

Naming, Claiming & Sustaining the Role of the Chaplain on an Interdisciplinary Palliative Care Team

Session S4
Sunday, April 6, 2008
National Association of Catholic Chaplains
2008 Conference
Indianapolis, Indiana
Ira R. Byock, MD
Linda F. Piotrowski, MTS, BCC



www.climateprotect.org

Solutions

- [Clean Energy Economy](#)
- [Personal Choices](#)
- [Adoption of Renewables](#)
- [Enhanced Energy Efficiency](#)
- [Innovative Leadership](#)

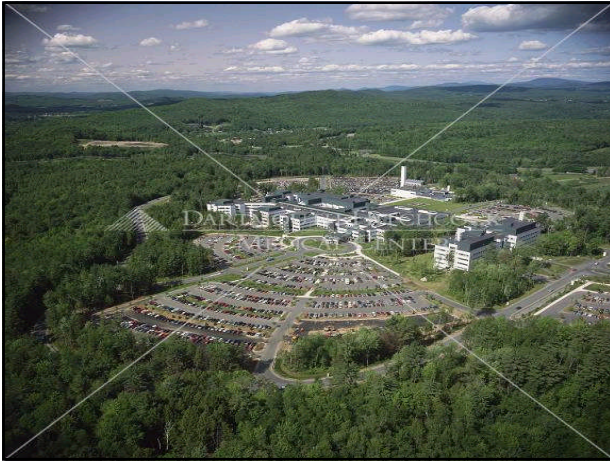
"The poor and the sick are the heart of God. In serving them we serve Jesus, the Christ."



- St. Camillus de Lellis

Session Objectives

1. Understand the role of the chaplain on an interdisciplinary palliative care team.
2. Learn about care documentation, cultural awareness, staff support, research, education, rituals and advocacy efforts.
3. Introduction to Byock's developmental stages at End of Life and MQOLI.
4. Engage in care discussion cases highlighting the role of the chaplain.



Dartmouth Hitchcock Medical Center

Is located on a 225-acre campus in the heart of the Upper Connecticut River Valley, in Lebanon, New Hampshire.

Is made up of:

- Mary Hitchcock Memorial Hospital
- The Dartmouth-Hitchcock Clinic
- Dartmouth Medical School
- Veterans Affairs Regional Medical and Office Center (White River Junction)



Mary Hitchcock Memorial Hospital (MHMH)

- Is a charitable hospital
- 396 inpatient bed/353 beds currently in operation
- Only teaching hospital in New Hampshire
- Major tertiary-care referral site for Northern New England



Spirituality

“Human spirituality arises in response to the awe-inspiring and terrifying mystery of life and the universe. We reflexively seek to make meaning of our experience in the world and make or strengthen our connections to others.”

Ira Byock, MD
American Journal of Hospice & Palliative Medicine® /
 Vol. 23, No. 6, December/January 2007



Spiritual Care

...is discovering, reverencing and tending to the spirit of another person.

-Rev. Joseph Driscoll

Palliative Care

...is an approach that improves the quality of life of patients and their families facing the problems 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.

Developed for [Cancer Pain Relief and Palliative Care, Geneva: WHO, 1990.](#)

Palliative Care

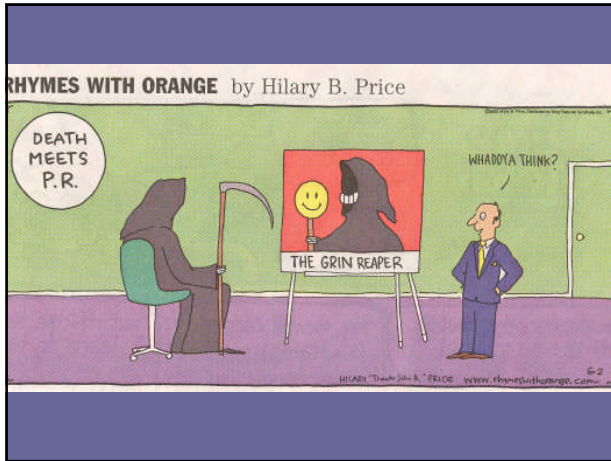
- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.

World Health Organization

Interdisciplinary Team

A team of caregivers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs. An interdisciplinary team typically includes one or more physicians, nurses, social workers / psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

Center to Advance Palliative Care
www.capc.org



Palliative Care at DHMC

...is an interdisciplinary specialty that focuses on improving comfort and quality of life for patients and families experiencing a life-threatening illness or injury.

