Proceedings of UCLA Health
-VOLUME 25 (2021)-

CLINICAL COMMENTARY

Advance Care Planning in Heart Failure Patients

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When I was a medical student, my attending said he gets to know some heart failure patients very well because they get admitted so many times for heart failure exacerbations. "We diurese them, they get better, and they get discharged. Several months later they come back, we diurese them again, and they get discharged." He said. "They get admitted more and more frequently, and one day I realize I haven't seen them in a while." At that time I thought my attending was implying that the patients did not like our hospital and decided to go somewhere else, or maybe that they simply got better. Later I realized my attending was implying that these patients often die.

Heart failure is a complex disease where the heart is unable to fill or eject adequate amounts of blood to meet the metabolic demands of the body. The clinical manifestations of heart failure include dyspnea, decreased exercise tolerance, and fluid retention such as pulmonary or peripheral edema.[1] Its prevalence in the United States is rising, from 5.7 million adults in 2009-2012 to 6.2 million in 2013-2016. The lifetime risk of developing heart failure for Americans above 40 years of age is 20%, and the 5-year mortality rate is approximately 42.3%.[2] Overall, mortality is improving due to advancements in various heart failure treatments, but it still remains high.

Heart failure patients experience debilitating physical and emotional symptoms, loss of independence, and disruptions to social roles which all lead to decreased quality of life.[3] Studies report a lack of improvement of health-related quality of life after hospital discharge is associated with rehospitalization and mortality.[4,5] One aspect of healthcare that can improve patients' quality of life is advance care planning.

Advance care planning (ACP) is a supportive process to understand and share personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences.[6] Known benefits of ACP in patients with heart failure include increased quality of life, satisfaction with end-of-life care, and quality of end-of-life communications.[7] Moreover, patients who are more informed about ACP and life-supportive measures often elect for less aggressive measures at end of life, which can lead to decreased cost of healthcare.[8]

Despite evidence that ACP can be beneficial in patients with chronic illnesses such as advanced heart failure, less than 50% of middle-aged or older people have any form of advance directive.[9] One study of 24,000 admissions for heart failure found that at the time of admission only 12.7% of patients had a documented advance directive.[10] Although most patients with heart failure do not have documented ACP, studies show patients and families do wish to engage in ACP conversations with their provider.[11] So the question is – why is it not being done? The answer is many reasons.

One commonly cited barrier to advance care planning in heart failure is the uncertainty regarding the trajectory of heart failure.[8,11-13] Unlike other serious illnesses that can follow a gradual but steady decline, organ system failures like heart failure tend to cause long-term lack of reserve and intermittent exacerbations, making the timing of decline unpredictable. Patients often go through cycles of feeling well and decompensated states until they enter the refractory phase of their illness, and it is difficult for clinicians to determine when advance care planning would most benefit the patient. General practitioners report lack of knowledge about complex heart failure cases. These include cases involving implantable cardioverter-defibrillators, as contributing to decreased comfort with discussing ACP in heart failure patients.

Another commonly cited barrier to ACP in heart failure is lack of knowledge and skills in ACP. Effective ACP can be initiated by any provider and by no means is limited to a palliative care specialist. If every heart failure patient were referred to a palliative care specialist for advance care planning, there would not be enough palliative care physicians to handle the patient load. However, not all primary care or cardiology providers are comfortable or trained to handle these conversations.[8,14] Cardiologists report a general lack of knowledge of what ACP entails, as well as lacking the training or skills in bringing up these topics with patients.[14]

Another barrier reported in the literature is clinician attitude regarding ACP. Providers were less likely to be comfortable with ACP if they thought of it as a setback to treatment efforts, rather than a complementary component of patient care in serious chronic medical conditions. It is important to note that ACP is appropriate at any age or stage of illness. However, since there is no clear set of criteria for when, how, and in whom it should happen, perhaps it does not get prioritized.[3,11,15] A cardiologist may believe ACP should be done by the primary care provider who has a long-standing relationship with the patient. Conversely, primary care providers may believe that the cardiologist is better equipped to discuss ACP in heart failure because of their expertise in the disease.[14] When providers do not effectively communicate these expectations, patients were less likely to have any ACP discussions.

Other barriers that healthcare providers reported include, (1) not wanting to alarm patients, (2) fear of destroying hope, (3) lack of resources such as time, trained staff, appropriate setting to discuss sensitive topics, and (4) competing demands of their clinical responsibilities, such as managing medical conditions and providing additional treatment options.[14]

Barriers to ACP from the patients' perspectives are less frequently discussed in the literature. Most studies regarding ACP in heart failure study the health care provider's side, which can help health care providers and institutions make changes to improve the rate of ACP in heart failure patients. Understandably, it is easier to survey providers and design studies on interventions from the providers' side. A review of the literature between 1987 and 2010 revealed that conversations between patients and physicians mostly focused on disease management and less on goals of care and patient preferences for care.[11]

Based on scarce data, one possible reason that patients may not engage in ACP may be that they overestimate their life expectancy[8,13] when compared to predictions from validated heart failure survival models such as SHFM (Seattle Heart Failure Model) or HFSS (Heart Failure Survival Score).[15] One study found that most patients overestimate their expected survival by 40%,[16] and another study found that only 37% of patients with end-stage heart failure are aware of their poor prognosis.[17] One proposed explanation for the differences between patient's self-perception of prognosis and reality is inadequate communication between clinicians and patients, combined with the physician's inability to predict the risk of mortality in advanced heart failure. Another possible explanation is that patients predict longer life expectancy in themselves as a way to maintain hope.[16] When patients do not understand their prognosis, it may affect their willingness to participate in ACP discussions as well as the kinds of decisions they may make about their healthcare.

Factors that facilitate ACP in heart failure patients include (1) competency in the use of ACP and clinical management of end-stage heart failure, (2) being able to provide holistic end of life care, (3) having a trusting and long-term relationship with the patient and caregivers, (4) patients initiating the ACP conversation first (may make it more comfortable for providers to discuss ACP), and (5) being able to deliver ACP at a time and place appropriate for the patient.[14]

Our aim is to highlight key findings in the current literature regarding ACP in heart failure and advocate for implementing changes that can overcome barriers to ACP to help improve patient quality of life. Living with heart failure can be challenging for a myriad of reasons, whether it be physical, emotional, and/or psychosocial in nature. What can make things even more difficult for our patients is when a patient does not know his or her prognosis and is not given the opportunity to express his or her preferences for clinical care. In highly morbid chronic illnesses such as heart failure, ACP is one important part of healthcare that goes unaddressed in the majority of patients. Based on the current literature, we can envision some strategies to increase effective ACP discussions and documentations in heart failure patients. Training providers, both generalists and specialists, in what ACP is and how to effectively integrate it into our healthcare approach would address one of the barriers. Improving communications between primary providers and cardiologists specifically regarding ACP would be helpful in sharing the workload and providing a more holistic approach to ACP. Further, we should understand that each patient with heart failure is unique and may not share the same needs or barriers to ACP. The question we should be asking is, "What is my patient's barrier to participation in ACP?" Advance care planning, puts patient values and goals in the center of medical care. ACP in heart failure patients increases their quality of life and satisfaction with end of life care. We need to identify patients' needs and adapt our practice for their benefits.

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