Palliative Care in Transplant Medicine

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Palliative Care in Transplant Medicine

• Palliative Care—The Basics

• Palliative Care in Transplant Medicine
  – Estimation and Communication of Prognosis
  – Establishing Goals of Care
  – Specific Topics
Palliative Care Is...

- Specialized medical care for people with serious illnesses
- Focuses on providing patients with relief from the symptoms and stress of a serious illness
- Goal is to improve quality of life for both the patient and the family
- Typically provided by a specially-trained team of doctors, nurses and other specialists—an extra layer of support
- Appropriate at any age and at any stage
- Can be provided along with curative treatment

Center for Advancement of Palliative Care CAPC.org or GetPalliativeCare.org
Palliative care isn’t just hospice care...

- **Palliative Care**
  - Covered by most insurances
  - Interdisciplinary care
  - *At Any Age, At Any Stage*
  - Can be provided along with life-prolonging therapies

- **Hospice Care**
  - Started as a Medicare *Insurance Benefit*
  - Interdisciplinary care
  - For Patients with life expectancy less than 6 months
  - No longer receiving life-prolonging therapies
Why Early Palliative Care?

- Data primarily from cancer literature shows that early palliative care interventions lead to:
  - Improved symptom control
  - Decreased depression
  - Improved QOL scores

- Potentially Longer Survival...
  - *NO PALLIATIVE CARE INTERVENTION STUDY HAS EVER BEEN SHOWN TO SHORTEN LIFE EXPECTANCY*

Palliative Care: *What is yours, and what is mine?*

- All primary providers should be able to:
  - Form a relationship with patient and family
  - Provide medical data and medical message
  - Provide prognostic information
  - Make recommendations
  - Manage common symptoms

- Specialists should be included for cases with:
  - Complex family dynamics
  - Complex symptom management
  - Complicated medical message and prognosis
Core Palliative Care Concepts

- Estimation and Communication of Prognosis
- Establish Goals of Care
- Symptom Management
- Specific Choices in Transplant Medicine

- *Transplant medicine is an appropriate field for the palliative care techniques and skills*
Before I give you your results, I’m going to put on some very sad music…
Communication of Prognosis—Part Art, Part Science

- Estimation of Life Expectancy and Clinical Course

- Communication of Prognosis
Communication of Prognosis—A Procedure

- Prepare
- Ask questions
- Provide information
- Allow for emotion
- Acknowledge the reaction
- Assess for understanding
- Make a plan
Communication of Prognosis—*What about Hope?*

- Acknowledge uncertainty
- The cheerleader vs the grim reaper
- *Best Case, Worst Case, Most Likely*
Core Palliative Care Concepts

- Estimation and Communication of Prognosis
- Establish Goals of Care
- Symptom Management
- Specific Choices

- *Transplant medicine is an appropriate field for palliative care involvement*
Goals of Care ≠ DNR
A Brief Public Service Announcement

• Essentially ALL of our patients should have Advance Directives
  – Healthcare Representative (who speaks for you)
  – Living Will (specific details)

• At a minimum, a patient who is admitted to the hospital, sick enough to be seen by you, should leave with a healthcare rep named and documented
Establishing Goals of Care—Four Questions

• What is your understanding about your illness?

• What are you worried about?

• What are you hopeful for?

• What are you willing to sacrifice to try to get to what you’re hoping for? And what aren’t you willing to sacrifice?
Establishing Goals of Care

Three Paths:

Restorative Care

Conservative Medical Management

Aggressive Symptom Management
Core Palliative Care Concepts

- Estimation and Communication of Prognosis
- Establish Goals of Care
- Symptom Management—A *Topic for Another Day!*
- Specific Choices

- *Transplant medicine is an appropriate field for palliative care involvement*
Core Palliative Care Concepts

- Estimation and Communication of Prognosis
- Establish Goals of Care
- Symptom Management
- Specific Choices in Transplant Medicine

*Transplant medicine is an appropriate field for palliative care involvement*
Specific Choices in Transplant Medicine

• CPR and limits of care, in the potential transplant candidate
  – A complicated decision made even more complicated...
CPR in the potential transplant candidate

• What are the patient’s other comorbidities?

• *How likely is the patient to survive CPR, and to survive to hospital discharge?*

• If the patient does survive CPR:
  – Will the patient be left too sick to receive a transplant?
  – Will the patient be left in a state that they would not find acceptable?
In-Hospital CPR Outcomes in Patients with Chronic Disease

<table>
<thead>
<tr>
<th></th>
<th>No Chronic Disease</th>
<th>Advanced COPD</th>
<th>Advanced Malignancy</th>
<th>ESRD on Dialysis (Age 18 or Older)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survival to Discharge</strong></td>
<td>17.3 %</td>
<td>14.8 %</td>
<td>11.3 %</td>
<td>21.0%</td>
</tr>
<tr>
<td><strong>Median Survival after Discharge</strong></td>
<td>26.7 months</td>
<td>5.0 months</td>
<td>3.5 months</td>
<td>5.0 months</td>
</tr>
</tbody>
</table>

Clinical States That Patients Rate Worse than Death...

Figure. Ratings of States of Functional Debility Relative to Death by Hospitalized Patients With Serious Illnesses

Percentage

0 10 20 30 40 50 60 70 80 90 100

- Bowel and Bladder Incontinence
- Rely on Breathing Machine to Live
- Cannot Get Out of Bed
- Confused All the Time
- Rely on Feeding Tube to Live
- Need Care All the Time
- Live in a Nursing Home
- At Home All Day
- Moderate Pain All the Time
- In a Wheelchair

- Much better than death
- Somewhat better than death
- Little bit better than death
- Neither better nor worse than death
- Worse than death

Rubin EB, JAMA Internal Medicine
August 2016
Clinical States That Patients Rate Worse than Death...

![Bar chart showing the percentage of patients rating different clinical states as worse than death.](Image)

- **Bowel and Bladder Incontinence**: 100%
- **Rely on Breathing Machine to Live**: 90%
- **Cannot Get Out of Bed**: 80%
- **Confused All the Time**: 70%
- **Rely on Feeding Tube to Live**: 60%
- **Need Care All the Time**: 50%

Legend:
- **Much better than death**
- **Somewhat better than death**
- **Little bit better than death**
- **Neither better nor worse than death**
- **Worse than death**

This chart illustrates the distribution of patient ratings of each queried health state on a 5-point Likert scale, indicating whether they considered the state to be much better than death, somewhat better than death, a little bit better than death, neither better nor worse than death, or much worse than death.
Clinical States That Patients Rate Worse than Death...

- Live in a Nursing Home
- At Home All Day
- Moderate Pain All the Time
- In a Wheelchair

Legend:
- Much better than death
- Somewhat better than death
- Little bit better than death
- Neither better nor worse than death
- Worse than death
Palliative Care in Transplant Medicine

• Palliative Care—*Specialized care for patients with serious illness, focused on reducing burdens, and improving quality of life*

• Focus on Including Palliative Care Concepts and Techniques
  – Estimation and Communication of Prognosis
  – Establishing Goals of Care
  – CPR and other specific issues

• *All care that we provide should be done in the context of our patients’ comorbidities and their Goals of Care*
For more information...