



# Advancing a Quality of Life Agenda: Innovation, Ingenuity & Advocacy

June 11, 2014 · HESI Annual Meeting

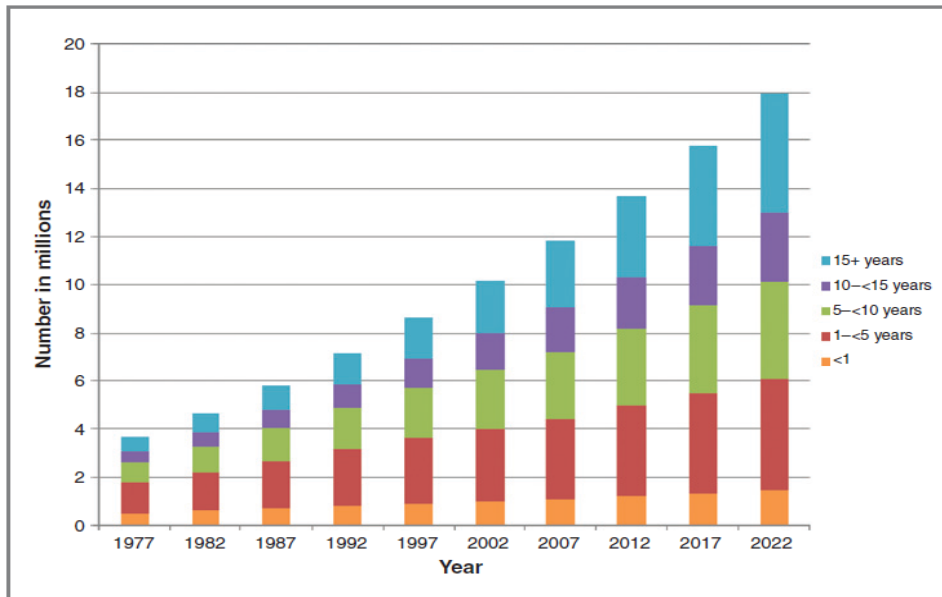
Rebecca Kirch  
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American Cancer Society

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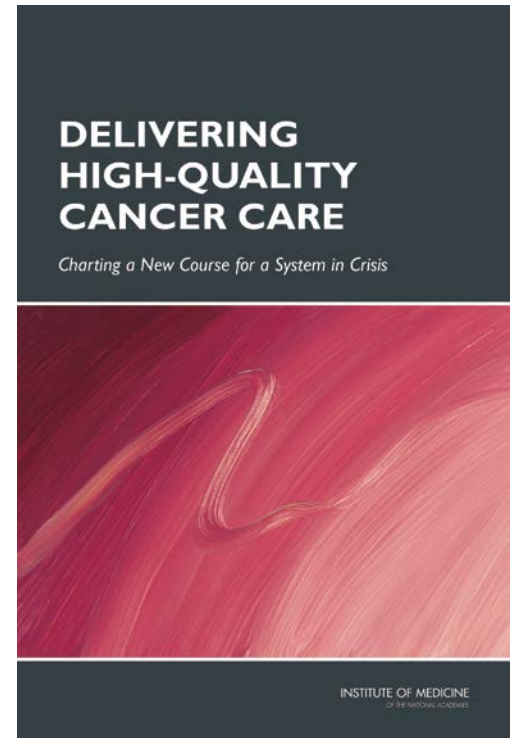



# Key Cancer & Survival Statistics

- Annually in the US, we expect about **1.67 million new cancer cases** and **585,720 deaths** (~1600 per day) (American Cancer Society Facts & Figures 2014)
- Nearly **14 million people** are now living in US with history of cancer. This will jump to **18 million people** by 2022.
- Nearly **380,000 survivors** of childhood & adolescent cancer are living in the US now. Most experience persisting health problems and chronic conditions. (Facts & Figures 2014 special section)



[www.nap.edu/qualitycancercare](http://www.nap.edu/qualitycancercare)





## Consumers want person-centered and goal-directed care...

- Concerns about the level of care patients with serious illness receive.
- Biggest concerns relate to **information sharing**, personal **choice and control**, **communication** and **quality time**.
- But they don't know how to ask for the care they all want and need.

(Public Opinion Strategies 2011 Consumer Research Findings, Commissioned and funded by Center to Advance Palliative Care, American Cancer Society, and ACSCAN)

# Personalized medicine

*What is important to you?*



# Helping Make Good Plans

## Person Centered & Goal Directed Care

Amy Berman's Quality Care Trajectory



“I don't want longer length of life if it is a bad time.

