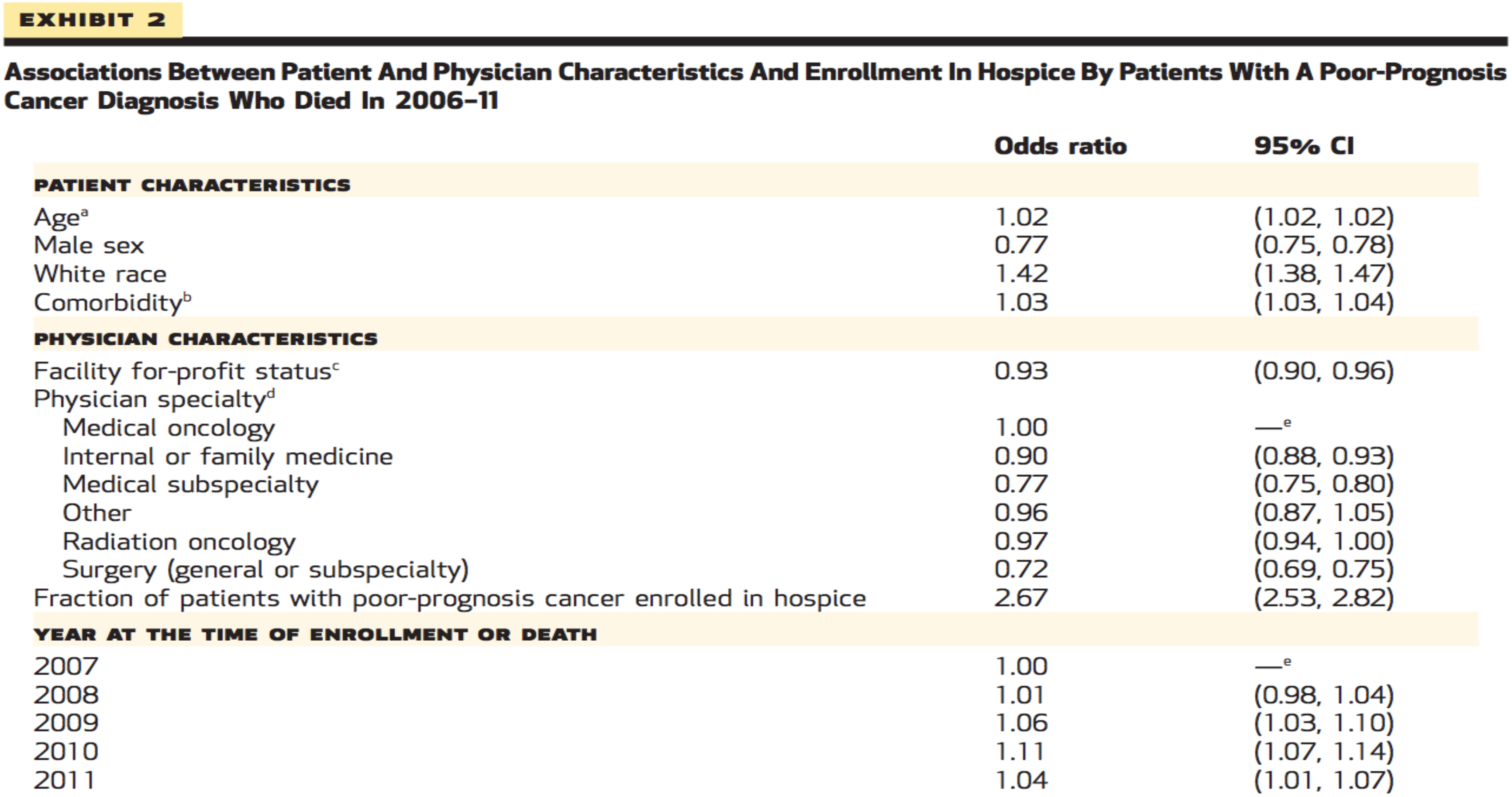


EXHIBIT 2

Associations Between Patient And Physician Characteristics And Enrollment In Hospice By Patients With A Poor-Prognosis Cancer Diagnosis Who Died In 2006–11

	Odds ratio	95% CI
PATIENT CHARACTERISTICS		
Age[a]	1.02	(1.02, 1.02)
Male sex	0.77	(0.75, 0.78)
White race	1.42	(1.38, 1.47)
Comorbidity[b]	1.03	(1.03, 1.04)
PHYSICIAN CHARACTERISTICS		
Facility for-profit status[c]	0.93	(0.90, 0.96)
Physician specialty[d]		
Medical oncology	1.00	—[e]
Internal or family medicine	0.90	(0.88, 0.93)
Medical subspecialty	0.77	(0.75, 0.80)
Other	0.96	(0.87, 1.05)
Radiation oncology	0.97	(0.94, 1.00)
Surgery (general or subspecialty)	0.72	(0.69, 0.75)
Fraction of patients with poor-prognosis cancer enrolled in hospice	2.67	(2.53, 2.82)
YEAR AT THE TIME OF ENROLLMENT OR DEATH		
2007	1.00	—[e]
2008	1.01	(0.98, 1.04)
2009	1.06	(1.03, 1.10)
2010	1.11	(1.07, 1.14)
2011	1.04	(1.01, 1.07)

Obermoyer Z, Health Affairs, 2015.

