Spiritual Care Research in the Palliative Care Setting - Issues and Possibilities

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To describe the importance of spirituality, religiosity, and spiritual distress in the palliative care setting.

To describe research health outcomes concerning spirituality, religiosity and spiritual distress in the palliative care setting.

To describe research health outcomes concerning multidisciplinary spiritual care interventions for patients with advanced illnesses and their caregivers.
• Outpatient at the Palliative Care clinic
• 62 y/o male, chronic smoker
• No prior medical history
• Advanced Lung Cancer, which has spread to bone and liver. Now receiving chemotherapy and radiation
• Married, 3 adult children. Now living with one daughter.
• Pain in chest and back, fatigue, not eating well, and insomnia (too much thinking).
• We talked about the physical issues and how he was coping with everything that has been happening with him…
TELL ME A LITTLE BIT MORE ABOUT THAT PAIN…

• “Can’t resist this pain…not worth to live…
• It’s deep inside of me…
• Do you have pain in your soul?
  
  \textit{It is just horrible…}

• What do you think is causing you that pain?
  \textit{I feel I have lost everything… I can’t control it…}
  \textit{I have failed to my family…and too my self…}
  \textit{I don’t want to be a problem to them…}

• No suicidal thoughts or plan
• What are your worries? Your fears?
WHAT DOES GIVE YOU STRENGTH AT THIS TIME OF YOUR LIFE…

• I guess…in the middle of this “hell”… I don’t know…
• What has been important in your life…even before your diagnosis? And now…
• My wife… my grandkids…
• Is God an important part in your life? It has been always… I guess I need to go back to church…
• Do you have a relationship with Him… YES
IT IS A PROCESS IN LIFE…

Life Review: identifying what has helped him in difficult moments also.
Helping him to reconnect with his Higher Power and reconnect with his family.

*I’m just grateful to have them with me…*

It is important to continue to have your faith, because it might give you strength through all these moments. Also it might give you strength and the peace to accept things when you are not able to change them…

Our interdisciplinary team continued to provide support and counseling to the patient and caregivers.
We work as a team and we care about you… we will continue to provide you the best quality of life and comfort and continue to walk with you through this process…
TALKING TO THE CAREGIVER…

• How are you doing… How are you holding up with this situation?
  
  I’m OK…and she started crying…

• It must be really difficult to see your loved one in this situation…
  
  Honestly…sometimes I feel abandoned and at times I feel mad at God…

• How has your relationship been with God?
  
  I Love God, and I know He is here with us…I guess I look for that strength always…
  
  I pray…and many people are praying for us.

• It is a process, and you are doing a great job for being here.
THE PATIENT AND CAREGIVER

• His physical symptoms were better controlled and he was feeling more at peace.
• Patient continued to receive and complete his cancer treatment.
• Currently there is no evidence of recurrence. Followed up by his oncologist.
• Patient continues to visit Palliative Care Outpatient clinic for his symptoms management.
• He completed his Advanced Directives
• Counseling and support has continued to be provided to the patient and his caregiver.
Symptom Distress

Advanced illness Patients

- Pain
  - Somatic Neuropathic
  - Advanced age Comorbidities

- Cognitive Impairment Delirium

- Fatigue Cachexia
  - Lymphedema

- Nausea and Vomiting

- Constipation, Bowel Obstruction, Ascites

- Dyspnea

- Socio/cultural and financial distress

- Emotional and Spiritual Distress

- Sexual Distress

- Family/Caregiver Distress

SUFFERING/ANGUISH

- Preoccupation with future or past
- Sense of disconnection from self, others, phenomenal world, ultimate meaning
- Crisis of meaning; an existential vacuum; inability to find solace or peace
- A need to be in control

Emotional and Spiritual Distress
Loss of Being and Relationships
QUALITY OF LIFE CONTINUUM

• Life-threatening illness is an assault on the whole person—physical, psychological, social, spiritual, and also Sexual.