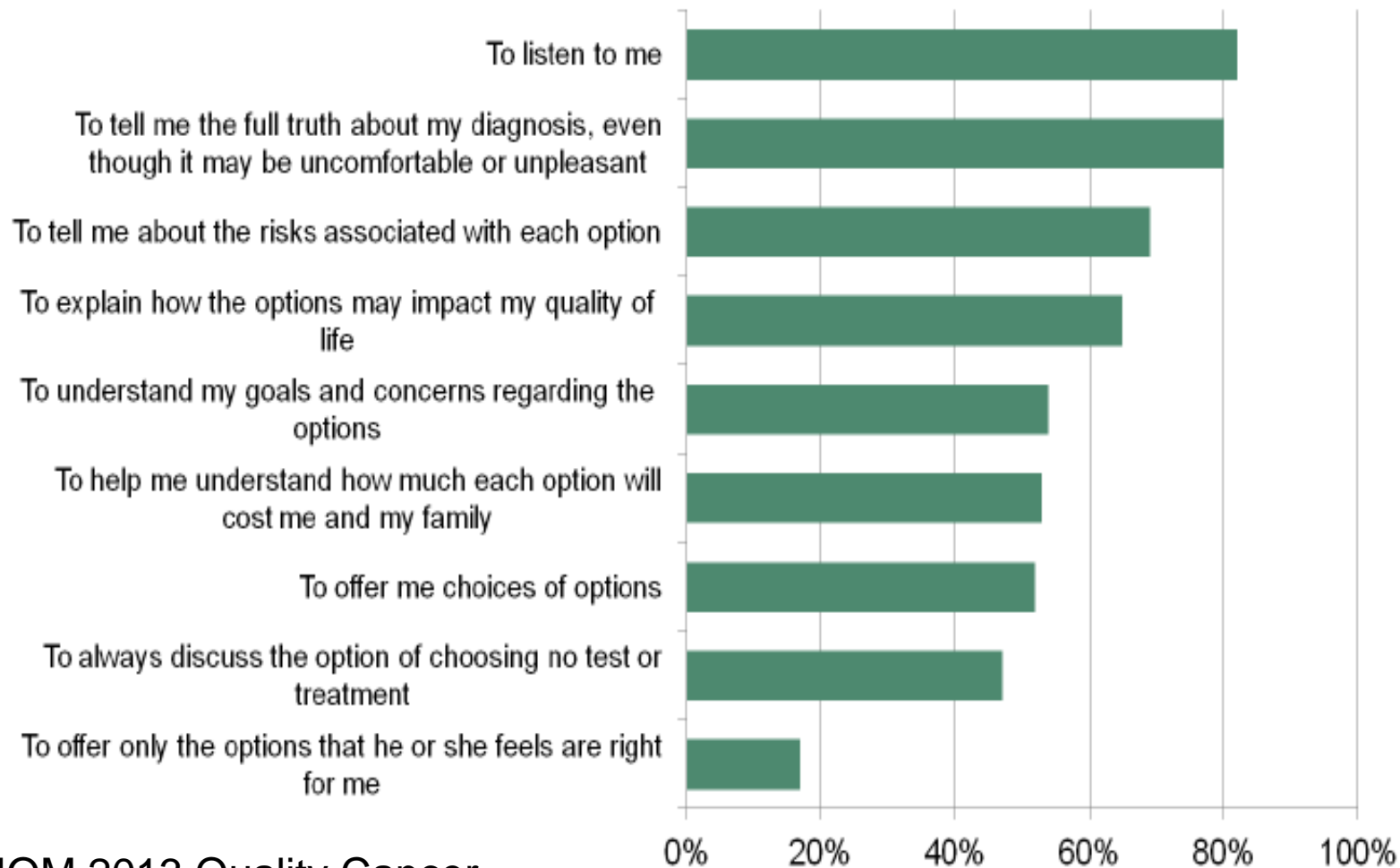
I want a good time for as long as possible”

Berman A, *Health Affairs* , Living Life In My Own Way—And Dying That Way As Well (April 2012 vol. 31 no. 4, 871-874).



# Patients & Families Want Involvement

**Figure 1. People want involvement in evidence and decisions**  
*Bars show the percent of people surveyed who strongly agree with the statement: "I want my provider..."*





# System shortcomings change the seriously ill

Toxicities of cancer treatment are a very real price paid for progress.

(Niraula, et al. JCO August 2012)

Adults & children living with serious illness like cancer often experience:

- ✓ Inadequately treated symptoms
- ✓ Fragmented care
- ✓ Poor communication with their doctors
- ✓ Enormous strains on family caregivers

# Long term effects of life saving treatments

- High prevalence of adverse health outcomes among adult survivors of childhood cancers that ***last lifetimes***
  - **95%** suffered chronic health condition by age 45 (Hudson JAMA 2013)
  - Cancer survivors **8x** more likely than siblings to have severe or life threatening chronic health conditions. (Oeffinger NEJM 2006)
- Significant & ongoing physical, emotional and other ***suffering for children & families***
- System must support that children both ***survive AND thrive*** – requires care continuity across multiple transitions & over many years





# Palliative care is a medical innovation targeting a perfect storm

- Unprecedented growth of an aging population
- Failure to recognize and treat pain and other distressing symptoms
- Widespread use of costly medical technologies that fail to restore health and functional independence
- Exponential cost increases in care
- Dissatisfaction and confusion about medical care and the health system





# What is Palliative Care?

- Palliative care focuses on **relieving the pain, symptoms, and stress** of a serious illness — whatever the diagnosis.
- The goal is to **improve quality of life** for both the patient and family.
- It is appropriate at *any age and at any stage* and *can be provided along with curative treatment*.

# Key ACS Palliative Care Partnerships



**Research:** Together funding dedicated palliative care and symptom management grants and building the next generation of clinical researchers and a collaborative community for their work. [npcrc.org](http://npcrc.org)



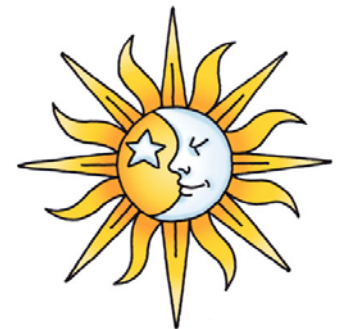
**Programs:** Technical assistance, training, and resources for palliative care teams at every stage, including tools to achieve new palliative care quality care standards. [capc.org](http://capc.org)



