Challenges and Roadblocks with Palliative Care in Oregon
And how we can fix them.

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Introduction and Disclosures

• I have worked in Hospice, Home Health and Palliative Care in Oregon since 1985.
  • For 3 & ½ years, I also visited 30 states and >100 home care programs as a Joint Commission Surveyor.

• I have been in my position with the OHPCA and WSHPCO since July of 2015.

• I am not an expert on Palliative Care.

• I have no affiliations to disclose.

• All photographs used in slides are either from my personal collection or are from “Creative Commons” and they have not been altered.
Let’s discuss which issues are challenges and which may be roadblocks. Or are some issues both?
Two questions:
1) Why is Palliative Care the “red-haired stepchild” of healthcare?
2) Why do Palliative Care Providers have to hide the “H” word?
Palliative care, a misunderstood specialty

Palliative care is misunderstood as a medical specialty, according to Dr. Joe Contreras, chair of the Institute of Pain and Palliative Medicine, Hackensack Meridian Health, and can improve overall outcomes if started earlier.

"Palliative care, what makes it unique is it's really focused on the well-being of the person in the setting of serious illness. And we approach it holistically, mind, body, and spirit," Contreras says.

Full Story: Oncology Nursing News (11/22)

Hospice helps those nearing the end of life *

The unique services of hospice offer a welcoming, reassuring option for care at the end of life. Management of pain and other symptoms in the home can honor and respect a patient's wishes, comfort families and help them cope with the loss of a loved one.

Full Story: The Columbus Telegram (Neb.) (11/20)

*But it may be better to not have the word “Hospice” on your name badge if you’re a PC provider.
Here’s another confusing headline from this week:

• This headline appears to epitomize the phrase “Mixed Message”.
An Illustrative Example:

- Imagine you get a telephone call one morning, as I did recently...
  - A woman said she lives in eastern Oregon.
  - She’s heard about “Palliative Care”.
  - She’s not ready for Hospice, because her Physician told her she’s not ready, as she has more than a one-year prognosis.
  - She’d like to receive this service called “Palliative Care”.
  - She asks: “How does I go about getting it?”
  - What would you tell her?
A Second Illustrative Example:

- Imagine you are talking with the mother of a child who has a serious (perhaps life-threatening) illness.

- This mother has been doing research online and networking with other parents. She hears about this service call “Palliative Care” and this other benefit called “Concurrent Care”.

- She knows of another child who is receiving palliative care and even hospice care--while also continuing to receive curative treatment.

- She asks you why her child, who happens to be covered by an insurance company, cannot receive both palliative or hospice care and curative care simultaneously.

- What do you tell her?
What other examples come readily to mind?

- What about the seriously ill person who needs frequent transfusions?
- Or the person who is receiving dialysis treatments several times a week?
- Or the seriously-ill person who is still able to be a “snowbird”?
- Could they benefit from “Palliative Care”?
Challenge: A Lack of Agreement on What Palliative Care “Is”

- It’s not that “There is no there there.”, as Gertrude Stein once famously said.
- It’s more that there’s a lack of agreement about and an understanding of what “PC” is.
- It varies by:
  - What programs decide to provide;
    - Which often varies by which providers are available to provide it;
  - What payers are willing to cover;
  - What other funding sources may be available;
Let’s treat this like a mystery novel...

• Who’s providing PC?
  • Who’s receiving PC? Who should receive it?
• What are they providing?
• Where is PC being provided?
• When are they providing it?
• Why is PC even being provided?
• How is PC being provided? How is it being covered?
Who?

- Sometimes one hears: “We already provide/cover Palliative Care.”
- If this means that “Provider-based billing under Medicare Part B” is what is being provided/covered—
- Or if this means that PC is being provided/covered in metro areas—
- Is that enough?
- Should “Interdisciplinary Team” Services be covered? “Case Management”, “Social Services” or “Spiritual Care”?
- Should PC be available everywhere in the state?
Who is Providing PC in Oregon?

