The Role of the Long-term Services and Supports System in Providing End-of-Life Care

Diane E. Meier, MD
Center to Advance Palliative Care
Department of Geriatrics and Palliative Medicine
Mount Sinai School of Medicine
diane.meier@mssm.edu
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Objectives

- Understand the case for palliative care in LTSS
- Define palliative care and its relationship to hospice
- Identify the existing range and impact of LTSS models for palliative care
- Case study: alternative payment models and NH palliative care
- Recognize policy and payment incentives supporting palliative care delivery in LTSS

Mr. B

- An 88 year old man with dementia admitted via the ED for management of back pain due to spinal stenosis and arthritis.
- Pain is 8/10 on admission, for which he is taking 5 gm of acetaminophen/day.
- **Admitted 3 times in 2 months for pain (2x), falls, and altered mental status due to constipation.**
- His family (83-year-old wife) is overwhelmed.
- Dual eligible in MLTC plan

Mr. B:

- Mr. B: *"Don't take me to the hospital! Please!"*
- Mrs. B*: "He hates being in the hospital, but what could I do? The pain was terrible and I couldn't reach the doctor. I couldn't even move him myself, so I called the ambulance.* ***It was the only thing I could do."***

Modified from and with thanks to Dave Casarett

Before and After

Usual Care

- **4** calls to 911 in a 3-month period, leading to
- **4** ED visits and
- **3** hospitalizations, leading to
- Hospital acquired infection
- Functional decline
- Family distress

Palliative Care

- Housecalls referral (HCBS via MLTC contract)
- Pain management
- 24/7 phone coverage
- Support for caregiver
- Meals-on-Wheels
- Friendly visitor program
- **No 911 calls, ED visits, or hospitalizations in last 18 months**

Implications of Mr. and Mrs. B: Families Need Help with Pain and Symptoms

Disabling pain and other symptoms reduce independence and quality of life.

HRS- representative sample of 4703 community dwelling older adults 1994-2006

Pain of moderate or greater severity that is "often troubling" is reported by **46%** of older adults in their **last 4 months of life** and is worst among those with ***arthritis***.

Smith AK et al. Ann Intern Med 2010;153:563-569

Implications of Mr. and Mrs. B: Families Need Help at Home

- Mobilizing long term services and supports in the community is key to helping people stay home and out of hospitals.
- Predictors of success: 24/7 *meaningful* phone access; high-touch consistent personalized care relationships; focus on social & behavioral health; integrate social supports with medical services.

Implications of Mr. and Mrs. B: Clinicians are not trained in palliative care or symptom management

- Nowhere in the revolving door in and out of hospital did anyone recognize his actual care needs.
- Nowhere did anyone have the confidence to treat his pain with low dose opioids, instead believing hospitalization is the 'safer' option.
- Referred to housecalls practice because of a coincidence the 3rd time he was in the ED- not because of a systems approach.

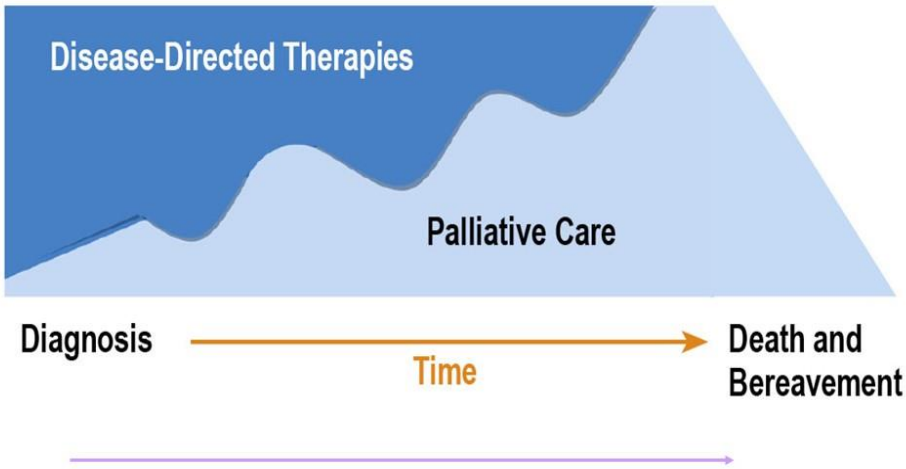
Mr B.- The exemplar LTSS beneficiary

- Functional Limitation
- Frailty
- Dementia
- Exhausted overwhelmed family caregivers
- Social + behavioral health challenges
- +/- Serious illness(es)

What is Palliative Care?

