



Integrating Spiritual Care into Palliative Care: A Whole Person Approach

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Spirituality and Health

- Making the Case For Spirituality in Pall Care
 - WHO resolution
 - Ethical guidelines
 - Models and Recommendations
 - Generalist-Specialist Model
 - Diagnosis and Treatment of Spiritual Distress
 - Taking a Spiritual History



WHO Palliative Care Resolution

Strengthening of palliative care as a component of integrated treatment within the continuum of care, Jan. 23, 2014

- Bearing in mind that palliative care is an approach that improves the quality of life of patients... ***through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;***



WHO Palliative Care Resolution

Strengthening of palliative care as a component of integrated treatment within the continuum of care, Jan. 23, 2014

- :Acknowledging that palliative care is an ***ethical responsibility of health systems, and that it is the ethical duty of health care professionals*** to alleviate pain and suffering, whether physical, psychosocial or spiritual...”



WHO Palliative Care Resolution

Strengthening of palliative care as a component of integrated treatment within the continuum of care, Jan. 23, 2014

- ...the delivery of quality palliative care is most likely to be realized where strong networks exist between professional palliative care providers, support care providers (***including spiritual support and counseling, as needed***)...



Spirituality: Meaning, Purpose and Connectedness

(Puchalski, Vitillo, Hull et.al. International Conference on Global Integrating Spirituality into Health, 2013)

- Spirituality is a *dynamic and intrinsic* aspect of humanity through which *persons seek ultimate* meaning, purpose, and *transcendence*, and *experience relationship* to self, *family*, others, *community*, *society*, nature, and the significant or sacred. *Spirituality is expressed through beliefs, values, traditions, and practices.*



Spiritual Growth

In dying we move from chaos to surrender to eventual transcendence.

Initial encounter with illness and the prospect of dying can result in chaos. Surrender is when one is open to one's deeper being. Transcendence is going deeper into spiritual integration.

K. Dowling-Sing



What are potential clinical triggers for spiritual growth?



Clinical Triggers for potential spiritual growth

- Serious illness or chronic illness challenges
- Aging (gerotranscendence)
- Loss of loved one, previous state of health
- Stress
- Life change
- Social events, tragedies
- Why me?



Making the Case for Interprofessional Spiritual Care

- Ethical guidelines
- Evidence
 - Effect on healthcare outcomes
 - Patient need
- Clinical consensus based guidelines
- International consensus based standards



Ethics: Attending to suffering

- It is the responsibility of all clinicians to attend to physical pain and psychosocial and spirituality suffering
 - American College of Physicians, 2004
 - WHO Palliative Care Resolution, 2014
 - National Consensus Project 2006, NQF, 2010
 - IOM Report on Dying in America, 2014
 - EAPC Palliative Care Goals, 2014



Healthcare outcomes

- Research that shows spirituality and/or religion impact on
 - quality of life (existential and spiritual wellbeing)
 - coping,
 - Decreased depression, anxiety
 - Improved social functioning and maintaining social relationships
 - (Cohen SR, Mount BM, Tomas JJ, Mount LF. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. *Cancer* 1996; 77:576. Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: a two-year longitudinal study. *J Health Psychol* 2004; 9:713.; Fitchett G, Murphy PE, Kim J, et al. Religious and spiritual struggle: prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. *Int J Psychiatry Med* 2004; 34:179. Fitchett et al, *Cancer* 2015)



Effectiveness of an Interdisciplinary Pall Care Intervention in Lung Cancer patients and Family Caregivers

- Spiritual care intervention: one of four modules was on spiritual issues
- Outcomes
 - Less depression and less anxiety
 - Improved spiritual wellbeing
 - Improved patient experience
 - Sun, V., Grant, M., Koczywas, M., Freeman, B., Zachariah, F., Fujinami, R., ... & Ferrell, B. (2015). *Cancer*, 121(20), 3737-3745



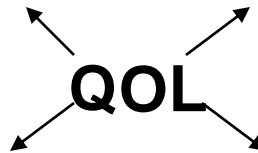
Quality of Life Model

Physical Well Being

Fatigue
Sleep Disruption
Function
Nausea
Appetite
Constipation
Aches/Pain

Psychological Well Being

Anxiety
Depression
Helplessness
Difficulty Coping
Fear
Useless
Concentration
Control
Distress



Social Well Being

Isolation
Role Adjustment
Financial Burden
Roles/Relationships
Affection/Sexual Function
Leisure
Burden
Employment

Spiritual Well Being

Meaning
Uncertainty
Hope
Religiosity
Transcendence
Positive change



What does it mean to attend to
a person's suffering?



