

# Spiritual Care of the Dying

Daniel B. Hinshaw, M.D.  
Palliative Care Program, Section of  
Geriatrics, and GRECC  
VA Ann Arbor Healthcare System  
Department of Surgery  
University of Michigan



He who has a *why* to live for can  
bear with almost any *how*.

Nietzsche



# Objectives for this Presentation

- Define spirituality, particularly in the context of terminal illness
- Define the concept of a “good death” and whether current practice meets the expectations of the dying
- Explore and characterize the nature of suffering
- Recognize spiritual distress
- Identify ways that caregivers can address the spiritual distress of their patients
- Discover the potential for healing in the terminally ill



# Clinical Practice Domains

National Consensus Project for Quality Palliative Care

- Structure and Processes of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care
- **Spiritual, Religious and Existential Aspects of Care**
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care



“... the American people want to  
reclaim and reassert the spiritual  
dimension in dying.”

“Spiritual Beliefs and the Dying Process”

The George H. Gallup International Institute

October, 1997



# Spirituality

“...that which allows a person to experience transcendent meaning in life. This is often expressed as a relationship with God, but it can also be about nature, art, music, family, or community - whatever beliefs and values give a person a sense of meaning and purpose in life.”

(Puchalski, C and Romer, AL J. Pall. Med. 3:129-137, 2000)



# Are You Religious or Spiritual?

( Gallup, Jr, GH, Americans' Spiritual Searches Turn Inward - Gallup Poll  
Tuesday Briefing, February 11, 2003, [www.gallup.com](http://www.gallup.com))

- In a January 2002 poll:
- 50% of Americans described themselves as religious
- 33% are “spiritual but not religious”
- 11% are neither
- 4% are both
- 2% ?



# Factors Considered Important at the End of Life by Patients, Family, Physicians and Other Care Providers

(Steinhauser, KE, et al. *JAMA* 284: 2476-2482, 2000)

- Random national survey, March-August, 1999.
- Importance of 44 attributes of quality at EOL.
- Patients, bereaved family members, physicians, nurses, social workers, chaplains, and hospice volunteers were surveyed.
- 26 items rated as important across all groups including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a 'whole person'.





# Factors Considered Important at the End of Life...

(Steinhauser, KE, et al. *JAMA* 284: 2476-2482, 2000)

- Patients and families rank ordered 9 pre-specified attributes of the end-of-life experience.
- “Freedom from pain” and “Being at peace with God” were ranked as most important (and were statistically equivalent).



# Factors Considered Important at the End of Life...

(Steinhauser, KE, et al. *JAMA* 284:2476-2482, 2000)

- Issues important to patients and others but not so important to physicians ( $p < 0.001$ ):
  - 1) Be mentally aware.
  - 2) Be at peace with God.
  - 3) Not be a burden to family.
  - 4) Be able to help others.
  - 5) Pray
  - 6) Have funeral arrangements planned.
  - 7) Not be a burden to society.
  - 8) Feel one's life is complete.

# Are Physicians Out of Step with Their Dying Patients?



“It is seldom a medical man has true religious views - there is too much pride of intellect.”

George Eliot



# Religiousness and Spiritual Support Among Advanced Cancer Patients...

## Coping with Cancer Study

- Interviews of patients (N=230) with advanced cancer (prognosis <1 yr), failure of first-line chemoRx, and an identified unpaid caregiver
- Patients rated their religiousness (importance of religion to them and their attendance at religious services or private religious/spiritual activities, i.e., prayer) before and after the cancer diagnosis. They also rated the spiritual support they received from their religious community and from the medical system.



