the schwartz center
FOR COMPASSIONATE HEALTHCARE

Webinar Series

Navigating Discussions of Prognosis: Balancing Honesty With Hope

Tuesday, January 13, 2015

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2

Today's Speakers

Vicki Jackson, MD, MPH
Chief, Division of Palliative Care
Massachusetts General Hospital

Beth A. Lown, MD
Medical Director, The Schwartz Center for Compassionate Healthcare,
Associate Professor of Medicine,
Harvard Medical School

3

Navigating discussions of prognosis: balancing honesty with hope

Vicki Jackson, MD, MPH
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4

Financial Disclosures

- None to report

5

Learning Objectives

- Appreciate the benefits of discussing prognosis with patients with serious illness
- Describe the myths about and barriers to discussing prognosis
- Apply a cognitive model for discussing prognosis with patients

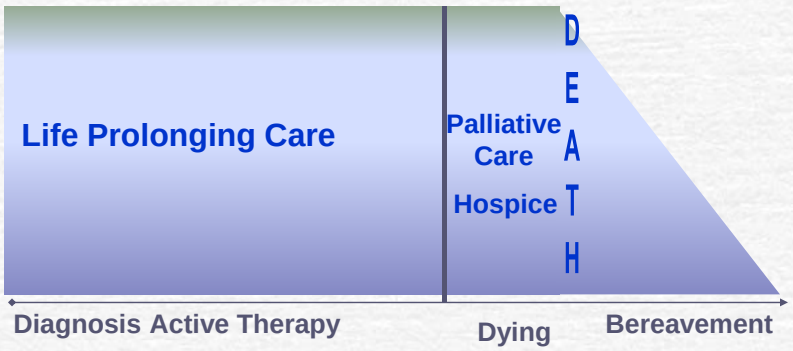
6

Subspecialty of 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 or prognosis. It is an extra layer of support to the patient's other clinicians.

7

Traditional model for care of patients with serious illness



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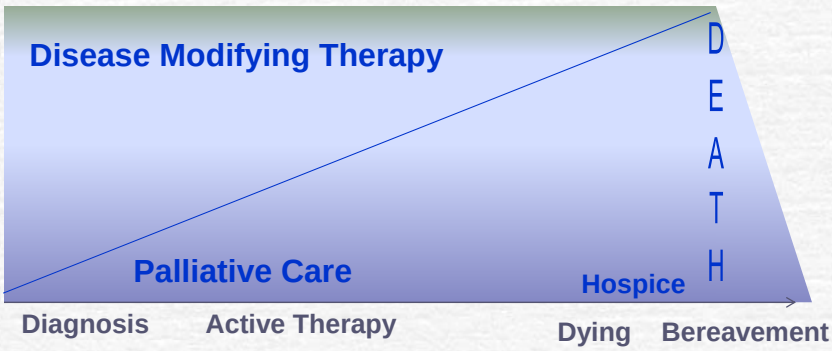
Primary Palliative Care should begin early in the course of serious illness



9

Our job is to help patients cultivate prognostic awareness

- Prognostic awareness is a patient's capacity to understand his or her prognosis and the likely illness trajectory

