Integration of Spirituality in Palliative Care Education and Research

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Professor and Director
City of Hope National Medical Center
Objectives

• Discuss spiritual care as a component of Education and Research Projects at City of Hope Medical Center 1989 – 2015

• Describe national training programs which have focused on improving spiritual assessment and care by health care professionals.

• Describe research projects that have included spirituality as a component of interventions and outcomes.

• Identify opportunities for collaboration between spiritual care providers and clinical researchers to advance spiritual care and the evidence base for practice.
Spirituality as a Component of Education and Research Projects at City of Hope Medical Center 1989-2015
Quality of Life Model Applied to the Patient

**Physical Well Being**
- Functional Ability
- Strength / Fatigue
- Sleep & Rest
- Overall Physical Health
- Nausea
- Appetite
- Constipation
- Aches/Pains

**Psychological Well Being**
- Control
- Anxiety
- Depression
- Enjoyment/Leisure
- Pain Distress
- Happiness
- Fear
- Cognition/Attention

**Social Well Being**
- Family Distress
- Roles and Relationships
- Affection/Sexual Function
- Appearance
- Employment
- Isolation
- Finances

**Spiritual Well Being**
- Meaning of Illness
- Uncertainty
- Hope
- Religiosity
- Transcendence
- Positive change

**QOL**
Quality of Life Model Applied to Family Caregivers

Physical Well Being
- Fatigue
- Sleep Disruption
- Function
- Nausea
- Appetite
- Constipation
- Aches/Pain

Psychological Well Being
- Isolation
- Role Adjustment
- Financial Burden
- Roles/Relationships
- Affection/Sexual Function
- Leisure
- Burden
- Employment

Social Well Being
- Anxiety
- Depression
- Helplessness
- Difficulty Coping
- Fear
- Useless
- Concentration
- Control
- Distress

Spiritual Well Being
- Meaning
- Uncertainty
- Hope
- Religiosity
- Transcendence
- Positive change
National Consensus Project Clinical Practice Guidelines & 8 Domains

Domain 1: Structure and Processes of Care
Domain 2: Physical Aspect of Care
Domain 3: Psychological and Psychiatric Aspects of Care
Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious and Existential Aspects of Care
Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient at the End of Life
Domain 8: Ethical and Legal Aspects of Care
Education Projects
End of Life Nursing Education Consortium, (ELNEC)

- Initiated in 2000
- Curriculum includes ELNEC Core, Pediatrics, Geriatrics, Critical Care, DNP, Advanced Practice
Module 6: Relating
Talking About Uncertainty
Improving Quality of Life and Quality of Care for Oncology Family Caregivers

• **Investigators:**
  Principal Investigator Betty Ferrell, PhD, RN
  Co-Investigator Marcia Grant, PhD, RN

• **Funder:**
  National Cancer Institute
  Grant # 1 R25 CA 132664-01A2

• **Years:**
  May 1, 2010 – April 30, 2015
Course Agenda
Day 3: July 12, 2013

Focus on Spiritual Well-Being

• State of the Science Lecture: Spiritual Well-Being and Family Caregivers: Deriving Meaning and Faith in Caregiving

• Models of Excellence: Spiritual Well-Being
Spiritual Assessment of Patients and Families

Recommendations

• Spiritual screening
• Assessment tools
• All staff members should be trained to recognize spiritual distress
• HCP’s should incorporate spiritual screening as a part of routine history/evaluation
• Formal screening by Board Certified Chaplain
• Documentation
• Follow-up
• Response within 24 hours
Pain Resource Nurse (PRN) Course
24th Annual Course

Course Syllabus

AUGUST 26 to 28, 2014
7:30 a.m. to 4 p.m.

Featured Speaker
Chris Passier, M.S., R.N., BC, FAAN

Sponsored by:
City of Hope, Depomed, Purdue, Salix, Teva

Faces Pain Rating Scale

0 Hurt
2 Hurts little bit
4 Hurts little more
6 Hurts even more
8 Hurts whole lot
10 Hurts worst

0-10 Numeric Pain Rating Scale

© Pain Resource Nurse Training Course, 2014
Preparing Professional Nurses for Cancer Survivorship Care

• **Investigators:**
  Principal Investigators: Marcia Grant, RN, PhD, FAAN, Mary McCabe, RN, MA
  Co-Investigator: Betty Ferrell, RN, PhD, FAAN, FPCN, CHPN
  Project Director: Denice Economou, RN, CNS, AOCN

• **Funder:**
  National Cancer Institute
  Grant # NCI R25 CA151077

• **Years:**
  2011-2016
Preparing Professional Nurses for Cancer Survivorship Care

