Communication and Decision-Making About Prognosis in Heart Failure Care

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ABSTRACT

Background: Therapies to prolong life and improve quality of life for heart failure (HF) have expanded in both number and complexity. Clinicians, patients, and families are faced with an array of decisions about interventions with complex risks and benefits. Physicians must also discuss prognosis of HF and its inherent uncertainties.

Methods and Results: This article applies knowledge of participatory decision-making and communication about prognosis from other health care settings to HF care. Strategies should generally follow an “ask-tell-ask” format, beginning with a patient’s understanding of his or her HF, identifying the information a patient desires, and then giving them small amounts of information at any given time, asking for feedback to clarify understanding.

Conclusions: Despite the inherent uncertainty in individual outcomes with heart failure, physicians should discuss prognosis as desired by the patient or as needed to plan care, particularly when anticipated survival is shorter than 1 year. Exploring and reflecting patient responses and attending to their emotions can decrease patient anxiety and promote shared decision-making. (J Cardiac Fail 2008;14:106–113)

Key Words: Communication, heart failure, physician-patient relations, prognosis, dying, decision-making.

Heart failure (HF) is a major cause of morbidity and mortality.1 Several therapeutic interventions are available in HF care, increasing the complexity of decision-making, particularly in individuals with advancing age, frailty, or comorbid conditions.2

Communication and joint decision-making between clinicians and patients and their families are integral to high quality, patient-centered medical care.3 Clinical decision-making that consciously and explicitly includes the patient is referred to as “shared,” “informed,” “joint,” or “participatory” and is associated with improved patient sense of control, satisfaction,4 and clinical outcomes.5 The American College of Cardiology/American Heart Association Guidelines for the Evaluation and Management of Chronic Heart Failure recommend specific communication with patients, including “careful discussion of the prognosis and options for end of life care” in persons with refractory HF.6 Communication and decision-making between clinicians and HF patients have not been well studied.

Adapting concepts of participatory decision-making about interventions and communicating about prognosis in HF has several challenges:

- The course of HF for an individual patient is uncertain.
- In the face of uncertainty, people tend not to follow logical decision-making.7
- Many HF patients are unaware of the life-limiting potential of HF.8
- Patients have difficulty interpreting numeric data and understanding statistics.9
- Cognitive function is often impaired in those with HF.10
- The time pressures of clinical practice makes long discussions difficult.

Despite this, data from studies in other specialties show that patient-centered communication is possible. This article will apply the current knowledge about discussing prognosis and participatory decision-making to HF care.
The various proposed communication models espoused in the literature contain similar core precepts, including: 1) using language the patient understands; 2) assessing the patient’s goals and preferences for information and decision-making role prior to giving information; 3) following a structure of asking the patient, giving the information for which they asked, and then asking them to confirm understanding and for additional questions (“ask-tell-ask”); and 4) responding empathetically to patients’ emotions and reactions.

Language

Patients frequently do not understand the medical language used by their physicians regarding health care and decision-making. For example, in one study, a third of patients misunderstood the term heart failure to refer only to acute episodes of shortness of breath. Clear communication from clinicians that uses “plain” language rather than medical terminology is most effective. When medical terms are employed, they should be defined in lay language. (For medical terminology is most effective. When medical terms are employed, they should be defined in lay language. For example, “We will perform a cardiac catheterization, a test to see the arteries in the heart by injecting dye through a tube into your heart arteries.”).

Probabilities, risks, percentages, or likelihood of outcomes may not be comprehended by patients (or families) and descriptive terms (such as “rare” or “frequent”) may mean very different things to patients than physicians. The format in which outcomes are presented can also influence treatment choices. Treatment effects or risk reduction should be presented in absolute numbers rather than relative terms to avoid inflating the perceived effect, and outcome information may need to be presented in a variety of ways to bring balance. Proportions (“2 out of 5”) are often better understood than percentages or probabilities. Diagrams or pie charts may help convey numeric information.