10

Prognostic awareness promotes informed shared decision making

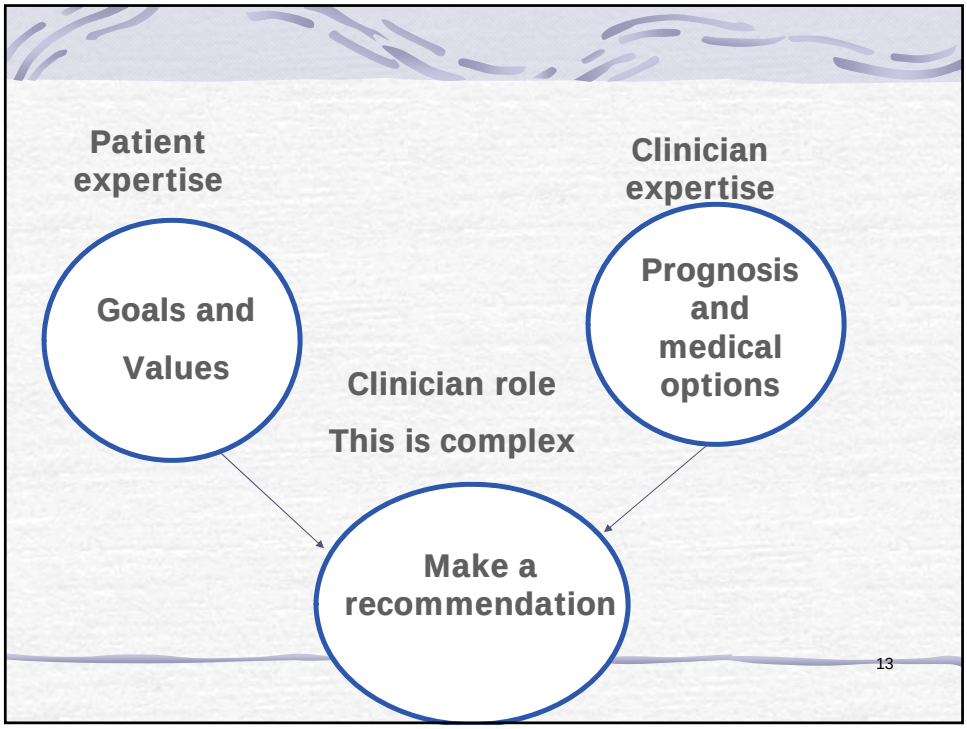
- With more information patients can:
  - Match decisions about medical treatment with personal goals and values
  - Weigh burdens and benefits of treatment
  - Prepare themselves and loved ones for the future

11

Advance care planning
Why can it be so difficult?

- It is a dynamic relationship between patient and clinician
- Clinician has a deeper understanding of the illness and must find a way to communicate that so the patient can make fully informed medical decisions

12



Patients with serious illness want:

- Relief of pain and other symptoms
- Relief of burdens on family
- Achieve a sense of control
- Assistance strengthening relationships with loved ones
- Informed shared medical decision-making with medical care team
  - Avoid inappropriate (unwanted) prolongation of the dying process

Singer et al, JAMA 1999

14

Prognostic awareness can help...

- **Relieve burdens on family**
- Achieve a sense of control
- Assistance strengthening relationships with loved ones
- Informed shared medical decision-making with medical care team
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Singer et al, JAMA 1999

15

Serious illness can be financially and psychologically difficult for families

- In 20%, a family member quit work or made a major life change to provide care to the patient
- 31% lost most or all of the family savings

Covinsky JAMA 1994; 272: 1839

Compared to death at home with hospice:

- Death in ICU associated with 5X family risk of PTSD

Wright A et al. JCO 2010

16

Prognostic awareness can help patients...

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Singer et al, JAMA 1999

17

Provision of prognostic information changes care

- Patients who expected 6-mo survival are 2.5 times more likely to choose and receive life-extending therapy, but did not have longer survival
- Patient understanding of 10% chance of dying in 6 months led to less aggressive treatment decisions

- *Weeks JC et al. JAMA 1998;279: 1709-1714*

18

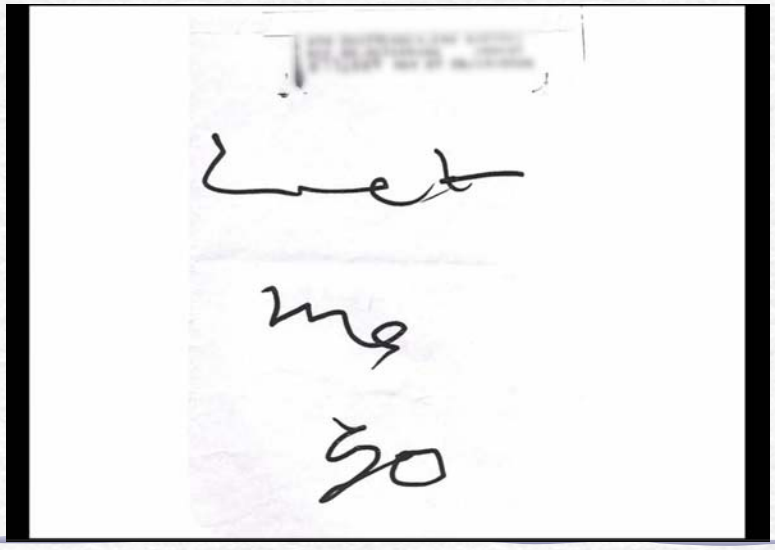
Advance care planning can help patients achieve a sense of control