September 11-13, 2014
Annapolis, MD

R25 CA151077
Funded by the National Cancer Institute
Preparing Professional Nurses for Cancer Survivorship Care

Agenda

Day 1  Thursday, September 11, 2014

7:00 – 8:00  Breakfast

8:00 – 8:20  Pre Test- K & A Exam

8:20 – 8:30  Introduction & Welcome, Marcia Grant, RN, PhD, FAAN

8:30 – 9:00  Preparing Professional Nurses for Cancer Survivorship Care
              IOM Video, Marcia Grant, RN, PhD, FAAN

9:00 – 10:00  Building a Survivorship Program-The Nurse as Architect
              Mary McCabe, RN, MA

10:00 – 10:15  Break

10:15 – 10:45  Listening to Survivors’ Perspectives
              The Wounded Healer, Professional Survivor: Deborah K. Mayer, RN, PhD, AOCN, FAAN
              Lay Survivor Videos-Memorial Sloan-Kettering Cancer Center

IOM COMPONENTS OF SURVIVORSHIP CARE

Communication

10:45 – 11:45  Treatment Summaries & Survivorship Care Plans: Approach, Value & Feasibility
              Linda Jacobs, PhD, RN

Prevention

11:45 – 12:30  Prevention in Survivorship Care: Promoting Wellness, Wendy Demark-Wahnefried, PhD, RD

12:30 – 1:30  Lunch – Setting Specific Table Talk

Interventions: Physical Well Being

1:30 – 2:30  Fatigue, Pain, Sleep: Evidenced-Based Management Strategies in Cancer Survivors,
              Linda Jacobs, PhD, RN

2:30 – 3:15  Introduction to Goal Refinement, Denise Economou, RN, CNS, CHPN
              Goal Breakouts–Small group breakouts for goal refinement

3:15 – 3:30  Break

Interventions: Physical Well Being

3:30 – 4:30  Cardiovascular and Pulmonary Late Effects After Cancer Treatment:
              Evidenced-Based Management Strategies For Survivors, Deborah K. Mayer, RN, PhD, AOCN, FAAN

4:30-5:15  Spiritual Care as a Dimension of Survivorship Care, Betty Ferrell, RN, PhD, FAAN,
            FPCN,CHPN

5:15 – 5:30  Evaluations

Resource Fair throughout Day
Communication Training COMFORT

• COMFORT™℠ Communication for Palliative Care Teams (Archstone Foundation)
  – Course Date: January 28-29, 2015
  – Location: Los Angeles, CA

• COMFORT™℠ Communication for Oncology Nurses (NCI R25)
  – Course Dates: June 11-12, 2015 & October 15-16, 2015
  – Locations: Anaheim, CA & Washington, DC

*Website for more information: www.pccinstitute.com
After weeks of suffering debilitating fatigue, Mrs. Rothstein, a previously independent and very active, 74-year-old female with mild cognitive impairment, is hospitalized, requiring ICU level of care for severe heart failure. Referred by the ICU team, the palliative care physician and nurse meet with Mrs. Rothstein’s husband of 50 years, who also has mild cognitive impairment, and her brother, a retired psychotherapist, to share one-on-one, cardiac tumor.
Integration of Spirituality in the COMFORT™ Curriculum

• Module O-Openings
  – Module focuses topics of conversation that allow providers to address transitions in care
  – Spiritual distress is identified as an opening and spiritual review is taught
  – Training video depicts chaplain conducting spiritual review with a patient

• Module R-Relating
  – Module focuses on discussing quality of life
  – AMEN Protocol is described for patients/families believing in and waiting for a miracle cure
  – Training video features nurse-family caregiver discussion about forgiveness and regret
Communication Resources

• Palliative Care Communication Institute
  — Provides resources for providers, patients, and families based on communication research.

• iOS Health Communication App
Research Projects
Eliminating Barriers to Pain and Fatigue Management

• NCI Funded R01- Betty Ferrell, PhD
• Testing and institutional change model
Integration of Spiritual Care Across Projects


Reducing Barriers to Pain and Fatigue Management

Assessing Spirituality: FICA

Distress, including spiritual distress, refers to unpleasant emotions that may interfere with the ability to cope with cancer. A diagnosis of cancer can be a crisis of faith or belief (NCCN Distress Guidelines)

FICA Acronym:

F - Faith, Belief, Meaning

Do you consider yourself spiritual or religious?

"Do you have spiritual beliefs that help you cope with stress?"

What gives your life meaning?

I - Importance and Influence

What importance does your faith or belief have in your life?

