Community-Based Palliative Care
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Objectives

- Discuss the vital continuum of hospital- and community-based palliative care models
- Describe successful models of community-based palliative care
- Discuss the opportunities and challenges for the expansion of community-based palliative care from the existing model of hospice care.
- Highlight some of the financial models that support home and community-based palliative care.

What is Palliative Care?

- Specialized medical care for people with serious illness(es). (Palliative Medicine)
- Team-based (interdisciplinary), focused on improving quality of life for patients AND their families by providing:
  - Expert symptom management
  - Emotional and spiritual support
  - Guidance in navigating the healthcare system
  - Assistance with difficult medical decisions
...what is Palliative Care?

- Any life-threatening diagnosis
- Any age
- Any stage
- Partnership with treating physicians
- Extra layer of support
- Provided alongside curative treatment

Different from Hospice

- Hospice is a form of palliative care supported by an insurance benefit that people are eligible to use when they are terminally ill.
- Hospice provides palliative care for terminally ill patients with an estimated prognosis of <6mos to live.
- Hospice patients:
  - Must sign on to their hospice benefit (elect)
  - Must be ‘certified’ by physician(s) as eligible.
  - Must stop ‘curative’ treatments for the hospice diagnosis.

Conceptual Shift for Patient-Family Centered Care

Old
Life Prolonging Care
Medicare Hospice Benefit

New
Life Prolonging Care
Hospice Care
Palliative Care
Dx
Death

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What Do Patients with Serious Illness Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones


And What They Get: Suffering in U.S. Hospitals

National Data on the Experience of Advanced Illness in 5 Tertiary Care Teaching Hospitals:

- 9000 patients with life-threatening illness, 50% died within 6 months of entry
- Half of patients had moderate-severe pain >50% of last 3 days of life.
- 38% of those who died spent >10 days in ICU, in coma, or on a ventilator.

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) JAMA 1995;274:1591-98

The Modern Death Ritual: The Emergency Department

Half of older Americans visited ED in last month of life and 75% did so in their last 6 months of life.

What Do Family Caregivers Want?

Study of 475 family members 1-2 years after bereavement:

- Loved one’s wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

Tolle et al. Oregon report card. 1999 www.ohsu.edu/ethics

And What They Get:

Family Satisfaction with Hospitals as the Last Place of Care

2000 Mortality follow-back survey, n=1578 decedents

- Not enough contact with Physician: 78%
- Not enough emotional support (pt): 51%
- Not enough information about what to expect with the dying process: 50%
- Not enough emotional support(family): 38%
- Not enough help with pain/SOB: 19%


Caregiving Increases Mortality

Nurses Health Study: prospective study of 54,412 nurses
- Increased risk of MI or cardiac death: RR 1.8 if caregiving >9 hrs/wk for ill spouse

Lee et al. Am J Prev Med 2003;24:113

Population based cohort study 400 in-home caregivers + 400 controls
- Increased risk of death: RR 1.6 among caregivers reporting emotional strain

More Medical Care Leads to Lower Satisfaction with Care

Family members of decedents in high-intensity hospital service areas report lower quality of:
- Emotional support
- Shared decision-making
- Information about what to expect
- Respectful treatment


Physicians practicing in high health care-intensity regions report more difficulty:
- Arranging elective admissions
- Obtaining specialty referrals
- Maintaining good doctor-patient relations
- Delivering high quality care


Aging and illness...

“Over the past 30 years the rapid causes of death have declined, while gradual causes have grown exponentially. Most people today do not die suddenly, they die incrementally.”

Stephen Kiernan, Last Rights: Rescuing The End of Life from the Medical System 2006
Aging and illness...

“The delivery of health care, from staffing to billing, is organized around institutions instead of patients. Gradual dying is treated as a medical crisis instead of a natural process.”

Kiernan

Costs by Age Categories


The Silver Tsunami
Older Adults are More Likely to Have Multiple Chronic Conditions

The Very Ill Utilize the Most Resources

What do we get for our money?

• Among OECD member nations, the United States has the:
  – Lowest life expectancy at birth.
  – Highest mortality amenable to health care.
  • The inequality of healthcare in America means that people here die prematurely from treatable causes — typically our young adults and middle age without insurance.
Higher spending does not lead to better outcomes at end of life

![Graph showing quality of life vs. per capita cost with adjusted P = .006](image)

Berwick DM, Nolan TW, Whittington, J. Health Aff May 2008 vol. 27 no. 3 759-769.

Improving the U.S. health care system requires simultaneous pursuit of three aims:

- improving the experience of care,
- improving the health of populations, and
- reducing per capita costs of health care.