# ...**Religiousness** and Spiritual Support Among Advanced Cancer Patients

Religion very important – 68%

Somewhat important – 20%

Not important – 12%

More African Americans (89%) and Hispanics (79%) rated religion as very important compared to whites (59%)

Increasing patient-reported distress at time of study enrollment was associated with increasing religiousness

Attendance at religious services at least once a month before cancer diagnosis – 56%

Attendance decreased to 44% after cancer diagnosis

\* Private daily religious/spiritual activities (e.g., prayer) increased from 47% before diagnosis to 61% after diagnosis



# ...Religiousness and **Spiritual Support** Among Advanced Cancer Patients

- Spiritual needs supported by religious communities to a large extent or completely – 38%
- Spiritual needs supported by religious communities to a small extent or not at all – 47%
- For religious African Americans, religious communities completely supported their spiritual needs in 52% compared with 19% of religious whites and 26% of religious Hispanics



# ...Religiousness and **Spiritual Support** Among Advanced Cancer Patients

- \*The medical system met the spiritual needs *to a small extent or not at all* in 72% of study patients
- \*Little to no support of spiritual needs from either a religious community or the medical system reported by 42%
- 52% reported visits by chaplains which were positive experiences

(Balboni, TA, et al. *J Clin Oncol* 2007; 25:555-560)





# The Dilemma:

## Technology and End of Life Care vs. Spirituality

“Death is the edge of a mystery, and turning our faces toward the problematic, through the persistent use of technology, at the hour of death keeps us from having to face mystery. Death is no problem to be solved; it resists any such formulation...by keeping our attention on end-of-life *problems*, we ignore the *mystery* of the end of life.”

(Bevins, M and Cole, T, Ethics and Spirituality: Strangers at the End of Life? pp 16-38 in Annual Review of Gerontology and Geriatrics, Lawton, MP, Ed. 2000, Springer, NY)



# Suffering

At the heart of the spiritual  
distress of the dying is suffering.



“Nothing is a faster  
teacher than suffering...”

Elisabeth Kubler-Ross

as quoted in:

Egnew, TR. Ann Fam Med 2005; 3:255-262.



# Human Suffering...

- “...Suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person.”
- “Suffering is experienced by persons.”
- “Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.”



# ...Human Suffering

“...Suffering can occur in relation to any aspect of the person, whether it is in the realm of social roles, group identification, the relation with self, body, or family, or the relation with a transpersonal, transcendent source of meaning.”

(Cassel, EJ. “The Nature of Suffering and the Goals of Medicine”, *NEJM* 306:639-645, 1982)



# Suffering and Persons

- A person is a psychosomatic unity. “The understanding of the place of the person in human illness requires a rejection of the historical dualism of mind and body.”

(Cassel, EJ, The Nature of Suffering and the Goals of Medicine, *NEJM* 306:639-645, 1982)

- Attempting to cure disease without caring for the person (breaking up the psychosomatic unity) can cause suffering.



# Total Pain

(Dame Cicely Saunders)

- Physical
- Psychological
- Social
- **Spiritual**



# Diagnosing Suffering...

- If you don't recognize or diagnose it, you can't relieve it.
- Since suffering affects persons, the standard 'objective' measures used to diagnose physical ailments will not be helpful.
- Typically, suffering involves a symptom(s) which threatens the integrity of the patient as a person.





# ...Diagnosing Suffering

- The meaning that the symptom(s) has for the individual patient defines the nature of the suffering experienced (e.g., if cancer-related pain is progressing, the fear of impending death can cause intense suffering).
- Failure to recognize and treat suffering is often a reflection of the inability of the caregiver to focus on the person rather than the disease.
- To make a diagnosis of suffering, one must be looking for it - “Are you suffering?”

(Cassel, EJ *Ann Intern Med* 131: 531-534, 1999)



If there is a meaning in life at all,  
then there must be a meaning in  
suffering. Suffering is an  
ineradicable part of life, even as  
fate and death. Without suffering  
and death human life cannot be  
complete.

*Man's Search for Meaning*  
Victor Frankl



# Recognizing Spiritual Distress



# The Spiritual History...

- Give the dying patient permission to discuss spiritual issues.
- F: *Faith* - Do you consider yourself religious or spiritual? Do you have a faith?
- I: *Importance* - Is it important in your life?
- C: *Community* - Are you part of a spiritual (or faith) community?
- A: *Address* - How can your healthcare providers address (and respect) these issues in your care?

