STARTING THE CONVERSATION: HOW TO INCREASE PALLIATIVE CARE AWARENESS, KNOWLEDGE AND ACCESS FOR CANCER PATIENTS

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Objectives

1) Identify the role of palliative care in cancer care
2) Address barriers to palliative care
3) Outline ways in which patient care is improved by early palliative care

Palliative Care in Oncology

- ASCO published a special article regarding palliative care in oncology in 1998
- ASCO definition:
  - Palliative care is focused on the **relief of suffering**, in all of its dimensions, *throughout the course* of a patient's illness.
  - Palliative management focuses on the care of patients with advanced illness or a significant symptom burden by emphasizing:
    - medically-appropriate goal setting
    - honest and open communication with patients and families
    - meticulous symptom assessment and control

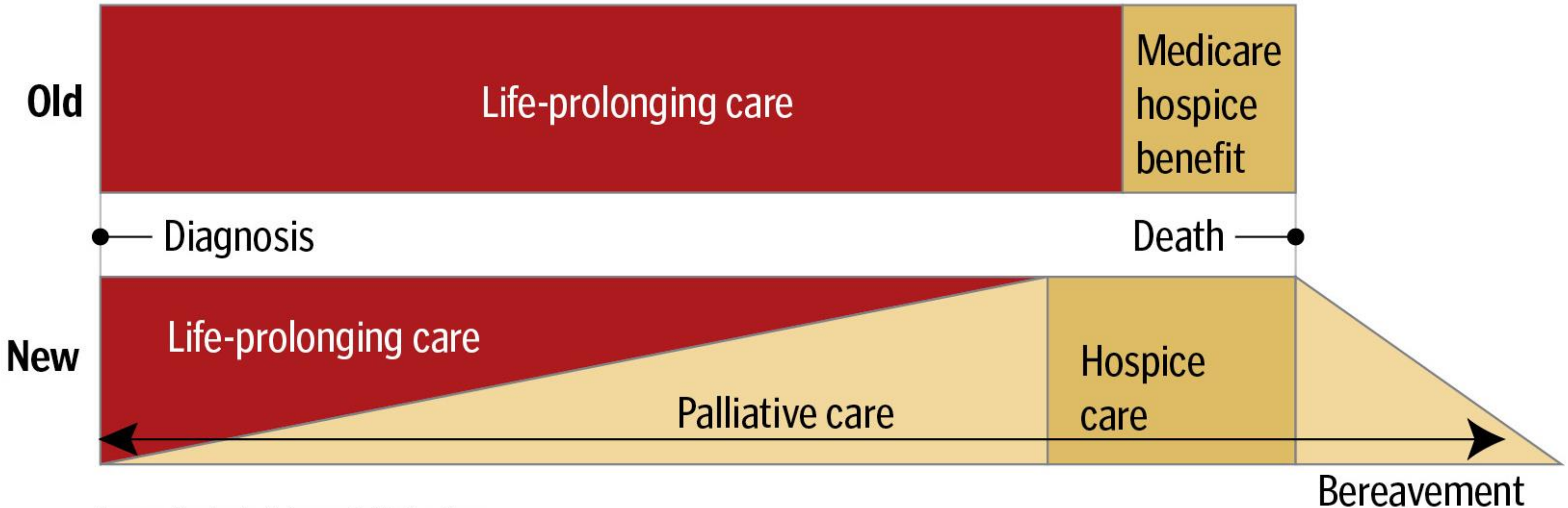
Are cancer patients informed about palliative care as an option?

Oncologists' Perception of PC

- Qualitative study of 74 medical oncologists in academic medical centers with PC clinics revealed that there were 3 main barriers to PC, two of which were:
  - Persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy
  - Predominant belief that providing palliative care is an integral part of the oncologist's role
  - Lack of knowledge of locally available resources

-Schenker et al., J Onc Practice vol 10, issue 2, 2014: e37-e43

PALLIATIVE CARE MODELS



Old

Life-prolonging care

Medicare hospice benefit

Diagnosis

Death

New

Life-prolonging care

Palliative care

Hospice care

Bereavement

Source: Center to Advance Palliative Care

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Quality palliative cancer care “requires access to and availability of state-of-the-art palliative cancer care rendered by skilled clinicians, buttressed when necessary by palliative care experts.”

