

Childhood Cancer Activities Update

COCA-I 2014

Rebecca Kirch
Director, QOL & Survivorship



What we'll cover

- Research and resources
- Advocacy activities and alliances
- The QOL Agenda
- **Your questions AND your input!**



How I Got Here



**UNDERCOVER
BOSS**



Jim Rogers, left, and 'Tim Bickford,' right.

RESEARCH and TRAINING

ACS is currently supporting **49** active, multi-year childhood cancer research grants for a total of **\$23.6 million**

All proceeds raised through Hoda Kotb's **Shine a Light** campaign will be dedicated to pediatric cancer research (\$505K raised so far)

<https://www.crowdrise.com/hoda>



Relentlessly Pursuing Answers

Cancer doesn't fight fair at any age, but perhaps no cancer is more emotionally devastating than those that occur in children. The fear and uncertainty these young patients and their families face can hardly be measured, but the progress the American Cancer Society has made in seeking new cures for childhood cancer can. Today, a child's chance of dying from cancer is 55% less than it was in 1975. The substantial progress in childhood cancer is largely attributable to improvements in treatment and the high proportion of pediatric patients participating in clinical trials. The Society is deeply committed to finding new answers that will benefit every child with cancer.

An estimated 15,780 children under the age of 15 are expected to be diagnosed with cancer in 2014. Following are some of the top scientists funded by the American Cancer Society who are working to find the answers that will save more lives from pediatric cancer.

- Patrick Brown, MD, at Johns Hopkins University in Baltimore, Maryland, is working to identify the genetic change in one type of childhood leukemia that continues to have a very low cure rate. Those whose leukemia cells have a mutation in a specific gene called MLL would benefit from improved therapy.
- Rene L. Galindo, MD, PhD, at the University of Texas Southwestern Medical Center, Dallas is studying the cause of the muscle-type tumor rhabdomyosarcoma, an aggressive tumor that strikes children. By correcting the defective behavior of the genes identified in a model system, cells lose their tumor behavior. The goal is to inform the development of a new drug treatment for this tumor.
- Rani E. George, MD, PhD, at the Dana-Farber Cancer Institute in Boston is exploring a genetic abnormality in the cells of neuroblastoma associated with resistance to treatment with crizotinib. The ultimate goal of this study is to develop treatment strategies for this pediatric tumor.
- Maciej Lesniak, MD, at the University of Chicago (Illinois), is working to re-engineer a virus that causes the common cold, empowering it to attack the cells within fast-growing brain tumors.
- Steve Lessnick, MD, PhD, at the Huntsman Cancer Center in Salt Lake City, Utah, is exploring specific cell processes involved in Ewing's sarcoma, seeking better treatments for this disease.
- Mollie Meffert, MD, PhD, at Johns Hopkins University School of Medicine in Baltimore, Maryland, is studying a signaling pathway involved in brain cancer that explores how focused treatments can destroy tumor cells while minimizing negative effects on brain function.
- Kevin Shannon, MD, at the University of California at San Francisco, is exploring genetic changes in cells that occur in leukemia patients, re-creating these genetic reactions in the lab to seek out newly targeted therapies.

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Advocacy & Alliances



Advocacy Agenda

- Increase federal cancer research funding – NIH funds about \$200 million a year in pediatric grants
- Affordable Care Act patient protections implementation
- Promote childhood cancer specific legislation
- Integrate childhood cancer objectives in state comprehensive cancer control plans
- Advance QOL legislation



PROGRAMS AND SUPPORT

- **Creating healthier environments to keep children well:** making it easier to eat healthy; reducing second hand smoke exposure; promoting nutrition and physical activity
- **ACS resources for patients /families and health professionals:** online resources, printed publications, 24/7 NCIC phone support