Information should be provided in small digestible amounts. No matter what the format of data, the patient should be asked to explain his or her understanding back to the physician (or another member of the clinical team) and it should be clarified until there is a common understanding. Patients typically only remember a fraction of what they are told, so important information about HF may need review. Often, patients and their families require time to process new information. Providing written summaries of key points and directing patients to written, Internet, or other resources may help them assimilate information. Physicians can suggest patients write their questions down to be addressed at the next visit to further clarify understanding.

Preferences for Information and Decision-making

Patient preferences vary for participation in, or control over, decision-making. Although most individuals prefer to be offered choices and asked their opinions, about half prefer to leave the final decision to the physician. In the Medical Outcomes Study, more than two-thirds of patients (69%) with serious chronic illness preferred to defer medical decisions to the physician, but preference for an active role in decision-making increased with younger age, higher education, type of intervention, and severity of their illness. Early in their relationship, the clinician should explicitly ask how involved in decision making and how much information a patient wants (“Would you like to consider all the options, or my opinion about the options that fit best with what I know about you?”). In future decision-making, the physician can appeal to the early discussions to identify any modification in the patient’s preferences.

Values and Goals for Care

Understanding the patient’s values allows the physician to apply them to choices and make recommendations. This is particularly important when time to make a decision is limited. Many patients will not have formed relevant goals for their care in advance of a decision, or may make general statements (such as “no machines” or “no surgery”), which should provoke the physician to ask for clarification, especially if a patient is potentially forgoing treatment from which he or she would likely benefit. Helpful questions to understand patient values include: “Looking back at your life, what has been important to you?” or “At this point, what is most important for you to do?” The physician can reflect back the values when formulation recommendations. (“I understand that being out of the hospital and spending time with your family is more important to you than potentially living a little longer—is that correct?”).

Ask-Tell-Ask

A fundamental model for communication is “ask-tell-ask.” A conversation to deliver information should be started by asking the patient what he or she understands about the illness or condition (“Tell me what you understand about your HF”; “What do you expect will happen with your HF?”). This first question elucidates how much the patient already knows, as well as whether significant misunderstandings, beliefs, or fears might influence the patient’s approach to his or her care. The physician then tells information, building on the patient’s statements and providing new information in context with the patient’s current knowledge, correcting misunderstandings, or confirming impressions about HF or about the patient’s status. This model allows the doctor to show interest in the patient’s perspective and to make recommendations in context of their knowledge of the patient’s values, preferences, and disease state. Finally, the clinician asks for feedback from the patient, verifies that they have a common understanding of important issues, and identifies additional patient concerns (“Tell me what you understand”; then “What additional questions or concerns do you have?”). Using the words “what are” rather than “do you have” encourages the patient to ask questions. The ask-tell-ask format can be repeated as the clinician provides different pieces of information.
Empathic Response

Responding with empathy (recognizing, naming, and then responding to the emotional state of the patient) is a basic skill that can be learned. As outlined in Table 1, clinicians can respond empathetically by clarifying or restating (“Let me see if I understand...”), by exploring the patient’s experience (“Tell me how this has affected your life”), or by reflecting on what they hear (“I imagine that has caused you to dramatically change your lifestyle” or “I can see you are upset”). Data suggest that patients prefer physicians who show empathy and that even 40 seconds of empathy results in increased satisfaction and decreased anxiety.

Applying Communication Skills to HF Care

The volume of education and information that should be imparted to HF patients to manage their illness and the varied interventions available may challenge clinicians’ communication skills. Communication and decision-making occur as a process over time and build on prior conversations at turning points in the illness. The following recommendations outline how core communication skills can be applied in critical times in HF care.

Initial Diagnosis of HF

Poor public understanding of HF and its potentially life-limiting nature distinguish the delivery of a HF diagnosis from that of other serious illnesses such as cancer. We know little about how patients hear a diagnosis of HF, nor about their preferences regarding being told the diagnosis. Some have suggested that other terms (impairment or insufficiency, for example) be used to avoid the word failure. However, use of euphemisms to describe HF may leave the patient with more misperceptions about the illness and its life-limiting potential. Attempts to “soften the blow” by using imprecise language may provoke more anxiety and depression than a straightforward explanation or lead HF patients to feel physicians were not honest with them.

