Palliative Care, Hospice, and Goals of Care Discussions
Spiritual Care Volunteer Speaker Series

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www.med.stanford.edu/palliative-care
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Roadmap

- What is palliative care?
- What is hospice?
- What are goals of care discussions vs. advance care planning?
Defining Palliative Care

- Palliative care sees *the person* beyond the disease.
  - “A person living with cancer” vs. “cancer patient”
Defining Palliative Care

- **Definition:**
  - Palliative care is specialized health care for **people living with a serious illness**.
  
  - This type of care is focused on **providing relief from the symptoms and stress of the illness**.
  
  - The goal is to **improve quality of life** for both the **patient and the family**.

Center to Advance Palliative Care (CAPC), 2019
Defining Palliative Care

- Provided by a specially-trained team, palliative care specialists work together with a patient’s other doctors to provide an extra layer of support.

- Palliative care is based on the needs of the patient, not on the prognosis. It is appropriate at any age and at any point in a serious illness and can be delivered with curative treatment.

Center to Advance Palliative Care (CAPC), 2019
Living with a serious illness

**Common Diagnoses**

- Any life-limiting illness
- Cancer
- Heart failure
- Liver, Kidney, or Lung Disease
- Dementia
- ALS, Parkinson’s Disease
- Multiple hospitalizations
- Functional Decline

**Diagnoses Less Well Served by PC**

- Hypertension
- Diabetes
- High cholesterol
- Infections that are expected to improve or get better (influenza, common cold)
- Chronic pain that is not from a serious illness
Relief From Symptoms and Stress

- Pain
- Shortness of breath
- Nausea
- Constipation
- Anxiety
- Depression

- Coping/Stress
- Fatigue
- Poor appetite/Weight Loss
- Neuropathy
- Caregiving
Improve Quality of Life for Patient and Family

- Ensure that your overall care plan matches with what matters most to you

- Recognize that patient and families are a unit
Team-Based Approach

- Who’s On Our Team:
  - Doctors
  - Nurses
  - Social Workers
  - Chaplains
  - Medical Assistants

Derived from World Health Organization definition of palliative care, 1998
Extra-Layer of Support
Any Age, Any Stage and Can Be With Curative Treatment

- Palliative Care is appropriate at any age and can be provided alongside curative treatment.

- Examples of patients I see in clinic:
  - New diagnosis
  - Cured but with ongoing symptoms
  - Pursuing curative treatment
  - Pursuing treatment but unable to cure
  - Living with their illness and no longer receiving treatment targeting their underlying illness
If it were a pill, it would be worth millions

- Median Estimates of Survival:
  - 11.6 months early PC group
  - 8.9 months in standard group
Palliative Care has many benefits

- Improved
  - Quality of life
  - Symptom control (i.e. pain, shortness of breath)
  - Spiritual wellbeing
  - Psychological symptoms
  - Satisfaction with care

- Fewer hospitalizations
- Fewer hospital days
- Less burden on caregivers
What it looks like in real life

In Palliative Care, Comfort Is the Top Priority

The New York Times

They have become converts. “It was quite a relief,” Mr. Chin said. “Our doctor listened to everything: the pain, the catheter, the vomiting, the “Our doctor listened to everything: the pain, the catheter, the vomiting, the tiredness.”

worker helps the family grapple with home care schedules and insurance. Mr. Chin, who frequently translates for his Cantonese-speaking mother, ...but her son now wishes the family had agreed to palliative care earlier...

wishes the family had agreed to palliative care earlier.
Palliative Care

Hospice
Roadmap

- What is palliative care?
- What is hospice?
- What are goals of care discussions vs. advance care planning?
What is hospice?

1. A philosophy of care
2. An insurance benefit
3. A set of services
A philosophy of care

- Comfort-focused care
- Delivered where patients want to be
An insurance benefit

- Covered by all insurance plans (including Medicare and Medicaid)
- Insurance guidelines mandate that patients have a 6 month or less estimated prognosis
  - Typically does not cover cancer-directed therapy (such as chemotherapy or immunotherapy)
- Discussion about specific treatments is possible
A set of services

- Interdisciplinary Team
  - Doctor
  - Nurse-Case Manager
  - Social Worker
  - Chaplain
  - Volunteer
  - Home health aide
- Home-Based Care (if desired)
- 24hr Nurse Call Line
- Ability to send “on demand” nurse to home

- Ability to transfer to nursing home if desired
- Prescribe and provide all medications
- Prescribe and provide all medical equipment
  - Hospital bed
  - Bedside commode
  - Wheelchair
- Does not provide 24hr care
Roadmap

- What is palliative care?
- What is hospice?
- What are goals of care discussions vs. advance care planning?
Goals of Care Discussions & Advance Care Planning

Goals of Care Discussions

Current
- Family Meeting
- “Goals of Care” Meeting

Future
- Advance Health care planning
- Advance Directive
- DPOA
- POLST
When Should GOC Discussions Happen?

- Goals of care discussions should not occur in a vacuum.

- Ideally, begin at the kitchen table, continue in clinic, and evolve with time.

- Should not be limited to goals of end-of-life care (ie, focusing on death and dying) but should be as much about how the patient wants to live.
“The Tree of Life”

Health Status or Prognosis

Goals, Values, Priorities
What Matters Most
What Makes Life Worth Living

“Comfort-Focused Care”

More Chemotherapy
Hospice

“Life Prolonging Treatment”

Artificial Nutrition
CPR
Breathing Machine
Dialysis

Chemotherapy

Stanford Medicine
Palliative Care
Department of Medicine
“The Tree of Life”

Health Status

What Makes Life Worth Living

Health Care Decisions
What is Advance Care Planning?