# ...The Spiritual History

## *SPIRIT*

- **S**: spiritual belief system
- **P**: personal spirituality
- **I**: integration with a spiritual community
- **R**: ritualized practices and restrictions
- **I**: implications for medical care
- **T**: terminal events planning

(Maugans, TA. *Arch Fam Med*. 1996; 5:11-16)



# ...The Spiritual History

- Spirituality is an important component of each patient's overall well being (particularly true for the dying).
- Spirituality is an ongoing issue - readdress it over time.
- Don't impose your beliefs on others - respect a patient's autonomy and vulnerability.



# ...The Spiritual History

- Refer to chaplains, spiritual directors, etc. when appropriate.
- Know thyself - "...You can't address a patient's spirituality until you address your own."

(Puchalski, C and Romer, AL *J. Pall. Med.* 3: 129-137, 2000)



# “Are You at Peace?”

## A Gateway to Larger Discussions

- Non-threatening and nonsectarian means of opening a conversation about emotional and spiritual concerns
- Strong correlation of peacefulness with measures of emotional and spiritual well being but also to a lesser extent with measures of physical, functional, and social well being
- Patient’s response will guide further inquiry

(Steinhauser, KE, et al. *Arch Intern Med* 2006; 166:101-105.





# Spiritual Needs of the Dying

- Meaning

“Why am I suffering”

“Have you thought about what all this means?”

- Value

“Do I still have value even though I can no longer work?”

“Are you able to hold onto a sense of your own dignity and purpose?”

- Relationship

“Who have I wronged?” “Who has wronged me?”

“Is there anyone to whom you need to say ‘I love you’ or ‘I’m sorry’?”

- Sulmasy, DP. *JAMA* 2006; 296:1385-1392



# Meaninglessness

- Loss of **future**
- Loss of **relationships**
- Loss of **autonomy**



# Spiritual Distress and Loss of Control

It is not uncommon that for much of one's life the need for control is the operative force. Spiritual issues lie dormant until the situation becomes desperate - beyond one's apparent control.

(Friedemann, M-L., et al. *J Adv Nurs* 39:325-332, 2002)



# Signs of Spiritual Distress

- Physical distress (e.g., pain) unresponsive to standard therapies
- Acting out or refusal to cooperate - the “bad” hospice patient
- Emotional withdrawal
- Fears of loss of control or increasing dependence



# Denial and the Spiritual Distress of the Dying

- “Clinicians agree that denial generally should not be challenged when a patient is in the midst of a crisis because doing so risks undermining the patient’s psychological equilibrium.”

(Block, SD. Psychological Considerations, Growth, and Transcendence at the End of Life. *The Art of the Possible*. JAMA, 285:2898-2905, 2001)

- How often have we missed an opportunity to uncover and address spiritual distress when we follow this precept?



# Intersection of Culture and Spirituality in EOL Care...

- Western emphasis on individual autonomy can create conflicts in the care of patients with cultural and religious traditions that differ from the dominant culture.
- Decision making and communication may be more family-based - delegated to another family member (e.g., Mediterranean cultures) .
- Perceived and real inequities in healthcare access or historical quality of care may influence a whole subculture's approach to various issues (e.g., African-Americans' reticence to request DNR orders and lower enrollment in hospice).



# ...Intersection of Culture and Spirituality in EOL Care

- Some cultures are quite reticent to discuss death directly (e.g., Japanese, Native Americans).
- The western “right to know” can be in direct conflict with the perceived power of the spoken word: ***What is not explicitly said, may not become reality.***
- Seeking support for dying loved ones from agencies outside of the family (e.g., hospice) may be viewed in some cultures (e.g., Hispanic culture) as a failure to fulfill one’s responsibility.