Giving a patient a HF diagnosis is a “bad news” conversation (delivery of information that may lead to a strong negative emotional reaction), and thus should follow a series of steps (Table 2). The diagnosis of HF requires an explanation of the illness and both the likelihood of doing well with treatment and the bad news that this is a chronic, potentially life-limiting illness. HF patients may recover normal or near-normal function with appropriate medical management, and the majority of patients will live for years if they carefully adhere to diet and medication, so offering hope and optimism is very reasonable. Yet the conversation should also be structured to allow patients to understand the potential for exacerbations and death, and the importance of learning and adhering to new medications, diet, and lifestyle to give them the best odds of living longer. Informing and exploring both sides of this dichotomy (both the potential for long-term stability and the possibility of an early death) and then jointly identifying goals for managing the illness helps to develop a partnership between the physician and the patient and family that is based on the patient’s clinical reality. The strong emotions the conversation may evoke can decrease accurate understanding, requiring physicians and other clinicians to check patients’ understanding at subsequent visits.

The complex tasks of informing patients about the disease, its prognosis, and the critical requirements of treatment may need to be accomplished over several visits using several clinicians (nurse, dietician, pharmacist, and physician) or providing information in a variety of formats (oral, written, video, Internet). Educational materials about interventions and treatments should be offered.

Interventions should be presented with a description of the likely course for the patient and of potential adverse outcomes. Printed materials, including pictures when appropriate, can improve patient comprehension of options and their potential outcomes. It is appropriate for the physician to provide guidance in the form of a recommendation about what treatments are consistent with the patient’s clinical condition and personal preferences (“Based on what you’ve told me is important to you and what we know about your medical condition, I recommend we pursue the option of cardiac catheterization and attempt angioplasty.”). When the physician reasonably believes the burden from an approach would be great, an alternative should be provided (“I wish surgery were a better option for you, but we can more reliably help you by continuing medical management.”). Using the words “I wish” or “I am sorry to say” allows the physician to identify the limitations of treatments empathetically and acknowledges the physician’s emotional response (disappointment, sadness) to recommending treatments that are more limited than the patient would prefer.

Discussing Resuscitation Preferences

The need to plan how to manage a sudden death event means discussion about preferences for an attempt at cardiopulmonary resuscitation (CPR) should occur early in HF care. The CPR discussion should recur at critical points when the patient’s medical status changes and the physician should introduce the context for the discussion. Table 3 lists

<table>
<thead>
<tr>
<th>Approach</th>
<th>Examples</th>
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<tr>
<td>Acknowledge</td>
<td>“You seem surprised”</td>
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<td>“This is very sad”</td>
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<td>Legitimize</td>
<td>“Many people in this situation would feel angry”</td>
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<td>“This is frightening for many people”</td>
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<td>Explore</td>
<td>“Tell me more about what that means for you”</td>
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<td>“What would be the most frightening thing for you?”</td>
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<td>Empathize</td>
<td>“I wish the news could be different”</td>
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<td>“I can only imagine what a disappointment this is”</td>
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<td>Reinforce your commitment and partner</td>
<td>“We will work together to try to reach your goals”</td>
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<td>“I will continue to try to help you feel as good as possible”</td>
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steps example

We will work with you to help you know how best to live with your heart
Reinforce your commitment to ongoing treatment and care.

Make a clear plan for follow-up and next steps.

We will treat you now to get fluid (liquid or water) out of your system, and
Anyone hearing this news would feel frightened and upset.
Respond to and normalize emotions.

Tell the diagnosis clearly using language that is unlikely to be misunderstood.
Find out what the patient already knows and believes; build your
Set the context for the discussion and normalize it: use the word

uncertainty are in Table 4. The uncertain outcomes should be acknowledged and normalized. Treatment options, their likely outcomes, and the values that align with each option should be presented with a statement that portrays openness to the patient’s input about what is important to them (“What treatment we recommend depends on your medical condition, but also on what approach to care you prefer and what is important to you at this point in your life”).

