Goals of Care in Primary Care

Or: Can you have a goals of care conversation in a 15-minute office visit?

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Disclosure Statement

- Relevant Financial Relationships
  - None
Objectives

- Understand the landscape for the development of Palliative Care
- Explore the benefits to the generalist of improving communication skills
- Learn techniques to navigate challenging conversations
- Develop a systematic approach to providing goal-aligned care for your patients
How did we get here?
1900
Average life expectancy 50 years
<table>
<thead>
<tr>
<th>Time</th>
<th>Function</th>
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<tbody>
<tr>
<td>Low</td>
<td>High</td>
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<tr>
<td>Time</td>
<td>Function</td>
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| Low  | Rapid decline and death

Rapid decline and death
Figure 3. Number of deaths due to heart disease and cancer for the non-Hispanic white population: United States, 2000–2014

NOTES: Leading cause is based on number of deaths. Access data table for Figure 3 at: http://www.cdc.gov/nchs/data/databriefs/db254_table.pdf#3.
Increase in Prevalence of Two or more chronic conditions, 1999-2009

Ages 45-64:
- 1999: 16.1
- 2000: 21.0

Ages 65 +:
- 1999: 37.2
- 2000: 45.3
PREVALENCE OF ALZHEIMER’S DISEASE
(BY DECADES IN U.S.A. FROM 1900-2050)

YEARLY VICTIMS:
- AGE 65-74 YEARS
- AGE 75-84 YEARS
- AGE 85+ YEARS

YEARLY VICTIMS:
- AGE 65-74 YEARS
- AGE 75-84 YEARS
- AGE 85+ YEARS
Medicine’s shift in focus ...

- Science, technology, communication
- Improved sanitation, public health, antibiotics, other new therapies
  - Increasing life expectancy
    - 1995 avg 76 y (F: 79 y; M: 73 y)
    - 2009 avg 78 y (F: 81 y; M: 76 y)
- Marked shift in values, focus of North American society
  - “Death denying”
  - Value age, family, interdependent caring -> Value productivity, youth, independence
Where do people want to die?

- At home: 70%

Where do people die?

- At Home: 25%
- In Institutions: 75%
  - In hospitals 50%
  - In Nursing Homes 25%

What do people want to talk about?

- 80% say they’d like to talk to their doctor about end of life care

What do people talk about?

- 7% have had a doctor talk to them about end of life care

Top ten causes of death 2015

- Heart disease 23.4%
- Cancer (malignant neoplasms) 22.5%
- Chronic lower respiratory disease 5.6%
- Accidents (unintentional injuries) 5.2%
- Stroke (cerebrovascular diseases) 5.1%
- Alzheimer's disease 3.6%
- Diabetes 2.9%
- Influenza and pneumonia 2.1%
- Kidney disease 1.8%
- Suicide 1.6%
<10% Sudden death, unexpected cause

- Myocardial Infarction
- Accident
- Etc
Slow decline, periodic crises, death

- CHF
- COPD,
- Alzheimer’s-type dementia
- Many Cancers
Frailty

Function

Time

Death
Palliative Care

- **Palliative care** is an approach that improves the quality of life of patients and their families facing the problem associated with serious illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- **Palliative care** is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. It can be provided at any time during the course of an illness, along with “curative” treatment.

Source: WHO definition, CAPC
Domains of Concern for Patients and Families facing serious illness

- Disease Management
- End-of-Life Care
- Physical Symptoms
- Psychological
- Grief
- Spiritual
- Social
- Functional Status

Goals of Care?

Isn’t there more to it than this?
- Cure of disease
- Ensuring family is supported
- Being at home
- Maintenance or improvement of function
- Mending relationships
- Dignity
- Optimized quality of life
- Relief of suffering
- Resolving financial burdens
- Spiritaul growth
- Avoiding hospitalization

- Often may be conflicting
- Evolve over time
- Priority of goals changes
Figure 1: Palliative Care Integration in the Disease Trajectory

Preventive Care
No Illness
Primary Palliative Care

- What is Primary and Specialty palliative care?
  - Primary palliative care refers to basic skills and competencies required of all health care workers
    - Symptom assessment and management
    - Basic communication skills
    - Routine Advance Care Planning discussions
  - Specialty palliative care:
    - Management of complex pain and refractory symptoms
    - Comprehensive assessment of psychosocial distress and suffering
    - Communication with challenging goals of care, complicated family dynamics

Parish et al. NEJM 2013
Components of Primary Palliative Care

- Symptom Assessment
- Support for Quality of Life
  - Maintaining Functional Status
- Caregiver Support
- Communication Skills
  - Routine Advance Care Planning
  - Basic Goals of care conversations
  - POLST conversations
Why NOT to do Primary Palliative Care?