It addresses not only physical needs, but also the spiritual, emotional, and social aspects of life for patients and their families in the DHMC community.



DHMC Palliative Care Service

- Advance Practice Nurses Palliative Care Certified (4) 3.3FTE
- Physicians (Palliative Care Board Certified) 4/2.8 FTE
- Clinical Social Worker 35% salary
- Pastoral Care Coordinator 100% grant funded
- Volunteer Coordinator 0.5 FTE
- Healing Arts Practitioner funded by nursing .5FTE
- Palliative Care Advisory Board (volunteer)
- Program Manager 1.0 FTE
- Clinical Secretary 1.5 FTE



"Those who think it cannot be done should get out of the way of those doing it."

– Chinese Proverb



DHMC Palliative Care Service

- Monday/Thursday IDT Meeting
- Tuesday/Wednesday/Friday Morning Huddle
- Weekly Palliative Care Conference-educational
- Monthly Team Support Meeting
- Monthly Business Operations Meeting
- Monthly Sectional Meeting
- Weekly Bereavement Service
- Quarterly Memorial Services
- Referrals
 - inpatient-attending physician
 - outpatient-inclusion in some clinical pathways

Spiritual Assessment

- Spiritual care professionals are trained to do assessments
- Other members of healthcare team:
 - Recognize spiritual themes, issues, resources of strength and conflicts
 - Provide environment where patients can share these concerns if the patients desire to (non-coercive)
 - Work out of personal spiritual call of service to others (compassionate presence, altruism, love)
 - Refer to appropriate spiritual care professional or resource

Clinical Practice Guidelines for Quality Palliative Care

1. Structure and Processes of Care
2. Physical aspects
3. Psychological and psychiatric aspects
4. Social aspects
5. Spiritual, religious and existential aspects
6. Cultural aspects
7. Ethical and legal aspects

National Consensus Project for Quality Palliative Care, 2004

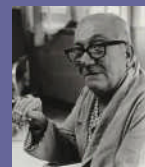
Therapeutics within a Developmental Framework



Developmental Landmarks



- *Sense of completion with worldly affairs*
 - Transfer of fiscal, legal and formal social responsibilities



Mal Warshaw collection

Developmental Landmarks

- *Sense of completion in relationships with community*

- Completing multiple social relationships
- Leave taking; the saying of goodbye

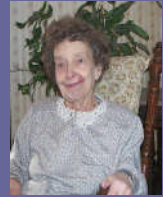


St. Paul Pioneer Press Dying Well: The miracle of death, Spring 2000

Developmental Landmarks

- *Sense of meaning about one's individual life*

- Life review
- The telling of "one's stories"



Developmental Landmarks

- *Experienced love of self*

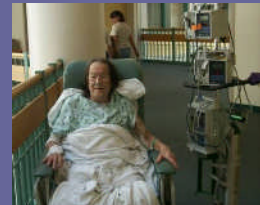
- Self-acknowledgement
- Self forgiveness



Developmental Landmarks

- *Experienced love of others*

- Acceptance of worthiness



Developmental Landmarks

- *Sense of completion in relationships with family and friends*
 - Completing (including reconciling)
 - Leave taking; the saying of goodbye



Deidre Scherer collection

Developmental Landmarks

- *Acceptance of the finality of life - of one's existence as an individual*
 - Acknowledgement of the totality of personal loss
 - Expression of the depth of personal tragedy
 - Decathexis from worldly affairs and cathexis with an enduring construct
 - Acceptance of dependency



Developmental Landmarks

- *Sense of a new self beyond personal losses*
 - developing connection to something larger and enduring than oneself.



Mal Warsaw collection

Developmental Landmarks

- *Achieving enhanced sense of meaning about life in general*
 - Achieving a sense of awe
 - Recognition of transcendent realm
 - Developing/achieving a sense of comfort with chaos



Developmental Landmarks



- *Surrender to the transcendent - "letting go"*



St. Paul Pioneer Press Spring 2000

Assessing Spiritual Well-being or Dis-ease

"Sometimes, a serious illness or injury such as this can shake people's faith in God or otherwise threaten their spiritual well-being..."



Assessing Spiritual Well-being or Dis-ease

"...at other times, people who survive a near-fatal accident or who are diagnosed with a life-threatening condition say that the experience deepened their faith and inner confidence.

Have either of these things happened for you?"