Attending to suffering: Accompanying the patient

- Spiritual care is attending to suffering
- Being present not fixing
- Reflective listening—helping the patient find their own voice, their own path

- To accompany : to be present, to support to commit to be there for the patient
- Accompaniment is part of our call, our vocation

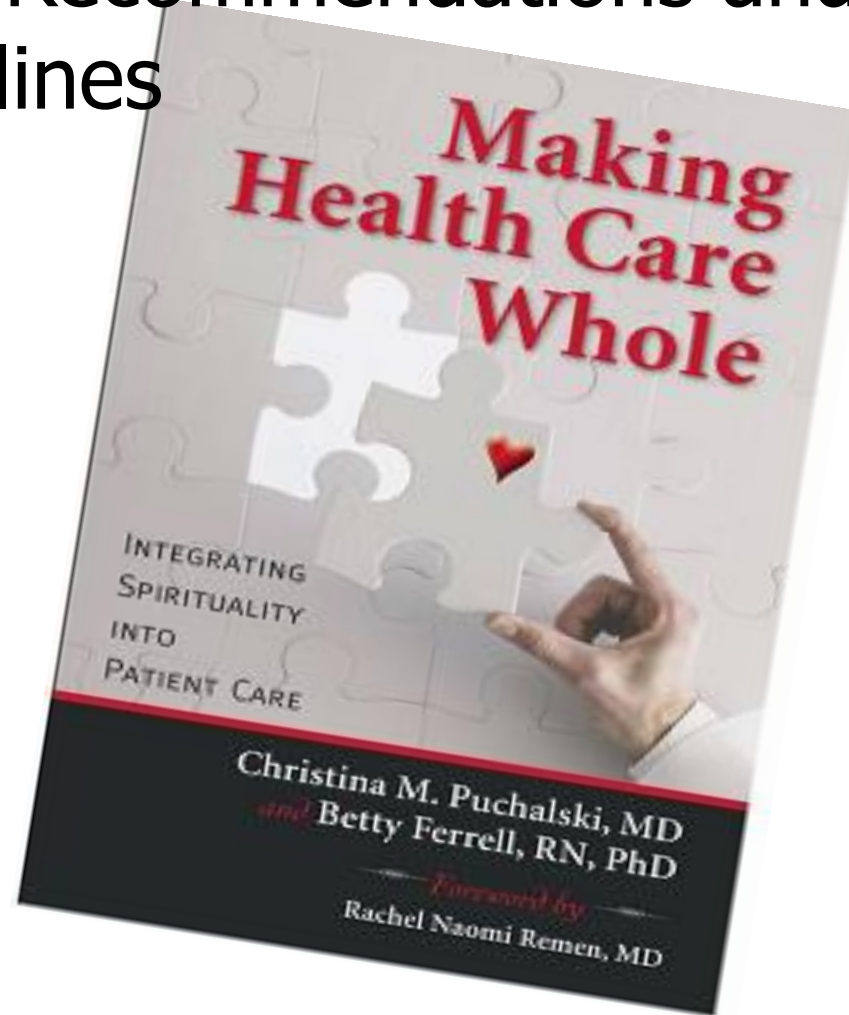


Compassion in Health Care: An Empirical Model

- Qualitative study of palliative cancer patients understanding experiences of compassion in care. Found seven themes.
- Virtues- genuineness, love
- Relational Space- engaged caregiving
- Virtuous Response- person as priority
- Seeking to Understand
- Relational Communicating-demeanor, affect
- ***Attending to Needs- physical comfort, spiritual, emotional***
- **Patient Related Needs- alleviates suffering**
- Sinclair et al. (2016) J of Pain & Symptom Management, 51(2), 193-203. (Open Access)