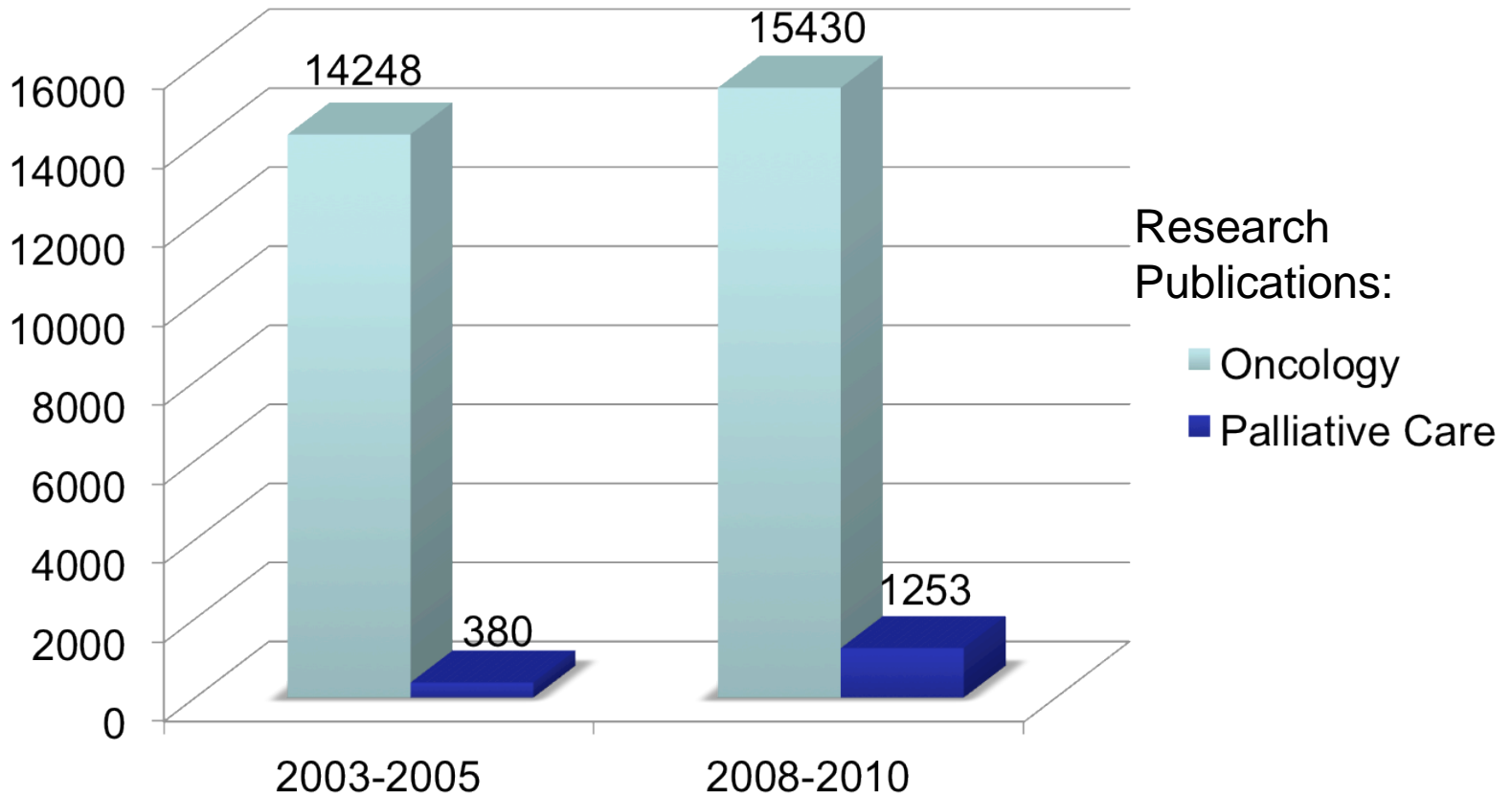
**Advocacy:** New QOL **federal legislative proposals** addressing palliative care research, workforce and access barriers. Menu of complementary **state model legislation options** and strategies also building steam. [acscan.org/qualityoflife](http://acscan.org/qualityoflife)

# Palliative Care's Decisive Moment

1. **Robust and growing evidence base** to guide clinical practice *and* make the case
2. Already one of fastest growing health care trends
3. New **quality standards**
4. Oncology got on board. Then came heart. Neurology and pulmonology soon...
5. Consumer research shows strong **public interest**
6. New QOL legislative suite and public policy/advocacy platform



# QOL not an NIH priority

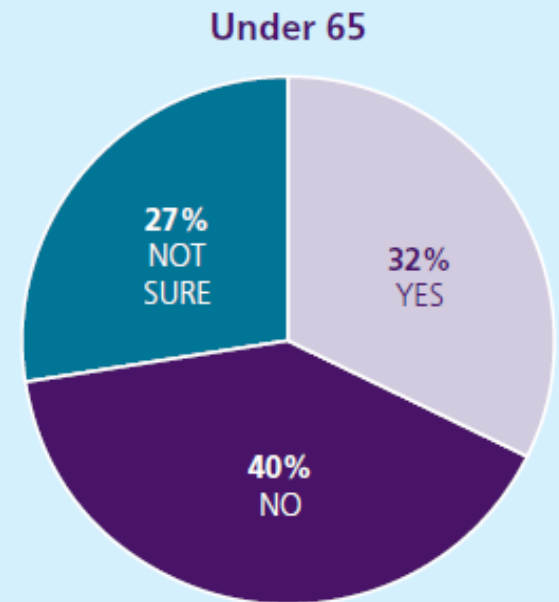
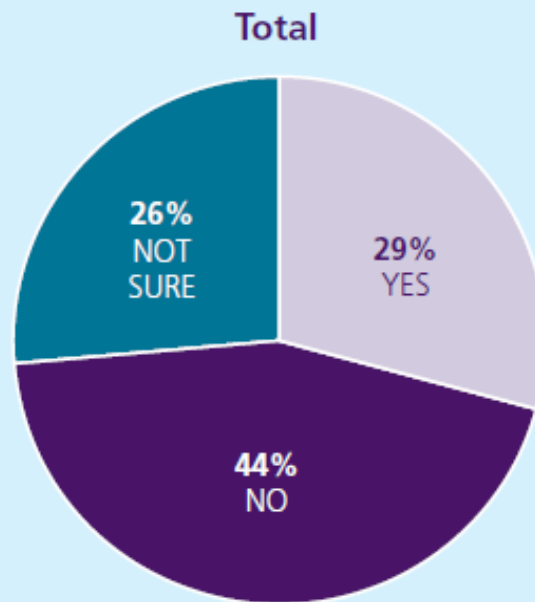


(Gelfman & Morrison J Palliat Med 2008 & 2013)

# QOL not a clinical priority

**Q: After diagnosis and before starting treatment, did anyone on care team ask what is important to you/family in terms of QOL?**

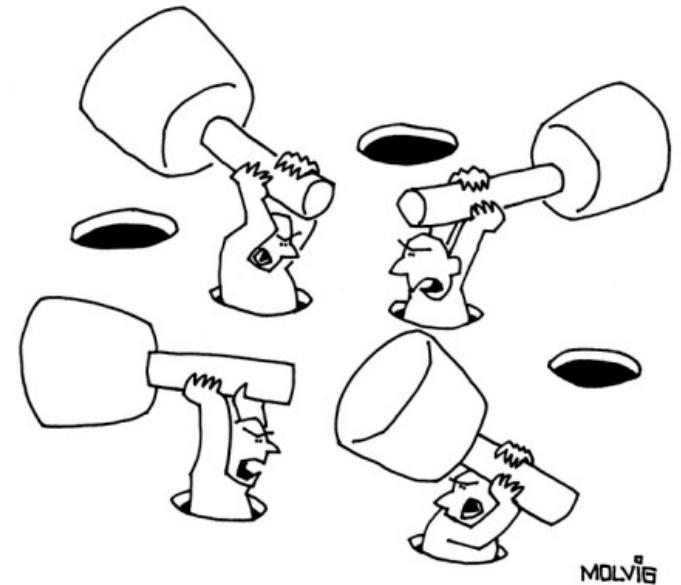
**Q:** After (your/your relationship's) cancer diagnosis *but before treatment*, did a doctor or another person on the medical team ask (you/your relationship) what is most important to (you and your family) (her/him and her/his family) in terms of quality of life during and after treatment?