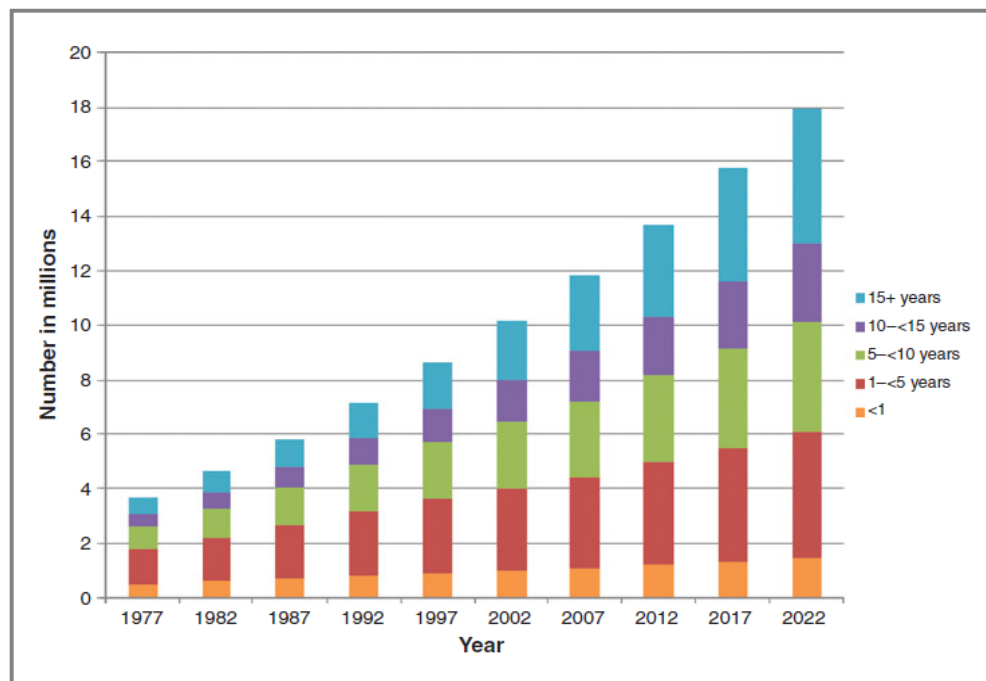




QUALITY OF LIFE AGENDA

Key Starter Statistics

Survivor numbers now and looking ahead



Source: Institute of Medicine 2013 Quality Cancer Care Report

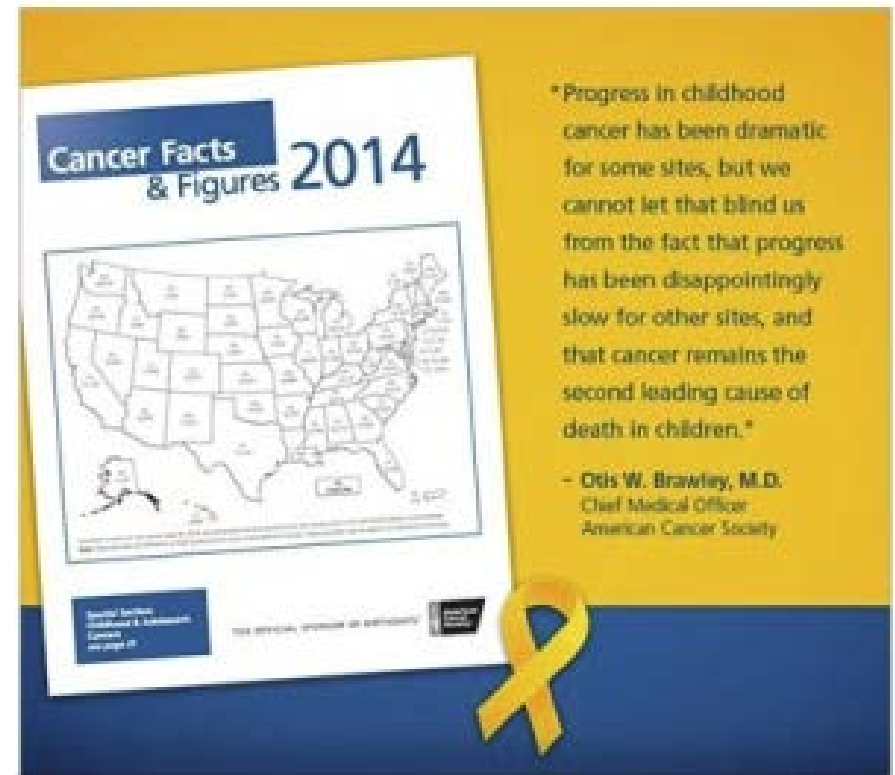
The Society's 2014 Facts & Figures statistics report estimates:

- **1.67 million** new cancer cases and **585,720** deaths annually
- **14 million** survivors now. This will jump to **18 million** by 2022
- Nearly **380,000** survivors of childhood & adolescent cancer

**Improve survival with high QOL
for all adults and children**

Children and adolescents

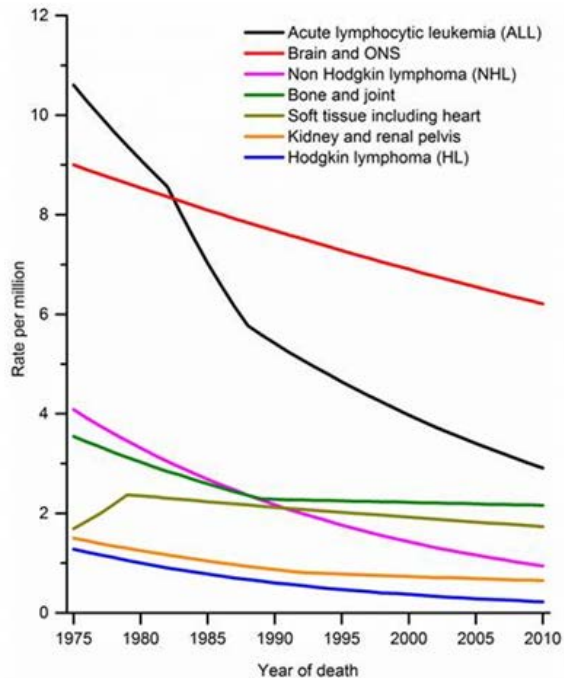
- **15,780** new cancer cases and **1,960** deaths expected this year
- Cancer remains **THE** leading cause of disease death in children
- 1 in 530 adults aged 20 to 39 are childhood cancer survivors.
- Most experience persisting pain, symptoms, and late effects that affect quality of life (QOL) for child & family



**Facts & Figures 2014 Special Section:
Childhood and Adolescent Cancers**
www.cancer.org

Progress and Challenges

Trends: Pediatric cancer mortality rates by site Birth to 19 years from 1975 to 2010



ONS=other nervous system.

Note: Lines represent joinpoint fitted trends. Source: National Center for Health Statistics, Centers for Disease Control and Prevention.

- Cancer types that develop in children and adolescents differ from those that develop in adults
- Most common childhood cancers:
 - Leukemia
 - Cancers of the brain and CNS
 - Lymphoma
- Progress in survival has been substantial for some cancer types, but not others

Facts & Figures 2014 special section on childhood and adolescent cancer statistics

Long term effects of life saving treatments

Toxicities of cancer treatment remain a real and steep price paid for progress

- Significant and ongoing physical, emotional and other *suffering for children & families*
- High prevalence of adverse health outcomes that *last lifetimes*
 - **95%** suffered chronic health condition by age 45 (Hudson JAMA 2013)
 - Childhood cancer survivors **8x** more likely than siblings to have severe or life threatening chronic health conditions (Oeffinger NEJM 2006)



Compelling call to action

COMMENTARY

Because Statistics Don't Tell the Whole Story: A Call for Comprehensive Care for Children With Cancer

Jennifer Cullen, PhD, MPH¹



“Worse yet, as we would be counseled in great detail, the cost of trying to save our young daughter would be **certain and permanent cognitive devastation.**”

Survive and thrive

Person-centered and personalized care

What matters to the patient is important.
Not just what is the matter with them!



What is important to you?

Fact:

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



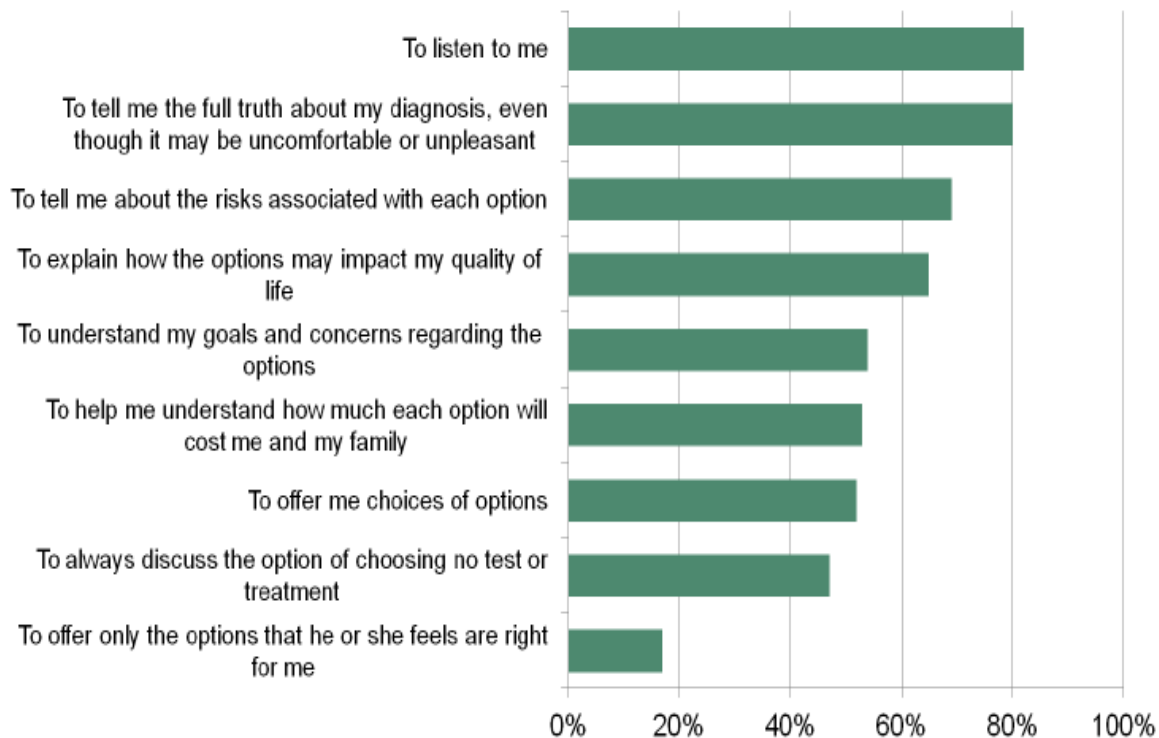
Fact:

Our ability to relieve the pain, symptoms, and stress of cancer has never been greater.

Patient & Family Priorities

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..."

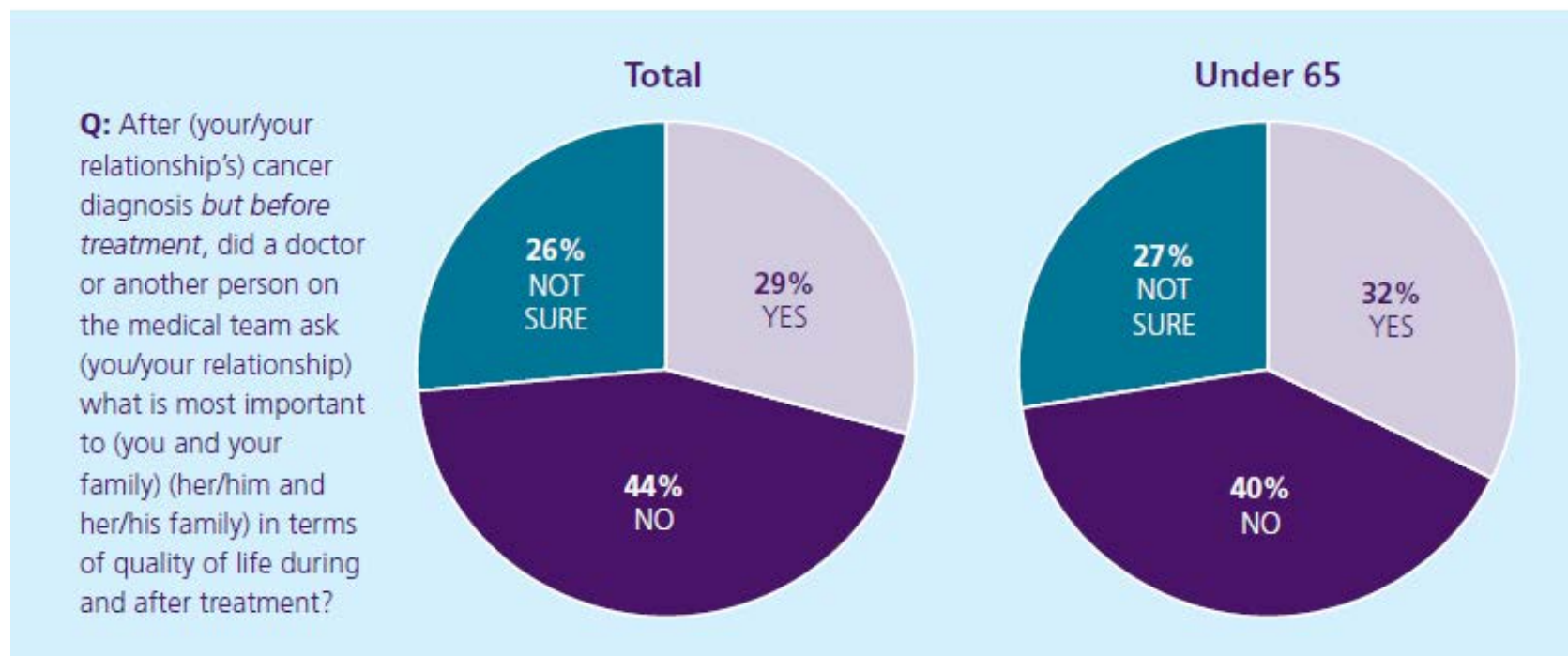


What people want:

- Tell full **truth**
- Tell about **risks**
- Explain impact on **QOL**
- Understand their **goals and concerns**

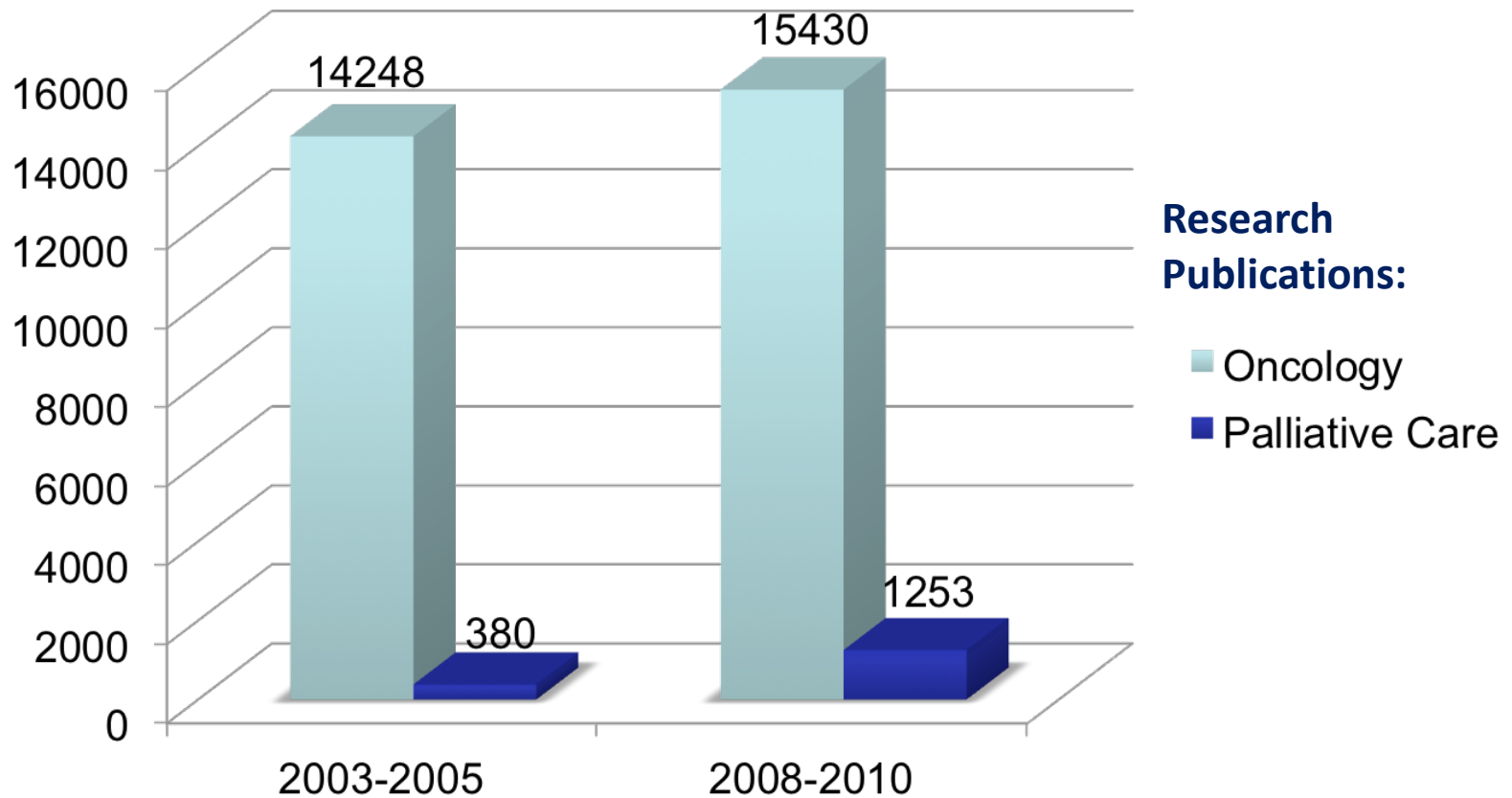
QOL concerns are not raised or discussed

