National Cancer Policy Forum:
Strategies for Communicating About Palliative and End-of-Life Care

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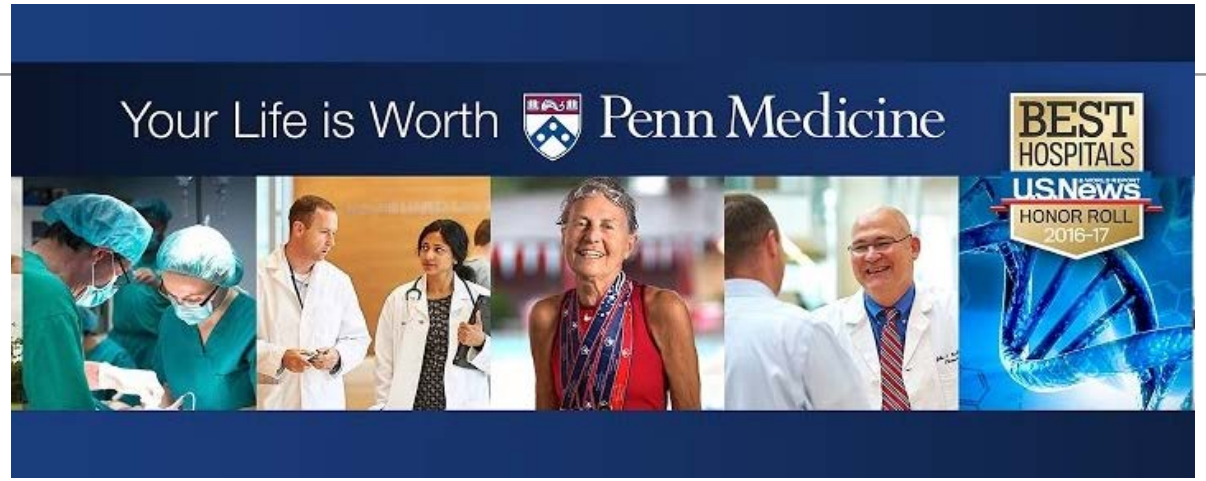
Penn Medicine


Your Life is Worth
Penn Medicine
BEST HOSPITALS
U.S.News
HONOR ROLL
2016-17


NEXT TO CREATING A LIFE, THE FINEST THING A MAN CAN DO IS SAVE ONE.
— ABRAHAM LINCOLN
PENNSTAR
Penn Medicine


ABRAMSON CANCER CENTER
PHILLY FIGHTS CANCER


the cure is within
ABRAMSON CANCER CENTER

Key Questions

- **What are the challenges to communication about palliative and end-of-life care? Why is this so difficult to bring up?**
- **How can we ensure that 100% of cancer patients have a conversation about their goals, values, and end-of-life preferences?**
- **What are scalable models for integrating palliative care in cancer care?**

What Is Palliative Care?

- Specialized medical care for patients with serious illness
- Expert pain and symptom management
- Emotional support and assistance with coping
- Advance care planning and end of life discussions
- Partnership with a patient's other doctors

Available anytime during a cancer journey as "an extra layer of support", regardless of other treatments.

Source: Center to Advance Palliative Care

Palliative Care Is Not the Same as Hospice Care

Palliative Care	Hospice Care
A consultative specialty provided in hospitals, clinics, and the community	All-inclusive care for patients with a terminal illness
Available anytime during a serious illness	Must have prognosis less than 6 months
Can still receive chemotherapy, radiation, surgery, clinical trials, rehab	Comfort care only; does not usually include life-prolonging therapies

Palliative Care Needs Change Over Time

40% emotional support
30% coping skills
30% symptom management

50% advance care planning
30% symptom management
20% emotional support

60% end-of-life decision making
20% emotional support
20% symptom management

100% family counseling and bereavement care

Palliative care may also be helpful to patients with high chance of cure.

