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

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“Next to creating a life, the finest thing a man can do is save one.”

— Abraham Lincoln
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

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

- **Diagnosis**: Life-prolonging care
  - 40% emotional support
  - 30% coping skills
  - 30% symptom management
  - 50% advance care planning

- **Palliative care**
  - 30% symptom management
  - 20% emotional support

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

- **Bereavement**
  - 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

Common Misconceptions Create Barriers

Palliative Care = Hospice Care = Giving Up

Hopes less likely to be realized

Hopes more likely to be realized

“He’s a fighter…”

“I want to stay positive…”

“Don’t take away hope”

Systems Issues Also Create Barriers

- Very few physicians have received **formal training** in communication about palliative care and end-of-life planning¹

- **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 FTE²
  - Only 300 palliative care fellows graduate annually

Palliative Care for Cancer: Towards a Scalable Model

Palliative Care Specialists
- Palliative care specialists to consult on difficult cases and teach other clinicians

Palliative Care Champions
- Select oncology clinicians receive extra training from palliative care specialists to serve as local resources

Palliative Care Skills for all Oncologists
- All oncology clinicians receive training in practical communication tools
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

- 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
“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

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