-Ferris, et al. Palliative Cancer Care a Decade Later: Accomplishments, the Need, Next Steps-From the American Society of Clinical Oncology. *JCO* 27 (18); 2009: 3052-3058

Primary Palliative Care

- Basic management of pain and other symptoms
- Basic management of depression and anxiety
- Basic discussions about prognosis
- Establishing or clarifying goals of treatment
- Addressing suffering
- Determining code status

Specialty Palliative Care

- Management of ***refractory*** pain or other symptoms
- Assistance with ***conflict resolution*** regarding goals or methods of treatment:
    - within families
    - between staff and families
    - among treating teams
- Management of ***more complex*** depression, anxiety, grief, and existential distress
- Assistance in addressing cases of ***non-beneficial treatment***

ASCO's 2012 "Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care"

Recommendation: Concurrent palliative care with standard oncologic care from initial diagnosis for patients with metastatic cancer or high symptom burden.

You are here

WE WANT YOU!

Why do we need to educate others about palliative care?

1) Patients don’t know what palliative care is

In 2011, the ACS and ACS-CAN asked CAPC (Center to Advance Palliative Care) to query the public:

- ***Only 8%*** of those surveyed were “knowledgeable” or “very knowledgeable” about palliative care
- 70% were “not at all knowledgeable”

Conclusion: The term palliative care has little or no meaning to consumers. Many ***inside the industry*** frame it as end of life care or hospice. Barriers include lack of awareness and physician attitudes about palliative care.

-www.capc.org

2) When patients understand what palliative care is, they want it!

After being given the scripted CAPC definition of palliative care,

- 95% of respondents agree that it is important that patients with serious illness and their families be educated about palliative care.
- 92% of respondents say they would be likely to consider palliative care for a loved one if they had a serious illness.
- 92% of respondents say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.

3) Americans are unlikely to engage in advance care planning without facilitation.

- 94% of Americans agree that having a conversation about EOL wishes is important BUT…

only 1/3 of Americans have had a discussion.

-*Conversation Project* survey

- Of surveyed Americans who had not done ACP…
  - 25% didn't think it necessary ("not sick yet")
  - 20% thought they'd upset their loved ones ("not the right time")
  - 17% didn't know how to start the conversation

-*Conversation Project* survey 2013

- Difficult to predict the many future scenarios
- Perception that executing an AD is difficult

-DHHS report 2008

And they are right about ADs…

A 2011 review of advance directive legal statutes for all 50 states showed that laws in all states were:

1) written above the 12th grade reading level,
2) restricted surrogates in 40 states, and
3) had execution requirements to produce a legally valid form

- The reviewers concluded that unintended negative consequences of the legal restrictions would disproportionately affect vulnerable patients and prevent them from having their EOL wishes carried out.
- They recommended to improve readibilty, allow oral directives, and eliminate witness or notary requirements.
    - Castillo, Lesley, et al. Ann Int Med 2011: 154 (2) 121-128

4) Preparation for EOL improves outcomes.

- Patients with cancer are more likely to receive EOL care that is consistent with their preferences when they have had the opportunity to discuss their wishes for EOL care with a physician. They also experienced less physical distress.

-J Clin Oncol. 2010; 28:1203-1208

- Patients with advanced cancer who reported having EOL conversations with physicians had significantly lower health care costs in their final week of life. Higher costs were associated with worse quality of death.

-Arch Intern Med. 2009;169(5):480-488

- Patients who were treated by oncologists who underwent a 2-day communication training had patients who rated them more highly in the following domains: emotional support, setting up a supportive environment, and ability to deliver information. Patients were also less depressed.

-J Clin Oncol, 2014 Jul 10;32(20):2166-72

5) Addressing EOL Wishes Doesn’t Diminish Hope: It Promotes Autonomy and Invites Reframing Hope

- EOL discussions were associated with less aggressive medical care near death and earlier hospice referrals (and NOT associated with an increase in MDD or “worry”)
- Aggressive care was associated with worse patient quality of life and worse bereavement adjustment.

-JAMA. 2008; 300(14):1665-1673

- 93% of surrogates of ICU patients felt that avoiding EOL/prognosis discussions was an unacceptable way to maintain hope. This knowledge helped surrogates prepare emotionally and logistically for death. *-Ann Intern Med 2008; 149:861-868*
- A study of CPR preferences in patients with advanced cancer showed that viewing a video decision support tool resulted in fewer patients opting for CPR (pre=49% v. post=20%) compared to patients hearing a verbal script (pre=54% v. post=48%) *-JCO 2012; 31:380-386*

6) Concurrent Palliative Care Does Not Shorten Life

- Retrospective review of 4,493 Medicare patients—those
  an
  - 2006
- ng
  - -742
- no
  enrolled earlier in palliative care.
  - Bakitas, et al. JCO 2015, 33(13): 1438-1445

> “Perhaps unsurprisingly, reducing patients’ misery may help them live longer.”
>
> -Diane Meier, MD

7) Patient Understanding Improves

- Many cancer patients believe that they suffered from a potentially preventable harmful event during their cancer treatment.