One must elicit the patient’s view about risk-taking because this will influence his or her views about using invasive medical technologies. Preferences about advanced therapies or risk cannot be assumed from demographic factors or clinical status. Idiosyncratic health beliefs and overall health literacy may further modify the patient’s views.

Involving a patient who meets established criteria in the decision about implanting an implantable cardioverter-defibrillator (ICD) or other intervention that would result statistically in perhaps a 7% decrease in 5-year mortality risk is difficult. This conversation must acknowledge sudden cardiac death risk, with and without ICDs, and dying

Decision-making in the Face of Uncertain Outcomes

The uncertain course and prognosis for individual HF patients create specific challenges. Strategies for negotiating approaches to discussing CPR. This conversation should begin with a discussion of goals and tie recommendations to these goals. Framing the discussion of CPR as a choice between an “attempt at reviving” versus “allowing natural death” puts a positive slant on both options and avoids the pitfall of asking the patient to choose between “doing something” and “doing nothing.” Patients can be asked to define conditions in which they would not wish their life prolonged, rather than attempting to decide about interventions they do not understand. Clinicians should be aware of the odds of surviving CPR given the severity of the patient’s HF and the presence of comorbid diseases and should not refrain from making recommendations for or against CPR given the patient’s goals and the odds of success for returning to independent living.

Table 2. Delivery of Bad News

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<th>Steps</th>
<th>Example</th>
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<td>Sit down to talk with the patient and significant others the patient identifies</td>
<td>“I’d like to talk with you about [your diagnosis]. Would you like to ask [significant other] to join us in this discussion?”</td>
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<td>Find out what the patient already knows and believes; build your conversation on this.</td>
<td>“Tell me what you know about your illness”</td>
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<td>Ask the patient if he or she is ready to discuss your findings. If the patient is ready, first give a warning.</td>
<td>“Are you ready to talk about what we learned?”</td>
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<td>Tell the diagnosis clearly using language that is unlikely to be misunderstood.</td>
<td>“I am afraid I have some bad news for you…”</td>
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<td>Give additional information that is key for immediate management in small amounts and that is as asked for by the patient.</td>
<td>“You have heart failure, which means that your heart is having trouble pumping blood through the body.”</td>
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<td>Respond to and normalize emotions.</td>
<td>“Heart failure is a chronic illness that can lead to death, usually over years. Medications and limiting the salt in your diet can help you feel well and live as long as possible.”</td>
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<tr>
<td>Make a clear plan for follow-up and next steps.</td>
<td>“Anyone hearing this news would feel frightened and upset”</td>
</tr>
<tr>
<td>Reinforce your commitment to ongoing treatment and care.</td>
<td>“I am sorry to have to tell you this, …but it is important for you to know so we can decide together on the next steps”</td>
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Table 3. Recommendations for Discussion of Resuscitation Preferences

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<th>Recommendations for Discussion of Resuscitation Preferences</th>
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<td>Set the context for the discussion and normalize it: use the word “when” rather than “if” (everyone’s heart will stop someday)</td>
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<td>Broadly describe alternatives</td>
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<td>Identify undesired states broadly</td>
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<td>Discuss specific preferences that modify the approach or location of care</td>
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<td>Be prepared to present the chance of returning to the patient’s current level of function with an attempt at cardiopulmonary resuscitation</td>
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<td>Encourage the patient to complete advance directives and clarify preferences with a healthcare proxy.</td>
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from HF in general. To discuss interventions, the physician should present the benefit and potential adverse events in terms of natural frequencies (absolute risks or number needed to treat) for that intervention and that patient’s status, as a decision to be made in the context of the patient’s values.

Communicating Prognosis

Given the uncertainty inherent in HF, doctors often wonder about how much information to provide about prognosis. The physician should use available tools to clarify the patient’s likely prognosis before embarking on a discussion with patients.

Physicians vary significantly in their estimates of prognosis in HF and may misinterpret statistical data. Risk scores can identify HF patients for early transplantation, identify populations of patients at high likelihood of dying in selected periods of time, or characterize mortality risk and life expectancy. Although these help clinicians understand a patient’s status, the prognostic scores and algorithms identify categories of persons at risk of death in a given time frame, yet can not prognosticate with specificity for individual patients.