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)

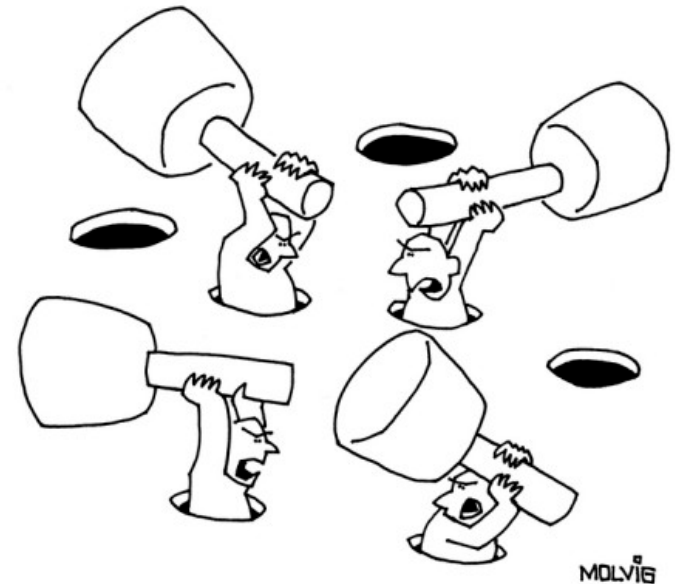
Evidence Base: QOL not a priority



(Gelfman & Morrison J Palliat Med 2008 & 2013)

Our Policy Environment

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



Job 1: Reorienting Priorities



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

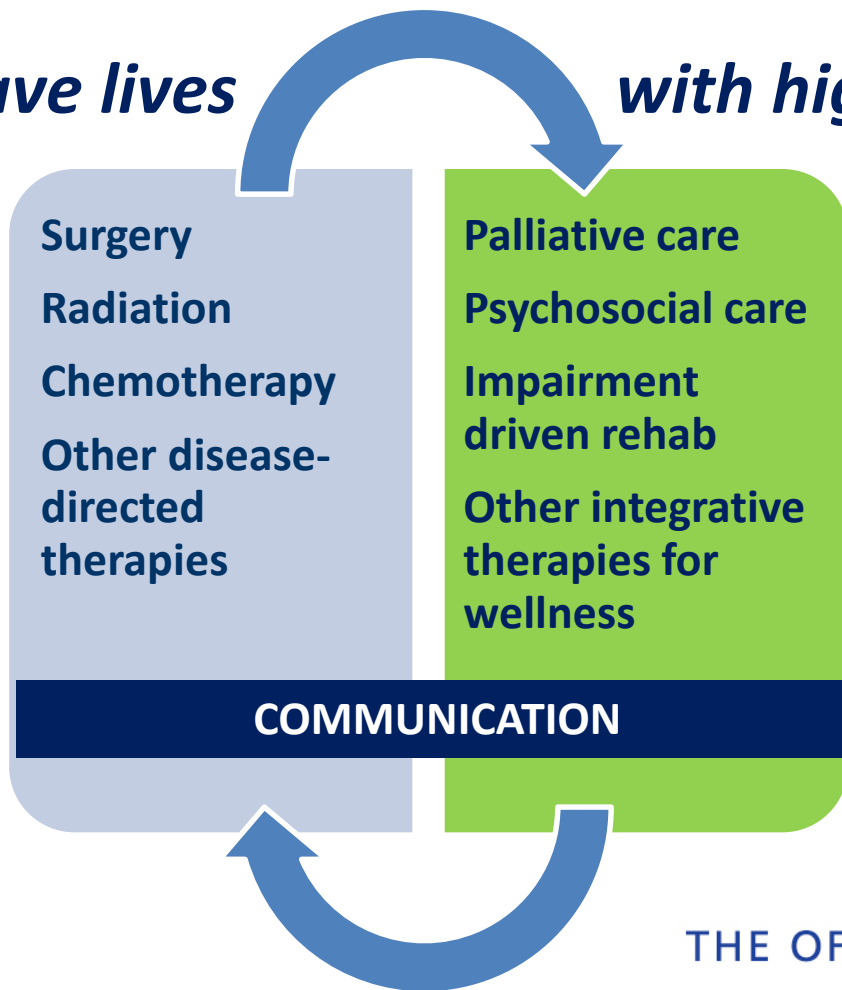
for *any age* and *any stage* and for *all audiences*



Quality cancer care

Save lives

with high quality of life...



For all adults and children at any age and any stage

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Key partners



Research: Funding dedicated palliative care and symptom management research grants while building next generation of clinical researchers and collaborative community for the work.

npcrc.org



Programs: Technical assistance, training, and resources for palliative care teams and generalist practitioners at every stage, including tools to achieve new quality standards.

capc.org



Advocacy: New QOL campaign and coalition addressing research, workforce and access barriers through federal and state legislation.

acscan.org/qualityoflife & patientqualityoflife.org

What's in a name?