Physician Characteristics Strongly Predict Hospice Enrollment

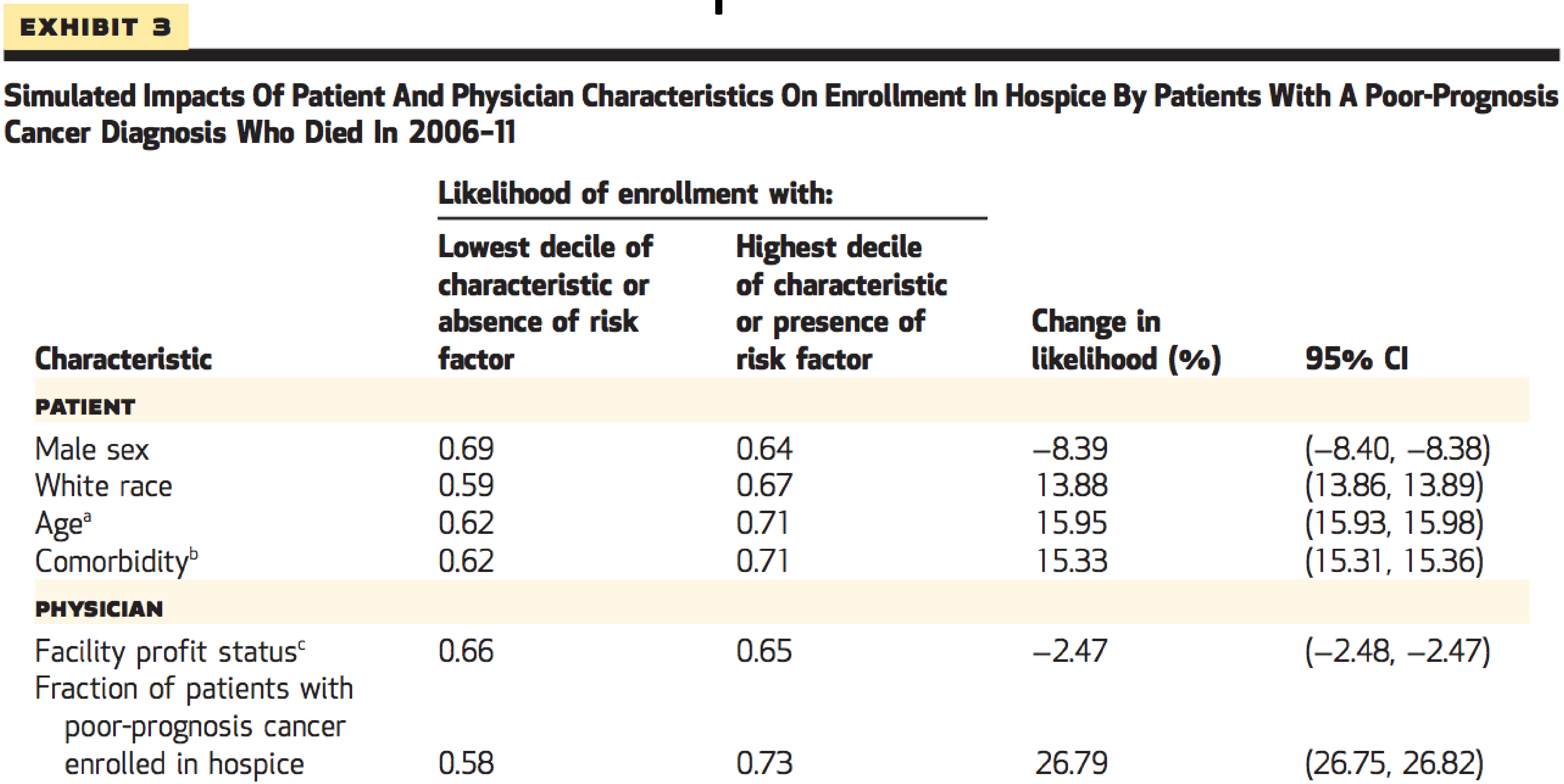


EXHIBIT 3

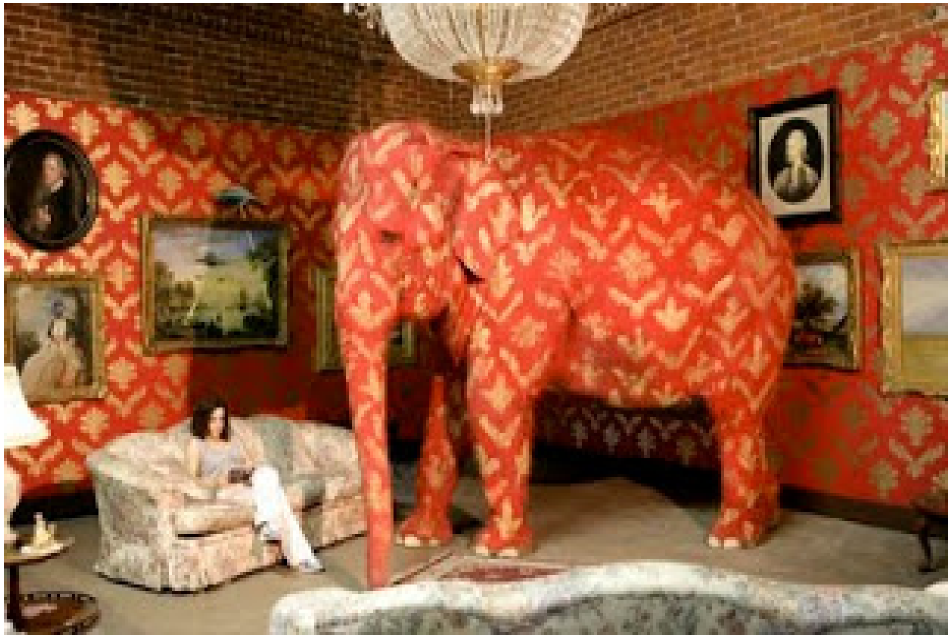
Simulated Impacts Of Patient And Physician Characteristics On Enrollment In Hospice By Patients With A Poor-Prognosis Cancer Diagnosis Who Died In 2006–11

Characteristic	Likelihood of enrollment with: Lowest decile of characteristic or absence of risk factor	Likelihood of enrollment with: Highest decile of characteristic or presence of risk factor	Change in likelihood (%)	95% CI
PATIENT				
Male sex	0.69	0.64	–8.39	(–8.40, –8.38)
White race	0.59	0.67	13.88	(13.86, 13.89)
Age[a]	0.62	0.71	15.95	(15.93, 15.98)
Comorbidity[b]	0.62	0.71	15.33	(15.31, 15.36)
PHYSICIAN				
Facility profit status[c]	0.66	0.65	–2.47	(–2.48, –2.47)
Fraction of patients with poor-prognosis cancer enrolled in hospice	0.58	0.73	26.79	(26.75, 26.82)

Obermoyer Z, Health Affairs, 2015.

Most people want to be at home and prefer comfort-focused care at the end of life, but often *not* the reality.

How to bridge the gap between what patients *want* and what they *get*?