- Does anyone have an accurate list of all of the PC programs in the state?
- Attempts are made at “Mapping PC”.
- For inpatient PC provided in hospitals: “Probably”.
- For “Primary Palliative Care” provided in an outpatient setting: “Maybe”.
- For PC provided in “Long Term Care” Facilities?
- For community-based PC? Who has a current list?
Challenge or Roadblock related to **Who:** Workforce Shortage

At least in Oregon, we don’t have the same challenge faced by Texas Hospice providers:

- **Texas SB 916** passed in 2019. It requires
  - Providers of in-home supportive palliative care services must hold a HCSSA license with home health designation
- Hospice agencies must not admit and provide supportive palliative care to individuals who have not elected hospice or who are ineligible for hospice.
- It’s not just the licensure issue—programs also have to pass state licensure surveys for the type of license required by this law.
Who:
Oregon SB 177 passed during the 2019 Legislative Session

- Senator Sara Gelser and Rep. Rachel Prusak were our champions—thank you to each of them!
- “Notwithstanding ORS 443.305 to 443.350 requiring an in-home care agency to obtain a license to provide services that are necessary to assist an individual in meeting the individual’s daily needs but are not curative or rehabilitative, a hospice program licensed under ORS 443.860 is not required to be licensed as an in-home care agency under ORS 443.315 to provide palliative care, as defined by the Oregon Health Authority by rule.”
So, who is/will be allowed to provide outpatient PC in Oregon?

• Under Medicare/Medicaid: anyone who can bill under Part B: Physician, NP, PA, LCSW, Physical, Occupational or Speech Therapists.


• Oregon HB 2981: The authority shall adopt by rule the eligibility requirements and provider qualifications for the program and

• The palliative care services, as determined and provided by an interdisciplinary team, must be provided in the patient’s choice of residence.
  • Who is able and willing to make “House Calls”?
Who is/may be allowed to bill for PC? S 2565:

• “(4) PARTICIPATING PROVIDERS.—Providers eligible to participate under the model may include palliative care teams working as
  • an independent practice or
  • associated with a hospice program,
  • home health agencies,
  • hospitals,
  • integrated health systems,
  • and other facilities determined appropriate by the Secretary.

• Other Payers: as determined by written agreements.
Who: Should PC “Certification” Be Required?

- In 2019 with SB 179, we said: “Certification or Training” should be required.
- What is the current estimate for the shortage of PC-Certified Providers? “In the thousands.”
- S 2565: “(5) TEAM-BASED APPROACH.—Under the model, at least one member of the multi-disciplinary palliative care team shall be certified in hospice and palliative care.”
- If Palliative-Care certification is required, vast areas of the state will not have access to palliative care.
Who: Should anyone be excluded from receiving PC?

• Should anyone be excluded, even when other eligibility criteria may be met?

• What about seriously-ill persons who
  • Didn’t “sign themselves up” for PC? (i.e. a family member or caregiver did)?
  • Aren’t willing to follow a mutually-agreed upon care plan?
  • Have previously been discharged from another or your PC program?
  • Have chronic pain and use opioids for pain management?
  • Or who have a history of drug use or drug diversion within their households?
What?
(Why are there so many PC definitions?)

- Which definition or “version” of Palliative Care should we use?
- **CMS**: Palliative care (§418.3) means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
- The goal of palliative care is to relieve suffering and provide the best possible quality of life for the resident and his or her family.
Other Definitions:

CAPC:

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

https://www.capc.org/about/palliative-care/

NHPCO:

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.

https://www.nhpco.org/palliative-care-overview/
Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

When we’re discussing “What”, we can’t forget about children!
Do all PC definitions (or bills or contracts) include pediatric palliative care?

- HR 4952 was introduced on August 6th, 2021.
- the Children’s Program of All-inclusive Coordinated Care (referred to in this Act as “ChiPACC”) provides all-inclusive care for children with life-threatening conditions and their families from the time of diagnosis and—
- (A) fills a gap in coverage under the Medicaid program of integrated, multi-disciplinary services that are reasonable and necessary for the palliation and management of seriously ill children;
- https://www.congress.gov/117/bills/hr4952/BILLS-117hr4952ih.pdf
What?
Legislative Definitions:
Federal Bill S 2565

• A model to provide community-based palliative care and care coordination for high-risk beneficiaries,
• in co-management with other providers of services and suppliers,
• aimed at improving outcomes and experience of care and reducing unnecessary or unwanted emergency department visits and hospitalizations (in this subsection referred to as the ‘model’), and
• that is intended to replace the Medicare Care Choices Model due to sunset on December 31, 2021.
• This is a co-management model with palliative care aligning with primary and specialist care for a team-based approach.
• Care must be coordinated across providers and community services for inclusion of all pain, symptom management, disease-modifying and curative treatments, and other palliative care services.
A Few Words about the Medicare Care Choices Model:

The Medicare Care Choices Model (MCCM) offers eligible Medicare beneficiaries the option to receive supportive services from participating hospices while continuing to receive treatment for their terminal condition through fee-for-service Medicare. Participating hospices receive $400 per beneficiary per month.

