Palliative Care: When to Refer a Patient and How to Have This Important Discussion

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March 25, 2014
Thank you for Joining the Webinar Today.

The Presentation will Begin Shortly.
Palliative Care for Heart Failure Patients

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March 25, 2014
Objectives

• To review the differences between hospice and palliative care services

• To discuss the role of palliative care in HF

• To discuss the management of symptoms commonly experienced by HF patients at end of life

• To address important issues in advance care planning for patients with HF
Definition → Palliative Care

- Palliative Care:
  - The clinical specialty focused on relief of the pain, symptoms and stress of serious illness
  - The goal is to improve quality of life
  - Palliative care is appropriate at any point in an illness and can be provided at the same time as curative treatment
  - 63% of US hospitals with 50+ beds have inpatient palliative care services
The Old Model of Palliative Care

Life Prolonging Care

Medicare Hospice Benefit
Palliative Care Continuum: An integrated model for chronic progressive illness

Services along the continuum are focused on the person with the illness as well as the family and caregivers.
Definition → Hospice

- Hospice:
  - A program to provide care for terminally ill people
  - Patients have a prognosis of six months or less as certified by a physician
  - Interdisciplinary team-oriented approach to expert medical care, pain management and emotional and spiritual support for patients and families
  - Emphasis is on caring, not curing
  - Patient does not need to be DNR
  - Patient can be receiving palliative treatments
  - Enrollment in hospice is voluntary
  - There are currently 5,300 hospice programs in the USA
What is the difference between hospice and palliative care?

**Palliative Care**
- Supportive care for anyone with a serious illness
- Available at any stage of a serious illness
- Can have it along with curative treatment
- Not dependent on prognosis

**Hospice**
- Specialized care for terminally ill patients
- Available at the end stages of an incurable illness
- No longer receiving curative treatment
- Prognosis is usually 6 months or less
Goals of Palliative Care

• Improve quality of life
• Provide relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression
• Improve ability to tolerate medical treatments
• Help patients have more control over their care by improving communication to facilitate patient understanding of treatment choices and whether or not to pursue treatment
Where is palliative care delivered?

- Hospital (inpatient consults or inpatient unit)
- Outpatient clinic practices
- Assisted living facilities
- Home
- Nursing homes
What are the key elements of palliative care?

- Pain and symptom control
- Communication and care coordination
- Emotional, psychological, social and spiritual support
- Family and caregiver support
Palliative care communication goals with patients and families

- Understand what to expect given the diagnosis
- Share what programs and resources are available
- Help make medical decisions about treatment choices and options
- Match the patients goals and values to their medical care
- Explore the benefits and burdens of treatment options
Other important palliative care facts

Maintenance of primary provider

Palliative care team provides an extra layer of support and works in partnership with each patient’s primary provider (primary care and/or specialist treating provider).

The primary doctor will continue to direct the patients care and play an active role in their treatment.

Team based approach

Usually a team of specialists, including palliative care doctors, nurses and social workers, provide this type of care.

Massage therapists, pharmacists, art and music therapists, nutritionists and others might also be part of the team.
## Generalist Palliative Care versus Specialist Palliative Care

<table>
<thead>
<tr>
<th>Generalist Palliative Care Skill Set (Skills all providers in the hospital are expected to gain comfort with)</th>
<th>Specialist Palliative Care Skill Set (Skills beyond the generalist level that palliative care experts can offer)</th>
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<tr>
<td>Basic management of symptoms including pain</td>
<td>Management of refractory pain or other symptoms</td>
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<tr>
<td>Basic management of depression and anxiety</td>
<td>Management of more complex depression, anxiety, grief and existential distress</td>
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<tr>
<td>Basic discussions about:  • Prognosis  • Goals of treatment  • Suffering  • Code status</td>
<td>Assistance with conflict resolution regarding goals or methods of treatment:  • Between patient and family  • Within families  • Between staff and families  • Among treatment teams</td>
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<td>Assistance in addressing cases of near futility</td>
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What are the Triggers for a Palliative Care Consult?