(Thomas, ND. The Importance of Culture throughout All of Life and Beyond. *Holist Nurs Pract* 15:40-46, 2001)



# Spiritual Experiences as Death Approaches

- Near the transition to active dying, cognitive changes occur - **often dismissed (or treated) as delirium by physician.**
- Dream life changes - vivid and often symbolic dreams may occur (e.g., taking a journey, finishing a building project). The dying patient may be uncertain if it occurred while asleep or awake.
- Not infrequently the dying person will be found speaking to unseen presences - often deceased relatives.
- Experiences are usually comforting (although they may be perplexing to loved ones and caregivers).





# Spiritual Integrity and the Relief of Suffering - Case Example

- “C” is a female patient in her early 70s who presents with a locally advanced unresectable colon cancer which has replaced the lower half of her abdominal wall with a large, stinking, fungating mass.
- Nursing staff have noted that she rarely requires pain medication.
- On further inquiry, it is found that she addresses her pain with continual prayer.
- “Be still, and know that I am God.” (Psalm 46:10)



# Spiritual Care

“...it is important to view spiritual care not as a compartmentalized feature of treatment but as an attitude that infuses the overall approach to whole-person care regardless of one’s defined role in the care of a dying person.”

(Kaut, KP. *Am Behav Scientist* 46: 220-234, 2002)



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- Religious
- Complementary
- Provider-based
- Medical



# Types of Interventions in Spiritual Care

- **Psychotherapy**
- Pastoral (chaplains)
- Religious
- Complementary
- Provider-based
- Medical



# Patient Biography as a Means of Healing

- “Life review enables a person to identify what has been accomplished or created, and what will be left behind as a result...a sense of meaning may be captured in the recognition of the uniqueness of the individual.”
- Volunteer ‘biographers’ first record an oral biography on tape and then prepare a written transcript which is bound for the patient to pass on to loved ones.

(Lichter, I et al. Pall. Med. 7: 133-137, 1993)



# Dignity Therapy

## An Extension of Patient Biography

- Brief individualized psychotherapeutic intervention for those experiencing existential distress (a loss of meaning)
- Goal of the intervention – to engender a sense of meaning and purpose in order to reduce suffering in the dying
- 30-60 min taped interview (usually one) at bedside or in patient's home which was then reshaped (edited) into a narrative
- Narrative read to the patient in another session and patient allowed to edit it
- A potential legacy for loved ones

(Chochinov, HM, et al. *J Clin Oncol* 2005; 23:5520-5525)



# Dignity Therapy

## Sample Questions from the Protocol

- “Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? Are there specific things for your family to know or remember?”
- What roles have you played? What are your most important accomplishments?
- Are there particular things that you feel still need to be said to your loved ones?
- What have you learned from life? What advice do you have for those left behind?”



# Dignity Therapy

## Roots in Logotherapy

Logotherapy is focused on the meaning of human existence as well as on man's search for such a meaning. It helps individuals in spiritual distress discover who they are, how they wish to interpret their present situation, and what they want to become.

