Addressing Spiritual Needs Across the Cancer Care Continuum

November 29, 2016
2:30-3:30PM EST
Agenda

• Welcome and introductions (5min)
• Brief introduction of the topic (5min)
• Brief presentations by expert speaker (10min)
  – Jamie Aten
  – Leslie Piet
  – Christina Puchalski
• Open Discussion (20min)
• Wrap up
Learning Objectives

• Learn lessons on cultivating cancer patients and survivor spirituality and resilience
• Learn about psychology of religion/spirituality and disaster research that can help inform spirituality oriented care of cancer patients and survivors
• Compare/contrast case management and palliative care
• Identify at least three aspects of spirituality/cultural assessment
• Understand the potential value of teaching The Four Things That Matter Most
• Describe the role of spirituality in the care of patients with cancer care
• Discuss an interprofessional model of spiritual care in cancer care
• Identify ways to communicate with patients about their spiritual issues
Understanding the Role of Spirituality in Cancer Survivorship: A Personal Reflection

Jamie D. Aten, Ph.D.
Founder & Director,
Humanitarian Disaster Institute
Wheaton College
A Walking Disaster
What Not to Say or Do

• Avoid making spiritual assumptions
• Don’t focus on finding THE answers
• Avoid bumper-sticker theology and phrases
• Be careful not to be pushy or judge spiritual experiences
• Don’t be hesitant to refer for additional spiritual care
Spiritual Support

• Can improve access to social support and resources
• Buffers against common negative psychological stressors
• Associated with fewer spiritual struggles
• Can help address wide range of needs
Meaning Making

- Helps make sense of cancer experience
- Difference between meaning making attempts and meaning making made but similar outcomes
- Buffers against PTSD symptoms while improving life satisfaction and well-being
- Important to fostering positive coping, especially positive religious coping
- Doesn’t happen over night, takes time
Spiritual Surrender

• Correlated with greater positive spiritual outcomes
• Helps clarify what people have control over and don’t have control over
• Sometimes a passive avoidance response; can actually be an incredibly powerful willful act of faith
• Can paradoxically enhance locus of control
Resources

Humanitarian Disaster Institute
www.wheaton.edu/HDI
Faith for Enduring Life’s Disasters
www.jamieaten.com
To Heal & Carry On
www.psychologytoday.com/blog/heal-and-carry
Twitter @drjamieaten
https://twitter.com/drjamieaten
Spiritual Advice for Surviving Cancer and Other Disasters
A Walking Disaster (Video)
https://www.youtube.com/watch?v=ER26CNWUy5w
This presentation was made possible through the support of a grant from the John Templeton Foundation (Grant #44040). The opinions expressed in this publication are those of the author(s) and do not necessarily reflect the views of the John Templeton Foundation.
Spirituality and Palliative Care

A Palliative Care Case Management Perspective

Presented by: Leslie Piet, RN, MA, CCM, CHPN
November 29, 2016
Objectives

• Compare/contrast case management and palliative care
• Identify three goals of a Spiritual assessment
• Understand the potential value of teaching the four things that matter most
Case Management Definition

• Case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality, cost-effective outcomes.

• [www.cmsa.org/Definition](http://www.cmsa.org/Definition)
Palliative care definition

- Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.
- Palliative care is provided by a specially-trained team of doctors, nurses, social workers and other specialists who work together with a patient’s doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

https://getpalliativecare.org/whatis/
Case Management and Palliative care

Case management
- Collaborative process
- Holistic assessments on going
- Care coordination
- Communication across disciplines
- Meet patient/family needs
- Promote quality/cost effective outcomes
- Identify/promote patient goals of health care and life
- For those with serious illness who are high risk for readmission

Palliative care
- Collaborative process
- Holistic assessments on going
- Care coordination
- Communication across disciplines
- Meet patient/family needs
- Promote quality of life
- Identify/promote patient goals of health care and life
- For those with serious illness at any point in the continuum
Spirituality Assessment

Learn:

• the beliefs/values of patient
• cultural practices that may affect care decisions
• how the patient seeks comfort/meaning during tough times
The WHO definition of palliative care includes taking care of the spiritual (care) needs of patients. It is essential that the spiritual (care) needs of patients, family and carers in all settings are adequately met. There is much discussion about the definition of spirituality. Based on the 2009 Consensus Conference in the US, at the invited conference in October 2010 this taskforce has agreed upon the following working definition and comment:

- **Spirituality** is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.
- **The spiritual field** is multidimensional:
  - Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
  - Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).
  - Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).

The Four Things That Matter Most

“Please forgive me.”
“I forgive you.”
“Thank you.”
“I love you.”

http://irabyock.org/books/the-four-things-that-matter-most/
I learned something from a doctor that I know, which you may find helpful. It is about everyday relationships, but it becomes even more important if you are facing a serious illness. That is to say the four things that matter most. They are: “Please forgive me. I forgive you. Thank you. And I love you.” What do you think?
Some Feedback

• Three family members told me the last words from their loved one was “I love you.”
• A doctor’s office told me that the patient came in two weeks before he died to tell them thank you for their good care.
• A daughter asked her dying mother for forgiveness for all the times she hadn’t been a good daughter.
Addressing Spiritual Needs in Cancer Care

Christina M. Puchalski, M.D., FACP, FAAHPM
Professor of Medicine
The George Washington Institute for Spirituality and Health (GWish)
The George Washington University School of Medicine and Health Sciences
Washington, D.C.
“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 Needs in Patients with Cancer
(369 oncology outpatients in NYC)

<table>
<thead>
<tr>
<th>Spiritual need</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Overcoming fears</td>
<td>37%</td>
</tr>
<tr>
<td>Finding peace of mind</td>
<td>30%</td>
</tr>
<tr>
<td>Finding hope</td>
<td>28%</td>
</tr>
<tr>
<td>Finding meaning in life</td>
<td>27%</td>
</tr>
<tr>
<td>Spiritual resources</td>
<td>27%</td>
</tr>
<tr>
<td>Talk about meaning of life</td>
<td>20%</td>
</tr>
<tr>
<td>Talk about death and dying</td>
<td>20%</td>
</tr>
</tbody>
</table>
N=230 patients with advanced cancer.