Areas of Relationship

~ To Self
~ To the other
~ To the Holy
~ To the environment
~ To the Evil
Spirituality is a lifelong developmental task, lasting until death.
Spirituality, Religiosity and Spiritual pain in advanced cancer patients and caregivers

- N: 100 advanced cancer patients
- Median Age: 53 y/o (range 21 – 85) Female: 61%, Married 58%, Single 11%
- Caucasian: 74%  African American: 18% Hispanic: 4%, Others: 4%
- Cancer Diagnosis
  - Breast: 19%
  - Sarcoma: 13%
  - Gynecologic: 10%
  - Head and Neck: 9%
  - Other: 9%
  - Lung: 15%
  - Gastrointestinal: 11%
  - Genitourinary: 9%
  - Hematologic: 5%

<table>
<thead>
<tr>
<th><strong>Results</strong></th>
<th><strong>Frequency (0 vs. 1-10)</strong></th>
<th><strong>Median intensity (interquartile range)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you consider yourself a spiritual person?</td>
<td>97 (98%)</td>
<td>9 (7-10)*</td>
</tr>
<tr>
<td>Do you consider yourself a religious person?</td>
<td>94 (98%)</td>
<td>9 (5-10)*</td>
</tr>
<tr>
<td>Is spirituality/religiosity a source of strength and comfort to you?</td>
<td>99 (100%)</td>
<td>10 (8-10)*</td>
</tr>
<tr>
<td>Does spirituality/religiosity help you cope with your illness?</td>
<td>98 (99%)</td>
<td>10 (8-10)*</td>
</tr>
<tr>
<td>Does spirituality/religiosity help your family member/caregiver cope with your illness?</td>
<td>89 (99%)</td>
<td>9 (6-10)*</td>
</tr>
</tbody>
</table>

* [0 to 10 (max) scale]

SPIRITUALITY AND RELATED ASPECTS

- Positive Effect on:
  - * Chronic pain
  - * Psoriasis in patients receiving phototherapy
  - * Greater social support
  - * Fewer depressive symptoms geriatrics pts.
  - * Increased physical and mental health
  - * Improves Quality of Life

Chochinov HM, Cann BJ. J Palliat Med 2005;8S1:103-115
LANGUAGE COMFORTABLE AND ACCESSIBLE

OPENNESS TO ONGOING DIALOGUE REGARDING EMOTIONAL AND SPIRITUAL CONCERNS

A COMPASSIONATE ENVIRONMENT TOWARDS HEALING

The relationships as a Blessing
Empathic understanding is about absolute valuing of the other person and the world that they live in. Without this, they will not feel cared for, trusted or worthwhile.

‘Could a greater miracle take place than for us to look through each other's eyes for an instant?’ Henry David Thoreau (2008)

Palliative care clinicians who are continually exposed to others' emotions without actually receiving adequate support themselves may well end up experiencing emotional exhaustion and, eventually, burnout.

Nyatanga B. British Journal of Community Nursing 2013
Cratitude

Well-Being

Savoring positive life circumstances
Coping with negative life circumstances
Trying to counteract negative emotions

Happiness

PATIENTS’ SPIRITUAL NEEDS AND CLINICIANS

- Help in overcoming fears (51%)
- Finding hope (45%)

- Finding meaning in life (40%)

- Finding spiritual resources (39%)

- Having somebody to talk about with about the meaning of life and death (25%)

- Treated as whole persons and with sensitivity *

SPIRITUAL NEEDS IN PATIENTS WITH ADVANCED ILLNESS

“Assisting The Elderly And Palliative Care.”

Palliative Care, He Said, “Is An Expression Of The Properly Human Attitude Of Taking Care Of One Another, Especially Of Those Who Suffer. It Bears Witness That The Human Person Is Always Precious, Even If Marked By Age And Sickness.”

Pope Francis, Vatican 2015
• ...An urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases.
• ...is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure.
PALLIATIVE CARE

•...is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual. (WHO, 2002a)
Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.

Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

73 FR 32204, June 5, 2008

Medicare Hospice Conditions of Participation – Final Rule
EVOLUTION OF PALLIATIVE CARE

1990’s –
Review of WHO definition of Palliative Care and WHO analgesic ladder
Evolving and fluctuating terminology: Support Teams, PC Teams, Pain and Palliative Care Teams, Supportive and PC Services/Teams

1987 –
WHO definition of palliative care
WHO analgesic ladder for cancer pain control
Palliative Medicine subspecialty of Medicine (UK- Dr. Doyle)
1975- First Hospital “Support Teams”/Palliative Care Teams

1967 – Modern Hospice Movement
(St Christopher’s London)
1900 – St. Joseph’s Hospice
Modern (catholic) Hospice

Medieval Hospice

Fallon M, Smyth J. Eur J Cancer 2008;44:1069-1071
TRADITIONAL CONCEPT OF PALLIATIVE CARE

Potentially Curative Treatment → Palliative Care → Death

Time
KEY ELEMENTS OF PALLIATIVE CARE

• Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness.

• …Integrated into the existing health system at all levels of care, especially community and home-based care.

