Palliative Care Beyond the Hospital and Clinic
2016 North Dakota Cancer Coalition Annual Conference

By
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Objectives
• Distinguish three basic elements of palliative care that can be utilized outside the hospital setting.
• Identify three challenges to palliative care away from urban care settings.
• Describe two palliative approaches currently used in rural settings

Have You Ever Heard...
• My doctor doesn’t listen to me
• No one seems to care about my pain and issues
• I wish there was someone who would not see me as a disease
• The doctor said there is nothing more he can do, now what?
• I don’t want to have to travel just to get care
• What are my all of my options?
• Am I going to die?
What Is Palliative Care?

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

~World Health Organization (WHO)

What Is Palliative Care? (continued)

“Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis— an extra layer of support. The goal is to improve quality of life for both the patient and the family.”

~Center to Advance Palliative Care (CAPC)

Palliative Care is a Bridge
Palliative Care...
- Relieves pain and suffering
- Ensures the best possible quality of life
- May be provided with curative treatments
- Promotes excellent communication - patient goals
  - Addresses benefits and burdens of treatment
  - Addresses the changing goals of care
  - Discusses when to begin or discontinue treatments
- Care for the whole person
- Support for family and other staff
- Provides a team approach to care

Physical
Functional Ability
Strength/Fatigue
Sleep & Rest
Nausea
Appetite
Constipation
Pain

Psychological
Anxiety
Depression
Enjoyment/Leisure
Pain Distress
Happiness
Fear
Cognition/Attention

Social
Financial Burden
Caregiver Burden
Roles and Relationships
Affect/sexual function
Appearance

Spiritual
Hope
Suffering
Meaning of Pain
Religiosity
Transcendence

Adapted from Ferrell, et al. 1991

Palliative Care Versus Hospice
HOSPICE
- Patient considered “terminal” with less than 6 months to live
- Patient/family chooses NOT to receive aggressive, curative care
- Focuses on “care” versus “cure”
- Expenses are covered by Medicare, Medicaid, and most private health insurers

PALLIATIVE CARE
- Ideally begins at the time of diagnosis of a serious illness
- No life expectancy requirement
- Can be used to complement curative care
- Expenses are covered by philanthropy, fee-for-service, direct hospital support
- For pediatric patients, care is provided through mandates from the Affordable Care Act
Case Study: Mary

Mary is a 36-year-old mother of four young children, diagnosed with stage 4 colon cancer 6 months ago. She is experiencing nausea/vomiting, fatigue, weight loss, and anxiety associated with her chemotherapy. Her husband, Matt, has his own business – if he misses work, he does not get paid. No family in the area to assist with child care or visits to the cancer center during her chemotherapy.

Spiritually, she wonders if God is punishing her.

Palliative Care for Mary & Her Family

- Provide interdisciplinary care to address and manage symptoms (nausea/vomiting, fatigue, weight loss, anxiety)
- Address goals of care
- Provide attention to the children through use of a child life specialist (if available, in a center)
- Have social worker address financial and childcare concerns
- Chaplain visit to discuss her concern that God may be “punishing” her
- All members of the team would meet frequently to discuss on-going care for Monica and her family

Cost Benefits of Palliative Care

According to data from a 2011 study, for those who received palliative care:

- There was a savings of $1696 in direct costs per admission ($279/day), compared with usual care (for those who were discharged from the hospital)
- There was a savings of $4908 in direct costs per admission ($374 a day), compared with usual care (for patients who died in the hospital)
- WHY THESE LOWER COSTS?
  - Fewer laboratory/diagnostic tests and medications were ordered, less intensive care admissions

* Physician and APRN visits usually are billed to insurance. Other ancillary services are a part of program.

(Morrison et al., 2011, Smith, 2014)
Palliative Care Statistics

- Half of caregivers of Americans hospitalized with a serious illness report less than optimal care (CAPC & NPCRC, 2014).
- Studies have shown that 24% of health care costs can be attributed to persons living with long-term, serious illnesses (CAPC & NPCRC, 2015).
- West & East North Central Report Card
  - A grade: Minnesota, Nebraska, South Dakota, Wisconsin
  - B grade: Iowa, Missouri, North Dakota, Illinois
  - C grade: Kansas

Institute of Medicine (2014)

Health care delivery organizations should take the following steps to provide comprehensive care:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community).
- Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed (including geriatricians).
- Depending on local resources, access to this team may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise.