Whole Person Models of Care: Recommendations and Guidelines





Interprofessional Spiritual Care: An Integrated

Model (Improving the Quality of Spiritual Care as a Dimension of Palliative Care: Puchalski, Ferrell et al JPM 2009)

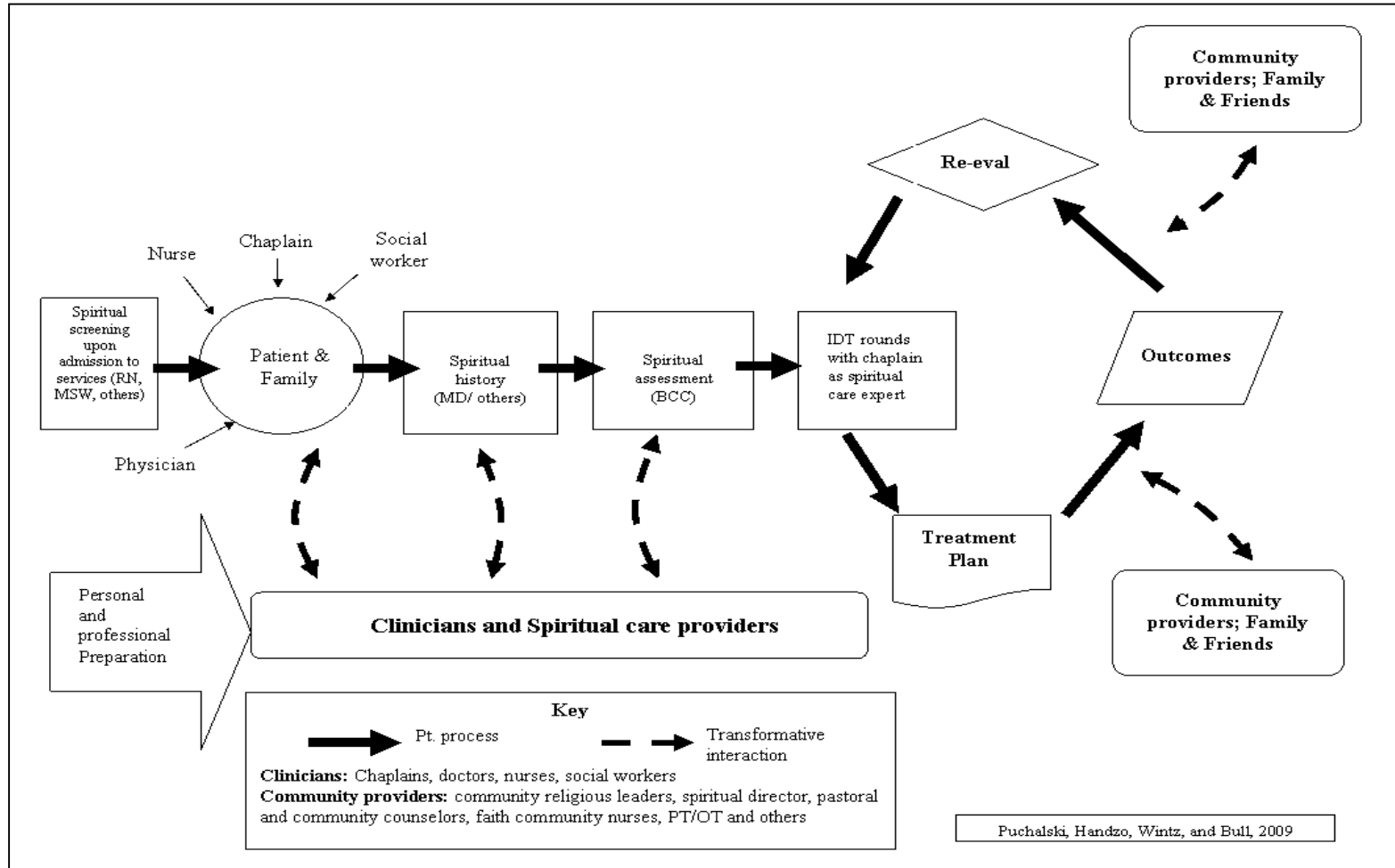
Recommendations:

- Integral to any patient-centered healthcare system
- ***Based on honoring dignity, attending to suffering***
- ***Spiritual distress treated the same as any other medical problem***
- Spirituality should be considered a “vital sign”
- ***Interdisciplinary (including Chaplains)***
 - ***Generalist specialist model of spiritual care***
- ***All patients get a spiritual history or screening***
- ***Integrated into a whole person treatment plan***

- Puchalski, Ferrell, Virani et.al. JPM, 2009



Consensus Conference: Spiritual Care Models





Spiritual Diagnosis

<i>Diagnoses (Primary)</i>	<i>Key feature from history</i>	<i>Example Statements</i>
Existential	Lack of meaning / questions meaning about one's own existence / Concern about afterlife / Questions the meaning of suffering / Seeks spiritual assistance	“My life is meaningless” “I feel useless”
Abandonment God or others	Lack of love, loneliness / Not being remembered / No Sense of Relatedness	“God has abandoned me” “No one comes by anymore”
Anger at God or others	Displaces anger toward religious representatives / Inability to Forgive	“Why would God take my child... its not fair”
Concerns about relationship with deity	Closeness to God, deepening relationship	“I want to have a deeper relationship with God”
Conflicted or challenged belief systems	Verbalizes inner conflicts or questions about beliefs or faith Conflicts between religious beliefs and recommended treatments / Questions moral or ethical implications of therapeutic regimen / Express concern with life/death and/or belief system	“I am not sure if God is with me anymore”



Spiritual Diagnosis (Con' t.)

<i>Diagnoses (Primary)</i>	<i>Key feature from history</i>	<i>Example Statements</i>
Despair/ Hopelessness	Hopelessness about future health, life Despair as absolute hopelessness, no hope for value in life	“Life is being cut short” “There is nothing left for me to live for”
Grief/loss	Grief is the feeling and process associated with a loss of person, health, etc.	“I miss my loved one so much” “I wish I could run again”
Guilt/shame	Guilt is feeling that the person has done something wrong or evil; shame is a feeling that the person is bad or evil	“I do not deserve to die pain- free”
Reconciliation	Need for forgiveness and/or reconciliation of self or others	“I need to be forgiven for what I did” “I would like my wife to forgive me”
Isolation	From religious community or other	“Since moving to the assisted living I am not able to go to my church anymore”
Religious specific	Ritual needs / Unable to practice in usual religious practices	“I just can’ t pray anymore”
Religious/Spiritual Struggle	Loss of faith and/or meaning / Religious or spiritual beliefs and/or community not helping with coping	“What if all that I believe is not true”



Diagnosis Discernment in Clinical Care (Diagnosis Pathway)

- Is the patient in distress? If so, is it physical, emotional, social or spiritual or a combination of these?
- Who needs to be involved on the team to address the different sources of distress? (mental health, chaplain, clergy, etc.)
- What can the clinician identifying the distress do on his/her own? (SIMPLE VS. COMPLEX)



The role of the non chaplain clinicians

- Address spiritual issues in care
- Identify or diagnosis spiritual distress
- Incorporate spiritual distress in assessment and plan
- Support spiritual resources of strength
- Work with trained chaplains and others on the team



Communication with Patients About Spiritual Issues: A Narrative and Medical approach



Communication about spiritual issues

- Narrative:
 - Inner story,
 - compassionate, deep, listening
- Medical: Diagnosis of spiritual distress
 - Diagnosis of spiritual distress
 - Identify spiritual resources of strength
 - Make the connection of spirituality with health, well-being, illness coping



Communicating About Spiritual Issues

- Recognizing spiritual themes, diagnosis or resources of strength
- Following a patient's lead
- Responding to spiritual cues
- Spiritual screening/spiritual history/
- Spiritual assessment (full assessment done by BCC)



Spiritual History

- Comprehensive
- Done in context of intake exam or during a particular visit such as breaking bad news, end of life issues, crisis
- Done by the clinician who is primarily responsible for providing direct care or referrals to specialists such as professional chaplains.



