Every Breath Counts: When to Involve Palliative Care

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Disclosures

Allyson Rupp has no financial interest to disclose.

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- Bayer: Consultant
- Gilead: Consultant

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Differentiate between Palliative Care and hospice.
2. Identify four circumstances for which a Palliative Care referral/consultation might be advantageous.
3. Discuss obstacles to obtaining hospice care for individuals with PAH.
Outline

• Definitions
• Types of Palliative Care
• Impact of Palliative Care
• Implementation of Palliative Care
• Barriers to Implementation
• Future Directions
Palliative Care (PC)

- Focus on providing relief from symptoms, pain, and stress of serious illness
- Improve quality of life for patient and family
- PC provided by doctors, nurses, other specialists
- Appropriate at any stage of illness
- *Can be provided along with curative treatment*

http://www.who.int/cancer/palliative/definition/en/
<table>
<thead>
<tr>
<th>Palliative Care</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can be seen earlier in disease course</td>
<td>Terminal diagnosis</td>
</tr>
<tr>
<td>Life limiting illness</td>
<td>6 months or less to live</td>
</tr>
<tr>
<td>Symptom management with curative therapies</td>
<td>Comfort measure are the focus</td>
</tr>
<tr>
<td>Any insurance</td>
<td>Medicare benefit</td>
</tr>
<tr>
<td>Inpatient (hospital, SNF and outpatient models (home, clinic))</td>
<td>Mostly home based but can do SNF</td>
</tr>
</tbody>
</table>
Evolution of Palliative Care

American Association of Hospice and Palliative Medicine

Courtesy Rab Razzak, MD
Levels of Palliative Care

Primary Palliative Care

- Integration of palliative care into a clinician’s everyday practice
- Basic management of pain and symptoms
- Basic discussion about:
  - Prognosis
  - Goals of care
  - Suffering
  - Code status

T. Quill & A. Abernethy. NEJM 2013; 368;13:1173-1174
Levels of Palliative Care

Secondary

- Provided by teams of dedicated PC specialists
- Management of refractory symptoms
- Conflict resolution re: goals or methods of treatment
  - Within families
  - Between staff
  - Among treatment teams
- Assistance addressing near futility

T. Quill & A. Abernethy. NEJM 2013; 368;13:1173-1174
Benefits of Palliative Care

- Palliative care superior to usual care:
  - emotional/spiritual support
  - information/communication
  - care at time of death
  - access to services in community

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


ABSTRACT

BACKGROUND
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.
## Impact on Patient-Centered Outcomes

### Quality of Life

<table>
<thead>
<tr>
<th>Tool</th>
<th>Standard Care</th>
<th>Early PC</th>
<th>P-value</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT-L</td>
<td>91.5(15.8)</td>
<td>98.0(15.1)</td>
<td>0.03</td>
<td>0.42</td>
</tr>
<tr>
<td>LCS</td>
<td>19.3(4.2)</td>
<td>21.0(3.9)</td>
<td>0.04</td>
<td>0.41</td>
</tr>
<tr>
<td>TOI</td>
<td>53.0(11.5)</td>
<td>59.0(11.6)</td>
<td>&lt;0.01</td>
<td>0.52</td>
</tr>
</tbody>
</table>

### Depressive Symptoms

Impact on Survival

HR=1.70
95% CI 1.14-2.54
p=0.01

Multivariable analysis, adjusted for age, sex, and baseline ECOG status

Harms of Failure to Address Goals of Care/ EOL

• Patient receipt of care NOT c/w personal goals
• Worse QOL
• Prolonged death with increased suffering
• Worse bereavement outcomes for family members
• Increased cost w/o benefits to patients

Bernacki & Block. JAMA Int Med 2014; Supplement E1-10
Need for PC in PAH?

Edmonton Symptom Assessment Survey

Setting at Time of Death

Awareness of PC: PAH Pts /Caretakers

Degree of Awareness: Caretaker

Focus group at PHA Biennial Meeting 2014, support groups MD/DC area
N=34
Aware of PC: 5/34*
Discussed PC: 1/34

Degree of Awareness: Patient

Integration of Palliative Care into PAH Treatment Plans

Symptom burden, quality of life, and attitudes toward palliative care in patients with pulmonary arterial hypertension: Results from a cross-sectional patient survey