Ask patients about their values and priorities

Bolster Physician Communication

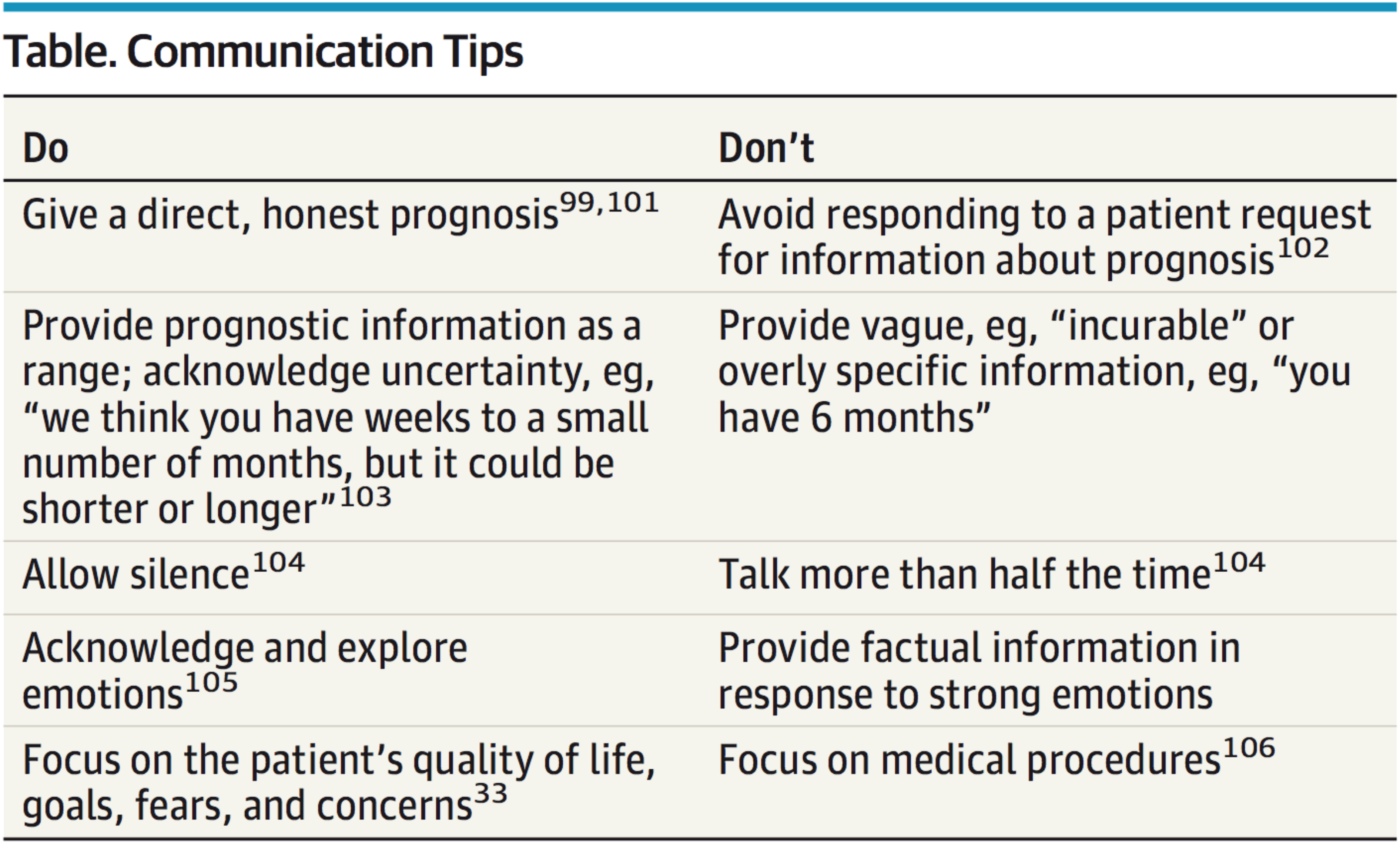
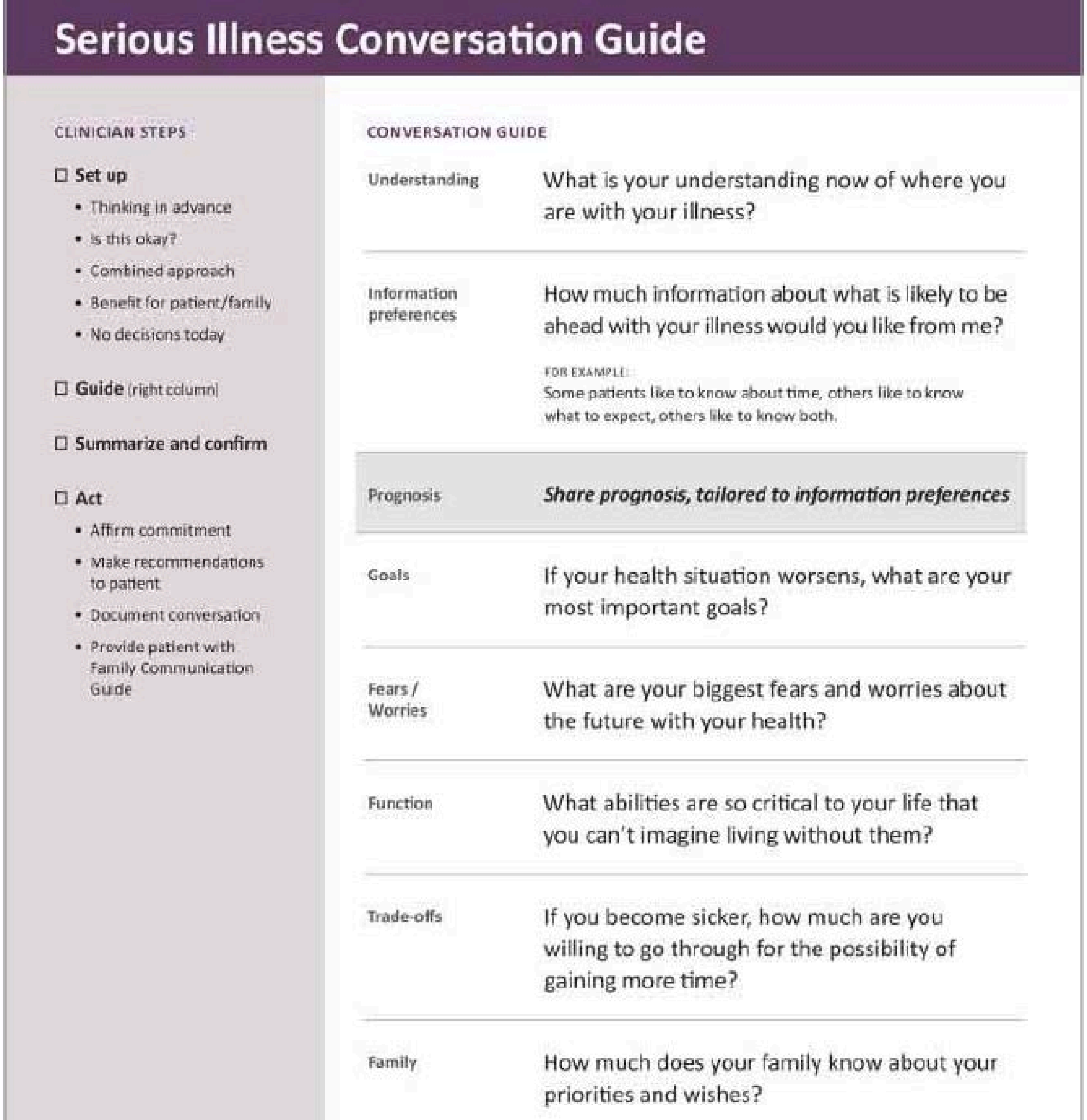


Table. Communication Tips

Do	Don't
Give a direct, honest prognosis[99,101]	Avoid responding to a patient request for information about prognosis[102]
Provide prognostic information as a range; acknowledge uncertainty, eg, "we think you have weeks to a small number of months, but it could be shorter or longer"[103]	Provide vague, eg, "incurable" or overly specific information, eg, "you have 6 months"
Allow silence[104]	Talk more than half the time[104]
Acknowledge and explore emotions[105]	Provide factual information in response to strong emotions
Focus on the patient's quality of life, goals, fears, and concerns[33]	Focus on medical procedures[106]

Bernack RE, et al. JAMA Internal Medicine 2014



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**

☐ **Act**
  - Affirm commitment
  - Make recommendations to patient
  - Document conversation
  - Provide patient with Family Communication Guide

CONVERSATION GUIDE

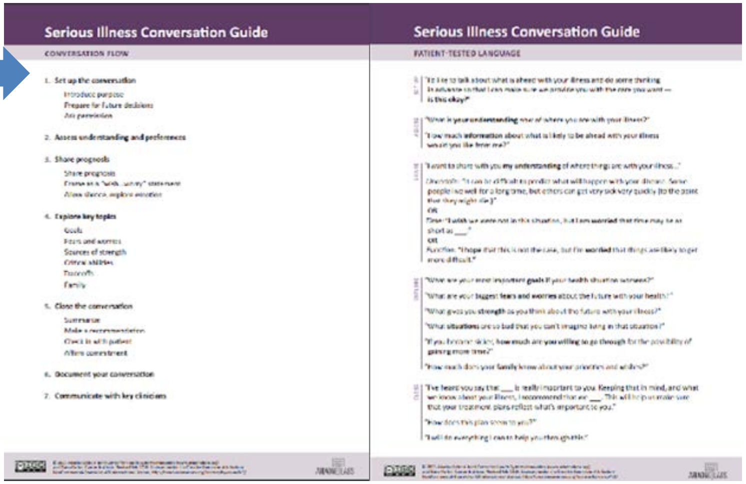
Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.
Prognosis	***Share prognosis, tailored to information preferences***
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?

Bernacki RE, et al. JAMA Internal Medicine 2014

Set up the conversation

Setting up the conversation builds trust, helps patients feel in control, and allows the conversation to begin gently, without scaring the patient

- Introduce the idea:
  - *"I'd like to talk about what is ahead with your illness and do some thing in advance so that I can make sure we provide you with the care you want."*
- Ask permission:
  - *"Is this ok?"*
- Introduce the benefits:
  - *"The goal is to make sure that I have all of the information I need about what matters most to you so I can provide you with the care you want, and so I can best support your family if they ever have to make decisions for you."*



Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission
2. **Assess understanding and preferences**
3. **Share prognosis**
   - Share prognosis
   - Frame as a "wish...worry" statement
   - Allow silence, explore emotion
4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment
6. **Document your conversation**
7. **Communicate with key clinicians**

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

"I'd like to talk about what is ahead with your illness and do some thinking in advance so that I can make sure we provide you with the care you want — **is this okay?"**

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

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

"I want to share with you **my understanding** of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. Some people live well for a long time, but others can get very sick very quickly (to the point that they might die)."
OR
Time: "**I wish** we were not in this situation, but I am **worried** that time may be as short as ___."
OR
Function: "**I hope** that this is not the case, but I'm **worried** that things are likely to get more difficult."

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **situations** are so bad that you can't imagine living in that situation?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"

"How much does your **family** know about your priorities and wishes?"