- **Patient and Family**
  - Uncontrolled Symptoms (pain and non-pain)
  - Distress related to disease or treatment
  - Determination of Goals of Care
  - Concerns regarding medical decision making
  - Assistance with withdrawal of life sustaining interventions
  - Assistance with care of actively dying patients
  - Assistance with transition planning including assessment for hospice eligibility
From: Palliative Care in Congestive Heart Failure

Schematic Etiology of Heart Failure Symptoms


Figure illustration by Rob Flewell. RAAS = renin-angiotensin-aldosterone system; TNF = tumor necrosis factor.

Date of download: 3/9/2014

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A depiction of the clinical course of heart failure with associated types and intensities of available therapies.


Transition to Advanced Heart Failure:
- Oral therapies failing
- A time for many major decisions
- Consider MCS and/or transplantation, if eligible
- Consider inversion of care plan to one dominated by a palliative approach, which may involve formal hospice


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Palliative Care Assessment: A comprehensive review of physical, psychological, social and spiritual needs of the patient and family.

Physical
- Functional Ability
- Strength/Fatigue
- Sleep & Rest
- Nausea
- Appetite
- Constipation
- Pain

Psychological
- Anxiety
- Depression
- Enjoyment/Leisure
- Pain Distress
- Happiness
- Fear
- Cognition/Attention

Social
- Financial Burden
- Caregiver Burden
- Roles and Relationships
- Affection/Sexual Function
- Appearance

Spiritual
- Hope
- Suffering
- Meaning of Pain
- Religiosity
- Transcendence

Quality of Life

Montefiore
Why is PC important in the management of HF?

- HF is very common:
  - #1 cause hospitalizations in Medicare population
  - A leading cause of death in US

- High symptom burden:
  - Pain, dyspnea, fatigue, edema, depression
  - Physical function scores 2SD below average

- Symptoms are treatable
Palliative Care in HF Management

In general, PC has been demonstrated to improve patient outcomes:
- Symptom management
- Quality of life
- Satisfaction with care

“palliative care can be integrated with conventional HF care that emphasizes life-prolonging treatment. This duality of care should be considered a normal approach to patients with HF”*

*Hauptman and Havranek, Arch Intern Med 2005
Key elements of PC for HF

- Discussing prognosis and treatment options
- Eliciting patient’s goals of care
- Supporting advance care planning
- Team-based approach to symptom management
  - Physical
  - Psychological
  - Emotional
  - Spiritual
  - Existential
- Caregiver support
Cardiac Medications

• As indicated:
  – Ace-inhibitor
  – Beta-blocker
  – Diuretic
  – Spironolactone

ALLEVIATE SYMPTOMS AND IMPROVE QoL
Prognostication in HF

• Very difficult: we are unable to predict timing of exacerbations or sudden cardiac death (up to 50% of patients)

• In general, clinicians tend to overestimate life expectancy (by a factor of 5.3)*
  – Increased duration of patient-physician relationship, less accurate prognostication

*Christakis and Lamont, BMJ 2000
Why is prognostication important?

- Allows patients to:
  - Identify priorities based on life expectancy
  - Make informed decisions about their care
  - Complete advance directives and designate a PoA
  - Attend to legal and financial matters
  - Focus on life closure and legacy issues
  - Emphasize participation in pleasurable activities
Functional Capacity

- The most important predictor of mortality in HF
- Decline in functional capacity is associated with high 3 month mortality*

*Lunney JR, JAMA 2003
From: Patterns of Functional Decline at the End of Life


Figure Legend:
Error bars indicate 95% confidence intervals.
Prognostication in HF

• **Poor prognostic factors:**
  – Ischemic etiology
  – Recent cardiac hospitalization
  – High BUN, cr > 1.4, Na <135, anemia
  – SBP <100 or HR >100
  – EF <45%
  – Treatment resistant ventricular dysrhythmia
  – Cachexia
  – Decreased functional capacity
  – Liver dysfunction or delirium due to hypoperfusion
  – Intolerance of AceI due to hypotension
  – Comorbidities: DM, depression, COPD, cirrhosis, CVA, cancer, HIV
Symptom Management in HF
Common Symptoms in Advanced HF

- Pain – 78% (as high as cancer patients)
- Dyspnea – 61%
- Depression – 59%
- Insomnia – 45%
- Anorexia – 43%
- Constipation – 37%
- Nausea / Vomiting – 32%
- Anxiety – 30%
Pain Management