Assessing Quality of Life

Missoula – VITAS Quality of Life Index

Dimensions

Symptoms
Functional
Interpersonal
Well-Being
Transcendent

www.DyingWell.org

Missoula – VITAS Quality of Life Index

Well-Being

10. My affairs are in order; I could die today with a clear mind. - OR - My affairs are not in order; I am worried that many things are unresolved.



www.DyingWell.org

Missoula – VITAS Quality of Life Index

Well-Being

11. I am more satisfied with myself as a person now than I was before my illness.



www.DyingWell.org

Missoula – VITAS Quality of Life Index

Transcendent

13. I have a better sense of meaning in my life now than I have had in the past. - OR - I have less of a sense of meaning in my life now than I have had in the past.



www.DyingWell.org

Missoula – VITAS Quality of Life Index

Transcendent

14. Life has become more precious to me; every day is a gift. - OR - Life has lost all value for me; every day is a burden.



www.DyingWell.org

Spiritual/Religious Beliefs in the Clinical Setting

- Impacts understanding of illness
- Impacts healthcare decision-making (feeding tubes, advance directives, use of pain meds, level of alertness etc)
- Impacts who might be support or decision-maker (might be clergy or spiritual care professional)
- Impacts treatment choices (med use, CAM, prayer)
- Impacts treatment plan (chaplain referral, meditation, yoga etc)
- Impacts how patients cope and deal with illness

Puchalski, 2004

Spiritual/Religious Beliefs in End of Life Care

- Religions have theological, historical and communal understanding of suffering.
- Offer rituals to give expression to life experience, to spiritual longings.
- Offer community support and context-- give people stories by which to understand their own journey.
- Offer prayer, ritual, meditation, guidance
- Prayer and meditation is way to achieve contemplation — a place of spiritual depth, understanding, surrender

Puchalski & O'Donnell, 2005

Spirituality in the Clinical Setting

- Coping
- Developing resiliency of spirit
- Connecting to God/other
- Finding meaning, hope, love
- Becoming comfortable with mystery, unknown
- Finding social support
- Reframing death to alleviate death anxiety
- Offers a sense of control over what seems out of control

adapted from
Puchalski, 2004

Chaplains as Change Agents

- Take risks, stand up for the non-traditional path
- Navigate work culture
- Use language, definitions that are broad
- Focus on spirituality in context of clinical care
- Develop practical tools

MSOP Report III: Spirituality, Cultural Issues and End-of-Life Care

- Spirituality is recognized as a **factor that contributes to health** in many persons.
- The concept of spirituality is found in all cultures and societies.

Association of American Medical Colleges, 1999

MSOP Report III: Spirituality, Cultural Issues and End-of-Life Care

- It is expressed in an individual's search for **ultimate meaning** through participation in religion and / or belief in God, family, naturalism, rationalism, humanism and the arts.
- All these factors can influence how **patients and health care professionals perceive health and illness and how they interact with one another.**

Association of American Medical Colleges, 1999

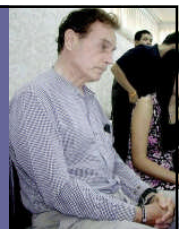
“It is our duty to prefer the service of the poor to everything else and to offer such service as quickly as possible. If a needy person requires medicine or other help during prayer time, do whatever has to be done with peace of mind. Offer the deed to God as your prayer.... Charity is certainly greater than any rule. Moreover, all rules must lead to charity.”



St.
Vincent
DePaul

Mr. J

- 52 year old Jewish, male
- Wife
- two sons 20, 14, one daughter, 12
- Pt's family lives in other states
- Initial diagnosis poorly differentiated colon adenocarcinoma in 11/05/05
- Children not told about cancer diagnosis until cancer reoccurred in 10/06/06
- Chaplain initial consult 11/06/06 outpatient
- Pt readmitted 12/05/06
- Surgery 12/8/06 – Children told on 12/11/06



Mr. J



- Two youngest children visit 12/15/06
- 1/4/07 Pt's wife tells children of end of treatment options & impending death
- 1/5/07 Eldest son visits
- 1/12/07 Pt discharged to home
- 2/1/07 Pt readmitted to hospital
- 2/2/07 Pt dies in hospital with wife & chaplain at bedside.

DHMC Documentation

Pt Name, Medical Record Number and Date of Service all automatically appear

Narrative: I received a call from pt's wife requesting a visit. Pt sitting in bed with emesis basin in hand. "Hi, Linda, I bet S called for me. They couldn't place a G tube. I really think that S needs you more than I do. I just want to get things settled and get on to do whatever is next." S sat at the bedside quietly sobbing while pt spoke to me.

Assessment: Pt appeared irritated, agitated and angry. S is very upset that the pt could not have a G tube placed. S is fearful regarding the meaning of this in relation to pt's length of life, nutritional status, etc.