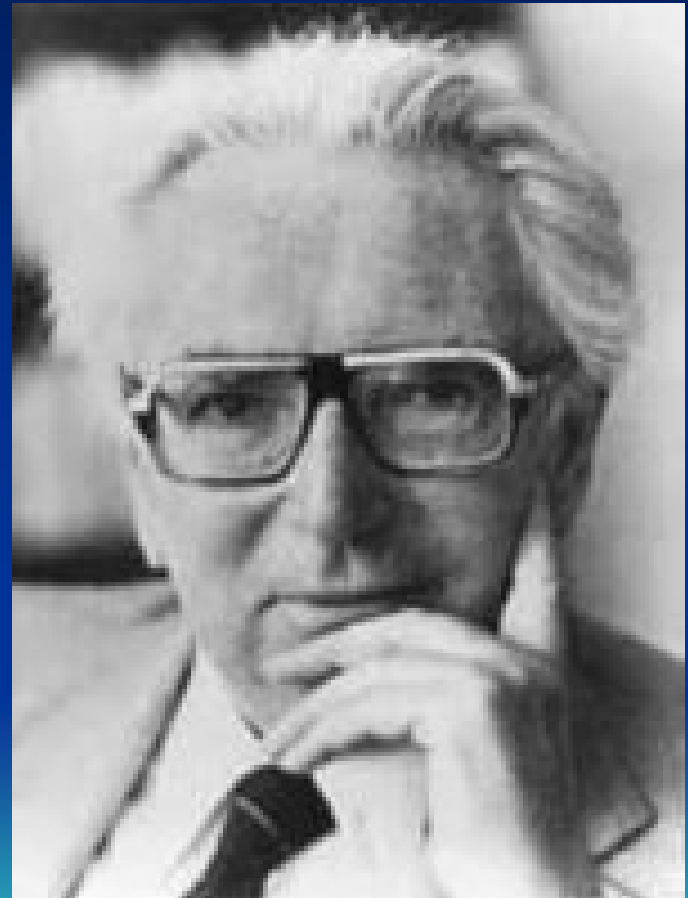




# Victor Frankl and Logotherapy

Logotherapy  
developed by Dr  
Victor Frankl, a  
psychiatrist and  
Holocaust survivor  
(1905-1997)

Described his  
experiences in *Man's  
Search for Meaning*



# Frankl's Major Principles of Logotherapy...

- 1) Life has meaning and never ceases to have meaning up to the last moment of life
- 2) Desire to find meaning is a primary instinct and motivator of human behavior
- 3) Humans have the freedom to find meaning in existence and to choose their attitude toward suffering



# ...Frankl's Major Principles of Logotherapy

Three main sources of meaning in life:

- 1) *creativity* – one's work, deeds, dedication to causes
- 2) *experience* – art, nature, humor, role, relationships, love
- 3) *attitude* – the attitude one takes in response to unavoidable suffering



# Meaning Centered Group Psychotherapy for Patients with Advanced Cancer

- Group psychotherapeutic application of Logotherapy as compared with individual orientation of Dignity Therapy
- 8 week intervention with one 1.5 hr session each week incorporating a mixture of didactics, discussion, experiential exercises focused around themes related to meaning and advanced cancer
- Patients given assigned readings and homework related to themes of each session



# ...Meaning Centered Group Psychotherapy for Patients with Advanced Cancer

## Session themes:

- 1) Concepts of meaning and sources of meaning
- 2) Cancer and meaning
- 3) Meaning and historical context of life
- 4) Storytelling, life project
- 5) Limitations and finiteness of life
- 6) Responsibility, creativity, deeds
- 7) Experience, nature, art, humor
- 8) Termination, goodbyes, hopes for the future

(Breitbart, W. *Support Care Cancer* 2002; 10(4): 272-280)



# Multidisciplinary Intervention to Address QOL in Patients with Advanced Cancer...

RCT based on the concept that QOL includes several functional domains:

- cognitive
- physical
- emotional
- **spiritual**
- social

Similar to Total Pain concept of Dame Cicely  
Saunders



# ...Multidisciplinary Intervention to Address QOL in Patients with Advanced Cancer

- Radiation therapy patients with advanced cancer and an estimated 5 yr survival of 0-50% (N=103) randomly assigned to usual care or eight session intervention (90 min each) designed to address 5 domains of QOL
- QOL (measured by self assessment with linear analog scales) was maintained at 4 weeks (during XRT) in the intervention group whereas, significant decrease in QOL in control group ( $p=0.009$ ); no differences at baseline, 8 and 27 weeks after start of Rx

# ...Multidisciplinary Intervention to Address QOL in Patients with Advanced Cancer

- Structured multidisciplinary intervention (90 min x 8 sessions) designed to address all 5 identified functional domains of QOL
- Sessions consisted of an initial 20 min of conditioning exercises followed by educational information, cognitive-behavioral strategies for coping with cancer, open discussions and support from leaders and other group members.
- Sessions were balanced with didactics, a Q&A period, sharing, reflecting, relaxation, and physical activity.





