Primary Palliative Care Skills
Over the Life Trajectory

ACP Oregon | November 2021

Caroline Hurd, MD, FACP, FAAHPM
Clinical Assistant Professor, University of Washington
Portland Site Director, UW Graduate Certificate in Palliative Care
Providence Oregon, Course Director, Primary Palliative Care Training Program
Commercial Financial Disclosures

▪ Commercial - None

▪ Non-Profit

  Cambia Health Foundation: Grant Funding

  VitalTalk Distinguished Faculty: Teaching Stipend
By the end of this session you will be able to:

- Explain how to elicit personal stories and values that inform goals.
- Share serious news using a headline.
- Describe the NURSE(S) tool for responding to emotions.
- Explain the return on investment for advance care planning (ACP).
This session works best with you involved!

Open up “SLIDO”

- What is your professional role (Physician, PA, NP, Resident, Student etc.)
- What setting (inpatient, outpatient, primary care vs. specialty care etc.)
- Where do you practice
Primary Palliative Care
Aging Population

↑ Chronic Illness

Fragmented Care

Caregiver Burdens

Integration Upstream

Limited Specialists

↑ Demand for Palliative Care
Primary vs. Specialty Palliative Care

Specialty Palliative Care: Consultation with a team of specialists who have expertise in complex communication, symptom management and psycho-social-cultural-spiritual needs, focused on those with serious illness.

Primary Palliative Care: Palliative care philosophy and principles applied over the life trajectory across all aspects of a patient’s care.

Quill Abernethy NEJM 2013
Primary Palliative Care Training Model

4* Regional Champions

- Grad Cert 9-mo
- VitalTalk Faculty

48+ Clinic Champions

- Grad Cert 9-mo

>1000+ Clinicians

Intermediate Foundational

- Multiple training modalities using available & newly created resources
Story
# PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

**NAME:**

**DATE:**

Over the last 2 weeks, how often have you been bothered by any of the following problems? (use *+* to indicate your answer)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself...or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed, or the opposite...being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead, or of hurting yourself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

(Hitcare professional: For interpretation of TOTAL, please refer to accompanying scoring card)

**TOTAL:**

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
- Somewhat difficult
- Very difficult
- Extremely difficult

Copyright © 1999 Pfizer Inc. All rights reserved. Reproduced with permission. PRIME-AD-C is a trademark of Pfizer Inc.

A53537 10-01-2004
ACP Life Stages

(ACP=Advance Care Planning)

HEALTHY

CHRONIC ILLNESS

SERIOUSLY ILL

LAST 1-2 YEARS OF LIFE

FINAL WEEKS TO MONTHS

Age 18

EOL

Advance Directive

GOC

GOC

POLST

HOSPICE

Trusted Decision Maker

Health Care Rep

Serious News

What Matters

(Portable Orders for Life-Sustaining Treatment)
Age 18

**Advance Directive**
Trusted Decision Maker
Health Care Rep

Sage comes to clinic to establish primary care.
What questions do you ask to learn your patient’s story?
Can knowing your patient’s story improve their healthcare?
Relationship as an Investment in Trust

- **Relationships**
  - Spiritual

+ **Community**
  - Good day

= Piggy bank with coins

- **Relationships**
  - Spiritual

- **Serious illness**
  - Tradeoffs

= Piggy bank with coins

- **Relationships**
  - Spiritual

- **Serious illness**
  - Tradeoffs

= Empty piggy bank
How does personal story impact ACP?

People may be more likely to engage in ACP if:

- We incorporate and acknowledge their faith community and the role their spiritual or religious practices has on their decisions.

- Allow for family/community decision making rather than focus on patient autonomy.

- Connect on a personal, relational level that builds a strong foundation of trust.

Hendren, Academic Medicine 2019
Slocum, Heart Lung 2019
Ragan, Seminars in Oncology Nursing 2017
Dang, BMC Med Educ 2017

Menon, JPSM, 2018
McDermott, JPSM 2018
Saunders, Cambridge Univ Press 2018
www.ethnomed.org
Personal Story Questions

- What is a Good/Typical Day
- People in your Life
- Sources of Strength
- Spiritual Cultural
- Hopes Concerns
- What Else?
ACP Task Force recommendations on ‘Restoring the Story’

An ACP Task Force made recommendations about turning the clinical note into a thoughtful assessment and care plan that captures patients' stories and distinguishes between documentation and communication.
Clinician: Are there important people in your life?

