Prognosis, Communication, and Advance Care Planning in Heart Failure: A Module for Students, Residents, Fellows, and Practicing Clinicians

April Zehm, MD*, Charlotta Lindvall, MD, PhD, Kimberly Parks, DO, Kristen Schaefer, MD, Eva Chittenden, MD

*Corresponding author: AZehm@mgh.harvard.edu

Abstract

Introduction: The increasing prevalence, high symptom burden, and medical advances that often prolong the advanced phase of heart failure mandate an organized and thoughtful approach to medical decision making. However, many clinicians have difficulty discussing prognosis and goals of care with patients. Barriers include disease- and therapy-specific prognostication challenges in heart failure and a lack of evidence-based primary palliative care education initiatives. Methods: In response, we developed this 45-minute training module, which consists of a case-based small-group session and a communication guide. The curriculum highlights prognostication challenges in heart failure and introduces an illness trajectory-based framework to cue iterative goals of care conversations. Results: We piloted this learning module with 46 internal medicine residents and interdisciplinary palliative care fellows in groups of three to 15 and obtained anonymous quantitative and qualitative postsession learner survey data to examine feasibility and acceptability. Trainees rated the session highly. One hundred percent of learners either strongly agreed or agreed the session was clinically useful. Learners unanimously found the teaching methods effective, and most felt they could easily apply these skills to their clinical work. In open-ended feedback, learners said the session gave them a better understanding of the heart failure illness trajectory, an improved framework for discussing goals of care with heart failure patients, and specific language to use when having these discussions. Discussion: This module represents a new paradigm for teaching both prognostication and advance care planning in heart failure in which illness trajectory guides timing and content of goals of care conversations.

Keywords
Communication, Palliative Care, Small Group, Prognosis, Heart Failure, Case-Based Learning, Patient Care Planning, Serious Illness, Care Goals, Advance Care Planning

Educational Objectives

By the end of this session, learners will be able to:
1. Describe how prognosis in advanced heart failure is highly variable and uncertain but illness trajectory is more predictable and clinically useful.
2. Illustrate the trajectory of illness in heart failure and use this model to promote disease understanding amongst patients and families.
3. Demonstrate communication skills and strategies to discuss illness trajectory and advance care planning tailored to a patient's stage of illness.

Introduction

The public health burden of heart failure in the United States and worldwide is great, and end-stage heart failure has one of the largest effects on quality of life of any advanced disease. For patients living with heart failure and any serious illness, palliative care relieves symptoms, improves outcomes such as patient and family satisfaction with care, and decreases costs.\(^1\)\(^2\) Palliative care to address quality of life and enhance medical communication is relevant throughout the course of heart failure, not just in advanced...
stages of the disease, and can be used in conjunction with life-prolonging treatments.

The importance of concurrent palliative and disease-targeted care has been widely recognized. Recent guidelines advocate provision of palliative or supportive care concurrent with efforts to prolong life in heart failure. Only a small fraction of heart failure patients receive palliative care, and when palliative care or hospice services are utilized, it is often so late in the course of illness that their efficacy is decreased. Furthermore, evidence demonstrates ongoing communication gaps in heart failure. Bereaved family members of heart failure patients with nonsudden cardiac deaths report minimal communication from physicians about what to expect.

There are many reasons for the discrepancy between the ideal and actual care provided. Heart failure poses distinct prognostic challenges. Unlike many malignancies, which are characterized by a steep linear decline in performance status during the last months of life, heart failure has a prognosis that is highly variable and uncertain, making it difficult for clinicians to provide anticipatory guidance and discuss advance care planning with patients and families. Other unique challenges include the management of implantable cardiac devices, ventricular-assist devices, and the option for heart transplantation, all of which can dramatically change the clinical trajectory. Additionally, the supply of palliative care specialists is small, resulting in reliance on other clinicians who care for heart failure patients but who may lack training and experience necessary to meet patients' palliative care needs. There is also a paucity of educational material to address this shortcoming. Currently, there are no educational materials in MedEdPORTAL that address prognostication and communication in heart failure. This represents an enormous opportunity to expand the palliative care knowledge base for all clinicians. As palliative care physicians and cardiologists who have worked with heart failure patients in the inpatient, outpatient, and hospice setting, we feel we have unique expertise to share with learners.