Over 80% of patients and families report wanting:

- Treatment preferences in writing
- Feeling prepared for death

Steinhauser et al, JAMA 2000

19



20

Prognostic awareness can help patients...

- Relieve burdens on family
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- **Assistance strengthening relationships with loved ones**
- Informed shared medical decision-making with medical care team
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Singer et al, JAMA 1999

21

Families of hospitalized seriously ill patients need more support

Family members of decedents in high-intensity hospital service areas report lower quality of:

- Emotional support for the patient
- Shared decision-making
- Information about what to expect
- Respectful treatment

Teno et al. JAGS 2005;53:1905-11.

22

Prognostic awareness can help patients...

- Relieve burdens on family
- Achieve a sense of control
- Assistance strengthening relationships with loved ones
- **Informed shared medical decision-making with medical care team**
  - **Avoid inappropriate (unwanted) prolongation of the dying process**

Singer et al, JAMA 1999

23

Difficult conversations correlate with improved outcomes

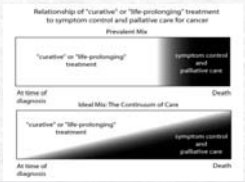
- Multisite, longitudinal study of 332 patient-family dyads
- 37% of patients reported having prognosis discussion at baseline
  - Associated with:
    - Lower rates of ventilation
    - Lower rates of resuscitation
    - Lower rates of ICU admission
    - Earlier hospice enrollment
      - Wright et al. JAMA 2008 300(14):1665-1673.

Wright, 2008

24

Can we improve the care for seriously ill patients? Palliative Care Research at MGH

Pilot Feasibility Study




ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

2001 2003 2005 2007 2010 2011 2015

150 patients with newly diagnosed metastatic NSCLC

Early palliative care integrated with standard oncology care

Standard oncology care

R01 Recruitment nearly complete RCT of Early, Integrated PC in 350 Advanced Cancer Patients

25

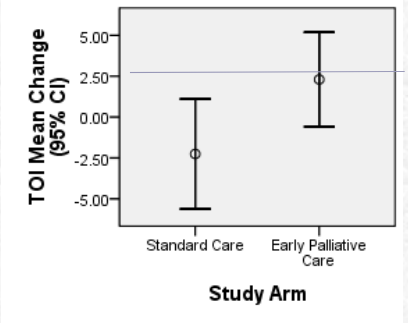
Early intervention palliative care study

- Randomized controlled trial of 151 patients
- Comparing standard oncology care plus early referral to palliative care to standard oncology care
- Population: patients with newly diagnosed metastatic non small cell lung cancer
- Intervention: At least monthly visits with the palliative care team
- Primary outcomes: Quality of life
- Secondary outcomes: Mood, end of life outcomes

