Palliative Care, Hospice, & End of Life Care in Urologic Oncology

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12th Annual Advances in Urology Symposium
“Life is pleasant. Death is peaceful. It’s the transition that’s troublesome.”

-Isaac Asimov
Death and Dying in America?
• Everyone dies
• We are a “death-denying” culture
Position statements/Standards

- **ASCO**: Provisional Clinical Opinion: Integration of palliative care services into standard oncology practice at the time a person is diagnosed with metastatic or advanced cancer
- **AAHPM**: Withholding non beneficial medical interventions, access, guidelines for quality palliative care, ethics, etc.
- **ANA**: Foregoing nutrition and hydration, euthanasia, assisted suicide & aid in dying, nursing care and DNR decisions, etc.
- **HPNA**: Palliative sedation, evidence-based practice, pain management, etc.
Quality

- Appropriate, high-quality EOL care occurs when goals are addressed and reduces cost, improved QoL and QoD.
- High-cost, life-sustaining care is associated with a decreased QoD.
Why should I care about this?

- Our patients are older
  - Bladder: Median age at dx is 73
    Median age at death is 79
  - Kidney: Median age at dx is 64
    Median age at death is 71
  - Prostate: Median age at dx is 66
    Median age at death is 80

By the year 2030, there will be more than 72.1 million Americans over the age of 65
Why should I care about this?

- Our patients (and families) care about this
  - Desire for a “good death” and avoid inappropriate prolongation of the dying process
  - Appropriate treatment of pain and other symptoms
  - Achieve a sense of control
  - Communication regarding their care
  - Coordinated care throughout the course of illness
  - Relieve burdens on families
  - Strengthen relationships with loved ones
  - They want to talk and be heard
    - McDonagh, et al. → increased family speech associated with increased satisfaction
Why should I care about this?

- Frontline health care providers get little/inadequate formal training
  - Most medical and nursing schools offer didactic courses
    - Lectures, preclinical, elective clinicals, little attention to home care, hospice, nursing home care
  - Communication labs
    - Student-student, but rarely student-patient
  - Many studies conducted show HCP report widespread deficiencies and discomfort with basic palliative care competencies including managing chronic pain, communication skills, educate patients, manage psychological aspects
ASCO Survey (1998)

- 3,227 respondents
- 90% learned about palliative care through “trial and error”
- 38% - significant source of their education stemmed from a traumatic patient experience
- 81% - Inadequate mentoring or coaching in discussing poor prognosis
- 65% - Inadequate education about symptom management
- 33% - Heard palliative care lectures in fellowship training
- 10% - Rotation on palliative care service or hospice

Urologist Attitudes Toward Palliative Care

• Bergman, et.al. (2013)—Interview and analysis of 20 trainees from 4 institutions
  – 5 Juniors, 6 Seniors, 5 Fellows (Urology), 2 Fam Med Fellows, 2 Int Med Fellows

• 4 Central Themes
  1. Desired ideal outcomes for patients, but defined outcomes by patients’ own values and preferences
  2. Viewed current care as shoddily organized and poorly integrated, with lack of scaffolding during training as a possible cause
  3. Expressed a desire to engage in discussions regarding EOL preferences
  4. Identified a need to honestly discuss prognosis and assess patient goals

• 3 Implications
  1. Education must be improved
  2. Clinicians should be guided to deliver value-congruent, patient-centered, high-quality care at the EOL
  3. EOL care must be properly integrated
Progress…

• Hospice and Palliative Medicine Fellowship Training
  – Approved by ACGME in 2006
  – 97 (ACGME), 12 (AOA)
  – ~234 Fellowship Positions
  – In North Carolina: Duke, Mountain Area Health Education Center Program (Asheville), Wake Forest

• Fellowships for Advanced Practice Nurses
  – Currently 7 for Nurse Practitioners

• SUO Fellow Training in Urologic Oncology
  – Fellowship programs must educate fellows in the evaluation and treatment of urologic cancers to include an understanding of the molecular mechanisms of cancer development and progression, urologic cancer pathology, radiation and chemotherapy treatments, surgical management options and supportive care.