• What is underlying etiology?
  – Angina, edema, comorbidities (OA)

• Avoid NSAIDs / Cox2-inhibitors
  – Antagonize effects diuretics and Ace-I
  – Affect renal function
  – Increase fluid retention/ edema

• Low-dose opioids:
  – 2-5mg morphine po q2h prn
  – Up-titrated as needed
  – Stimulant laxative to prevent constipation
Dyspnea

• Specific Etiologies:
  – Fluid overload
  – Pleural effusion
  – Pericardial effusion
  – Arrythmia

• Management
  – Diuresis:
    • Very high doses loop
    • IV / SC dosing of loops
    • Add thiazide
      – HCTZ 25-100mg
      – Metolazone 5-20mg
  – Repositioning
  – Air circulation
  – Opioids
Opioids for Dyspnea in HF

• Opioids affect CNS processing of input from the lungs and PNS that leads to the sensation of dyspnea.

• Goal is not to stop respiration but to ease the subjective sense of breathlessness.

• Patients may take slower, deeper, more effective respirations.

• Start low, go slow (in up-titration).

• 2-3mg oral morphine suspension q2h prn.

• Benzodiazepines may be used as adjuvant to opioids (esp if high levels of anxiety).
Diagnosing Depression at EoL

- Vegetative symptoms (decreased energy, poor sleep, decreased appetite) may be due to underlying disease

- More specific for depression at EoL:
  - Guilty, hopelessness, worthlessness
Treating Depression at End of Life

- Short-term psychotherapy
  - Problem-based
  - Meaning-based
  - Dignity-based

- SSRI (sertraline)
  - Effect in 1-2 months

- Psychostimulants: use with caution in HF
  - Effect in days
  - May increase appetite, energy and mood
  - Unknown if increases risk of arrhythmia
  - Ritalin 2.5 – 5mg BID (second dose early afternoon)
Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology

Tiny Jaarsma*, James M. Beattie, Mary Ryder, Frans H. Rutten, Theresa McDonagh, Paul Mohacsi, Scott A. Murray, Thomas Grodzicki, Ingrid Bergh, Marco Metra, Inger Ekman, Christiane Angermann, Marcia Leventhal, Antonis Pitsis, Stefan D. Anker, Antonello Gavazzi, Piotr Ponikowski, Kenneth Dickstein, Etienne Delacretaz, Lynda Blue, Florian Strasser, and John McMurray on behalf of the Advanced Heart Failure Study Group of the HFA of the ESC
Goals and steps in the process of providing palliative care in patients with heart failure

- Patient features: >1 episode of decompensation/
  - 6 months despite optimal tolerated therapy
- Need for frequent or continual i.v. support
- Chronic poor quality of life with NYHA IV symptoms
- Signs of cardiac cachexia
- Clinically judged to be close to the end of life

Confirm diagnosis

- Essential to ensure optimal treatment
- Patient education:
  - Principles of self-care maintenance and management of heart failure
- Establish an advanced care plan
  - Designed with the patient and a family member. Reviewed regularly and includes the patients' preferences for future treatment options

Services should be organized.

- The patients' care within the multidisciplinary team,
  - to ensure optimal pharmacological treatment, self-care management, and to facilitate access to supportive services.

- Symptom management
  - Requires frequent assessment of patients' physical, psychological, social, and spiritual needs

- Patients frequently have multiple co-morbidities that need to be identified

- Identifying end-stage heart failure
  - Confirmation of end-stage heart failure is advisable to ensure that all appropriate treatment options have been explored and a plan for the terminal stage of illness should be agreed upon

Breaking bad news to the patient and family

• Explaining disease progression and a change in treatment emphasis is a sensitive issue and must be approached with care
• Establishing new goals of care
  – End-of-life care should include avoidance of circumstances which may detract from a peaceful death.
  – All current pharmacological treatment and device programmes should be considered.
  – Resuscitation orders should be clear

What outcomes can be expected from the consult

Pain and symptom control
- Specific recommendations on treatment of symptoms to improve quality of life
- Follow-up assessment on treatment recommendations

Communication and care coordination
- Conducting family meetings
- Coordinating care among different providers
- Assisting with transition planning

Emotional, psychological, social and spiritual support
- For the patient
- For the family and caregivers
- For the clinical team in the hospital
Elements of Communication About Prognosis With Heart Failure Patients and Families

"Bad news" conversation

Plan the delivery of sad or unexpected information, and warn the patient that you have bad news; follow the points below.