Beneficiary enrollment started on January 1, 2016 when the first cohort of hospices began implementing MCCM, followed by a second cohort on January 1, 2018. The model was recently extended an additional 12 months, through December 31, 2021.

84% of enrollees elected the Medicare hospice benefit after an average of 99 days in the model and 46 days prior to death.

12% died while enrolled in MCCM with access to supportive services through the model.

96% of caregivers indicated that they would definitely or probably recommend the model to friends and family members.

KEY TAKEAWAYS
Initial impact findings indicate that MCCM led to substantial reductions in total Medicare spending for deceased MCCM enrollees during the first 3 years of the model. Total Medicare expenditures decreased by 25%, generating $26 million in gross savings and $21.5 million in net savings, largely by reducing inpatient care through increased use of MHB. Most caregivers reported positive experiences in the model. Caregivers of enrollees who did not transition to MHB reported lower satisfaction rates.

* (55,967 net savings per decedent) driven by reduced inpatient spending in the last 7-180 days of life for the 3,603 MCCM enrollees who died before September 30, 2019.

This comment may be all we need to know about how CMS feels the MCCM model went...

“We are very pleased.”
Another legislative “definition”: Oregon HB 2981

- (b) “Palliative care services” includes:
  - (A) Palliative care assessment;
  - (B) Advanced care planning including a discussion regarding completing a POLST;
  - (C) Case management and care coordination provided by a registered nurse in an interdisciplinary team;
  - (D) Pain and symptom management;
  - (E) Mental health and medical social work services;
  - (F) Twenty-four-hour clinical telephone support;
  - (G) Spiritual care services; and
  - (H) Other services prescribed by the Oregon Health Authority by rule.
A Few “Caveats” about HB 2981

• It doesn’t absolutely “require” Medicaid to cover Palliative Care Services.

• It doesn’t even cover everyone who is on Medicaid, only those who are covered by a CCO.

• It leaves a lot “TBD” by rule and through negotiation with CCOs.

• From the bill:

• The authority shall administer a program to provide palliative care services through coordinated care organizations.

• A provider of palliative care services under the program and a coordinated care organization shall determine the reimbursement paid for services by mutual agreement.

We greatly appreciate the sponsorship of Representatives Nosse and Wilde and the support of Representatives Prusak, Dexter, Noble, Schouten and Senators Patterson and Gelser
The Dec. 1st update from the OHA: “I have not set any dates yet as far as meetings, RACs, and the like. I anticipate that I’ll begin to do that pretty much now (December). We’re at a nascent/early stage.”
A question: As a state, did we bunt or swinging for the fences with the PC bill in Oregon?
WA state may be swinging for the fences!

- The WA State Hospice & Palliative Care Organization has been meeting with the Office of the Insurance Commissioner and legislators to discuss sponsoring legislation which would require Medicaid **AND** private insurance to cover Palliative Care services.
- One of the compelling reasons: the lack of a concurrent care benefit for pediatric patients covered by private insurance.
What? (other examples)
California SB 1004

Palliative Care Services must include:
- Advance Care Planning
- Palliative Care Assessment and Consultation
- Plan of Care
- Palliative Care Team: *recommends* to include, but is not limited to the following team members:
  - a doctor of medicine or osteopathy (Primary Care Provider if MD or DO);
  - a registered nurse; a licensed vocational nurse or nurse practitioner (NP) (Primary Care Provider if NP);
  - and a social worker.
- Access to Chaplain services (but not reimbursed)
- Care Coordination
- Pain and Symptom Management
- Mental Health and Medical Social Services
Hawaii CBPC Medicaid Project
Required services under the benefit:

**Assessment:**
- Comprehensive interdisciplinary palliative care assessment
- Individualized care plan
- Caregiver needs assessment

**Clinical Services:**
- In-person or telemedicine visits by an interdisciplinary team
- Medication management and reconciliation
- Available 24 hours/day, 7 days a week
- Advance Care Planning Family
- Caregiver education and training

**Care Coordination:**
- Collaboration with patient, family and other providers
- Care coordination and patient navigation
- Coordination with MCOs for authorization and referral to additional services
- Education on hospice services

Where? (Where besides in an ACF, that is?)

- HB 2981: The palliative care services, as determined and provided by an interdisciplinary team, must be provided in the patient’s choice of residence. Also:

- (3) A residential care facility or a skilled nursing facility is not subject to the rules adopted by the authority under subsection (2) of this section in the provision or arrangement of palliative care services for residents of the facilities.

