

# PCNOW Position Statements and QI Projects

2016

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The Mission of the Palliative Care Network of Wisconsin (PCNOW) is “To support the growth of palliative care services through education, systems change, and advocacy”. To help meet this mission, PCNOW has developed a series of advocacy alerts/QI projects and one clinical position statement, all provided in this document or individually at: <http://www.mypcnow.org/qi-projects>. The purpose of this work is to help improve care through systems changes within health care institutions—led by whomever is most in a position to help facilitate change. This might include a hospital ethics committee, palliative care program staff, chief medical or nursing officer, quality improvement staff, chaplaincy, etc.

The process of changing the culture and practice of care for seriously ill patients is complex and time consuming but can be achieved through a deliberate process that includes the following key steps:

#### Awareness Building

- share one of the following documents with key stakeholders
- ask stakeholders if they believe that a problem exists that could benefit from a new model of care delivery—review any available data that supports the need for change

#### Planning

- Form a small committee of key stakeholders-include staff from administration/quality improvement
- Develop an Action Plan that includes key next steps and a timeline-each of the following documents includes suggested key planning steps
- Designate a leader who is charged with holding committee members responsible to completing assigned tasks

#### Develop/pilot new processes

- Depending on the issue, all the following documents call for some change in practice, whether it be a new documentation form, data collection, education, etc.
- Pilot test the new practice change initiative
- Collect pilot data and revise as needed

#### Embed the new practice

- A final step is to embed the new practice in the routine care.
- Be deliberate in reviewing possible unintended consequences
- Collect outcome data and report project successes

Suggested Reading: The Eight Step Process for Leading Change. Kotter  
<http://www.kotterinternational.com/the-8-step-process-for-leading-change/>

#### **PCNOW Board of Directors**

## PCNOW Board of Directors Position Statement: Partial or Slow Codes

July, 2016

In response to the recent JAMA article by Rousseau (2), PCNOW has written a position statement on the issue of "partial or slow" CPR attempts. We encourage you to distribute this to your hospital ethics and intensive care committees. The full position statement is provided below.

**PCNOW Position Statement on Partial or Slow Codes:** PCNOW discourages the use of partial or slow codes. We urge Wisconsin health care institutions to review/revise their CPR/DNAR policies to explicitly oppose partial and slow codes. We urge Wisconsin health care institutions to provide DNAR communication training in parallel to existing CPR skill training programs.

**Background:** Respect for patient autonomy and a shared medical decision-making process enable patients to align treatment plans with their personal goals and values. When patients are unable to make decisions for themselves, surrogates can express patient values, if known. However, certain medical interventions must be offered as an entire procedure in order to work effectively. Cardiopulmonary resuscitation (CPR) is an example of such an intervention, which must be performed as a whole in order to provide the optimal possibility of patient benefit (1,2,3). In circumstances in which patients and families are unable to agree to a do not attempt resuscitation (DNAR) order, some authors have advocated the use of "partial codes" (some resuscitative efforts are done while others are withheld) or "slow codes" (a deliberate, but half-hearted attempt at CPR in a medical situation in which CPR is highly likely to be ineffective). The use of partial or slow codes is typically performed when clinicians view the full procedure as extremely unlikely to be effective (i.e. futile), but the patient or family continues to request CPR. This process has been justified by invoking preservation of patient autonomy, minimizing treatment bias regarding pre-cardiac-arrest conditions, and fostering the grieving process of surviving loved ones (4).

Evidence suggests there is a near-certainty of death within days when partial codes are performed (5). Partial or slow codes can expose patients to substantial risk of suffering, can increase family suffering, and cause clinician moral distress (2,3,6,7). Lastly, performing partial or slow codes, that is, deliberately performing a medical procedure with no intended benefit, undermines clinician professionalism. Since the bioethical principle of patient autonomy is not absolute, and clinicians should also adhere to the principles of beneficence ("act to benefit the patient") and non-maleficence ("do no harm"), there is no ethical mandate that clinicians perform requested medical treatments, which expose patients to significant harm without a meaningful chance of benefit (8,9).

