Supporting Palliative Care Outreach in Rural Populations

December 8, 2021
Pat Justis, MA; Salom Teshale, PhD
HCBS Conference
Introduction to Palliative Care

- Speaker: Salom Teshale, Policy Associate, National Academy for State Health Policy
Background

- National Academy for State Health Policy (NASHP)
  - Non-partisan academy of and for state officials
  - 30+ year history in helping state policy leaders lead and implement innovative policies
Overview

• What is palliative care?
• Why is it important for states?
• Where are there gaps in knowledge about palliative care?
Serious illness is “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains the caregiver.”

Kelley and Bollens-Lund, 2018
What is palliative care?

- **National Consensus Project**: “a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness”

- Specialized services for people with complex or serious illness that provide symptom relief, stress relief, and support person-centered goals
  - Includes an interdisciplinary care team
  - Can be delivered across settings, including hospital settings and home-based settings
  - Can be provided through the continuum of care / in addition to curative care
Why is it important for states?

• Evidence shows that palliative care can support improved patient quality of life and is related to lowering avoidable costs
• Morrison et al., 2011: Palliative care related to savings for Medicaid enrollees with serious illness
• States can support awareness of and sharing information about palliative care
Where are there gaps in knowledge about palliative care?

- **Underserved populations:**
  - **CAPC**: 94% of large hospitals have palliative care teams; 60% of public hospitals have palliative care teams
  - Many palliative care programs are within hospitals, so communities with fewer hospitals may not have equivalent access if home-based programs are not also present
  - Access to palliative care outside hospice contexts
  - Access & uptake
State strategies to raise awareness about palliative care

• Policy levers include:
  • Support outreach to communities
State strategies to raise awareness about palliative care

• **Support outreach to communities**
  • Palliative care task forces
  • Public education information campaigns and content
States with Palliative Care Task Forces
States with Palliative Care Task Forces

New York State Palliative Care Education and Training Council

The New York State Palliative Care Education and Training Council was established by the New York State Department of Health, Section 2807-n, as of July 1, 2007. The Council consists of 14 members appointed by the Commissioner of Health, including representatives from medical schools and hospital organizations, medical academies, patient advocate groups, representatives of palliative care providers, hospital administrators, family physicians, nursing, social work, hospice, home care, pain management, geriatrics, primary care, geriatrics, and the patient (living) community. The Task Force on Palliative Care in New York State was established under the authority of Section 2807-n.

New York State Palliative Care Education and Training Council Members

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<thead>
<tr>
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Palliative Care Interdisciplinary Advisory Council

The Palliative Care Interdisciplinary Advisory Council is a subcommittee of the New York State Palliative Care Education and Training Council. The Council is composed of members from medical schools and hospital organizations, medical academies, patient advocate groups, representatives of palliative care providers, hospital administrators, family physicians, nursing, social work, hospice, home care, pain management, geriatrics, primary care, geriatrics, and the patient (living) community.

Background

In 2010, the New York State Legislature passed a bill (S.3615) creating a joint task force to study palliative care in New York State and make recommendations to the legislature. The Council was established to provide input to the task force and to ensure that the recommendations were implemented.

The Council is composed of members from medical schools and hospital organizations, medical academies, patient advocate groups, representatives of palliative care providers, hospital administrators, family physicians, nursing, social work, hospice, home care, pain management, geriatrics, primary care, geriatrics, and the patient (living) community.

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Education for Multiple Health Care Professionals

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<td>The purpose of this program is to provide education for health care professionals who work with patients and families who have advanced illnesses. The program is designed to meet the needs of health care professionals who work in a variety of settings, including hospitals, hospices, home care agencies, and specialty clinics. The program covers topics such as symptom management, communication, decision-making, and the ethics of end-of-life care. The program is offered online and is self-directed.</td>
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States with Palliative Care Public Education Webpages

[Map showing states with palliative care public education webpages]
PALLIATIVE CARE

Palliative care is an approach to care that focuses on improving the quality of life for patients and their caregivers coping with a life-threatening illness or injury. Palliative care centers on preventing, diagnosing, and treating physical, emotional, social and spiritual sources of distress. It is important to know that although hospice is a form of palliative care, palliative care is not hospice. While hospice is designed to meet the needs of patients at the end-of-life, palliative care may be given at any time during an illness or injury, from the point of diagnosis onwards.

What is Palliative Care?

Palliative Care:

- Uses the expertise of a multidisciplinary team (physicians, nurses, social workers, chaplains) to comprehensively address the needs of a patient
- Provides support to help patients live as actively as possible
- Incorporates emotional and spiritual support into patient care
- Provides a support system to help the family cope during the patient’s illness or injury
- Can be incorporated early in treatment, as well as during the end of life
- Is not prognosis or diagnosis dependent
- Is attuned to providing care that is aligned with the patient’s values and goals
States with Palliative Care Public Education Webpages

Palliative Care

If you or your loved one has a serious, potentially life-limiting condition it is important to seek out and receive palliative pronounced (pah-lee-uh-tiv) care.

