PRIMARY PALLIATIVE CARE
EVERYONE’S RESPONSIBILITY

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OBJECTIVES

1. Define primary palliative care
2. Describe benefits and challenges of palliative care in rural settings
3. Compare aspects of palliative care that a non-specialist can perform
WHAT IS PALLIATIVE CARE

Palliative (Latin): To Cloak or Cover, to alleviate,
“to reduce the violence of”
“An approach which improves the quality of life of patients and families facing 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, psychological, and spiritual.”

(www.who.int/en)
PALLIATIVE CARE (CONT.)

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.

*(www.who.int/en)*
CHARACTERISTICS OF PALLIATIVE CARE PHILOSOPHY AND DELIVERY

- Interdisciplinary care
- Excellent communication between patients, families, health care providers
- Services provided concurrently with or independent of curative/life-prolonging care
- Hopes for peace and dignity are supported throughout the course of illness and pre-post dying process

(ELNEC, 2017)
EIGHT DOMAINS OF PALLIATIVE CARE

1. Structure and process of care
2. Physical aspects of care
3. Social aspects of care
4. Psychological aspects of care
5. Spiritual aspects of care
6. Cultural aspects of care
7. Care of the patient at end of life
8. Ethical and legal aspects of care

National Consensus Project Clinical Practice Guidelines PDF
HOSPICE

• Palliative care is not the same as hospice.
• Hospice cares for people with a six month prognosis (if the disease follows it’s expected course).
• Usually delivered at home; also delivered in facilities.
• Medicare benefit, other insurances mirror the Medicare structure.
What is Primary Palliative Care?

PRIMARY PALLIATIVE CARE

• Essential palliative care services
• Deliver high-quality primary palliative care to all patients
• Integrated in routine medical care
• Improve symptom burden, quality of life, and patient & caregiver satisfaction
SKILL SETS FOR PRIMARY & SPECIALTY PALLIATIVE CARE

Primary
• Basic management of pain & symptoms
• Basic management of depression & anxiety
• Basic discussions about prognosis, goals of treatment, suffering, code status

Specialty
• Management of refractory pain or other symptoms
• Management of complex depression, anxiety, grief, existential distress
• Assistance with conflict resolution regarding goal or methods of treatment within families, between staff & families, among treatment teams
• Assistance in address cares of near futility, non-beneficial

 MODELS OF INTEGRATION FOR PRIMARY PALLIATIVE CARE DELIVERY

1. Time-based model- based on chronological criterion
2. Provider-based (palli-centric) model which discusses primary, secondary and tertiary palliative care
3. Issue-based (onco-centric) model which illustrates the advantages and disadvantages of the solo practice, congress and integrated care approaches
4. System-based (patient-centric) model which emphasizes automatic referral based on clinical event
EXAMPLES OF PALLIATIVE CARE PROGRAMS

• Hospitals
• Palliative care clinics
• Palliative care home programs
• Nursing homes
• Community-centric programs

TOP PALLIATIVE SKILLS FOR PRIMARY PALLIATIVE CARE

1. Assessment and Management Pain & Symptoms - nausea, vomiting, dyspnea, anxiety, impaired sleep, xerostomia
2. Communication, Goals of Care Planning and Shared Decision Making
3. Advance Care Planning
4. Appropriate Palliative Care and Hospice Referral
5. Care at the End-of-Life
6. Caregiver support
7. Care Coordination/Continuity of Care
#1- TO COMFORT ALWAYS

- Pain and Symptom Assessment and Management
- Relieve distress and suffering
- 2nd Domain- National Consensus Project (Eight Domains of Palliative Care)
- Quality of Life Factors
- Intensity
- How do they affect the person’s ability to function
- Resources:
  - National Comprehensive Cancer Network (NCCN) Guidelines
  - HPNA E-Learning and Position Statements
  - MNHPC resources

#2 IMPORTANT CONVERSATIONS

- Preparation
- Skills
- Information requested versus information known
- Risks, Benefits, Burdens and Expected Outcomes
- Hope versus Truth Telling
- Disease Trajectories
PROGNOSIS, TREATMENT OPTIONS AND IMPLICATIONS OF TREATMENT

- Explore available treatments
- Benefits vs burdens, expected outcomes
- Emergency interventions
- Code status discussions
- Goals of Care Planning
- Facilitating Family Meetings

(CHF, 2015)
MAINTAINING HOPE AND TRUTH TELLING

- Balance between maintaining hope and truth telling
- Hope may change
- Ask "What are your hopes for the future?"
- Discuss upcoming events they wish to participate in – a wedding, birth, trip, etc.- options of plan A and B based on health.
- Encourage the patient to make short, medium, and long range goals with an understanding that the course of terminal illness is always unpredictable.
- Support the patient in recognizing and grieving their possible losses.
- Utilize “I wish…” statements – “I wish there was more we could do for your disease but what if time may be getting short?