Palliative Care Improves Cancer Outcomes

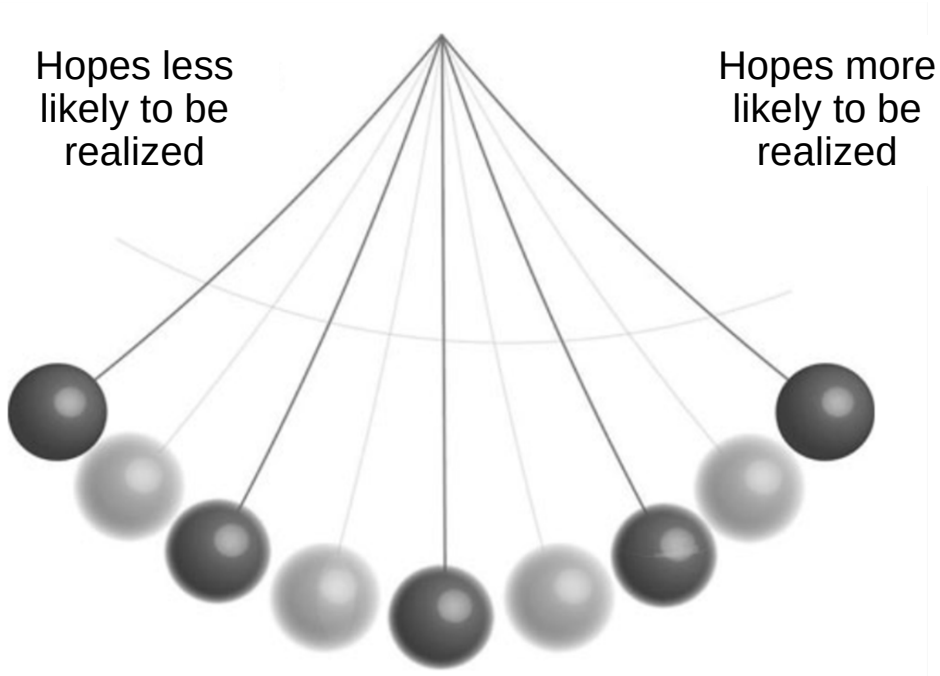
- **Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer;** *Temel et al, 2010*[1]
  - Patients who received palliative care integrated with standard cancer care had higher quality of life, more hospice care, and longer survival

- **Palliative Care Consultation During Stem Cell Transplant for Acute Leukemia;** *El-Jawahri et al, 2019*[2]
  - Patients who received palliative care had lower levels of anxiety and depression during the transplant, and less PTSD after transplant

[1]Temel J et al. NEJM. 2010;363:733-42. [2]El-Jawahri A et al. J Clin Oncol. 2019;35:3714-21.

Common Misconceptions Create Barriers

Palliative Care = **Hospice Care** = **Giving Up** / **Hastening Death**



"He's a fighter…"

"I want to stay positive…"

"Don't take away hope"

