Living and dying with heart failure: it’s time to talk

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This editorial refers to ‘End of life preferences of elderly patients with chronic heart failure’¹, by H.P. Brunner-La Rocca et al., on page 752

Dramatic advances in the care of heart failure (HF) patients have emerged over the last two decades, resulting in an improvement in survival after diagnosis.¹,² With the development of novel therapies, the number of patients living with HF has increased. Unfortunately, HF is a disease associated with high symptom and co-morbidity burden, resulting in repeated hospitalizations. This emerging epidemic of HF hospitalizations has placed an enormous economic burden on the healthcare system in many countries. In an era of increasing focus on patient-centred medicine, the matching of patient preferences to resource use becomes of mounting importance in caring for our ageing population. However, assessment and knowledge of patient preferences regarding treatment and end of life care remain suboptimal.

Brunner-La Rocca and colleagues³ report provocative findings from an analysis of patients enrolled in the Trial of Intensified versus Standard Medical Therapy in Elderly Patients with Congestive Heart Failure (TIME-CHF), which compared symptom-guided with N-terminal pro brain natriuretic peptide (NT-proBNP)-guided medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quantity of life over medical therapy. Among the 622 HF participants, elicited end of life preferences revealed a predilection for quality of life over mortality, though there was little association between patient end of life preferences and all-cause mortality.

The literature investigating end of life preferences in HF patients is sparse. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was a multicentre study enrolling patients with one of nine high-mortality conditions.⁴ Of the 936 participants with HF, 23% did not want to be resuscitated, and 19% of patients changed preference after 6 months. Physicians incorrectly perceived patients’ preferred resuscitation status 24% of the time. The most powerful predictor of physician belief that a patient would not want to be resuscitated was the physician’s personal preference for resuscitation if they were placed in similar circumstances. Similar to the TIME-CHF analysis, these results underscore the dynamic nature of patient end of life preferences, and highlight the need for recurring patient–physician discussions on end of life care. However, it is alarming that there was a disconnection between physician perception and patient preference for resuscitation even after patient–physician discussions occurred, calling into question whether medical training has provided physicians with the skills necessary to elicit patient preferences accurately regarding end of life care.

The time trade-off utility was also administered in patients hospitalized with HF enrolled in the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheter Effectiveness (ESCAPE) trial.⁵ In contrast to the study of Brunner-La Rocca et al., gathered information on time trade-off and resuscitation preferences at enrolment, 12, and 18 months among patients with active HF and a recent HF hospitalization. In contrast to most trial populations, TIME-CHF participants more closely mirrored community HF patients, as they were quite elderly (mean age 77 years), frequently female (41%), and had a high burden of co-morbidities, making generalization of their findings to the representative European communities less problematic. The authors found that three-quarters of patients were not willing to trade any time alive for an improved quality of life at enrolment, and only one-third of participants expressed a willingness to trade longevity for improved quality of life at any point in the study. While some independent predictors of willingness to trade were identified, including older age, female sex, a lower activity level, and higher depression scores, they exhibited a poor ability to predict end of life preferences (Model C-statistic 0.710). A minority (39%) of patients did not wish to be resuscitated, though the proportion approached 50% in those aged 75 and older. Perhaps most intriguingly, there was no correlation between patient preferences regarding time trade-off or resuscitation and all-cause mortality.

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et al. ESCAPE participants were willing to trade almost all time alive to feel better in 28% of cases, possibly reflecting the high level of acuity and associated symptom burden in these hospitalized patients. Unlike TIME-CHF, ESCAPE authors noted some association between time trade-off and mortality, as patients who died shortly after enrolment had expressed the greatest willingness to trade time alive for improved quality of life.

The TIME-CHF analysis is particularly thought provoking, and prompts us to examine the type of conversation we should be having with our HF patients regarding end of life. While this study highlights that most patients would not trade longevity for improved quality of life if given a choice, in some cases extending life is not a viable option. Despite advances in HF therapy, the diagnosis still carries a median survival of 5 years in community studies, and HF patients may overestimate their prognosis, which could influence advanced care planning decisions. Allen et al. reported that HF patients at a tertiary care centre overestimated their life expectancy by a median of 3 years compared with the Seattle Heart Failure model. Certainly, if patients perceive their survival to be limited, this may affect decision-making, including preferences for end of life care. The TIME-CHF analysis found no association between end of life preferences or resuscitation status and mortality, which may reflect a lack of accurate understanding of prognosis.

In order for patients to make informed decisions regarding end of life care, they need to receive accurate information regarding their own prognosis. While the majority of critically ill patients are willing to discuss end of life preferences and prognosis with their physicians, most do not. As such, HF patients have a poorer understanding of their prognosis and are less involved in decision-making than patients with other chronic diseases such as malignancy. Providers may be hesitant to discuss prognosis with patients for a variety of reasons, in part because predicting prognosis is difficult given the variable clinical course that HF patients may experience. Though prognostic models in HF exist, providers may not be familiar enough to use them in day to day practice and/or may not fully trust their predictive ability. In many cases, the models were developed in populations that differ from the type of HF patients seen in the community, as many were validated using trial populations, predict only short-term outcomes, pertain solely to systolic HF patients, or can be applied only in the inpatient setting. Providers need user-friendly, accurate prognostic models that can be easily applied in the clinical setting, and that generate information in a way that can be communicated with patients.

If prognosis can be assessed and accurately communicated with patients, then there will be a better foundation for discussing end of life preferences and the role of additional therapies (Figure 1). It is our job as providers to help patients make informed decisions regarding the appropriateness of therapies, taking into account their current health status and prognosis. For instance, patients may be likely to accept therapies, such as cardiopulmonary resuscitation (CPR), that they perceive as less invasive, but this willingness may be highly influenced by an overestimate of the resultant probability of survival. Further, some HF therapies, such as implantable cardioverter-defibrillators, may be viewed as carrying a low treatment burden with opportunity for prolonging life, but, in some circumstances, such as end-stage cardiomyopathy, their use may be inappropriate. Without provider input on the individualized risks and benefits of therapies and resuscitation, patient preferences regarding the aggressiveness of ongoing care may be misguided.
In patients whose prognosis is grim, the real question we should be asking is ‘Given limited quantity of life, how can we maximize quality?’ As the end of life nears, the goals of care should also change, and the alleviation of adverse symptoms becomes the most important objective. Despite the fact that >80% of patients with chronic diseases such as HF say that they would want to avoid hospitalization while they are dying, there is a marked increase in both hospitalizations and associated costs at the end of life. In a US Medicare population with HF, an overwhelming 80% were hospitalized within the last 6 months of life, and end of life costs rose 26% from 2000 to 2007. The care of HF patients places a tremendous economic burden on many healthcare systems, and it is of mounting importance that available resources are properly matched to patient preferences for care. Several steps need to be taken to move in this direction, beginning with conducting studies to assess how resource use and hospitalization vary according to end of life preferences. Based on these data, systems of care need to be implemented to match HF patient preferences and resource use at the end of life more efficiently.

End of life care should honour patient preferences, which requires open, repeated communication regarding prognosis and advanced care planning between patients and providers. By utilizing a patient-centred approach, medical decision-making can be individualized to reflect goals and appropriateness of care, particularly when patients near the terminal portion of a chronic disease.

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References