National Palliative Care Registry

Eligibility Requirements

Palliative care programs are eligible to participate if they meet the following criteria:

1. The palliative care program is part of a formally organized and legally constituted entity that primarily provides health care services, or a sub-unit of a legally constituted entity that may be, but need not be, health related.
2. The palliative care program has been providing palliative care services for at least three months.
3. The palliative care program provides care to patients at one or more locations within the broad continuum of care settings (e.g., hospital, home, office, long-term, hospice, nursing home).
4. The palliative care program representative(s) act in good faith in providing complete and accurate information to the Registry.

(Registry, 2016)


15 (of 54) ND Counties with Palliative in Hospitals (by County) Palliative Care Registry (2011)

1. Adams County: West River Regional Medical Center
2. Barnes County: Sacred Heart Hospital
3. Burleigh County: Medcenter One
4. Cass County: Innovis Health
5. Dickey County: Oakes Community Hospital
6. Grand Forks County: Altru Health System
7. Grant County: Jacobson Memorial Hospital Care Center
8. McIntosh County: Ashley Medical Center
9. Pembina County: Pembina County Memorial Hospital and Wedgewood Manor
10. Pierce County: Heart of America Medical Center
11. Stark County: St. Joseph’s Hospital and Health Center
12. Stutsman County: Jamestown Hospital
13. Traill County: Sanford Medical Center
14. Wells County: St. Aloysius Medical Center
15. Williams County: Mercy Medical Center

Current ND Cities with Reported Palliative Care Programs (CAPC, 2016)

1. Ashley- Ashley Medical Center
2. Belcourt- Public Health Service Indian Hospital - Quentin N. Burdick Memorial Health Facility
3. Bismarck- Sanford Bismarck
4. Cavalier- Pembina County Memorial Hospital and Wedgewood Manor
5. Dickinson- St. Joseph’s Hospital and Health Center
6. Fargo (3)- Sanford Medical Center Fargo, Essentia Health Fargo, Fargo Veterans Affairs Health Care System
7. Grand Forks- Altru Health System
8. Harvey- St. Aloysius Medical Center
9. Hettinger- West River Regional Medical Center
10. Hillsboro- Sanford Hillsboro Medical Center
11. Jamestown- Jamestown Regional Medical Center
12. Mayville- Sanford Mayville Medical Center
13. Valley City- Mercy Hospital
14. Wishek- Wishek Community Hospital and Clinics
Palliative Certified Physicians in ND

Beulah
- Aaron Garman, MD
Bismarck
- Laura Archuleta, MD
- Suresh Joishy, MB
Grand Forks
- Kevin Panico, MD
- Laura Lizakowski, MD
- Ngozi Nwakamma-Okoro, MD
Minot
- Kevin Collins, MD
- Robert Durkin, DO
- Kristina Schlecht, MD
Fargo
- Neville Alberto, MD
- Mark Gitau, MD
- Weimin Hao, MD
- Darko Hauer, MD
- Tricia Langlois, MD
- John Leitch, MD
- Mohammed Sanaullah, MD
- Preston Steen, MD
- Rajendra Potluri, MD
- Shelby Terstriep, MD

Hospice and Palliative Credentialing Center (HPCC)

Advanced Certified Hospice and Palliative Nurse (ACHPN) - 4
- Michelle Conley (Fargo/Grand Forks)
- Susan Harris (Lamoure)
- Nancy Joyner (Grand Forks)
- Rachel Salberg (Grand Forks)
Certified Hospice and Palliative Nurse (CHPN) - 27
Certified Hospice and Palliative Licensed Nurse (CHPLN) - 2
Certified Hospice and Palliative Nursing Assistance (CHPNA) - 3
Certified Hospice and Palliative Pediatric Nurse - 0
Certified Hospice and Palliative Care Administrator - 0
Certified in Perinatal Loss - 0

Other Palliative Care Certifications

- Social Worker (CHP-SW)
  National Association of Social Workers
  http://www.socialworkers.org/credentials/credentials/achp.asp
- Chaplain Certified Hospice and Palliative-Board of Chaplaincy Certification Inc (BCCI), an affiliate of the Association of Professional Chaplains (APC)
  Hospice & Palliative Care Specialty Certification
  http://bcci.professionalchaplains.org/content.asp?contentid=45
Institute of Medicine (2014)

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Current Models of Palliative Care Delivery (Smith et al, 2006, Morrison, 2013)

• Hospice (since 1974)
• Hospital based palliative care (1990s)
  – interdisciplinary consultation teams
  – inpatient units
Newer Models (2000s)
• Ambulatory consultation clinics
• Interdisciplinary home care
• Palliative care teams -managed care plans
• Hospital-based teams with physician home visits

Problem #1

The focus of palliative care delivery has been on developing inpatient palliative care units and services in academic, tertiary care medical centers.

