LUNG CANCER PATIENT SUPPORT ECHO SESSION 13
SUPPORTING PATIENTS WITH ADVANCED DISEASE:
END OF LIFE AND HOSPICE
Laurie McLouth, Ph.D. & Jennifer Gabbard, MD
Robert Smith, Ph.D. (Facilitator)
May 30, 2019
9:00 AM ET
TODAY’S AGENDA

<table>
<thead>
<tr>
<th>Time</th>
<th>Presentation</th>
<th>Presenter(s)</th>
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<tbody>
<tr>
<td>9:00-9:10</td>
<td>Welcome, roll call, housekeeping</td>
<td>Robert Smith, Ph.D.</td>
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<tr>
<td>9:10-9:50</td>
<td>Didactic Presentation: ECHO Session 11</td>
<td>Laurie McLouth, Ph.D. Jennifer Gabbard, M.D.</td>
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<td>9:50-10:00</td>
<td>Q &amp; A/Discussion</td>
<td>Presenters/Robert Smith</td>
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<td>10:00-10:15</td>
<td>Program/Case Presentation:</td>
<td>Angi Caton</td>
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<td>10:15-10:25</td>
<td>Q &amp; A/Discussion</td>
<td>Robert Smith</td>
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<tr>
<td>10:25-10:30</td>
<td>Conclusions</td>
<td>Dawn Wiatrek, Octavia Vogel, Robert Smith</td>
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*Sessions will be recorded.
*Please mute phones when not speaking. Mute cell phones and try to reduce extraneous noise.
*Remember to e-mail Octavia Vogel by 6/4 if you are requesting CME/CEU credit.
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The following planners and faculty disclose that they have no financial relationships with any commercial interest: (next slide)
FACILITATOR & PRESENTERS

Presenters: Laurie McLouth, Ph.D.
NCI R25 Training Grant Fellow (PI: Avis)
Wake Forest School of Medicine
Wake Forest Baptist Comprehensive Cancer Center

Jennifer Gabbard, M.D.
Assistant Professor
Program Director, Hospice and Palliative Medicine Fellowship
Wake Forest School of Medicine
Department of Internal Medicine
Section of Gerontology and Geriatric Medicine

Facilitator: Robert Smith, Ph.D.
Vice President, Cancer Screening, Prevention
and Early Detection American Cancer Society

Case Presenter: Andria Caton
Northeast Georgia Cancer Center
LEARNING OBJECTIVES

This session will provide an overview of the role of palliative care in advanced stage lung cancer treatment.

Upon completion of this session participants will be able to:

1. **Describe the guidelines for palliative care in lung cancer.**
2. **Identify common concerns in advanced stage lung cancer and potential emerging concerns in the setting of immunotherapy.**
3. **Describe challenges and barriers of discussing prognosis.**
4. **Develop a plan to better integrate prognostic discussions into routine care.**
PALLIATIVE CARE IN LUNG CANCER CARE: EVIDENCE-BASED, UNDERUTILIZED, AND CHANGING

LAURIE MCLOUTH, PHD
OUTLINE:

1. OVERVIEW OF PALLIATIVE CARE IN LUNG CANCER

2. PRELIMINARY DATA ON PALLIATIVE CARE CONCERNS & IMMUNOTHERAPY

3. POTENTIAL RESOURCES
WHAT IS PALLIATIVE CARE?

Palliative Care:
- Specialized medical care
- Provides relief from symptoms, stress of serious illness
- Improve quality of life for patient and family

(Center to Advance Palliative Care, American Cancer Society)

Specialty Palliative Care (boarded, certified)

Primary Palliative Care (i.e., Generalist Palliative Care)

(Institute of Medicine)

Hospice: specific type of palliative care

Resource: Palliative Care vs. Hospice (link from National Hospice and Palliative Care Organization)
PALLIATIVE CARE IS NEEDED IN LUNG CANCER

High Need for Supportive Services

- Older population, multiple comorbidities
- High symptom burden (fatigue, dyspnea, pain)
- High distress
- Multiple unmet supportive care needs