Spiritual History

- Intake: part of social history (formal)
- Follow up on patient lead
 - Listen to spiritual themes
 - Hope, despair, faith community, what is important, dreams, goals, meaning



Spiritual History

- FICA (Puchalski, 1996, 2000, 2006)
- Spirit (Maugins, 1996)
- Hope (Anandarajah, 2001)





Validation (COH)

- Inter-item correlation between FICA quantitative and COH spirituality domain of QOL instrument:
 - Religion
 - Activities
 - Change over time
 - Purpose
 - Hope
 - Spiritual



Faith/Belief/Meaning Theme (n=73)

- Appreciation of life and family 47
- Life activities work, purpose) 31
- Faith/Hope in healing 18
- Relationship with God 12
- Appreciation for life 7
- Reading Bible 5
- Agnostic 5
- Positive state of mind 5
- Religious affiliation 4
- Prayer 4
- Fate in God's Hands 4
- Nature 4



Community Theme (n=73)

- Family/friends 47
- Church 21
- Prayer 8
- Does not identify with community 5
- People with similar situations 4
- God 4
- Religious affiliation 3
- Medical team 1



Address in Care (n=73)

- Important but not necessary in care 15
- Integrate into care 41
- Provider should not be involved 5
- Unsure 10

Borneman T., Ferrell B., Puchalski C. (2010) Evaluation of the FICA Tool for Spiritual Assessment. *J. of Pain and Symptom Management*. 20(2), p. 163-173.



Chart documentation

- All clinicians and chaplains need to document spiritual issues in chart
- What needs to be documented:
 - spiritual diagnosis
 - relevant information from the spiritual history that pertains to the clinical situation
 - assessment and plan for the spiritual diagnosis including and follow up that is needed



Spiritual History

- F** - Do you have a spiritual belief? Faith? Do you have spiritual beliefs that help you cope with stress/what you are going through/ in hard times? What gives your life meaning?
- I** - Are these beliefs important to you? How do they influence you in how you care for yourself?
- C** - Are you part of a spiritual or religious community?
- A** - How would you like your healthcare provider to address these issues with you?



Developing Whole Person Assessment and Treatment Plans



Whole Person Treatment Plans

1. Is the patient in distress? Physical, emotional, spiritual, social? What are the resources of strength in each of these domains?
2. Make a diagnosis
3. Distinguish simple from complex
4. Recommend interventions/referrals
5. Referral to chaplain for complex spiritual issues
6. Write up plan that integrates all dimensions
7. Follow up



Interventions Clinicians Can Do

- Compassionate presence and follow up
- Reflective listening/query about important life events—spirituality as connection
- Support patient sources of spiritual strength and note in chart
- Connect patient to community resources
- Referral to chaplain or other spiritual care professional



Yvonne

Yvonne is a 68 year old female recently diagnosed with metastatic breast cancer. She has a life partner James and two children ages 42 and 47. She has severe right hip pain from a pathologic fracture which has left her wheelchair bound. Pain is 8-10/10. She has been active all her life and assumed she would travel the world with James when they both retired at age 65. She feels so sad that her life is cut short; she is angry with god—"Why me?" She does not share her deep despair with anyone as she does not want to burden her family; she feels very alone and scared about the uncertainty. She was offered surgery to rebuild her hip but she wonders if 3 months in rehab is worth it-she does not know how long she will be alive.



Spiritual History

- **F:** Methodist; church is important to her. Praying to God helps. (“ although now my prayer is about my anger with him”)
- **I:** Very important in her life, has always helped her cope
- **C:** Strong Community at church; but she does not really want to burden them so she stays at home
- **A:** Likes to talk with the chaplain but is afraid to share her anger about God with her pastor for fear she will be judged. She does wonder about her life and whether something she did caused this.