Question: Could offering palliative care upstream influence decision making and result in fewer patient entering the hospital at the end of life?
Rural Palliative Care: What’s Different

Case Study:
- Helen Johnson is an 83 year old married lady who is Norwegian and Lutheran. She is admitted to a local critical access hospital with recurrent ovarian cancer, ascites, and dyspnea.
- She is transferred to the “academic center” - 90 miles away
- Gyn-Onc recommends chemo. Helen has limited English language skills/ accepts treatment (because the doctor offered it)
- Family unable to visit
- Helen dies alone in the hospital from neutropenic fever and sepsis

Critical Access Hospital Criteria

- Must be rural, located within a state participating in the Medicare Rural Hospital Flexibility program
- Must be more than a 35-mile drive from any other hospital or CAH (or, in the case of mountainous terrains or in areas where only secondary roads are available, more than 15 miles from any other hospital are CAH)
- Must have 15 or fewer acute inpatient care beds (or, in the case of swing bed facilities, up to 25 inpatient beds which can be used interchangeably for acute of SNF-level care, provided no more than 15 beds are used at any one time for acute care) as reported on the cost report
  (CAH Legislative History website)

Critical Access Hospital Criteria (cont.)

- Must restrict patient length of stay to no more than 96 hours unless a longer period is required because of inclement weather or other emergency conditions, or a physician review organization (PRO) or other equivalent entity, on request, waives the 96-hour restriction
- Must offer 24-hour emergency services
- Must be owned by a public or nonprofit entity
- If a hospital does not meet the above conditions, it may be designated by other state criteria as a critical access hospital
  (CAH Legislative History website)
Scope of the Problem- Defining Rural

Rural Urban Community Areas Classification

Rurality is defined by:
- Population sparsity (low density) and
- Remoteness (distance between a given area and the nearest urban center.
- Nonmetro counties include some combination of:
  - Open countryside
  - Isolated small rural town (places with fewer than 2,500 people)
  - Urban areas with populations ranging from 2,500 to 49,999 (large rural 10,000-49,999, small rural 2,500-9,999)
  - Metropolitan (population 50,000 or greater)

Rural Palliative Care Challenges

- Service gaps
- Cost of services in relation to the population
- Sustainability
- Difficulty in demonstrating improvements in outcomes
- Geographic isolation
- Nature of palliative health care services
- Nature of rural relationships
- Competencies required for rural palliative care.
### Variability in Access to Palliative Care and Hospice

- Less access to palliative care services
- Greater need—disproportionately ill, disabled, poor, and older, range of chronic conditions
- Dissemination of advances/Education
- Interventions

### Other Barriers

- Understanding of palliative care vs. hospice
- Multiple stakeholders
- Financial constraints
- Different settings and disciplines
- Lack of prior experience working
- Relationships among the participating organizations

### Staffing Needs

- Training rural health care professionals
- Community EMS
- Community representatives
- Community–academic partnerships
- Innovative with telehealth and community lay navigators
Volunteers - Extend the Reach of Palliative Care

- Parish Nurses
- Community lay representatives “navigators”
  - Non-healthcare professions
  - Established members of the community they serve
  - Recruit those who are “natural helpers” - “who in the community would you expect to have helpful guidance if…”
  - Retired school teachers, cancer survivors, people who have some medical exposure (e.g., worked at the desk of a local doctors office)

Navigator Role

- Empowers the patients to:
  - Identify and connect with resources
  - Communicate desires and goals
  - Recognize clinical symptoms
  - Understand disease and treatment
  - Engage in end-of-life discussions with their providers
  - Take an active role in their healthcare

(Bakitas et al, 2009, Bakitas et al, 2013)

Navigator Role (cont.)