This small-group, case-based workshop introduces a palliative approach to heart failure that is offered alongside standard cardiology care. The module is appropriate for clinicians at various levels of training and experience. While our presentation is geared towards internal medicine residents, it may also be appropriate for medical students, residents of other specialties, or even practicing clinicians. Likewise, it is appropriate for fellows, including those in cardiology or palliative care training programs. In fact, we adapted this module and successfully piloted it with a group of interdisciplinary palliative care fellows that included adult- and pediatric-trained physicians, nurse practitioners, social workers, and pharmacists (see Appendices B & D). By the conclusion of this module, learners have the framework and techniques for communications in heart failure that are based on expected phases of illness trajectory. Learners discuss the difficulties surrounding prognostication in heart failure, and the importance of quality goals of care discussions for these patients throughout the course of illness. Learners review a case that highlights declining functional status and quality of life as triggers for ongoing serious illness communication, as well as suggested language to promote care that is concordant with patients' values and goals. Learners also are equipped with a serious illness communication guide reviewing anticipated illness trajectory, predictors of outcome, and advance care planning in heart failure.

The resource also includes objectives and materials addressing the role of palliative care consultation for patients with heart failure, as well as preparedness planning for patients undergoing mechanical circulatory support or cardiac transplantation, so it can be modified for specialty-level palliative care providers.

**Methods**

In this module, teaching occurs in a small group led by a facilitator, preferably a clinician with some background and/or interest in palliative care or communication and heart failure. The small group is attended by anywhere from three to 15 learners and can include medical students, residents, fellows, nurse practitioners, physician assistants, or interdisciplinary practicing clinicians. However, we recommend learners within a group be at the same training level (e.g., medical students, residents, etc.). Advised
The length of the session is 45 to 60 minutes, and an appropriate learning environment is a room that is conducive to small-group discussion and equipped with a chalkboard or whiteboard. Additional required materials include copies of the following appendices.

The learner’s guide (Appendix A) includes the three learning objectives listed above, a patient case with associated questions for discussion, and a reference list with both recommended and additional reading; it is to be distributed to learners at the beginning of the session. We used a modified guide (Appendix B) for our palliative care fellows that included the same case and questions plus two questions meant to define the role of palliative care consultation for patients with heart failure and to generate a discussion on preparedness planning for patients undergoing mechanical circulatory support.

The instructor’s guide/facilitation manual (Appendix C) includes the same learning objectives, case, and questions as the learner’s guide but adds answers, important discussion points, and suggested time frames for each question. As with the learner’s guide, we created one variation of this (Appendix D) that was intended to target specialty-level palliative care consultants or trainees.

The illness trajectory and serious illness communication guide (Appendix E) is a take-home reference guide that can be used by participants when providing patient care in the future; it should be distributed at the conclusion of the case and discussion. The guide includes a formal illness trajectory drawing (which learners are encouraged to share with their patients), major predictors of outcome in heart failure, advance care planning needs during advancing phases of illness, and suggested language for providers to use when sharing prognostic information, eliciting patient values and goals, and making medical recommendations.

The palliative care in advanced heart disease PowerPoint is a 13-slide presentation (Appendix F) used only for the sessions involving specialty-level palliative care clinicians, if desired. It reviews prognostic challenges in heart failure, formal heart failure classification systems, our illness trajectory graph, symptom burden in heart failure, basic goals of mechanical circulatory support, and national guidelines for palliative care involvement in mechanical circulatory support patients' care. It is to be referenced briefly as the group progresses through the case, mainly to share some statistics and graphics. While the initial slides regarding prognostication and classification schemes could be shared with less advanced learners, the focus on premechanical circulatory support palliative advance care planning and counseling is targeted to palliative care trainees.

The learner evaluation form (Appendix G) is an assessment tool intended to be distributed to and collected from learners at the end of the session and includes three evaluation questions using a 5-point Likert scale that assess clinical utility, efficacy of the teacher and methods, and anticipated practice change. Open-ended feedback is also requested.