Ask what the patient understands (before you talk).

Ask-Tell-Ask

Correct misunderstanding and

Tell your information.

Ask what questions they have, clarify information.

Simple, honest language

Define medical terms. Speak plainly and avoid euphemisms and relative statistics or percentages. Use numbers ("1 out of 5 people...").

Simple statistics

Describe both chance of death and chance of life.

Ground data in more than 1 way

Ask what the patient hopes for, and identify what you can also hope for.

Hope for best, plan for the worst

Plan for death or other bad outcomes "if things do not go as we hope."

"Both-And"

Create a dichotomy and address both issues.

Normalize uncertainty

Acknowledge that we can’t know for sure, "like many things in life."

Partner and plan

Tell the patient (you or your team) will work with them to meet specific goals.

Deliver length of life in broad range

Provide a broad range "months to years," and allow for error on either end.

Empathize

Name your emotions ("I feel sad"). And identify emotions the patient expresses or might reasonably have ("you look surprised," "many would feel angry").

Follow up

Summarize the plan and set an appointment to follow up on plans and their status.

**Figure Legend:**

The palliative care conversation

- Communication is a complex process in all circumstances, but becomes challenging in advanced illness
- Palliative care teams are extremely skilled communicators
- They are experts at assisting with communication between patients, their families and the various involved medical providers
- The goals of communication are to ensure that patient and family needs are fully met
- These conversations include establishing goals of care, help with decision-making and coordination of care
Purpose of the conversation

- Find out from the patient who they want to help plan and give care
- Help the patient understand their illness and what to expect in the future
- Help the patient figure out what is important
- Try to meet the patient's likes and dislikes
- Help the patient work together with his or her health care provider and health plan to solve problems
Communication skills

Effective communication skills are essential in palliative care at the generalist and specialist level. These include:

• Developmentally appropriate sharing of information
• Active listening
• Determination of goals and preferences
• Assistance with medical decision-making
Family Meeting Rules

- Sit down, take plenty of time
- Do not interrupt
- Ask questions
- No jargon
- Use silence
- Empathize
Legal and Ethical Aspects of Palliative Care

• Advanced directives
  – Health Care Proxy
  – Living will
• Determination of patient’s decision making capacity
• Working with health care proxies and surrogate decision makers
• Physician orders
• Montefiore Forms
• MOLST form
• Utilization of an ethics consult or the bioethics committee or a legal consult
Coordinating Care for Patients With Chronic HF

Effective systems of care coordination with special attention to care transitions should be deployed for every patient with chronic HF that facilitate and ensure effective care that is designed to achieve GDMT and prevent hospitalization.

Every patient with HF should have a clear, detailed and evidence-based plan of care that ensures the achievement of GDMT goals, effective management of comorbid conditions, timely follow-up with the healthcare team, appropriate dietary and physical activities, and compliance with Secondary Prevention Guidelines for cardiovascular disease. This plan of care should be updated regularly and made readily available to all members of each patient’s healthcare team.

Palliative and supportive care is effective for patients with symptomatic advanced HF to improve quality of life.
Decision Making in Advanced Heart Failure: A Scientific Statement From the American Heart Association
Larry A. Allen, Lynne W. Stevenson, Kathleen L. Grady, Nathan E. Goldstein, Daniel D. Matlock, Robert M. Arnold, Nancy R. Cook, G. Michael Felker, Gary S. Francis, Paul J. Hauptman, Edward P. Havranek, Harlan M. Krumholz, Donna Mancini, Barbara Riegel and John A. Spertus

Circulation. 2012;125:1928-1952; originally published online March 5, 2012;
• Data on palliative care in patients with HF are limited, several guidelines and reviews recommend integration of palliative care for all patients with advanced HF
• Can and should be done by all clinicians involved in the care of these patients.
• Referral to a palliative care team should be considered for assistance with difficult decision making and refractory symptom management in advanced disease, even as patients continue to receive disease-modifying therapies.
• It is important to integrate palliative care into the care of patients with heart failure before they enter stage D.

