

Palliative Care: Thinking Beyond the Advance Directive

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Objectives

1. Provide information to enhance quality of life at the end of life
2. Describe differences between palliative care and hospice
3. Discuss the importance of community in quality end of life care

Why Such a Focus on Palliative Care?

- A number of events:
 - Patient's Self-Determination Act
 - Advance Directives
 - Cruzan case, the Supreme Court's affirmed the constitutional right to refuse life-sustaining medical treatment
 - SUPPORT Study 1995
 - Physician-Assisted Suicide

Advance Directives

- Instructional
 - Oregon health decisions
 - The “Five Wishes” document
 - Person to make health care decisions
 - Medical treatment wanted or not wanted
 - The degree of comfort wanted
 - How to be physically and emotionally supported
 - What loved ones should know
 - Living will
- Proxy directives
 - Durable power of attorney for health care
 - Designate another person
- POLST
 - Physician authority

AD and QOL

- 1,553 bereaved family members
 - 70.8% of the decedents had completed an AD
 - Used less LST (11.8% vs 22.0%)
 - Were on a respirator (25.6% vs 36.7%)
 - Used a feeding tube (17.3% vs 26.8%)
 - 25% unmet need in pain control
 - 50% inadequate emotional support for the dying person
 - 33% inadequate family emotional support

The SUPPORT Study

- The experience of dying in 5 tertiary care teaching hospitals
- Controlled trial to improve care of seriously ill patients
- 9000 patients with life threatening illness, 50% died within 6 months of entry

The SUPPORT Study

- 46% of DNR orders were written within 2 days of death.
- Of patients preferring DNR, <50% of their MDs were aware of their wishes.
- 38% of those who died spent >10 days in ICU.
- Half of patients had moderate-severe pain >50% of last 3 days of life.

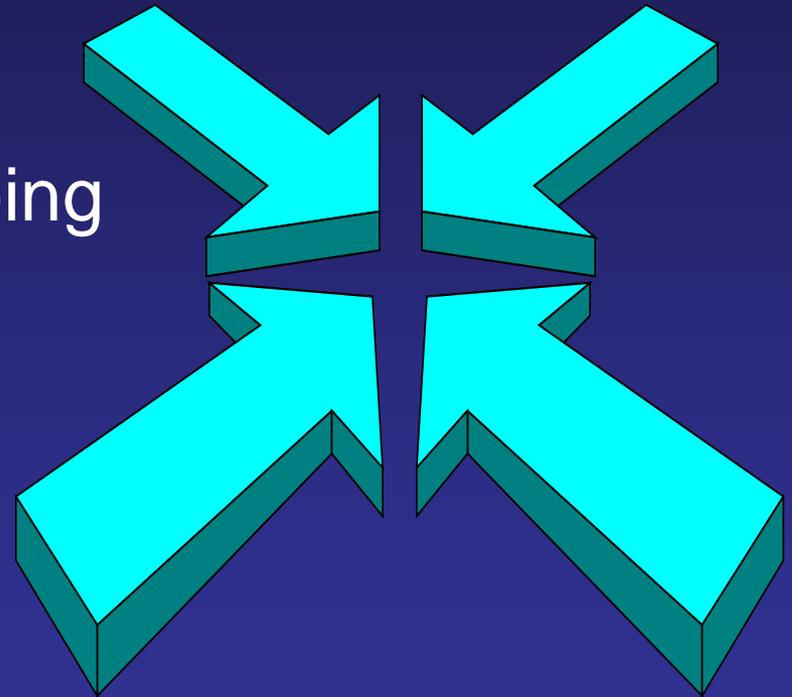
Palliative Care: Definition

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, and other symptoms, and of physiological, social and psychological problems, is paramount. The goal is achievement of the best quality of life for patients and their families. Many aspects are applicable earlier in the course of the illness in conjunction with active treatment.”