**Managing CPR Conflicts:** Requests for a slow or partial code by a patient, surrogate, or medical treatment team typically represents a breakdown in communication. The following steps are advised:

- A goals of care conference (a.k.a. Family Meeting) involving the medical treatment team, surrogate and/or patient. Such a conference should entail:
  - A discussion of the underlying medical condition and prognosis;
  - When the use of CPR is deemed medically inappropriate, a clear recommendation is made that CPR not be done at the time of natural death, rather than offering a choice: "do you want us to try to restart the heart"; (see Fast Fact #24)

- Presentation of the best available medical evidence regarding success rates of CPR;
- Reflective listening, exploratory questions and guided discussion aimed to better allow clinicians to understand the underlying reason for persistent requests for CPR;
- When one or more conferences fail to achieve resolution, seek out specialist palliative care consultation and/or an ethics consultation.

### **Hospital Policy Considerations:**

- DNAR orders should only direct clinicians in the case of cardiopulmonary arrest and should not be confused with treating pre-cardiopulmonary-arrest conditions such as respiratory distress or cardiogenic shock.
- Code status orders and forms should offer the choice of full code or DNAR with no menu CPR procedure components (e.g. mechanical ventilation, pacemaker).
- Health care institutions should avoid medical orders or advance directives, which confuse DNAR orders with the appropriate treatment of pre-cardiac arrest conditions such as incipient respiratory failure.
- The performance of slow codes or partial codes should be considered a sentinel event which should be reviewed and utilized to foster system-based quality improvement.
- Health care institutions should involve key stake-holders (e.g. clinicians, nurses, social workers, chaplains, ethics committee members) to develop a clearly delineated policy and process for resolving CPR futility concerns.
- Health care institutions should develop educational programming that provide opportunities for clinicians to practice discussing CPR/DNAR with patients and surrogates.

### **Resources:**

#### PCNOW Fast Facts:

- [#23-24](#): DNR Orders
- [#179](#): CPR Survival in the Hospital Setting
- [#183-4](#): Conflict Resolution Parts 1 and 2
- [#222-227](#): Family Meetings (Goal of Care Conference)

#### PCNOW Member Portal:

- DNR Lecture
- Communication Curriculum Guide
- Communication Trigger Video-good/bad examples of DNR Discussion

### **References:**

1. Perbedy MA, Kaye W, et al. Cardiopulmonary resuscitation of adults in the hospital: a report 14,720 cardiac arrests from the National Registry of Cardiopulmonary Resuscitation. *Resuscitation* 2003;58(3):297-308.
2. Rousseau P. Partial codes—when “less” may not be “more.” *JAMA Intern Med.* 2016; doi:[10.1001/jamainternmed.2016.2522](https://doi.org/10.1001/jamainternmed.2016.2522).
3. Sanders A, Schepp M, Baird M. Partial do-not-resuscitate orders: a hazard to patient safety and clinical outcomes? *Crit Care Med.* 2011;39(1):14-18.

4. Lantos JD, Meadow WL. Should the “slow code” be resuscitated? *Am J Bioeth.* 2011;11(11):8-12.
5. Dumot JA, Burval DJ, Sprung J, et al. Outcome of adult cardiopulmonary resuscitations at a tertiary referral center including results of “limited” resuscitations. *Arch Intern Med.* 2001;161(14):1751-1758.
6. Morrison W, Feudtner C. Quick and limited is better than slow, sloppy, or sly. *Am J Bioeth.* 2011;11(11):15-16.
7. American Association of Critical Care Nurses, Moral Distress Resources:<http://www.aacn.org/wd/practice/content/ethic-moral.pcms?menu=practice>
8. AMA Futility Policy: <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page>
9. AMA DNR Policy: <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion222.page?>

