Goals of Care for the Heart Failure Patient

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9.1 Case Study: Setting the Stage

Mr. Smith is a 64-year-old male with past medical history of hypertension, diabetes mellitus, and continued tobacco abuse. He had significant coronary artery disease and underwent four vessel coronary artery bypass grafting approximately 10 years ago. He now has continued ischemic cardiomyopathy with an ejection fraction of 10%; Heart Failure with Reduced Ejection Fraction (HFrEF). He has evidence of right-sided heart failure (HF) as well. Due to his refusal to stop smoking he is not a candidate for a left ventricular assist device or heart transplant. He has been admitted to the hospital three times in the last six months with acute decompensated heart failure. Unfortunately, he is also showing evidence of cardio-renal syndrome with an elevated creatinine of 2.5. He is readmitted a fourth time with acute decompensated systolic and diastolic heart failure and hypervolemia. His creatinine is now 3.8. His cardiologist attempts to mention hospice care, to which Mr. Smith replies, "I'm not ready for hospice care." What do you do next? How do you attempt to discuss goals of care and code status with Mr. Smith? What conversations could you have had earlier to help Mr. Smith process the terminal nature of his heart disease?

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9.2 Palliative Care in Heart Failure

9.2.1 What Is Palliative Care?

Formally, the World Health Organization (WHO) (2020) defines palliative care as: "An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [1]."

Historically, palliative care has been viewed as only being applicable to patients at the end of life and most commonly associated with cancer diagnoses [1–4]. However, due to the labile nature and unpredictable course of heart failure, this view has evolved and the importance of integrating palliative care into the management of heart failure is now being recognized throughout the disease trajectory, often suggesting introduction of services at diagnosis [3, 5–7]. Palliative care is both a philosophy of care and a medical approach to care and may be provided in conjunction with other life-prolonging and guideline-directed medical therapies. Palliative care should not be confused with the hospice benefit which requires a physician to declare a life expectancy of less than 6 months [3, 4, 7, 8]. Hospice will be discussed in more detail later in this chapter. Palliative care services include: pain management, symptom management, identification and clarification of patients' goals of care by means of advance care planning, coordination of care, psychosocial support and spiritual support; thereby offering a holistic model of care and a patient-centered approach [1, 3, 9, 10].

Palliative care services may be provided by either specialists or general practitioners and are offered in various settings such as the acute care setting, ambulatory care setting, or at home [1, 10, 11]. Due to the lack of specialty trained palliative care providers, there is a growing belief that all clinicians providing care for patients with heart failure should possess the basic skills needed to deliver competent primary palliative care. Therefore, an emphasis is currently being placed on the importance of incorporating the principles of palliative care into clinical and didactic training programs [6, 8, 9, 11, 12].

9.2.2 Why Is Palliative Care in Heart Failure Important?

The recommendation for the early integration of palliative care in heart failure is suggested by all major cardiovascular societies and is included in national heart failure treatment guideline recommendations published by the American College of Cardiology Foundation (ACCF) as well as the American Heart Association (AHA) [7, 11, 13–16].

Heart failure carries a five-year mortality rate of nearly 50% and places patients at a higher risk for sudden cardiac death [3, 9, 15]. In addition to the five-year 50% mortality rate, the average survival for patients with HF is just 16 months following the first hospital admission, making this worse than the expected survival rate for numerous cancers [3, 8, 11]. Furthermore, it is estimated that the cost of caring for heart failure is approaching $100 billion dollars and is the costliest diagnosis incurred by Medicare [6, 9, 11, 15].

Studies have shown that patients with heart failure experience symptom burdens that are comparable, if not worse, than those experienced by patients living with cancer [7, 9, 16]. The most commonly reported symptoms experienced by patients living with heart failure include: peripheral edema, dyspnea, fatigue, anorexia/early satiety, anxiety, spiritual and psychosocial distress, caregiver burden, depression, and pain; though pain is often overlooked and thereby is undertreated in heart failure [5, 7, 9, 10]. The Center to Advance Palliative Care (CAPC) website serves as an excellent resource of information for clinicians providing palliative care across specialties. This website offers numerous evidence-based assessment tools that can aid providers in the clinical assessment of patients and evaluates their palliative care needs [17].