Review of Systems

- Physical: Pain 8-10/10, managed on Mscontin and dilaudid, occasional nausea associated with dilaudid, constipation, occasional insomnia
- Emotional: sad not depressed not anxious uncertain about surgery decision (her decision vs her family's)
- Social: good supports, but no one to talk to about deep issues
- Spiritual: anger at god, fear of uncertainty, existential distress, despair



Interventions by the team

- Elicit her Life Story
- Compassionate presence as she shares her suffering, despair, existential issues
- Explore sources of hope, meaning
- Help her identify spiritual goals for this phase of her life
- Referral to chaplain
- Inviting family to visit and encouraging patient to share if she would like



The Whole Person Assessment and Plan

Yvonne is a 68 yo female with end stage metastatic breast ca, severe pain managed on opioids, med associated nausea, constipation, occasional insomnia, spiritual and existential distress,

Physical

Continue with current pain regimen, add Zofran, add trazodone prn, and bowel regimen referral to ortho-onc for possible surgery to treat pain and improve mobility so patient can travel

Emotional

Supportive counseling, presence.

Social

Encourage family meeting to discuss prognosis, goals of care, encourage patient sharing if she would like,

Spiritual

Spiritual counseling with chaplain, team continues to be present, exploring sources of hope



Chaplain's Intervention

- Give patient permission to be angry with God
- Explore why me ?
- Help her to further articulate her despair, hopelessness
- Explore sources of potential guilt and perceptions of causing her illness
- Participate in family meeting to help with goals of care and empowering patient to speak her voice
- Help her to identify and communicate hopes, dreams, beliefs



Compassionate Care: Clinical Dance of Science and Spirituality

- Assessment and Diagnosis; Reflection and Compassion
- Clinical models create tools that enable us to hear the patient's whole story, give voice to patient and his/her suffering, dreams, wishes, concerns in the clinical context
- Deep listening helps patient heal their suffering, their distress



Spirituality and Health Education: Whole Person Care

- Patient care
 - Spiritual history
 - Spiritual distress diagnosis and treatment
 - Biopsychosocialspiritual Assessment and treatment plan
 - Compassionate presence to persons' suffering
- **Student/resident/clinician formation**
 - **Inner life focus**
 - **Meaning, purpose, call to serve**
 - **Authenticity**
 - **Compassionate presence– to self**



The National Initiative to Develop Competencies in Spirituality for Medical Education: A National Consensus Conference

(Puchalski, C, Blatt, J. Kogan, M, Butler, A , Spirituality and Health: Development of a
Field Academic Med, 2014)



Compassionate Presence

- Discuss why it's a privilege to serve the patient
- Describe personal and external factors that limit your ability to be present to others
- Describe strategies to be more present with patients
- Describe how you as a clinician/student can be changed by your relationship with your patient



Competency-based initiatives

- GTRR—Reflection Rounds
- GW Curriculum Change--- Reflection as essential to formation of student



The Gift Of Presence: Spiritual Hospitality

Listening is much more than allowing another to talk while waiting for a chance to respond. Listening is paying full attention to others and welcoming them into our very beings.

The beauty of listening is that those who are listened to start feeling accepted, start taking their words more seriously and discovering their true selves. Listening is a form of spiritual hospitality by which you invite strangers to be friends, to get to know their inner selves more fully, and even to dare to be silent with you.

Nouwen, H. Bread for the Journey



Formation of Doctors

- GTRR Reflection Rounds
 - Piloted in 17 medical schools
 - Use of specially trained mentors
 - Currently integrated into required curriculum
 - Based on competencies and group spiritual direction
 - Connecting the mind and heart of students (David Irby, 2006)



GTRR Modified verbatim

- How were you affected emotionally by the encounter?
- Were there any aspects of this encounter that carried spiritual significance for you or the patient?
- What was uniquely spiritual/humanistic about what you did?
- What attitudes, beliefs, values, assumptions, previous personal relationships and experiences influenced you and how you responded to this patient/family?
- Did this experience change your subsequent encounters with patients in any way?
- One competency-based question for reflection?