## PCNOW ADVOCACY ALERT #1

### REDUCING CONFLICTS IN THE INTENSIVE CARE UNIT

June, 2015

An important Policy Statement (1) was recently published on responding to requests for potentially inappropriate treatments in the ICU, endorsed by five critical care organizations, authored by many of the leading international voices in ICU Palliative Care and ICU Medical Ethics. This policy statement represents a wonderful opportunity to engage your hospital in establishing policies and processes to manage ICU conflicts in an organized fashion, instead of relying on each ICU clinician and palliative care team to find solutions on an ad hoc case-by-case basis. Key policy recommendations:

- Institutions should implement strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of expert consultation (including palliative care).
- The term “potentially inappropriate” should be used, rather than “futile,” to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. Clinicians should communicate and advocate for the treatment plan they believe is appropriate. Requests for potentially inappropriate treatment that remain intractable despite intensive communication and negotiation should be managed by a fair process of dispute resolution.
- The term “futile” should only be used in the rare circumstance that an intervention simply cannot accomplish the intended physiologic goal. Clinicians should not provide futile interventions and should carefully explain the rationale for the refusal.
- The medical profession should lead public engagement efforts and advocate for policies and legislation about when life-prolonging technologies should not be used.
- The policy statement includes suggested systems change and clinician education steps to improve communication along with a suggested due process for managing intractable conflicts.

PCNOW urges all members to help move these policy guidelines from theory to practice. You should look upon the specific recommendations as starting points for discussion and adapt them to meet the needs of your setting. Here are some concrete steps that PCNOW users can take:

- a) Provide a copy of the article to your Chief Medical, Nursing and Quality Officer, Ethics Committee chair, ICU medical and nursing directors and director of Risk Management; do not send by mail, deliver face to face.
  - b) Ask to have this topic as an agenda item for the hospital ethics, critical care, and quality committees.
  - c) Offer to serve on an implementation committee to develop the specific policies, system changes and education efforts recommended in the article.
  - d) Offer to help develop a communication skills training program for ICU staff and other clinicians.
  - e) Advocate for the ICU to adopt the suggested system-change recommendations.
1. An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units  
<http://www.atsjournals.org/doi/abs/10.1164/rccm.201505-0924ST#.VXX411xViko>

## PCNOW ADVOCACY ALERT #2

### DOCUMENTING GOAL OF CARE CONVERSATIONS

October, 2015

As the saying goes, *if it isn't documented, it didn't occur*. When it comes to documenting goal-of-care conversations for seriously ill patients, there is often a gap between current practice and the ideal. Failure to adequately document these conversations can lead to over-medicalization of the dying patient, increased patient/family and health professional suffering, unnecessary and prolonged hospital stays, and higher health care costs. This Advocacy Alert is designed to ensure that all hospitals and long-term care settings have goal of care conversation templates in their Electronic Medical Record.

**What is a Goal of Care Conversation (GOCC)?** The GOCC is when discussion takes place between the patient or surrogate and health care team to define patient goals—physical, social, spiritual or other patient-centered goals—that arise following an informed discussion of the current disease(s), prognosis, and treatment options. These conversations should include:

- Who was present
- What was discussed
- What was decided
- What are the next steps

**Supporting features that should also be documented include:**

- Presence or absence of an advance care planning document
- Whether the patient has decision making capacity; if not, who is making decisions and with what legal authority
- Clinician prognostic estimate (time and function)

**For patients in whom a decision is made to withdraw life sustaining treatments, additional key information can include:**

- Recommendation for hospice referral
- Role of current/future artificial nutrition/hydration
- Decisions regarding re-hospitalization
- DNR status
- Disposition plan

**What can you do?**

- ✓ Review [PCNOW Sample templates](#)
- ✓ Learn if your facility has an EMR or paper GOC template
- ✓ Learn the process at your site to develop and standardize a documentation tool
- ✓ Convene key stakeholders: ICU, ED, Palliative Care, Hospitalist program, Nursing, Social Work, Discharge Planning, EMR team
- ✓ Share your tools and experiences with PCNOW

## PCNOW ADVOCACY ALERT #3

### GENERALIST PALLIATIVE CARE—ENGAGING HOSPITAL LEADERS

November, 2015

PCNOW's mission is *To support the growth of palliative care services in Wisconsin through education, systems change, and advocacy.* Systems change was included in recognition that specialty palliative care teams cannot meet all the palliative care needs of seriously ill patients and their families.

