2013 Webinar Series
State of the Science:
Dementia Evaluation and Management Among Diverse Older Adults and Their Families

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PALLIATIVE CARE AND DEMENTIA

Stephanie M. Harman, MD, FACP
Arnold P. Gold Clinical Assistant Professor, Stanford University

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Dementia Evaluation and Management among Diverse Older Adults and their Families
2013 WEBINAR SERIES

“Palliative Care and Dementia”

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About the Presenter

Stephanie M. Harman, MD, FACP is the Arnold P. Gold Clinical Assistant Professor in Stanford’s Division of General Medical Disciplines. She received her MD from Case Western Reserve University and went on to complete an internal medicine residency and palliative care fellowship at Stanford. She is the director of Stanford Hospital’s Palliative Care Program and is an associate program director for the Stanford Medicine Residency.

Learning Objectives

- Review the current definition of palliative care
- Describe the integration of palliative care in the continuum of dementia care
- Identify communication strategies for advance care planning in dementia
A Case...

- 80 yo man w/metastatic prostate cancer, CAD s/p 3vCABG 2000, and Alzheimer’s dementia is seeing you in follow-up after being hospitalized for pneumonia. The patient has no complaints today and has completed his course of antibiotics. He is still able to perform his own ADLs, but is no longer able to drive as he gets lost. He is accompanied by his wife, who ambulates with a walker.

What is Palliative Care?

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis.

The goals is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Public opinion research www.capc.org, commissioned by CAPC and ACS
Emerging Model of Palliative Care

Life prolonging care  Hospice Benefit  Old
Disease progression

Hospice Care  Palliative care  New
Life prolonging care

Diagnosis of serious illness (Dementia)  Death
EPEC-EM

Global Trajectories of Illness

Lunney, JR et al. JAMA 2003 May 14;289(18):2387-92

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Palliative Care Interfaces with Dementia

- Advance Care Planning/Goals of Care
- Symptom management
- Support for Caregiving

Stages of Dementia and Palliative Care

<table>
<thead>
<tr>
<th></th>
<th>Early</th>
<th>Moderate</th>
<th>Severe</th>
<th>Terminal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>Memory deficits</td>
<td>Cognitive impairment, difficulty with judgment</td>
<td>Can speak a few words (&lt;6),</td>
<td>Nonverbal, unable to communicate</td>
</tr>
<tr>
<td>Function</td>
<td>Independent for ADLs, can still live independently</td>
<td>Assistance with ADLs, can’t live independently</td>
<td>Fully dependent for ADLs</td>
<td>Bedbound with loss of ambulation, loss of ability to swallow</td>
</tr>
<tr>
<td>Palliative Care Issues</td>
<td>Advance Care Planning</td>
<td>Symptom Management, Caregiver Support</td>
<td>Revisiting the goals of care, planning for hospice</td>
<td>Symptom management and hospice care</td>
</tr>
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Early Stage Dementia and Palliative Care

• Emphasis on advance care planning discussions
  ◦ Diagnosis and prognosis: what’s the road map for dementia?
  ◦ Advance directives: begin the discussion now
    • Tools: The Conversation Project, 5 Wishes
  ◦ Financial planning and estate planning: start the process

• Patient/Family goals and expectations
  ◦ Goal-setting
  ◦ Disease-modifying therapy


Early Stage Dementia and Palliative Care

• Linkage to resources and initial support
  ◦ Support groups
  ◦ Alzheimer’s Association and local organizations
Advance Care Planning (ACP)

- Patients in this early stage participate fully in discussions

And

- Caregivers/family members should be a part of these discussions

Toolbox: Framework for the ACP Conversation

- Ensure your understanding of their life prior to dementia
- Ensure their understanding of their diagnosis/prognosis
- Elicit overall goals of care
- Empower patients/families with a plan to ensure their wishes and goals are followed
Toolbox: Framework for the ACP Conversation

- Ensure your understanding of their life prior to dementia
  - “What work did you do before retiring?”, etc
- Ensure they understand their diagnosis/prognosis
  - “Can you tell me in your own words what you understand of your dementia and what the future holds?”