2010 ACS CAN National Poll on Facing Cancer in the Health Care System  
([www.acscan.org](http://www.acscan.org))

# Our Policy Environment: An(other) Inconvenient Truth

- Affordable Care Act issue fatigue
- Health reform = buzzword bingo
- Cost neutral culture
- Polarized policymakers
- Lingering death panel skittishness
- Pain stigma & drug control overdrive



# BIG language barrier

“I don’t want to achieve immortality through my work. I’d rather achieve it by not dying.”

Woody Allen



**Palliative care is NOT about death, dying and end of life. It is about quality of life and the quality of how people are *living*. And it is about personal choice – “what is important to you”.**



# Job 1: Reorienting Priorities



Frame QOL &  
palliative care as an  
*essential* aspect of  
quality care...

for *any age* and *any stage*  
and for *all audiences*

**Survival with high QOL**

# *What is important to you?*

FACT: Treating the pain, symptoms, and stress of cancer is as important as treating the cancer.



# QOL consensus blueprints already exist across care continuum



## Institute of Medicine Series 2000 to 2013

- Quality cancer care
- Palliative care
- Psychosocial care
- Survivorship care
- Pain care

**Stopping suffering is our  
common denominator.**

# Quality Care focused on patient & family needs – including QOL at any age & any stage

## Cancer treatment Toolbox

Surgery  
Radiation  
Chemotherapy  
Other disease-directed therapies



## Quality of life clinical toolbox

**Palliative care** for pain, symptom & stress management  
**Psychosocial care** for emotional support  
Impairment-driven **rehabilitation**  
Promote other aspects of health & **wellness**

## Person-centered clinical communication skills

Essential quality bedrock to ensure treatment & planning aligns with people's care goals and preferences

***Bring palliative care everywhere***

# Igniting a Quality of Life Movement

## *Collaborative partners with missions aligned*

### Improve survival with high QOL

- **Dedicated research and training** support to boost evidence base, quality care delivery, and community of collaborative research
- **Educating everyone** about palliative care, QOL priorities & building communication skills
- **Building bridges in communities** to the people, tools, and resources required to deliver and receive high quality cancer care.



# QOL Research Support

## Innovative Grant Program Partnership

- Since 2007, ACS has awarded more than \$23 million dedicated funding to palliative care & symptom management research in partnership with NPCRC
  - NPCRC Director is Society's newest **Clinical Research Professor**, providing research consultancy and mentorship to further build the field
  - Annual **Kathleen Foley research retreat** and associated mentoring is building a strong community of researchers and project collaborations among them
- *ACS Pathfinder in Palliative Care Award* recognizes exceptional professional innovation & ingenuity in advancing the field



# Palliative Care's TRIPLE AIM TRIFECTA

## Better and longer survival...

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August 18, 2010

## Palliative Care Extends Life, Study Finds

By DONALD G. McNEIL Jr.

In a study that sheds new light on the effects of end-of-life care, doctors have found that patients with terminal lung cancer receiving palliative care immediately upon diagnosis not only were happier, more mobile and in less pain as the end near, but also lived nearly three months longer.