- Eliminates Barriers
  - Links patients with resources to get to appointments
  - Connects patients to providers to address symptoms
  - Coordinates care between multiple providers
- Ensure Timely Delivery of Care
  - Helps patients navigate the healthcare system
  - Assists with access to care

(Bakitas et al, 2009, Bakitas et al, 2013)
Navigator Training

- 5 days face to face training and team building sessions
- Ongoing training in person and webinars
- Content included training on:
  - Conceptual Model for program/Multilevel Interventional Model
  - Core Concepts of: Health, Health Promotion and Empowerment
  - Navigation History
  - Navigator role and responsibilities
  - Boundaries
  - Genetic basics
  - Cancer basics
  - Advanced cancer
  - Multi-morbidities
  - Symptom burden (pain, fatigue, etc.)
  - Communication Skills

- Health Literacy
- Advance care planning
- Documentation/Tool usage

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Navigator Activities

- Keeping patients out of the ER
  - Proactive identification of symptom issues
  - Point of contact to guide resource utilization
    (e.g., patient with anxiety having a panic attack)
- Providing continuity
  - Inpatients with changing teams
  - Hospice patients providing feedback to primary provider
- Assisting with access (e.g., transitioning from a surgical team/unit to medical oncology)

(Bakitas et al, 2009, Bakitas et al, 2013)
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<tr>
<th>Technology</th>
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<tbody>
<tr>
<td>• Tele-health</td>
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<tr>
<td>• Telemedicine</td>
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<td>• Telementoring</td>
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<tr>
<td>• Community–academic partnerships, and training rural health care professionals</td>
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<th>Why Telehealth / Telephone Intervention?</th>
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<td>• Increases the rate of Healthcare Directives</td>
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<td>• Improves clinician/patient communication about EOL care</td>
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<td>• Increases rate of deaths at home</td>
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<td>• Increases hospice involvement and LOS</td>
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(Bakitas et al, 2009, Bakitas et al, 2013)

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<th>Telehealth Challenges in Rural Areas</th>
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<tr>
<td>• Patient No Shows</td>
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<tr>
<td>• Hearing Issues- not good with phone</td>
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<td>• Literacy</td>
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<td>• Low attendance at phone “groups”</td>
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<td>• Limited cell service, cell phone charges</td>
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<td>• Limited internet connections</td>
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Project ECHO®

Project ECHO® has 70 hubs worldwide
48 in the United States
22 in 11 additional countries
covering more than 45 complex conditions.

Project ECHO® is

Extension- to build strength and capacity of an underserved community with shared interest
(We work with greater confidence when supported)
Community Healthcare-local knowledge with expert support= potent combination, strength
Outcomes- Monitor progress/effectiveness – impact on staff and patient’s knowledge

(Max Watson, MD, Northern Ireland Hospice)

Project ECHO® Model

Extension of Community Healthcare Outcomes
• ‘Democratizes’ specialist knowledge
• Tele ‘mentoring’ (multi-point) vs telemedicine
• Hub (experts)- links to Spokes (generalists-primary providers, nurses, etc.)
• Uses PANG (Palliative Adult Network Guidelines – UK)
• Case-based learning
• Educational focus vs clinical focus
• Uses IT to monitor quality improvements

(Max Watson, MD, Northern Ireland Hospice)
“Force Multiplier”

• Videoconferencing with telementoring
• Building expertise exponentially
• Mind center of collaboration
• Defines Community practice- it takes a village
• Increases medical knowledge
• Use “educational governance”

(Max Watson, MD, Northern Ireland Hospice)

What is Your Plan?

To integrate palliative care into current services,
• Utilize local palliative care specialists
  – Educational sessions
  – Send patients to them
  – Have them come to facility
• Utilize local trained ACP facilitators
• Train/utilize navigators or community representatives
• Enlist volunteers - Partners
• Telehealth with palliative care providers

Conclusion

• Numerous elements of palliative care can be utilized outside the hospital setting.
• Although there are challenges to palliative care away from urban care settings, they can be overcome.
• What palliative approaches will you use?
Final Thoughts

National Healthcare Decisions Day 2016 Theme
"It Always Seems Too Early, Until It’s Too Late."

“We work with greater confidence when supported.
We work with greater confidence when we do not feel isolated.”

(Watson, M. 2016)

References

• Bakitas, M. & Kvale, E. (2013). Enhancing Access to Rural Palliative Care Presentation (used with permission of the Center to Advance Palliative Care, Diane E. Meier, MD, Director).
• CAH Legislative History website, Retrieved http://www.aha.org/advocacy-issues/cah/history.shtml

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For More Information

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