• Certification Programs
  – Nursing (NBCHPN): ~1,000 APRN, 9,000 RN
  – Social Work
  – Chaplaincy
Advance Directives

Set of directions given to medical team if you ever lose ability to make decisions for yourself. **NC has 3 ways to make a formal advance directive**

1. **Living Will**
   1. Legal document that tells others you want to die a natural death
   2. Goes into effect only when provider determine patient meets one of the conditions specified in the document

2. **Health Care Power of Attorney**
   1. Legal document in which patient names a person(s) as health care agent to make medical decisions if patient becomes unable to make decisions

3. **Advance instructions for mental health treatment**

   *All of the above must be written, signed by patient, witnessed by 2 adults, and notarized*
Palliative Care Myths

• Palliative care = Hospice
• Palliative care is only in hospitals and hospice is only at home
• A referral to palliative care means giving up active treatment
• Palliative care only addresses pain
• Palliative care means death is imminent
OLD VS NEW APPROACH

OLd

Diagnosis of serious illness

Disease Progression

Life Prolonging Care

Hospice Care

Palliative Care

Bereavement

Hospice Care

Medicare Hospice Benefit

New

Death

Life Prolonging Care
What is Palliative Care?

WHO Definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
WHO definition

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
It is not...
Early Palliative Care

151 patients newly diagnosed metastatic NSCLC

Baseline Data Collection

Randomized

Early palliative care integrated with standard oncology care

Meet with palliative care within 3 weeks of signing consent and at least monthly thereafter

Meet with palliative care only when requested by patient, family or oncology clinician.

ECOG 0-2

Standard oncology care

Courtesy of Temel et al., ASCO 2010
Results

• Palliative care patients had better QoL
• Less depression
• Less likely to use aggressive treatment at the EOL
• Lived longer (11.6 mo vs 8.9mo)
Early Palliative Care

- Retrospective study
- N=1,225 referred to Stanford Hospital’s palliative care service
- Referred during 1\textsuperscript{st} week
  - Shorter LOS
  - Lower in-hospital mortality
  - As compared to patients who had been referred 1 week after admission (overall increased length of stay of 2.70 days, p<.001)

Barriers

- Time
- Lack of knowledge
- “Giving up hope”
- Taboo topic
- Lack of resources
- Making assumptions
- Cultural, religious differences
North Carolina

Grade B

- 89 ABHPM-Certified Physicians
- 20 NBCHPN-Certified Advanced Practice Nurses
- 477 NBCHPN-Certified Registered Nurses

*2012 data

Hospitals with Palliative Care
North Carolina

<table>
<thead>
<tr>
<th>Hospital Group</th>
<th>State</th>
<th>Region</th>
<th>National</th>
</tr>
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<tbody>
<tr>
<td>For-profit</td>
<td>75% (3/4)</td>
<td>6% (1/18)</td>
<td>26%(108/419)</td>
</tr>
<tr>
<td>Public</td>
<td>72% (18/25)</td>
<td>38% (10/26)</td>
<td>54% (192/356)</td>
</tr>
<tr>
<td>Sole Community Provider</td>
<td>56% (5/9)</td>
<td>11% (1/9)</td>
<td>37% (151/406)</td>
</tr>
<tr>
<td>&gt; 300 beds</td>
<td>94% (16/17)</td>
<td>50% (6/12)</td>
<td>85% (597/699)</td>
</tr>
<tr>
<td>≥50 beds</td>
<td>75% (55/73)</td>
<td>28% (16/58)</td>
<td>63% (1568/2489)</td>
</tr>
<tr>
<td>≤50 beds</td>
<td>19% (4/21)</td>
<td>4% (1/28)</td>
<td>22% (326/1500)</td>
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“You’ve got one foot in the grave. Further testing will determine if it’s your left or your right.”
Palliative Care in GU Oncology

- Advanced Prostate Cancer
  - Bone pain (70%)
    - XRT—~ 80% experience some pain relief
    - Bone protective agents
      - Zolendronic acid→ decreased risk of SRE and lowered pain score
      - Denosumab
    - Glucocorticoids—short-lived
    - Analgesics
  - Pelvic pain
    - Caused by local advancement into the rectum and sacral plexus
    - XRT, analgesia
    - Regional anesthesia
    - Pelvic exenteration in highly selected cases
# Palliative Care in GU Oncology

<table>
<thead>
<tr>
<th>Pain Level</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild to Moderate</td>
<td>NSAIDs, acetaminophen, acetylsalicylic acid</td>
</tr>
<tr>
<td>Moderate</td>
<td>Opioids: Codeine, dihydrocodeine, oxycodone, hydrocodone</td>
</tr>
<tr>
<td>Severe</td>
<td>Opioids: morphine, hydromorphone, methadone, fentanyl, levorphanol</td>
</tr>
</tbody>
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Analgesics for bone pain
Palliative Care in GU Oncology

• Advanced prostate cancer
  - Bladder Outlet Obstruction
    • Indwelling urethral catheter, SPT, CIC
    • Palliative TURP*
    • XRT
    • Cystoprostatectomy in highly selected cases
  - Ureteral Obstruction
    • XRT
    • PCN
  - Spinal Cord Compression (10% in mCRPC)
    • Steroids
    • Decompressive surgery
    • XRT
    • Decompressive surgery +/- XRT
Palliative Care in GU Oncology

