

7-23-2013

Ethics of Shared Decision-Making for Advanced Heart Failure Patients

Catherine Lauridsen RN, BSN

Shawnee Mission Medical Center, Catherine.Lauridsen@shawneemission.org

Follow this and additional works at: <https://aquila.usm.edu/ojhe>

Recommended Citation

Lauridsen, C. (2013). Ethics of Shared Decision-Making for Advanced Heart Failure Patients. *Journal of Health Ethics*, 9(1). <http://dx.doi.org/10.18785/ojhe.0901.05>

This Article is brought to you for free and open access by The Aquila Digital Community. It has been accepted for inclusion in *Journal of Health Ethics* by an authorized editor of The Aquila Digital Community. For more information, please contact aquilastaff@usm.edu.

ETHICS OF SHARED DECISION-MAKING FOR ADVANCED HEART FAILURE PATIENTS

Catherine Lauridsen, RN, BSN

Transition Care Coach
Shawnee Mission Medical Center
9100 West 74th Street
Shawnee Mission, KS 66204
Phone: 913-676-6811 Fax: 913-676-7699
Email: catherine.lauridsen@shawneemission.org

Abstract

This article argues that caregivers have an ethical duty to ensure that shared decision making and palliative care measures are fully discussed with and understood by their advanced heart failure patients. This is not a trivial issue. Heart failure is reaching epidemic proportions, while advances in treatment options available for heart failure patients have made it possible to prolong the life of many patients. The potential benefits and burdens of available treatments must be clearly understood by the heart failure patient so the patient can make decisions consistent with his or her values and wishes. However, too often patients are not given full information about how such treatments will affect their quality of life or about appropriate palliative care measures. The solution to this problem requires shared decision-making about treatments and palliative care measures to ensure proper goal setting, reevaluation with changes in prognosis, and end of life preparedness planning.

Keywords: Shared Decision, Ethics, Heart Failure, Informed, Patient

INTRODUCTION

Health care providers have an ethical duty and responsibility to ensure that their advanced heart failure patients are fully informed about and understand the benefits and disadvantages of undergoing the treatment options that are available to them. Heart failure in the United States is a major cause of morbidity and mortality, and accounts for an immense cost in healthcare. Advanced technologies, and the application of “specialized therapies” that include heart transplantation, ventricular assist devices, implantable cardioverter defibrillators, and cardiac resynchronization therapy have created a complex array of treatment options beyond medications for clinicians to use in treatment for the advanced heart failure patient. Patients who would have died from acute heart attacks in the past are now living through these events, largely due to coronary artery bypass surgery, angioplasty, stenting and intravenous thrombolytic medications. However, these life-prolonging treatments and advanced treatment options do not come without significant tradeoffs. Patients often experience significant quality of life issues, including pain, depression, stress, impact on caregivers, and economic burden.

Unfortunately, too often caregivers pay far too little attention to ensuring that their advanced heart failure patients fully understand the impact of various treatment alternatives and the range of palliative care options available to them. This is inconsistent with the principle of “patient centered care,” which the Institute of Medicine has identified as one of six pillars of quality, and which is defined as “care that is respectful of and responsive to individual preferences, needs and values and ensuring that patient values guide all clinical decisions (Institute of Medicine, 2001).” Shared decision making, which requires early discussions between the clinician and the advanced heart failure patient about the patient’s values, goals, and wishes, is the best and most appropriate means of implementing patient centered care.

Accordingly, shared decision making becomes imperative when creating clinical treatment plans for patients with advanced heart failure. Intimate dialogue between physician and patients is necessary to ensure that the patient recognizes that there are complex trade-offs when facing medical decisions. Shared decision making should involve clinicians fully informing the patient about the risks and benefits of treatments, keeping the patients' goals, values, and wishes in mind.

Heart Failure Epidemic

Heart failure affects 2.4% of the adult population, nearly 6 million people, and over 11% of the expanding population over 80 years old in the United States. Approximately 500,000 to 700,000 new cases of heart failure are identified each year (Lloyd-Jones et al., 2010). The risk of developing heart failure increases with advancing age. The number of people diagnosed with heart failure is due to rise with the aging of the baby boomer generation.

Heart failure is one of the most resource-intensive conditions with direct and indirect costs in the United States estimated at \$39.2 billion in 2010. These costs are projected to reach 44.6 billion by 2015 (Allen et al., 2012). Heart failure ranks as the most frequent cause of hospitalization and rehospitalization among older Americans. In 2005, rehospitalizations accounted for \$15 billion in Medicare spending, of which 12 billion was related to potentially preventable readmissions.