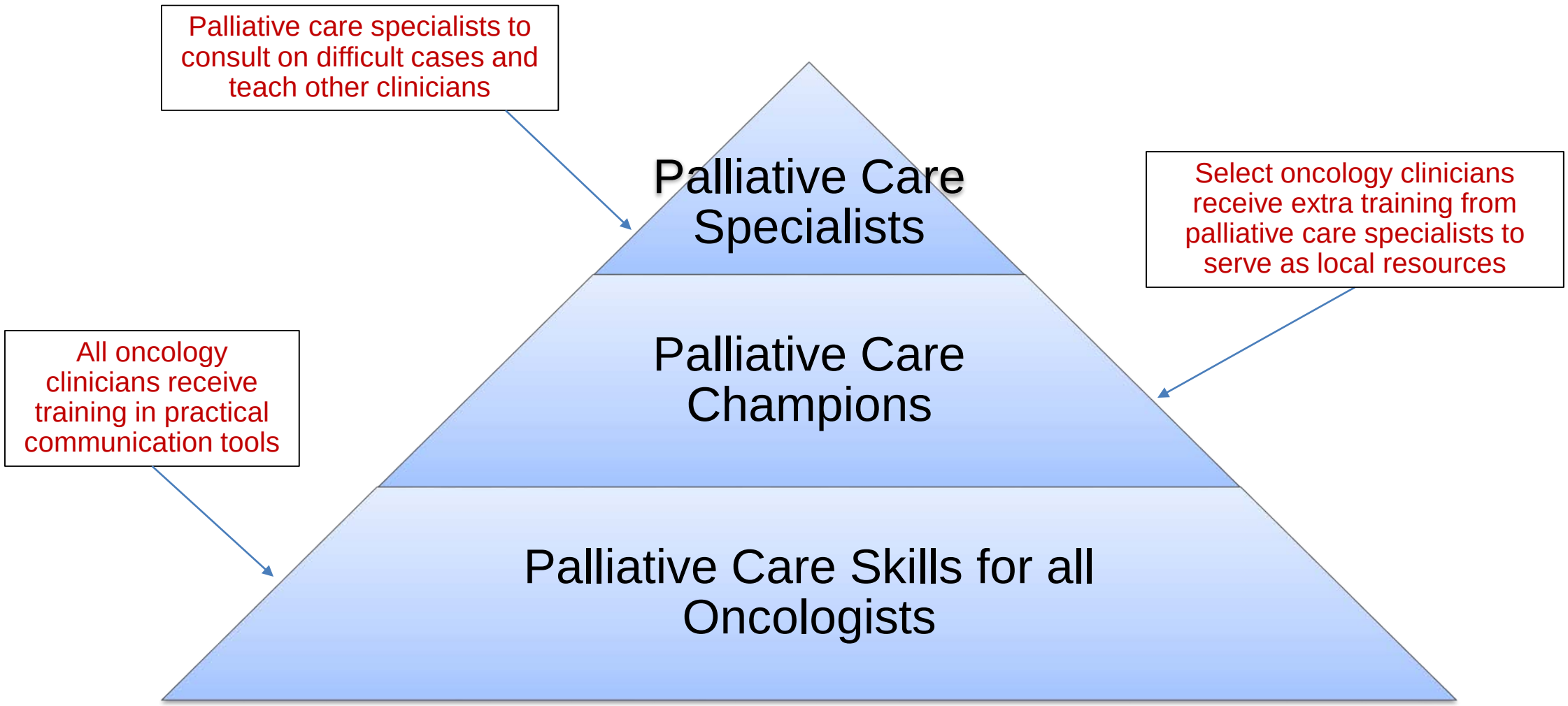
Jacobsen J et al. J Pall Med. 2014;17:463-469.

Systems Issues Also Create Barriers

- Very few physicians have received **formal training** in communication about palliative care and end-of-life planning[1]
- **Clinical pressures** create barriers to prolonged patient-centered discussions about end-of-life preferences
- A **national workforce shortage** limits the availability of palliative care specialists to care for patients and teach others
  - Estimated shortage of 2787-5810 FTE[2]
  - Only 300 palliative care fellows graduate annually

[1]Horowitz R et al. Medical Education. 2014;48:48-65. [2]Lupu D. J Pain Symptom Manage. 2010;40:899-911.

Palliative Care for Cancer: Towards a Scalable Model



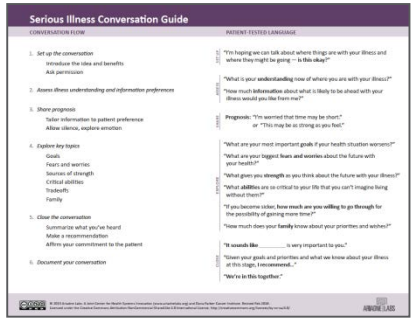
Practical Communication Strategies for Cancer Centers