When initiated early and utilized appropriately, the holistic approach of palliative care has been shown to increase quality of life, improve survival, decrease physical and emotional symptom burden, decrease cost of caring, decrease the numbers of hospitalizations and unwanted advanced therapies at the end of life, and facilitate earlier referrals to hospice [3, 4, 6, 9–11, 18, 19].

9.3 Current State of Palliative Care in Heart Failure

Despite being included in both international and national heart failure treatment guidelines, the use of palliative care in heart failure is grossly underutilized [8, 13]. It is estimated that less than 10% of end-stage heart failure patients receive a palliative care consultation [8]. This is problematic as cardiac patients in the last month of life utilize acute care services at a higher prevalence than patients living with cancer [8]. The current barriers that have been identified to integrate palliative care into heart failure management include: scarcity of specialty palliative care providers, lack of generalist palliative care training, difficulty in prognostication, the need for identifiable “triggers,” advancement of late-stage heart failure therapies, lack of disease state awareness, and institutional barriers [6–9, 13, 15, 16].

9.3.1 How and When to Refer to Palliative Care for the Primary Care Provider

Primary care providers should approach and assess each patient with heart failure on a case by case basis and refer to specialty palliative care providers based on individual patient need, regardless of where the patient is in the course of the disease trajectory [6, 16]. Some triggers for referral include: increasing symptom burden, psychosocial or spiritual distress, worsening ejection fraction, repeat hospital admissions, patient-reported decrease in quality of life, decrease in functional status, initiation of palliative inotropes, implantable-cardioverter defibrillator (ICD) placement, refractory to medical therapy, not a candidate for advanced therapies, need for goals of care discussion, or need for hospice care [6, 8, 10, 13, 19].

For a patient with heart failure, it is never too early to refer to palliative care for introduction of services [7, 13, 16]. The introduction of services allows for early and ongoing support and the degree of palliative care involvement may vary based on need throughout the disease trajectory [7]. Not only does palliative care serve as another layer of support to the patient, but involving palliative care also ensures adherence to heart failure management and practice guidelines [7, 11, 13–16].

9.4 Goals of Care Discussions in Heart Failure

9.4.1 Components of Goals of Care Conversations

Goals of care discussions are ongoing conversations that occur between clinicians, patients, and families in the setting of a chronic and progressive illness such as heart failure and may occur with or without specialist palliative care involvement [19, 20]. Goals of care conversations should be initiated at diagnosis of such conditions and continue throughout the trajectory of the illness and be updated on a regular basis [20–22]. These discussions provide an opportunity for providers to discuss prognosis and treatment options and afford patients the opportunity to ask questions and clarify any misconceptions related to their current medical condition [19]. It has been shown that advanced care planning is associated with lower risk of inpatient hospital deaths, lower costs, and higher utilizations of hospice care [23].

In addition to ensuring patients' prognostic awareness, goals of care discussions are centered around understanding patients' goals, values, and preferences in the context of such illness and may also include conversation related to completion of advance directives, appointment of a healthcare proxy, resuscitation status, symptom management, and preferences for end of life care [19, 20, 22, 24]. Goals of care conversations help to foster an environment of shared decision-making and allow for the development of individualized care plans that are aligned with patients' goals and values [20, 22, 24].

9.4.2 Current State of Goals of Care Conversations

Similar to the recommendations put forth by national societies for the integration of palliative care, it is also recommended that goals of care are discussed on an annual basis and after any change in functional status. These conversations should be documented in the electronic medical record so they are accessible to the entire care team [6, 10, 16, 25, 26]. Despite these recommendations, it is believed that only 12–17% of patients with heart failure have engaged in goals of care conversations with their providers and most patients with heart failure have not completed formal advance directives [6, 8, 20, 22]. The barriers to engaging in goals of care conversations have been identified and are well documented. These barriers include: (a) lack of provider confidence in facilitating such conversations; (b) lack of provider education in executing the conversation; (c) difficulty in the prognostication of HF making timing for initiation of such conversations unclear; (d) uncertainty around appropriate clinical triggers for goals of care conversations; (e) provider belief that patients do not want to discuss preferences for end-of-life care; (f) lack of tools to help facilitate conversations; (g) lack of time; (h) fear of taking, “hope,” away from the patient; (i) uneasiness in discussing end-of-life [4, 13, 20, 21, 26].