# ...Multidisciplinary Intervention to Address QOL in Patients with Advanced Cancer

- Essentially a coping with cancer program
- Only 25% of eligible subjects agreed to participate (selection bias)
- Time intensive
- Expensive (~\$2000 per participant for the complete program)
- Not likely an option in smaller community centers
- Unclear whether a less complex or intensive intervention might also be effective

(Rummans, TA, et al. *J Clin Oncol* 2006; 24:635-642)



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- Religious
- Complementary
- Provider-based
- Medical



# Chaplain's Role in Spiritual Care

- Understand and clarify the spiritual meaning of all that is experienced by those involved within palliative care in the context of the chaplain's own relationship and understanding of God
- Discern spiritual needs of dying patients (and providers)
- Offer a ministry of word and sacrament (if appropriate) or pastoral counseling to patients, family caregivers, and to the organization (providers)
- Most critically, be present alongside those facing death or grief, transcending traditional religious boundaries

(Adapted from Speck, P. Oxford Textbook of Palliative Medicine, p.812, 1998)



# The Listening Presence

“Listening is one of the greatest spiritual gifts a chaplain can give a suffering patient.”

(Sr. Sharon Burns, *The Spirituality of Dying. Pastoral Care's Holistic Approach Is Crucial in Hospice*, *Health Prog* 72:48-54, 1991)

This applies to all who care for suffering.



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- **Religious**
- Complementary
- Provider-based
- Medical



# Religion and Spiritual Care

- Spirituality is often grounded in a specific religious faith.
- Religion is a source of meaning and framework in which to understand the great existential questions of suffering and death.
- Religious rituals 'actualize' belief/doctrine and provide tangible comfort and meaning.
- Chaplains and providers often are intermediaries in assisting patients find appropriate religious support.
- Ask about potential need for specific religious support earlier rather than later.



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- Religious
- **Complementary**
- Provider-based
- Medical



# Complementary Therapies and Spiritual Care of the Dying - Music Therapy

- Music therapy can provide a comforting and calming presence.
- Knowing the patient's musical "history" is important.
- Music can sometimes serve as the catalyst for release (emotional and spiritual) at the end of life.

(Krout, RE, *Am J Hospice Pall Care* 20:129-134, 2003)





# ...Complementary Therapies\* and Spiritual Care of the Dying

- Touch (e.g., massage)
- Art
- Poetry
- Animal companions

\*Common to all of these approaches – an effort to reduce the isolation of the dying and reawaken the living person



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- Religious
- Complementary
- **Caregiver-based**
- Medical



# Addressing the Spiritual Needs of the Dying

## Basic

- Express empathic concern
- Be respectful of the patient's ultimate concerns
- Be present for them, affirming their value
- Listen to what they have to say about life and its meaning

## Complex

- Refer to chaplain or patient's own clergy

(Sulmasy, DP. *JAMA* 2006; 296:1385-1392)



# Empathy

“The intellectual identification with or vicarious experiencing of the feelings, thoughts, or attitudes of another”

Webster’s New Universal Unabridged Dictionary, 2003, Barnes & Noble Publishing, Inc.

Original root from Greek word pascho – suffer; entering into the suffering of another



# Barriers to Empathy...

- To have pain is “to have certainty.” The patient has this certainty - the caregiver does *not*. Caregivers must overcome their tendency to doubt the patient.
- Caregivers should listen to their patient’s complaints of pain (their suffering) “not to explain but to understand, not to diagnose but to witness and help.”

(Schweizer, H To Give Suffering a Language. Lit. and Med. 14: 210-221, 1995)



# ...Barriers to Empathy

- Sometimes patients are not particularly likeable, indeed they may be abusive and threatening to the caregiver.
- Finding a common history or shared experience can serve as a bridge in developing a relationship of caring for the “difficult” patient.

(Liaschenko, J J Pall. Care 10: 83-89, 1994)



# Empathy

“He whom we look down upon, whom we cannot bear to see, the very sight of whom causes us to vomit, is the same as we, formed with us from the selfsame clay, compacted of the same elements. Wherever he suffers we also can suffer.”