WHAT IS ADVANCED HEART FAILURE?

The American Heart Association characterizes patients with end stage heart failure as a group of patients for whom symptoms limit daily life despite usual recommended therapies and whose prognosis is not likely to improve. Advanced heart failure is characterized by marked symptoms,

including symptoms at rest or with minimal exertion, end-organ hypoperfusion at rest, and the requirement of specialized interventions to manage symptoms or prolong life (Goodlin, Quill, & Arnold, 2004). It is more clearly defined by the European Society of Cardiology Criteria for Advanced Chronic Heart Failure found in Table 1, which was reprinted in Allen et al. (2012):

Table 2. European Society of Cardiology Criteria for Advanced Chronic Heart Failure

1. Moderate to severe symptoms of dyspnea and/or fatigue at rest or with minimal exertion (NHYA functional class III or IV)
2. Episodes of fluid retention and/or reduced cardiac output
3. Objective evidence of severe cardiac dysfunction demonstrated by at least 1 of the following:
 - Left ventricular ejection fraction <30%
 - Pseudonormal or restrictive mitral inflow pattern by Doppler
 - High left and/or right ventricular filling pressures or Elevated B-type natriuretic peptide
4. Severe impairment of functional capacity as demonstrated by either inability to exercise, 6-min walk distance <300 m, or peak oxygen uptake <12 to 14 mL * g⁻¹ * min⁻¹
5. History of at least 1 hospitalization in the past 6 months
6. Characteristics should be present despite optimal medical therapy

NHYA indicates New York Heart Association.

Reprinted from Metra et al, with permission of the publisher. Copyright © 2007, Oxford University Press

(Allen et al., 2012).

Heart problems, including advanced heart failure, can be caused by a variety of factors. Among them are heart valve dysfunction, congenital heart abnormalities, infections of the heart, large or multiple heart attacks, diabetes, and long standing hypertension (Kirkpatrick and Kim, 2006).

DIFFICULTIES WITH PROGNOSIS

Assessment of prognosis is the foundation for selection among therapies for any life-threatening disease, but is particularly challenging for heart failure. The clinical course varies

dramatically across the spectrum of disease severity, and is relatively unpredictable for individual patients. Even in late stage heart failure, patients often enjoy “good days” and periods of apparent stability, which can lull them and their care providers into postponing vital decisions (Allen et al., 2012).

Mortality is the focus with most prognostic models for heart failure, with little considerations for clinical outcomes and quality of life. A full discussion of prognosis should include not only the risks of death, but also the potential burdens of worsening symptoms, limited functional capacity, loss of independence, reduced social function, decreased quality of life, and increased caregiver commitment. Ideally, the time to begin discussing the uncertain prognosis and variable trajectory of heart failure should begin at the time of diagnosis of heart failure with a trusted and known health care provider. Moreover, because the clinical course of heart failure often has sudden changes, ongoing and frequent discussions between clinicians and patient concerning treatment alternatives and clinical pathways is necessary to clarify expectations, guide communication, and facilitate rational shared decision making.

SPECIALIZED THERAPIES FOR ADVANCED HEART FAILURE

The need for shared decision making between patient and clinician about treatment and palliative care options has been made more acute as technology and advanced heart failure treatments have improved dramatically in the past decade. Advanced medical management, such as use of intravenous inotropic agents, heart transplant, and implantable devices such as ventricular assist devices (VADs), implantable cardioverter defibrillators (ICDs), and cardiac resynchronization therapy (CRT) have drastically changed the care options for patients in acute heart failure (Lindenfeld et al., 2010).

For end stage heart failure, the primary life-prolonging therapy has been cardiac transplant, which for many patients is not an option. With only 5,000 donor hearts available annually in the world, many patients die while on the waiting lists. In the United States, there are approximately 2,200 heart transplants performed annually with more than 3,500 patients waiting on the national list (U.S. Organ Procurement and Transportation Network, 2009). VADs, which are mechanical pumps that support failing hearts, were initially used to “bridge” patients waiting for heart transplants. However, VADs are now used as “destination therapy,” for long term support for the heart, or for “bridge to destination” for those who are not transplant candidates at the time of VAD implantation, but may become so later. The technological advances in VAD development and design are likely to increase the number of patients eligible for this treatment. Problems with the need for substantial specialized support post-implantation, risk of infection and stroke, and strong caregiver engagement are all factors that can add complications that must be discussed with heart failure patients.