Engaging in routine and ongoing goals of care discussions along with the development of a patient value-driven care plan increases quality of life, decreases symptom burden, decreases unwanted advanced therapies at the end of life, decreases financial burden to both the patient and the healthcare system at large, and leaves the patient and families with a more auspicious outlook on hospice care and better prepared for end-of-life situations [4, 13, 19, 24, 26]. The importance of these conversations is so great that in 2016 the Center for Medicare and Medicaid Services began reimbursing providers for engaging in these discussions and may serve as a motivating factor for primary care providers [20, 25].

9.4.3 How to Initiate Goals of Care Conversations

Once the need for a goals of care conversation is recognized, goals of care conversations in the primary care setting should be planned in advance and should be scheduled to allow for an adequate amount of time so that the conversation is not rushed and all parties are given sufficient time to provide information and ask questions [20–22]. Prior to entering into a goals of care conversation, the clinician should engage in a thorough review of the patient’s chart and become familiar with all necessary and pertinent medical information that may factor into future complex medical decision-making [20]. It is also important to inform patients and families of the nature of the visit prior to the scheduled appointment day to enable them to come prepared to enter into such conversation [20].

At the time of the scheduled meeting, the clinician should set the agenda and begin by assessing the prognostic awareness of the patient and family followed by providing a medical update and clarifying any information that may have been misinterpreted by the patient [20, 21]. Throughout the meeting, the clinician should engage the patient by asking open-ended questions while taking time to acknowledge and respond to any emotion [20]. After all of the information has been presented and the patients’ goals and values have been identified, the clinician should recommend a medically appropriate plan of care that is congruent with the stated wishes [20]. If any changes are made to the patients’ plan of care following a goals of care conversation, the outcome of the conversation should be documented in the electronic medical record and communicated to all members of the patients’ care team [14, 20, 26]. It is important to recognize that these conversations should be iterative and may not occur in a single setting but rather require a set of subsequent meetings to fully complete the conversation and facilitate decision-making [20, 21].

9.5 Special Considerations for Goals of Care Conversations in Heart Failure

9.5.1 Difficulties in Discussing Goals of Care

These authors advocate that goals of care discussions are especially important in heart failure patients due to the many life sustaining technological devices such as aortic balloon pumps, temporary left ventricular support (i.e., Impella device by Abiomed), ventricular assist devices (LVAD), palliative inotropes, dialysis, and extra-corporal membranous oxygenation (ECMO). These devices or therapies may be placed urgently when a patient is in cardiogenic shock and may make a transition to hospice care more difficult or ineligible for hospice care. Tragically, these devices may result in a "bridge to nowhere" if the patient is unable to improve and is not a candidate for long-term mechanical circulatory support or transplant. For families of these patients, end of life care that has these forms of technological life support has been associated with increased family anxiety, depression, poorer quality of life, and overall less satisfaction with the dying process [27]. Therefore, clear goals of care discussions early in the disease process and preferably in the outpatient setting may prevent initiation of these devices when a hospice transition may have been more appropriate.

These discussions can take many forms including simple advance care planning conversations defining a medial power of attorney or completion of a living will. A medical power of attorney or healthcare power of attorney is a person whom the patient trusts to make healthcare decisions for them when they are unable. This is a simple discussion and a way in which to begin a goals of care conversation. An advance directive is "the general term that refers to the various documents that could include a living will, instruction directive, health care proxy or health care power of attorney" [28].