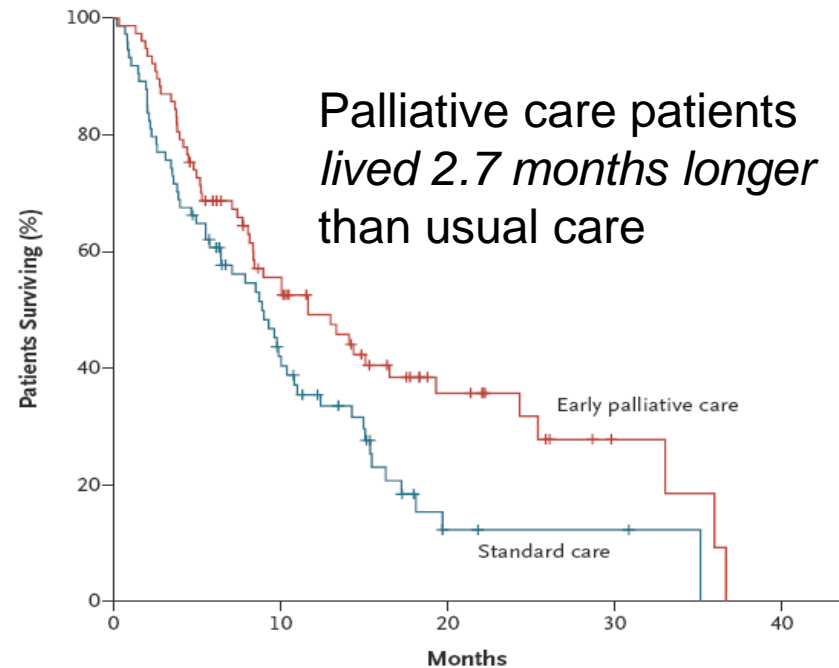
THE NEW ENGLAND JOURNAL OF MEDICINE

ORIGINAL ARTICLE

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

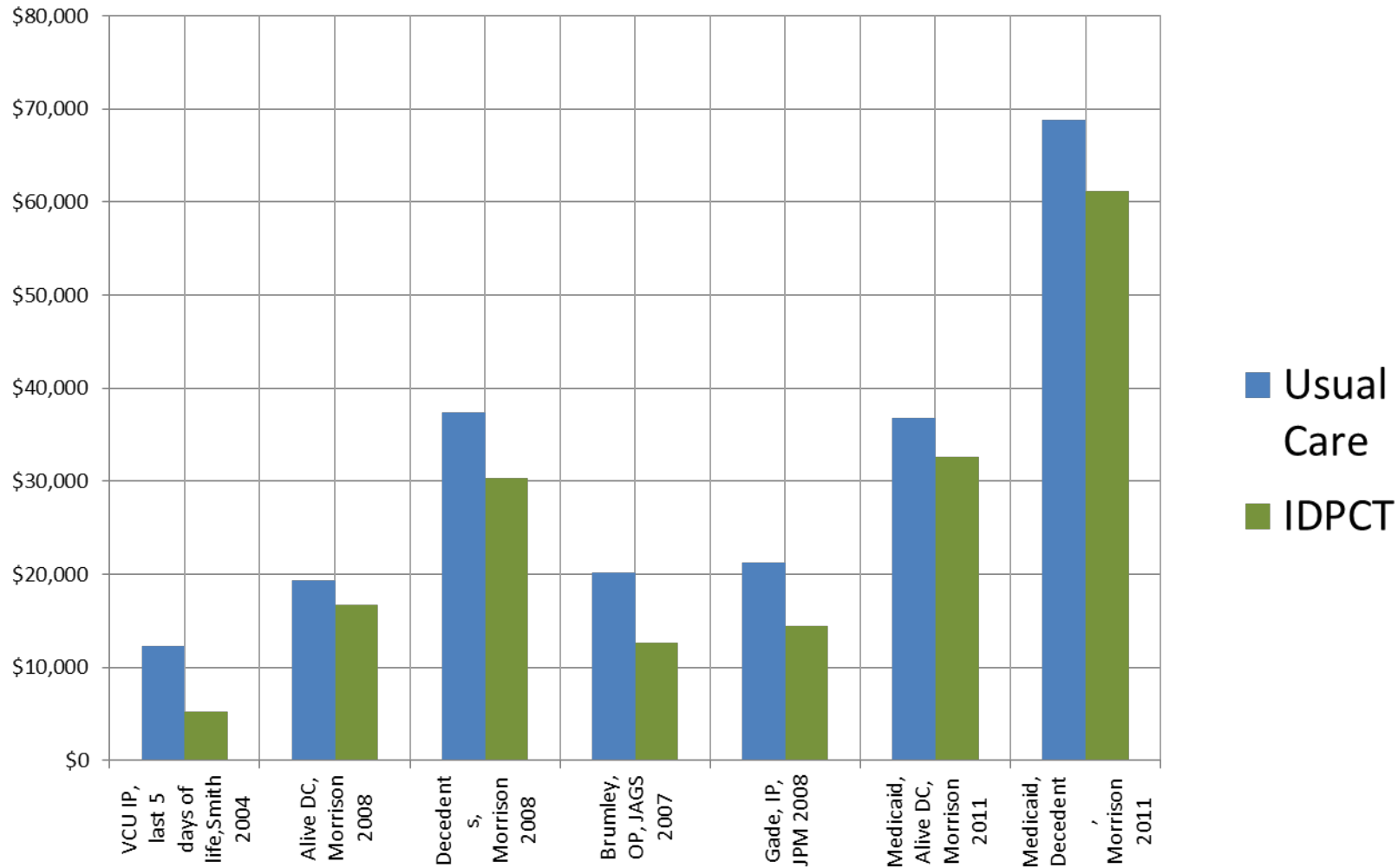
Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D.,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

(Temel NEJM 2010)



# And reduced costs

***Every study to date shows significant savings from palliative care – in addition to better care***

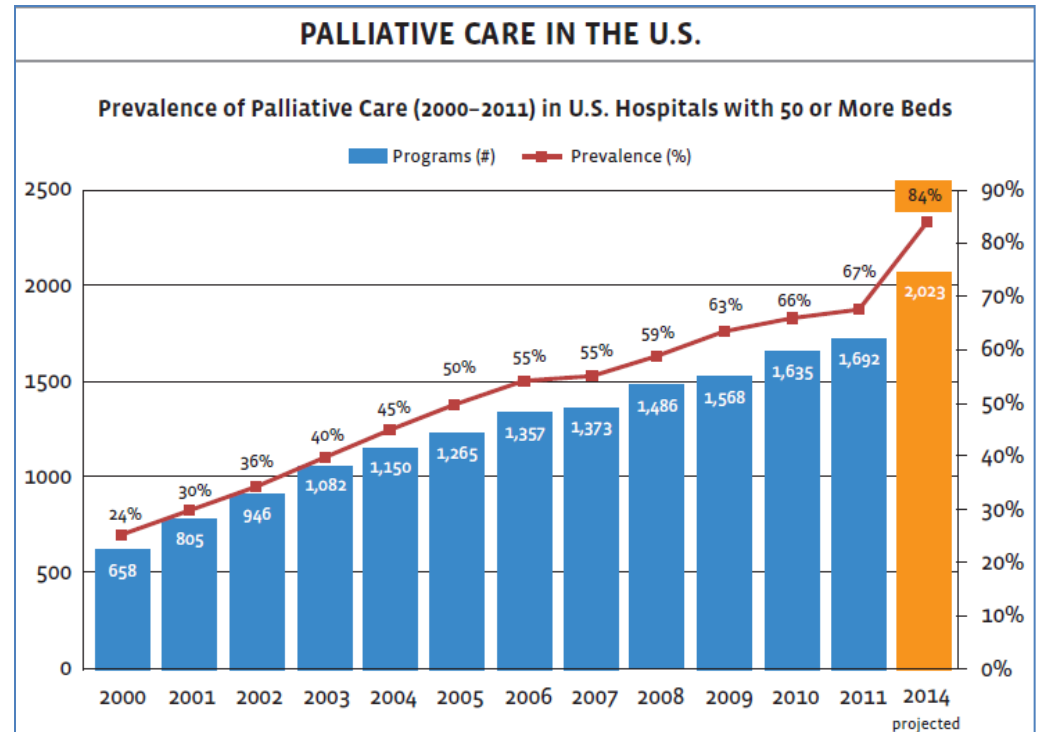


(Hughes M, Smith TJ. Annual Reviews in Public Health, 2014 March)