(Jerome - quoted in Risse, GB Mending Bodies, Saving Souls: A History of Hospitals. Oxford University Press, 1999)



# Hope and the Terminally Ill

- The “*positive expectation for meaning attached to life events.*”  
(Parker-Oliver, D *Am J Hospice Pall Care* 19: 115-120, 2002)
- “ Hope lies in *meaning* that is attached to life, not in events themselves.”
- “...As long as there is meaning, there is hope.”
- It is a loss of meaning and thus a loss of hope which often underlies requests for physician - assisted suicide.





# Redefining Hope...

- Patients need to know that they are dying.
- The role of being 'sick' must transition to that of 'dying'.
- Hospice can facilitate this transition by creating a new identity and point of reference for the dying patient.
- Hope can then be redefined in terms relevant to the new circumstances.



# ...Redefining Hope

- Caregiver commitment to dying patient generates hope.
- The dying person will not be abandoned.
- Pain and other distressing symptoms will be controlled.
- The dying person will be remembered.
- Reconciliation and forgiveness can occur.



# Training Nurses to Relieve Meaninglessness of Terminally Ill Cancer Patients

Japanese Spiritual Care Task Force

- Five hour educational workshop on 'meaninglessness'
- Workshop included lecture, role play, and assessment and development of care plans for two clinical scenarios
- 147 nurses trained with pre and post assessment of self-reported attitudes and practice regarding care of patients experiencing meaninglessness as well as their confidence, burnout, death anxiety, and meaning of life
- Self-reported practice and confidence were better and sense of helplessness, emotional exhaustion, and death anxiety were decreased after the training

(Morita, T, et al. J Pain Symptom Manage 2007; 34:160-170)



# Home as a Therapeutic Environment to Address the Spiritual Needs of the Dying

- “Within the home environment, the dying person is among familiar surroundings and can be more at ease yielding to the spiritual journey of searching for meaning and purpose in his or her life.”

(Vassallo, BM. The Spiritual Aspects of Dying at Home *Holist Nurs Pract* 15:17-29, 2001)

- The challenge - to create an experience of “home” for that majority who will die in an institution .



# Reconciliation and the Dying

“Reconciliation is the most crucial thing for the dying irrespective of whether or not the person is religious or secular. Even as their bodies are disintegrating they are becoming whole.”

(Sr. Sharon Burns of Stella Maris Hospice as quoted by Vigen Guroian in *Life's Living toward Dying*)



# Reconciliation

## The Work of the Dying

- “Forgive me.”
- “I forgive you.”
- “Thank you.”
- “I love you.”
- “Good-bye.”

(Byock, I as quoted in Parker-Oliver, D Am J Hospice Pall Care 19:115-120, 2002)



# Conversations with the Dying

- Difficult to contain within a short clinic visit or single ward encounter
- Content/depth depends on level of trust
- Trust depends on a relationship, often built over time
- May often involve questions that do not have easy answers

Puchalski, CM *Health Progress*, July-August, 2004, vol. 85 (4)



# Partnership in Spiritual Care

- Healing can not occur in a vacuum.
- “Partnership implies that the journey is one of shared experience where two people work together toward a resolution rather than one in which the expert doles out advice, leaving the patient to sort through the problems alone.”

Puchalski, CM *Health Progress*, July-August, 2004, vol. 85 (4)





# Hearing and Listening

- Hear – “perceive by the ear” or “listen to; give or pay attention to” (often in a favorable light)
- Listen – “to give attention with the ear; attend closely for the purpose of hearing; give ear” with a secondary meaning – “pay attention; heed; obey” but also “**wait attentively** for a sound”

Webster’s New Universal Unabridged Dictionary, 2003, Barnes & Noble Publishing, Inc.



# How can we listen with all the noise?

Finding stillness or silence in the  
therapeutic encounter

*Hesychia*



“Silence is always beautiful,  
and a silent person is  
always more beautiful than  
one who talks.”