(Warm & Weissman, 2015, Guila, 2017)
ADVANCE CARE PLANNING - MORE THAN A FORM

- Advance Care Planning
  - Life Long Process
  - Discussion
    - Patient’s understanding - diagnosis, prognosis
    - Patient’s values, goals, preferences
    - Patient’s options
- Documentation
  - Healthcare Directives - agent, living will
  - Code Level – inpatient/out of hospital
  - POLST Care Continuum Toolkit: www.polst.org/toolkit

THE PROCESS

- A facilitated, on-going process
- A patient-directed document
- Physician orders that translates patients wishes into medical orders
IDENTIFYING PEOPLE APPROPRIATE FOR PALLIATIVE CARE

• You would not be surprised if patient died within year or two
• >1 or 2 admissions in several months
• Symptom complexity
• Decline in function, i.e., failure to thrive
• Advanced disease: met cancer, chronic home oxygen use; NH + fall

IDENTIFYING PEOPLE APPROPRIATE FOR PALLIATIVE CARE (CONT)

• Advanced illness + no advance directive
• Admission to hospital from hospice
• Complex care requirements
• Limited social support in setting of serious illness
#4 INTRODUCING PALLIATIVE CARE AND HOSPICE TO PATIENTS & FAMILIES

• Getpalliativecare.org

• Hospice conversations → Hospice Enrollment

#5 CARE AT THE END OF LIFE (DOMAIN #7 NATIONAL CONSENSUS PROJECT)

• Signs and symptoms of impending death are recognized and communicated

• As patients decline, team introduces or reintroduces hospice

• Signs/symptoms of approaching death are developmentally, age, and culturally appropriate
PREPARING FOR A GOOD DEATH

• The important role of the team
• Hydration?
• Resuscitation?
• Hasten death request?
• Palliative sedation?

TWO ROADS TO DEATH

NORMAL

THE USUAL ROAD

SLEEPY
Lethargic
Restless
Confused
Tremulous
Hallucinations
Seizures
Mumbling Delirium
Myoclonic Jerks
Semicomatose
Comatose
Obtunded

DEAD

THE DIFFICULT ROAD

ELNEC, 2017
#6 CARE FOR THE CAREGIVER

*Study of 475 family members 1-2 years after bereavement*

- Loved one’s wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to

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WHAT MATTERS MOST?

- Defining their own goals for care
- Focus on quality or quantity?
- Encouraging family & patient to say important things - the last one
- Spiritual Care is extremely important
- Life review, telling stories, and giving permission to laugh
- Giving the patient found meaning in the life that is ending?
- Leaving a legacy
- Reconciliation
- Who’s missing from the picture?
- Important phone calls
- Final wishes (video, [Parent’s Wish](https://www.youtube.com/watch?v=WishOnYouTube))

*(David, D., 2010)*
#7 CARE COORDINATION / CONTINUITY OF CARE

- Goals of Care Discussions
- The Bridge Philosophy
- The Patient Advocate
- The Third arm of a triangle
- Choices of Opt in/Opt Out- Explore all options
- Time Limited Trial
BENEFITS (AND CHALLENGES) OF PRIMARY PALLIATIVE CARE IN RURAL SETTINGS

PALLIATIVE CARE STATISTICS

- Half of caregivers of Americans hospitalized with a serious illness report less than optimal care.
- 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

(CAPC & NPCRC, 2014, 2015)
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.

VARIABILITY IN ACCESS TO PALLIATIVE CARE AND HOSPICE

• Less access to palliative care services.
• Greater need:
  • Disproportionately ill
  • Disabled
  • Poor
  • Older
  • Range of chronic conditions
• Dissemination of advances/education
• Interventions
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
  - Geriatric basics
  - Cancer basics
  - Advanced cancer
  - Multi-morbidities
  - Symptom burden (pain, fatigue, etc.)
  - Communication Skills
  - Health Literacy
  - Advance care planning
  - Documentation/tool usage
NAVIGATOR ACTIVITIES
• Keep 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)
• Provide continuity
  • Inpatients with changing teams
  • Hospice patients- providing feedback to primary provider
• Assist with access
  (e.g., transitioning) from a surgical team/unit to medical oncology

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

Patient Satisfaction

Overall how satisfied are you with the PCC Navigation Program?