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.***

Definition developed through consumer research commissioned by CAPC and the Society/ACS CAN. Shareable summary of findings available at www.capc.org

Treat 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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Bring quality of life and care together for the millions of families facing cancer.



acscan.org

~~Radiation~~



People Want Palliative Care

Once informed about palliative care:

- **95%** say patient & family education about palliative care as part of treatment is important
- **92%** would be likely to consider palliative care for themselves or their families
- **92%** also said they believe patients should have access to palliative care at hospitals nationwide

Data from CAPC/ACS Public Opinion Strategies national survey of 800 adults conducted June 2011. www.capc.org

Better QOL and survival

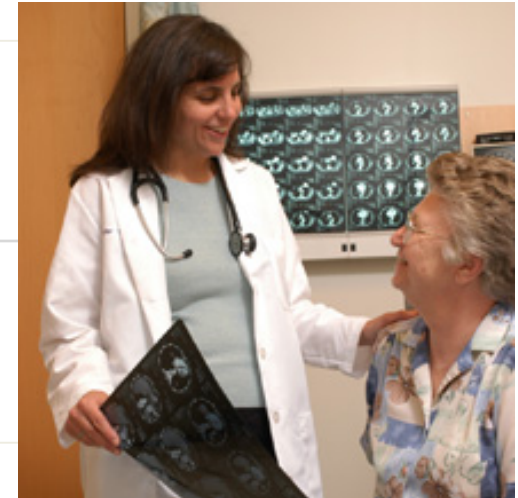
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August 18, 2010

Palliative Care Extends Life, Study Finds

By DONALD G. McNEIL Jr.



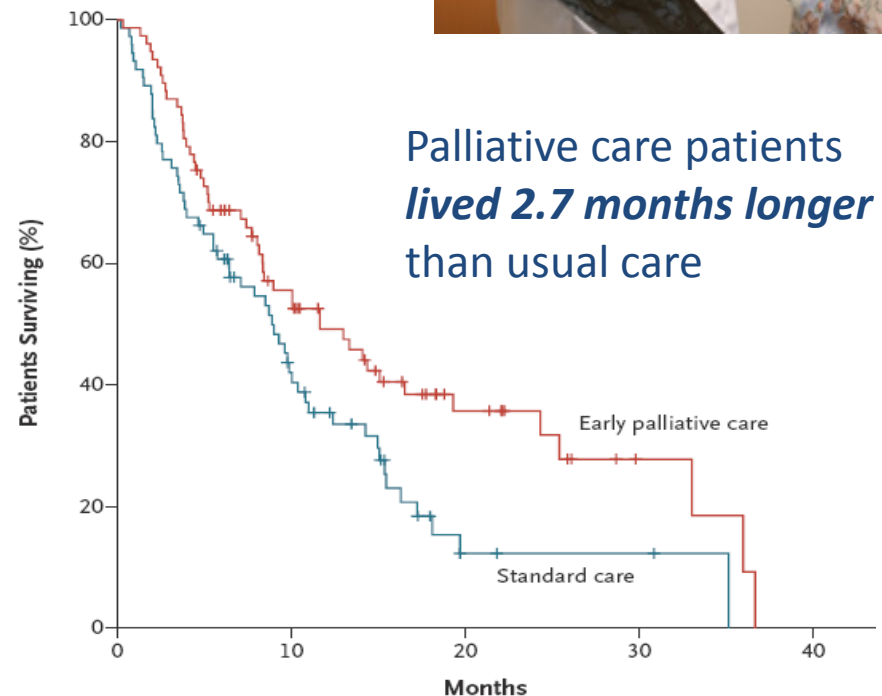
THE NEW ENGLAND JOURNAL OF MEDICINE

ORIGINAL ARTICLE

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

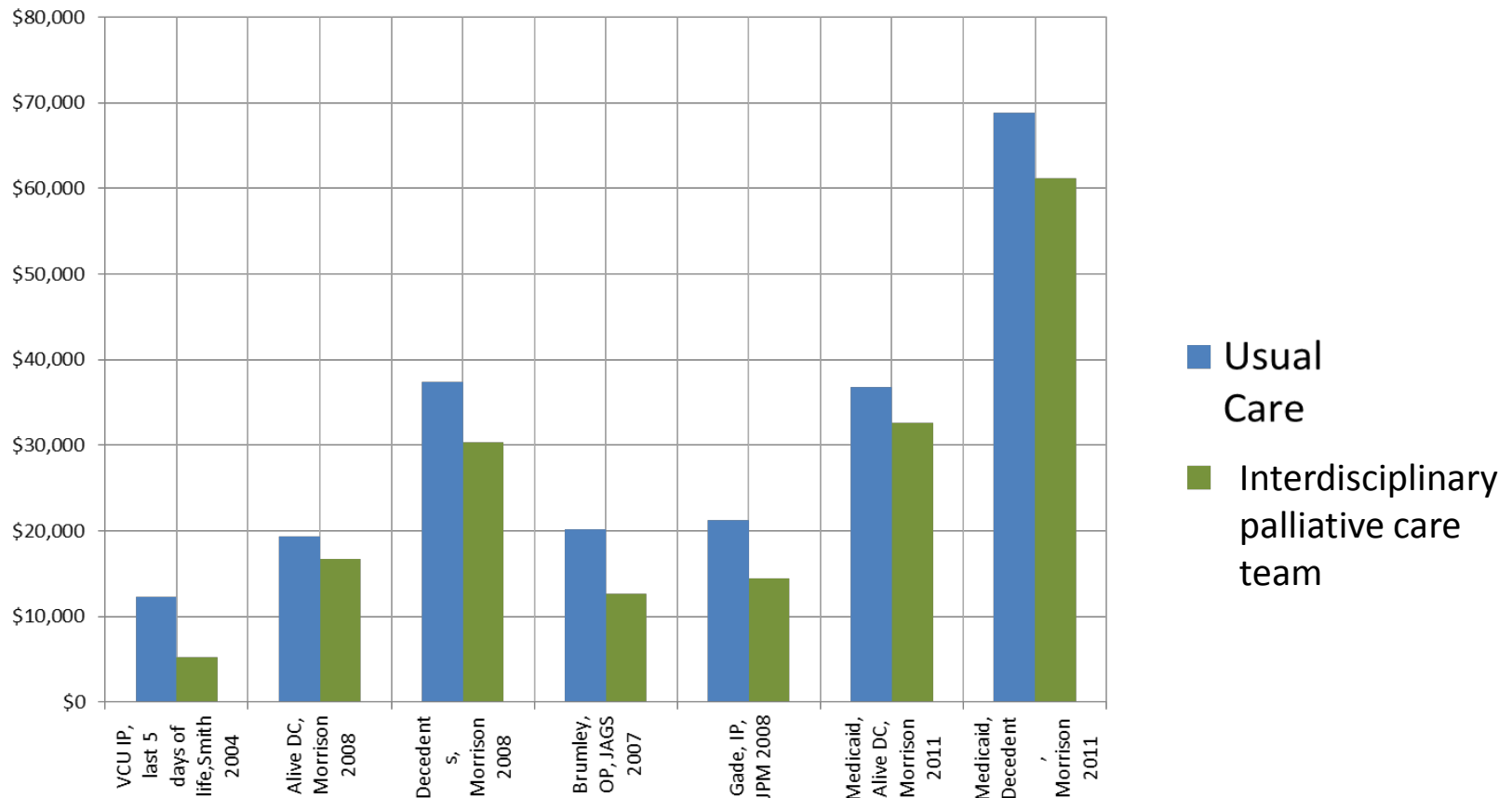
Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D.,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