Sage: “I don’t get along with my mother….we haven’t talked in years and my dad died when I was young. So, it’s just me and my brother, but I also have some close friends.”
What type of ACP would be important to do with Sage?
2. **MY HEALTH CARE REPRESENTATIVE.**

I choose the following person as my health care representative to make health care decisions for me if I can’t speak for myself.

Name: ____________________________  Relationship: ____________________________

Telephone numbers: (Home)____________ (Work)____________ (Cell) ________________

Address: __________________________

E-mail: ____________________________
Sharing Serious News: Headlines
Sage comes back for a follow up visit for abdominal pain and weight loss. CT scan shows liver masses and colonic wall thickening concerning for colon cancer.
Knowledge Gap

81% Stage IV Colorectal Cancer
69% Stage IV Lung Cancer

Did not understand that chemo was not at all likely to cure
Ineffective ‘headlines’ that cause confusion

Crystal Ball

Hedge

Chronology
Share information using a headline

Information + Meaning

MEDICINE

JOURNALISM

Headline tips: 3 “asks” before the “tell”

- Ask what they already know
- Ask what/how much they want to know
- Ask permission
What headline would you share with Sage?
Advance Directive
Trusted Decision Maker
Health Care Rep

Healthy

CHRONIC ILLNESS

SERIOUSLY ILL

Age 18

Age 58

Headline: “The CT scan shows masses in your liver and an area in your colon that is thicker than normal. When we see this, we worry this is colon cancer.”

Sage: “What, this can’t be happening! Are you sure?”
When Sage asks, “Are you sure?” do they want more information?
Responding to Emotions: NURSE(S)
NURSE(S) to respond to emotions

Name “That sounds frustrating.”
Understand “I can only imagine how hard this is.”
Respect “I can see you really care about your mother.”
Support “We are here to support you through this process.”
Explore “Can you tell me more about what you’re thinking?”
Silence Intentional presence
Don’t bury your empathy:

Explicitly acknowledge emotions
Responding to emotions:

- Higher Satisfaction and Trust
- Retain More Information
- Increased Connection
- Share their Values and Reasoning
- Saves Time
40 seconds

Visits with at least 1 empathic response were 2-3 mins shorter

Levinson, JAMA 2000
Compassionomics, 2019
Evoke the Right Emotions

It’s tempting to activate emotions like fear or shame to get people to take a vaccine. But fear immobilizes us, and shame is likely to achieve the opposite reaction we’re hoping for. Look to more constructive emotions like pride, hope and parental love to get people to act.

People form judgements and make decisions based on emotion, but when it comes to conveying scientific information, there’s a tendency to eschew emotion. Particular emotions can motivate people to action or immobilize them. Using emotions intentionally can close the chasm between intention and action.
How can you respond to Sage’s emotions when they say:

“What, this can’t be happening! Are you sure!”

“What, this can’t be happening! Are you sure!”
Late Illness: Serious Illness Conversation Guide
After a recent recurrence of Sage’s colon cancer, Sage was admitted to resect new liver masses. However, during surgery, they found widespread cancer and peritoneal carcinomatosis and deemed the cancer inoperable. Sage is following up with you in clinic and asks, “what does this mean?”
Serious Illness is a Journey

It’s hard for people to talk about what’s important if they don’t know where they are headed

- Vital Talk, Back, JPM 2014
What do you already know about where you are with your illness?

Sharing Serious News

Eliciting Story/Values

Sharing Serious News

Information Preferences

How much information about what's likely to be ahead with your illness would you like to know?