- 47% believed one of the following communication errors occurred:
  - Not being told about treatment options
  - Inaccurate information being provided
  - Clinician not listening to the patient
    - Mazor, et. al. JCO 2012; 30(15): 1784-1790

- 25% of patients at time of diagnosis of a solid malignancy misunderstood the goal of their chemotherapy treatment
  - Of the patient-physician dyads that were discordant, 66% of patients believed they were being treated for cure when physicians reported the goal was non-curative.
    - Lennes, et al. *Cancer* 2013: 691-699

- When patients with newly-diagnosed NSCLC were randomized to receive either early palliative care with standard oncology care vs. standard oncology care alone,
  - Pts with PC were more likely to become accurate in their perceptions that their cancers were not curable (83% v 60%)
  - Pts with PC were less likely to receive IV chemo within 60 days of death (9.4% in PC group v 50% in standard group)
    - Temel, et al. *JCO* 2011; 29(17): 2319-2326

8) Patient Quality of Life Improves

- ENABLE II RCT showed higher QOL, lower symptom intensity, and lower depressed mood in the intervention arm.

-Bakitas, Maire et al. *JAMA* 2009; 302 (7): 741-749

- JCO study in 2009 showed patients receiving outpatient palliative care consultation had:
  - 10% improvement in overall symptom control (for 10 symptoms, including pain)
  - 15% improvement in patient satisfaction
- A study by Zimmermann showed that early PC outpatient consultation improved symptoms and patient satisfaction in all instruments by 4 months of intervention.

-*Lancet* 2014; 383: 1721-1730

9) PC is a solution to our health care crisis.

Bending the Cost Curve
in Cancer Care:

Clinical trials comparing usual oncologic care to palliative cancer care have shown:

- Cost savings
- Reduced hospital stays

- Smith, *NEJM* 2011

10) We have to!

ASCO special article in 2009 outlined ASCO’s vision of comprehensive cancer care by 2020:

- Identified effective palliative cancer care requiring an IDT that can provide care in ALL patient settings
- Called for changes in current policy, drug availability, and education
- Consistent palliative cancer care is delivered from the day of diagnosis
- Palliative cancer care is an integral part of oncology fellowship training and the certification examination

- In 2011, Governor Paterson signed into law The New York Palliative Care Information Act, which requires physicians who treat patients with terminal illnesses to offer them or their representatives information about:
    - Prognosis
    - Range of options appropriate to the patient
    - Risks and benefits of various options
    - Patient's "legal rights to comprehensive pain and symptom management at the end of life“
- NCCN (National Comprehensive Cancer Network) released “Guidelines for Supportive Care: Palliative Care” in 2012 that stated “institutions should develop processes for integrating palliative care into cancer care, with appropriate screening, educational programs, and quality monitoring.”

- ACS Commission on Cancer’s “Cancer Program Standards 2012: Ensuring Patient-Centered Care” includes a standard that mandates the availability of palliative care on site or by referral. EOL care is measured annually to ensure IP admissions and ED visits during the last 30 days of life and chemo provided last 14 days of life are within national benchmarks.
- Institute of Medicine (IOM) has included palliative care in 6 reports as an essential component of quality health care. In the 2014 report on *Dying in America,* the recommendation is that “all people with advanced serious illness should have access to skilled palliative care.”

-IOM Report Dying in America, Key Findings and Recommendations

We have work to do…

Conclusion

- Early concurrent palliative care in cancer care is the gold standard for comprehensive cancer care.
- Integrating palliative care can only be achieved by improving 1) public awareness and 2) both primary and specialty palliative care education of current and future health care workers.
- We have made a great deal of progress, but we still have a long way to go in order to improve access to quality palliative care for every patient.

Helpful Resources

- www.capc.org
- www.vitaltalk.org
- www.getpalliativecare.org
- www.theconversationproject.org
- www.palliativedoctors.org
- www.hpna.org
- www.aahpm.org
- www.swhpn.org