Temel et al NEJM, 2010

26

Early palliative care was associated with improved quality of life at 12 weeks



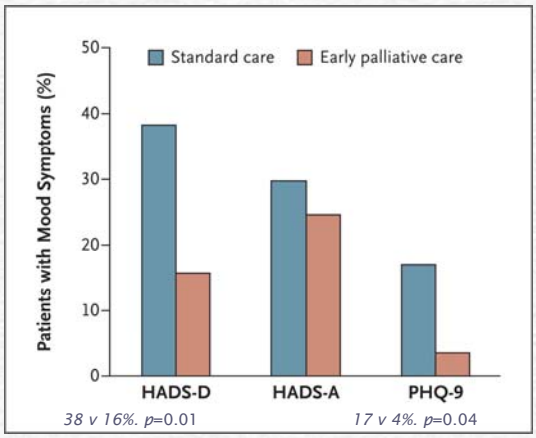
Mean change Standard Care = **- 2.3**

Mean change Early Palliative Care = **+ 2.3**

***p*=0.04**

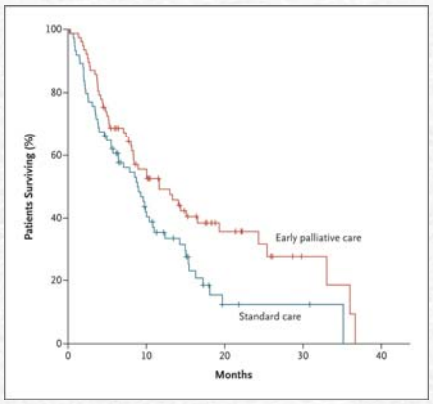
27

Early palliative care was associated with a 50% lower rate of depression



28

Patients who received early palliative care had prolonged survival



Palliative Care=11.6 months
Standard Care=8.9 months
Entire Sample=9.8 months
*Log Rank p<.02

Controlling for age, gender and PS, adjusted HR=0.59 (0.40-0.88), p=0.01

29

Patients with prognostic awareness

- Can engage in more fully informed medical decision making
- Can have a more meaningful discussion of their goals and values for their treatment
- Make different treatment decisions
- Video illustration-Exploration of goals and values
  - http://youtu.be/D01lT0aBBgM

30

If it is better for patients, why don't we do it?

- We are worried....
  - We will take away hope
  - That we are inaccurate in our prognostic estimates
  - That some patients don't really want this information
  - It will take too much time

31

Myth:
Promotion of prognostic awareness takes away hope

Truth:

Talking about prognosis **is** hard but it does not take away hope

32

Patients and families want to talk about prognosis

- Helps with decision-making
- Not associated with more worry or depression
- Better bereavement adjustment
- Hope can be increased or at least preserved with serious discussions

Wright JAMA 2008

Wright, JCO 2010

Mack, JCO 2007

33

Myth:
We don't ever really know prognosis so we can't talk about it

Truth:

There is prognostic uncertainty.

We need to find a way to talk about it.

34

Physicians struggle to determine prognosis

- Physicians overestimate survival by a factor of 5.3
- As the duration of physician-patient relationship increases and time since last contact decreases, prognostic accuracy decreases
- Physicians in the upper quartile of practice experience are most accurate

Christakis, 2000

35

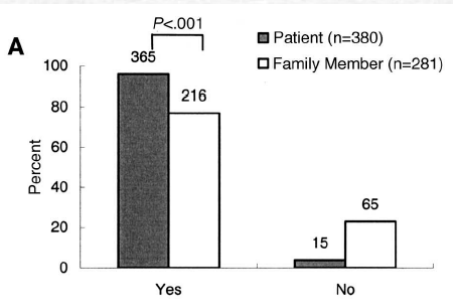
Myth:
No one really wants to know their prognosis

Truth:

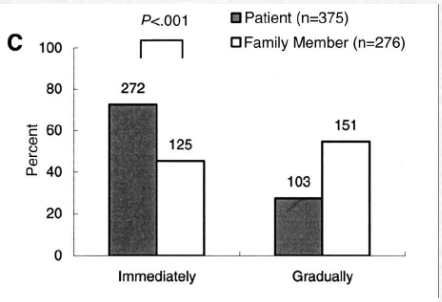
Patients do want to know but it is hard to talk about

36

Patients with advanced cancer want to know prognosis, early in the course of illness



Do you want to be informed the truth?



When is the appropriate time to be informed the truth?

Yun, JCO 22 (2) 2004

37

Patients are ambivalent about receiving prognostic information.