How is a clinician to translate the probabilities with their inherent uncertainty to a patient? Would your patient be one of the unlucky 5% of persons to die in the next year or in the 25% of persons who die in 5 years, or is she likely to live far beyond the mean to her late 80s? Is it more important to convey to the patient how long she may live or how soon he or she might die or some combination? Should such information always be offered or just when asked about by the patient? How should the amount of information be negotiated? These dilemmas, approaches to addressing them, and examples of language are in Table 5. How much and which information to provide should be dictated by the decisions that need to be made and by the patient’s desire for information. Informed decisions by patients will require some understanding of this type of probabilistic data. The “ask-tell-ask” format helps promote a common understanding between patients and clinicians.

Most patients do not understand HF to be a life-limiting illness. Early in care, telling patients that HF is likely to be life-limiting and that sudden death may occur is adequate for many, though the physician should be prepared to provide more information when desired by the patient or family. In a community study, 40% of older persons with advanced disease including life-limiting HF preferred to not have a prognosis discussion; however, when patients believed they had a year or less to live, more than 4 of 5 wished to discuss prognosis. One reason to offer to discuss prognosis is that patients may choose treatments based on their understanding of prognosis. In the Study to Understand Prognosis and Preferences for Outcomes and Results of Treatment (ie, SUPPORT), advanced cancer patients who believed they would live longer than 6 months were more likely to receive noncurative chemotherapy than patients who believed their prognosis was limited, and HF patients who believed they were unlikely to survive at least 2 months were more likely to request a do not resuscitate status.

The End of Life

When the end of life nears, prognosis should be revisited. Whether or not a conversation about the poor prognosis of advanced HF is “shocking” will depend on both the patient’s prior understanding of HF and how the news is presented. Despite the uncertainty in individual outcomes with HF, physicians should discuss prognosis as needed to plan care. Under these circumstances, patients who do not wish to hear information about end-of-life care should be asked to designate someone who will communicate and participate in decision-making on their behalf. The discussion of poor prognosis need not leave either the doctor or patient and family feeling hopeless if the conversation identifies options and hopes, while acknowledging and anticipating the prospect of death (“hope for the best, and plan for the worst”).

Identification of the likelihood of dying from HF must acknowledge the uncertain course with advanced HF; even at the end of life, we cannot predict which HF patients may live 2 years or longer. The conversation should be normalized, because no medication or treatments give immortality. The emotion involved in talking about death should be acknowledged. Plans “for the worst” include finishing a legal will, writing letters to children to open at the time of future significant events, and an explicit approach to management of distressing symptoms and of the death event itself. Written booklets or lists help with such planning, but involvement of an interdisciplinary team to
Table 5. Questions Confronted in Talking with Heart Failure Patients about Prognosis and Dying

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<tr>
<th>Questions</th>
<th>Approaches</th>
<th>Examples of Language</th>
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<td>How should the topic be initiated?</td>
<td>Follow a “bad news” conversation; ask the patient or family for their impression.</td>
<td>“I’d like to talk with you about your heart failure. How do you feel you’re doing right now?”</td>
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<td>How should uncertain prognosis be presented?</td>
<td>Uncertainty should be identified and normalized.</td>
<td>“Like many things in life, we don’t know what will happen.”</td>
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<td>Present average lengths of life, with the possibility for exceptions in both directions.</td>
<td>“The average person with your degree of heart failure will live 6 to 12 months. Some will live longer, and we will do all we can so that you will, but some live shorter, so we need to make sure you have made preparations for that possibility.”</td>
</tr>
<tr>
<td>How should a clinician talk about dying with a patient?</td>
<td>Make recommendations in a “hope for the best, prepare for the worst” form.</td>
<td>“What do you hope for at this point?...but in case things don’t go as we both hope, what things should you do now to prepare yourself and your family?”</td>
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<tr>
<td>1. Early in care, heart failure should be acknowledged as a disease people die from, but a dichotomy should be set up that allows hope for good quality of life with good management of diet and treatments.</td>
<td>“People do die from heart failure or from other illnesses while they have heart failure, but with medications and careful management of your diet and fluids we hope you will feel well and live many years.”</td>
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<tr>
<td>2. Patient’s fears and concerns should be addressed and normalized.</td>
<td>“What are your concerns and fears?”</td>
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<td>3. When death is likely, this bad news should be presented to the patient and family with a plan or options for care.</td>
<td>“Many people would worry about what to expect”</td>
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<tr>
<td>4. Acknowledge emotions encountered</td>
<td>“If you were to die sooner rather than later, would there be things you would regret not having done?”</td>
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<tr>
<td>Should information be framed as length of life or time to death or both?</td>
<td>Patients should be asked what information is important to them. To be best prepared, most people eventually need to hear both parts of this equation.</td>
<td>“I am afraid I have bad news. Your heart failure has worsened. At this point many people die within the next year or 2. We can offer you treatment which won’t prolong your life, but may help you feel better. We need to make plans about your care, so we need to understand what is important to you now....”</td>
</tr>
<tr>
<td></td>
<td>For patients who wish specific information provide an estimate in a range of time or data from relevant clinical trials</td>
<td>“This is a sad topic.”</td>
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support the patient and their family with plans, emotional responses, and spiritual issues is critical.