# Integrate Palliative Care in Practice

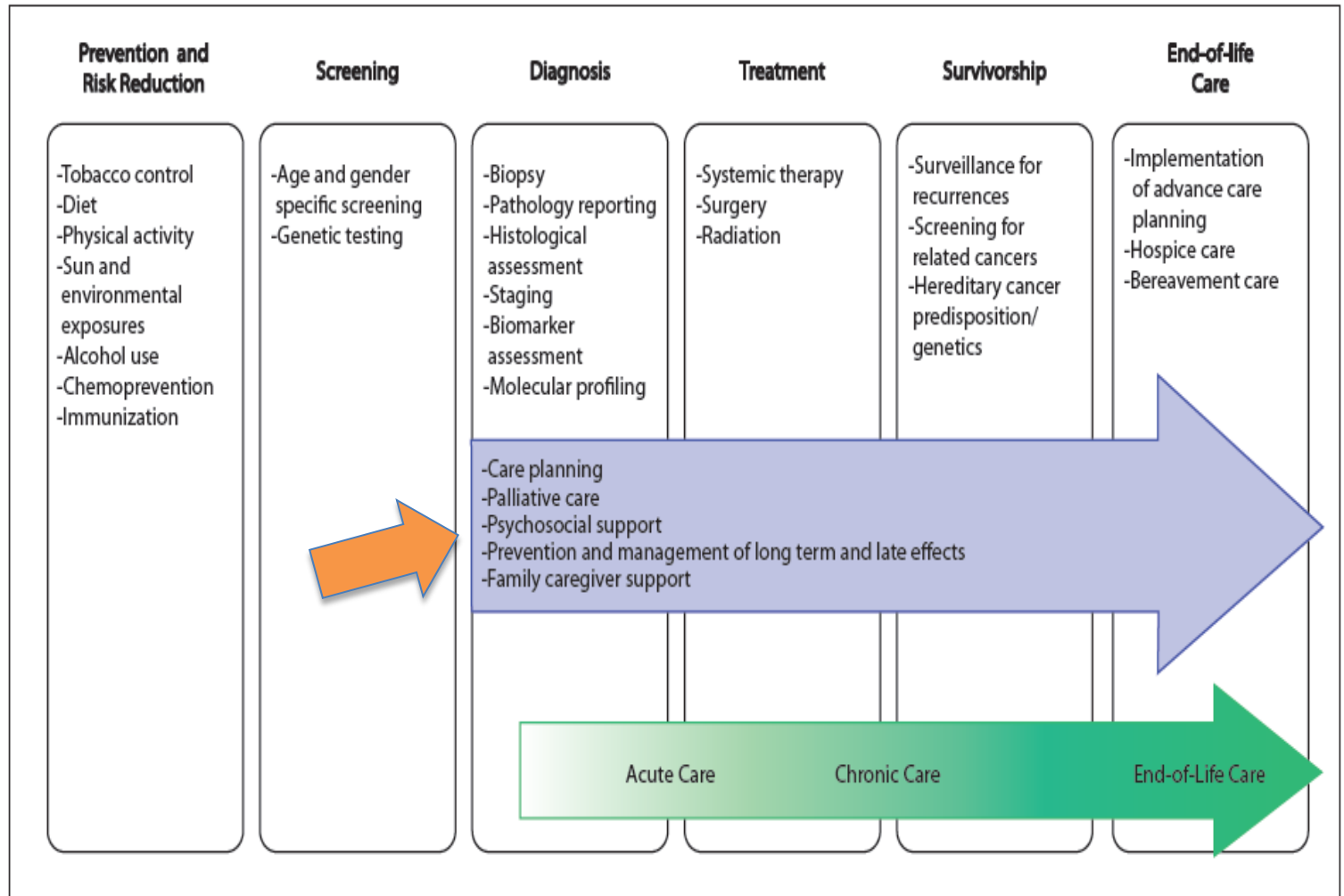
## New QOL Standards, New Opportunities



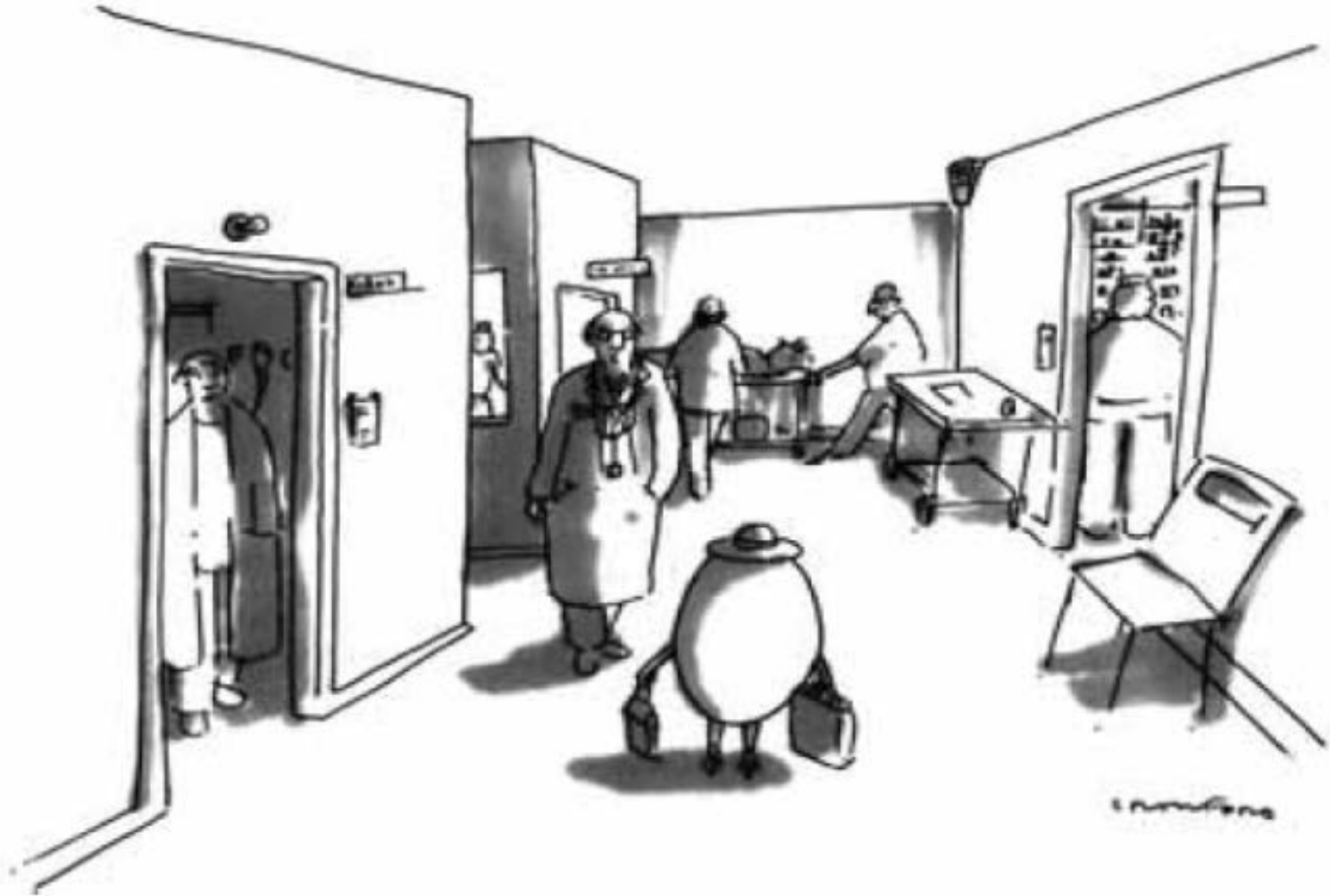
### Next: Bring palliative care everywhere

