The Expanding Role and Relevance of Palliative Care
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The importance of the team

“Whole person care requires a whole person. Until one comes along, use your team.”
Balfour Mount

Introduction to terms

- What is Palliative Care?
- What are the similarities and differences with Hospice care?

What is Hospice?

- Hospice: A health care benefit and a type of care
  - Medicare (Part A) and Medicaid benefit since 1982; many private insurances have a “hospice benefit”
  - Two MDs certify prognosis ≤ 6 months if “disease runs its usual course”
  - Focus is on comfort and relief of suffering, not life prolongation
  - Interdisciplinary team provides care
    - Different from multidisciplinary team in that team together provides one care plan
    - It is not a place; primarily home based

www.nhpco.org
What is Palliative Care?

- Palliative Care
  - "An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through prevention of and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual"

World Health Organization (WHO)

What is Palliative Care?

- Palliative Care
  - Can be provided in conjunction with life prolonging treatment (i.e. no need to choose between treatment plans)
    - Does not take the place of curative care!
  - Any prognosis or stage of illness; any diagnosis; no age requirement; not just “actively dying” or “comfort care”
  - Primarily hospital based (although outpatient and home based care are available); Interdisciplinary team
  - The goal is not to hasten nor prolong the dying process

Hospice Care and Palliative Care

- All hospice care is palliative care (type of care to alleviate suffering), but not all palliative care is hospice care (you can still get curative care and have any prognosis).

- Hospice and Palliative care need each other
  - Provides a continuum of care for seriously ill patients and families

Conceptual Shift in Palliative Care
“When my mother-in-law, Laura Foote, was dying from cancer, we all knew she was dying. At least one reason why our family never talked about her dying was that until two days before she died, we remained fixed on the incremental remedies that medicine continued to offer. However clear her deterioration, there was always another treatment option. As long as small puzzles could be solved, fixing this or medicating that, the big issue of mortality was evaded. Each specialist carried out his task with some success, and the patient died.”


- Dame Cicely Saunders founded St. Christopher’s Hospice in 1967
  - Florence Wald, RN founded the first hospice in the US in 1974 – Connecticut Hospice
  - Now, >5500 hospices in the US
- APNs, RNs, SWs, chaplains have specialty certification for Hospice and Palliative Care
History of Hospice and Palliative Care

- Balfour Mount (a surgeon) started the first Palliative Care program at the Royal Victoria Hospital in Montreal in 1975
- Spread to the USA in the 1980’s
  - Now, 1,744 hospital based palliative care programs in the US for hospitals with >50 beds

What do we do?

- “An extra layer of support”
- “No agenda”
  - Each patient is unique and their path is their own
  - Not “one size fits all”
- For patients with serious and/or life threatening illness:
  - Clarification of goals of care
  - Family meetings
  - Pain and symptom management (not chronic non-malignant pain or addiction)
  - Communication
  - Assist with safe transitions between care settings
  - Psychosocial, spiritual assessment and support
  - Patient, family, staff education and support
  - Advance Care Planning

Up to the Table

- 2006: American Board of Medical Specialties recognized Hospice and Palliative Medicine as a unique specialty (like Oncology, Geriatrics, Cardiology, etc.)
  - 2012: All Palliative Medicine physicians need to have fellowship training to be boarded in HPM
    - Physicians from 10 different fields can train in HPM and be board-certified

Palliative Care helps patients and families

- Focuses on the “illness”, not just the “disease”
  - What is this patient’s and family’s experience of the disease, and how can we help them all live as fully as they can in whatever time they have?
- People who have conversations with their health care providers about what type of care they want, their goals and priorities when they are very ill:
  - Less suffering and improved QOL
  - Improved pain and symptom management
  - Fewer days in hospital
  - Less likely to die in an ICU

Wright et al. JAMA 2008
Palliative Care helps hospitals too

- Decreases 30-day readmissions
- Decreases LOS
- Decreases Mortality Index (O/E ratio)
  - Also eliminates some patients from disease-specific quality indicators
- Decreases ED visits
- Decreases hospital admissions at end of life
  - Increases hospice referral
- Helps coordinate care across settings
- Saves money
  - >$2 million/year for an average inpatient Palliative Care Consultation service

Cassel JB. J Pain Symptom Manage 2015

Just because we can do something doesn’t mean we should....

- More aggressive care doesn’t necessarily mean longer life or less suffering:
  - Palliative chemotherapy fails to improve quality of life near end of life, and may cause more harm than benefit.
    - Prigerson et al. JAMA Oncology September 2015.
  - Early Palliative Care for Patients with Metastatic Non–Small–Cell Lung Cancer led to significant improvements in both quality of life and mood and longer survival (~2.5 months).
    - NEJM Temel et al. 2010

Palliative Care and Hospice Care

- Patients don’t need to abandon the hope of better quality of life just because they have an illness we can’t fix.
- Aligning patient and family goals with treatment options—ask them what they are hoping for and clarifying their understanding of their illness.
  - BUT, this takes time, and it is easier to do “business as usual” and just offer more medical treatment

Palliative Care

- Palliative Care fills in the space between:
  - Do you want to live longer, or do you want to be comfortable?
  - Most people want both….to live as long as they can as comfortably as they can
    - Palliative Care aligns the best possible medical care with patient and family’s values and goals
The discussion is happening in the country: What is optimal care?

“If your problem is fixable, we know just what to do. But what if it’s not? The fact that we have no adequate answers to this question is troubling and has caused callousness, inhumanity and extraordinary suffering.”

