

Creating a Rural  
Palliative Care Network  
*Forging the Future of Palliative Care*  
*2018 Summit*

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# Disclosures

I have no financial disclosures

# Objectives

- Describe the opportunities and challenges in developing palliative care in rural communities
- Identify approaches to developing a rural palliative care network
- Describe initial steps in creating or expanding a network

# Outline

1. Review challenges we face in caring for people with serious illness, especially in rural communities
2. Discuss the role of networks: success factors and impact on palliative care
3. View examples of palliative care networks
4. Identify opportunities and challenges for you

# Dave and Mary Johnson

- Are an 84 year old couple, married 50 years, live in small Alabama town, adult children live in California. Dave has afib, COPD, DM, and worsening heart failure. Mary has metastatic colon cancer with worsening pain, but her overall quality of life is good.
- The primary care physician asks “what services do we have to help support this couple? I would not be surprised if either died within the next two years.”

# Group Discussion

- Planning a palliative care program?
- Palliative care program in place in your community?
- What are 2 challenges that you face today?

# Palliative care is:

- Specialized medical care for people with serious illness
- Focused on relieving symptoms, pain, stress
- Is appropriate at any age and at any stage, together with curative treatment
- Goal is to improve quality of life for pt/family
- Is provided by a team of physicians, nurses and other specialists who work with the patient's other doctors to provide an *extra layer of support*

Center to Advance Palliative Care (CAPC)

# Pillars of Palliative Care

- Pain and symptom management
- Psychosocial and spiritual support  
(patient and family)
- Information and support to make decisions  
that reflect goals and values
- Continuity of the care plan



# Who does palliative care help?

- People with chronic diseases ( heart, lung, brain)  
→75% of US deaths
- Perinatal and pediatric patients
- Addresses gaps: Medicare and our systems of care are targeted to acute care/episodic care, not the needs of children and adults with chronic illness
- 46 million Americans live in rural areas with higher incidence of cancer, stroke, heart disease, chronic respiratory

# Vision: quality palliative care programs

- Care consistent across disease course
- All settings: hospital, long term care, community-at home, clinics where patients/families need access
- Integration with health care system (not separate)
- Meet or exceed quality standards

# Our environment: Forces at play

- Aging of population
- Economic and racial disparities
- Cost of health care continues to grow
- Health care funding is changing: value based
- Technology and innovation
- Patient centered care is goal

# Theoretical Framework: 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

Kelley (2007)

# Positive Rural Attributes

- Commitment to people in our communities
- Experience in designing solutions to problems
- Wear many hats
- Know resources: people, organizations, culture
- Other:

# What is a Rural Health Network?

- 3 or more rural health providers or other stakeholders that join forces to address mutually agreed-upon needs in the community
- Members may include health care providers, nonprofits, government, public health, educational providers and other organizations

# Group discussion

- Experience in being part of a network?
- What did you gain? What worked well/not so well?

# Successful Networks: Characteristics

- Effective Leadership
- Cross organizational and professional boundaries
- Complement services and resources
- Creative and collaborative
- Willing to engage in mutual problem solving



# Successful Networks: Processes

- Common agenda/purpose
- Shared management
- Mutually reinforcing activities
- Continuous communication
- Backbone organization

# Types of networks

- Local: support a clinical program
- Regional: support multiple programs, clinicians and community resources
  - Learn through shared commitment to well defined goal
  - All members have valuable insights and experience to contribute

# Group Discussion

- How might a rural palliative care network help you?
- What ideas do you have for building a network?

# Examples of Palliative Care Networks

- Palliative Care Network
- Wisconsin PC Now
- Minnesota: Rural Palliative Care Initiative and State organization

# Palliative Care Network

- International organization
- Founded 11 years ago
- Grass roots
- Uses technology to link clinicians across the globe
- [Palliativecarenetwork.com](http://Palliativecarenetwork.com)

# Wisconsin PC Now

- Mission statement
  - To support the growth of palliative care services in Wisconsin through education, systems change, and advocacy.
- Goals
  - Advance the care of Wisconsin patients and families through the growth of generalist and specialist palliative care services in all health care settings.
  - Advance the knowledge and skills of all health professionals providing care for seriously ill patients.
  - Advocate for improved palliative care services through changes in health care policy, regulations and legislation.