- Specialized medical care for people with **serious illness** and their families
- Focused on **improving quality of life**. Addresses pain, symptoms, stress of serious illness.
- Provided by an interdisciplinary **team** that works with patients, families, and other healthcare professionals to provide **an added layer of support**.
- Appropriate at **any age, for any diagnosis, at any stage** in a serious illness, and provided **together with disease treatments**.

Conceptual Shift for Palliative Care: Needs based, NOT prognosis based



11

Palliative Care Improves Value

Quality improves

- Symptoms
- Quality of life
- Length of life
- Family satisfaction
- Family bereavement outcomes
- MD satisfaction

Costs reduced

- Hospital cost/day
- Use of hospital, ICU, ED
- 30 day readmissions
- Hospitality mortality
- Labs, imaging, pharmaceuticals

How does it work?

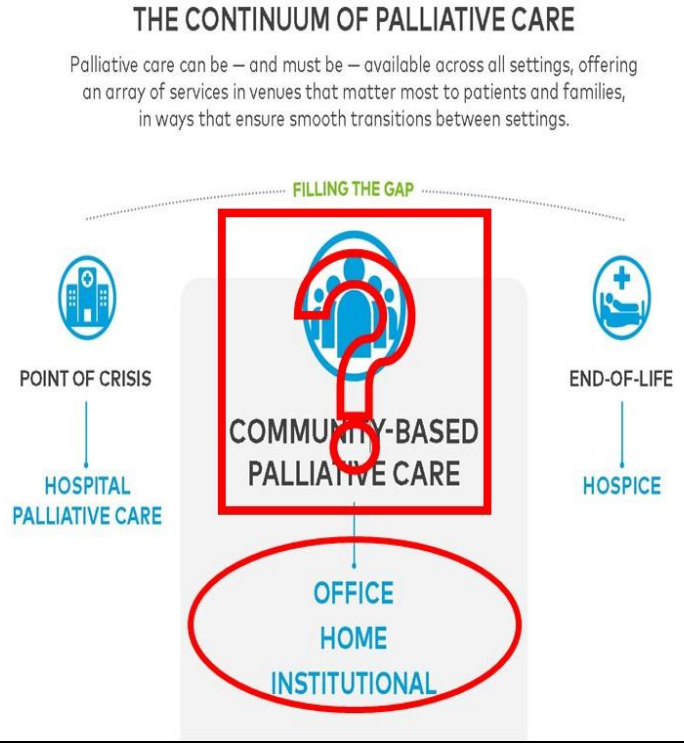
13

Top 6 Characteristics of *Effective* Palliative Care

1. Adequately staffed and educated teams *in the relevant settings*
2. Screen, then target the highest risk people
3. **Ask people what matters most to them, then plan for that**
4. Support family and other caregivers, food, housing, transportation
5. Expert pain/symptom management
6. 24/7 access, all settings

No payment model (outside of MA/MLTC) supports this approach, which is why it is still so hard to find.

14



Age at death in the U.S.

Most deaths in US occur in old age, high prevalence of cognitive and functional impairment among decedents

- 90% of deaths in US occur in people over 75 years of age
- Prevalence of dementia rises exponentially with age
- >85 prevalence = 50% (underestimate given underdiagnosis)

Locations of death: U.S. 2017 data

1. Home (includes assisted living)	31% ↑
2. Hospital	30% ↓
3. Nursing facility	21% ↓
4. Hospice residence	8% ↓

https://www.nejm.org/doi/full/10.1056/nejmc1911892

Causes of death: majority have underlying dementia and functional decline

Inaccurate because based on death certificates

1. Heart disease: 696,962
2. Cancer: 602,350
3. COVID-19: 350,831
4. Accidents (unintentional injuries): 200,955
5. Stroke (cerebrovascular diseases): 160,264
6. Chronic lower respiratory diseases: 152,657
7. Alzheimer's disease: 134,242
8. Diabetes: 102,188
9. Influenza and pneumonia: 53,544
10. Nephritis, nephrotic syndrome, and nephrosis: 52,547

LTSS and Medicaid

= Primary system of care for people with dementia, especially those nearing end of life

LTSS funded by Medicaid

- Total Medicaid LTSS $162 billion 2019
  - **HCBS 59%** 5.8 million people
  - **Nursing Facilities 41%** 1.9 million people
- Institutional long-term care: 62% Medicaid
- Managed LTSS now in 25 states
- State by state variation in coverage

https://www.kff.org/medicaid/issue-brief/a-look-at-nursing-facility-characteristics-through-july-2022

Dementia costs are 3-fold higher than costs among non-demented peers.

