

Palliative Care in Rural Communities: Social Workers and Spiritual Providers

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Overview

- Case Story
- Palliative Care – General Information
- Assessment
- Intervention Areas
- Resources
- Questions/Discussion

Case Study

- “Dorothy” - 84 year old, Caucasian, female
- Lifelong resident – western MN, rural community, 2,000 (approx) residents.
- She and her husband were farmers for 50+ years on their land before moving to town.
- Raised six children, had grand and great grandchildren.

Case Study

- Her husband died about 2 years after moving to town from leukemia, did not remarry.
- She was active in her local Lutheran congregation, which she attended from birth.
- Socially very active and connected.
- Knitted and gave slippers and afghans to relatives.

Case Study

- Experienced two strokes at age 83. Acute hospitalization in Sioux Falls, SD.
- Her six children urgently arrived to be at her bedside and a family conference was held.
- She had a health care directive.
- She was offered a potentially aggressive surgical intervention that would have led to a longer hospital stay possibly involving being vented, sedated in the ICU, then long rehab.

Case Study

- Unable to communicate with family due to her deficits including an inability to speak. She also had lost much capacity on her right side.
- Family disagreed on how to proceed.
- Surgery was declined by her health care proxy (daughter) based upon her interpreted, stated desires in her health care directive.

Case Study

- Once stabilized she was transported to her town's nursing home.
- She was not enrolled in hospice, but the decision was made to not pursue aggressive care for her disease.
- She lived for about another year and died surrounded by her family.

Hallmarks of Palliative Care

- Holistic view
- Transdisciplinary
- Symptom management
- Goals of care

Building Interdisciplinary Care in Rural Settings

- Using community resources
 - Pastors, chaplains, lay pastoral volunteers
 - Parish nurses
 - Social Workers in various settings

Rural Communities

- Potentially “broad base” of support
- Community centered
- Informal, often rapid transmission of information

Cautions

- Cannot “fix” serious mental illness in patient/family and/or entrenched family dysfunction
- We all operate from our own frame of reference
- Self awareness is critical

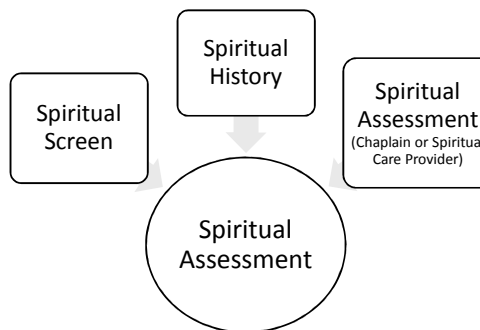
Cautions

- Confidentiality can be challenging and is important
- The “good death” doesn’t always happen
- Compost happens

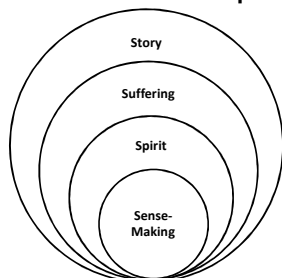
Assessment

- First step for all disciplines
- Dynamic, ongoing process

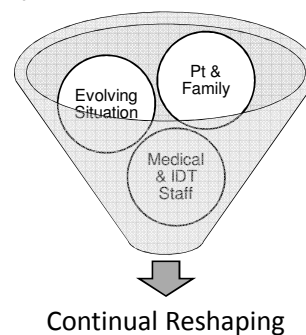
Assessment - Spiritual



Assessment - Spiritual



Story – The Medical Picture



Spirit (Consensus Definition of Spirituality, Puchalski et al, 2009)

Elements of Definition	Possible Intervention Examples
Meaning – sought & expressed	Scripture reading/exploration
Purpose – sought & expressed	Reflective conversation
Connectedness to the moment	Breath attention and awareness; "By-heart" prayers
Connectedness to the self	Nearing death ritual
Connectedness to others	Bed-side journal; after death ritual
Connectedness to nature	Ritual – Blessing of the senses
Connectedness to significant/sacred	Contemplative prayer

Psychosocial Assessment

- Social Work is holistic, strengths based
- Purpose is generally to support and strengthen within the Palliative Care context

Psychosocial Assessment

- Family
- Support System
- Financial
- Coping/Mental Health Issues
 - Clinical Depression versus Grief
- Concurrent Stressors

Psychosocial Assessment

- Symptoms
- Understanding of Disease/Progression
- Understanding of Cause of Disease
- Hope
- Spiritual

Goals of Care

- Spectrum of Interventions/Timing
- Health Care Directives
 - Educate
 - Encourage Completion
 - Encourage Discussion
- Health Care Agents

Care Conferences

- Involvement of community support people (pastor, social worker)
- Solicit from patient/family who should be there
- Value of provider preconference

Caregiver Needs

- Recognize losses for family caregivers
 - Change in roles/relationships
 - Change in how the patient is perceived by family/others
- Additional responsibilities
- Barriers to caregivers getting their own needs met

Patient and Caregiver Support

- More apparent when patient is in hospital or other facility
- Often more need for support when patient is at home
- Importance of community networks recognizing support needs
- Special needs of children

Symptom Management

- Coping (Patient/Family)
 - Support strengths
 - Refer for mental health expertise when needed (LCSW Clinical Social Worker, Psychologist)

Symptom Management

- Physical/Emotional
 - Simple Massage (Patient should be able to consent)
 - Distraction
 - Textures
 - Story Telling
 - Prayer
 - Using Family/Supportive Others

Family Dynamics/Conflict

- What's the problem?
- What's the goal?
- Pastors may have valuable knowledge.
- Social workers have skills for facilitating.

Life Legacy Work

- Creating something to pass on to others
- Can include
 - Life story
 - Lessons learned
 - Values and beliefs
 - Hopes and dreams for loved ones

Life Legacy Work

- Educate
- Provide opportunities
- Time to do this is when the person has time and energy
- Booklet availability

Bereavement Follow-up

- Assessing bereavement risk
- Death is an event. Grief is a process.
- Sudden death versus death preceded by illness.

Resources/Reference

- Resources – See separate handout
- Reference for slide # 17
 - Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P. & Bull, J. et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. J Pall Med, 2009; 12 (10): 885-904.

Questions/Discussion