Outcomes of Palliative Care:

- Reduction in symptom burden
- Care concordant with pt/family wishes
- Improved patient and family satisfaction
- Reduced costs

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Mr. S

- 84 yo gentleman with a diagnosis of pulmonary fibrosis
- First Palliative Care consultation – ambulatory, moderately symptomatic (NYHA 2), mild-moderate functional changes (modifying leisure activities) PPS 70%
- Outcomes:
  - Education re disease and its process
  - Discussion:
    - Symptom Management – how and when
    - Goals of Care
    - Quality of Life
    - Advance Care Planning – POA

Mr. S

- Returns in 5 months – now more symptomatic with fatigue and SOB
- Hasn’t pursued ACP, now more interested
- Moderately symptomatic, not on oxygen, PPS still 70%
- Discussion:
  - Symptom Management
  - GOC, QoL
  - Preferences at EOL
  - Living with advanced illness – nutrition, exercise modifications, safety
Mr. S

- Returns in 6 months – more symptomatic with fatigue and SOB, using supplemental oxygen, sleeping more. Unintentional weight loss.
- NYHA 3, PPS 60%.
- ACP – more specific re directives (limited but desired hospitalizations), DNAR
- Outcomes:
  - Symptom Management
  - POLST Form
  - Caregiving discussion
  - Living with advanced illness – safety, do not drive
  - Transition of site of care to home-based

...Mr. S

- Home-Based Palliative Care – now at home, requiring oxygen 24/7, de-saturating.
- napping. NYHA 3-4, PPS 50-60%.
- Increasing evidence of heart failure, worsening kidney function.
- Outcomes:
  - Opioids for SOB
  - Safety, fall prevention
  - Added NP visits, SW visits for caregiver support

...Mr. S

Within months –
- Progressive symptoms and functional limitations
- Syncopal episodes
- Further weight loss
- NYHA 4, PPS 50%
- Outcome – admitted to hospice care
...Mr. S

- Mr. S was in hospice care for the next 12 months, demonstrating a gradual steady decline. He continued to be seen monthly and as needed by the Palliative Medicine physician in the home setting.
- in addition to the RN, SW, Chaplain and 2 Volunteers.
- He consistently rated his quality of life as 10/10 and was able to enjoy his family.
- He celebrated the birth of a great grandchild.
- In the final three weeks of his life, he became more detached emotionally and socially, sleeping most of the day with diminishing oral intake.
- He developed agitated delirium and severe dyspnea requiring skilled care beyond what could be safely and effectively managed in the home setting and was urgently admitted to inpatient hospice.
- He died peacefully in that setting twelve days later.

...Mr. S

- During Mr. S's 4+ years receiving Palliative Care support he was never hospitalized and never went to the Emergency room despite a serious progressive illness.
- He lived until he died with a patient/family-centered plan of care that prioritized his goals of care.

Lessons from Mr. S

- Create access points for PC outside of the hospital
- Create robust home-based palliative care that can respond to the needs of progressive serious illness for patients and families.
- Create horizontal integration such that people do not have to earn support through suffering and relationships can be supported.
The Palliative Care Continuum HBPC

Patients who benefit from home-based palliative care
- Advanced complex illnesses or life-limiting diagnoses
- High risk of morbidity and mortality.
- Do not have a predictable prognosis and/or are not eligible for or interested in hospice services.
- Significant symptoms, particularly, pain and depression.
- Prefer to be cared for in the home setting.

...Home-based Palliative Care (HBPC)

- The effort to move to other settings for evaluation and treatment may not be the patient’s preference or in their best interest.
- Palliative care provided in the home achieves:
  - reduction in symptom burden
  - increase in patient and caregiver satisfaction
  - decreased utilization of resources and costs.
  - increased likelihood to die at home
  - less likelihood to be hospitalized at the EOL and when hospitalized spend less time in the hospital.

“Home Bound?”

Palliative care delivered in the home is ideal for patients who are “homebound”.

Homebound status – home health requirement – must be patients with serious illness(es) and those who have experienced a serious injury:
- Need the aide of supportive devices (eg, crutch, cane, wheelchair, walker, or special transportation) OR
- Require the assistance of another person in order to leave their place of residence OR
- Have a condition that renders leaving his or her home medically contraindicated.

In addition, patients should be unable to leave the home normally such that attempts to do so would require a considerable and taxing effort.
Patients receiving home based palliative care are not required to meet the definition of being homebound as it applies to home health. The clinician determines it is medically necessary to see a patient in the home setting to optimize their assessment and treatment plan. Documentation of the need (medical necessity) for homebound care is required for medical coverage.

Medicare defines Medical Necessity as:

"Services or supplies that are needed for the diagnosis or treatment of your medical condition, meet the standards of good medical practice in the local area, and aren’t mainly for the convenience of you or your doctor."

Reason for Visit?