Yet low service use


Multiple Markers of Need for Improved Care

- 33-67% may expect cure from treatment
- 40-82% receive aggressive care at end of life

Temel et al., 2011, JCO, Mrad et al., 2018, JOP; Karanth et al., 2018, JTO
KEY EVIDENCE FOR PALLIATIVE CARE IN LUNG CANCER:
TEMEL ET AL’S LANDMARK STUDY IN 2010

Standard care

N = 151 mNSCLC
ECOG 0-2

Early palliative care (within 8 weeks dx)
- In-person visit with PC clinician (boarded PC physician or advanced practice nurse)
- At least monthly visits until death
  (Mean # visits = 4)
- Co-management model
- Topics: physical, psychosocial symptoms; goals of care; decision making; coordinating care

Temel et al., 2010, NEJM
KEY EVIDENCE FOR PALLIATIVE CARE IN LUNG CANCER: TEMEL ET AL’S LANDMARK STUDY IN 2010

12-week f/up assessment:

FACT-L TOI – 12 week change

Depression, Anxiety Sx

Survival (11.6 m vs. 8.9 m)

Potential Mechanisms? Symptom and comorbidity management, QoL, Mood, Coping, Optimal use of tx (stopping tx when indicated) and hospice?

Irwin et al., 2013, *Chronic Respiratory Disease*
### GUIDELINE: CONCURRENT, EARLY (WITHIN 8 WEEKS OF DIAGNOSIS) PALLIATIVE CARE

<table>
<thead>
<tr>
<th>Year</th>
<th>Category</th>
<th>Who?</th>
<th>When?</th>
<th>What?</th>
<th>How?</th>
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<tbody>
<tr>
<td>2012</td>
<td>ASCO Provisional Clinical Opinion</td>
<td>Pts with mNSCLC</td>
<td>Within 8 weeks of dx</td>
<td>Rapport, relationship, symptoms and functioning, illness understanding, prognosis, treatment goals, coping, support needs, medical decision making, referrals, care coordination</td>
<td>Interdisciplinary teams</td>
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<tr>
<td>2016</td>
<td>ASCO Clinical Practice Guideline Update</td>
<td>Pts with advanced cancer</td>
<td>Within 8 weeks of dx</td>
<td>Rapport, relationship, symptoms and functioning, illness understanding, prognosis, treatment goals, coping, support needs, medical decision making, referrals, care coordination</td>
<td>Interdisciplinary teams</td>
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(Updated through references: Smith et al., 2012, JCO; Ferrell et al., 2017, JCO)
Workforce shortages

Need for interventions, trials in underserved populations
  
  Rural communities
  
  Racial, ethnic minorities
  
  (Lynch, 2012, AJHPM)

Low palliative care literacy

71% - Never heard of palliative care

(Huo et al., 2019, JPSM)

Changing therapeutic landscape

Hospital Palliative Care Availability – CAPC 2015 Report

(D): 20-40% w/PC

(A): >80% w/PC
PALLIATIVE CARE AND IMMUNOTHERAPY
Challenges?

- Prognostic conversations
- New symptoms to manage
- Financial toxicity
PRELIMINARY DATA (N = 60 METASTATIC NSCLC PATIENTS ON IMMUNOTHERAPY; PI: MCLOUTH)

Sample demographics (N = 60)

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<tr>
<td>Male</td>
<td>40%</td>
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<tr>
<td>Age</td>
<td>Mean = 62 (9 yrs)</td>
</tr>
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<td>African American</td>
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<td>Income &lt;$25k</td>
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<tr>
<td>First line tx</td>
<td>45%</td>
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<tr>
<td>Immuno-chemo</td>
<td>45%</td>
</tr>
<tr>
<td>ECOG 2 or 3</td>
<td>32%</td>
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Design: Cross-sectional survey

Questions:
1. Prognostic understanding?
2. Palliative care use and barriers?
3. Symptoms and supportive care needs?
PROGNOSTIC UNDERSTANDING: HALF EXPECT A CURE FROM IMMUNOTHERAPY

Perceived Likelihood of Cure

- Extremely likely, 12%
- No chance, 9%
- Likely, 37%
- Unlikely, 42%

(Prognosis Treatment and Perception Questionnaire)

