The Intangibles: Factors In Healthcare That We Can’t Readily See, Touch, Hear, Taste, or Smell

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Disclosure

I have no actual or potential conflict of interest in relation to this program/presentation.
WHAT IS SPIRITUALITY?

• The relationship of a person’s inner being to a larger reality, however it is conceived and expressed.

• The inner search for meaning, purpose, and understanding of universal questions of human existence.
  • “Who am I?”
  • “Why am I here?”
  • “What is my purpose in life?”
WHAT IS RELIGION?

• A system of beliefs and practices relating to a higher power and shared by a group of people.

• Provides a community for groups of people to join together and give expression to their common beliefs, values, and spirituality.
CORE CONCEPTS OF SPIRITUALITY

• Spirituality is a search to find meaning while asking universal questions of human existence such as “Who am I?” “Why am I here?” and “What is my purpose in life?”

• Spirituality and religious beliefs are highly personal and are often considered private.

• There are generally direct connections between religious or spiritual beliefs and one’s moral values and judgments which inform the basis of patients’ decision making.
Core Concepts of Spirituality (cont’d)

• Spirituality is highly personal and is usually expressed in ways that are individual and unique in prayer, meditation, and other spiritual practices.

• Spirituality encompasses all aspects of an individual including the physical, emotional, psychological, cultural, and social aspects of the person

• Although many aspects of belief and faith are indescribable, it is important for people to feel free to be able to discuss their beliefs
North Carolina-AARP Survey Data*
*The Carolina Center for Hospice and End of Life Care & AARP, Sept. 2003

Majority of People Agreed as being “Very Important”

- At peace spiritually
- Not being a burden
- Knowing what meds are available
- Honest answers from MDs
- Things settled with family
- Physical comfort
- Understanding treatment options
- Free from pain
- Finances in order
- Visits from family/friends
- Knowing how to say goodbye
SPIRITUALITY

5 Areas of Spiritual Importance to Patients

Patients have need for:
• Belonging and relationship
• To explore the meaning of one’s life
• To explore the meaning of one’s suffering & death
• For reconciliation
• To be given HOPE

APPEAL CURRICULUM
Concepts of HOPE
We must accept finite disappointment. But never lose infinite hope.
“The miserable have no other medicine; but only hope”

-William Shakespeare

Measure for Measure, Act 3, sc. 1

Concepts of HOPE
“Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, not matter how it turns out.”

-Vaclav Havel

*Disturbing the Peace*

**Concepts of HOPE**
“Hope does not lie in a way out, but in a way through.”

Concepts of HOPE
HOPE AND MEANING-MAKING

- Meaning of life
  - Life has meaning and never ceases to have meaning even up to its last moments
  - Meaning may change but it never ceases to exist
MEANING-MAKING

• "The meaning of our existence is not invented by ourselves, but rather detected", p. 157
• "What matters, therefore, is not the meaning of life in general, but rather the specific meaning of a person’s life at a given moment.", p. 171
Spiritual Distress
SPIRITUAL DISTRESS

- Patients often draw upon spiritual aspects of their lives to cope with the stress of illness and treatment.

- However, sometimes spiritual issues themselves become problematic, and patients may experience spiritual distress as an additional and complicating stressor.

- Let’s look at three observable indicators of spiritual distress that may have implications for a patient's care and proposes direct and inviting questions.

NOTE: This resource is an adaptation of “Spirituality & Pain: Assessment For Spiritual Distress,” developed by John Ehman, Kurt Wieser, Ralph Tampa, and Janet Abrahm (Hospital of the University of Pennsylvania, 1998). The indicators above are based upon, but not confined to, the North American Nursing Diagnosis Association diagnosis of Spiritual Distress.
THREE KEY SPIRITUAL DISTRESS FACTORS

1) *Religious Practice*

Possible Indicators of Spiritual Distress: Interruption of religious practices (especially prayer/meditation and social religious activities)

Possible Questions:
Are there any religious activities or practices that have been interrupted because of your illness?

Possible Role: Connector

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2) **Issues of Meaning amid Change**

Possible Indicators of Spiritual Distress:

- Questions/expresses inner conflict about the meaning or purpose of his/her pain/illness or life in general
- Expresses a sense of injustice, hopelessness and despair
- Withdrawal from, or loss of, relationships
- Evidences grief, including anticipatory grief
- Evidences a lack of acceptance of changes/losses
SPIRITUAL DISTRESS FACTORS (CONTINUED)

2. *Issues of Meaning amid Change (continued)*

Possible Questions:
Do you feel at peace with the changes in your life that have come about because of your illness?