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

Slide courtesy of Bernacki RE, et al.
Bernacki RE, et al. JAMA Internal Medicine 2014

Prognosis

"I want to share with you my understanding of where things are with your illness…"

1. Time-based prognosis:

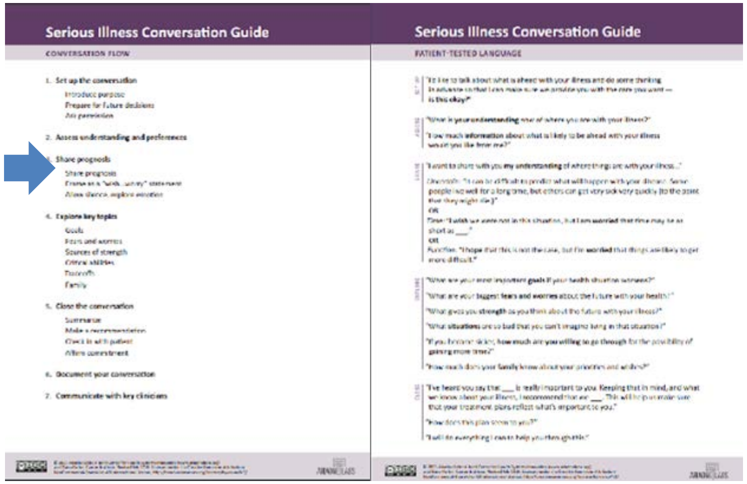
- *"I wish we were not in this situation, but I'm worried that time may be as short as ___. I'm worried that, in terms of time, we may be talking about months to a year. Of course, we don't know for sure, and it could be longer or shorter."*

2. Functional prognosis:

- *"I hope that this is not the case, but I'm worried that things are likely to get more difficult.*

3. Unpredictable prognosis:

- *"It can be difficult to predict what will happen with your disease. Some people live well for a long time, but others can get very sick very quickly (to the point that they might die.)"*



Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission
2. **Assess understanding and preferences**
3. **Share prognosis**
   - Share prognosis
   - Frame as a "wish…worry" statement
   - Allow silence, explore emotion
4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment
6. **Document your conversation**
7. **Communicate with key clinicians**

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

Slide courtesy of Bernacki RE, et al.
Bernacki RE, et al. JAMA Internal Medicine 2014

Serious Illness Communication Project

Cluster-randomized controlled trial in outpatient oncology

- 90 oncology clinicians (MDs, NPs, and PAs) volunteered and enrolled (72% participation rate)
- 278 patients with advanced cancer enrolled and randomized
  - 131 patients died

Conversation Outcomes

- More conversations (92.7% vs 74.7% p=0.006)
- Earlier conversations (147 days vs 62 days p=0.003)
- More accessible in EHR (59.4% vs 10.2% p=0.001)

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811

Significant Improvements in Conversations

Significant increase documentation about:

- Values and goals (85% vs 40%, p=0.0001)
- EOL care planning (85% vs. 55%, p=0.009)
- Prognosis (85% vs 30% p=0.001)

Two weeks post conversation:

- Proportion of patients with **moderate/severe anxiety** in intervention group **<u>half</u>** that of control (4.8% vs 11%, p=0.05)
- Proportion of patients with **moderate/severe depression** in intervention group **<u>half</u>** that of control (10.9% vs. 21.8%, p=0.03)

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811

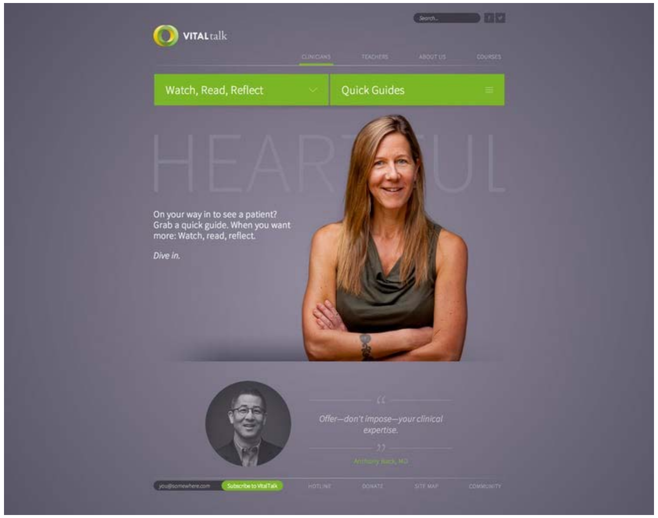
Patients Report Positive Experiences

Practical planning	"Making changes to my will. Plan my funeral."
Communication with family	"More realistic in my approach with family and friends about my prognosis."
End-of-life care planning	"Made a complete list of all my last wishes, such as when I can no longer go to the bathroom myself I want hospice house care."
Well-being	"I am doing the same stuff as before, just feeling less anxious about the future (hope for the best, prepare for the worst)."
Values, goals, and priorities	"I have started to think about what my priorities are in terms of quality of life."
Therapeutic relationship	"Mostly the conversation brought us closer (Dr. X)."

Preliminary Qualitative Analysis

Slide courtesy of Bernacki RE, et al.; ClinicalTrials.gov: NCT01786811

Bolster Physician Communication



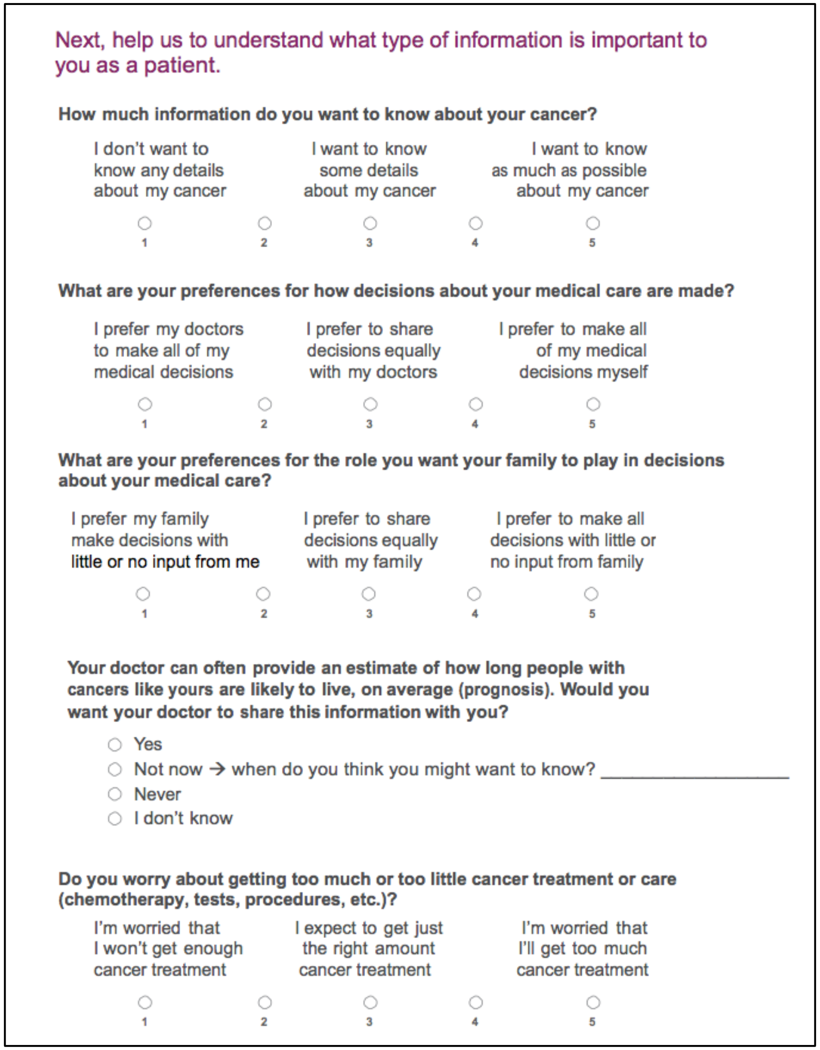
On your way in to see a patient? Grab a quick guide. When you want more: Watch, read, reflect.

Dive in.

Offer—don't impose—your clinical expertise.

Anthony Back, MD

Activate Patients and Physicians



Next, help us to understand what type of information is important to you as a patient.

How much information do you want to know about your cancer?

I don't want to know any details about my cancer		I want to know some details about my cancer		I want to know as much as possible about my cancer
○ 1	○ 2	○ 3	○ 4	○ 5

What are your preferences for how decisions about your medical care are made?