Temel NEJM 2010

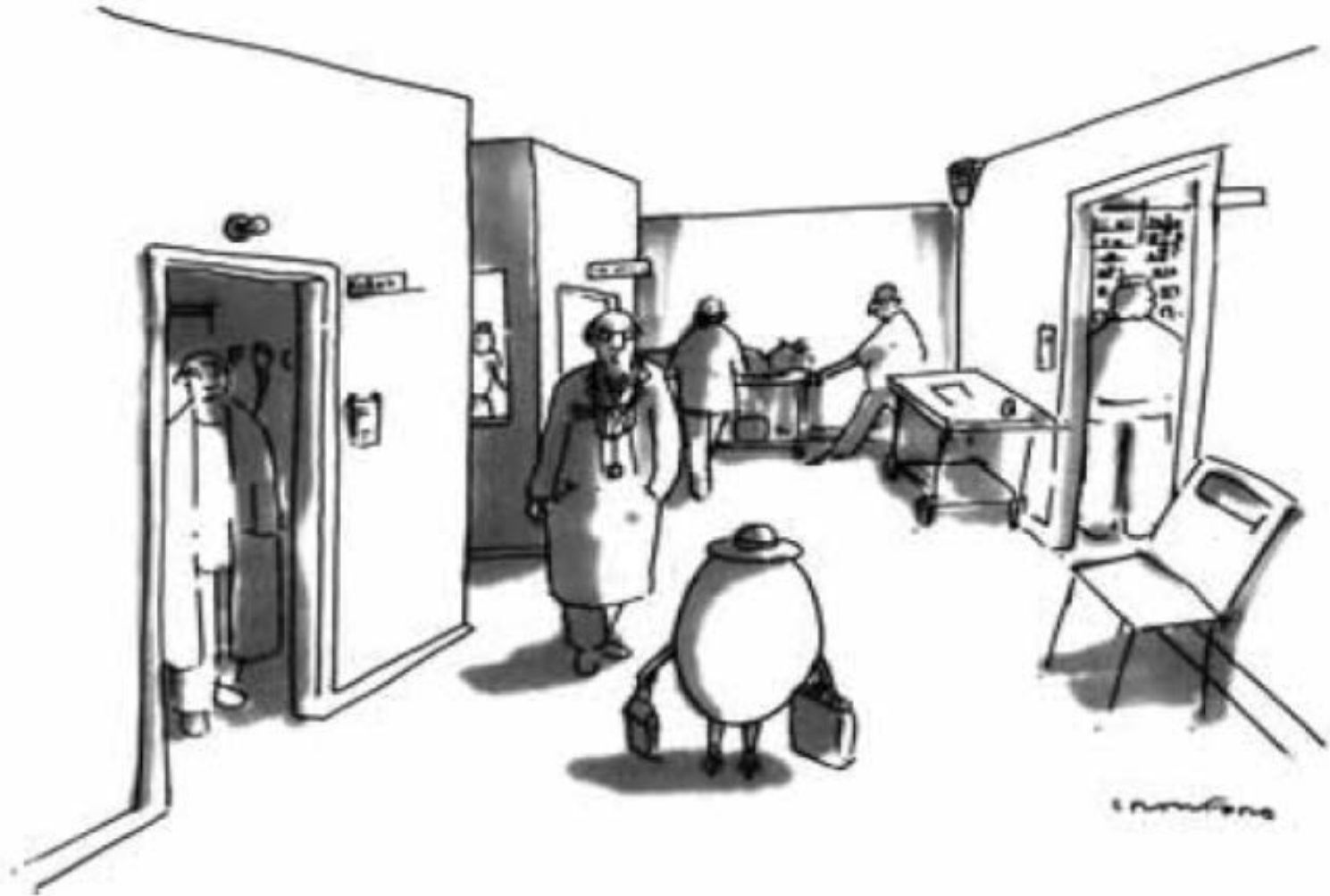


And reduced costs

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



Who provides palliative care? Everyone.



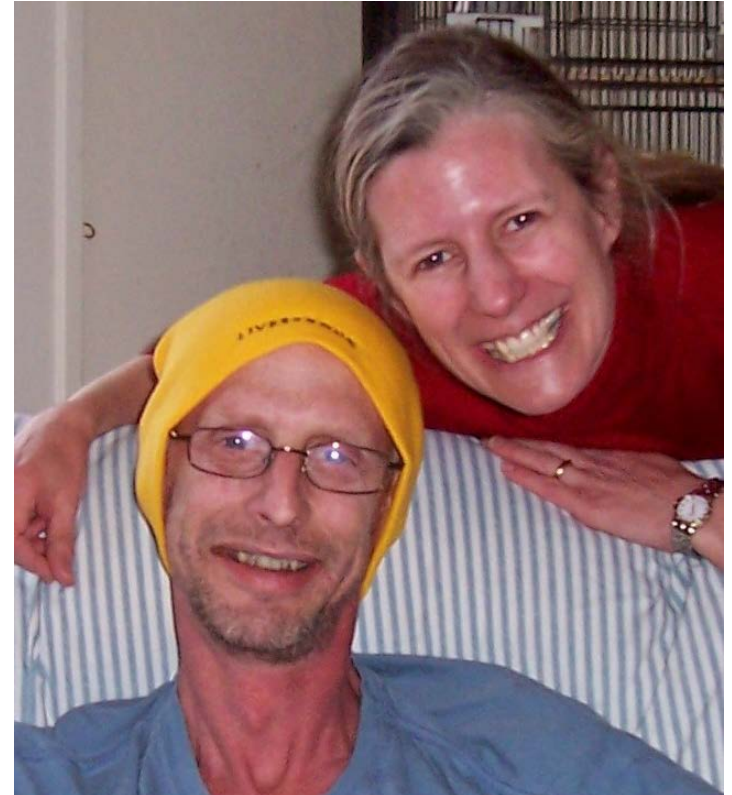
"You might want to sit down, Mrs. Dumpty."

Goal: Survival with High QOL

1. All **patients and families** will know about palliative care and be empowered to request it
2. All **healthcare professionals** will have the knowledge and skills to provide palliative care
3. All **healthcare institutions** will be able to support and deliver high quality palliative care

How Do We Get There?

- Address misconceptions
- Improve access and quality
- Build the workforce
- Expand the evidence base



Bring palliative care everywhere!