Symptom management and quality of life factors are also implicated by the increasing use of ICDs or “pacemakers” to treat lethal arrhythmias by pacing or shocking the heart back into normal rhythm. Although ICD’s abort lethal arrhythmias, they do not improve cardiac function or heart failure symptoms. Risks that may not be known to patients also often arise because patients can be shocked at inappropriate times causing the patient acute distress.

THE NEED FOR AND IMPLEMENTATION OF SHARED DECISION-MAKING

Given the complexity of the benefits and burdens of many heart failure treatment options, shared decision-making between clinicians and their patients is required to ensure that the patients understand all of the implications of such treatment. Patients with advanced heart

failure who have one or more of the specialized heart procedures often experience serious quality of life issues, causing unexpected complications and burdens. Indeed, many such patients find that they face symptom burdens, including pain, stress, financial burdens, and poor quality of life, similar to that experienced by patients with advanced malignant cancers or other chronic diseases (Bekelman et al., 2008). The clinical features of treating advanced heart failure, therefore, raise multiple ethical issues. Among the most important issues relate to informed consent, selection processes, symptom management, advanced care planning, and the planning and treatment near the end of life, including palliative and hospice care.

High quality decisions are chosen from medically reasonable options and are aligned with values, goals, and preferences of an informed patient (Allen et al., 2012). Planning for unanticipated events, and determination of any advanced directives, should be included when determining interventions and treatment options. Informed consent, as defined by Farber Post, Blustein, and Neveloff Dubler (2007) starts with full disclosure by the physician to a patient with the decisional capacity to understand sufficient information regarding treatment options. The informed patient is then able to communicate consent or refusal to the proposed medical intervention without compulsion or coercion (Farber Post et al., 2007).

Ideally, the time to begin discussing the uncertain prognosis and variable trajectory of heart failure should begin at the time of diagnosis of heart failure with a trusted and known health care provider. If the clinician waits until the patient's heart failure advances to discuss advanced treatment options and advanced care planning, they risk losing the opportunity to involve the patient in a shared discussion (Tanner, Fromme & Goodlin, 2011).

Shared decision-making, however, goes beyond mere informed consent. It also addresses the ethical need to fully inform patients about the risks and benefits of treatments (Frosch &

Kaplan, 1999). It also supports “autonomy,” one of the four basic principles of health care ethics. This principle requires that the patient have autonomy of thought, intention and action when making decisions regarding their health care. The decision making process must be patient centered, free of coaxing or coercion when considering treatment opportunities. Shared decision making provides the platform to ensure that a patient with heart failure clearly understands all the risks and benefits of treatment options.

The American Heart Association has made a list of the “Top Ten Things to Know” for shared decision-making in advanced heart failure:

Top Ten Things to Know

1. Shared decision making is the process through which clinicians and patients share information with each other and work toward decisions about treatment chosen from medically reasonable options that are aligned with the patients’ values, goals, and preferences.
2. For patients with advanced heart failure, shared decision making has become both more challenging and more crucial as duration of disease and treatment options have increased.
3. Difficult discussions now will simplify difficult decisions in the future.
4. Ideally, shared decision making is an iterative process that evolves over time as a patient’s disease and quality of life change.
5. Attention to the clinical trajectory is required to calibrate expectations and guide timely decisions, but prognostic uncertainty is inevitable and should be included in discussions with patients and caregivers.
6. An annual heart failure review with patients should include discussion of current and potential therapies for both anticipated and unanticipated events.
7. Discussions should include outcomes beyond survival, including major adverse events, symptom burden, functional limitations, loss of independence, quality of life, and obligations for caregivers.
8. As the end of life is anticipated, clinicians should take responsibility for initiating the development of a comprehensive plan for end-of-life care

- consistent with patient values, preferences, and goals.
9. Assessing and integrating emotional readiness of the patient and family is vital to effective communication.
 10. Changes in organizational and reimbursement structures are essential to promote high-quality decision-making and delivery of patient-centered health care.

(Allen, et al., Table 1, 2012).

This helpful list makes clear that early discussions between the clinician and an advanced heart failure patient should include clarification of the patient's values, goals, and wishes. This not only serves as an appropriate guide for making decisions about possible therapy options, but also builds trust for the entire shared decision-making process. Moreover, clearly defined treatment options should be presented to the patient with all reasonable alternatives, together with all reasonably likely "pros and cons" of any particular treatment option. Among the factors that must be thoroughly explained and discussed with advanced heart failure patients are the possible impact on the patient's quality of life, including pain and mobility, associated costs, burdens, and stresses on the patient and the patient's family associated with a particular treatment option.