“Most patients believed their PAH physician had excellent understanding of PAH progression/plan of care (92%), but less were satisfied with care regarding QOL management (77%). Few patients considered PC (8%), or had pain management (4%) or PC involved (1%). Most common reasons were beliefs that patients were doing well/not sick (63%) or that PC had not been suggested (22%).”
Norms for Palliative Care Referrals

Table 2: Common reasons reported by physicians for palliative medicine referral in patients with pulmonary arterial hypertension

<table>
<thead>
<tr>
<th>Reasons</th>
<th>n  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>End of life/active dying</td>
<td>45 (59)</td>
</tr>
<tr>
<td>Hospice referral</td>
<td>35 (46)</td>
</tr>
<tr>
<td>Dyspnea management</td>
<td>30 (39)</td>
</tr>
<tr>
<td>Impaired quality of life</td>
<td>30 (39)</td>
</tr>
<tr>
<td>Goals-of-care discussion</td>
<td>24 (32)</td>
</tr>
<tr>
<td>Pain management</td>
<td>19 (25)</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>11 (14)</td>
</tr>
</tbody>
</table>

Note: Percentages are based on n = 76 respondents.

Physician attitudes toward palliative care for patients with pulmonary arterial hypertension: results of a cross-sectional survey

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Abstract: Pulmonary arterial hypertension (PAH) is a chronic, progressive, life-threatening illness; however, it is complex, with variable expression regarding impact on quality of life (QOL). This study investigated attitudes and comfort of physicians regarding palliative care (PC) for patients with PAH and explored potential barriers to PC in PAH. An iron-based, mixed-methods survey was distributed to Pulmonary Hypertension Clinicians and Researchers, a professional organization within the Pulmonary Hypertension Association. Only responses from physicians involved in clinical care of patients with PAH were analyzed. Of 355 clinicians/researchers, 79 (22%) returned surveys, including 76 (21%) providers involved in clinical care. Responding physicians were mainly pulmonologists (67%), practised in university/academic medical centres (86%), and reported a high level of confidence in managing PAH (87%), advanced PAH-specific pharmacologic interventions (91%), and end-of-life care (89%). Smaller proportions were comfortable managing pain (62%) and QOL issues (59%). Most physicians (91%) reported initiating PC consultation at least once in the prior year, primarily in the setting of end-of-life/care dying (50%), hospice referral (46%), or symptomatic dyspnea/impaired QOL (44%). The most important reasons for not referring patients to PC included non-agreement by the patient/family (11%) and concern that PC is “giving up hope” (9%). PAH may result in symptoms that impair QOL despite optimal PAH therapy; however, PC awareness and utilisation for PAH providers is low. Opportunities may exist to integrate PC into care for PAH patients.

Keywords: symptom control, palliative care, quality of life, pulmonary arterial hypertension.

Timing of Palliative Care Introduction

• Palliative care as a *philosophy*:
  – At ANY time on the continuum
  – PH therapies all treat symptoms, diagnosis is progressive and non-curable, and therapies and symptoms are life-limiting
  – When current PAH therapy includes undesirable side effects

• Rationale
  – Palliative care focuses on managing and treating physical, psychological, social and spiritual symptoms affecting a patient’s quality of life
  – Focus on Advance Care Planning, adjustment, identifying values, goals and family needs
* Can happen SIMULTANEOUS to aggressive treatment
Timing to Incorporate Palliative Care and PAH Treatment

Palliative care as an option or transition:

– When patients present with challenging psychological, social or spiritual symptom management issues
– At significant transition points in illness trajectory (i.e. worsening function, escalation of care suggested, hesitation or inability to advance therapy)
– Transplant wait-listing
– Frequency of ED visits/admissions within 12 months with same or worsening symptoms/findings
– To aid with family coping/planning (i.e. children’s supports) and resource linkage
## Physician Perceived Barriers to Palliative Care