Percentage Reporting a Cure was Likely by Clinical Factors

<table>
<thead>
<tr>
<th></th>
<th>% Cure Likely</th>
<th>p</th>
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<tbody>
<tr>
<td>Reimaged to assess response</td>
<td>37%</td>
<td>.018*</td>
</tr>
<tr>
<td>Not yet reimaged</td>
<td>67%</td>
<td></td>
</tr>
<tr>
<td>Responding to treatment</td>
<td>55%</td>
<td>.274</td>
</tr>
<tr>
<td>Not responding</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>ECOG 0-1</td>
<td>35%</td>
<td>.002*</td>
</tr>
<tr>
<td>ECOG 2-3</td>
<td>79%</td>
<td></td>
</tr>
<tr>
<td>First line immunotherapy</td>
<td>59%</td>
<td>.154</td>
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<tr>
<td>Second line immunotherapy</td>
<td>41%</td>
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Steffen (McLouth)…Gabbard et al., ASCO Palliative and Supportive Care in Oncology Symposium, 2018
LOW USE OF PALLIATIVE CARE, DESPITE UNMET NEEDS AND SYMPTOM CONCERNS

Referred to Palliative Care (per EMR): 12%

Percent with at Least Moderately Bothersome Symptom in Past Week (NCI-PRO-CTCAE items):

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% with at least 1 unmet need</th>
</tr>
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<tbody>
<tr>
<td>Muscle ache</td>
<td>40%</td>
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<tr>
<td>Joint pain</td>
<td>33%</td>
</tr>
<tr>
<td>Rash</td>
<td>27%</td>
</tr>
<tr>
<td>Cough</td>
<td>25%</td>
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<tr>
<td>Constipation</td>
<td>22%</td>
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<tr>
<td>Diarrhea</td>
<td>19%</td>
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Supportive Care Domain (SCNS-SF34):

- Health and Information: 58%
- Physical and Daily Living: 55%
- Psychological: 55%
- Sexual: 27%
MULTIPLE BARRIERS TO PALLIATIVE CARE USE

17% Interested in Palliative Care

**Misconceptions and Knowledge Deficits**
- Cannot get it while on treatment: 18%
- Same as hospice: 35%
- Do not know what it is: 38%
- For people who are about to die: 45%

**Logistical and System Barriers**
- Transportation concerns: 23%
- Cost concerns: 24%
- Time concerns: 41%
- Oncologist did not tell me I should: 47%
SUMMARY AND SUGGESTIONS TO CONSIDER

- 50% of patients with metastatic NSCLC may expect a cure
- Unmet needs - especially about concerns for those close to them, maintaining daily function
- Bothersome symptoms: arthralgia, myalgia, rash, respiratory symptoms, GI symptoms
- Oncologists are likely key in overcoming pc misconceptions

Suggestions:
1. Prognostic understanding is a continuous conversation. (their hopes, how tx is going, their worries, your worries)
2. What activities do pts want to do, but aren’t? (IDs sx)
3. Normalize palliative care and reassure about what it is not
FINANCIAL HARDSHIP – AN EMERGING PALLIATIVE CARE CONCERN?
Financial hardship is a significant concern for lung cancer patients

Financial vulnerability
Lung cancer incidence and mortality is higher in rural areas
32% of rural Americans report trouble paying for medical bills
Lung cancer patients 4x as likely to declare bankruptcy

Financial hardship is associated with poor outcomes
Mortality
Quality of life
Treatment adherence

Treatment costs are rising
2.4 fold increase in drug cost to add pembrolizumab

Robert Wood Johnson Foundation Rural Health and Wellbeing in America
Ramsey et al., JCO, 2016; Lathan et al., JCO 2016; Zafar, 2015 JNCI; Chino et al., JAMA, 2017;
Albaba et al., Pharmacoeconomics, 2017;; Bestvina et al., 2017
PATIENTS ARE LIVING LONGER ON THESE NEW REGIMENS