Generalist clinicians, those individuals without special palliative care training or certification, must provide basic services as the next key step toward providing the benefits of palliative care services to all patients and families in need. The publication this week of the *Improving Generalist Palliative Care* Guidebook is the perfect opportunity to engage your hospital and health system leaders in this discussion.

What is the benefit to a health system of a generalist palliative care initiative? Key metrics that hospitals care about are inpatient mortality, readmissions and patient satisfaction—each of which can be improved through systematic patient identification and proactive work to match a realistic discussion of the illness and patient prognosis with patient goals—a cornerstone of generalist palliative care

Here are the steps you can take to engage your hospital leaders:

1. [Download the PowerPoint](#) presentation reviewing the multi-year work at Aurora West Allis Medical Center.
2. Make an appointment to meet with your key leaders, such as Chief Medical, Nursing and Quality officers and ask for 30 minutes to discuss generalist palliative care.
  - Send them the presentation ahead of time and say that you'd like to discuss this at the meeting.
3. At the meeting, ask:
  - Did you have a chance to review the presentation?
  - What are your thoughts about starting this work at our hospital?
  - Would you be open to forming a planning committee?
  - What key goals would you want to achieve from this initiative?
  - What are your concerns about this approach?

PCNOW has many resources for Generalist Palliative Care within the [Member Portal](#) (free membership). Please contact PCNOW with questions/comments—we would love to hear how your hospital leaders respond to developing a Generalist Palliative Care initiative.

## PCNOW ADVOCACY ALERT #4

### GUIDELINE FOR VENTILATOR REMOVAL

February, 2016

There comes a time for many critically ill patients when mechanical ventilation is no longer meeting a patient-centered goal; when the patient is dying and removal of mechanical ventilation is the most appropriate procedure to alleviate suffering and honor patient/family wishes. However, the steps taken to remove the ventilator and ensure patient and family comfort is often completed in a haphazard manner, resulting in preventable patient/family and staff suffering.

Best practice recommendations for ventilator withdrawal exist that respect the needs of patients, families and minimize any suffering/distress of the procedure.

PCNOW recommends that members assess the current practice for ventilator removal in your setting and help spur development of a written guideline to minimize clinical variation and reduce suffering.

#### Advocacy Steps

1. Reach out to both physician and nursing Intensive Care Unit leaders and ask if there is an existing written ventilator removal protocol. If present, ask if the protocol is routinely used and if there are any specific problems with applying the protocol in practice.
  - If you have been involved in sentinel case(s) where a bad outcome resulted from lack of a protocol, discuss that case with ICU leaders.
2. If there is a protocol that is poorly used or no protocol exists, ask if you can participate in a committee to develop a revised or new protocol. Suggest that membership of the committee should include ICU staff, Palliative Care staff, Pharmacy, and members of the Quality Improvement department.
3. Review the references listed below for best practice standards and sample protocols and seek out other resources.
4. Work to develop both a written protocol and a quality development process to ensure that the protocol is uniformly used and updated on a timely basis.

#### References:

- [Fast Facts #33-35](#)
- American Association of Critical Care Nurses-Ventilator Withdrawal Guidelines <http://www.aacn.org/WD/Palliative/Docs/mgh8.pdf>
- Campbell, ML, Yarandi, HN and Mendez M. A Two-Group Trial of a Terminal Ventilator Withdrawal Algorithm: Pilot Testing. J Pall Med 2015; 9: 781-784.
- Ohio State Palliative Ventilator Withdrawal Protocol <https://evidencebasedpractice.osumc.edu/Documents/Guidelines/PalliativeVentilatorWithdrawal.pdf>