<table>
<thead>
<tr>
<th>Barrier statement</th>
<th>Respondents who agree, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>--PAH patient or family was not agreeable to consultation</td>
<td>39 (51)</td>
</tr>
<tr>
<td>--There is concern that palliative medicine consultation may be viewed by patients as “giving up hope”</td>
<td>33 (43)</td>
</tr>
<tr>
<td>--I am comfortable dealing with issues of quality of life and end-of-life care and do not feel palliative care consultation was necessary</td>
<td>27 (36)</td>
</tr>
<tr>
<td>--PAH patients are not eligible to have palliative care if they continue to receive active therapies (i.e., prostanoids)</td>
<td>21 (28)</td>
</tr>
<tr>
<td>--It is hard to treat PAH as aggressively as is needed and have palliative care at the same time</td>
<td>15 (20)</td>
</tr>
<tr>
<td>--Given that many PAH patients are young, it is hard to consider them for palliative medicine consultation</td>
<td>14 (18)</td>
</tr>
<tr>
<td>--The name “palliative” has a negative connotation</td>
<td>13 (17)</td>
</tr>
<tr>
<td>--PAH patients have a chronic disease, may live for years, and are not appropriate for palliative medicine as they are not “end-of-life”</td>
<td>8 (11)</td>
</tr>
<tr>
<td>--Palliative medicine and hospice are the same thing, and the patient wasn’t ready for hospice</td>
<td>5 (6)</td>
</tr>
</tbody>
</table>

*Note* Percentages are based on n = 76 respondents. PAH: pulmonary arterial hypertension (TABLE 3).

Practical Barriers to Palliative Care

• Location, location, location!
  – More remote areas may not have robust services
  – Sophistication of care center/ community resources
  – Limited home-health providers and “bridge” or Advanced Illness Management programs

• Psychology of “palliation”
  – How the concept is introduce may impact acceptance/ incorporation of care
  – Cultural / value-based practices
What to Expect with Palliative Care

• Team approach
  – Medical provider(s) (MD, PA, NP, RNs)
  – Social worker and / or mental health provider(s)
  – Spiritual care provider/ chaplains
  – Child life specialists and pediatric mental health providers for children affected by patient’s illness

• Helps families understand tx options and goals

• Focus on improving QOL and symptoms on the care continuum

• MAY (likely to) work in concert with primary PH team
Palliative Care in Hospital

• Consult service – works in concert with primary treatment team for primary presenting problem
  – Recommends symptom-reducing measures
  – Aids in determining capacity, strengths and limitations in returning home
  – Optimization of therapies toward discharge home
  – Ensures communication & upholding of values to all consulting entities

• Coordinates and problem solves toward return home
Palliative Care at Home

Community Palliative Care programs

– Team of visiting practitioners
– Psychosocial needs highlighted for pt and family
– Symptom management and monitoring with goal to avoid re-admission to hospital
– Reduction/ removal of therapies is NOT necessary
  • Parenteral therapies with family managing allowed
  • Home Inotrope possible
– Expands routine home care services*
  *still requires a “skilled need” to qualify
Timing of Introduction to Hospice

Hospice care as a *transition*:

- When the focus on keeping the patient COMFORTABLE is the priority
- Patient expresses desire to de-escalate or to not further escalate care
- When the patient and medical provider have decided the disease can no longer be treated effectively, and the patient is estimated to have 6 months or less to live
Barriers to Home Hospice

• Specialty PH medications & Inotropes
  – Cost
  – Access
  – Unfamiliarity with safe home weaning

• Parenteral therapies
  – Philosophy
  – Safety in administering with mental status changes
  – Potential for hospital/ ED readmission from infection, pump malfunction
Barriers to Home Hospice

• Timing
  – difficult to transition off aggressive therapies comfortably
• Lack of access to comfort measures at home
  – iNO
  – High flow O2
  – Inability to wean off vent
  – IV diuresis
• Transportation home
• Round-the-clock care provision
Overcoming Barriers

• EARLY goals of care discussions
  – May circumvent addition of therapies that cannot be withdrawn
  – Prepares all for possible transition limitations
  – Provides lead time toward needed interventions

• Specialty pharmacy advocacy
  – Patient assistance programs
  – Supply count/ reconciliation
  – Training of caregivers/ hospice RNs

• Exploration of “non-PAH” diagnoses as admitting hospice diagnosis
Overcoming Barriers

• PAH MD to hospice MD to advocate & justify philosophy

• Respiratory therapy evaluations/ training
  – Interface with home O2 providers – accessing equipment/ supplies
  – Training to family/ caregivers

• Use of “bridge” programs for palliative care before hospice-eligible
  – Can plan medication shipments to enhance supply
  – Preparation and psychosocial support building
Future Directions

• Standard of care approaches that include palliative care language/ introduction early
• Exploration of “special circumstances” or exemptions for individuals electing hospice to sustain PAH regimens
  – “Clearing house” for donated PH medications
• Studies examining the role of Palliative Care in the management of PH & best practices for integration into patient care
“Death should not be viewed as a medical failure but as a natural conclusion to life.”

Thank you! QUESTIONS?
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