Explore our other resources and pages to learn more about palliative care in Kansas.

- Program Overview
- Brochure
- Infographic
Reaching state policymakers

THE PROBLEM?

Fewer than 1 in 20 hospitalized patients who could benefit from palliative care actually receive it.

HOW can states improve access to high-quality palliative care?

- Educate patients, providers, and the public about its benefits.
- Build a workforce of trained palliative care providers.
- Create Medicaid palliative care reimbursement policies.
- Measure and track the quality of palliative care.
- Develop standards and definitions of palliative care within their state licenses and regulations.
NASHP’s Palliative Care Work

- How States Can Frame the Message and Gather Support
- Building Infrastructure and Promoting Quality
- Sustainability and Value: State Reimbursement Strategies
Thank You

Disclosure: I have no commercial relationships to disclose.

SALOM TESHALE
STESHALE@NASHP.ORG
DECREASING RURAL INEQUITIES IN ACCESS TO PALLIATIVE CARE

Pat Justis, MA, Executive Director,
Washington State Office of Rural Health
Objectives

- Describe the rural inequities in access to palliative care (PC) services
- Describe a community engagement driven model for rural and the advantages of a Learning Action Network (LAN)
- Describe how rural PC services differ from urban and suburban
- Discuss the WA model
- Offer ideas on how other states can begin to develop rural PC
Most rural hospitals in the west have 25 beds or less…

“Over the past 16 years, the percentage of hospitals (50 or more beds) with a palliative care program has tripled.”

Center for the Advancement of Palliative Care (CAPC) Accessed 10/22/2021

“Ninety percent of hospitals with palliative care are in urban areas. Only 17% of rural hospitals with 50 or more beds report palliative care programs.”

https://reportcard.capc.org/
Accessed 10/22/2021
Of the total Washington State land area: 96.4 % is rural and 3.6% is urban (2010 Census-Reviewed 2021)

11-16% of the population is rural (varies with definition used)

Four-tier Rural Urban Classification by ZIP code

Note: Geography is classified using a modified scheme, based on Census 2010, Rural Urban Commuting Area (RUMA) codes; into urban (e.g., Seattle), suburban (e.g., North Bend), large town (e.g., Oak Harbor), and small town/rural (e.g., Goldendale).
What is Palliative Care?

What came before the big bang?

What happened to the dinosaurs?

But what is palliative care?
What is palliative care?

Washington Rural Palliative Care Initiative

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.

Adapted from the Center for the Advancement of Palliative Care (CAPC) and the National Consensus Project for Quality Palliative Care
Piper Hawley, Bmed, FRPC
University of British Columbia, Head of Palliative Care Division
Palliative Care in Alignment with other Population Health Services

Community-based Supports

Care Transitions between Health Care Settings

Palliative Care

More intensive care management/support seriously ill with focus on goals of life and care, symptom management

Limited population - more focused reach, potential for immediate impact. Evidence based care standards

Care Management/High Risk Population

Team-based care focused on effective treatment of chronic disease

Process based, broad reach for those seeking services.

Population Health/Community Wellness

Broadest reach, longest timeframe to see results (but potentially biggest impact)
Formula for program development

- Community data and goals/Stakeholder input/Community-based team
- Access to national standards, intervention models, and resources
- Participation in a learning community of peers
- Structured process for development/implementation (Facilitated Community Team Planning)

= Custom-designed, community-based program

Adapted from

Stratis Health
Community capacity development theory (CCDT)

- Communities tackle problems through collective problem solving
- Change happens by enhancing existing capacities
- Approach is strength based
- Requires leadership, broad participation, learning over time

Adapted from Stratis Health
Why this approach works in rural communities

- Rural communities know their strengths and weaknesses
- Rural communities know their culture best
- Rural providers know their patients
- Rural communities can identify and tailor solutions that best fit their unique situation
What does a rural palliative care program look like?

- Wide variation in structure and focus.
- Inter-disciplinary teams sometimes multi-organization.
- Dynamic issues of capacity to manage when workforce fluctuates.
- Windshield time for home visits can be significant, for example Okanogan County is frontier, and larger than Maryland, Rhode Island and Delaware combined.
- Moving forward, telehealth will be integral.
Washington Rural Palliative Care Initiative
Objectives

- Assist rural health systems and communities to integrate palliative care in multiple settings, to better serve patients with serious illness in rural communities.
- Decrease transfers to urban tertiary services.
- Move upstream to serve patients with serious illness earlier in their experience of illness.
- Develop funding models for sustainable services
Washington State Rural Palliative Care Initiative