DHMC Documentation

Intervention: I spoke with pt and S regarding this chink in their plans. Pt was angry with his S's dismay over the inability to place the G tube. I provided pastoral presence and supportive counseling. At pt's request I took S from the room and met with her privately. S hovers over pt which angers him. I encouraged S to give pt some space by going home to take a shower, cry, be with her children and return when she had a chance to rest and restore her energy a bit.

Plan: Continue to meet with pt and S to assess their ongoing needs and determine appropriate interventions.

Linda F. Piotrowski
Ext 4992 Pager Number 9593



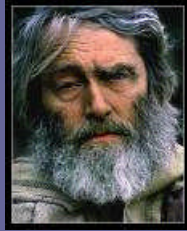
"When people are overwhelmed by illness, we must give them physical relief, but it is equally important to encourage the spirit through a constant show of love and compassion. It is shameful how often we fail to see that what people desperately require is human affection. Deprived of human warmth and a sense of value, other forms of treatment prove less effective. Real care of the sick does not begin with costly procedures, but with the simple gifts of affection, love, and concern."

His Holiness, The Dalai Lama

Mr. Wilson

•71 yo male

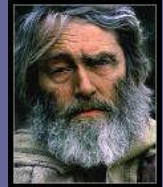
- Myelodysplasia → AML
- Pancytopenia
- Recurrent neutropenic fever



www.dustylens.com

Mr. Wilson 71 yo male

- I'd like to just get it over with..."
- "I'm like an old tired horse. They should dig a hole and just shoot me."



www.dustylens.com

Mr G

- 45 year old Christian male
- Large trucking corporation service manager
- Wife and 3 children 8, 12, 14
- Pt's mother & some other family live on large tract of family owned land.
- Initial diagnosis of non small cell lung cancer 2/01/07
- Cancer metastasis to nervous system & brain 8/24/07



©Stephen Levine

Mr G

- My initial visit in outpt clinic 5/21/07
- Followed as outpt
- Inpt on 9/12/07
- Discharged to home with hospice 9/14/07
- Died at home 10/21/07



©Stephen Levine

DHMC Documentation

Pt Name, Medical Record Number and Date of Service all automatically appear

Narrative: Extended visit, initially alone with pt. Pt's wife arrived. We were joined by Drs. Daniel Stadler and Nathan Smischney. Initially, pt and I spoke about his feelings regarding his changed diagnosis. He shared that his cancer had returned in several areas of his body. "I'm still hoping for miracle but if it isn't to be, I'm okay with that. I know God has a place for me. I'm worried about D and the girls but I know that even that will be okay."

Pt's wife, D, arrived. She was tearful but bustling about putting on a brave face. When the doctors arrived and talked with pt and D about DNR status and code status pt became tearful and expressed his concern for his life and not wanting to do anything to make things harder for her. D at the same time was reassuring pt that these were decisions he had to make about what was best for him. He did determine that he did not want to have artificial nutrition or hydration. He did want to be DNR. He signed papers outlining these wishes.

When the physicians left pt shared pictures and memories of his three daughters with D. joined in telling various stories about when photos were taken. We look at the materials about ethical wills that I had promised to bring. As I prepared to leave pt asked if we might pray together. We held hands and prayed.

DHMC Documentation

Assessment: Pt remains strong in his faith and trust in God and the caregivers at the medical center. Pt's wife is strong with a good family and community support system. Her faith is a strong support for her. Both the pt and his wife are facing these challenges with grace and dignity.

Intervention: Pastoral presence, active/reflective listening, counsel, sharing of memories, provision of written resources on ethical wills, prayer.

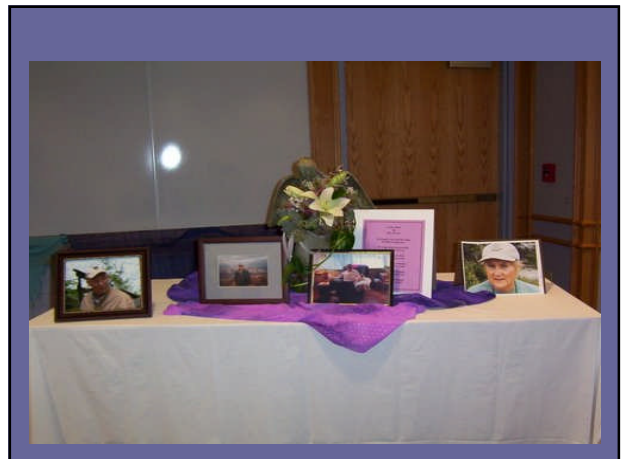
Plan: Pt being discharged home with hospice. Is scheduled to return on 9/24 for outpt visit. I will follow-up with pt and his wife at that time.