Out of pocket: 4X higher
Medicare: 3X higher
Medicaid: 22X higher

Average Annual Per-Person Payments by Payment Source for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2021 Dollars*

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	$21,024	$7,576
Medicaid	6,478	291
Uncompensated	184	229
Health maintenance organization	1,867	2,193
Private insurance	1,468	916
Other payer	893	401
Out of pocket	9,844	2,420
Total	**41,757**	**14,026**

*Payments for beneficiaries with Alzheimer's or other dementias include payments for community-dwelling beneficiaries and beneficiaries living in residential care settings.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2018.[260]

How is life in a nursing home?

- Inconsistent to poor quality
- Poor pain control
- Under resourced
- Understaffed
- Frequent, burdensome transitions
- OIG report ~22% experienced an adverse event
  - Substandard treatment
  - Inadequate monitoring
  - Failures/delays in necessary care

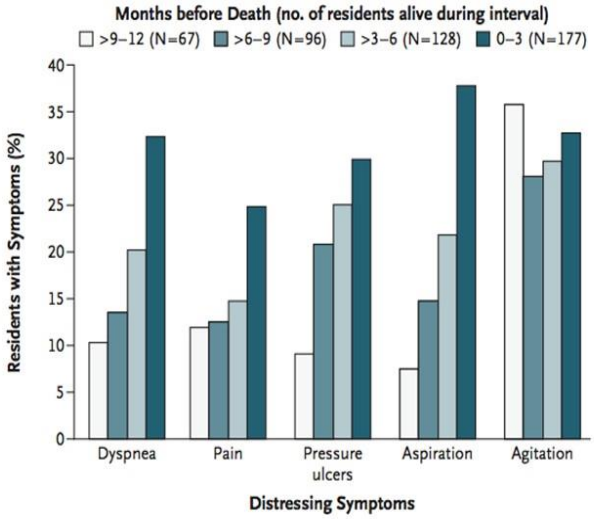
Advanced Dementia is a Terminal Disease

CASCADE: Prospective study of 323 nursing home residents with advanced dementia from 22 nursing homes **over 18 months**

18-month mortality = 53%

Mitchell S L et al. N Engl J Med 2009;361:1529-1538

Sources of Suffering in Dementia



Mitchell S L et al. N Engl J Med 2009;361:1529-1538

Palliative Care in NHs and HCBS is Necessary

- Hospice, too little too late
- High prevalence of serious illness, death in NH and among HCBS recipients
- High levels of physical suffering
- Extremely vulnerable population: cognitively + functionally impaired in underfunded, overregulated and inadequately staffed care setting
- NH ranked lowest among the last places of care by family members
- NH is frequently named as a *"fate worse than death"* by older adults

Given the needs of the population, why isn't palliative care standard in NHs and HCBS?

Why it doesn't change: The payment system

We are asking systems, provider groups, social service agencies, community-based organizations, persons living with dementia, and their families, to coordinate and provide services not reimbursed by third-party payers.

"Medicare has no or limited statutory authority to provide these services to beneficiaries. Comprehensive dementia care is built on the foundation of caregiver education, support, and services, and all current payment schemes fail at this foundational level. "

Why it doesn't change: The regulatory system LTC

providers are punished for the natural progression of disease

Current NH quality measurements do not allow for a different set of metrics for end-of-life care. Measures include % with:

1. **Increased ADL dependency**
2. **Moderate-severe pain**
3. **Restraints**
4. **Most of time in bed or chair**
5. **Decreased ability to move**
6. UTI
7. **Increased depression-anxiety**
8. **Weight loss**
9. **Pressure sores**
10. **Bowel-bladder incontinence and use of indwelling catheters**

CMS NH Quality Initiative

Why it doesn't change? Limitations of hospice

- **Most people with dementia are not eligible for hospice because of uncertain prognosis**
  - **Even in advanced dementia, the trajectory is uncertain** ***Mitchell 2010 JAMA***
- There are some patients for whom the hospice benefit will never be acceptable.
- OIG, CMS penalties→ reluctance of hospice providers to enroll if prognosis uncertain → very short hospice stays

Studies on Impact of Palliative Care in the Nursing Home

- Retrospective case control study comparing care processes in 125 end stage dementia patients receiving palliative care consultations (2007-2009) to 125 historical controls (2006) receiving usual care
- Single facility (Hebrew Rehabilitation) in Boston
- Data source: MDS
- Composite outcome based on utilization patterns, depression, and pain and other clinical Indicators, and change on this composite score (and the individual outcomes) over a 1-year period.