- Centers of Excellence in Rural Palliative Care
- Community engagement
- Clinical skills and culture change
- Telehealth case consults
- Direct to patient clinical telemedicine
- Fiscal sustainability
Learning Action Network (LAN)

- Learning and Action Networks are designed as an ongoing cohort dedicated to deep shared learning about a specific concept.
- LANs provide a forum for bringing together healthcare teams, and other supportive partners around an evidence-based agenda to achieve wide-scale improvement.
- **Peer to peer learning and support**
Community Engagement

- Identify champions
- Coaching on how to start and the development path
- Community Asset and Gap Analysis
- Community Action Plan—more than healthcare
- Tools for public and clinical team education
Clinical skills and culture change

Ariadne labs serious illness care

Cambia Center for Excellence in Palliative Care-University of WA

VitalTalk
Levels of expertise in palliative care

- Direct telemedicine to patient and family in clinical and home settings
- Case consultation via telehealth
- Build skills and services in rural community

Clinical complexity and level of expertise in palliative care
Disparities beget disparities

- Broadband and satellite coverage gaps in rural areas accentuate rural inequities in access.
- Covid-19 instigated WA Department of Commerce to build out 300 new hotspots.
Lessons learned

- Serious Illness communication skills training creates confidence.
- Close collaboration with the member organization(s) for hospice, and home health is critical.
- Highly likely that eligible patients will outstrip capacity-start small, very small.
Lessons learned

- Early adopters might be the people who have too many top priorities for transformation.
- Disruption from leadership turnover can jeopardize or stall fledgling services.
- Telehealth case consults are of large value to our cohort teams.
- Clinical telemedicine direct to patients is here to stay; but different than we envisioned.
PALLIATIVE CARE ROAD MAP
A GUIDE for living with serious illness and conditions for patients and those who care for them
PALLIATIVE CARE ROAD MAP
QUESTIONS YOU MAY HAVE ALONG THE WAY

When healthy: At any age
- Why do I need to think about this when I am healthy?
- What would I want if I become seriously ill or injured?
- What is the difference between a living will and an advance directive?

Worried about symptoms
- When should I see a healthcare provider and what questions do I need to ask?
- Where can I get more information about my specific symptom and treatment options?
- What do I need to consider if I become seriously ill?

Diagnosis
- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

Early in the journey
- What can I expect now?
- How do I set priorities?
- How will I manage my daily life, including employment, family, etc., now and in the future?

Changes: When the illness or health condition worsens
- What will happen to me in the future?
- Who will provide the help I might need?
- Is my healthcare agent prepared to follow my wishes if I become unable to speak for myself?

Recovery and survivorship
- How do I live with the threat of my illness or condition coming back and what will happen if it does return?
- How do I live with the after-effects of treatment and the trauma I’ve experienced?
- Will the old me ever be back?

End of life, dying, and death
- How will I know I am nearing the end of my life?
- What are my ideas about a good death?
- How can I make sure my wishes about the end of my life are expressed and followed?
DIAGNOSIS

You may be wondering
- What does my diagnosis mean and what can I expect?
- What decisions do I need to make?
- Where can I get more information and support?
- What do I tell other people? How should I tell them?

What to expect
- You may not fully understand what your condition means. You might feel embarrassed about things that are confusing and be reluctant to ask questions.
- You are likely to experience many different emotions.
- You may wonder about the future, what will happen next, how the illness will progress, and what will be in your control to influence.
- You may realize your needs are no longer met by a member of your present healthcare team. It can be hard to make a change in your care team, but can make a large difference in trust and well-being.

What you can do
- Gather information and ask questions. You may want a second opinion.
- You can decide how much privacy is important to you and who will have access to what information. Decide who needs to be with you to hear news and help make significant decisions. Consider which family and friends can be “real” with you and offer a sense of ease.
- Know you don’t have to do it alone. Put together a team and a list of specific actions where you will allow others to help you, for example rides to appointments, walking a dog, researching resources, or picking up prescriptions.
- You have the right to understand the risks and benefits of treatment including non-traditional or complementary approaches. You also have the right to understand the risks and benefits of not choosing a particular treatment.

“Life is choices and they are relentless.”
— Atul Gawande
To download the PDF or order printed copies at no charge:

https://www.doh.wa.gov/forpublichealthandhealthcareproviders/ruralhealth

OR

https://waportal.org/partners/home/washington-rural-palliative-care-initiative
Getting started in your state: rural palliative care

- Environmental scan-statewide
- Bring together an advisory team; palliative care experts, rural health leaders, telehealth experts, medical schools, nursing programs
- Build a model to support developmental work for rural healthcare systems and communities
- Learning Action Network is an effective method
- Integrate QI rapid cycle improvement
- Take the long view
Two rural initiatives

Minnesota-Stratis Health - over 20 rural communities offering palliative care

Washington Rural Palliative Care Initiative
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