## PCNOW ADVOCACY ALERT #5

### REDUCE CLINICIAN CONFUSION REGARDING ADVANCE CARE PLANNING, HOSPITAL POLICIES AND STATE LAWS.

May, 2016

Clinicians are confused about the rules, protections, and responsibilities concerning state-approved advance directive forms, DNR/DNI policies, and if present, futility policies. A PCNOW blog post of April 19 outlined the problems in detail along with three suggestions (insert link: <http://www.mypcnow.org/#!/Clinician-confusion-The-mess-of-advance-care-and-endoflife-planning/c1y2u/5714c0b30cf28d4bbf4c7106>)

**Step 1.** Each hospital should develop a *Guide to Advance Directives and End-of-Life Decisions*, as a collaborative process between key stakeholders. The *Guide* should include copies of advance directives promoted by the hospital, relevant state laws, key hospital policies, and a FAQ section to answer the common questions listed above. The *Guide* should be reviewed/updated annually.

**Step 2.** Each hospital should develop a testing process to assess clinician knowledge followed by training in the relevant issues. The test should be administered both for new hires and at re-credentialing times along with administration at other educational venues.

**Step 3.** Quality Improvement activities should be developed to track compliance with hospital policies.

This Advocacy Alert is designed to highlight the problem and encourage clinicians to start a dialog at their institution and implement the three steps. To facilitate Step 2, PCNOW has developed a generic 10 item-quiz that can be used in all 50 states to a) assess clinician knowledge of relevant state laws and hospital policies and b) serve as a springboard for educating clinicians. Suggestions for using the quiz include:

- New orientation for all new clinician hires
- Include as part of the clinician credentialing and re-credentialing process
- Use in a clinician training session on advance care planning/medical ethics

#### Advocacy Steps:

1. Assemble a small group of key stakeholders to work on this project.
2. Assemble the relevant state/local documents and policies.
3. [Download the clinician quiz.](#)
4. Administer the quiz to a small group (n=10-20) of clinicians to obtain baseline data;
  - this data may be needed to convince others of the need for a system-wide clinician education project.
5. Develop a testing/education implementation strategy in partnership with hospital/system administration.
6. Work with your quality department to establish a process to assess project impact.

## PCNOW ADVOCACY ALERT #6

### CASE FINDING FOR PALLIATIVE CARE UNMET NEEDS

September, 2016

This Advocacy Alert addresses case finding for patients with unmet palliative care needs in any health care setting. In order of frequency, the following methods are currently used:

**Method 1.** Physician referral based on an identified problem, most commonly helping patients determine the appropriate match of medical interventions to prognosis or difficult to control symptoms. In a few settings, nurses or patients can initiate a referral. This approach has the drawback of being clinician, not patient centered, introducing clinician biases into a) identifying the unmet need and b) determining the need and timing for specialist involvement.

**Method 2.** A screening tool (aka trigger system) is used to identify patients with unmet needs who are then referred to specialist palliative care services, either automatically or by asking the attending clinician for a referral. This approach is increasingly used in settings like the ED, ICU, oncology or heart failure clinic.

**Method 3.** A screening tool is used to identify patients with unmet needs. Once identified, a system is established whereby generalist clinicians (e.g. hospitalist, unit nurse) complete a set of tasks (e.g. encourage ACP documentation, conduct a goal of care discussion, complete a thorough symptom assessment). Referral to a palliative care specialist is reserved for patients whose needs cannot be met by the generalist team.

#### Choice of Screening Tool

Many different approaches to screening have been developed. The two most common include:

- A single indicator, most often The *Surprise Question*: would you be surprised if this patient died within the next 12 months (or shorter depending on setting)
- Combination of indicators taken from the published literature (1)

#### Advocacy Recommendations

PCNOW strongly believes that a patient-centered approach to care, that minimizes care variation, includes a system to prospectively identify patients with unmet palliative care needs, irrespective of diagnosis, prognosis, or care setting. The following steps can be taken to develop the process in your setting.