- Why don’t more physicians have these conversations?
  - Time
  - Uncomfortable bringing it up
  - Worried that families will feel abandoned, “giving up”
  - If they can’t be cured, I don’t know what to offer them- helplessness
    - People have concerns other than just whether they live or die.
  - Financial concerns
The problem with Autonomy

Paternalism → Shared Decision-making, "Enhanced Autonomy" → Autonomy
THE CONVERSATION

- Relationship building/Trust
- Assessing patient and family understanding of illness
- Understanding values/goals/priorities of patient and family
- Understanding trade-offs: what the patient is and isn’t willing to go through
- Making recommendations based on values and concerns elicited
Goals of Care

- Not simply a code discussion
- Ongoing process
- Reflect on the patient’s goals, values, and beliefs
  - How they should inform current and future medical care
- Use this information to accurately document their future health care choices
  - Ideally after an exploration of the patient/caregiver’s knowledge, fears, hopes, and needs
Stages

- **Routine ACP**
  - Disease Progression - SICG, SPAM etc
  - Late goals of care
Routine ACP/early goals of care

- Who should have these?
  - Everyone?
  - Adults >65
  - Anyone with a serious, potentially life threatening diagnosis

- Possible decisions
  - Decision Maker
  - Living Will
Preparation

- Prepare for the Conversation
  - Review the case facts, identify concerns of patient, family, nurses, doctors, etc
  - Know family dynamics
- Prepare the Interview Atmosphere
  - Arrange for uninterrupted time in a private room
  - Include appropriate family/support members
  - Silence phones, beepers, radio, T.V.
  - Sit close to patient
    - Appropriate touch during interview discussions
How to initiate these conversations?

- Welcome your patient
- Ask about your patient’s main concerns for the visit
  - Prioritize
- Explain your agenda
- Propose an agenda that combines the patient’s and your concerns
- Be prepared to negotiate
- Ask for feedback
  - I hope this discussion was helpful for you
- Welcome emotion
  - Acknowledge
Living Will

- What people generally mean when they say “Advance Directive”
- General outline of a person’s wishes in the event they are unable to speak for themselves

Requirements
- Few
- No clear guidelines for what types of treatments must be addressed
- Requires signature of patient and TWO witnesses
  - Witnesses cannot be healthcare providers involved in care
    - Can be family, but not recommended
Durable Power Of Attorney for Healthcare

- Designates Health Care Agent
- Makes Decisions on patient’s behalf:
  - ONLY when the patient IS NOT ABLE TO speak for him/herself, or is deemed to not have capacity to make decisions (due to illness or other condition)
- Principle of *Substituted Judgment*
  - Implies a conversation
- Montana surrogacy without DPOA
  - Spouse, Adult child, Parent, Adult sibling, Nearest adult relative
- Requires two witnesses
  - No notarization

ADVANCE CARE PLANNING

- ACP has significantly improved multiple outcomes
  - Higher rates of completion of ADs
  - Increased likelihood that clinicians/families understand and comply with a patient’s wishes
    - A reduction in hospitalization at the end of life
    - The receipt of less intensive treatments at the end of life
    - Increased utilization of hospice services
    - Increased likelihood that a patient will die in their preferred place
Billing for Advance Care Planning

- **CPT Code 99497**
  - “Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional”
  - Completion of advance directive NOT required
  - First 30 minutes, can bill at 16 mins
  - Face-to-face with the patient, family member(s), and/or surrogate
  - Document separately:
    - “Additionally, 20 minutes was spent in discussion about patient and family goals of care, and review/completion of advance care planning documents”

- **CPT Code 99498**
  - Each additional 30 minutes, bill at 46 minutes
  - (List separately in addition to code for primary procedure)
Stages

- Routine ACP
- Disease Progression - SICG, SPAM etc.
- Late goals of care

Routine ACP

Disease Progression - SICG, SPAM etc.

Late goals of care
Who should have these?

- Triggers for initiating or following up on goals of care
  - Discharge from hospital
  - After new diagnosis of chronic/serious condition
  - Shortly after a specialist visit, i.e. cardiology/neurology/pulmonology/nephrology

What is the goal of these?