- S 2565: “(6) LOCATION.—Care may be furnished under the model in any beneficiary ‘home’, including a caregiver’s residence, an extended care facility, or a community setting as appropriate based on the individual’s ability to access services. The model shall include access within an in-patient stay so long as the patient begins receiving palliative care services prior to admission.
Where—and more importantly, where is PC not available?

- We know palliative care is provided in the majority of Oregon’s hospitals. (CAPC gave Oregon an “A” grade in 2019 for 24/27* hospitals w/ >50 beds having an inpatient PC program.)
  - *Note: Oregon has 60 Acute Care Hospitals.

- We know that Hospice is available in every county in Oregon—although access is challenging in some rural areas of the state.

- But there is a huge gap in coverage between inpatient care and hospice care.
When?

- The average Hospice LOS in Oregon in 2019 was 60 days, compared to the national average of 92.6 days.
- The median LOS for a Hospice patient in Oregon in 2019 was only 28 days compared to the national median of 18 days.
When?
Questions about Timing:

1. If an inpatient PC referral is needed, is it available on weekends, during evenings or only M-F, daytime hours?
2. Should a PC referral be made to prevent an inpatient stay?
3. Can a referral for PC be made from an Emergency Department or Urgent Care?
4. Or should a PC referral only be made by a Primary Care Provider?
5. Should it be made after a hospital discharge?
6. Should it be required to be considered after any inpatient stay?
When Should a Referral for PC Be Made?

- Oregon population: ~4.2-4.3 million
- How do we estimate the # of people who “need” palliative care?
- Hospice utilization in 2019: 54.5% of Medicare deaths (22,096 patients), ranking 13th in the country.
- What was Hospital utilization in 2019?
- But we know that Oregon has the lowest # of hospital beds per capita in the country: 1.65 per 1000 persons. (https://www.kff.org/other/state-indicator/beds-by-ownership/?currentTimeframe=0&selectedDistributions=total&sortModel=%7B%22colId%22:%22Total%22,%22sort%22:%22asc%22%7D)
Challenge or Roadblock: Why?

• What are the eligibility criteria for the Palliative Care you’re providing?
• Does every payer source get to decide?
• Does PC need to become a “defined” benefit under Medicare/Medicaid to promote other payers using the same “rules”?
Why: Eligibility Criteria: Disease vs. Prognosis vs.___?

2019

- Oregon HB 2981: “Loosely based” on 2019 SB 179, which required:
  - 1) A patient shall qualify for palliative care if:
    - (a) The patient has been diagnosed with a serious illness with a life limiting prognosis of 24 months or less that negatively impacts the patient’s or caregiver’s quality of life;
    - (b) Palliative care is ordered by a physician or primary health care provider; and
    - (c) The patient may be at risk for frequent emergency department visits or frequent hospitalizations.

2021

- HB 2981 Passed in the 2021 Legislative Session—the “24 months or less” language was removed:
  - The authority shall adopt by rule the eligibility requirements
    - (a) A patient qualifies for palliative care services under the program if the patient:
      - (A) Has been diagnosed with a serious illness with a life-limiting prognosis that negatively impacts the patient’s quality of life or the quality of life of the patient’s caregiver; and
      - (B) Palliative care is ordered by the patient’s physician or other primary care provider.
Why?
California SB 1004 General Eligibility Criteria:

• Members of any age are eligible to receive palliative care services if they meet all of the criteria outlined in Section I.A. below, and at least one of the four requirements outlined in Section I.B.

A. General Eligibility Criteria:
• 1. The member is likely to, or has started to, use the hospital or emergency department as a means to manage the member’s advanced disease; this refers to unanticipated decompensation and does not include elective procedures.
• 2. The member has an advanced illness, as defined in section I.B below, with appropriate documentation of continued decline in health status, and is not eligible for or declines hospice enrollment.
• 3. The member’s death within a year would not be unexpected based on clinical status.
• 4. The member has either received appropriate patient-desired medical therapy or is an individual for whom patient-desired medical therapy is no longer effective. The member is not in reversible acute decompensation.
• 5. The member and, if applicable, the family/member-designated support person, agrees to:
  • a. Attempt, as medically/clinically appropriate, in-home, residential-based, or outpatient disease management/palliative care instead of first going to the emergency department; and
  • b. Participate in Advance Care Planning discussions.

California SB 1004 Disease-Specific Eligibility Criteria: “Must meet (a) and (b)” (“or (c) alone”).

1. **Congestive Heart Failure (CHF):** Must meet (a) and (b)
   a. The member is hospitalized due to CHF as the primary diagnosis with no further invasive interventions planned or meets criteria for the New York Heart Association’s (NYHA) heart failure classification III or higher;
   b. The member has an ejection fraction of less than 30 percent for systolic failure or significant co-morbidities.