Advance QOL national movement

ADVOCACY



Federal legislation

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

State palliative care model legislation

Promoting balance in federal and state pain policies

For campaign information: www.acscan.org/qualityoflife
For coalition information: www.patientqualityoflife.org



Improving Quality of Life for Children with Cancer



Cancer is the leading cause of death by disease in the United States for children ages 5 to 14, with approximately 16,000 children ages 0 to 19 facing a diagnosis this year.¹

Research has improved treatments and boosted survival in some types of pediatric cancer, but treatment toxicities still cause a majority of children to experience distressing side effects and late effects — conditions that often cause significant suffering that continues into adulthood and can last a lifetime.²

Additional scientific research is essential to drive advances in childhood cancers that remain deadly, and to improve quality of life and minimize symptoms for the more than 379,000 childhood and adolescent cancer survivors living in the US today.

Pediatric Palliative Care Improves Quality of Life for Children and Families

- Adding an extra layer of support. For most children and their families, treating the pain, stress, and other symptoms of cancer is as important as treating the disease.³ Consequently, pairing pediatric palliative care with delivery of anti-cancer therapies has emerged as the new model for optimal comprehensive care that focuses on the quality of life for the child and family as an essential aspect of managing the disease.^{4,5}
- Team-based comprehensive care. Pediatric palliative care is provided by a team of doctors, nurses, social workers, child life specialists, and others who partner with a child's oncologists and other clinicians to relieve the child's symptoms, help with communication and coordination of care, and ensure the child and family have the physical, emotional, and mental strength to carry on with daily life.⁶
- Surviving and thriving. Pediatric palliative care is appropriate at any age or stage of disease, and can be provided along with treatments meant to cure. Recognizing palliative care's benefits to children and their families, the American Academy of Pediatrics has recently called for integration of early pediatric palliative care as an essential aspect of providing optimal treatment, beginning at the time of diagnosis and continuing along the child's course of care.⁷

Quality of Life Campaign: Expanding Access for Families to Integrated Pediatric Palliative Care

Access to pediatric palliative care is improving, but must be expanded. The number of pediatric palliative care teams in ambulatory and hospital settings is on the rise, but the level of services and staffing available varies considerably across the country.⁸

ACS CAN's Quality of Life Campaign (acscan.org/qualityoflife), in partnership with the Patient Quality of Life Coalition, is focused on expanding workforce training and access to integrated palliative care services for all adults and children facing serious illness — at any age or stage — so these patients and families can benefit from the most comprehensive care possible.

- The Patient Centered Quality Care for Life Act (H.R. 1666) would increase palliative care research grants, expand primary palliative care skills training for clinicians across multiple disciplines, and educate the public, practitioners, and insurance providers about palliative care and its benefits in delivering better health and better care at lower cost across the entire care continuum.
- The Palliative Care and Hospice Education and Training Act (H.R. 1339 / S. 641) would expand specialized palliative care training and support through leadership centers and medical and nursing school faculty development, and create essential incentives for health professionals to teach and/or practice integrated palliative care.

¹ American Cancer Society. *Cancer Facts & Figures 2014 Special Section: Cancer in Children & Adolescents*. <http://www.cancer.org/qualityoflifecampaign/researchdocuments/childrenandadolescents-2014.pdf>

² Hudson MA, Hays IX, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA* 2013;309:2371-2381.

³ Collins L. Because statistics don't tell the whole story: a call for comprehensive care for children with cancer. *CAC: A Cancer Journal for Clinicians*. (2014) doi: 10.3323/cac.2014.01.01

⁴ Goodman L. *Living Well Ordinary*. The New Yorker. Jan. 20, 2014.

⁵ Waldman E. Palliative care for children with cancer. *Seminars in Oncology*. 2013;40:10100-7.

⁶ What is Pediatric Palliative Care. <http://www.patientqualityoflife.org/what-is-pediatric-palliative-care/>

⁷ American Academy of Pediatrics. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics* 2013;132:966-972.

⁸ Neuhoff, G, et al. Pediatric Palliative Care Programs in Children's Hospitals: A Cross-Sectional National Survey. *Pediatrics* 2013; 131.6: 1063-1070.

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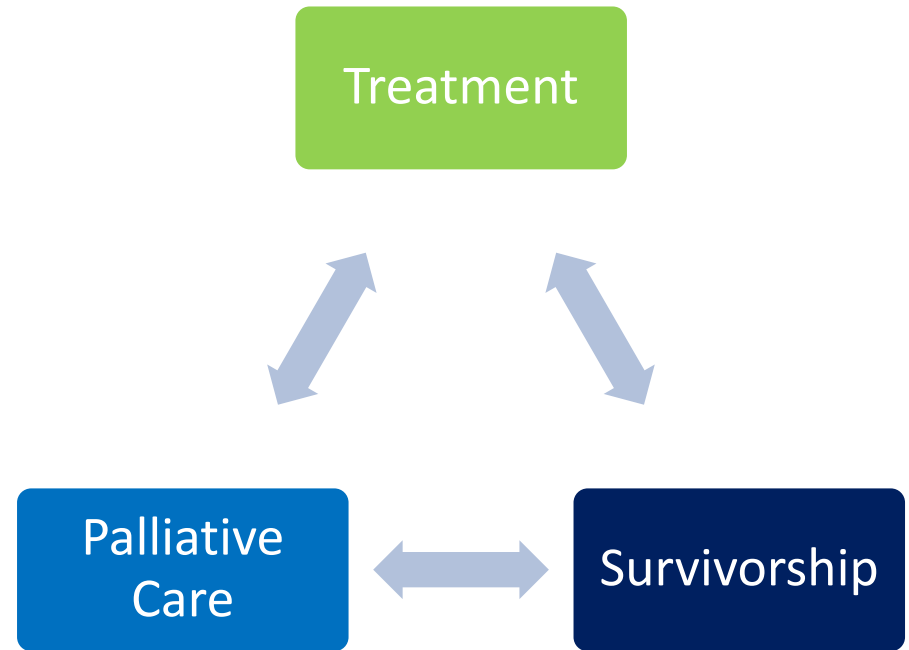


Paired with health system engagement



Health system staff =

Boots on ground partners for palliative care integration efforts



Initial deployment strategy: Engage all adult and pediatric hospitals/cancer centers

Steady drumbeat, same QOL message



Putting Pediatric Palliative Care in Prime Time Improving Quality of Life for Children with Cancer

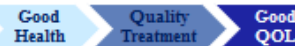
Rebecca Kirch, JD¹, Diane Meier, MD² and Christina Ullrich, MD, MPH³

¹American Cancer Society, Washington, DC; ²Icahn School of Medicine at Mount Sinai School, New York, NY; ³Dana Farber Cancer Institute, Boston, MA



Background

QUALITY TREATMENT =
QUALITY CANCER-DIRECTED TREATMENT + CONCURRENT PEDIATRIC PALLIATIVE CARE



- 380,000 childhood and adolescent cancer survivors are now living in the US, with 15,780 new cancer cases and 1,960 deaths expected this year. 1 in 530 adults aged 20 to 39 are childhood cancer survivors.
- Research has improved treatments and boosted survival in some types of pediatric cancer, but treatment toxicities still cause a majority of children to experience distressing side effects and late effects—conditions that often cause significant suffering that continues into adulthood and last lifetimes.
- For these children and their families, treating the pain, symptoms and stress of cancer is as important to them as treating the disease.
- Pairing pediatric palliative care with delivery of anti-cancer therapies has emerged as the new model for optimal comprehensive cancer care that focuses on the quality of life for the child and family as an essential aspect of managing the disease.