I prefer my doctors to make all of my medical decisions		I prefer to share decisions equally with my doctors		I prefer to make all of my medical decisions myself
○ 1	○ 2	○ 3	○ 4	○ 5

What are your preferences for the role you want your family to play in decisions about your medical care?

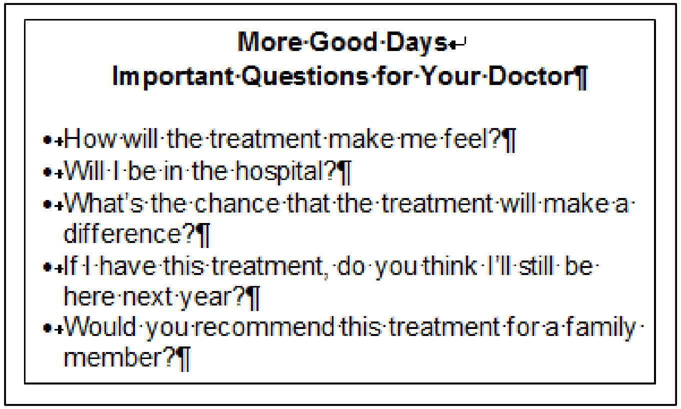
I prefer my family make decisions with little or no input from me		I prefer to share decisions equally with my family		I prefer to make all decisions with little or no input from family
○ 1	○ 2	○ 3	○ 4	○ 5

Your doctor can often provide an estimate of how long people with cancers like yours are likely to live, on average (prognosis). Would you want your doctor to share this information with you?

○ Yes
○ Not now → when do you think you might want to know? ___________________
○ Never
○ I don't know

Do you worry about getting too much or too little cancer treatment or care (chemotherapy, tests, procedures, etc.)?

I'm worried that I won't get enough cancer treatment		I expect to get just the right amount cancer treatment		I'm worried that I'll get too much cancer treatment
○ 1	○ 2	○ 3	○ 4	○ 5

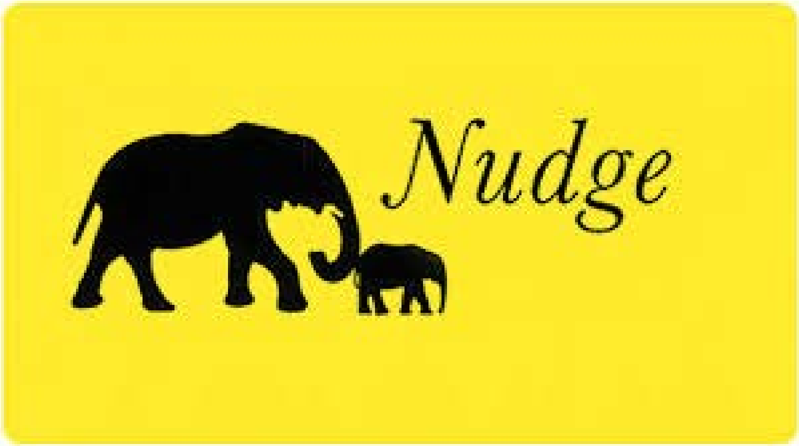


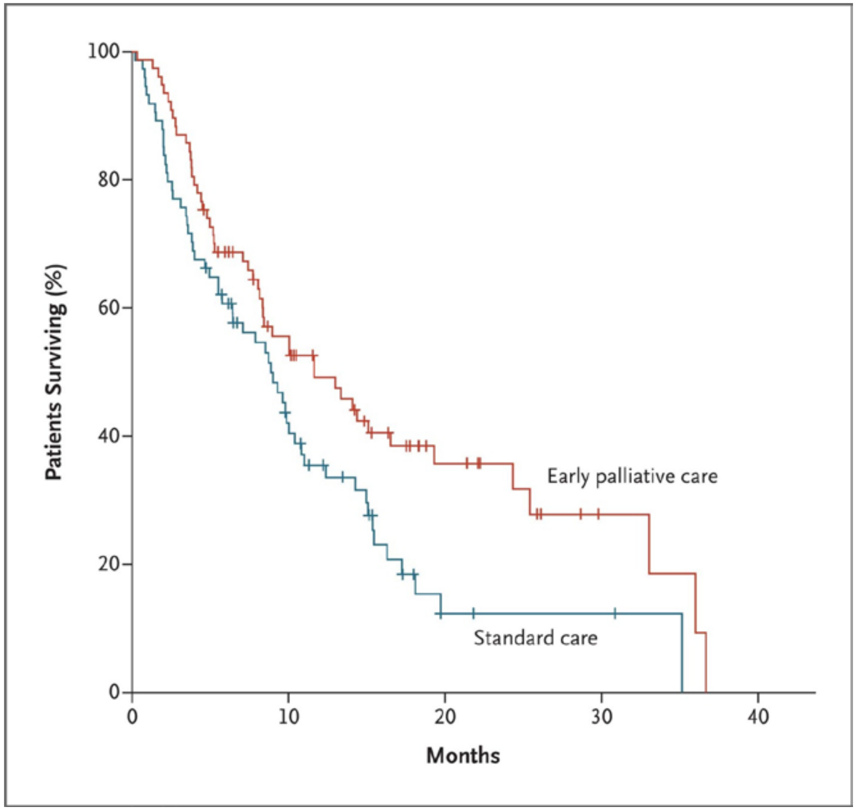
More Good Days
Important Questions for Your Doctor

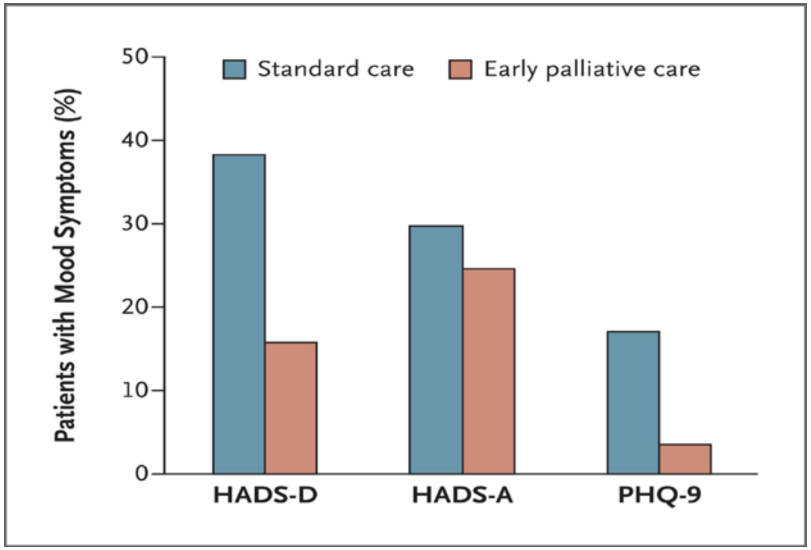
- How will the treatment make me feel?
- Will I be in the hospital?
- What's the chance that the treatment will make a difference?
- If I have this treatment, do you think I'll still be here next year?
- Would you recommend this treatment for a family member?