GWU--Spirituality as part of Patient Care

- Spiritual history integrated in total history (since 1996)
- Spiritual distress assessment and treatment-whole person assessment and treatment
 - Oliver mann orientation
 - Chronic care
 - Wellness
- Working with trained chaplains
- Integrated in palliative care, chronic illness
 - Breaking bad news, living with dying
 - Reflections on gross anatomy



Formation in New GWU curriculum

- Formation within small reflection groups
 - pre-clerkship years and
 - Reflection rounds during the clerkship years.
- Objectives for students will include
 - attaining awareness of their own
 - spirituality, suffering call or motivation, authenticity
 - recognition of inner resources to attend to patients' distress, (psychosocial and spiritual)
 - development of skills to
 - listen deeply to the patient's story (spiritual, other)
 - Capacity for Presence
 - Boundaries (vs. Distancing)
 - Self care, wellness,
 - Medical error
 - Palliative Care (breaking bad news, dealing with dying)
 - "Meditation" ;Threaded throughout the curriculum



Global Network for Spirituality Health (GNSAH)

- **GNSAH** was formed to enhance the provision of high quality comprehensive and compassionate care to patients and families globally through the integration of spirituality into health systems.
- The role of this network is to provide a way members can work together to more fully integrate spiritual care, including training, service delivery, and standards into health systems. This global network will:
 - Facilitate information sharing among members
 - Foster collaboration among members
 - Collect and disseminate emerging best practices
 - Provide a platform for advocacy



Recommended Standards for Spiritual Care

1. *Spiritual care is integral to compassionate, person-centered health care and is a standard for all health settings.*
2. *Spiritual care is a part of routine care and integrated into policies for intake and ongoing assessment of spiritual distress and spiritual well-being.*
3. *All health care providers are knowledgeable about the options for addressing patients' spiritual distress and needs, including spiritual resources and information*
4. *Development of spiritual care is supported by evidence-based research.*
5. *Spirituality in health care is developed in partnership with faith traditions and belief groups.*
6. *Throughout their training, health care providers are educated on the spiritual aspects of health and how this relates to themselves, to others, and to the delivery of compassionate care.*



Recommended Standards for Spiritual Care

- 7. Health care professionals *are trained in conducting spiritual screening or spiritual history as part of routine patient assessment.*
- 8. All health care providers are *trained in compassionate presence, active listening, and cultural sensitivity*, and practice these competencies as part of an interprofessional team.
- 9. All health care providers are *trained in spiritual care commensurate with their scope of practice*, with reference to a spiritual care model, and tailored to different contexts and settings.
- 10. Health care systems and settings provide opportunities to develop *and sustain a sense of connectedness with the community they serve*; healthcare providers work to create healing environments in their workplace and community.
- 11. Health care systems and settings support and encourage health care providers' *attention to self-care, reflective practice, retreat, and attention to stress management.*
- 12. Health care systems and settings focus on *health and wellness and not just on disease.*



430 Members From All around the World





Global Examples of Spiritual Care

- Betty Ferrell, PhD, RN ELNEC 91 countries (all resource poor)
- Europe: various models
 - Masters in Spiritual Care (Belgium)
 - CPE based in Scotland
 - Pastoral theologians, pastoral counselors developing Masters In spiritual care (clergy, pastoral counselors, clinicians) Switzerland
- South Africa
 - Pastoral Counselors volunteering in spiritual care for general population
 - Training with palliative care team Oct 2017
- Asia
 - Hawaii Pacific Health Ministry CPE training program
 - Catholic University Seoul, Korea
 - Sr. Julianna Yong 3 month training program for the Catholic Sisters(Nurses) on addressing spiritual issues (Textbook Spiritual and Health ,Oxford University Press (Cobbs, Puchalski, Rumbold (ed) translated into Korean, 2016)
- Chile: Universite de Catholique, Mexico
 - CPE –based program
 - Curriculum for medical school; palliative care team



Care of the person: based on honoring dignity, attending to suffering



We can cure physical diseases with medicine, but the only cure for loneliness, despair, and hopelessness is love. There are many in the world who are dying for a piece of bread, but there are many more dying for a little love....

— *Mother Teresa* —

AZ QUOTES



GWish, www.gwish.org

- Education resources (SOERCE, National Competencies)
- Interprofessional Initiative in Spirituality Education (nursing, medicine, social work, pharm, psychology)
- Retreats for healthcare professionals (Assisi, U.S.)
- Time for Listening and Caring: Oxford University Press
- Making Healthcare Whole, Templeton Press
- FICA Assessment Tool—online DVD
- Spiritual and Health Summer Institute, July 10-13, GWU
- INSPIR
- Christina Puchalski, MD, 202-994-6220,
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