• Even as patients are being considered for transplantation, mechanical circulatory support, or trials of novel therapeutics and pharmacological agents, palliative care can be increasingly integrated to ensure that patients’ symptoms are appropriately controlled and that patients understand the nature of these interventions, as well as the full complement of alternative therapies.
Advanced Directives

- Written advance directives are legal in every state.
- Laws and forms, however, vary state to state.
- There are two general types of advance directives:
  - **Health care proxy** - a document in which the patient appoints someone (a health care agent) to make decisions about his/her medical care if he/she cannot make those decisions.
  - **Living will** - a written document in which a patient's wishes regarding the administration of medical treatment are described if the patient becomes unable to communicate at the end of life. Some documents are combinations of the two.
Determination of medical decision making capacity

- Determination of capacity is situation and decision specific
- The attending physician who is responsible for the care of patients should be able to perform routine capacity assessments – a mental health professional is not needed to determine capacity
Medical decision making when the patient cannot participate

If the patient lacks capacity is there a signed health care proxy form in the chart or prior medical record?

- The form must be signed by the patient and two witnesses to be valid.
- Assigns a primary health care agent and can assign an alternate health care agent
- Health care proxy forms can be filled out at any point with a patient who has capacity and can be changed at any time the patient requests

If there is no health care proxy form who is the surrogate?

- In New York State refer to the Family Health Care Decisions Act (2010)
- Potential Surrogates (in order of priority): (1) Court-appointed guardian (2) Individual designated orally by the subsequently incapacitated individual (3) Spouse or domestic partner (4) Adult son or daughter (5) Parent (6) Adult brother or sister (7) Close relative or friend

What if the patient has no surrogate available?

- The FHCDA authorizes the attending physician to act as surrogate for routine medical treatment.
- For major medical treatment, a physician may act only upon the concurrence of another physician that such major medical treatment is necessary.
- A physician may withhold or withdraw life-sustaining treatment for individuals without a surrogate only upon the independent concurrence of another physician that life-sustaining treatment offers no medical benefit to the patient because the patient will die imminently and the provision of life-sustaining treatment would violate accepted medical standards.
OTHER KEY POINTS TO TAKE AWAY

• Caring for patients with advanced illness is challenging
• Engaging an interdisciplinary team is essential to address the full scope of the patient’s and family’s needs
• Excellent communication helps facilitate care that is patient centered and honors patient’s wishes
• Team members should remember that self care is important
Prognosis is not only about expectations for survival.

Thank You!

Montefiore
**Palliative care:** The process of shared decision making = central tenet of palliative care=the patient and clinician reach an understanding

- Interdisciplinary care aimed at improving quality of life for patients by preventing and relieving suffering and supporting families.
- It can be offered simultaneously with all other appropriate medical therapies.
- Not synonymous with end-of-life care or hospice but can encompass them as the disease advances.
- Allows for continued disease-modifying therapies while ensuring symptom relief and interventions that address psychosocial, physical, and spiritual needs.
  - treating symptoms
  - patients’ treatment plans match their values and goals
Figure Legend:

Schematic Depiction of Comprehensive Heart Failure Care
Figure illustration by Rob Flewell.
Advance Care Planning
Advance Care Planning

- Code Status
- Power of Attorney for Health Care (proxy)
- Advance directive / Living Will: may include
  - Use of artificial nutrition and hydration
  - Do not hospitalize
  - Management of ICD
  - Management of pacemaker
- Financial planning

- Heart Failure Society of America educational module for patients and families (high literacy level)
When to Initiate the Discussion?