- Hospitals (adult & children's)
- Cancer centers/outpatient clinics
- Community
- Home

# When does palliative care begin? At the onset.

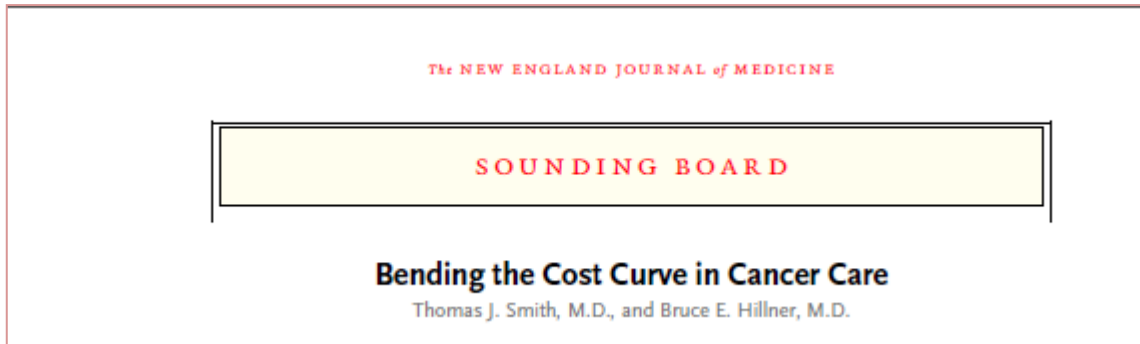


# Who delivers palliative care? Everyone.



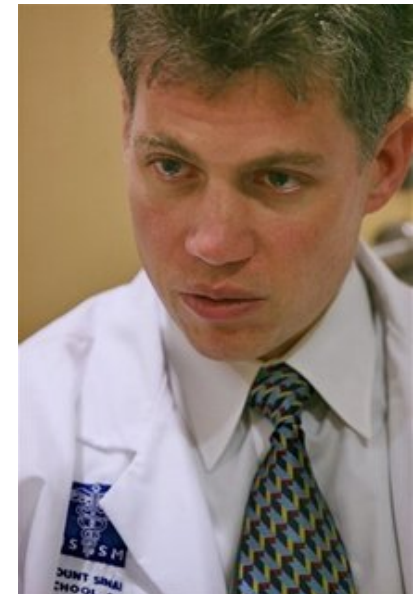
*"You might want to sit down, Mrs. Dumpty."*

# The Cost Savings are Real



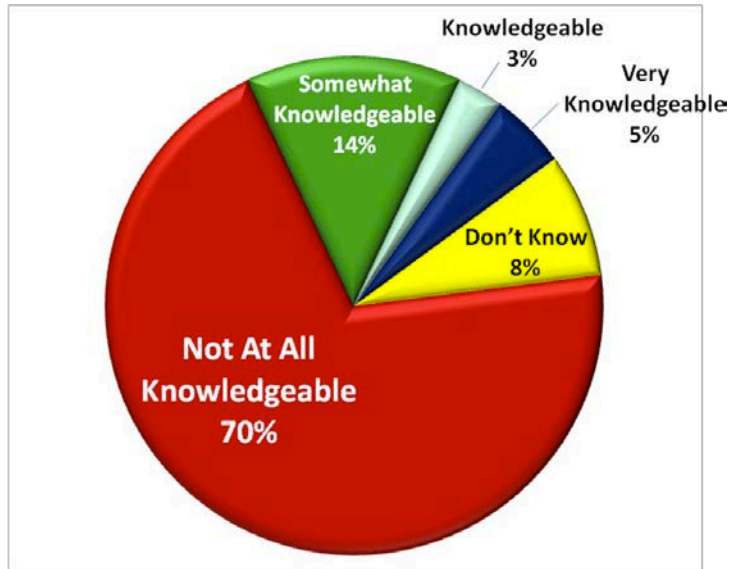
**Hospital palliative care teams create efficiencies that deliver significant savings.**

- Patients enrolled in Medicaid at 4 New York state hospitals who received palliative care **incurred \$6,900 less** in hospital costs than a matched group receiving usual care. (Morrison Health Affairs 2011)
- On average, palliative care consultations in 8 diverse hospitals resulted in **reductions of \$1700** in direct costs per admission for live discharges and reductions of \$4900 per admission for patients who died in the hospital. (Morrison Arch Intern Med 2008)



# Overcoming the identity problem

**Q: How knowledgeable, if at all, are you about palliative care?**



**Access consumer research report summary with key findings at: [www.capc.org](http://www.capc.org)**

National survey of 800 adults age 18+ conducted June 2011 commissioned by CAPC, ACS & ACSCAN

- Palliative care is a relative unknown among **consumers** (92% really don't know what it is)
- Most **health professionals** wrongly equate palliative care with EOL and hospice – curative vs. palliative perspective
- People understand and want palliative care if we **use their words** to define & describe it.

# What's in a name? Language matters.

## Palliative care...

**Focuses on relieving symptoms, pain and stress** of serious illness.

**Improves quality of life** for both patient and family.

Provided by a team who works with a patient's other doctors to **provide an extra layer of support.**

Appropriate at **any age and any stage** and can be provided **along with curative treatment.**

Definition and data from CAPC/ACS Public Opinion Strategies research and national survey of 800 adults age 18+ conducted June 2011.

Access report summary with key findings at: [www.capc.org](http://www.capc.org).

## People Want Palliative Care:

**95%** say education is important for patients & their families about palliative care options available to them as part of treatment.