Methods

- A national telephone survey was conducted in June 2011 among 800 adults age 18+ to develop effective messages and provide a roadmap for communicating with consumers and policymakers on the benefits and future direction of palliative care
- In addition, an American Childhood Cancer Organization online survey completed in October 2014 by 275 parents of pediatric cancer patients asked about their pediatric palliative care knowledge, experience and preferences regarding its availability as part of comprehensive cancer treatment.

Results

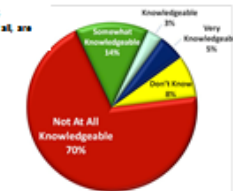
OVERCOMING THE IDENTITY PROBLEM

- Palliative care is a relative unknown among consumers (92% really don't know what it is), yet many providers still associate palliative care with terminal prognosis and believe it is relevant only near the very end of life.
- These misconceptions—associating it with “giving up hope,” EOL or hospice remain one of the biggest barriers that keep patients and families from accessing palliative care's benefits.
- How you define palliative care has a big impact on how people feel about it. People understand and want palliative care if we use their own words to describe it.



Consumer Awareness

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



“Give us the words to use to get the care we need”

KEY MESSAGES TO INTRODUCE AND EXPLAIN CONCURRENT PALLIATIVE CARE:

- Palliative care helps to provide the best possible quality of life for patients and their families.
- Palliative care helps patients and families manage the pain, symptoms, and stress of serious illness.
- Palliative care is a partnership of patient, medical specialists, and family.
- Palliative care provides an extra layer of support for families and patients with serious illness.
- Palliative care is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

Summary of consumer research findings available at www.ccpcc.org

CHILDREN AND FAMILIES WANT WHAT PEDIATRIC PALLIATIVE CARE DELIVERS

- Using consistent and clear consumer-tested messages to explain palliative care really matters
- Once people understand what palliative care is, they have an extremely positive feeling about this type of care:
 - ✓ 95% say patient & family education about palliative care as part of treatment is important
 - ✓ 92% would be likely to consider palliative care for themselves or their families
 - ✓ 92% also said they believe patients should have access to palliative care at hospitals nationwide
- A majority of the 275 parents of pediatric cancer patients responding to the October 2014 survey (preliminary findings) that used the same consumer-tested key messages and definition explaining concurrent palliative care reported similar positive feelings:

Q: Considering this definition, how likely, if at all, would you be to consider pediatric palliative care for your child during cancer treatment?

How likely?	Percentage
Very likely	26%
Likely	68%
Unlikely	6%
Not likely	2%

Q: How important do you think it is that hospitalized pediatric patients receive the most available EOL (End-of-Life) services for children in the U.S. and their families?

How important?	Percentage
Very important	25%
Important	68%
Not important	6%
Not at all important	2%

PEDIATRIC PALLIATIVE CARE RESOURCES

- Brochure explains pediatric palliative care and its benefits as an integral part of cancer treatment and survivorship care
- Includes palliative care definition from consumer research
- A new book about pediatric palliative care for families will soon be available from the American Childhood Cancer Organization (acco.org)
- Brochure and related short video are available for free download at: www.cancer.org



Future Directions

Pediatric palliative care is positioned to play a prominent role in addressing the challenges of childhood cancer and survivorship across the continuum:

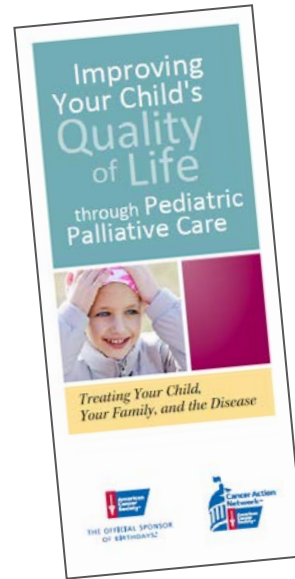
- Additional focused research is essential to improve quality of life and minimize impact of symptoms, toxicities, and late effects for all childhood cancer patients, survivors, and their families.
- Expanding access to pediatric palliative care services in ambulatory and hospital settings is essential to improve consistency in the level of services and staffing available to children and their families across the country.
- Practitioner advocacy and engagement in advancing the palliative care public policy agenda will be instrumental in expanding workforce training and access to integrated palliative care services for all seriously ill adults and children so these patients and families can benefit from the most comprehensive cancer care possible. Campaign information is available at: www.accoan.org/qualityoflife

PPC becoming a key standard of practice

100% of the U.S. News 2014 – 2015 Honor Roll Children's Hospitals Have Palliative Care Services

- Ann and Robert H. Lurie Children's Hospital of **Chicago**
- **Boston** Children's Hospital
- Children's Hospital Colorado, **Aurora**
- Children's Hospital **Los Angeles**
- Children's Hospital of **Philadelphia**
- Children's Hospital of **Pittsburgh** of UPMC
- **Cincinnati** Children's Hospital Medical Center
- Johns Hopkins Children's Center, **Baltimore**
- Nationwide Children's Hospital, **Columbus**, Ohio
- Texas Children's Hospital, **Houston**

Resources



COURAGEOUS PARENTS NETWORK

Empowering parents caring for children with life-limiting illness.

View the new ACS video at:
<https://www.youtube.com/watch?v=9GRI9r6eIJ0>

- Quality of Life info resources
 - ✓ ACS video, brochure, fact sheet (cancer.org/childhood and acscan.org/qualityoflife)
 - ✓ American Childhood Cancer Organization pediatric palliative care book (acco.org)
 - ✓ Courageous Parents Network (courageousparentsnetwork.org)
- Institute of Medicine March 2015 workshop on comprehensive childhood cancer care
- ACS publications: Facts & Figures 2014 ; CA A Cancer Journal for Clinicians article series



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

Changing the Culture of Communication



Partnering to equip clinicians...

while empowering patients and families.



VITALtalk



Mastering tough conversations
oncology workshops

Access tools for clinicians and faculty
www.vitaltalk.org



Access the decision support tool for patients
www.prepareforyourcare.org

Survive and thrive



Q&A

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