1. Gather a small committee to explore case finding options.
2. Collect data that a problem exists.
  - If your setting already has a specialist palliative care program, a simple method is to count the number of referrals over a given period of time from different clinicians (e.g. all hospitalists) or different care units, searching for variation that would indicate unequal patient access to specialty palliative care services.
  - In the hospital setting you can get data on the ratio of specialist palliative care referrals to inpatient deaths, measured in different care units or across a cohort of clinicians; again, searching for unacceptable variation.
3. Make a decision about developing a system that will assess all patients, or just those in a certain care setting (e.g. oncology clinic).
4. Invite key stakeholders to participate in determining what screening tool(s) will be used to identify patients.
5. Discuss the role of generalist clinicians vs. palliative care specialists in managing the unmet needs.

6. Once you have identified a process for patient identification and management, test the process with a small cohort of patients, revise and retest.
7. Share your story and success on the PCNOW Forum

**Reference**

1. Weissman DE and Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: consensus recommendations. J Pall Med 2011;14:1-7.

**PCNOW Resources ([www.mypcnow.org](http://www.mypcnow.org))**

Home Page: [Improving Generalist Palliative Care Guidebook](#)

Home Page/Member Portal: [Resources Tools for your Palliative Care Program](#)

- Using Screening Criteria PowerPoint Presentation
- Weaving Palliative Care into Primary Care Booklet
- Mortality Quality Improvement Template
- ICU Screening Toolkit (CAPC)

## PCNOW ADVOCACY ALERT #7

### SHARED DECISION-MAKING IN ADVANCED HEART FAILURE

November, 2016

**Background:** Advanced heart failure (AHF) can be a bewildering illness for patients, caregivers, and clinicians alike due to an illness trajectory that can be difficult to describe and predict. Many AHF patients are crippled with a high burden of symptomatic disease and recurrent visits to emergency departments, yet hospice is an underutilized resource in comparison to other chronic illnesses such as cancer or dementia. Considering the growing number of Americans with AHF and growing complexity in decision-making, many large medical organizations have advocated for the involvement of specialized palliative care teams to help AHF patients, families, and clinicians wade through the difficult decisions and improve symptom management. Yet, even palliative care clinicians may not know where to begin in improving the end of life care delivered to AHF patients.

**2012 Consensus Statement:** An American Heart Association sponsored multidisciplinary panel which included experts in cardiology, palliative medicine, and quality improvement assembled to identify best practices to optimize the shared-decision making between AHF patients and their clinicians. Palliative care clinicians should be aware of the following guiding principles from this panel:

- Anticipation is a central tenet of shared-decision making. Difficult discussions conducted early in the disease trajectory will simplify difficult decisions in the future.
- Clinicians should perform annual heart failure reviews. These annual reviews should include a discussion of the patient's illness, estimated survival, and preferences for current and potential therapies. Collaboration with palliative care specialists should be considered to optimize the quality of discussions generated from these visits.
- Sentinel events such as AHF hospitalizations, defibrillator shocks, kidney failure, or loss of independence should trigger a more focused discussion or "milestone review." In this milestone review, clinicians should utilize the sentinel events as a "bridge" to either:
  - Optimizing medical therapy
  - Pursuing interventional options – e.g. inotropic support, cardiac revascularization, ventricular assist device, transplant.
  - Transition of care goals including hospice care.
- Many clinicians may not be fully informed about the concept of shared-decision making. The panel created a tip sheet of the "Top 10 Things" to know for optimal shared decision-making in AHF. *See appendix 1.*

#### **Systems-Based Steps You Can Do at Your Own Institution:**

1. Reach out to your cardiology/AHF clinician colleagues. Ask if they:
  - Are struggling with their AHF patients in terms of decision making and symptom control.
  - Are confused about how best to utilize palliative care and hospice services.
  - Are aware of the AHA's 2012 Consensus Statement for AHF.
  - Are interested in developing a collaborative relationship to develop protocols, patient information, and quality improvement activities for AHF patients.
2. Consider a data collection process to better understand the outcomes of AHF patients:
  - Hospice length of stay
  - Inpatient deaths: ward and ICU