Possible Role:
Comforter
SPIRITUAL DISTRESS FACTORS (CONTINUED)

3) Religiously focused expressions of possible distress

Possible Indicators of Spiritual Distress:

- Expresses feelings of abandonment by his/her own religious group or by God
- Mentions "evil," "the enemy," or similar concepts
- Interprets pain/illness as punishment, especially as "deserved" punishment
- Expresses or evidences guilt (refers to self as "bad," "sinful," or "unlovable"
- Expresses or evidences anxiety or fear regarding an afterlife
SPIRITUAL DISTRESS FACTORS (CONTINUED)

3. **Religiously focused expressions of possible distress (continued)**

✓ Avoids the topic of spirituality and spiritual needs
✓ Questions the moral or ethical implications of therapies, especially those involving: reproductive system, blood transfusion, amputation or removal of organs

**Possible Questions:**

Illness is a hard thing physically. Has it been a hard thing spiritually for you?

**Possible Role:**

Counselor
SPIRITUAL ISSUE: LACK OF MEANING & PURPOSE
“WHY AM I STILL HERE?”

• Mr. L is a 65-year-old gentleman with metastatic lung cancer. Over the last month, he has become increasingly dependent and now requires moderate assistance with his ADLs. He is frustrated by his limitations: “I can’t do anything for myself or anyone else. I can’t even play with my grandchildren. I may as well be dead already. Why am I still here?”
INTERVENTIONS FOR A LACK OF MEANING AND PURPOSE

• Reflective and supportive listening  
  (face-to-face, eye contact)

• Do a life review
  • What activities or goals have given life meaning in the past?

• Find ways to give life meaning now

• Referral to chaplain or pastoral counselor

From Putalschaka L, NHPCO Plenary Session. April 2003  
Lo B et al. JAMA 2002;287:749-754
SPIRITUAL ISSUES: GUILT OR SHAME

“I DESERVE THIS. I’VE DONE BAD THINGS.”

• Mr. K is an 80-year-old man with prostate cancer metastatic to bone. Although he is in significant pain he repeatedly declines pain meds. After multiple attempts by the health care team to persuade Mr. K to take the meds, he says to the nurse, “I deserve this pain. During my lifetime, I’ve done some really bad things to good people.”

Cameron, 2005. AAHPM Review Course
INTERVENTIONS FOR GUILT/SHAME

• Listen to the patient and his/her story
• Don’t necessarily try to dissuade or offer premature reassurance
• Ask about spiritual beliefs
• Recommend forgiveness of self/others
• Referral to chaplain or spiritual counselor

From Putalschaka L, NHPCO Plenary Session, April 2003
Lo B et al. JAMA 2002;287:749-754
INTERVENTIONS FOR UNCOVERING AND ADDRESSING SPIRITUAL CONCERNS

• Practice a compassionate presence using reflective listening
• Obtain a spiritual history
• Explore how the patient and family’s belief systems influence their understanding of illness, guide treatment decisions and goals of care, and serve as a coping resource.
• Avoid going beyond your expertise and role or imposing your religious beliefs on the patient. Recognize your own limitations and boundaries
• Make chaplains a key component of the interdisciplinary team

From Putalschaka L, NHPCO Plenary Session, April 2003
Lo B et al. JAMA 2002;287:749-754
Role of Chaplains

- Essential part of team of professionals caring for patients at the end of life
- Spiritual/Emotional support to patients/families
- Prayer, meditation, culturally appropriate rituals
- Links with community-based clergy
- As appropriate, bring patient’s spiritual needs and concerns to team
Triggers for Referral to Chaplain

- Spiritual concerns are a source of suffering for patient/family
- Spiritual issues are of particular significance to patient/family
- Patient/family request spiritual counsel
- Spiritual needs of patient/family exceed your level of comfort or expertise
- Specific community spiritual resources needed
Spiritual Assessment

• Invitation to enhance the provider-patient relationship
• Can help health care providers understand the patient's/families spiritual beliefs
Spiritual Assessment (cont’d)

- Should be done as routine practice
- Should be done early in physician-patient relationship
- Two models of assessment: HOPE and FICA
Spiritual Assessment

**HOPE Model**

**H:** Sources of hope, meaning, comfort, strength, peace, love, and connection

**O:** Organized religion

**P:** Personal spirituality and practices

**E:** Effects on medical care and end-of-life issues
Spiritual Assessment

*FICA* Model

**F:** What is your faith or belief?

**I:** Is your faith important in your life?

**C:** Are you a part of a spiritual or religious community?

**A:** How would you like me to address these issues in your care?
Summary

Respect and encourage patients' spirituality

Get in touch with your spiritual self

Refer patient to clergy when appropriate

Remain open to patient's request for prayer

Do a spiritual assessment
Miracles
The Reasons People Want One

- Witnessed The Impossible
- The Development Of Their Faith
- Legacy Question: Who Will Cry?
- Existed But Never Lived
- Expensive Original vs. Cheap Copy
- Unfinished Business
- Why Not?
SAY AMEN
Acknowledge The Hope