Keating NL, Wright AA; ClinicalTrials.gov: NCT03392090

Automate with EHR Triggers (Default)



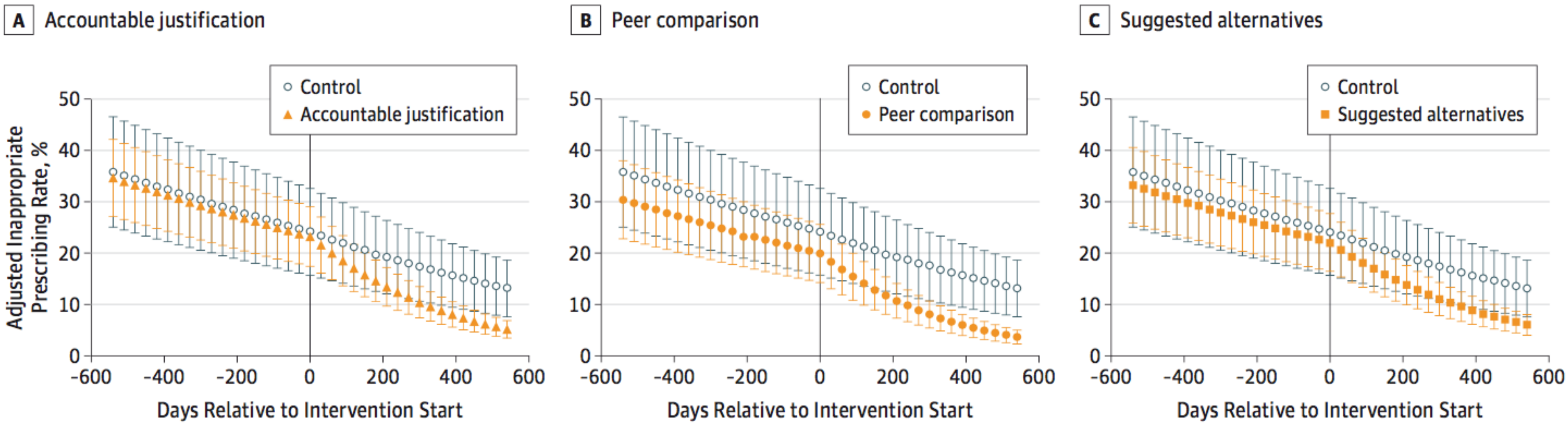




Temel JS, et al. N Engl J Med, 2010
Halpern SD, ClinicalTrials.gov: NCT02100566
Courtright KR, et al. Annals 2017

Behavioral Economics: Multi-Component Physician Intervention

Figure 2. Adjusted Rates of Antibiotic Prescribing at Primary Care Office Visits for Antibiotic-Inappropriate Acute Respiratory Tract Infections Over Time



Meeker D, et al, JAMA 2016

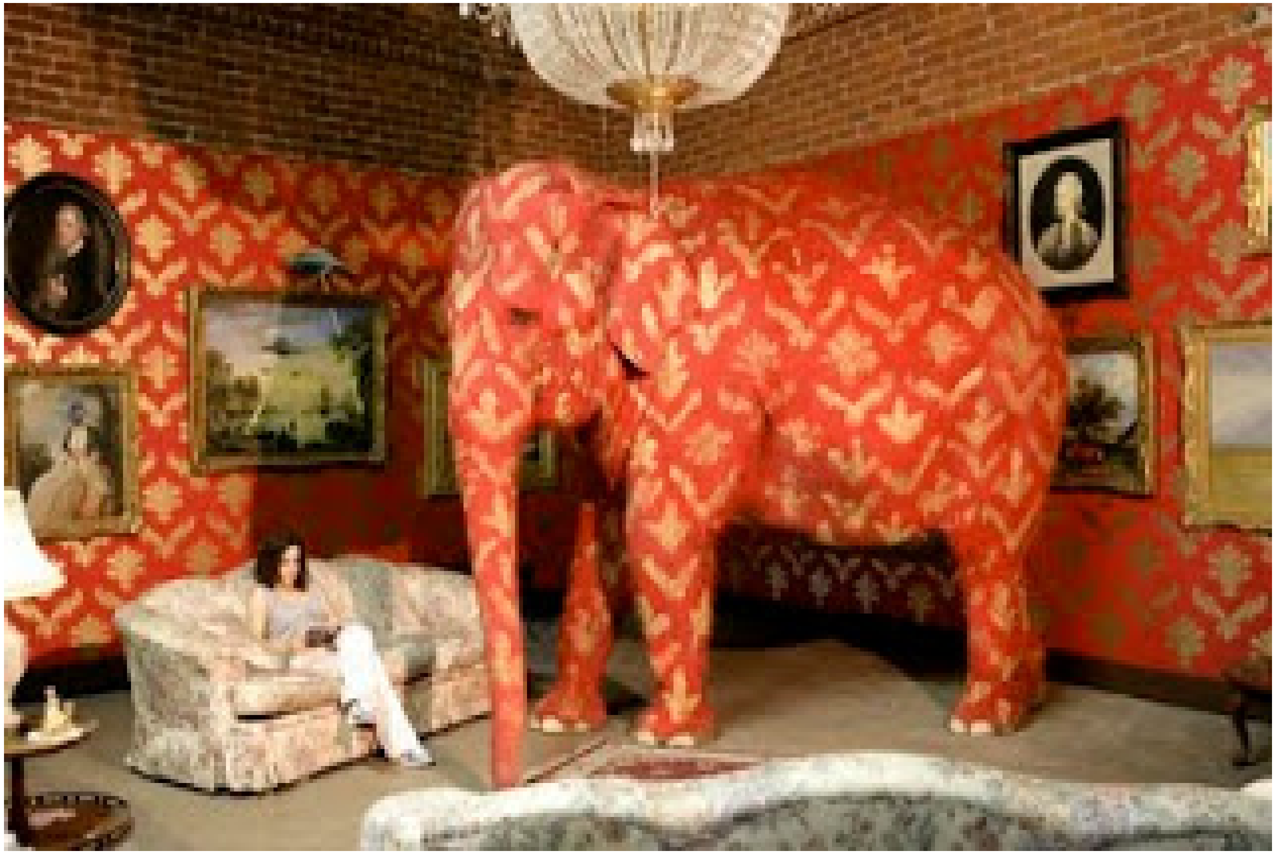
Take Homes

- End-of-life care is not yet patient-centered
- End-of-life discussions are key:
  - Enhanced goal-concordant care
  - Improved quality of life
  - Reduced suffering
  - Better patient and family coping
  - ↓Non-beneficial care and costs
- Early efforts to scale end-of-life discussions
- There's still a lot to be done

Take Homes

- You have a critical role in improving patient care by improving conversations
  - Identify patients at high risk who would benefit most from serious illness conversations.
  - Initiate conversations using best practices.
  - Document the discussions in a retrievable location in the EHR so all providers can access.
  - Set an example of high-quality communication for colleagues and trainees.

Questions?



Acknowledgements

- Nancy Keating, MD MPH
- Deb Schrag, MD MPH
- Mary Beth Landrum, PhD
- Jane Weeks, MD MSc
- Ursula Matulonis, MD
- Larissa Meyer, MD MPH
- Andrea Enzinger, MD
- Pallavi Kumar, MD MPH
- Laura Hatfield, PhD
- Craig Earle, MD
- Angel Cronin, MS
- Huichuan Lii, MS
- Yang Xu, MS
- Kate Esselen, MD MBA
- Alex Melamed, MD MA
- Sarah Coseo Markt, ScD
- Stephanie Schonholz, BS
- Niki Raman, BS