More involved and complex goals of care conversations include determining code status, deactivation of devices, and discussions about transitioning to a hospice level of care. To reiterate, the American Heart Association recommends an "Annual Heart Failure Review" much like an annual wellness visit. The goal is to have continued ongoing conversations about symptom burden, quality of life, estimation of prognosis, patient's goals, review of therapies, and anticipatory planning for future events [26]. By continuing ongoing conversations, this allows patients and their loved ones to redefine their goals as their illness progresses. Why are these conversations so difficult? Heart failure is a terminal and progressive condition. However, patients are often unaware that their heart failure cannot be cured and will continue to worsen over time. Unlike cancer, the primary care physician or cardiologist cannot show the patient a CT scan that visually shows progression of disease. There is no evidence that the patient can physically see that allows them to process that their heart failure is indeed progressing. Secondly, patients are readmitted to the hospital, undergo diuresis, and discharged back to home with their shortness of breath improved and their edema resolved. This gives patients and families a false sense of security that with each admission the disease will be kept in check and managed.

How can the patient believe they are actually dying from a terminal illness if each time the healthcare team makes them feel better? Therefore, before even having a meaningful conversation regarding goals of care, the medical provider must educate and explain the terminal nature of heart failure to the patient and family.

Patients and families need concrete examples of how to understand their disease is, in fact, progressing. Clinicians understand that heart failure disease progression is evidenced by recurrent readmission rates, hypotension that may result in intolerance to heart failure medications, volume overload refractory to diuresis, worsening cardio-renal syndrome, hyponatremia, and increasing symptom burden. A very simple and accurate prognostication tool is the surprise question. "Would you be surprised if this patient was alive 1 year from now?" If the answer is yes, then the clinician should be explaining the terminal nature of heart failure to patients and embark on serious goals of care discussions [29]. Explaining heart failure to patients can be simply telling them that progression of their disease means that they will begin to have more frequent admissions, the oral medications may no longer work at removing their fluid accumulation, and their blood pressure may be too low to continue to take the medications that are helping their failing heart. It is important for patients to process that disease progression means that they will spend less time at home and be more frequently admitted to the hospital. If patients truly understand recurrent readmissions are a very poor prognosis, they can begin to think about when they may want to remain at home and transition to a hospice level of care. This is a process. A process of continuing to reevaluate what each admission means and how the disease is progressing. If patients understand the significance of multiple readmissions earlier in their disease trajectory, they can begin to consider an earlier transition to hospice [29].

9.5.2 Code Status Discussions

Code status discussions can be very complicated discussions in patients with heart disease. Patients may have had successful resuscitation in the past. They may have had their defibrillators discharged resulting in restoring life sustaining rhythms and prolongation of their life. They may come to falsely believe that if their heart stops, simple shocks will result in restoring their health. In this author's opinion, for these reasons, code status discussions are more difficult and challenging discussions in cardiac patients rather than other disease populations. It is important to understand that most patients hospitalized with heart failure will want resuscitation in the event of cardiac arrest [30]. Krumholz found that of patients hospitalized with heart failure, only 23% did not wish for resuscitation, and of those 23% of patients, 40% would go on to change their minds after their hospitalization ended [30]. Therefore, code status should be continued to be readdressed throughout the patient's illness and with each decline in clinical status. A patient may insist on remaining full code due to past experiences with resuscitation. These authors suggest, rather than try to convince the patient to change their mind, a useful discussion at this point is to discuss "what if." What if you are alive but remain on life support? What if you are alive but have an anoxic brain injury? What is meaningful quality of life for you and when would you want the medical team to remove life support? Would your family know what to do? When would you want life sustaining support removed? This now introduces the concept that not all resuscitation will restore the patient back to full functional capacity. It also begins a dialogue of what is meaningful quality of life for the patient and what would they want in a "worst-case" scenario if they continue to remain full code.