- What percentage of patients want their doctor to be honest?
- 100%
- What percentage of patients want their doctor to be optimistic?
- 91%

Kutner, 1999

38

Myth:
Talking about prognosis takes too much time

Truth:

It does take some time but is a skill that can be learned

39

Discussing prognosis is a skill that can be learned

- Discussions about serious illness in the primary care setting
  - Non expert 5.6 minutes
    - MD talked most of the time
    - Little exploration of the patient's values
    - More focus on procedures
  - Experts 14.7 minutes
    - Patient talked more of the time
    - Focused more on patient's goals
    - More partnership for treatment decisions
      - Tulsky et al Annals 1996; Roter Arch Int Med 2000

40

Before talking about prognosis: a word about patient coping

- The cultivation of prognostic awareness
  - Is a process
  - Happens over multiple visits
  - Changes over time

41

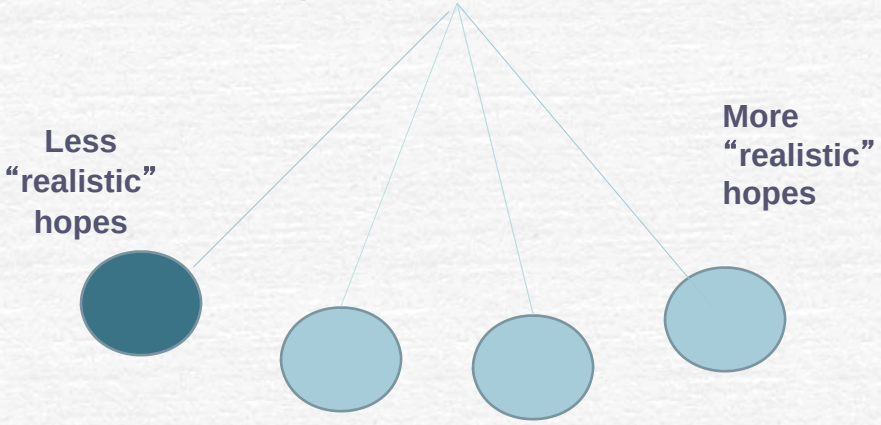
Patients coping with serious illness have two main tasks

- To understand the likely trajectory of their illness
- To integrate their prognosis and life expectancy

To achieve this they must develop **both a cognitive and emotional** understanding

42

Patients struggle to understand their own prognosis



43

Jackson JPM 2012

Integration happens over time

- It is a process
  - 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.

44

Cognitive model for providing prognostic information

- Assess desire for information
  - Ask/Tell/Ask
- Communicate prognosis kindly
  - Hope/worry
- Identify the affect
  - Name and respond to it
  - I wish…
- Hope for things that are possible
  - I am hoping…
- Concluding with a plan

45

Provide prognostic information to help patients make informed decisions

- Patients can ask for two different types of prognostic information
  - "Doc, how much time do I have left?"
  - "What is going to happen to me with this illness?"
    - Both kinds of information tell the patient something about prognosis
    - But we will answer the questions differently

46

Experts use specific skills to address patient ambivalence

- ASK-TELL-ASK
  - Assess what patients really want to know
    - Why is the patient asking?
    - What do they want to know?
    - Permission that there are no right answers here
  - Avoids giving too much information
  - Allows honest discussion at the level the patient needs
  - Vital Talk Website

Back, 2005

47

Some patients want to know life expectancy

- Use a standard method to provide prognostic information about length of time the person has to live
  - Days to weeks
  - Weeks to months
  - Months to years

48

Some patients want to know what the future will be like

- Patients do not know what it looks like to be ill and eventually die from a terminal illness
- They are often surprised that the decline is slow
- They want us to tell them what the illness trajectory will look like

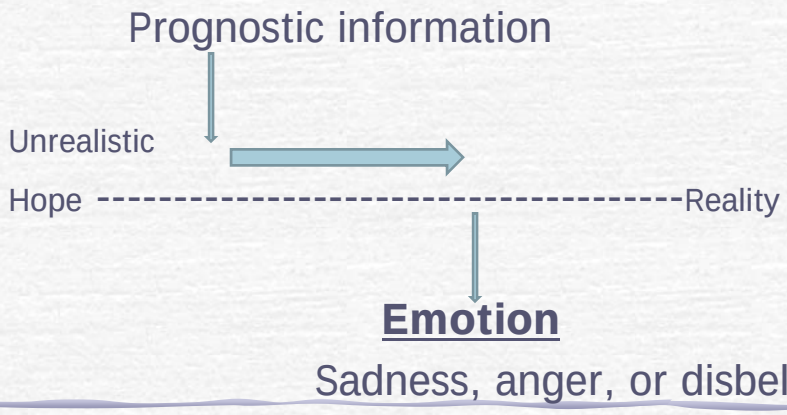
49

Prognostic information can be given kindly

- Patients want to know that we **hope** they will do well.
- The HOPE/WORRY technique
  - "I **hope** that you do well for a long time, at the same time I **worry** that it could be as short as a few months"
  - "I **hope** that you regain some function in your legs, at the same time I **worry** that you may not"
  - Acknowledges uncertainty
  - Aligns with the patient
  - Allow MD to be honest about prognosis