# MN Rural Palliative Care Initiative: Scope of the Problem

- 30 % of Minnesotans live in rural communities
- 41 % are over age 65, and percentage will increase to over 50 % by 2030
- The greatest incidence of serious, chronic illness is found in this age group
- Over a fourth of Medicare spending is incurred in the last year of life

Minnesota Department of Administration

# The Story of the Minnesota Rural Palliative Care Initiative (MRPCI)

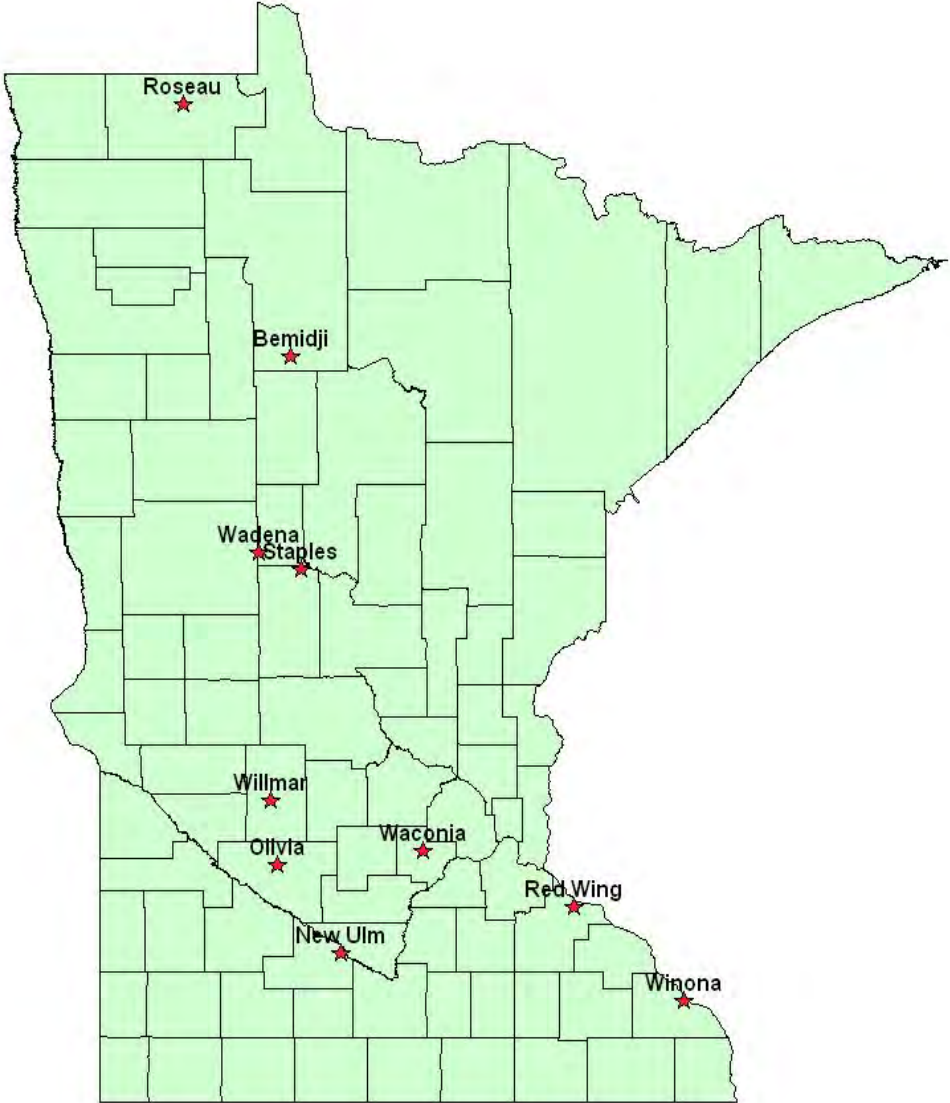
- Interest among our palliative care program, rural health, Foundation, and Quality Organization (Stratis Health) → Advisory Group
- Strong interest among rural health care providers to provide palliative care in their communities
- Availability of National Consensus Guidelines, National Quality Forum Preferred Practices
- Awareness that Palliative Care is needed by many Minnesota residents, many of whom are older adults and live in greater Minnesota



# The Minnesota Rural Palliative Care Initiative

- Partnership between a palliative care program and Quality Improvement organization
- Built on relationships between individuals and agencies in rural MN communities
- Key success factors:
  - Having something of value to contribute
  - Access to practical tools and resources from others
  - Infrastructure to support ongoing networking

# Participating Minnesota Communities



# Quality in Community-based Palliative Care Programs in Minnesota

## **MN Palliative Care Program Essential Components:**

- Interdisciplinary Team
- Assessment and management of symptoms
- Provider and care team expertise
- Process in place for patient and family centered ACP
- Care is accessible
- Education about prognosis, treatment options, goals and care planning

# Success Factors and MN Rural

- Common agenda/purpose
- Shared management
- Mutually reinforcing activities
- Continuous communication
- Backbone organization
- Desire to bring palliative care to our communities
- Everyone has a voice
- Calls, emails, conferences, website
- Communication predictable and scheduled
- Lead organization with partner in palliative care

# What Worked Well

- Built on existing relationships and commitment among team members
- Built community among teams with in person sessions → ongoing collaboration and learning
- Website, technical assistance and mentoring
- Guiding small tests of change to realistic goals
- Action plans and measures/outcomes
- Acknowledgement of progress

# Challenges

- Interest and need for education in clinical skills; desire for specialist clinicians
- Lack of a model to reimburse new services
- Financial challenges in communities
- Rural environment: distances, family caregiver availability, lack of mental health specialists
- Working across organizations
- Varying group project skills
- Hope for a comprehensive palliative care program
- Variable training in advance care planning

# Mn Network for Hospice and Palliative Care

- Palliative Care Directory : *Compare*  
Information submitted by programs:
  - contact information
  - population served
  - sites where services are provided
  - kinds of clinicians
  - information on symptom management and team interaction
  - how patients and families are involved
  - community involvement
  - advance care planning

# Where do we start?



# First Step: Needs Assessment

- Identify gap between current and needed palliative care resources
- Describe how network could help
- Confirms motivation for building a network
- Describes priorities of stakeholders to guide network development

# Stakeholders

- Who are they?
- What is important to them?
- What do they care about?
- Can we demonstrate outcomes of interest?