9.5.3 Defibrillator Device Deactivation

Implantable cardioverter defibrillators (ICD) are placed most commonly for primary prevention in patients with severe HF who are at risk for sudden cardiac death due to ventricular arrhythmias. While these devices increase survival by treating life-threatening ventricular arrhythmias, they do not add quality of life to the patient. Patients who have been previously shocked may not wish to have additional shocks in the future. Unfortunately, there is little information regarding the risk of defibrillator shocks at end of life [31]. However, one study revealed that 19% of patients received a shock in their last month of life and 8% in their last hour of life [31]. Deactivating a patient's ICD simply means to disable the shocking functionality. This renders the device unable to treat ventricular fibrillation or ventricular tachycardia with shocks. It is important to recognize that disabling the shock function does not interfere with the resynchronization therapy function or bradycardia pacing function. It is important to explain to patients that deactivation of the device will not result in death at the time of deactivation and that pacing functionality remains intact. Also, the device deactivation is easy and painless [32].

Many hospices prefer defibrillators be deactivated at the time of signing consents for admission to hospice care. This prevents unwanted shocks during the dying process. However, discussing device deactivation with patients can prove to be a difficult conversation and anxiety provoking for both the healthcare provider and the patient. The authors have found it helpful to first ask patients if their device has ever been discharged. Asking this question helps provide some insight into their illness and experiences with their defibrillator. If the answer is yes, patients may be actually relieved to deactivate their device. Some patients have shared with the authors that the shocks were painful, they received multiple shocks, and they lived in fear of when they may be shocked again. For these patients, device deactivation may actually improve their quality of life by lessening anxiety and fear. If the answer is no, these patients may be fearful that deactivating their device may hasten or cause death. It is imperative to reassure these patients that pacemaker function will remain intact. Explaining the dying process, and the unlikely event that their defibrillator may fire, can reassure the patient that device deactivation will not result in imminent death.

The patient has a right to refuse device deactivation. They are still entitled to enroll in hospice care with an active device. In the situation where patients refuse device deactivation, the hospice agency should ensure that a magnet is delivered to the home. In a patient receiving multiple shocks at the end of life, a magnet placed over the device pocket on the chest wall will stop the shocks. Device deactivation conversations can also be revisited over the course of the hospice admission and patient's illness. Just like code status, patients may change their minds at a later date and request that the hospice agency deactivate their device.

9.6 Hospice and End of Life Best Practices

9.6.1 Hospice Care

Hospice care is specialized care for patients at the end of their life. The hospice model of care emphasizes expert control of symptoms to ensure the best quality of life for the patient rather than aggressive life-prolonging care. Also, hospice care aims to support both the patient and caregivers emotionally with grief support and bereavement support to the family after the patient dies. Hospice care has been shown to alleviate symptoms and improve patient and family satisfaction [33]. Some studies have shown that hospice care is associated with improved survival benefit [34].

The Centers for Medicare and Medicaid Services (CMS) define hospice care as "a comprehensive, holistic program of care and support for terminally ill patients and their families. Hospice care changes the focus to comfort care (palliative care) for pain relief and symptom management instead of care to cure the patient's illness" [35]. To enter into hospice care, two physicians (the primary care physician or cardiologist and the hospice medical director) certify that the patient has a life expectancy anticipated to be six months or less. The patient signs a consent electing the Medicare Part A Hospice benefit for their hospice diagnosis and waives the right for all future Medicare payments related to their hospice diagnosis/illness. They are electing hospice care for their terminal diagnosis and waive additional hospitalizations and life prolonging therapies. There are several levels of hospice care including routine home care, continuous care at home, and inpatient respite care or inpatient care [35]. Hospice care provides medications for comfort, nursing and physician care, medical equipment, hospice aide, social services, spiritual counseling, and counseling to the family before and after the death of the patient. CMS eligibility criteria for heart failure includes patients with New York Heart Association Class IV symptoms at rest who have already been optimally treated for their disease and yet symptoms such as angina and dyspnea persist. They are not candidates for surgical procedures, or they have turned down such procedures. They have an ejection fraction of 20% or less but this is not required. Supportive symptoms that would support eligibility include but are not required are supraventricular or ventricular arrhythmias, history of cardiac arrest or resuscitation, syncope, brain embolism of cardiac origin, or concomitant HIV disease [36]. Hospice care for heart failure patients includes continuation of their oral medications and opioids for symptom management. Not all hospices can provide continued inotrope support or intravenous medications due to cost constraints and this should be considered when choosing hospice agencies especially if a patient is already receiving an inotrope.