- Data on cardiac device use among dying patients
3. Investigate the variety of PC-AHF collaboration models.
    - ENABLE: a phone- and manual-based intervention conducted by advance practice PC nurse coaches with patients and their primary family caregivers.
    - Dedicated heart failure palliative care teams: various models exist including a dedicated palliative care heart failure inpatient service to a single physician dually trained in cardiology and palliative care.
    - Reflexive palliative care consults for advance care planning on all patients prior to ventricular assist device implantation.
    - Palliative Care specialist attendance at multi-disciplinary advanced heart failure meetings.
  4. Develop an Action Plan for improving care that includes:
    - Early identification of patients at high-risk for unmet palliative care needs
    - Standardized assessment tool
    - Shared decision making documentation tools
    - Data collection and Quality improvement processes
    - Staff education (see *appendix 2* for AHF patient care tips).

## References

1. Allen LA, Severson LW, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation* 2011;125:1928-1952
2. Cubbon RM, Gale CP, et al. Changing characteristics and mode of death associated with chronic heart failure caused by left ventricular systolic dysfunction: a study across therapeutic eras. *Circ Health Fail* 2011;4:396-403.
3. Sullivan et al. Diagnosing and discussing imminent death in the hospital: a secondary analysis of physician interviews. *J of Pall Med* 2007; 10(4) 882-893.
4. Dionne-Odom JN, Kono A, et al. Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure and their family caregivers. *J of Pall Med*. 2014 Sep 1;17(9):995-1004.
5. Bakitas M., Lyons KD, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA*; 2009 302(7), 741-749.
6. Sagin A, Kirkpatrick JN, et al. Emerging collaboration between Palliative Care Specialists and Mechanical Circulatory Support Teams: a qualitative study. *Journal of Pain and Symptom Management*. 2016 Jul 9.

## Appendix 1: Top 10 Things to Know in Shared Decision Making for AHF Patients

1. Shared decision making involves clinicians and patients sharing relevant medical information to work towards medically reasonable decisions that are aligned with the patient's values.

2. Shared decision making has become more challenging and yet more crucial in AHF as duration of disease and treatment options have increased
3. Difficult discussions now simplify difficult discussions later.
4. Shared decision making is not a “one and done” discussion, but rather an iterative process that evolves with time.
5. A transparent acknowledgement of prognostic uncertainty should be included in AHF discussions with patients and caregivers.
6. An annual heart review should include discussion of current and potential therapies for anticipated and unanticipated events such as cardiac arrest, respiratory failure, or renal failure.
7. Discussions about potential therapies should include outcomes beyond just survival, including symptom burden, functional limitations, quality of life, and obligations on caregivers.
8. Clinicians need to take responsibility for initiating end of life discussions.
9. Assessing emotional readiness of the patient and family is vital to effective communication.
10. Changes in reimbursement and organizational structures are essential to improving medical decision making in AHF.

## **Appendix 2: Other AHF Patient Care Tips**

- Avoid waiting until you are certain death is imminent to begin advance care planning discussions. Clinicians often do not become certain death is approaching until patients have only hours to days left to live. This is often too late to begin a shared decision-making process.
- Utilize illness trajectory curves as patient education tool on the anticipated projection of AHF.
- Normalize hospice and palliative care by raising these terms earlier in the disease trajectory.
- Discuss the option of deactivation of implanted defibrillators at each annual heart failure review, hospitalization, or whenever the device is near the end-of-battery life.
- Collaborate with area hospice agencies to ensure appropriate AHF therapies can be offered by if needed to palliate specific AHF symptoms – e.g. intravenous or subcutaneous diuretic administration, beta blockers, or ace inhibitors.
- Collaborate with hospice agencies with regards to the appropriate deactivation of implanted defibrillators and withdrawal of ventricular assist devices or other more complex AHF therapies at home or hospice facilities.