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

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American Cancer Society
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
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?

*Let me know if you want to know why I am here.*
Helping Make Good Plans
Person Centered & Goal Directed Care

Amy Berman’s Quality Care Trajectory

Good Health → Quality Treatment → Good QOL

“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…”

- To listen to me
- To tell me the full truth about my diagnosis, even though it may be uncomfortable or unpleasant
- To tell me about the risks associated with each option
- To explain how the options may impact my quality of life
- To understand my goals and concerns regarding the options
- To help me understand how much each option will cost me and my family
- To offer me choices of options
- To always discuss the option of choosing no test or treatment
- To offer only the options that he or she feels are right for me

IOM 2013 Quality Cancer Care report
System shortchanges 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 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

Research Publications:

- 2003-2005:
  - Oncology: 14248
  - Palliative Care: 380

- 2008-2010:
  - Oncology: 15430
  - Palliative Care: 1253

(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?

2010 ACS CAN National Poll on Facing Cancer in the Health Care System (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...

Palliative care patients lived 2.7 months longer than usual care

(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.

IOM 2013 Quality Cancer Care Report
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?

- 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.

Access consumer research report summary with key findings at: www.capc.org

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

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.

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.
Treating the Person Beyond the Disease

Palliative care goes 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.

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
"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”
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.

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.

We Care About Cancer
And We WILL Be Heard!