It is suggested that the facilitator review the instructor’s guide before the session. While formal palliative care training is not required to teach this module, for faculty without this experience there are several additional, optional, preparatory resources to consider. A recent scientific statement from the American Heart Association provides a conceptual framework and overview of core competencies for decision making in advanced heart failure. The Center to Advance Palliative Care and VitalTalk websites offer additional online provider communication training and tools. If desired, nonpalliative care faculty could also review the case and discussion points with palliative care faculty prior to the teaching session.

The session begins with distribution of the learner’s guide (Appendix A or B) and a review of the educational objectives. The case of a patient with progressive heart failure is then introduced, which serves as an exemplar of embedding palliative care practices in standard heart failure care. The case demonstrates illness progression and highlights important accompanying goals of care and advance care planning considerations at various time points for providers. It is intended to be presented interactively. An alternative is to use a real-life case generated by the group.
To start, the participants are asked to draw and discuss the illness trajectory in heart failure and consider the prognostic challenges this poses. Asking learners to begin their formulation of a heart failure case in terms of illness trajectory, instead of more traditional heart failure classification models, is a novel approach that may be more clinically useful; this point should be underscored by instructors. Specific predictors of outcome can be discussed, time permitting. The majority of time is spent discussing a simple yet effective framework for an initial goals of care discussion that assesses patients’ prognostic awareness, information-sharing preferences, and values. Iterations of this framework are repeated as the case progresses, with the intentional absence of specialist-level palliative care involvement in the case itself. The lack of specialist-level palliative care providers allows the learners to demonstrate effective primary palliative care, or that which is provided by primary clinicians. In the adapted version for palliative care specialists, learners are asked to discuss a reasonable approach to a palliative care consultation with the patient as well as what a premechanical circulatory support discussion might entail.

Learners’ active participation is requested as they demonstrate and discuss these advanced communication skills, which should also be modeled by the instructor. Participants are encouraged to think about how they can use these skills in their own clinics and on the wards when caring for heart failure patients.

The second component of this learning activity includes distribution and review of a take-home serious illness communication guide (Appendix E) that diagrams illness trajectory in heart failure, highlights predictors of outcome, and reviews advance care planning at each phase of illness, complete with suggested language for communication encounters; this is expected to review and reinforce the prior discussion. Learners are encouraged to share the diagram with heart failure patients and families and to reference the communication strategies to enhance future patient care. Given the aforementioned universal shortage of palliative care specialists, both the case and guide are intended to encourage learners to integrate a palliative approach into the treatment of patients with heart failure on their own.

Results

During the monthly teaching sessions conducted in the 2016-2017 academic year, six palliative care physician faculty members served as facilitators, either alone or in pairs. Anonymous feedback (both quantitative and qualitative) was obtained after each teaching session using the learner evaluation form (Appendix G). A total of 46 learners provided feedback. Of these, 32 were internal medicine residents, and 14 were interdisciplinary palliative care fellows (physicians, nurse practitioners, social workers, and pharmacists). Quantitative feedback on clinical utility, teaching efficacy, and perceived resultant practice change was obtained using a 5-point Likert scale (Table).

| Item                                                                 | Strongly Agree | Agree       | Unsure | Disagree | Strongly Disagree |
|---------------------------------------------------------------------|----------------|-------------|--------|----------|-------------------|
| The session was clinically useful.                                  | 24 (52.2%)     | 22 (47.8%)  | 0 (0%) | 0 (0%)   | 0 (0%)            |
| The teacher and teaching methods were effective.                    | 26 (56.5%)     | 20 (43.5%)  | 0 (0%) | 0 (0%)   | 0 (0%)            |
| This session will change or improve my practice.                    | 19 (41.3%)     | 25 (54.4%)  | 2 (4.3%)| 0 (0%)   | 0 (0%)            |

Open-ended, qualitative feedback was also solicited from learners. Below is a sampling from internal medicine residents.

- “Loved the framework and list of phrases we could use.”
- “Improved model/framework for discussing goals of care with patients.”
- “Improved knowledge of congestive heart failure disease trajectory and role of hospice services/when to refer.”
• “Language in goals of care discussion (hope/worry/priorities/I’m worried).”
• “Good vocabulary for initiating goals of care conversations.”
• “Using hopes and fears in my discussions.”
• “More discussion about current coronary care unit cases would have been great, but overall useful.”
• “[Would like] more specific info on device eligibility and how prognosis changes.”