PALLIATIVE CARE

Palliative care is aimed at improving quality of life for patients by preventing and relieving suffering and supporting patients' families. This care is provided by an interdisciplinary team and can be offered simultaneously with all other appropriate medical therapies. Disease modifying therapies can be continued to ensure symptom relief, and unlike hospice, palliative care is based on patient need, rather than a patient's prognosis regarding life expectancy.

The central tenet of palliative care is shared decision-making. Preferences for life-prolonging therapy, symptom control, pain relief, and end of life care are made by a process of shared decision-making between clinicians and the advance heart failure patient (Allen, et al. 2012).

It is important to weave palliative care into an overall care plan for advance heart failure patients due to the changeable and complex nature of the disease. Palliative care teams consisting of physicians, social workers, nurses, chaplains, and other professions work together with the patient and care givers to ensure that all of the patient's needs are properly addressed.

CONCLUSION

Shared decision-making puts into practice the principle of "patient centered care" and is thus "respectful of and responsive to individual preferences, needs and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). Shared decision-making is the best and most appropriate means of effecting patient centered care, and therefore is required not only to achieve the best quality of care possible for the advanced heart failure patient, but is also the ethical responsibility of such a patient's caregivers.

Advanced heart failure patients face great obstacles and difficult decisions about complex treatments, which present difficult and challenging issues for such patients even after a successful procedure. Physicians, nurses, clinicians, and other caregivers owe it to patients to develop and use effective shared decision-making procedures to ensure that patients are fully informed so that they can make the best possible decision for themselves based on their values, interests, needs, and concerns.

REFERENCES

- Allen, L., Stevenson, L., Grady, K., Goldstein, N., Matlock, D., Arnold, R., Spertus, J. (2012). Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*, 125:1928-1952. Retrieved from: <http://circ.ahajournals.org/content/125/15/1928>.
- Bekelman, D.B., Rumsfeld, J.S., Havranek, E.P., Yamashita, T.E., Hutt, E., Gottlieb, S.H., Kutner, J.S. (2009). Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. *Journal of General Internal Medicine*, 24:592-598. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2669863/?tool=pubmed>.
- Farber Post, L., Blustein, J., & Neveloff Dubler, N. (2007). Handbook for health care ethics committees. Baltimore, MD: The Johns Hopkins University Press.
- Frosch, D.L & Kaplan, R.M. (2008). Shared decision making in clinical medicine: past research and future directions. *American Journal of Preventive Medicine*, 17:285-294.
- Goodlin, S.J., Quill, T.E., & Arnold, R.M. (2008). Communication and decision-making about prognosis in heart failure care. *Journal of Cardiac Failure*, 14:106-113
- Institute of Medicine (2001). Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academy Press.
- Kirkpatrick, J.N., & Kim, A.Y. (2006). Ethical issues in heart failure: overview of an emerging need. *Perspectives in Biology and Medicine*. 49:1-9. Doi: 10.1353/pbm.2006.0009.
- Linde, C., Braunschweig, F., Gadler, F., Bailleul, C., & Daubert, J. (2003). Long-term improvements in quality of life by biventricular pacing in patients with chronic heart

failure: results from the Multisite Stimulation in Cardiomyopathy Study. *American Journal of Cardiology*, 91:1090-1095.

Lindenfeld, J., Albert, N.M., Boehmer, J.P., Collins, S.P., Ezekowitz, J.A., Givertz, M.M., Walsh, M.N. (2010). HFSA 2010 comprehensive heart failure practice guideline. *Journal of Cardiac Failure*, 2010:16(6):e1-e194. Retrieved from: <http://download.journals.elsevierhealth.com/pdfs/journals/1071-9164/PIIS1071916410001739.pdf> .

Lloyd-Jones, D., Adams, R.J., Brown, T.M., Carnethon, M., Dai, S., Se Simone, G. . . . Wylie-Rosett, J. (2010). Heart disease and stroke statistics – 2010 update: a report from the American Heart association. *Circulation*, 121:e46-e215. Retrieved from: <http://circ.ahajournals.org/content/121/7/e46.full.pdf+html>.

Tanner, C., Fromme, E., & Goodlin, S. (2011). Ethics in the treatment of advanced heart failure: palliative care and end-of-life issues. *Congestive Heart Failure*, 17:25-240. Retrieved from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1751-7133.2011.00245.x/full>.

U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients (2009). *Annual report of the U.S. Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients: transplant data 1999-2008*. Rockville, MD: U.S. Dept. of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation. Retrieved from: <http://optn.transplant.hrsa.gov/ar2009/>.