- Advance care planning is making decisions about the health care you would want to receive if you become unable to speak for yourself.

- These are your decisions to make, regardless of what you choose for your care.

- The decisions are based on your personal values, preferences, and discussions with your loved ones.

National Hospice and Palliative Care Organization, 2019
What Type of Decisions Are We Talking About?

- Who would you want to make decisions for you if you were unable to communicate?

- What makes life worth living given your current health status?

- What would be important to you if you were seriously ill or even at the end of your life?
What Type of Decisions Should We Think About?

- Are there limitations you would put on life-prolonging treatment?
- Would you want to receive cardiopulmonary resuscitation or be placed on a breathing machine?
It's always too early, until it's too late”

-The Conversation Project, 2013
Most people agree that this is important

- **90%** say *talking to your loved ones about end of life care* is important
  - Only **27%** have actually done so

- **60%** say that making sure their *family is not burdened by tough decisions* is “extremely important”
  - But **56%** have not communicated their end of life wishes

- **82%** say it’s important to put their *wishes in writing*
  - Only **23%** have actually done it

Sources: CDC, Conversation Project National Survey (2013), Survey by the California Healthcare Foundation (2012)
Most people need help with decision-making

- 40% of all hospitalized patients are incapable of making their own treatment decisions.
- 70% of decedents age 60 and older at death faced treatment decisions in the final days of life and were incapable of participating in these decisions.

Raymont (2004) Lancet
Silveira (2010) NEJM

Photo by Sharon McCutcheon on Unsplash
Even for people who are healthy
When Should GOC Discussions Happen?

1. Too sick to get cancer-directed therapy
2. Metastatic cancer with progression of disease despite therapy
3. Would you be surprised if this patient died in the next year?
4. Concerns that burdens > benefits of treatment

Do Goals of Care Discussions Make a Difference?

- Reduced hospital utilization
- Increased use of hospice services
- Decreased family conflict
- Greater likelihood of receiving goal concordant care
- Dying in preferred place of death

- NO increase in anxiety, depression
- NO decrease in hope

JAMA. 2008;300(14):1665.
Set Up The Conversation

- Introduce all team members and family members present
- Introduce the purpose
- Prepare for future decisions
- Ask permission

“I’d like to talk about what is ahead with your illness and do some thinking about what is important to you so that I can make sure we provide you with the care you want – is that OK?”
Assess Understanding and Preferences

- “What is your understanding now of where you are with your illness?”
- “What have you heard from us (or the doctors) about where things are with your illness?”

- “How much information about what is likely to be ahead with your illness would you like from me?”
  – “Some people tell me they want all the details, others want just the big picture, and some people prefer we speak to their family about this and not directly to them.”
Share Prognosis

- Frame as a “wish…worry” or “hope....worry”
- Allow silence, explore emotion

- “I want to share with you my understanding of where things are with your illness…”
- “I wish we were not in this situation, but I am worried that time may be as short as weeks to months”

- “That may have been hard information to hear, how are you feeling about all of this?”
- “Was that information new or surprising to you?”
Explore Goals/Values/Priorities

- Goals
- Fears and Worries
- Critical Abilities
- Tradeoffs

- “Given this information, what are your most important goals? What are you hoping for?”
- “What are your biggest fears and worries about the future with your health?”
- “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
Close the Conversation

- Summarize
- Make a recommendation
- Check-in with patient
- Affirm commitment

- “I’ve heard you say that being home with your family and being comfortable is important to you. Keeping that in mind, I recommend we talk more about how hospice might be able to help meet that goal.”
- “How does this plan seem to you?”
- “I will do everything I can to help you through this”
**Bring It All Together**

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<tr>
<th>Step</th>
<th>Phrasing</th>
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<tbody>
<tr>
<td><strong>Set up</strong></td>
<td>“I’d like to talk about what is ahead with your illness so that I can make sure we provide you with the care you want. Is that OK?”</td>
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<td><strong>Assess Understanding</strong></td>
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<td><strong>Summary and Recommendations</strong></td>
<td>“I’ve heard you say ..... Keeping that in mind, I recommend ..... to help meet that goal. How does that sound to you?”</td>
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Pro Tips

- Don’t confuse “what the care should be” with “where or how the care should be delivered”

- Remember that code status reflects a decision about a very-limited range of treatments
Pro Tips: Self-Care

- Your goals/values may not align with the patient’s goals/values
- Some people need to go through difficult things to make difficult decisions
- Our perspective is only 1 part of how patients and families make decisions
Make A Referral to Palliative Care: Inpatient

- Inpatient Referral
  - Available in-person 7 days/week
  - Available by phone 24/7
  - Place a consult order through epic
  - Page #26254
Make A Referral to Palliative Care: Outpatient

• Outpatient Referral
  – Clinic available in Palo Alto, San Jose, and Emeryville
  – Provide in-person, telephone, and video visits
  – Offer co-management service
  – Place either a discharge referral or an order for Ambulatory Referral to Palliative care
  – We also accept patient self-referrals
    ▪ Patients can call 650-724-0385
Thank you!

Please complete our survey!

www.med.stanford.edu/palliative-care