# Step Two: Finding a Leader or Convener

- Quality organization
- Regional Palliative Care Program
  - Expertise in developing, growing and sustaining palliative care programs
  - Clinical and educational expertise
  - Research and Quality Improvement opportunities
- State hospice, aging, chronic illness organization
- Partnerships

# Step Three: Decide Network Focus and Structure

- Who-what-where; stratify needs
- Develop structure and processes
- Determine education, resources
- Elicit members and partnerships

# Develop Work Plan to include:

- Description of Project Aim and Purpose
- Objectives
- Target audience
- Activities
- Measures of success
- Due date/completed date
- Accountable individuals and groups

# Practical Matters

- Who will:
  - Set up time and place, determine technology
  - Develop agenda
  - Communicate meeting information
  - Facilitate meeting
  - Record and communicate conversation
  - Identify follow up items, communicate and monitor

# Practical Matters

- How will we:
  - Invite new members
  - Set ground rules
  - Communicate with one another
  - Make decisions
  - Promote successes and celebrate

# Examples of ways to network or what to share

- Policies, order sets, algorithms
- Templates and systems to communicate care plan across settings
- Examples ways to identify patients
- Marketing materials and strategies
- Payment options: existing codes, contracts with payers
- Mutual acknowledgement of achievements and encouragement



# Recommendations

- Conduct a Needs Assessment and set metrics early
- Define team roles and communication processes
- Encourage review of community resources
  - Extend use of Hospice volunteers
  - Senior services for caregiving, parish nurses
- Promote “High impact” processes:
  - Eliciting and communicating goals of care
  - Focus on transitions of care
    - Consistent medication order sets
    - Clinician to clinician handoff

# BUILDING A PALLIATIVE CARE PROGRAM

## What is Palliative Care?

### Palliative Care

is an approach that improves the quality of life for patients and their families facing life-threatening illness. This is achieved through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms. Problems with the physical, psychosocial and spiritual realms are also addressed.



### Palliative Care benefits:

- Improved Quality of Life
- Better Pain Control
- Whole-Person Care
- Help Deal with Grief
- Continuum of Care
- Improved Management of Symptom
- Comprehensive
- Resources
- Meets Individual Needs
- Manage Emotional Stress
- Person-to-Person Relationships
- Inform/Teach

### Goal:

“Improve Outcomes For  
Patients With Advanced Illness  
And Their families.”

A **multi-disciplinary team** will be establishing a formal program for persons with chronic and/or debilitating illnesses in our community.

## Components of Palliative Care:

- Pain Management
- Other Symptom Management
- Social Assessment - Financial
- Anticipation of Potential Problems
- Spiritual Assessment
- Physical Assessment
- Psychological Assessment
- Referral Process
- Supportive Care/Aggressive Therapy
- Include Families/Caregiver Support
- Volunteers



**Team Members:** Tri-County Community Health Services (Home Health Care), Tri-County Hospital, Sebeka Medical Clinic, Henning Medical Clinic, Ottortail Area Medical Clinic, Bertha Medical Clinic, Wadena Medical Center, Fair Oaks Lodge, Wadena County Social Services, Immanuel Lutheran Church (pastor & parish nurse), Caring Hands Home Care, Inc.

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# Let's Brainstorm

What would we like a palliative care network to look like here?

# Sustainability for You

- Resiliency, the ability to adapt to and recover from stress
- Self care is a key aspect for you and for your programs
- Consider the role of a network in supporting sustainability
- Build this in

# We Are Better Together:

- “We’ve connected with other communities and collaborated together to provided the best care for our patients.”
- “ The initiative helped us stay focused. It’s been a great help. I don’t think we would be where we are without it.”

*“Start where you are.  
Use what you have.  
Do what you can.”*

*- Arthur Ashe*



# Additional Resources

- <https://www.ruralhealthinfo.org/topics/hospice-and-palliative-care>
- <http://www.stratishealth.org/expertise/longterm/palliative.html>
- [www.culturecareconnection.org](http://www.culturecareconnection.org): online resource and learning center to improve culturally competent care

# Organizations

- State wide coalitions and organizations
- Center to Advance Palliative Care: CAPC
- National Palliative Care Research Center: NPCRC
- National Hospice and Palliative Care Organization: NHPCO
- National Comprehensive Cancer Network: NCCN
- Presence in related organizations: Aging, Pediatrics, Alzheimer's, trauma, other



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