- Very satisfied: 57%
- Satisfied: 25%
- Neither satisfied nor dissatisfied: 9%
- Dissatisfied: 2%
- Not satisfied: 1%
- Not satisfied at all: 2%

N=286 surveys

82% Satisfied or Very Satisfied
TECHNOLOGY

- Tele-health
- Telemedicine
- Tele “mentoring”
- Community–academic partnerships, and training rural health care professionals

WHY TELEHEALTH / TELEPHONE INTERVENTION?

- Increases the rate of Healthcare Directives
- Improves clinician/patient communication about EOL care
- Increases rate of deaths at home
- Increases hospice involvement and LOS

(Bakitas et al, 2009, Bakitas et al, 2013)
TELEHEALTH CHALLENGES IN RURAL AREAS

- Patient No Shows
- Hearing Issues- not good with phone
- Literacy
- Low attendance at phone “groups”
- Limited cell service, cell phone charges
- Limited internet connections

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.
MINNESOTA RURAL PALLIATIVE CARE INITIATIVE (MRPCI)

• To assist communities to establish or strengthen palliative care in rural Minnesota.
• Structure, accountability, customized guidance, tools, and networking across settings
• Support offered through educational learning, conferences and networking
• Healthcare reform and community model

(Ceronsky et al, 2013, McKinley et al, 2016)

MINNESOTA RURAL PALLIATIVE CARE INITIATIVE (MRPCI)

• Representation from organizations across settings of care in their communities
• Combining community capacity theory with a learning collaborative model
  • Transferable knowledge, skills, systems, and resources that affect change on the community & individual levels
• Interdisciplinary team approach

(Ceronsky et al, 2013, McKinley et al, 2016)
MRPCI NOW

• >150 organizations serving communities with populations of 1,200 to 200,000 represented

• Hospitals, home care organizations, hospice programs, long-term care facilities, clinics, assisted living facilities, a college department of nursing, parish nurses, clergy and public health agencies.

• Community self-assessments shared

• 15 new rural palliative care programs created

(McKinley et al, 2016)

MRPCI FINDINGS

• Enhances patient outcomes

• Enhances patient/family satisfaction

• Reduces costs—win-win for value-based care delivery

• Utilization of available resources

• National Quality Forum-endorsed measures

(McKinley et al, 2016)
PROJECT ECHO
(ROBERT WOOD JOHNSON FOUNDATION)

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

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)
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)

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**Figure 2:** Graphic and visual conceptual framework used with permission from Kent Unruh and Project ECHO.
"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)
NYT article: http://opinionator.blogs.nytimes.com/2014/06/11/the-doctor-will-stream-to-you-now/

- ECHO as a Performance Optimizer: A great short video (1.5 minutes) to explain the ECHO model and build
  TEDxABQ: Project ECHO – Changing the World, FAST http://www.youtube.com/watch?v=Y5niixac0g&list= 
- Project ECHO: Spreading Access to Specialty Healthcare http://www.youtube.com/watch?v=2l8fyOhI4_s
- ECHO website: http://echo.unm.edu/


Education Department NI Hospice, (028 90781836)
http://www.nihospicecare.com/newsstory/PROJECT_ECHO_NORTHERN_IRLAND_HOSPICE

www.nihospice.org

PALLIATIVE CARE IN ND

North Dakota Palliative Care Task Force
https://ruralhealth.und.edu/projects/nd-palliative-care-task-force

North Dakota Rural Community-Based Palliative Care
https://ruralhealth.und.edu/projects/community-palliative-care
CONCLUSIONS

• Primary palliative care is everyone’s responsibility.
• There are numerous aspects of palliative care that a non-specialist can perform.
• Benefits can outweigh challenges of palliative care in rural settings with unique individual plans.

FOR MORE INFORMATION

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CAH Legislative History website, Retrieved http://www.aha.org/advocacy-issues/ah/-history.shtml

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• Watson, M (2016). Northern Ireland Project ECHO presentation February 26, 2016, with permission from Dr. Max Watson, Northern Ireland Hospice, Barb Groutt ND Quality Health Associates and Jerry Jurena, ND Hospital Association.

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MNHPC Rural Palliative Care website.