Toolbox: Framework for the ACP Conversation

- Elicit the overall goals of care:
  - “As you look ahead, what are you hoping for?...What else are you hoping for?”
- Empower patients with a plan that ensures their goals/wishes are followed
  - “Thank you for sharing this with me. Here is what I would recommend we do to honor your wishes overall...Here are the next steps to take to record your wishes and make sure your medical providers/teams know...”
ACP Tools

- The Conversation Project
- Advance Directives
  - CMA
  - 5 Wishes: Value-based, straightforward language.

The Conversation Project
Your Conversation Starter Kit

weknowthat noguidenosingleconversationcan
cover alldecisions that you and your family may
face. What a conversation can do is provide a shared un-
derstanding of what matters most to you and your loved
ones. This can make it easier to make decisions when
the time comes.

www.theconversationproject.org

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The Conversation Project

**What matters to me is _____**
Start by thinking about what's most important to you. What do you value most? What can you not imagine living without?

Now finish this sentence: What matters to me at the end of life is _________.

Sharing your “What matters to me” statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what’s worth pursuing treatment for, and what isn’t.

**Where I stand scales**
Use the scales below to figure out how you want your end-of-life care to be.
Circle the number that best represents your feelings on the given scenario.

As a patient...

1. I only want to know the basics
2. I want to know as much as I can

Middle Stage Dementia and Palliative Care

- Emphasis on ACP: Assess for decision-making capacity and the involvement of the surrogate decision maker
- As caregiving needs increase, assess for caregiver fatigue and burnout
  - Discuss respite and adult day care programs
  - Plan for add’l caregiving

Middle Stage Dementia and Symptom Management

- Psychiatric and behavioral symptoms
  - Restlessness, paranoia, agitation
  - Declining functional status
- Pain management
  - Most patients can express when they have pain
  - Caution must be taken with initiation of pain medications; “start low and go slow.”

Severe Dementia and Palliative Care

- Readdress goals of care
  - Check in re: family understanding of prognosis
  - Hospitalization
  - The question of artificial nutrition
  - POLST
- Symptom management
- Caregiver support

**POLST: Physician Orders for Life Sustaining Treatment**

- POLST: originally developed in Oregon (1992), as an order set for patients with serious illness and a limited prognosis.
- The original POLST from Oregon includes sections on DNR, level/intensity of care, antibiotics, and artificial nutrition.
- California Assembly Bill 3000 (effective January 2009): recognizes POLST in addition to the DNR.

**POLST Map**

[Map showing POLST paradigm programs across the United States.]

http://www.ohsu.edu/polst/programs/state+programs.htm
POLST vs Advance Directive

• "The Physician Orders for Life Sustaining Treatment (POLST) form complements an advance directive by taking the individual’s wishes regarding life-sustaining treatment, such as those set forth in the advance directive, and converting those wishes into a medical order.”

  – A POLST does not take the place of an advance directive

www.leginfo.ca.gov
To Tube Feed or Not to Tube Feed

- The loss of oral function and increasing aspiration and risk
- Multiple studies (no RCTs) have demonstrated no survival benefit to tube feeding vs hand feeding, nor any reduction in aspiration or pressure ulcers
- Tube feeding is not recommended at this stage based on expert consensus and current data


Considering Hospice: Prognostication in Dem

- Prognostic tools:
- FAST: functional assessment staging
- Morbidity Risk index
- Others exist though not as well validated

When to Initiate Hospice

- Current guidelines (not requirements) suggest FAST score of 7a plus one or more of the following in the prior 6 months:
  - Aspiration pneumonia
  - Pyelonephritis
  - Septicemia
  - Decubitus ulcers, stages 3-4
  - Fever recurrent after antibiotics
  - Unintentional weight loss >10%

Terminal Stage and Palliative Care

- Hospice care
- Symptom management
- Ongoing caregiver support
How do Patients Die with Dementia?

- Infection
- Organ failure (from immobility)
- “Dementia is a terminal disease”—families often struggle with understanding that this neurodegenerative disease leads to death.


Q & A

- We now have some time to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, we would like to ask each of the participants to answer the short evaluation questionnaire.

Please complete our short survey. We appreciate your feedback.

NOTE: Continuing Education Participants must complete a final survey in order to receive CEU/CME credit.
Final Question
Thank You for Participating!

Reminder: Please complete our short survey. We appreciate your feedback.

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