Meet Them Where They Are First

Educate By Finding Different Ways To Inform

No Matter What, Journey With Them

Rhonda S. Cooper, MDiv, BSS, The Kimmel Cancer Center – Johns Hopkins
Time To Engage
MINISTRY ROLES OF HEALTHCARE PROFESSIONALS

Roles we DON’T play (although we would like to…)

- Problem “Fixer”
- Miracle Worker

Roles we DO play

- Partner in Discernment (moral decisions, treatment decisions, etc)
- Witness (i.e. God’s presence, the Church, etc.)
- Interpreter (medical language, meaning of suffering, etc.)
- Spiritual Caregiver and Nurturer
- Ritual Keeper
- Confidence Keeper
- Crisis Counselor
- Hand-Holder
- Go-fer/Servant (meal, cup of water, ride, etc.)
- Referee

NOTE:
This resource is an adaptation of a teaching on “Ministry Roles in Medical Crisis” developed by T.D. Rosell (2001).
MINISTRY ROLES OF HEALTHCARE PROFESSIONALS

Relating

✓ Don’t talk to people as if they understand everything that’s going on.

✓ Respect the patient’s/family’s experience and speak in a language they can understand (I.e. use of medical terminology) and do not expect them to adjust to your own.

✓ Everyone needs to be needed and to live the best quality of life whatever the circumstances. Therefore, family members need to feel as informed as they deem necessary and have choices and a sense of control.
MINISTRY ROLES OF HEALTHCARE PROFESSIONALS

Practicing Good Communication Skills

✓ Don’t Stereotype! We all want to be treated with dignity and respect. As such, Healthcare Providers should strive to treat patients and their families as unique cases-- not as part of a group labeled “critically ill or dying”.

✓ Use the basics of communication and be reminded of ways to relate the most effectively to others (i.e. looking at someone and making eye contact is important in making that human connection and communicating respect - put down your paperwork, clipboard, etc...).
MINISTRY ROLES OF HEALTHCARE PROFESSIONALS

16 Keys To Communication

1) Address the person and family members in the way they prefer.
2) Really listen to what is being asked or said.
3) Rephrase using different words, if the person does not understand.
4) Talk directly to the people and not to the room.
5) Take your time, one expression at a time.
6) Use body language to improve communication (non-verbal cues in how you use eye contact, gestures, and your distance from the person).
7) Use a tone of voice that is appropriate to the conversation.
8) Listen to the silence. Silence allows someone to think about what is being discussed or about a response.
MINISTRY ROLES OF HEALTHCARE PROFESSIONALS

16 Keys To Communication (continued)

9) Acknowledge feelings even if you do not agree with them.
10) Look for hidden meanings. (What may someone be telling you when she repeats things or talks about someone else's health or problems or family involvement?).
11) Encourage and reassure.
12) If possible, find meaning in his/her experience.
13) Wait for a response to questions.
14) Do not attempt to finish the person's sentences or thoughts for him/her.
15) Use humor when appropriate.
16) Keep terminology simple and avoid jargon and acronyms unless you can verify that the person understands the term (i.e. SLMB which is a government benefits program).
We Want To Create Hopeful Communities. Why Community?

- People live in community—not hospitals
- Healthcare and spiritual resources are in community
- The role of faith communities in end of life care is very important
Partnerships
Delivering Educational Programs – Any Faith-based program should offer intentional opportunities to increase the congregation’s awareness of “culturally sensitive” resources that are available to assist the seriously ill and dying as well as opportunities to improve the congregation’s ability to address issues related to death and dying.

Nurturing Skill Development – In addition to educational programs, we can help congregations establish programs to help members develop the skills within the congregation that will enable the Faith Community to effectively address the needs of the seriously ill and dying.
PARTNERSHIP ROLES (CONTINUED)

- **Advocacy** – Assist Faith Leaders in becoming knowledgeable enough to join the “circle of care” and effectively take their place as advocates for the persons that they serve, as-well-as partners with the medical community.

- **Development of Rituals** – Healthcare Professionals should encourage culturally sensitive rituals that value in death what the seriously ill and dying valued in life.
PARTNERSHIP ROLES (CONTINUED)

- **Facilitating Support Programs** – The Faith Community is a natural and ideal place for Healthcare Professionals to facilitate support groups for patients, family members and other persons who are impacted by a life-threatening illness.

- **Revealing the Use of Community Resources** – Because the Faith Community represents a large number of individuals, a congregation can be a key conduit for information about the resources that are available in the community for the community.