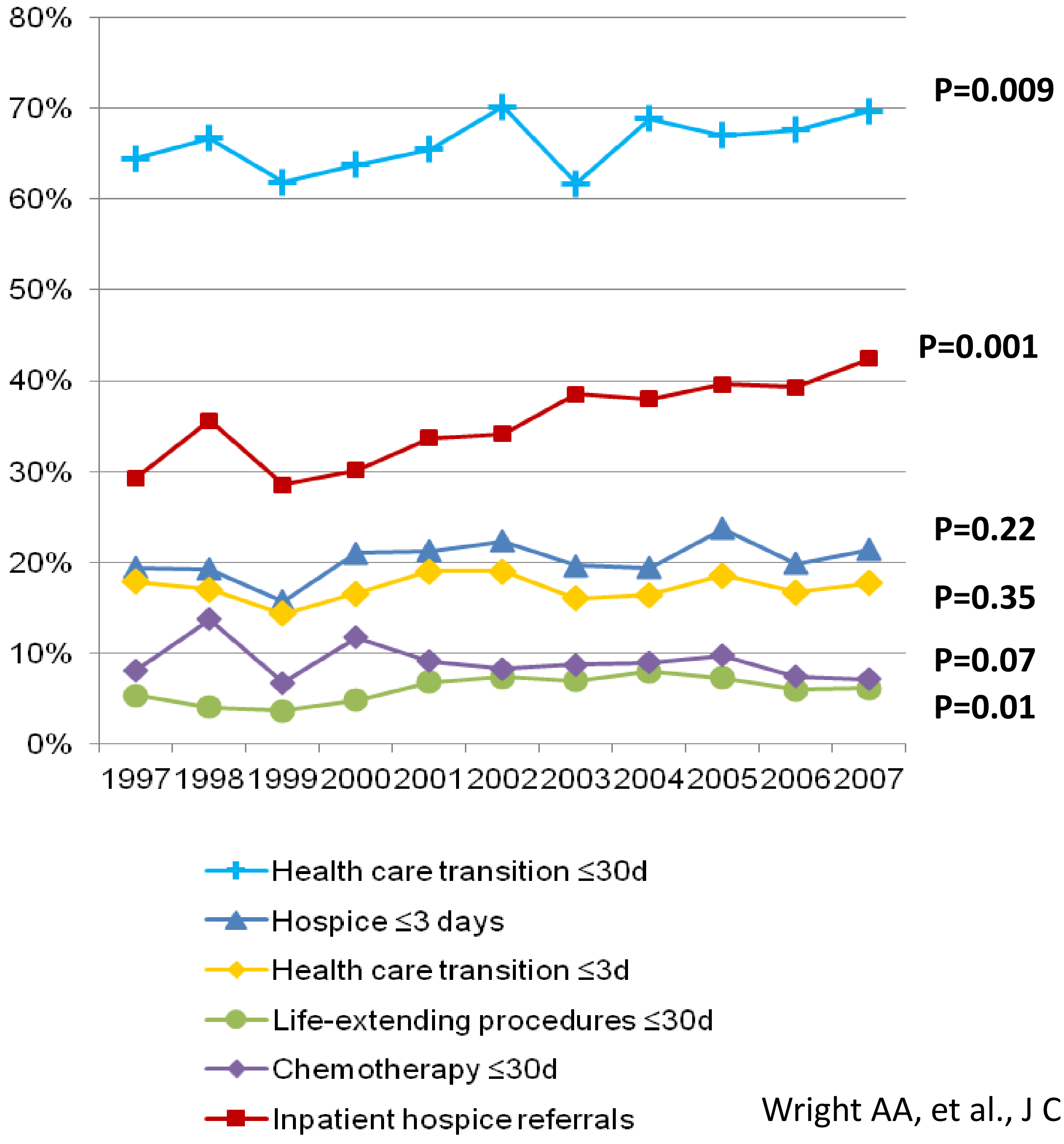
Funding:

National Cancer Institute
National Palliative Care Research Foundation
Agency for Healthcare Research and Quality

But we can’t provide this care to all patients with serious illness

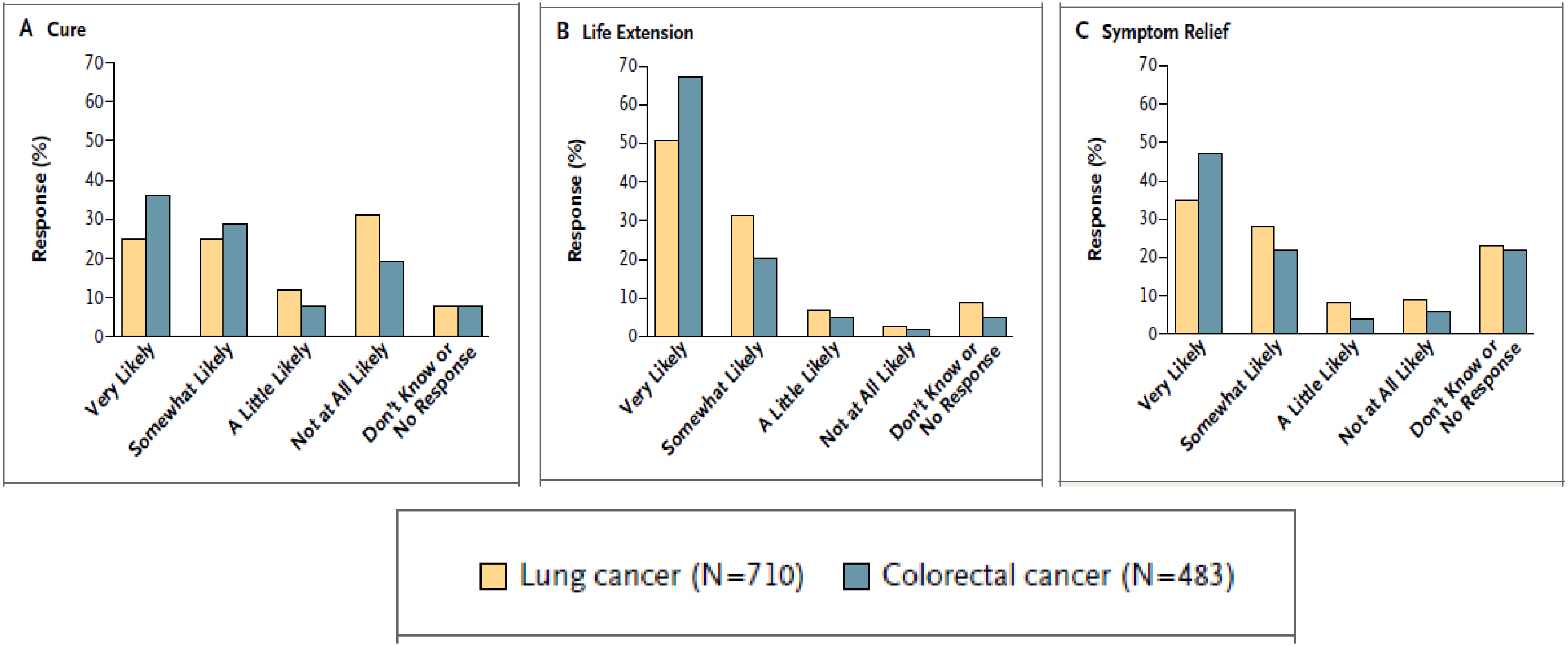
- We do not have enough palliative care physicians to provide access to palliative care for all patients with serious illness
- We need scalable interventions targeted at generalist (non-palliative care) physicians and other clinicians to assure universal access to key elements of palliative care

Health Care Transitions at the End-of-Life and Inpatient Hospice Referrals Rising