**92%** report they would be likely to consider palliative care for themselves or their families if they had serious illness

**92%** also said they believe patients should have access to palliative care at hospitals nationwide



# Treating the Person Beyond the Disease



**chemotherapy**

Palliative care sees the person beyond the cancer treatment. It gives the patient control. It brings trained specialists together with doctors and nurses in a team-based approach to manage pain and other symptoms, explain treatment options, and improve quality of life during serious illness. Palliative care is all about treating the patient as well as the disease. It's a big shift in focus for health care delivery—and it works.


Support palliative care legislation (H.R. 1339, S. 641 & H.R. 1666).  
Bring quality of life and care together for the millions facing cancer.



acscan.org


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# **R**adiation



# Sweeping the nation:

## Using public policy to build a QOL echo chamber



### Federal legislation boxed set – starter course

- Patient-Centered Quality Care for Life Act (HR 1666)
- Palliative Care & Hospice Education and Training Act (HR 1339/S 641)

### QOL state legislation & balancing pain policies

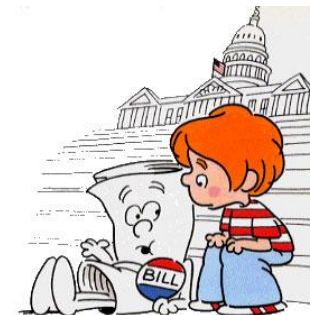
### Patient QOL Coalition

American Cancer Society Cancer Action Network ♦ American Academy of Hospice and Palliative Medicine ♦ American Academy of Pain Management ♦ American Childhood Cancer Organization ♦ American Osteopathic Association ♦ American Society for Pain Management Nursing ♦ American Society of Clinical Oncology ♦ Association of Oncology Social Work ♦ Cancer Support Community ♦ C-Change ♦ Center to Advance Palliative Care ♦ Hospice and Palliative Nurses Association ♦ LIVESTRONG Foundation ♦ National Alliance for Caregiving ♦ National Association of Social Workers ♦ National Coalition for Cancer Research ♦ National Coalition for Cancer Survivorship ♦ National Comprehensive Cancer Network ♦ National Palliative Care Research Center ♦ National Patient Advocate Foundation ♦ Oncology Nursing Society ♦ Society for Social Work Leadership in Health Care ♦ Supportive Care Coalition ♦ The Catholic Health Association of the United States



[QOL Campaign info:](#)

[www.acscan.org/qualityoflife](http://www.acscan.org/qualityoflife)





# Give everyone the words



*"There's no easy way I can tell you this, so I'm sending you to someone who can."*

# Changing the Culture of Communication



## Advanced Communication Skills for Difficult Situations

- Four one day workshops: Boston, Los Angeles, Miami & Minneapolis
- 58 clinical leader participants representing 17 institutions
  - **90%** rated this training as VERY IMPORTANT for development of their clinical skills
  - **95%** of participants said they would recommend this training to other colleagues
  - **88%** said this training should be required of *all* oncology clinicians



# Addressing shortfall of specialist palliative providers

## APRN Palliative Care Externship

- Intensive 1 week grant funded on-site didactic and experiential program
- Follow-up mentoring by national palliative care advanced practice leaders to promote translation of education into clinical practice
- 8 cohorts of 6 APRNs (CNSs & NPs)
- 48 APRNs from rural and community settings have completed program (36 completed by June 2014 with 12 accepted for Fall 2014)
  - Each participant commits to adding a palliative care dimension to his or her practice to promote quality palliative care.
  - Many participants say externship has been “transformational experience”

# Empowering Patients & Families



## Welcome

View the PREPARE Pamphlet

- 1 Choose a Medical Decision Maker
- 2 Decide What Matters Most In Life
- 3 Choose Flexibility for Your Decision Maker
- 4 Tell Others About Your Wishes
- 5 Ask Doctors the Right Questions

Your Action Plan

Hide Menu

## Welcome to PREPARE!

**PREPARE is a program that can help you:**

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you



**You can view this website with your friends and family.**

Click the NEXT button to move on.

[prepareforyourcare.org](http://prepareforyourcare.org)



Rebecca Sudore,  
MD

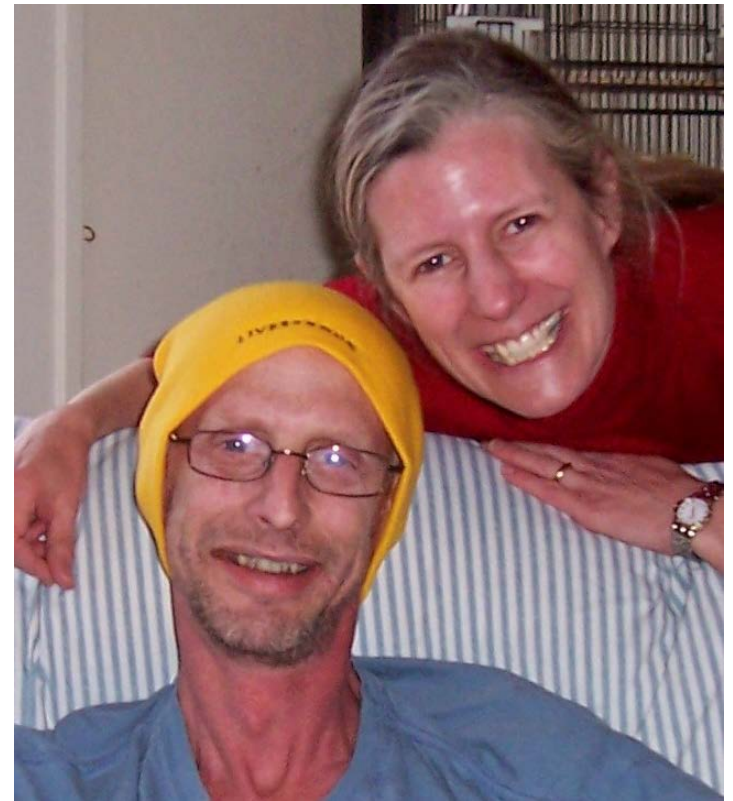


# Quality Care Goals

1. All **patients and families** will know to request palliative care in the setting of serious a illness
2. All **healthcare professionals** will have the knowledge and skills to provide palliative care
3. All healthcare **institutions** in the US will be able to support and deliver high quality palliative care

# How Do We Get There?

- Address public, professional and policymaker misconceptions
- Improve access and quality
- Build the workforce
- Expand the evidence base



# Survive and Thrive.