- At diagnosis
- At decrease in functional status / progression of disease
- During hospitalization for acute exacerbation
- At hospital follow-up appointment in the clinic

AT ANY TIME! IT IS A PROCESS
Code Status Discussions

- Always in the setting of disease state and overall prognosis
- Very important to address with patients with HF given high rates of sudden cardiac death
- Revisit the issue regularly and with significant changes in clinical status
- The alternative to resuscitation is medical care that is entirely focused on the patient’s comfort
- It is ok to give a medical opinion or recommendation
- A patient with a DNR code status should have ICD deactivated
Power of Attorney

- Does not need to be a relative
- Can be a verbal designation – document it
- Should be someone who can respect and relay the patient’s wishes
- Once the patient identifies a PoA, it is important that they discuss the patient’s wishes and what “quality of life” means according to the patient.
- “What have you told them (or want to tell them) about your preferences for care?”
Role of the PoAHC

- To reflect the wishes of the patient, not what they (PoAHC) would want if in that situation

- Never ask “what do you want us to do?” Ask “Have you ever had conversations with your father about his wishes if he were in this situation?” (other relatives illness, Terry Schiavo)

- Ask “what would your father say if he heard this information that you just heard, and could talk with us?”
Quality of Life

- “Tell me a little about your father. What was important to him?”

- “What made life worth living to your father?”

- “What would he think of his current QoL?”

- “Do you think he would want his current QoL prolonged?”
Informed Decision-making

- Make sure you have explained the *diagnosis, treatment options, and prognosis* to the best of your ability before you ask PoAHC to make a decision (informed consent)
Advance Directives

- Purpose is to ensure that the patient’s wishes are respected

- A “gift” to the PoA / patient’s family
  - Minimize burden of “decision-making”
  - Decreases conflict among family members

- Establishes trust between the patient and the medical system

- In New Mexico: Written instructions signed and dated, no lawyer or notary necessary
Advance Directive

- May include preferences regarding:
  - Use of intubation and cardiac resuscitation
  - Use of minimally invasive ventilation (Bipap)
  - Use of surgery or other invasive therapies
  - Use of artificial nutrition and hydration
  - Time-limited trials of therapies
  - Use of pacemaker or ICD
  - Deactivation of ICD
Deactivation of ICD

- Approximately 20% of patients with ICD are shocked within the last weeks of life: painful and decreases QoL

- Deactivation is legal and ethical: like refusal or discontinuation of any medical therapy

- Most patients do not know ICD’s can be deactivated and do not require removal

- The defibrillating/shocking capacity can be discontinued separately from the pacemaker function
Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices in Patients Nearing EOL or requesting withdrawal of therapy:

- Review legal, ethical, religious principles of withdrawal of life-sustaining therapies

- Highlight importance of proactive communication to reduce suffering at EOL

- Provide management scheme to guide clinicians in process deactivation
Deactivation of Pacemakers

- Rarely necessary

- Usually the stressed myocardium does not respond to pacemaker stimuli at EOL

- Situations in which quality of life is so poor (severe dementia) that any measures to prolong life are discontinued
Summary

- Patients with advanced disease can receive palliative care at any time, hospice care when prognosis is ≤6 months

- Prognostication in HF is difficult, there are models

- Opioids are an important therapy for dyspnea

- Advanced Care Planning is a process
  - Deactivation of ICD’s should be addressed
Resources:

- Fast facts: [http://www.eperc.mcw.edu](http://www.eperc.mcw.edu)
  - Brief answers to >200 palliative questions / topics

- Heart Failure Society of America: [www.hfssa.org](http://www.hfssa.org)
  - Information for clinicians and patients/families

- “Palliative Care for Patients with Heart Failure”
  Pantilat and Steimle, JAMA 2004

- UNM Inpatient Palliative Care Consult: x24868
• about preferences for life-prolonging therapy, symptom relief, pain control, and end-of-life care.

Unlike hospice care ("Use of Hospice Services"), the application of palliative care is based on patient need rather than patient’s prognosis or life expectancy.
“Bad news” conversation

Ask-Tell-Ask

Simple, honest language
Simple statistics
Ground data in more than 1 way

Hope for best, plan for the worst
“Both-And”

Normalize uncertainty

Partner and plan

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Empathize

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Create a dichotomy and address both issues.

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Provide a broad range “months to years,” and allow for error on either end.

Name your emotions (“I feel sad”), and identify emotions the patient expresses or might reasonably have (“you look surprised,” “many would feel angry”).
Want to learn more about Advanced Certification in Heart Failure?

Please visit [www.heart.org/certification](http://www.heart.org/certification) or email us at accreditation@heart.org.