Here is a sampling from interdisciplinary palliative care fellows:

• “Gives me a more concrete framework to think about/discuss heart failure with patients.”
• “Better understanding of heart failure illness trajectory.”
• “Session provided examples of language we can use when speaking with heart failure patients.”
• “I have a better framework for pre-ventricular assist device discussions.”
• “This directly pertains to the types of consults we are receiving, especially with ventricular assist device pre-op consults. It was extremely important.”
• “Case-based teaching was helpful.”
• “I am in pediatrics, so the underlying pathology and treatment options are different. We also deal with more prognostic uncertainty on a daily basis.”
• “Wish it could’ve been longer and addressed more of the associated symptoms.”
• “Unsure of cardiologist standpoint and how to interact.”

Throughout the qualitative resident feedback, participants indicated having a better understanding of the heart failure disease trajectory as well as a strong appreciation for the structured framework for goals of care discussions with specific language to use within this model. Themes of improved understanding of the heart failure illness trajectory and communication approaches were similar amongst the fellows. Additionally, the fellows felt better equipped to approach and carry out a premechanical circulatory support consult and felt the case-based teaching methodology was particularly useful.

Most constructive feedback from the learners related to topics that were not included in the objectives of our curriculum. Residents suggested using a current cardiac intensive care unit case to review and practice this communication framework, and one learner requested more specific information about device eligibility. Constructive feedback from the fellows included requests for more information on symptom management in heart failure, cardiologists’ perspectives and approaches to mechanical circulatory support decision making and informed consent, and pediatric-focused heart failure issues.

Discussion

This module introduces basic palliative care communication skills to providers caring for patients with heart failure, including a novel way to think about prognosis and an associated goals of care framework. All of the learning materials and methods included in this session are intended to empower and guide primary providers to more effectively communicate with their heart failure patients without specialty-level palliative care involvement. Encouraging this frontline primary palliative care will be critical as specialist shortages continue nationally and worldwide. At the same time, the case and objectives can easily be adapted to target palliative care clinicians looking to enhance their consultant role and their patient communication skills regarding prognostic uncertainty, advance care planning, and preparation for mechanical circulatory support in advanced heart failure. The interactive, case-based small-group session models real-life patient scenarios and encourages participants to generate answers on their own and to teach each other through discussion and practice of learned skills. The communication guide serves as a tangible reference tool that can be used to enhance patient communication during real-life clinical encounters in the future.

While our learner sample size is modest and we did not collect pre- and postsession knowledge data, we have demonstrated the acceptability and feasibility of this short session for a pilot cohort of learners. Our learning objectives, content, and methods could be adapted and used to develop more in-depth curricula...
for these and other learner groups, including cardiology trainees and practicing clinicians.

Other future goals include creating a laminated pocket card or even a mobile device app for personal reference after the session. Additionally, while the case mentions the significant symptom burden in heart failure, this is not the focus of this module, as we believe symptom management in heart failure warrants its own dedicated training module. A complementary symptom management–focused module could pair nicely with this one, as communication skills discussed here are only a part of high-quality, holistic heart failure care.

Didactics and even small-group discussions have their limitations. To actually practice, observe, and provide feedback on specific language and affect being used during patient conversations, clinician-patient role-playing may be useful and could be incorporated into the next iteration of this session. One learner suggested using a videotaped clinician-patient interaction to model these skills. Next steps for participants are to use learned skills in real-life scenarios; in fact, observing seasoned practitioners model skills and then practicing these in real time with feedback may be the best way to learn advanced communication skills.

Lastly, there are many opportunities to learn and incorporate palliative care in other diseases beyond heart failure, including malignancy, other types of organ failure (lung, renal, and liver), and neurologic conditions such as amyotrophic lateral sclerosis and dementia. Improved teaching of symptom palliation and advanced communication skills is desperately needed for all providers caring for patients with serious illness. We believe this module is a leap in the right direction in the cardiology world.