(WHO

Model of Quality of Life

Physical Well-Being
Psychological Well-Being
Social Well-Being
Spiritual Well-Being



(Ferrell et al., 1991)

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

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

Quality of Life

Social
Financial Burden
Caregiver Burden
Roles and Relationships
Affection/Sexual Function
Appearance

Spiritual
Hope
Suffering
Meaning of Pain
Religiosity
Transcendence

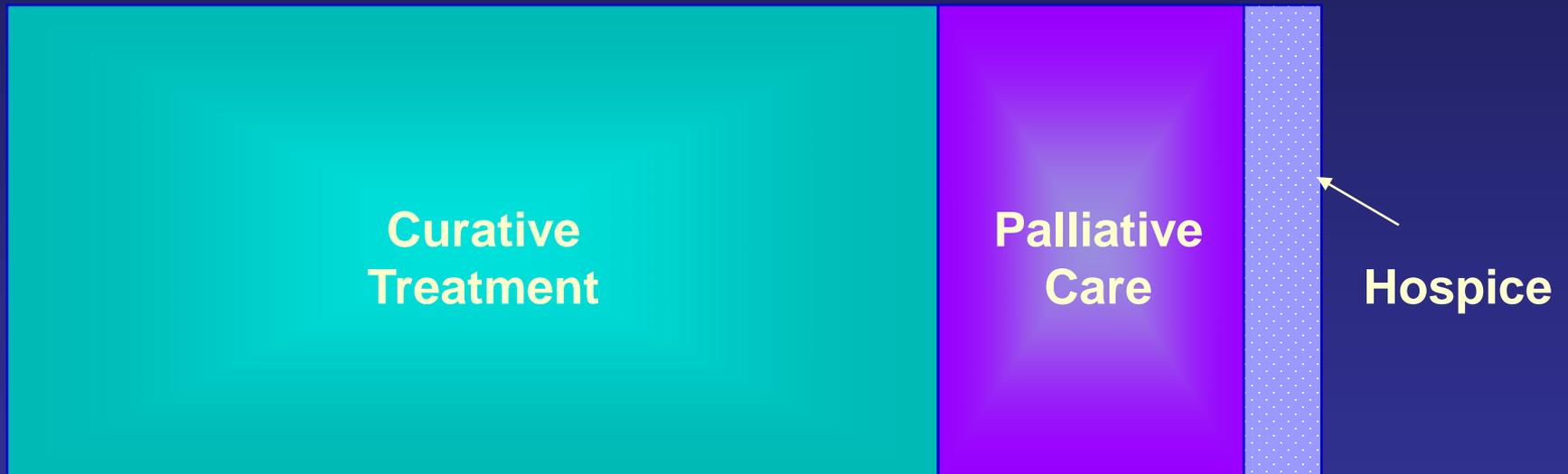
Palliative Care

Interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families. It is offered simultaneously with all other appropriate medical treatment.

Palliative Care:



Current Practice of Hospice and Palliative Care



Palliative Care for Advanced Disease

- Respect patient autonomy, values and decisions
- Continually clarify goals of care
- Minimize symptoms at EOL
- Delivery of appropriate supportive interventions and consultations
- Reduce unnecessary interventions

Palliative Care for Advanced Disease

- Support families by increased coordination of services
- Provide bereavement support to families and staff
- Facilitate transition to alternative care settings such as hospice, foster care, LTC when appropriate

Barriers to Quality Palliative Care

Realities of Life Limiting Diseases

- Failure to acknowledge the limits of medicine
- Inappropriate use of aggressive curative treatment
- Difficulties with prognostication
- **Delayed access to hospice and palliative care services**
- **Lack of adequate professional training**
 - Little attention in end-of-life medical or nursing curriculum

What Do Patients with Serious Illnesses Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

What Do Family Caregivers Want?

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
- Privacy
- To be remembered and contacted after the death

Models of Palliative Care

- Interdisciplinary team
- Integrated team
 - RN case management work with
 - Social workers, chaplains, hospitalists
 - Entire staff education 8 hours
- Single MD
 - As a consultant, not a team
- Advance practice nurse, NP
 - Palliative care coordinator

Palliative Care Positive Outcomes

- Improves health care quality
 - Pain and symptom management
 - Emotional and spiritual support
 - Communication
 - Patient and family satisfaction
- Save hospitals \$ (reduced cost per hospital day; \$183)
- Shorter ICU lengths of stay

Palliative Care in Rural Areas

What do we know

– Formal care refers to health care services delivered by paid providers

- Specialized palliative care and home care are especially limited in rural areas
- Most rural areas have substantially fewer hospice providers
- The more rural the family, the more limited and inadequate the formal resources
- The longer the dying trajectory of a person, the more inadequate the resources = greater the family caregiver burden

(Buehler and Lee, 1992; Congdon & Magilvy, 2001; Hunt & McCaul, 2001; Madigan et al., 2009; Wilson and colleagues, 2006)