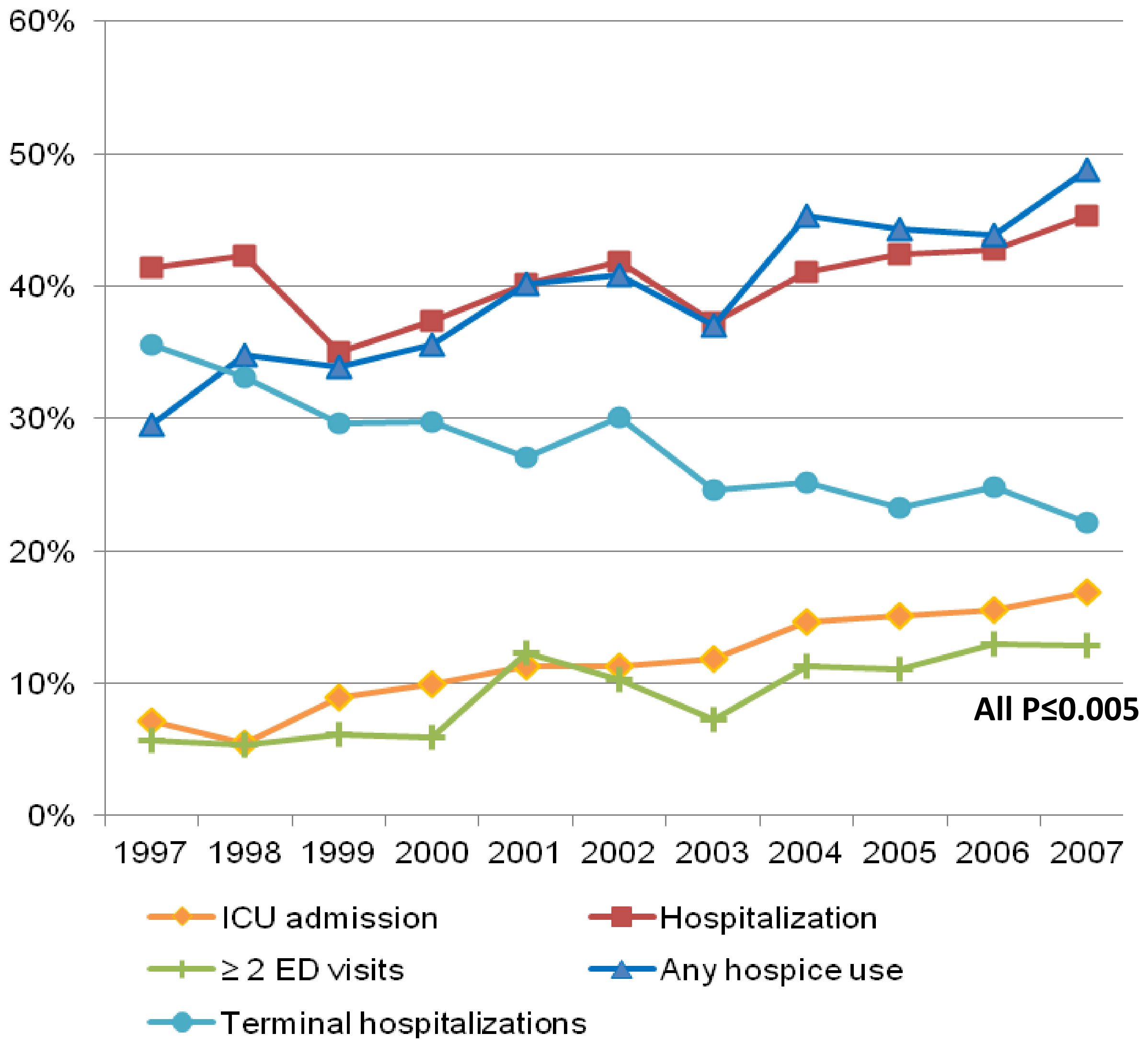
Wright AA, et al., J Clin Oncol, 2014

Patients' Expectations about Effects of Chemotherapy for Advanced Cancer



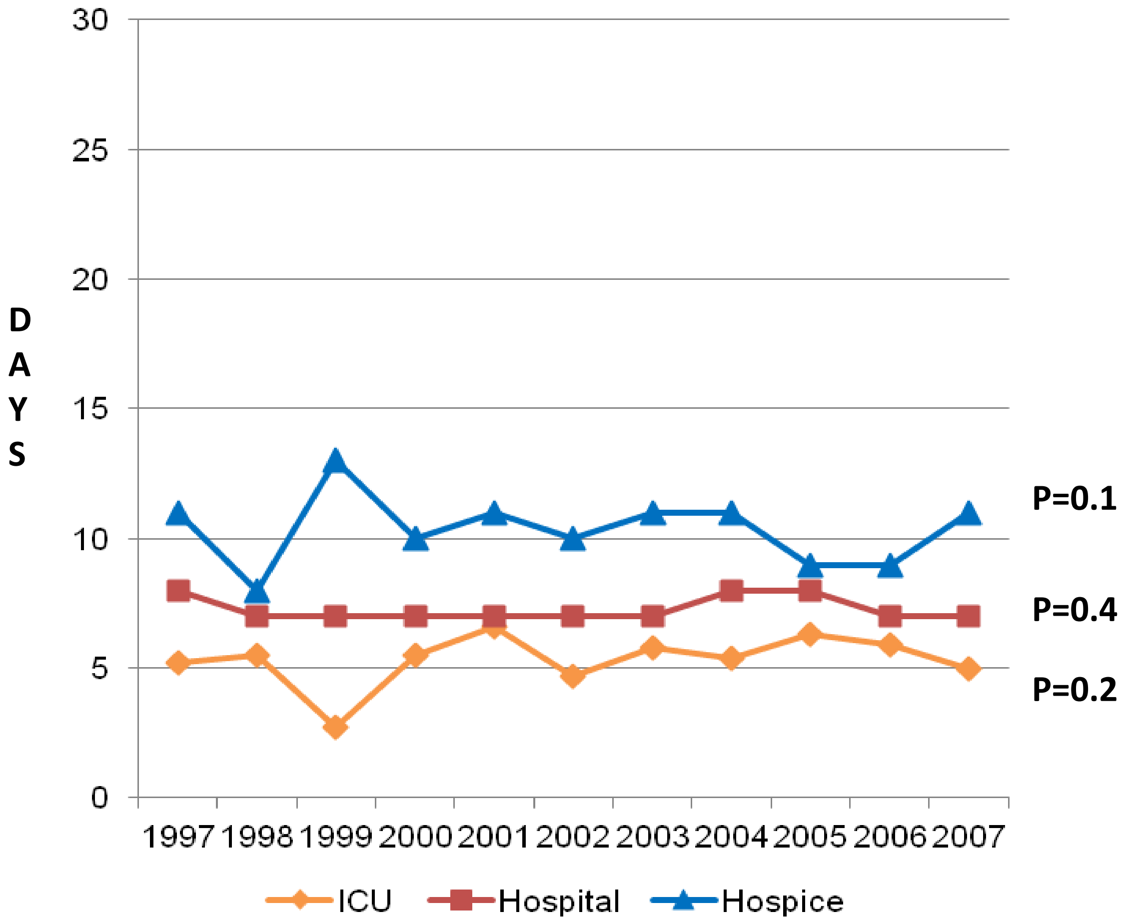
Weeks JC, et al. N Engl J Med, 2012

Increasing Hospice Use, Decreasing Terminal Hospitalizations, But More Medical Care Near Death



Wright AA, et al., J Clin Oncol, 2014

Dying Patients Spend 1 Week of their Last Month of Life in the Hospital on average



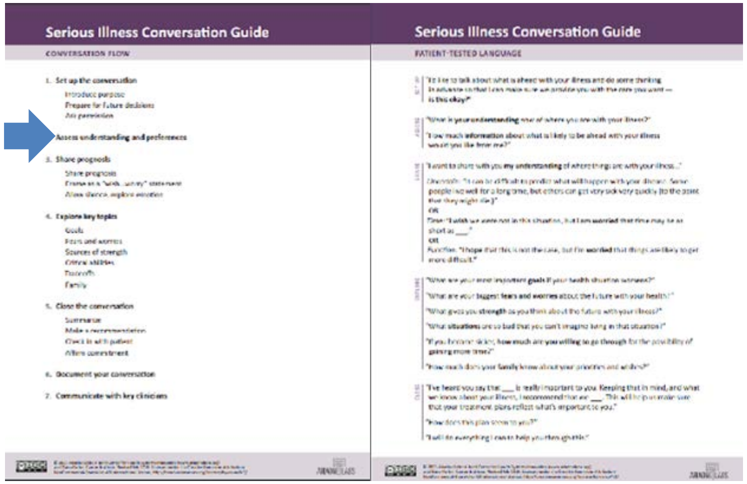
Assess illness understanding and information preferences

Illness understanding provides an indication of how realistic the patient is about prognosis and provides the clinician information about how much gentle pushing is needed to prepare the patient for what is ahead

- *“What is your understanding now of where you are with your illness?”*

Information preferences guide clinician in titrating information to patient preferences, and helps clinicians feel confident in moving forward with providing prognostic information

- *“How much information about what is likely to be ahead would you like from me?”*



Serious Illness Conversation Guide

CONVERSATION FLOW

1. Set up the conversation
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission

Assess understanding and preferences

3. Share prognosis
   - Share prognosis
   - Frame as a "wish...worry" statement
   - Allow silence, explore emotion
4. Explore key topics
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. Close the conversation
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment
6. Document your conversation
7. Communicate with key clinicians

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

Slide courtesy of Bernacki RE, et al.