First Line Pembrolizumab

Second Line Nivolumab
Quadrupled 5-year Survival


Gettinger…Brahmer; Journal of Clinical Oncology 2018, 36, 1675-1684
### Sample demographics (N = 60)

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### Measures:

- Medical Expenditure Panel Survey items
  - *(Because of your cancer or its treatment, have you...?)*
- FACIT-COST *(lower scores = more financial distress)*
Endorsed hardship in all 3 domains (psychological, coping, and material)

- Psychological: 63% Worried about family’s financial stability
- Coping: 28% Reduced spending on basics (food, clothing)
- Material: 17% Gone into debt
IMPORTANCE OF ASSESSING IMPACT ON CAREGIVER’S EMPLOYMENT

42% Caregiver took time off work, changed hours, duties

More likely to endorse all 3 domains of hardship
81% whose caregivers had made a change at work vs.
19% whose did not, $p < .001$

Worse FACIT-COST scores
(financial distress; lower score = more distress)
19.6 Mean COST for those whose CG had work change vs.
26.8 Mean COST for those whose CG had not, $p = .013$
SUMMARY AND SUGGESTIONS TO CONSIDER

- Most may be worried about impact on family’s finances
- 25% may experience financial hardship in multiple domains
- Caregiver change in employment: Patient more likely to be experiencing hardship and financial distress

Suggestions:

1. Screen: Trouble paying for the basics? Worried about their family’s financial future? Has their caregiver had to make a change at work?
2. Refer: Social work, financial counseling, navigators, psychology, pharmacy – medication review
3. Talk about it – part of decision making, patient values?
OVERALL SUMMARY

ASCO guideline: Palliative care within 8 weeks dx of advanced stage cancer; interdisciplinary team-based care

PC messaging matters: it’s a part of quality care, works alongside cancer tx, does not mean giving up on pt, etc.

More attention to function (e.g., activity loss, daily living concerns), caregiver, and financial concerns

Do not be discouraged if you do not have an embedded outpatient palliative care team. You can do a lot of “primary” palliative care. There are different models! (see resource pages at end of slide deck)
THANK YOU!

You may email questions (or comments) to:

Laurie
lsteffen@wakehealth.edu (thru June 2019; laurie.mclouth@gmail.com thereafter)
CHALLENGES OF PROGNOSTIC DISCUSSIONS AND STRATEGIES FOR HAVING THESE DISCUSSIONS

JENNIFER GABBARD, MD
WHAT IS PROGNOSTIC AWARENESS?

- Discussions of prognosis should not only address life expectancy but also include information about their likely cancer trajectory.
- This helps patients plan and set realistic goals.
- So prognostic awareness is the patient’s capacity to integrate the likely disease trajectory and their prognosis.

JACKSON 2013, WEISSMAN 1972
With deeper prognostic awareness patients can
- Weigh burdens and benefits of treatment
- Have more meaningful discussions of their goals and values
- Match treatment decisions to goals and values
- Reduced psychological distress

Chochinov et al., 2000; Innes and Payne, 2009; Lichtenthal et al., 2009; Thompson et al., 2009; Wright et al., 2008
PROGNOSTIC AWARENESS IS DYNAMIC, LIKE A SWINGING PENDULUM

We conceptualize this normal coping as a swinging pendulum of awareness, from more integrated and realistic to less integrated and less realistic.
INTEGRATION HAPPENS OVER TIME

- This takes time.....
  - Middle space of knowing - Weisman
  - Impossible to live with the awareness of one’s terminality every minute of the day
  - It is normal and healthy to have times when the patient almost forgets.
  - This reality makes it hard for clinicians to know what the patient needs.
PROGNOSTIC AWARENESS IS DYNAMIC, LIKE A SWINGING PENDULUM

Patient’s expressions of hopes that are less likely to be realized.

Patient’s expressions of hopes that are more likely to be realized.
NEED TO NURTURE HAVING HOPE WITH OUR PATIENTS

- Being hopeful is a key component of living fully and developing prognostic awareness.
- Helping patients live fully and hope promotes their ability to engage in difficult conversations about the illness.
- Learn how to enjoy it with them.
- Partner in realistic hopes and goals.
  - There are a lot of things patients can be hopeful about even if they have advanced/terminal cancer.
WHEN SHOULD YOU HAVE THESE DISCUSSIONS?
A greater percentage of patients assigned to early palliative care retained or developed an accurate assessment of their prognosis over time (82.5% vs 59.6%; P=.02) compared with those receiving standard care.