- **Advanced Urothelial Carcinoma**
  - Hematuria
    - Clot evacuation and Amicar
    - Intravesical therapy (silver nitrate/aluminum or formalin)
    - XRT
    - Embolization
    - Urinary diversion
    - Cystectomy and urinary diversion (if hematuria and pain)
Palliative Care in GU Oncology

• Advanced Renal Cell Carcinoma
  – Bleeding
    • XRT
    • Arterial embolization
  – Pain
    • Arterial embolization
    • For bone pain → same as prostate (−) ADT
  – Palliative nephrectomy
    • Treat/prevent further bleeding, anemia, pain
    • Differs from cytoreductive nephrectomy
UNC Palliative Care Program

- Started in 2002 by Dr. Steve Bernard and Dr. Laura Hanson
- Supportive Care Consult Service (outpatient) started in 2007
- Children’s Supportive Care Team started in 2012
- Services
  - Inpatient Consult
  - Outpatient supportive care: Consult and Clinic
- Research
- Education
  - 4th year medical student elective
UNC Palliative Care Program

• Inpatient consult service
  – Core team = Professional training/certification in palliative medicine or nursing
    • 2 Nurse Practitioners
    • 5 Physicians
    • 1 Social Worker
    • 1 Chaplain
  – Other members from SOM, SON, SOP, SOPH
  – Available to all inpatient units
UNC Supportive Care Program

• Outpatient Consult Service and Clinic
  – 1 MD, 1 APP, 1 PharmD
  – Oncology patients
    • Pain and other symptoms
    • Emotional, psychological, spiritual suffering
    • Nutritional problems
    • Concerns about medical decisions
    • Difficulty communicating values, goals, and personal choices
It is difficult to accept death in this society because it is unfamiliar. In spite of the fact that it happens all the time, we never see it.

*Elisabeth Kubler-Ross*
Palliative Care V. Hospice

All of hospice is palliative care, but not all of palliative care is hospice.
The Connecticut Hospice
Hospice Care

- Focus on comfort care
- Medicare benefit
  - Part A (Hospital), sign statement choosing hospice, Medicare-approved hospice
  - Two 90-day periods followed by unlimited number of 60-day periods
- Life expectancy of 6 months or less should the disease run its normal course
- Patient has elected comfort care in lieu of aggressive or curative treatment
- Must be able to document clinical progression of disease
- Home, nursing home, inpatient
- 1.5-1.6 million patients received hospice services in 2012
When should I consider hospice referral?

• “Would I be surprised if my patients dies in the next six months?”
• Goals of care more symptom focused than cure directed
• Increasing care needs and frequent hospitalization
Interdisciplinary Team Approach

- Volunteers
- Physicians
- Spiritual Counselors
- Social Workers
- Bereavement Counselors
- Home Health Aides
- Therapists
- Nurses

Patient & Family
Hospice Services

- Manage pain and other symptoms
- Assists patient/family with emotional, psychosocial, and spiritual aspects of dying
- Provides medications, medical supplies, and equipment
- Coaches family on how to care for patient
- Delivers special services like speech and PT when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or caregiver needs respite
- Provides bereavement care and counseling to surviving family and friends
UNC Hospice

- Founded in 1984
- Orange, Chatam, Lee counties (within an hour’s drive of one of their offices)
- Provide all services in previous slides
- Take referrals 24 hours/day
- Licensed by Medicare, Medicaid, and most private insurances
- Member of the National Hospice and Palliative Care Organization and the Carolinas Center for Hospice and End of Life Care
SHELDON HAS A POOR CHOICE OF COSTUME AT THE SENIOR CENTER HALLOWEEN PARTY.
Resources: Providers

- End of Life/Palliative Education Resource Center (EPERC)
- Medical College of Wisconsin
  - Educational materials (downloadable)
  - Suggested articles
  - Links to clinical and educational online resource centers
  - **Fast Facts**
    - 272 cheat sheets for clinicians ranging from symptom management, med management, communication, etc.
FAST FACTS AND CONCEPTS #136 PDF

Author(s): Joy E Cuezze MD and Christian T Sinclair MD

Background  The term ‘medical futility’ is commonly used by health professionals to discuss the appropriateness of a medical treatment option. Texas and California have defined statewide ‘futility’ policies and increasingly hospitals and nursing homes are developing their own futility policies. This Fast Fact will discuss the current understanding of the term futility.