Linda F. Piotrowski
Ext 4992 Pager Number 9593

DHMC Palliative Care
Quarterly Memorial Services



"Perhaps they are not stars but rather openings in heaven where the love of our lost ones shines down upon us to let us know their souls are at peace."
Eskimo legend



Resources-Articles

- Marie Bakitas, MS, ARNP, and others for the Project ENABLE Co-investigators, "Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in Three Settings." *Journal of Palliative Medicine*, Volume 7, Number 2, 2004.
- Byock, Ira, "The Nature of Suffering and the Nature of Opportunity at the End of Life," *Clinics in Geriatric Medicine*, Vol. 12, No. 2, pp 237-252, May 1996.
- Byock, Ira, "Hospice and Palliative Care: A Parting of the Ways or a Path to the Future?" *Journal of Palliative Medicine*, Volume 1, Number 2, 1998.
- Byock, Ira, "Improving palliative care in intensive care units: Identifying strategies and interventions that work," 11 (Suppl.), pp S416-S420, 2006
- Byock, Ira, "To Life! Reflections on Spirituality, Palliative Practice and Politics" *Journal of Hospice & Palliative Medicine*, Vol. 23, No. 6, pp 136-138, December/January 2007
- Piotrowski, Linda F., "Setting the Palliative Care Record Straight," *Plainviews*, 11/7/2007 Vol.4, No. 29 (www.plainviews.org)
- Steinhäuser, Karen E. and others, "In Search of a Good Death: Observations of Patients, Families, and Providers," *Annals of Internal Medicine*, Vol 132, Number 10, May 16, 2000.

Resources-Internet

- **Academy of Hospice and Palliative Medicine**
<http://www.aahpm.org>
- **ACE Project Achieving Clinical Excellence-City of Hope**
www.cityofhope.org/ACEproject
- **American Hospice Foundation**
<http://www.americanhospice.org>
- **Caring Connections**
<http://www.caringinfo.org>
- **Center to Advance Palliative Care**
<http://www.capc.org>
- **Dying Well (Ira Byock's web site)**
<http://www.dyingwell.org>
- **Griefworks BC**
<http://www.griefworksbc.com>
- **Growth House, Inc.**
<http://www.growthhouse.org>

Resources-Internet

- **Hospice Foundation of America**
<http://www.hospicefoundation.org>
- **Naropa University School-Contemplative End-of-Life Care: A Certificate Program for Healthcare Professionals**
<http://www.naropa.edu/contemplativecare>
- **National Hospice and Palliative Care Organization**
<http://www.nhpc.org>
- **National Prison Hospice Association**
<http://www.npha.org>
- **Robert Wood Johnson Foundation**
<http://www.rwjf.org>
- **Sacred Art of Living Center for Spiritual Formation-The Anam Cara Project**
<http://sacredartofliving.com>
- **Toolkit of Instruments to Measure End of Life Care**
<http://www.toolkit.htm>

Resources-Books

Books

- Byock, Ira, *Dying Well: The Prospect of Growth at the End-of-Life*, Riverhead, 1997.
- Byock, Ira, *The Four Things That Matter Most*, New York: Simon and Schuster/Free Press, 2004.
- Kiernan, Stephen, *Last Rights: Rescuing the End of Life from the Medical System*, St. Martin's Press: NY, 2006
- Lynn, Chaudhry, Simon, Wilkinson, & Schuster *The Common Sense Guide to Improving Palliative Care*, New York: Oxford University Press, 2007.
- Curtis & Rubenfeld, editors, *Managing Death in the Intensive Care Unit-The Transition from Cure to Comfort*, New York: Oxford University Press, 2001.

“Nevertheless, in order to imbue civilization with sound principles and enliven it with the spirit of the gospel, it is not enough to be illumined with the gift of faith and enkindled with the desire of forwarding a good cause. For this end it is necessary to take an active part in the various organizations and influence them from within.



Pope John XXIII

And since our present age is one of outstanding scientific and technical progress and excellence, one will not be able to enter these organizations and work effectively from within unless he is scientifically competent, technically capable and skilled in the practice of his own profession.”



Pope John XXIII



This presentation is dedicated to the patients and families who have shared their lives with the DHMC Palliative Care Team.

Ira.R.Byock@hitchcock.org
Linda.F.Piotrowski@hitchcock.org