Patients receiving early palliative care who reported an accurate perception of their prognosis were less likely to receive intravenous chemotherapy near the end of life (9.4% vs 50%; P = .02).
HONEST INFORMATION PRECIPITATES EMOTION

Prognostic information

Less realistic

Hope

more realistic hopes

Emotion

Sadness, anger, or disbelief.
WHERE SHOULD THESE DISCUSSIONS OCCUR?
LOCATION AND TIME MATTERS

- It is not uncommon for patients with advanced cancer to become ill and to arrive to hospital having had no prior discussions about their goals of care and prognosis.

- Multiple shows have shown that 50% or less of patients with advance cancer understand their prognosis. (Chen et al 2017) (Yennurajalingam et al 2018)

- Mack et al 2012 showed
  - Only 27% of oncologist had documented goals of care discussions with their patients.
  - Discussions took place a median of 33 days prior to death

- Raskin et al 2015 showed that in patients with end stage lung and pancreatic cancer:
  - Only 4% of patients with a life expectancy <1 year had documentation of a care plan in the event of an acute deterioration (i.e if they got sicker)
WHEN SHOULD YOU HAVE THESE DISCUSSIONS?

- Early after diagnosis
- With each change/transition to different chemotherapies or immunotherapies
- Declining functional status
- Worsening symptom burdens
- Progression of disease/treatment maybe no longer beneficial
HOW DO YOU HAVE THESE PROGNOSTIC DISCUSSIONS?
Start first with assessing how they are doing: “what’s your sense of how you are doing”?

- This can be a useful guide, if a patient states “I am fine!!!” vs quickly dissolves into tears, can help you get a sense of how they are coping in that moment but also can indicate the patient’s readiness for discussions of prognosis.

Inquire whether they can imagine getting sicker

- “I know we are hoping that things will go well for a long time but I wonder if we should prepare in case things don't go as well as we hope. Do you ever imagine what it would be like if things did not go so well or have you ever had times when you think about what it might be like if you get sicker?”
What is patient’s understanding (perception) of diagnosis, treatment, and prognosis.

“Tell me what you understand about your cancer.”

“To make sure we are on the same page, can you tell me what your understanding of your cancer is?”
Always ask permission before telling someone their prognosis because not everyone is ready to hear it or wants to know it.

- “Would it be ok for me to discuss where I think we are with your cancer and what the future may look like?”
- “Is that something that would be helpful for you to know?” or “is that something you would like to know?”

Ask how they would like to receive this information

- “How do you prefer to discuss medical information? Some people prefer a global picture of what is happening (best/worse case) and others like all the details (numbers), what do you prefer?”

Do you prefer I talk with you, your family, or both?
ANTICIPATE AND EXPLORE

- Anticipate ambivalence
- Talking about the future can be scary.
- “It sounds like part of you wants to know more and part of you doesn’t. Can you say more about how you’re feeling on both sides?”
- “If you are not sure if you would like to know this, maybe you could tell me how you see the pros and cons of discussing this?”
- “From what I know of you, talking about this information might affect decisions you are thinking about.”
I know this can be scary to talk about....what I would like to do is open this box and talk about it today and then we can close that box and not talk about it again unless things change but I think it’s important that we at least talk about it once, is that ok?
Some patient’s health is declining but they remain ambivalent or resistant to prognostic information
“I am beginning to worry that your____(maybe treatment) may be doing more harm than good for you now. I wish we did not have to discuss this, and I worry that if we don’t, we won’t be able to make good decisions about what’s most important to you. Do you think we can find a way to talk about this?”
Some patients do not want much information now, but would want to know if things changed....
“Let’s stay focused on treatment and hoping for the best. You can count on me to let you know if there ever comes a time when that plan is not working anymore and we need to shift gears.”
TELLING INFORMATION

- **Give a warning shot** “I have something serious we need to discuss”

- **Avoid Medical Jargon**

- **Give the news using a one sentence headliner**: “Your cancer has spread to your liver, and sadly its getting worse despite our treatments”
  - Incorrect: “there are multiple enhancing hypodensities in the hepatic parenchyma”.