Compared to cancer patients, heart failure patients are referred to hospice care late, usually within twelve days of their death compared to twenty days for cancer patients [37]. This study also found that heart failure patients were more likely to be referred to hospice care from inpatient hospitalizations or nursing facilities which may indicate that these referrals are being advocated by healthcare providers rather than patient preferences [37].

9.6.2 Barriers to Hospice Care Referral

Due to the difficulty with prognostication of the trajectory of heart failure, healthcare providers may wait until the patient is actively dying to consider referral to hospice care. Lack of early advance care planning conversations and the patient's poor understanding of the terminal nature of heart failure only add to these barriers. As previously stated, therapies such as mechanical circulatory support or inotropes may complicate hospice referral. Some hospices may be unfamiliar with left ventricular assist devices and lack confidence in their ability to care for these patients, thereby refusing admission to hospice unless the device is deactivated. Inotropes present a financial problem in that smaller hospices may not be able to cover the cost of this therapy. Smaller hospices may require infusions to be stopped or after the present infusion is completed, they will not re-order the inotrope. Having healthcare teams partner with their local hospice providers is essential to help troubleshoot these therapeutic barriers. This also ensures the healthcare provider is familiar with what services their local hospices can provide.

Late referral to hospice services has been associated with poor family satisfaction, lack of care coordination, and decreased awareness of the dying process and when death is imminent [38]. How can you as a provider help prepare a patient for hospice care? Introduce the concept of hospice care *BEFORE* you are ready to refer a patient. This can be done by providing "information only" conversations in conjunction with explaining that heart failure is a terminal disease. "I'm not referring you to hospice care at this time, but I want you to be aware of their services so you can think about when this may be a good option for you." Providing this information early introduces the possibility of an alternative to readmission to the hospital and empowering the patient to think about when they may want to choose hospice care as an option. A sample conversation may commence as follows, "I want you to be aware that as your disease progresses you may reach a point where you no longer wish to come to the hospital. I would like to provide you with information regarding hospice care, so you realize that there are other alternatives to readmission as your disease worsens. I want you to have time to think about this option and decide when hospice care might be the right choice you." Empowering the patient with information early, allowing time to process this information, and giving the patient control over when they would like to be admitted to hospice may help result in the patient being able to choose hospice care when appropriate for them.

9.7 Case Study: Putting It All Together

Referring back to the case at the beginning of the chapter, the question remains how could we have better cared for Mr. Smith? As his ejection fraction began to worsen and even before his creatinine began to climb, palliative medicine could have been consulted for introduction of services. Ideally, education about terminal heart failure and what to expect would be the basis to begin a basic goals of care discussion. Mr. Smith could have completed a medical power of attorney and started to process that as his disease advances, he would require more frequent admissions. Code status discussions could be initiated; however, the healthcare team would understand that he would most likely choose to be full code during those early discussions. The palliative care team would continue to follow him and evaluate him with each admission for increasing symptom burden and address symptoms that were contributing to worsening quality of life and help the primary team manage these symptoms. As his kidney function started to decline, early information regarding hospice care could be provided as an alternative form of care for end-stage disease. Ultimately, the goal would be to let Mr. Smith decide when he would be ready for hospice referral. Code status and goals of care would continue to be readdressed with each subsequent admission. This would be an iterative process with no agenda, rather simply a dialogue between Mr. Smith and his healthcare team to assess where he was in the process of accepting his terminal illness. As he became more ill, the healthcare team would recommend a do not resuscitate order, educate about the dying process, aggressively manage symptoms, and suggest considering more of a comfort-based plan of care. The healthcare team would recommend a referral to hospice care when they believed he has six months or less to live with his heart failure. He may not be ready at that time, but the team would agree to continue to reevaluate hospice care as an alternative to aggressive care that was now failing Mr. Smith. With palliative care referral early in his disease process, Mr. Smith would have education about the terminal nature of heart failure, many goals of care conversations and code status discussions, early information regarding hospice care and symptom management. This would have given him time to process his disease and empowered him to choose hospice care when he knew he was dying of his heart failure.

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