Some patients want to know everything, others are more comfortable with a general idea. Help them identify the specific information they need to make meaningful decisions about their care and treatment options.
Serious Illness Conversation Guide: Tradeoffs

Comfort   Function   Longevity

"Some people would choose....**EVEN IF**.....and other people would choose...."
Serious Illness Care Program

1. Patient selection
   - Finding the right patients

2. Patient preparation
   - Making sure patients are prepared for the conversation

3. Reminder to clinician
   - Knowing when to talk

4. Clinician/Patient conversation
   - Learning what's most important to patients

5. Documenting conversation
   - Making sure the information is easily accessible
Benefits of Advance Care Planning/Goals of Care Conversations

- Increased goal-concordant care (3x more likely to have wishes followed)
- Improved quality of life / patient well-being (↓ anxiety and depression)
- Fewer hospitalizations / Less nonbeneficial care
- Better patient and family coping (↑ patient and family satisfaction)
- More and earlier hospice care
- Increased clinician well-being

Lakin Health Affairs 2017; Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009
Bernacki 2019 JAMA Internal Medicine; Respecting Choices 2015; Temel NEJM 2010; Back JPM 2014; Donovan Adv Med Educ Pract 2019
“I’ve been a general internist for almost thirty years, and I started to feel marginalized and unimportant. After this training I feel connected to my patients in a way that I haven’t for a long time. This training has renewed my commitment to the profession. I feel important to my patients again.”

PMG Palliative Care Champion, 2020
<table>
<thead>
<tr>
<th>High Value Care is Cost Saving</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advance Care Planning:</strong></td>
</tr>
<tr>
<td>HCPOA or POLST</td>
</tr>
<tr>
<td>Lifetime savings: ~$9500/person</td>
</tr>
<tr>
<td><strong>Serious Illness Care Program</strong></td>
</tr>
<tr>
<td>Primary Care:</td>
</tr>
<tr>
<td>Last 6 Months: ~$2500/month</td>
</tr>
<tr>
<td>Last 3 months: ~$4100/month</td>
</tr>
</tbody>
</table>

Bond, JPM, 2018
Lakin, Healthcare, 2020
ACP Life Stages

(ACP=Advance Care Planning)

- **HEALTHY**
- **CHRONIC ILLNESS**
- **SERIOUSLY ILL**
- **LAST 1-2 YEARS OF LIFE**
- **FINAL WEEKS TO MONTHS**

- **Advance Directive**: Trusted Decision Maker, Health Care Rep
- **GOC**: Serious News
- **GOC**: What Matters
- **POLST**: (Portable Orders for Life-Sustaining Treatment)
- **HOSPICE**

Age 18

EOL
Resources
CORONAVIRUS PANDEMIC: The latest resources and guidance from Ariadne Labs

New Serious Illness Care COVID-19 Response Toolkit

Being Prepared in the Time of COVID-19

Clinical Resources Available for COVID-19
Published March, 2020

CAPC COVID-19 Response Resources

All toolkit resources and online courses have been made publicly available.
View CAPC’s COVID-19 FAQ here.
CAPC wants to know how your team is responding to COVID-19. Fill in the form to share policies, procedures, or technical assistance that your team has developed.
To connect with others in the field to share coping strategies, register for Virtual Office Hours.

VitalTalk makes communication skills for serious illness learnable.

Our evidence-based trainings empower clinicians and institutions.

Grow as a CLINICIAN
We support clinicians with expert strategies.

Join our FACULTY
We elevate clinicians into advanced educators.

Strengthen your INSTITUTION
We build your capacity to provide patient-centered care.

PREPARE for your care

COVID-19 & YOU
Be Prepared: Take Control

Have a hospital Go bag
Choose a medical decision maker
Share wishes and encourage loved ones to prepare

PREPARE COVID-19 Resources and Hospital Go Bag Details »
Essential Information for Health Care Professionals

Oregon POLST Guidebook for Health Care Professionals
Downloadable copy (version 2020.11)

Click Here

Patient Stories & Videos

Family Members Should Not Be Required to Sign a POLST for Their Loved One - A Story

Oregon POLST Program News

September 2021 Newsletter
Topics include: Revolutionary Changes to The Oregon POLST Program's Website – JAGS Publishes Systematic Review by Dr. Varnes and colleagues – Social Determinants of Health Associated with POLST Completion by Dr. Gievers and colleagues in The American Journal of Hospice and Palliative Medicine – September Oregon POLST Webinar POLST: Becoming More Inclusive of our NP and PA Colleagues presented by Susan Tolle, MD
The VitalTalk Tips app enables physicians, nurses, and other clinicians to improve their communication skills for patients who have a serious illness. For clinicians in hospital medicine, oncology, cardiology, nephrology, hepatology, neurology, trauma, emergency medicine, primary care, pediatrics, and palliative care.

[Download on App Store] [Get it on Google Play]
Questions
churd@uw.edu