*The Adolescent*  
Fyodor Dostoevsky



# Hesychia and Kenosis

- A life-threatening illness can focus one's attention like nothing else.
- A terminal illness and the process of dying are each person's kenosis.
- The kenosis of the dying (and of course we are all dying!) is a stripping away of the 'noise' so that real silence - hesychia can be experienced.
- This kenosis is the foundation for true hearing and listening.



# Hesychia and Listening

Stillness is a necessary precursor for real hearing and listening, as much for the caregiver as for the patient.



# Listening Beyond Listening



# Listening and Presence

- Giving one's full attention to another person
- Subordinating one's own ego completely to be fully open to the other
- Being fully present on all levels: physically, emotionally, intellectually, and ***spiritually***
- Transcending the limits of the space/time continuum



# Types of Interventions in Spiritual Care

- Psychotherapy
- Pastoral (chaplains)
- Religious
- Complementary
- Provider-based
- **Medical**





# Control of Physical Distress Essential in Spiritual Care

“...No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting.”

(Oxford Textbook of Palliative Medicine, 2nd Edition, p. 6, 1998)



# Remember Total Pain

Untreated depression and chaotic social circumstances will also inhibit effective 'work of the dying'.



# Palliative Sedation

- Intentional pharmacologically-induced state of heavy sedation
- Considered in situations of severe unremitting distress (including existential distress) not responsive to standard measures, usually in last hours or days of life
- Not thought to shorten life but controversial
- May be used as a form of respite (24 hrs) in the severely sleep-deprived patient to break cycle of pain
- Different from “terminal sedation”
- May interfere with the ‘work of the dying’



In my end is my beginning.

*East Coker - Four Quartets*  
T.S. Eliot

The Potential for Healing in Death



# Healing Independent of Cure

“...The personal experience of the transcendence of suffering.”

Egnew, TR. Ann Fam Med 2005; 3:255-262.



# Characteristics of Health in the Dying (and Living)

- Integrity/Wholeness
- Hope
- Reconciliation
- Acceptance



# The Paradox of Healing in the Dying

- All pretense is stripped away – the soul laid bare
- To see the world as it really is and to see themselves without illusion
- For some, to find that the greatest source of meaning may be relational – to still be able to help/care for/love another



# Healing is Relational...

“...To be whole is always to be whole in the presence of others.”

Eric Cassell as quoted in Egnew, TR. Ann Fam Med 2005; 3:255-262.





# ...Healing is Relational

“You are missing something, as well as the patient missing something, unless you come not merely in a professional role but in a role of one human being meeting another.”

Dame Cicely Saunders as quoted in Egnaw, TR. Ann Fam Med 2005;  
3:255-262



# Healing and Co-suffering

‘Come Mr. Frodo!’ he cried. ‘I can’t carry it for you, but *I can carry you* and it as well...’

Tolkien, J.R.R., *The Return of the King*



# The Reciprocal Character of Healing

- For healing to occur, it may only be necessary to experience or witness (be present for) the suffering of another or for the suffering one to experience the compassion and love of the caregiver.
- *The healer is the patient and the patient is the healer.*



# Transcendence of Suffering

L was a 67 yr old man with advanced pancreatic cancer who presented in a pain crisis with crescendo mid-epigastric pain radiating through to his back. The pain was keeping him from his usual activity of preparing and distributing boxes of food for the poor derelicts in his neighborhood. He promptly resumed these activities once his pain was controlled and continued them up to the day before his death.



Can physicians be healers?



“By... grounding treatment choices in the person rather than the disease, maximizing function, and actively minimizing suffering, physicians strengthen patients with the goal of maintaining intactness and integrity...By helping patients transcend suffering, physicians surpass their curative roles to claim their heritage as healers.”

*Egnew, TR. Ann Fam Med 2005; 3:255-262*



# Summary

- Taking a spiritual history should be a routine part of the care of a person with an advanced illness
- Don't 'medicalize' spiritual distress
- Address spiritual distress in the context of Total Pain
- When all else fails, shut up and listen – be truly present



“Deep, unspeakable suffering may well be called a baptism, a regeneration, the initiation into a new state.”

George Eliot  
in  
*Adam Bede*