April Zehm, MD: Palliative Care Physician, Division of Palliative Care and Geriatrics, Massachusetts General Hospital; Instructor, Harvard Medical School

Charlotta Lindvall, MD, PhD: Palliative Care Physician, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Palliative Care Physician, Division of Palliative Care, Brigham and Women’s Hospital; Instructor, Harvard Medical School

Kimberly Parks, DO: Advanced Heart Failure Cardiologist, Director of Ambulatory Cardiology, VA Boston Healthcare System; Assistant Professor, Harvard Medical School

Kristen Schaefer, MD: Palliative Care Physician, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Palliative Care Clinical Liaison, Advanced Heart Disease Team, Brigham and Women’s Hospital; Assistant Professor, Harvard Medical School

Eva Chittenden, MD: Palliative Care Physician, Division of Palliative Care and Geriatrics, Massachusetts General Hospital; Professor, Harvard Medical School

Disclosures
Dr. Zehm reports personal fees from Integritas Communications outside the submitted work. Dr. Lindvall reports grants from the National Palliative Care Research Center and the Palliative Care Research Cooperative Group outside the submitted work.

Funding/Support
None to report.

Ethical Approval
Reported as not applicable.

References
1. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. Circulation. 2009;120(25):2597-2606. https://doi.org/10.1161/CIRCULATIONAHA.109.869123
2. Connor SR, Teno J, Spence C, Smith N. Family evaluation of hospice care: results from voluntary submission of data via website. J Pain Symptom Manage. 2005;30(1):9-17. https://doi.org/10.1016/j.jpainsymman.2005.04.001
3. Casarett D, Pickard A, Bailey FA, et al. Do palliative consultations improve patient outcomes? J Am Geriatr Soc. 2008;56(4):593-599. https://doi.org/10.1111/j.1532-5415.2007.01610.x
4. Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. Chest. 2008;133(3):704-712. https://doi.org/10.1378/chest.07-1773
5. Finlay IG, Higginson UJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. Ann Oncol. 2002;13(suppl 4):257-264. https://doi.org/10.1093/annonc/mdf668
6. Higginson UJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? J Pain Symptom Manage. 2002;23(2):96-106. https://doi.org/10.1016/S0885-3924(01)00406-7
7. Gade G, Venohr I, Conner D, et al. Impact of an inpatient palliative care team: a randomized controlled trial. J Palliat Med. 2008;11(2):180-190. https://doi.org/10.1089/jpm.2007.0095
8. Higginson UJ, Romer AL. Measuring quality of care in palliative care services. J Palliat Med. 2000;3(2):229-236. https://doi.org/10.1093/jpms/3.2.229
9. McIlvennan CK, Allen LA. Palliative care in patients with heart failure. BMJ. 2016;353:i1010. https://doi.org/10.1136/bmj.i010
10. Hunt SA. ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (writing committee to update the 2001 guidelines for the evaluation and management of heart failure). J Am Coll Cardiol. 2005;46(6):e1-e82. https://doi.org/10.1016/j.jacc.2005.08.022
11. Yancy CW, Jessup M, Bozkurt B, et al. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. J Am Coll Cardiol. 2013;62(16):e147-e239. https://doi.org/10.1016/j.jacc.2013.05.019
12. Goodlin SJ, Hauptman PJ, Arnold R, et al. Consensus statement: palliative and supportive care in advanced heart failure. J Card Fail. 2004;10(3):200-209. https://doi.org/10.1016/j.cardfail.2003.09.006
13. Matlock DD, Peterson PN, Sirovich BE, Wennberg DE, Gallagher PM, Lucas FL. Regional variations in palliative care: do cardiologists follow guidelines? J Palliat Med. 2010;13(11):1315-1319. https://doi.org/10.1089/jpm.2010.0163
14. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: National Academies Press; 2015.
15. McCarthy M, Hall JA, Ley M. Communication and choice in dying from heart disease. J R Soc Med. 1997;90(3):128-131. https://doi.org/10.1177/0140768970900304
16. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation. 2012;125(15):1928-1952. https://doi.org/10.1161/CIR.0b013e31824f2173
17. Palliative care courses. Center to Advance Palliative Care Web site. https://www.capc.org/providers/courses/
18. Resources. VitalTalk Web site. http://vitaltalk.org/resources/