- Explore understanding of illness more deeply
- Assess values, priorities, tradeoffs

Arrange Emotional Atmosphere

- Sit down
- Make appropriate introductions
- Be sure facial tissues are in the room
  - Don’t rush
Pearls

- **Sharing Information:**
  - Use plain language, adapt to patient's communication style
  - Fire "warning shots"
    - "I was hoping that I had better news to share with you today."
  - Elicit and respond to patient’s feelings

- **Use therapeutic silence and touch appropriately**
  - Stop frequently

- **Provide reassurance, support and hope**

- **Make a follow-up plan**
Serious Illness Communication Guide

- **Understanding**
  - What is your understanding now of where you are with your illness?

- **Information preferences**
  - How much information about what is likely to be ahead with your illness would you like from me?

- **Prognosis**
  - Share prognosis as a range, tailored to information preferences

- **Goals**
  - If your health situation worsens, what are your most important goals?
Serious Illness Communication Guide

- **Fears / Worries**
  - What are your biggest fears and worries about the future with your health?

- **Function**
  - What abilities are so critical to your life that you can’t imagine living without them?

- **Trade-offs**
  - If you become sicker, how much are you willing to go through for the possibility of gaining more time?

- **Family**
  - How much does your family know about your priorities and wishes?
S.P.A.M.

- **Surrogate**
  - “If you became so ill that you couldn’t speak for yourself, who would you trust to make your medical decisions for you?”

- **Preferences**
  - What preferences for lifesaving treatment do you have, like being on a breathing machine, getting CPR, or having a feeding tube?

- **Assume full, aggressive care**
  - “Okay then. Until you tell us otherwise, we will provide full treatment and lifesaving measures, including CPR and breathing machine if you need it.”

- **More conversations**
  - “I’ll document our discussion in your medical record. You are free to change your mind and we may ask you about these issues again, especially if your medical condition changes. You may want to discuss this more with your family at some point. You can talk to us at any time to share your preferences.”
Types of introductions

- Broad, disarming
  - “These are things that many patients with serious illness like to discuss.”
  - “I’ve found having these conversations helps me provide more personalized care… make sure I’m providing the best care that’s right for you…. Make sure we’re on the same page about how you’re doing.”

- Focused, exploring emotion
  - “I want to check in on how you’re dealing with all of this, how it’s affecting you”

- Checking In
  - This all sounds pretty hard… I’d like to check in with you about how you’re making sense of all these changes.”
Code Status

- Have you thought about or discussed this before?
  - If so, how did you come to this decision? Forms?

- Discuss prognosis (if they agree)
  - Minutes to hours to days to weeks to months

- Needs to make medical sense
  - No compressions without intubation

- Normalize options
  - Some patients choose this, others another option
Basic techniques

- Talk less
  - Pause/silence
  - Tell me more
- How to respond to emotion
  - Acknowledge
- Ask Tell Ask
  - Asking permission improves comprehension and makes patients feel valued
- Hope
  - Evolution
  - Key for anxiety and depression
Cure of disease

Ensuring family is supported

Being home

Maintenance or improvement of function

Integrity of self

Optimized quality of life

Relief of suffering

Mending relationships

Dignity

Spiritual growth

Resolving financial burdens

Avoiding hospitalization

Being at home

Ensuring family is supported
Recommendations

- Based on elicited goals/values, provider can make recommendations.
  - Patient and families are looking for your experience and knowledge
  - Autonomy is a sharp double-sided sword
- “Based on what I’ve learned from you, can I make a recommendation?”
  - POA?
  - Advance directive?
  - POLST?
  - Hospice?
For those with serious illness and don’t want all treatment

A medical order

It needs YOUR signature as well as the patient or medical surrogate

Protects patient’s wishes outside of hospital

Reviews 3 things

Code status

Level of medical interventions

Artificial nutrition
When to consider transition to end of life care

- Patient is exhibiting:
  - Physical signs of end-stage illness
  - Significant physical decline
  - Not responsive to curative treatments

- Clues for doctor to switch from aggressive curative to palliative care approach:
  - E.g. “Would I be surprised if this patient died within the next year?”

- Relief of symptoms and patient comfort are goals throughout the illness
Hospice

- Life expectancy of less than 6 months
  - Median survival 18 days
- Services
  - Personnel
  - Equipment
  - Medications
- Bereavement services
- Maintenance of relationship with PCP
- Improved survival potentially
Questions?

What's your favorite pickle and why?
Summary

- Reframe conversations and situations
- Expect emotions
- Map out the future
- Align with values
- Plan treatments that match values

- Be a listener
- Don’t be afraid to laugh
- Be human

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