If the patient is a potential candidate for advanced technological interventions and willing to accept risks of adverse events, appropriate options should be described including transplantation, ventricular assist devices such as destination therapy, or cardiac resynchronization therapy versus “care at home” with home care or hospice. Describing the likely course with each option for a given patient may require consultation with experienced clinicians in both palliative care and advanced HF.

What information is given to patients and families should be directed by what information they request and what is necessary to provide care. Families concerns about what to expect and care needs may be addressed in the course of a conversation with the patient or with the patient’s permission in a separate discussion. Table 6 lists additional issues to be reviewed by a member of the care team with the patient or family in planning end-of-life care.

To address anticipated length of life, experts recommend providing a range of time that the “usual patient” with their condition may have and to allow for exceptions in both directions. Some patients may want more specific information such as odds and the ways in which patients with HF die. The clinician should be prepared to discuss the process of dying from sudden cardiac death or from worsened HF, including the associated probabilities and time frames. A recent secondary analysis of the Comparison of Medical, Pacing, and Defibrillation Therapies in Heart Failure (ie, COMPANION) trial provides some data about these issues. HF specialty practice studies suggest that most deaths in advanced HF patients managed by HF experts are associated with progressive cardiac and renal dysfunction or metabolic abnormalities, but not usually with congestion. The prospect of managing congestion with medications and other therapies...
may reassure patients that we can maintain comfort for most patients as they approach death.

**Discontinuing Therapies**

The discontinuation of medications when patients develop complications such as hypotension, worsened renal function, or volume overload with β-blockers, is a harbinger of the end of life. When HF becomes end-stage, it is appropriate for the physician to review goals for care. At this time, or when a decision has been made to no longer attempt life prolongation, the clinician should evaluate the potential benefits and burdens of all therapies in concordance with the patient’s current goals for care.

Patients may not understand that at the end of life ICDs might preclude sudden, painless death. If the goal is to allow natural death or if the patient hopes to “die in their sleep,” the ICD should be deactivated. An organized plan for ICD deactivation should be developed at every center that implants ICDs. Whenever possible, the ICD should be deactivated in a routine visit well in advance of imminent death. Similarly, other therapies that are inconsistent with the current goals of care should be discontinued.

**Conclusions**

Communication in HF care about prognosis and making decisions that enhance patient participation and control can be planned and formatted according to research regarding physician-patient communication in other disciplines of medicine. Communication should begin by asking what the patient knows or believes and what information they want. Bad news or prognosis information should be communicated in small understandable amounts, according to what the patient needs to know to be fully informed about risks and benefits. Decisions about care should be guided by the patient’s condition and preferences and by the physician’s expert medical opinion. The goal of physician-patient communication is to prepare patients and their families for coping with HF and to guide them in the best possible decisions given the complex and uncertain prognosis in HF and the benefits and burdens of treatments and advanced medical options.

### References