- **Use Pauses and Silence**
  - Wait for the patient and family to speak after giving bad news.
“I can see this is not what you were hoping for.”
“H wish I had better news”
“I know this is not what you expected to hear today”.
“I can’t imagine how difficult news to hear.”
Respond to emotion using “Nurse”
### NURSE statements for articulating empathy

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<th>Example</th>
<th>Notes</th>
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| **Naming** | “It sounds like you are frustrated”  
In general, turn down the intensity a notch when you name the emotion |
| **Understanding** | “This helps me understand what you are thinking”  
Think of this as another kind of acknowledgment but stop short of suggesting you understand everything (you don’t) |
| **Respecting** | “I can see you have really been trying to follow our instructions”  
Remember that praise also fits in here eg “I think you have done a great job with this” |
| **Supporting** | “I will do my best to make sure you have what you need”  
Making this kind of commitment is a powerful statement |
| **Exploring** | “Could you say more about what you mean when you say that…”  
Asking a focused question prevents this from seeming too obvious |
USE “I WISH” STATEMENTS
Use “I Wish” Statements

- After breaking bad news....
  - I wish I had some other kind of news to give you.
- “I want to stay alive until my daughter graduates from college”...
  - “I wish I could promise you that.”
  - “I wish that were possible. It sounds like all of us would be a lot happier if that were so. It must be very hard to contemplate missing out on your daughter’s future.”
- “Can’t you doctors do more to treat this illness?...
  - “I wish we could do more and that medicine had better answers for your cancer”

- “I don’t see how I can go on”...
  - I wish I could give you a simple formula for how to proceed, but I will work with you to find a way through this.
  - “I want everything possible done to save my father”......
  - “I wish we had treatments that could turn things around and allow him to wake up.”
  - “I wish I could say that the chemo always works”
  - “It must be very hard to come to the intensive care unit every day and see so little change. I wish medicine had the power to turn things around.”
Preserving Hope while being Honest

“I hope” _______ And(not but) “I worry”_______

• “**I hope** you’ll be able to attend you're granddaughters wedding **and I worry** that you may not have that much time?”
• “**I hope** you that you will regain the use of your legs; at the same time, **I worry** you may not.”
IS THERE ANY HOPE?

“I can see this isn’t what you were hoping for. Pause.....I want you to know I’ll be here for you on this journey.”

“I know this information can be hard to hear...Pause”

“There are all kinds of things we hope for, what comes to your mind when you think about hope?”
ALWAYS ASK IF THEY HAVE ANY QUESTIONS

- We’ve just talked about a number of things...
- Did I answer your question?
- What other thoughts or questions are coming up for you?
Provider training is key, one program is Serious Illness Care Program (SICP) through Adrian Labs.

A 2.5-hour training program includes a brief didactic session that introduces ACP, a demonstration and discussion of the Serious Illness Communication Guide, and more than 60 minutes of role-playing observed by a palliative care attending physician with personalized feedback.

Vital Talk

- 8 hour long training program with role-playing

Some others include The Conversation Project, Respecting Choices, Prepare for your care website.
## Serious Illness Conversation Guide

### Conversation Flow

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<th>Step</th>
<th>Patient-Tested Language</th>
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<td>1. <strong>Set up the conversation</strong></td>
<td>“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?”</td>
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</tbody>
</table>
| 2. **Assess understanding and preferences** | “What is your understanding now of where you are with your illness?”  
“How much information about what is likely to be ahead with your illness would you like from me?” |
| 3. **Share prognosis** | “I want to share with you my understanding of where things are with your illness...”  
*Uncertain:* “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”  
*OR*  
*Time:* “I wish we were not in this situation, but I am worried that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year).”  
*OR*  
*Function:* “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.” |
| 4. **Explore key topics** | “What are your most important goals if your health situation worsens?”  
“What are your biggest fears and worries about the future with your health?”  
“What gives you strength as you think about the future with your illness?”  
“What abilities are so critical to your life that you can’t imagine living without them?”  
“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”  
“How much does your family know about your priorities and wishes?” |
| 5. **Close the conversation** | “I’ve heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”  
“How does this plan seem to you?”  
“I will do everything I can to help you through this.” |
| 6. **Document your conversation** |
| 7. **Communicate with key clinicians** |
Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.
North Carolina Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