From Balboni et al, J of Clinical Oncology, 2007
Spiritual Distress

• 73% of cancer patients expressed at least one spiritual need (Astrow et al, J Clin Onc 2007)

• 40% of newly diagnosed cancer patients have significant levels of spiritual distress (Holland et al J NCCN, 2010)

• Illness can question issues of meaning, purpose (Puchalski, Ferrel, Viranit et al, JPM 2009)
Religion/Spiritual effect on health (Fitchett et al, Cancer 2015)

- Metaanalysis of four patient databases (cochrane, pubmed, psychinfo and health and allied health) of cancer patients
- R/S associated with better patient reported physical health, mental (less depression, anxiety, better mental wellbeing), and better social health (capacity to maintain social roles and relationships)
Palliative care and spiritual wellbeing in lung cancer patient and family caregivers

- Multidimensional definition of spirituality used
- Patients/fgc received four educational sessions one focused on spiritual wellbeing
- Both religious and non religious patients improved spiritual wellbeing post intervention
- Spiritual wellbeing core component of quality of life. Important to address this component
- Sun, Irish, Borneman, Sidhu, Klein and Ferrell, Psych Onc August 2015
Cancer Diagnosis: Why Me?

- Spirituality may help people find answers, find hope, meaning
  - Cancer patients report their spirituality helped them find hope, gratitude and positivity in their cancer experience
- Spirituality can help with reframing
  - My illness is a blessing
  - What an opportunity to see life in a different way

ASCO Palliative Care in Oncology Guidelines: Domain 3

- Domain 3: Spiritual and Cultural Assessment and Management.
  - Spiritual assessment of spiritual distress (faith, grief)
  - Basic spiritual support— for eg giving framework to consider goals, hope along with medical outcomes
  - Referrals to spiritual care professionals
  - Culturally appropriate language
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”

Multidisciplinary (including Chaplains)

All patients get a spiritual history or screening

Integrated into a whole person treatment plan

- Puchalski, Ferrell, Virani et.al. JPM, 2009
Formulation of a Biopsychosocialspiritual Assessment and Treatment Plan

Recommendations:

• Screen, History and Assess for spiritual distress and resources of strength

• All HCPs should do spiritual screening

• Clinicians who refer should do spiritual histories and develop appropriate treatment plans working with Board Certified Chaplain if possible

• Identify spiritual distress (Diagnostic labels and codes)

• Treatment plans that include psychosocial and spiritual

• Support/encourage in expression of needs and beliefs
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?
Ms. CM is an 88 year old patient coming to physicians’ office to discuss the results of a breast biopsy—est/pr/Her-2 negative. Options for treatment are surgery then chemotherapy. Breast surgeon asking her PMD to discuss findings and goals of care regarding medical decisions.
• Inter-item correlation between FICA quantitative and COH spirituality domain of QOL instrument:
  • Religion
  • Activities
  • Change over time
  • Purpose
  • Hope
  • Spiritual
Ms. CM’s Spiritual History

• F: Catholic, has deep personal relationship with God; meaning in helping others and her family
• I: central to her life, has gotten her through many challenges in her life
• C: Church regular attendance, sings in choir, supportive community
• A: Deep faith, some why me? Why god doing this? What is purpose? Many issues about independence being threatened and being a burden to her family? Great meaning in helping family and others and now wondering what that will mean for her in the setting of a big surgery and having cancer
Ms. CM is an 88 yo female with newly diagnosed breast cancer, (triple neg), HTN, hypothyroidism, supportive family, though she is concerned about loss of independence as son takes more caregiver role, deep faith and some questioning as to reason, also expresses some concern re loss of meaning. Goals of care include being present for family and continue to care for them, trying to do the next right things and treat the cancer without a lot of aggressive chemo and side effects that would affect her QOL.

<table>
<thead>
<tr>
<th>Physical</th>
<th>Discuss referrals to oncology, surgery and potential treatment options and help navigate Those appts. Education on differences in treatment options with prognosis</th>
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<tbody>
<tr>
<td>Emotional</td>
<td>No depression no anxiety</td>
</tr>
<tr>
<td>Social</td>
<td>Discuss with family and patient ways for her to maintain her independence</td>
</tr>
<tr>
<td>Spiritual</td>
<td>Continued presence, referral to chaplain on team, offer sacraments</td>
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Spiritual Care is Compassionate Multidisciplinary Care

• Listening to the whole story of the patient

• Attending to psychosocial and spiritual as well as physical pain and suffering

• Integrating patient’s beliefs, values, practices as appropriate, into the treatment plan

• “Healing” in relationship
GWish, www.gwish.org

- Education resources (SOERCE, National Competencies)
- Interprofessional Initiative in Spirituality Education (nursing, medicine, social work, pharm, psychology)
- Global Network in Spirituality and Health (GNSAH)
- 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, GWU
- Christina Puchalski, MD, 202-994-6220, cpuchals@gwu.edu
Thank you!
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@GWCCancer
www.cancergate.org
Post-presentation Evaluation Survey

https://www.surveymonkey.com/r/GATEATESpirituality
Ask the Expert sessions are components of the Generation and Translation of Evidence (GATE) Cancer Community of Practice (CoP), a project funded through a Patient-Centered Outcomes Research Institute (PCORI) Award #1426.

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