Palliative Care in Rural Areas

What do we know

- Informal care is provided by unpaid family members, friends, or volunteers
 - Built on rural strength and reciprocity
 - Effectiveness of informal care in rural communities may be a product of community willingness to help

A Few Facts

- Nationally, chronic disease is identified as the primary cause of death for 92% of dying people over age 65
- People over age 75 are reported to have, on average, three chronic health problems
- 69% of people receiving home health care services are aged 65 and older
- Many rural elders
 - do not anticipate they will experience chronic illnesses,
 - do not plan for long-term care, and
 - tend to remain in their homes until a crisis occurs
- Individuals are self-reliant in outlook

Study

End-of-Life Care for Rural-Dwelling Older Adults and their Primary Family Caregivers

Juliana C. Cartwright & Carol E. Craig
(co-investigators)

Rural, Agricultural County

- While 13.5% is aged 65 or older in the state, 16.4% are over age 65 in this county
- The state average death rate is 8.4 per 1,000 versus 10.8 per 1,000 in this county
- In the state 14.3% of the residents are below the federal poverty level, compared to 20.2% in this county
- 13.4% of the residents had no health insurance

Sample

- 23 primary caregivers:
 - Gender: Female = 16; Male = 7
 - Ages: \bar{X} = 60; range = 30 - 94 years
 - White: 96%
 - Relationship to the decedent was:
 - 36% of them were spouses or partners,
 - 56% an adult child,
 - 8% other including grand-daughters and daughter-in-laws.
 - Mean length of providing care: 28.36 months (range: 0.5 - 120 months).

Sample

- 23 decedents:
 - Gender: Female = 10; Male = 13
 - Ages: \bar{X} = 81.2; range = 65 - 97 years
 - Cause of death:
 - Cancer 12
 - Heart disease/failure 5
 - Failure to thrive 4
 - Alzheimer's disease 1
 - Lung disease 1

Analysis

- Qualitative description was conducted using constant comparative analysis of the family caregiver's experiences with formal and informal care provided while the decedent was dying.
 - 2 major themes and 9 subthemes:
 - Benefits to the end-of-life care experiences
 - Challenges focusing on limitations in resources

Findings: Benefits

Benefits to the end-of-life care experience included:

Formal care

1. Primary family caregivers sometimes personally knew the formal care providers.
2. Flexibility in organizational support

Informal Care

1. Family members provided a range of support.
2. Church members provided many types of support;
3. Neighbors and friends, seeing what needed to be done, often pitched in with chores.

Findings: Benefits

Neighbors and friends, seeing what needed to be done, often pitched in with chores:

- One new widow who lived alone talked about how her neighbors were willing to lend a hand.

“And the neighbors have been wonderful and still are. We have a young couple that lives across the street. He’s just incredible. ‘How’s your wood supply? You need more wood?’ (laughter). It’s marvelous. That’s the joy of this small town because everybody takes care of everybody else. And it’s really great.”

Findings: Benefits

Flexibility in organizational support:

- One family lived 45 miles out of town.

“Hospice was so good, I’m telling you... they would call me and say, does your grandma need anything today? I’d want a shampoo, to shampoo her hair without having to bath her like S (family member) was coming from T.(another state) and she wanted to be cleaned up. And they bought that in A (the town 45 miles away) and just brought me the receipt so it was taken care of... That’s how...anything I needed they were there.”

Findings: Challenges

Challenges to the end-of-life care experience included:

Formal care

1. Service boundaries lead to limited hours or availability of some formal services.
2. Lack of qualified caregivers.
3. Lack of continuity of care.

Informal care

1. Family caregiver stress.

Findings: Challenges

Service boundaries lead to limited hours or availability of some formal services:

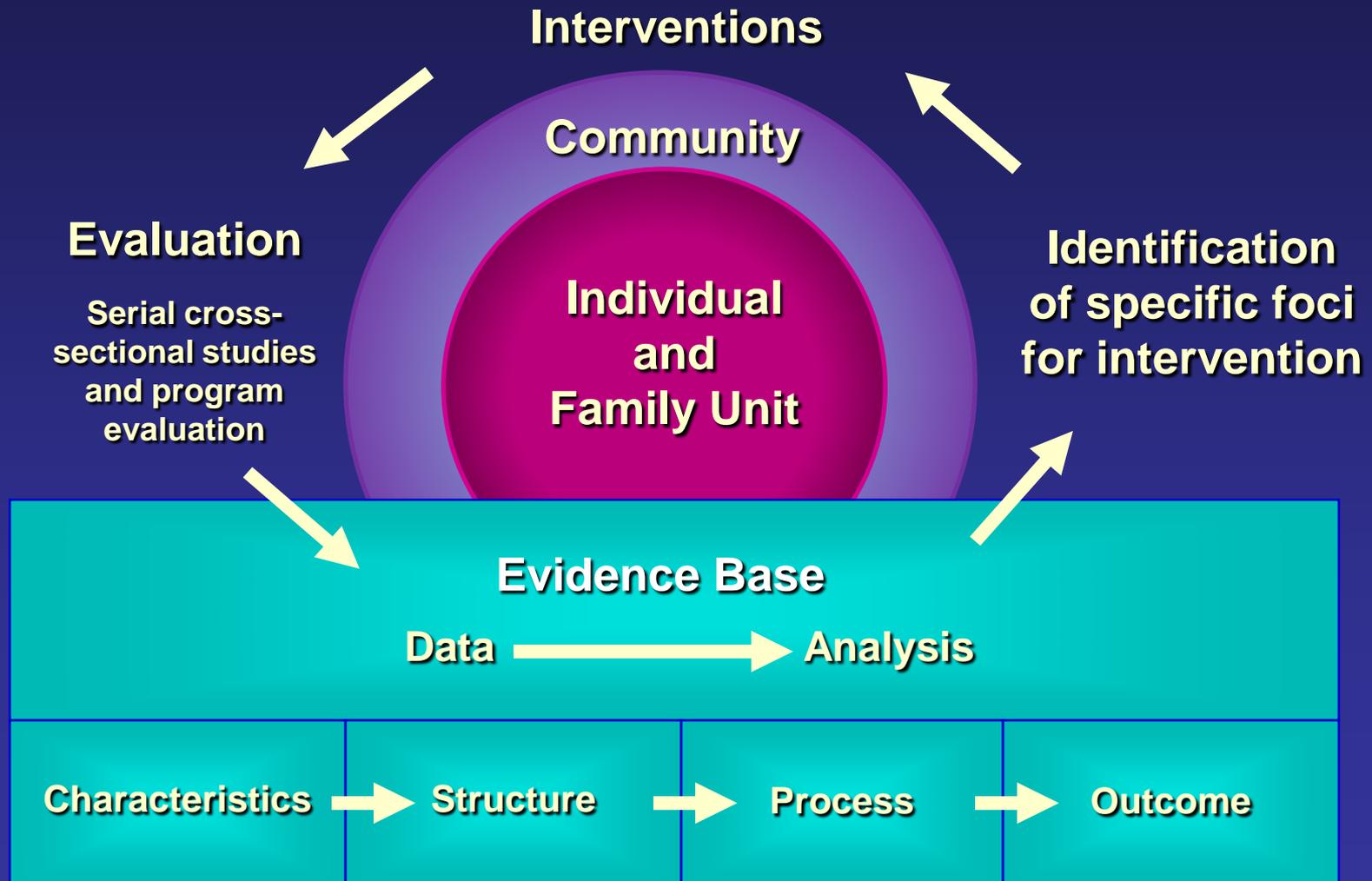
- One family needed medication at home on a Sunday, which proved to be impossible. *“...the nurses told me that in this whole town there is not a pharmacy open on a Sunday. If they need any meds they have to go to the hospital and see if they have it.”*

Findings: Challenges

Family caregiver stresses:

- An example was a 90-year-old woman within two weeks of her death with intractable pain who was not given adequate morphine because “*she might get addicted*”.

Conceptual Framework



Two Dimensions

- Individual-focused dimension:
 - involves the dying individual, his or her family including primary caregiver, and social network
- The community-focused dimension:
 - involves the collective experience and expectations of the whole community on improving quality of life for dying people and their families

Community-Focused Dimension

- Nursing homes
- Assisted living facilities
- Foster care
- Hospice
- Long term care providers
- Home care nurses

Last Place of Care

- Survey of family members of 1578 decedents
- 1059 died in an institution
 - 487 in nursing homes; 592 in hospitals
- 519 died at home
 - 256 had home hospice
- Results:
 - About 25% did not receive adequate pain or dyspnea treatment
 - About 25% reported concern with physician communication
 - > 33% vs 20% reported insufficient emotional support
 - Respect: NH 68.2%, hospital 79.6%, HH 96.2%

