Palliative Care as a member of the Heart Transplant Team

Giovanni Elia, MD
Associate Director Palliative Care Services

Objectives

1. Define and identify key domains of palliative care
2. Describe the palliative care needs of patients evaluated for heart transplant
3. Describe communication strategies with patients with serious illnesses and their families
4. Discuss models for optimizing palliative care for patients evaluated for heart transplant

Case overview

- 43 year old man with multiple pre-existing chronic illnesses: diabetes, hypertension, coronary artery disease, chronic kidney disease
- Transferred from a community hospital in cardiogenic shock.
- ECMO followed by LVAD (BTT)

Disclosure

Dr. Giovanni Elia has no relevant financial relationships to disclose
Case psychosocial details

- Post-op course:
  - Multiple complications
  - Hypoxic brain injury 1 month after admission.
  - Remained in ICU without neurologic recovery for almost 2 more months
  - Died after withdrawal of life support in setting of multi-system organ failure
- Significant distress among clinicians over ICU course related to treatments patient was receiving, likely outcome.

Timeline

Oct 15 Admission
Oct 21 ECMO (BTT) Nov 4 LVAD
Nov – Jan
- Multiple OR washouts
- Cardiac arrest (Nov 16)
- Hypoxic brain injury
- Multi-system organ failure
Jan 7 Died

Oct 27
- Initial Consult
- LVAD Preparedness Planning
- No AD
  - “fight”
  - “positive attitude”
  - “aggressive intervention”

Nov 18
- Meeting with Wife & Sister
  - “has a strong temperament”
  - “time with children”
  - “continue treatments”

Dec 2
- PCS Meeting with Wife & Sister
  - Bad news from neurology
  - “he did not contemplate negative outcomes”

Jan 7
- CT surgery team meeting w/ family – poor prognosis
- PCS support to family afterward
- Withdrawal of life support, death

What can we learn?

WHO Palliative Care……

- Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness……
- Provides relief from pain and other distressing symptoms
- Intends neither to hasten or postpone death
WHO Palliative Care

- uses a team approach to address the needs of patients and their families
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life...and includes those investigations needed to better understand and manage distressing clinical complications.

Definition of PC according to CT Surgery

“Palliative care is not synonymous with hospice but rather functions alongside invasive and curative treatments. Palliative care specialists assist patients with defining values and goals that inform decision-making.”

Kirkpatrick, Wieselthaler et al. BMJ 2015

Optimal Timing of Palliative Care

Palliative Care

Hospice
Domains involved in the experience of human suffering

- Physical
- Emotional
- Psychosocial
- Spiritual
- Practical
- Patient and family

Palliative Care is a Team Sport

- **Doctors**
  - Symptom management
  - Goals of care
- **Nurses**
  - Patient, family & staff education and support
- **Social Workers**
  - Coping & adapting to illness
  - Advance care planning
- **Chaplains**
  - Meaning of illness
  - Psychological & emotional support

Primary & Specialized Palliative Care

- **Primary Palliative Care**
  - Provided by the patient’s primary / main clinicians & the other members of the Transplant team

- **Specialized Palliative Care**
  - Provided by an interdisciplinary team with training and experience in palliative care
  - Supports patient & family
  - Key role is also to support primary providers (i.e. Transplant team members)

The evidence
Statistics

- CHF burden
  - 5 million patients
  - 550,000 new cases/year
  - $30 billion
- Most symptomatic
  - 10-15% of the CHF population
  - Account for 60% cost
  - Majority of 57,000 deaths/year

Thom et al. Circulation 2006
Miller and Lietz J Heart Transplant 2006

CHF Mortality and Prevalence

- 50% 5 years after diagnosis
  - Roger VL et al, JAMA 2004
- 36% in 1 year after admission for HF
  - Curtis LH et al, Arch Intern Med 2008
- Prevalence projected to increase by 25% 2010-2030
  - Roger VL et al, Circulation 2012

Palliative Care Needs: Heart Failure

- Breathlessness, fatigue, pain, drowsiness, dry mouth (50%+ of patients)
- Depression, psychological distress (40%+)
- Patient & CG psychosocial & spiritual support
- Advance care planning

Bekelman et al J Card Fail 2007
Rutledge et al J Am Coll Cardiol 2006

Benefits of Palliative Care

- Inpatient, prospectively randomized HF patients: 116/116
- 1 and 3 months follow-up
- Significant improvement of symptom burden (8.39/4.7 p<0.001), QOL (12.92/8 p <0.001) and ACP completion (HR 2.87 p<0.03)
- No change in 30-day readmission rate, hospice referral and 6 month mortality