Have your beliefs influenced you in how you handle stress?

Do you have specific beliefs that might influence your healthcare decisions?

C - Community

Are you a part of a spiritual or religious community?

Is this of support to you and how?

Is there a group of people you really love or who are important to you?

A - Address/Action in Care

"How should the healthcare provider address these issues in your healthcare?"

Extreme Distress

10

9

8

7

6

5

4

3

2

1

No Distress

(Puchalski, 1996; www.gwish.org)

Funded by NCI

Spiritual Care at City of Hope

"There is no profit in curing the body if in the process we destroy the soul"

Samuel H. Golfer

City of Hope Creed

The staff, at City of Hope, is committed to caring for our patients—body, mind and spirit. We truly believe that the mind and spirit are every bit as important as the body. So while our medical, nursing and psychosocial staff are working to heal the body and mind, our spiritual care department is committed to the spirit and addressing the suffering that is part of facing cancer.

Many people are very faithful to a particular tradition and would describe themselves as religious. Others might not be affiliated with a religious institution, but do consider themselves quite spiritual and connected to something greater than themselves.

Spiritual Care at City of Hope isn’t limited to those who identify with a particular religious tradition or teaching. Our chaplains provide spiritual care to each individual, providing support in whatever way best serves the patient and family.
# PCI Interdisciplinary Care Plan

## Patient Demographics & Disease Data

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>M □, F □</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Caregiver: □ Y □ N □</td>
</tr>
<tr>
<td>Children</td>
<td># Sons □ # Dtr □ # Other □</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Date of 1st Dx</td>
<td></td>
</tr>
<tr>
<td>Routinely Exercise</td>
<td>□ Y □ N</td>
</tr>
<tr>
<td>Other Cancer Dx</td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
</tr>
</tbody>
</table>

## Comorbidities

- Stage
- Supportive Services
- KPS
- Smoking Hx: □ Never Smoker □ Current Smoker □ Previous smoker but not currently a smoker
- Advance Directive: □ Y □ N
- Insurance: □ Y □ N □ Sponsored □ Charity
- Private: □ Medi-Cal □ Medicare □ None

## PHYSICAL DOMAIN

<table>
<thead>
<tr>
<th>Lab Values</th>
<th>Date:</th>
<th>Weight in Lbs:</th>
<th>BMI:</th>
</tr>
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<tbody>
<tr>
<td>WBC:</td>
<td>G/dL</td>
<td>(4.0-11.0)</td>
<td></td>
</tr>
<tr>
<td>Hgb:</td>
<td>K/mL</td>
<td>(11.5-15.5)</td>
<td></td>
</tr>
<tr>
<td>Albumin:</td>
<td>G/dL</td>
<td>(3.5-5.0)</td>
<td></td>
</tr>
<tr>
<td>BUN:</td>
<td>MG/dL</td>
<td>(4-20)</td>
<td></td>
</tr>
<tr>
<td>Cr:</td>
<td>MG/dL</td>
<td>(0.70-1.30)</td>
<td></td>
</tr>
</tbody>
</table>

## ADL (p3) Needs assistance with:

- □ NA

## IDT Suggestions

- □ NA

## Your Daily Activities (p 14) Needs assistance with:

- □ NA

- □ Use of telephone
- □ Get to places out of walking distance
- □ Shopping for ...........
- □ Prepare own meals
- □ Housework
- □ Take own meds
- □ Handle own money
- □ Eyesight
- □ Hearing
- □ Patient Self-Eval (any of last 4)
Summary of Key Opportunities
Integration of Spirituality in Education and Research

- Spirituality as a component of Self Care
- Spiritual Assessment
- Spirituality as a component of Culturally Respectful care
- Teaching about spirituality through role play, case studies, self assessment, panels, videos
- Spirituality as key in ethical consideration
- Use of models that incorporate spirituality
- View of professional practice as sacred work
Oxford Textbook of Palliative Nursing

- Chapter 28 – The Meaning of Hope in the Dying
- Chapter 29 – Bereavement
- Chapter 30 – Supporting Families in Palliative Care
- Chapter 31 – Planning for the Actual Death
- Chapter 32 – Spiritual Assessment
- Chapter 33 – Spiritual Care Intervention
- Chapter 34 – Meaning in Illness
Communication Programs are based on the COMFORT™ Curriculum

- Communication (clinical narrative practice)
- Orientation & Options
- Mindful Communication
- Family Caregivers
- Openings
- Relating
- Team

Preferred COMFORT™ Reference
Module 5: Openings
Common Ground, Self-Disclosure, and Quality of Life