- This form has 3 parts. It lets you:
  - Part 1: Choose a health care agent.
    - A health care agent is a person who can make medical decisions for you if you are too sick to make them yourself.
  - Part 2: Make your own health care choices.
    - This form lets you choose the kind of health care you want.
    - This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.
  - Part 3: Sign the form.
    - It must be signed before it can be used.

Think about what makes your life worth living. Put an X next to all the sentences you most agree with.

- My life is only worth living if I can:
  - talk to family or friends
  - wake up from a coma
  - feed, bathe, or take care of myself
  - be free from pain
  - live without being hooked up to machines
  - I am not sure

- My life is always worth living no matter how sick I am

- If I am dying, it is important for me to be:
  - at home
  - in the hospital
  - I am not sure

- Is religion or spirituality important to you?
  - yes
  - no

- What should your doctors know about your religion or spirituality?
FIVE WISHES

https://fivewishes.org/
WHAT IF YOU FEEL YOU NEED TO DISCUSS HOSPICE?
IT’S NOT WITHDRAWING CARE BUT CHANGING THE FOCUS OF CARE

- Hospice is not about dying, it is about helping someone live as well as they can for as long as they can
- An interdisciplinary team of hospice professionals can do a great deal to control pain, reduce anxiety and provide medical, spiritual and emotional comfort to patients and their families
Try to Align the Patient/Family Agenda with Hospice
“If I’m hearing you correctly, it seems that your main goal is to stay at home and spend time with your family...”

“In order to meet your goals we will need to help you in several ways......”

“One of the best ways to accomplish this is through involving hospice care......”
COMMON MISCONCEPTION

- Many think hospice is a place and is not provided in the home.
- Many think that hospice routinely provides 24 hour care, sadly they don’t.
- Patients may be concerned about leaving their health team and physician.
- Technically with most hospices, anyone can be the Attending of Record. Therefore a patient can select their PCP if the PCP is willing to be the attending of record for the hospice.
SUMMARY AND SUGGESTIONS TO CONSIDER

• It’s very common for patient’s to swing in a pendulum of awareness of their prognosis.
• It’s very important to assess if a patient’s ready to talk about prognosis before discussing.
• Use of Ask-Tell-Ask, Nurse (responding to emotion), I wish statements, and I hope and I worry, can be very helping when having prognostic discussions.

Suggestions:
1. Prognostic understanding is a continuous conversation.
2. It’s important to have these conversations early and as the disease progresses.
3. Try and involve family in these discussions as much as possible (as long as the patient agrees)
4. Don’t forget about the power of just Silence
THANK YOU!

Jennifer Gabbard, MD

You may email questions to:

jgabbard@wakehealth.edu
RESOURCES

Talking about prognosis:

• The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: A communication guide. Jackson et al., 2013
• Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. Bernacki et al 2019
• Approaching difficult communication tasks in oncology. Back et al., 2009
• How much time do I have?: Communicating prognosis in the era of exceptional responders. LeBlanc et al., 2018
• CAPC communication courses: https://www.capc.org/training/communication-skills/
• VitalTalk communication courses and app: https://www.vitaltalk.org/
  https://www.vitaltalk.org/vitaltalk-apps/

Talking about palliative care, hospice, advance care planning

• ACS palliative and supportive care: https://www.cancer.org/treatment/treatments-and-side-effects/palliative-care.html
• ASCO’s Palliative Care In Oncology Guide: https://www.asco.org/practice-guidelines/cancer-care-initiatives/palliative-care-oncology
• ASCO Answers: Advanced Care Planning (32 pg guide for patients and families)
• Clinical Practice Guidelines for Quality Palliative Care: 4th Edition, National Coalition for Hospice and Palliative Care, 2018
• Palliative Care vs. Hospice (link from National Hospice and Palliative Care Organization) https://www.nhpco.org/
• Prepare website: https://prepareforyourcare.org/welcome
Find palliative care providers: getpalliativecare.org

American Academy of Hospice and Palliative Medicine:
http://aahpm.org/education/overview

National Hospice and Palliative Care Organization:
http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3406

Choosing Wisely: Five Things Physicians and Patients Should Question about Hospice and Palliative Medicine.