• Important to paint a clear picture of the services provided in the documentation and why providing them in the home is medically necessary and in the best interest of the patient/family
• Not: “I was just in the neighborhood, so...”
  – Cannot be seen just because the physician at the SNF, ALF or passing by the home.
**Reasons for a Home Visit**

- Immobility, cognitive impairment, or a serious psychiatric condition
- Request prompted by a home health team member, the patient, or the patient’s family member

The opportunity to directly observe the patient in his or her home environment to:
- better assess the patient’s functional abilities,
- the caregiver’s understanding of the complex medical issues present and ability to meet the patient’s needs,
- and/or to verify eligibility for services by third-party providers

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**...reasons for a home visit**

- Meeting the patient with his or her caregiver in order to make medical decisions in a “comfortable” setting.
- The need to meet with community-based providers on-site.
- To assess care coordination and transitions of care in order to reduce hospital readmissions.

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**Models for HBPC services**

HBPC exists as part of...

1. A geriatrics or primary care practice with expertise in palliative care (primary and palliative care P&PC), or
2. Home health-based,
3. Hospice agencies, or
4. Hospital-based palliative care program

Barbour LT, Cohen SE, Jackson V, et al
Home-based primary and palliative care programs

- Integrates palliative care into comprehensive primary care via an interdisciplinary team: integration of palliative care principles into longitudinal health care relationships.
- Patients with multiple chronic medical conditions, high symptom burden, and/or complex care coordination needs.
- Most often led by an advance practice nurse and physician and can include nurses, clinical pharmacists, social workers, psychologists, and physical therapists.
- Team members with added training and expertise in palliative care.

...Home-based primary and palliative care programs

- Provide home visits during business hours and most provide 24-hour and weekend phone availability.
- Most programs are able to deliver medications to the home.
- Longitudinal primary care, urgent care, and transitional care.
- Reimbursed as FFS and increasingly as part of managed Medicare services.

Outcomes of HBP&PC

- Improve quality of life for patients and their caregivers,
- Lowers the burden of home care for the caregiver,
- Improves symptom management,
- Decreases unnecessary hospital and emergency room utilization.
- Patients reported significant reductions in symptoms including pain, anxiety, depression, fatigue, and loss of appetite.

Ornstein K et al. J Palliat Med. 2013
Home health-based model

Home health care:
- Post-acute care or without a preceding hospitalization.
- Covered under Part A Medicare
  - Intermittent skilled nursing
  - And/or physical, occupational, or speech therapy.
- Must have a skilled nursing need.
- The main mission is rehabilitation.
  - Most agencies do not offer 24-7 support or emergent home visits, and
  - Usually do not deliver medications to the home.

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...Home health-based palliative care

- Palliative home health care is typically provided by an interdisciplinary team.
- Not specifically reimbursed as a Medicare Part A benefit.
- Relies on private pay, grants, endowments or FFS reimbursement for providers who can bill (LCSWs, APNs)
- Typically no dedicated physician involvement.
- Clinicians less likely to have formal training in Palliative Medicine and Palliative Care.

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...Home health-based model

Outcomes:
- Improves quality of life for patients in palliative care and their caregivers,
- Lowers the burden of home care for the caregiver,
- Improves symptom management,
- Decreases unnecessary hospital and emergency room utilization.

Patients with advanced and/or end-stage disease may derive limited benefits
- Time limited to a particular episode for which skilled needs have been defined.
- Once the objective of care is met, the patient is usually discharged without assistance for ongoing care management. Vulnerable time for patients with complex illnesses.
- After home health care is discontinued, the organization of care frequently deteriorates, increasing the stress for the caregiver.
Hospice model

- Most intensive, refined form of HBPC for patients whose life expectancy is typically defined in months and who are no longer benefiting from disease-directed interventions.
- Supported by defined insurance coverage.
- Patients are formally certified as being in the terminal phases of an illness by their clinicians, defined as a life expectancy of six months or less.
- Provided by a dedicated interdisciplinary team comprised of nurses, physicians, social workers, chaplains, and home aides, all of whom have experience and knowledge caring for patients at the end of life.

Bridge programs

Hospice programs have established HBPC “bridge” programs for:
- Patients who do not choose to elect the hospice benefit.
- Or do not meet hospice eligibility criteria at assessment.
- The services vary widely and are not regulated or standardized.
- May be limited to volunteer support or intermittent social work visits.
- Result:
  - A broader population of patients and families can benefit from the expert IDT care.
  - Can also facilitate a transition to hospice care when the patient is eligible and desirous of hospice support.
- Private pay, grants, endowments or FFS for providers who can bill (LCSWs, APNs).

Outcomes of Hospice-run HBPC

Many programs have grown out of hospice care:
- Knowledge of home-based care, capitated payments.
- Expert IDT, seasoned in home-based delivery.
- Community-based, integrated into other systems of care.
Challenges of Hospice-run HBPC

- Payors do not want to contract with a hospice to provide HBPC – need separation.
- Different operational needs and processes.
- Different payment mechanisms.
- Cultural dissonance with the goals of care.
- Perspective and expertise of Providers.
- Corporate Practice of Medicine.