50

Honest information precipitates emotion



51

Emotions should be expected The key is what you say next

- Clinicians often struggle with what to say next
  - Common Pitfalls to Avoid
    - Reassurance about clinical possibilities
    - Offer unhelpful treatments
    - Retreat into medical details
    - Take back what was said

52

Patient's strong emotions can be supported

- Name the emotion and let the patient know we heard it
  - **"I can only imagine how sad this is to hear."**
- The "I wish" statement
  - A strategy for genuine empathy without taking back prognostic information
  - **"I wish I had different news"**

53

Patients hopes can be supported honestly

- I HOPE....
  - Focus on things that can be controlled
  - "*I am hoping that we can get you feeling better so you can spend good time with your son.*"

54

Cognitive model for providing prognostic information

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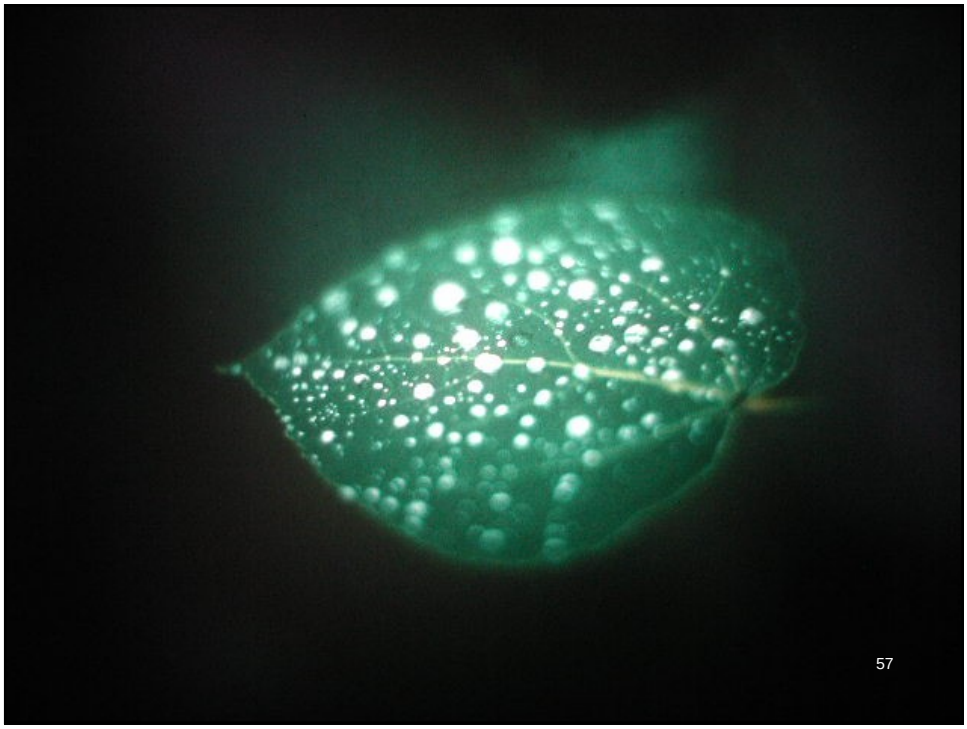
55

We all care for the seriously ill- Our job as healers

- Treat suffering
  - physical, psychological, existential
- Provide a sense of control and dignity
- Prepare the patient and family so they can do the work they need to do
- Find our own language to talk about difficult topics
- Avoid prolongation of dying
- Employ the assistance of a team and partner in this care

56



Questions & Answers

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58

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59


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61