- **Results: Residents receiving palliative care consultation had fewer ED visits ($p<.001$) and less depression ($p<.03$). Significant difference over time between the 2 groups ($p < .013$).**

Comart J et al. The Gerontologist 2012; dec 7. doi:10.1093/geront/gns154

Palliative care consultation in the NH markedly reduces hospitalization

Miller SC et al. JAGS 2016: 19 September 2016
DOI: 10.1111/jgs.14469

46 NHs in NC+RI, propensity score matched retrospective cohort study

Days Between Death and Initial Palliative Care Visit	Hospitalization in last 7 days of life	
	With Palliative Care Consultation	Without Palliative Care Consultation
≤7 days	21%	36%
8–30 days	11%	22%
31–60 days	13%	21%
61–180 days	7%	23%

4 Models for Palliative Care in the Nursing Home- *only one is financially feasible*

1. Contract with Payer (increasingly common due to ↑ MA)

Institutional and Duals/Chronic care SNPs
Other Medicare Advantage plan contracts

2. Fee-for-service external palliative care consultant (scarce)

Palliative care physician group
Hospice-related palliative care provider(s)

3. Medical Director (scarce)

May provide some palliative consultation within care planning role

4. Expert geriatric SNF specialized medical group (scarce)

Expert geriatric and palliative care providers required
Present and engaged in SNF
Often includes team-based care team with NP

Case Study from Optum

Optum CarePlus Institutional Special Needs Plan (I-SNP)

Medicare Advantage program designed for long-stay nursing home patients:

- Adds a specially trained nurse practitioner with training in:
  - Symptom management
  - Goals of care communication and advance care planning
  - Geriatric and complex care team
  - National network of expert medical directors for education and support
  - Works with the long-term care team for coordinated care planning
  - Accountable for reducing hospitalization
- Has been in place over 25 years
- Currently > 50,000 patients in over 1900 nursing homes in 35 states

CarePlus Nurse practitioner:

key role as _the_ accountable person

aka "care coordinator"

Evaluates the patient and creates personalized health care plan

Bridges the gap between the staff, medical director and primary care physician

Educates facility staff on specific patient needs

Serves as first point of contact if patient's condition changes

Visits patient routinely and in urgent situations

OPTUM® Complex Care Management

CarePlus Nursing Home Program Results

- 49% reduction in ER visits
- 60% reduction in hospitalization
- 48% reduction in total costs
- $9,000 in savings per member per month

ISNP models under MA

1. Specialized skills and accountable care team are required
2. **New payment models can support improved care delivery**
   - ✓ Improved quality
   - ✓ Reductions in readmissions support hospital partners
   - ✓ Reduction in hospitalizations, ER visits and total costs support value-based programs such as Medicare Advantage, MLTC

But, no data on PROs or family satisfaction

CSNP and DSNP palliative care

- Primarily delivered through MA contracting with vendors such as Aspire, Landmark, Prospero, and many others
- No regulatory standards
- No public reporting of outcomes
- No peer review
- No publishing
- Care delivery/model undefined
- Goal is to reduce spending for MA plan
- Result →reduces hospital admissions in last 3 months of life by making sure referral to hospice occurs in a timely manner. Savings to MA plans outweigh cost of vendor.
- Impact of hospice carve-in on these vendors? Impact on dementia population?

LTSS policy reform

Criteria for palliative care should be based on need, not on prognosis

- Palliative care delivery meeting standards and competencies as a condition of participation
- Quality measures should not restrict focus to 'improvement'
- Quality measures should apply to MA + their vendors
- Quality measures should capture person-centered goals as priority and recognize palliative care needs during the normal (and usually prolonged) dying process in dementia
- Payment model must incentivize complex care coordination, palliative care services in the home/NH and reduce financial incentives for intensive rehabilitation and repeated hospitalization for those who cannot benefit.

Policy: Dementia costs bankrupting Medicaid (LTSS) and soon, Medicare (aducanamab et al)

- Pressure to develop a coherent payment policy for dementia related costs is rising for states, the federal government, and MA plans.
- Multiple NIA and CMS studies demonstrate that comprehensive dementia care coordination improves quality and reduces cost for this population
- Comprehensive analysis of what a (bundled) dementia care alternative payment model might look like: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://portal.alzimpact.org/media/serve/id/5f1b511b98110 https://www.alz.org/news/2021/bipartisan-legislation-to-create-a-path-to-better
- https://alzimpact.org/comprehensive_act

Dementia Care Management: A Proposed Framework for an Alternative Payment Model

Palliative care IS the gold standard of care for dementia patients requiring LTSS

…but it will not become widespread until it is clearly defined and packaged and until there are policy, quality standards, and financial mechanisms to support it.

https://pubmed.ncbi.nlm.nih.gov/34953767/