Advance Cancer Care Planning:
https://www.cancer.net/sites/cancer.net/files/vignette/Advanced_Cancer_Care_Planning.pdf

Rural palliative care:
• Rural palliative care: a comprehensive review. Robinson et al., 2009
• Comparison of support needs between rural and urban family caregivers providing palliative care. Brazil et al., 2014
Immunotherapy toxicities, financial distress:

- Management of immune-related adverse events in patients treated with immune checkpoint inhibitor therapy...Brahmer et al., 2018 JCO
- ESMO Patient Guide on Immunotherapy Side Effects
- Immune checkpoint inhibitor toxicity review for the palliative care clinician. Hansen et al., 2018, JPSM
- NCI Financial Toxicity and Cancer Treatment Health Professional Version

Models of Palliative Care:

- Models of outpatient palliative care clinics for patients with cancer. Finlay et al., JCO, 2019
- Generalist plus specialist palliative care – creating a more sustainable model. Quill & Abernethy, NEJM 2013
- Integrating palliative care into the trajectory of cancer care. Hui & Bruera, 2016

ASCO Annual Meeting Opportunity: October 2019
CASE PRESENTATION

ANDRIA CATON, BSN, RN, OCN, CHPN
ASHLEY DERINGER, ANP-BC, ACHPN

Northeast Georgia Medical Center
THE REAL A TEAM
END OF LIFE CARE

Advance Care Planning

Advance Directives

POLST
Communication at the End of Life Care

- Requires skill and practice
- Families are more satisfied when clinicians provide assurance that the patient will not be abandoned before death and will not suffer, and support the family and patient’s decision whether it is to forgo or to continue therapy
Symptom burden is significant across the trajectory of lung cancer and impacts quality of life

- Top 5 reported symptoms of lung cancer
  - Dyspnea, Cough, Anorexia, Fatigue, and Pain

- As lung cancer advances, so do the symptoms
CASE STUDY – QUALITY OVER QUANTITY

- **Social**
  - 62 y/o who had quit a 2 pack/day tobacco habit at the age of 55
  - Married/no children
  - Four sisters had been estranged because of spouse

- **Medical**
  - Co-morbidities: COPD
  - NSCLC diagnosis – Stage IV
  - Treatments
CASE STUDY – QUALITY OVER QUANTITY

- Psychological
  - Fear of dyspnea and air hunger
  - Controlling spouse
    - Had alcohol dependence
    - Thought staff were killing the patient with morphine
    - Wanted patient to seek experimental treatments in Mexico
CASE STUDY – QUALITY OVER QUANTITY

- Patient decided to stop medical treatments when the benefit outweighed the burden
- Important for her to have a good quality of life for the remainder of her life
- Made herself a DNR
- Spent the morning of her last day on earth drinking mimosas and having breakfast with her sisters
- Last hours were spent with sisters singing to her
REFERENCES


THANK YOU ALL FOR PARTICIPATING IN THE LUNG CANCER PATIENT SUPPORT ECHO

WE WILL BE SENDING OUT A SURVEY IN THE NEXT 2-3 DAYS AND WOULD APPRECIATE YOUR FEEDBACK ON THE ECHO.

Be on the lookout for new clinical ECHO opportunities from the American Cancer Society in late Summer 2019:

Multiple Myeloma and ALL Treatment and Patient Support

Colorectal Cancer Treatment and Survivorship

Addressing Bone Health Issues In Breast and Prostate Cancer Patients

and

Additional sessions on Lung Cancer Screening and Patient Support