- **Co-locate** palliative care and oncology clinicians
- Create **pathways** in which all patients have a conversation about their end-of-life preferences
- Promote **simple patient-centered communication tools** with corresponding documentation tools in the electronic health record
- **Track** which patients have not had a conversation

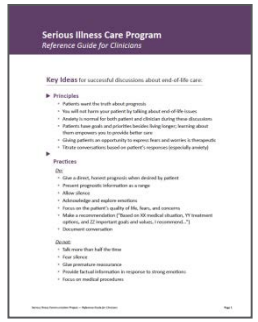
Serious Illness Conversation Program at Penn

Collaboration with Ariadne Labs and Harvard School of Public Health

Tools

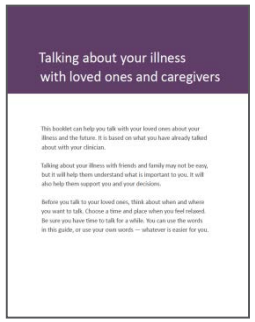


Serious Illness Conversation Guide



Clinician Reference Guide

Patient preparation materials



Family Comm. Guide

Training

Train and Coach Clinicians

3-hour clinician training
1 month post-training coaching

Systems Changes

Patient Identification → **Patient Preparation** → **Conversation Using the Guide** → **Document in PennChart** → **Retrievable Across Sites**

Measurement and Improvement

Penn Patient Experience of Serious Illness Conversations

- *“It was good, because it's hard to talk to people who don't know what's going on. Sometimes I can talk to my husband, but he… doesn't want to expect the worst, and I know someday that's going to happen. I think it was worthwhile.”*

- *“It made me think about a lot of things - the condition I'm in, how I want things handled. Made me think about my future, what I want to do.”*

- *“It's a conversation everybody has to have, so didn't create any awkwardness or anything like it. I think it was a good conversation, gives her a sense of direction on where I'm leaning, gives us both a sense of direction.”*

- *“I think it makes us a little bit closer, that I can talk to her about anything. She won't hide anything from me.”*

Serious Illness Conversations Impact Downstream Care

Data from all patients seen in two Penn Hematology-Oncology Clinics in Jan and Feb 2018
Hospice utilization includes hospice admission to Penn Hospice through Sept 2018

Risk of 6 month mortality	Number of patients	Percent of patients with Serious Illness Conversation documented in EHR	Percent with subsequent hospice WITHOUT Conversation	Percent with subsequent hospice WITH Conversation
0.00-0.25	10219	3%	1% →	10%
0.25-0.50	362	18%	3% →	9%
0.50-0.75	167	24%	5% →	18%
0.75-1.00	101	25%	7% →	8%

Making Conversations “Usual & Expected”

- **Cancer Center #1**
  - Oncology MDs receive their high risk list at Monday meeting
  - MDs circle patients for a Serious Illness Conversation that week
  - Clinic staff block extra time and place reminder on schedule

- **Cancer Center #2**
  - Nurses meet weekly to review high risk list for entire clinic
  - Nurses select patients for a Serious Illness Conversation next week
  - Reminder placed on Oncology MD calendar with appointment time

List generated using machine-learning algorithm to identify patients at high risk of 6 month mortality.

Policy Recommendations to Improve Communication

Recommendation #1: Improve Access to Palliative Care for Cancer Patients

➢ **Palliative Care and Hospice Education and Training Act (PCHETA)**

- Create training centers to expand palliative care workforce
- Fund research into best practices in palliative care
- Conduct public awareness campaign about palliative care

Currently pending in the House (H.R. 647) and Senate (S. 2080)

Policy Recommendations to Improve Communication

Recommendation #2: Promote Excellence in End-of-Life Communication

- **Support PCORI, NIH, and AHRQ research on serious illness**
  - ex: Evaluation of scalable communication training programs

- **Include palliative care measures in all CMS quality programs**
  - Will require development of practical end-of-life quality measures

- **Strengthen payments for Advance Care Planning CPT codes**
  - Ensure that all payers reimburse for these time-based codes