Sidebottom et al, J Pall Med 2015
CMS Requirements

Beneficiaries receiving VADs for DT

- must be managed by an explicitly identified cohesive, multidisciplinary team of medical professionals …
- Team must include “palliative care specialist”

LVAD/Transplant Candidate Pool

- 250,000-500,000 ESHF pts in terminal phase of disease
- Mean survival 3.4 months
- Inotrope dependent = up to 94% 1 yr mortality
- 80k-150k pts/yr could benefit from transplant
- 2200 heart transplants done per year
- LVAD as DT may be an alternative

Lietz et al. J Card Surg 2010

Benefits of Palliative Care

- “Proactive palliative medicine consultation for patients being considered for or being treated with DT improves advance care planning and thus contributes to better overall care of these patients.”
- “Our experience highlights focused advance care planning, thorough exploration of goals of care, and expert symptom management and end-of-life care when appropriate.”


The “What If” Question
Attitude

Unrealistic Expectations

Gratitude

Talking with Patients and Families

- Elicit understanding
  - “I was wondering if you could tell me what you understand about what is going on with you (your father)”
  - “What have the other doctors told you?”
  - “What did your cardiologist say about how he’s (you’re) doing?”

Curtis and White Chest 2008;134:835-43

Talking with patients and families

- Summarize the patient’s condition
  - Begin from where the family is
  - Avoid jargon (mechanical ventilation, pressors, CRRT)
  - Check for understanding

Curtis and White Chest 2008;134:835-43
Expressing Worry

- “I'm worried that your mother is getting worse despite our best efforts and best treatments.”
- “I worry that even if we attempt surgery, your brother will not be able to leave the hospital or even the ICU.”
  - Shares your concern
  - Shares uncertainty
  - Shares emotion/empathy
  - Softer way to share bad news

Make a Recommendation

- “Based on what I know about your mother and the medical situation... I recommend”
- Don’t force the family to decide
- Check for agreement and leave room for disagreement
  
  Use your expertise to help family with the decision making process

Communication in Cultural Diversity

- Non-English speaking
- Different Culture

- Use interpreter, never the family or friends for GOC discussions

- Patients’ relations specialists

Better Words to Say

- “There is nothing more we can do”
  “I wish there was something we could do to make your heart/lungs/kidneys get better.”
- “Would you like us to do everything possible?”
  “How were you hoping we could help?”
### Choosing words (Kelemen et al. Am J Cardiol 2016)

<table>
<thead>
<tr>
<th>Try to avoid</th>
<th>Consider using instead</th>
</tr>
</thead>
<tbody>
<tr>
<td>You are failing the inotrope</td>
<td>The inotrope is no longer working</td>
</tr>
<tr>
<td>You are not a candidate for the LVAD/Transpl, etc.</td>
<td>The LVAD/Transpl, etc. will not help you achieve your goal(s)</td>
</tr>
<tr>
<td>Keep him/her comfortable</td>
<td>Focus our care on managing pain and other symptoms of disease progression</td>
</tr>
</tbody>
</table>

### “Doctor, Do Everything”

- Request can have many meanings
  - “Do everything you possibly can to keep our loved one alive at all costs”
  - “Don’t abandon her/us”
  - “She is scared to die”
  - “I can’t bear the thought of him dying”
  - “I don’t believe that she’s really dying”


### Different Perspectives

<table>
<thead>
<tr>
<th>How we see it</th>
<th>How families see it</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOS</td>
<td>Length of life</td>
</tr>
<tr>
<td>Date of discharge</td>
<td>Date of death</td>
</tr>
<tr>
<td>68 yo AML, CHF..</td>
<td>Mom</td>
</tr>
<tr>
<td>Dying</td>
<td>Alive</td>
</tr>
</tbody>
</table>

### Maintain Perspective

- The family is suffering
  - Having a sick loved one is very stressful
  - Conflicting and contradictory information from providers can be very distressing

- Really difficult cases are stressful, but rare
  - All cases will resolve.........
  - Occasionally the patient will surprise you
“Doctor Do Everything”

- Provide consistent, clear information
- Avoid detailed discussions of medical management
- Demonstrate caring, concern, understanding
- Listen
- Stay engaged and collaborative

Minimize harm and foster collaboration

- Attempt small steps
  - DNR: “We’ll do everything to help, but if he dies suddenly, we will let him go in peace”
  - No escalation of treatments
- Stop discussing withdrawal of interventions
- Address your team’s discomfort
  - Empathy as the antidote for moral distress
  - Discuss as a team
  - Acknowledge concerns, correct misperceptions

Back to the case: What can we learn?

- Patient not “prepared” for the procedure if cannot consider unfavorable outcomes
- Normalize Palliative Care
- Palliative Care to focus on support of patient and family
- Regular teams’ huddles
- Support all team members once goals have been clarified