Atul Gawande, MD—surgeon at Brigham and Women’s Hospital in Boston

Atul Gawande:

- Many people have priorities beyond living longer.
  - The chance to shape one’s story is essential to sustaining meaning in life
- We have the opportunity to refashion our institutions, our culture and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives

Institute of Medicine 2014: Whole Person Care hit the Mainstream

- Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life
- Focused on the need for palliative care as an essential part of health care
  - Teaching Primary Palliative Care skills to all clinicians

Shifts in Medicare payments:

- Up until recently, primarily a fee–for–service payment schedule
  - The more you do, the more you get paid
- But this is changing....
  - Now and in the future, it will be the Quality of the Care you provide for which you will be reimbursed
  - What does quality mean to patients and families?
  - How is quality defined and measured?
Medicare:
- Medicare started reimbursing physicians for end of life conversations in November 2015
  - We have fortunately moved beyond “Death Panels”...
- Medicare Choices Model: Pilot project to allow concurrent palliative care services from hospice agencies AND curative care
  - 140 hospices (none in NM) with >150,000 Medicare beneficiaries
  - Cancer, COPD, CHF, AIDS

The American Society of Clinical Oncology (ASCO) recommends “palliative care be offered along with treatment to slow, stop, or eliminate the cancer for patients with metastatic cancer (cancer that has spread) when diagnosed and those who have many or severe symptoms”.

Bottom Line: Concurrent palliative care with standard oncological care is better care.

www.asco.org
What is unique about New Mexico?

- Poorest state in the country
- 6th least populated state in the country (12 people per square mile; population ~2 million)
  - Rural population—may have lack of basic amenities, s.a. indoor plumbing
- Highest percentage Hispanic ancestry (47%)
- 19 Pueblo tribes, the Navajo and the Apache Nations
- #1 state in the country for
  - Alcohol related liver disease
  - Unintentional opioid overdoses….high psychosocial burden (back and forth with West Virginia for top spot)
  - Child hunger

2014 Nash ruling re: Physician Assisted Suicide (Aid in Dying)

- January 2014: District Court judge Nash ruled that patients have the right to physician’s assistance in aid in dying (in Bernalillo County)
  - Two UNM Cancer Center physicians and patient
- August 2015: New Mexico Court of Appeals ruled that “aid in dying is not a fundamental liberty interest under the New Mexico constitution.”
  - Went to New Mexico Supreme Court.
- July 2016: State Supreme Court upheld the appeal (5-0).
  - "If we were to recognize an absolute, fundamental right to physician aid in dying, constitutional questions would abound regarding legislation that defined terminal illness or provided for protective procedures to assure that a patient was making an informed and independent decision.” Justice Edward Chavez
  - “…the final decision on the legality of the assisted suicide belonged not with the courts but with state lawmakers”.
- Efforts underway to approach this from the legislative approach (like Oregon, Washington, Vermont, California) vs. legal ruling (like Montana)– stay tuned

Access to Hospice and Palliative Care is a NECESSITY

- If people feel that their only options at end of life are
  - a. dying a medicalized, painful death or
  - B. ending one's own life,
- Then we have not done a good job educating the public about Palliative Care and Hospice services, AND
  - People need to have access to palliative care and hospice services
Who is appropriate for a Palliative Care consult?

- Patients/families ask for Palliative Care
- Ask “Would you be surprised if this patient died during this hospitalization? within the next 6 months? the next year?”
- Start thinking about Palliative Care

What are some reasons for consult?

- Unacceptable pain or symptom distress in patients with serious/life threatening illness
- Team/patient/family needs help with complex decision-making and determination of goals of care
- Advance Care Planning
- Prognostication and hospice eligibility
- Patient/Family support
- Team support (family goal setting conferences)

What are some reasons for consult?

- Disposition assessment for seriously ill and dying patients
- Uncontrolled psychosocial/spiritual distress
- Frequent hospitalizations for the same diagnosis (ex. 3rd hospitalization in 2 months for heart failure, COPD, etc.) with functional decline
- Prolonged LOS/ICU stay without evidence of progress
- Other?
How can palliative care programs help other providers?

- Time
- Communication
  - Assistance with challenging families (family meetings) to help clarify goals of care
- Education
- Support for your plan of care
- Help avoid costly interventions that may cause suffering and not provide benefit

How to introduce a Palliative Care consult

- “This is a team of doctors, nurses, social workers and chaplain that help with ________.”
- Ex. Your pain, your breathing problems, ideas for what we can do for you after this hospital stay, practical guidance about support at home, support for your family, etc.)
- “This is a team of people who help patients and their families dealing with a serious or life threatening illness.”

How not to introduce Palliative Care:

- “This is a team of people who help you die.”
- “This is a team of people who see you when there is nothing else to do.”
- “This is the team to withdraw care.”
- “This is the hospice team.”

“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
If you’re thinking Palliative Care may be helpful, make the referral

The Real World

- There will never be enough Palliative Care specialists to see all the patients who need it

What do we need to do?

- Ways to look at Palliative Care
  - The “Palliative Care approach to patient care”
  - Primary Palliative Care
    - Skills needed by all health care providers for seriously ill patients
  - Secondary Palliative Care
    - Specialist clinicians who provide consultations and specialty care
  - Tertiary Palliative Care
    - Care provided at tertiary medical centers where specialist knowledge for the most complex cases is researched, taught, and practiced

This conference will focus on:

- The Palliative Care approach to patient care
- Primary Palliative Care
Primary Palliative Care Skill Set

- Pain and symptom assessment
- Social and spiritual assessment
- Helping patients and families understand illness, prognosis and treatment options
- Identification of patient-centered goals of care
- Transition of care post-discharge

Weissman and Meier 2011

Thank you!

References

- Center to Advance Palliative Care (CAPC). www.capc.org
- National Hospice and Palliative Care Organization (NHPCO). www.nhpco.org