2. **Chronic Obstructive Pulmonary Disease:** Must meet (a) or (b)
   a. The member has a forced expiratory volume (FEV) of 1 less than 35 percent of predicted and a 24-hour oxygen requirement of less than three liters per minute; or
   b. The member has a 24-hour oxygen requirement of greater than or equal to three liters per minute.

3. **Advanced Cancer:** Must meet (a) and (b)
   a. The member has a stage III or IV solid organ cancer, lymphoma, or leukemia; and
   b. The member has a Karnofsky Performance Scale score less than or equal to 70 or has failure of two lines of standard of care therapy (chemotherapy or radiation therapy).

4. **Liver Disease:** Must meet (a) and (b) combined or (c) alone
   1. The member has evidence of irreversible liver damage, serum albumin less than 3.0, and international normalized ratio greater than 1.3, and
   2. The member has ascites, subacute bacterial peritonitis, hepatic encephalopathy, hepatorenal syndrome, or recurrent esophageal varices; or
   3. The member has evidence of irreversible liver damage and has a Model for End Stage Liver Disease (MELD) score greater than 19.
WHY? SB 2565*: Disease-Specific AND “other TBA”

- “(3) TARGET POPULATION. —
- “(A) IN GENERAL. The target population for the model is an individual—
  - “(i) entitled to, or enrolled for, benefits under part A of title XVIII; and
  - “(ii) with a diagnosis of a serious illness or injury, which may include a diagnosis of cancer, heart and vascular disease, pulmonary disease, human immunodeficiency virus/acquired immunodeficiency, Alzheimer’s and dementia, stroke, serious injury requiring rehabilitation including burns, kidney disease, liver disease, Amyotrophic lateral sclerosis, any neuro degenerative disease,
  - or any other serious illness or injury the Secretary determines appropriate.
- “(B) NO EXCLUSION FOR PRIOR USE OF 16 HOSPICE CARE BENEFITS. —

*https://www.congress.gov/117/bills/s2565/BILLS-117s2565is.pdf
How is Palliative Care being provided now?

By:

• Inpatient care providers;
• Primary care providers in an outpatient clinic;
• Primary care providers who make “house calls”;
• Hospice providers under the Hospice benefit;
  • Limitations: must have a six-month prognosis, must give up curative care
• Home Health providers under the HH benefit;
  • Limitations: must be homebound, must require an intermittent “skilled service”, typically for a short duration
• Private Duty home care providers or Home & Community-Based services under Medicaid?
• By any of the above providers under other funding sources;
• Are there others? Parish nurses?
How is care being covered now?

• By billing under Medicare Part A or Part B when possible;
• By billing insurance payers when possible;
• By using the service as a “loss leader” to promote another service (e.g. to increase Hospice LOS);
• Grant funding;
• Foundation funding;
• Memorial donations;
• Are there others not on this list?
Which of those funding sources are sustainable?
Could we stop dickering about the precise definition of Palliative Care?

- Could we compromise and agree on a basic premise of what should be provided and covered?
- What’s the minimum we should expect or require?
- What services must be provided and how often?
- What services should be “recommended” but not required? (E.g. “after-hours call”?)
- These discussions could all be part of the “rulemaking” process.
Let’s Decide: Challenge or Roadblock?
Challenge?

• Workforce shortages.
• Lack of PC training/certification in the workforce.
• Lack of agreement on what we want covered.
• Forgetting to include Pediatric Palliative Care.
• Lack of standardized metrics.
• Lack of **awareness**:  
  • Of what PC is.
  • Of which providers are providing it now.
  • Of what current funding options might be available & how to access them.
  • Of which patients could benefit and when to refer.
Roadblock?

- Not being a defined benefit with defined eligibility criteria and coverage
What Actions Can We Take?

• Raise awareness about PC in any way we can.
• Standardize WHAT we are asking to be covered.
• Participate in Rule-Making for HB 2981 and future legislation.
• Contact our Senators and Congressional Representatives to support:
  • More funding to support education of health care providers;
  • Palliative Care to become a defined benefit covered by Medicare and Medicaid. (e.g. SB 2565)
  • Pediatric Palliative Care legislation (e.g. HR 4952)
• Negotiate with Payers to fund Palliative Care—for everyone.
• Explore what metrics are important to payers and figure out how to capture the data.
• Educate everyone about the Palliative Care services you are already providing and what you could provide.
Questions, Comments or Suggestions?
Thank you for your attention.

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