Nursing Homes

- By 2040 40 to 50% of all deaths will occur in LTC
- Detecting problems vs acknowledging good care
 - State and federal regulations
- Sociocultural environment of nursing homes
 - Residents
 - Vulnerable with complex chronic health problems
 - Length of stay
 - Dying trajectory of fragility; 60% diagnosis of a stroke or a hip fracture; 50-60% of all deaths are residents with dementia
 - Physician visits (“missing in action”)
 - Staff
 - Nursing assistants: 32% of nursing home’s FTE employees
 - RNs: 7.6%
 - LPN 10.6%

(Wilson, 2010)

Assistant Living Facilities

- 26% of residents die in ALFs annually
- Regulated by state
- Resident assistant
 - Training, required competencies, monitoring, and continued education vary among states
- Advance care planning
- Pain and symptom management
- Plan of care

Community-Focused Study

- A convenient sample, 363 surveys
 - 50% - palliative care could be improved
 - >50% - not at all or only somewhat effective at:
 - Providing psychological support
 - Attending to spiritual needs
 - Providing grief support
 - **Barriers to initiating palliative care:**
 - Pressured by patients/families to continue treatment -87%
 - Knowing when to quit – 85%
 - Giving up too soon – 82%
 - Difficulties with communicating with families – 82%
 - Differences in training/experiences among personnel – 74%

(Van Vorst et al, 2006)

Dying in Assistant Living

- Symptom experiences = private homes
- Communication about care among care providers
- Lack knowledge of symptom management
- Monitoring inadequate

- High staff commitment to resident
- Respectful collaboration at all levels

Where Should These Conversations Take Place?

- Who owns the conversations ?

Conversations not happening

- Reluctance to initiate such discussions due to time constraints
- Lack of comfort with such discussions
- Lack of skills in such communications
- Fear of upsetting the patient and/or family even though he/she or they may wish to have the conversation
- Professional sadness and/or feeling of failure
- Do not want to take away hope

Think Outside the Box

- Hospital setting
- Community setting
- Transition
- What is current in place at you setting?
 - What works - build on that?
 - What to change?
 - Where to begin?

Administration

Administrative support is crucial

- Stakeholders
- Champignons
 - RNs, nursing assistants
- Use strength of relationships
- Residents and their families know the providers and visa versa
- Administrative procedures/guidelines:
 - Procedures in place to assess terminal status
 - Eligibility for hospice care
 - Belief about hospice

Questions:

- What is your understanding why you are here?
- What have you been told about your disease by doctors you have seen?
- What do you now find particularly challenging in your life?
- What activities or experiences are most important for you to do to maximize the quality of your life?
- What needs or services would you like to talk about?

The BATHE Technique

- Background
 - What is going on in your life?
- Affect
 - How does that make you feel?
- Troubles
 - What about it troubles you most?
- Handling & Coping
 - How are you handling that?
- Empathy
 - That must be very difficult

Quality Palliative Care

- Qualifications:
 - Communication skills
 - Competent in assessment skills
 - Up-to-date knowledge and skills related to providing treatment to alleviate symptoms such as pain, nausea, and breathlessness
 - Qualities and skills that arise from compassion, reciprocity, and professional commitment

Training of Care Providers

- Palliative Care Educational Resource Team (PERT)
 - 61 nursing assistants and 108 licensed staff
- End of Life Nursing Consortium (ELNEC)
 - American Association of Colleges of Nursing and City of Hope Medical Center
- Center to Advance Palliative Care (CAPC)
 - Palliative Care Tools, Training, & Technical Assistance

Examples

- Teaching sessions (hospice, SON)
- Workshops
- Topic on EOL for monthly family meeting
- Bereavement kits
- Palliative care screening tool for admissions
- Multiple formats for relieving pain
 - Non-pharmacological
 - Pet therapy; comfort food ...
- Staff retreat (self-care & caregiver fatigue)

Summary

- Advance directives address primarily treatments
 - E.g. emotional and spiritual support lacking
- What are the characteristics of patients and their families
- Think about what is it patients and their families want
- Palliative care encompasses 4 domains = increased quality of life
 - MDs, RNs, Nursing assistants, Chaplains, SW
- Cost

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- *As sickness progresses toward death, measures to minimize suffering should be intensified. Dying patients may require palliative care of an intensity that rivals that of curative effort. Even though aggressive curative techniques are no longer indicated, professionals and families are still called on to use intensive measures – extreme responsibility, extraordinary sensitivity, and heroic compassion.*

Thank You

Questions?

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