The Problem with ‘Futility’  The public, policymakers, ethicists, and the medical profession have been unable to agree on a clear, concise definition of futility that can be applied to all medical situations. One commonly used definition is that a futile intervention is one that a) is unlikely to be of any benefit to a particular patient in a particular medical situation, and b) will not achieve the patient’s intended goals. The sticking point in all futility definitions is the concept of benefit, as the perception of benefit is highly subjective. Physicians, patients and families often have very different views on what is potentially beneficial. For example, although a physician may believe that renal dialysis in an elderly demented patient is futile, the family that views preservation of life at all costs as part of their cultural ethos, may view dialysis as an important intervention to continue life. Furthermore, medical futility can be easily misunderstood as health care rationing. While economic issues may impact shared decision making, the ultimate question is not How much does this therapy cost? Rather, it is Do the advantages
Resources: Providers

- American Academy of Hospice and Palliative Care Medicine (AAHPM)
- American Society of Clinical Oncology (ASCO)
  - Palliative Care Checklist
- BMC Palliative Care
  - Open-access peer reviewed journal
- Center to Advance Palliative Care (CAPC)
- Education in Palliative and End-of-Life Care (EPEC)
  - Curriculum to educate HCPs in clinical competencies
- End-of-Life Nursing Education Consortium (ELNEC)
  - Curriculum to educate nurses in EOL and palliative care
- Harvard Medical School Center for Palliative Care
- Hospice and Palliative Nurses Association (HPNA)
- National Hospice and Palliative Care Organization (NHPCO)
- National Palliative Care Research Center (NPCRC)
Palliative Care Checklist

- Assess patient/caregiver medical literacy
- Assess patient/caregiver willingness to hear prognosis
- Assess patient/caregiver role preferences
  - Patient prefers to share the decision with
  - Patient prefers to decide him/herself after hearing the views of
  - Patient prefers that someone else decides
  - Patient prefers to decide on his/her own
- Assess patient/caregiver understanding of diagnosis, illness, and prognosis
- Offer clarification of treatment goals*
- Use standardized symptom assessment tools (Edmonton Symptom Assessment Scale or Condensed Memorial Symptom Assessment Scale)**
  - Pain*
  - Pulmonary symptoms (cough, dyspnea)*
  - Fatigue and sleep disturbance*
  - Mood (depression and anxiety)*
  - GI (anorexia and weight loss, nausea and vomiting, constipation)*
- Screen for distress (with tool such as Distress Thermometer)
- Refer for or conduct psychosocial assessment
- Refer for psychosocial support
- Refer to social work for practical issues (e.g. financial, caregiver, home health, transportation)
- For patients who are earlier in the disease course, consider referral for nutrition, physical and occupational therapy support.
- Identify care plan for future appointments*
- Document referrals to other care providers*/information and/or support sources
  - Document referral to hospice
  - Advanced Directive
  - DNR
- Document new medications prescribed*
- Document patient/caregivers primary concerns and/or issues
North Carolina Resources

• **Carolinas Center for Hospice and End of Life Care**
  – Represents over 100 hospice providers in NC & SC
  – Provides support to local hospice programs (technical, education, advocacy)
  – Extensive website including the following:
    • Educational opportunities, Hospice locator, stats, public awareness materials

• **Community Care NC**
  – North Carolina Palliative Care Resource Guide (104 pages!)

• **Hospice & Palliative Care Center**
  – First hospice in NC

• **North Carolina Dept. of Health and Human Services, Division of Health Service Regulation**
  – List of Hospices licensed in NC

• **Secretary of State Advanced Directive Registry**
Resources: Patients & Caregivers

• Americans for Better Care of the Dying (ABCD)
• Bereavement Support Group
• Center for Hospice Care
• Dying Well
• Get Palliative Care
• Hospice for Patients and Families
• Hospice Foundation of America (HFA)
• Pallipedia: Online palliative care dictionary
Future growth

- Include/improve palliative care curriculum in nursing & medical school
- Include/improve palliative care training in graduate education, residency
- Incorporate interdisciplinary care
- Continuing education
- Establish better access to care
- Funding and research
Pearls

• Palliative care does not equal hospice care
• Eliminate “There’s nothing more we can do” and replace with “There’s nothing more we can do to treat the cancer/disease, but…”
• Eliminate “We are going to withdraw care” and replace with “We are going to withdraw the breathing tube/cancer medication, etc.”
• Initiate a Palliative Care Consult sooner rather than later
• Make a list of goals of care with the patient and review/update frequently
• Know your own strengths and weaknesses
• Just because we can, doesn’t mean we should
• Allow yourself to grieve
Thank you