Palliative care consultative model

- PC team might partner with a community nursing or hospice agency.
- PC may be limited to patients:
  - who had been followed on the inpatient palliative care service, those
  - referred by primary care or specialists, or those
  - identified as high risk by the hospital for readmission.
- Variation seen in the populations served, as well as the way programs are structured and reimbursed.

Drivers Shaping Coverage For HBPC

- Need for continued support for patients with chronic illness across settings of care (the high-acuity, high-cost portion for medical spending).
- Prominent need for care coordination and interdisciplinary care.
- Changes in the Medicare reimbursement system penalize hospitals for 30 day readmissions.
- Increased interest in home-based care programs for most costly patients with serious or life-threatening illness.
- Insufficient reimbursement from the Fee-for-service model to support HBPC.
Drivers Shaping Coverage

- Emerging are new financial models that involve per-member, per-month reimbursements or shared savings
- Align incentives with what = meaningful care for patients and families and
- Better addresses efforts to provide population health management.

Payment reform in this area is in the early phases and is aligned with changes on a national level in the US.

Quality Outcomes in Palliative Care

- Improvements in symptom control
- Improved caregiver outcomes
- Improved patient and family satisfaction
- Increase likelihood:
  - Care is concordant with pt/family values
  - Decision making is without conflict
  - Death occurs in a preferred setting
  - Reduced LOS, utilization, and costs

Inpatient Palliative Care Nationally

- Growth of Palliative Care

Palliative Care Nationally

- 98% of NCI cancer centers have palliative care
  - Palliative care available in 78% of non-NCI cancer centers
- Palliative Care in Illinois
  - 67% of hospitals with more than 50 beds
  - 87% of hospitals with more than 300 beds
- Commission on Cancer (CoC)

Hui et al, JAMA, 2010

Palliative Medicine Subspecialty Recognition in 2006

10 Sponsoring boards:
- Anesthesiology
- Emergency Medicine
- Family Medicine
- Internal Medicine
- Obstetrics and Gynecology
- Pediatrics
- Physical Medicine and Rehabilitation
- Psychiatry
- Neurology
- Radiology
- Surgery

First boards exam 2008

Palliative Specialists

- Provide palliative treatment in the earlier stages of disease alongside disease-directed medical care,
- Improve quality of care and medical decision making regardless of the stage of illness.
- PC teams increasingly integral to capitated (risk) arrangements for services to patients with advanced and chronically progressive illness(es).
Significant Shortage of Palliative Medicine Specialists

- Current needs – moderate estimate = 6000+ FTE
  - in 2013 there are about 5000 PM physicians in the US
  - There are <1000 APNs with PM certification.
- Many physicians are not fulltime in HPM, estimate 8-10K needed to fill current needs.
- High need estimates are 10,810 FTE’s = 14,000 to 18,000 physicians.

A Tiered approach to integration of Palliative Care support:

1. Specialty Palliative Care
2. “Champion” Generalist Palliative Care
3. Generalist Palliative Care

Representative Skill Sets for Primary and Specialty Palliative Care:

Primary Palliative Care
- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care
- Management of intractable pain or other symptoms
- Management of more complex depression, anxiety, grief, and emotional distress
- Assistance with conflict resolution regarding goals or methods of treatment
- Within facility
  - Between staff and families
  - Among treatment teams
  - Assistance in addressing cause of near-futility
Coordinated Palliative Care Model

- Coordination of care across sites of care with access to PC expertise in each setting.
- Thoughtful allocation of resources through real-time planning.
- Enhanced communication – need for integrated EMRs and communication platforms.

Primary PC ↔ Specialty PC

- The primary palliative care curriculum must be taught — including to mid-career clinicians — and reinforced by performance measurements.

...Coordinated Palliative Care Model:

- Simplifies the health care system and reinforce existing relationships.
- Leads to and reinforce the skills of all clinicians, improving their ability to address basic palliative care needs.
So, in Summary...

- Discussed the continuum of hospital- and community-based palliative care models and the need for Generalist and Champion PC.
- Described different models of community-based palliative care – primary & palliative, home-health, bridge programs, hospice, consultative models.
- Discussed the opportunities and challenges for the expansion including the serious of illnesses, the need for 24/7, financial limitations, and limits of (wo)manpower.
- Highlighted some of the financial models that support home and community-based palliative care including FFS and increasingly managed-Medicare.

Four Stages of Life

- Four Stages of Life
- [Image of four stages]
- [Description of stages]

[Image of elderly person]
Be the Change you wish to see in the World

Gandhi