• …involving public and the private sector and are adapted to the specific cultural, social and economic setting.
PALLIATIVE CARE

• ...provides relief from pain and other distressing symptoms
• ...affirms life and regards dying as a normal process
• ...intends neither to hasten nor to postpone death
• ...integrates the psychological and spiritual aspects of patient care
• ...offers a support system to help patients live as actively as possible until death
INTEGRATED MODEL OF CURATIVE AND PALLIATIVE CARE FOR CHRONIC PROGRESSIVE ILLNESS

Disease-modifying therapy
(curative, life-prolonging or palliative in intent)

Bereavement Care
Hospice

Presentation Diagnosis Illness Death

Cultural Competent PALLIATIVE CARE
THE PALLIATIVE CARE TEAM...
THE COLLECTIVE SOUL
OWN CULTURE AND SPIRITUALITY

Improve Quality of Life for Patients and Families

- Physician
- Nurses
- Pharmacist
- Physical & Occupational Therapy
- Psychological Counselors
- Other Healthcare Professionals and Volunteers

- Social Worker
- Case Manager
- Chaplain
- Music & Art Therapy
- Case Manager
- Social Worker

- Music & Art Therapy
- Case Manager
- Social Worker
- Physician
- Nurses
- Pharmacist
- Physical & Occupational Therapy
- Psychological Counselors
- Other Healthcare Professionals and Volunteers
CONTINUUM OF CARE

Curative → Non-Curative → End-Stage

Supportive Care techniques (pain control) → Supportive and Palliative Care

Hospital-based care

Palliative Care (formerly Terminal Care)

In a Multicultural competent environment

Fallon M, Smyth J. Eur J Cancer 2008;44:1069-1071
Patient populations served by Palliative Care

- Pts. with congenital injuries or dependent on life-sustaining tx.
- Pts. with chronic and limiting injuries from accidents or other forms of trauma
- Pts. with acute, serious, life-threatening illness
- Pts. seriously and terminally ill
- Pts. living with progressive chronic conditions

(All ages, gender, cultures)
## OUTCOMES OF PALLIATIVE CARE INTERVENTIONS

<table>
<thead>
<tr>
<th>Citations</th>
<th>Symptoms</th>
<th>Quality of life</th>
<th>Mood</th>
<th>Satisfaction</th>
<th>Resource use</th>
<th>Advance care planning</th>
<th>Survival</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bakitas et al. 2009 (8)</td>
<td>Improved $p = 0.06$</td>
<td>Improved $p = 0.02$</td>
<td>Improved $p = 0.02$</td>
<td>Not measured</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
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<tr>
<td>Nurse-led intervention</td>
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<tr>
<td>Brumley et al. 2007 (13)</td>
<td>Not measured</td>
<td>Not measured</td>
<td>Not measured</td>
<td>Improved $p &lt; 0.05$</td>
<td>Cost $7,500 less, $p = 0.03$ Hospital days reduced by 4.36 ($p &lt; 0.001$) ED visits reduced by 0.35 ($p = 0.02$)</td>
<td>Not measured</td>
<td>No difference</td>
<td>Lower</td>
</tr>
<tr>
<td>PC team intervention</td>
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<tr>
<td>Gade et al. 2008 (34)</td>
<td>No difference</td>
<td>No difference</td>
<td>No difference</td>
<td>IPCS, greater satisfaction with care ($p = 0.04$) and communication ($p = 0.0004$)</td>
<td>Costs $6,766 less ($p &lt; 0.001$). Net cost savings of $4,855 ($p &lt; 0.001$). Longer median hospice stays (24 versus 12 days, $p = 0.04$)</td>
<td>IPCS patients had more ADs at discharge than UC patients (91.1% versus 77.8%; $p &lt; 0.001$)</td>
<td>No difference</td>
<td>Lower</td>
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<tr>
<td>PC team intervention</td>
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## OUTCOMES OF PC INTERVENTIONS

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<tbody>
<tr>
<td>Higginson et al. 2011 (45) PC team intervention in OP setting</td>
<td>Improved</td>
<td>Improved</td>
<td>NR</td>
<td>NR</td>
<td>Lower with PC</td>
<td>NR</td>
<td>NR</td>
<td>Lower</td>
</tr>
<tr>
<td>Temel et al. 2010 (97) PC team intervention</td>
<td>Improved $p = 0.04$</td>
<td>Improved</td>
<td>Less depression</td>
<td>Not measured</td>
<td>Less aggressive care $p = 0.05$, $2,200$ per-person savings</td>
<td>More ADs documented in PC group $p = 0.05$</td>
<td>11.6 versus 8.9 months $p = 0.02$</td>
<td>Lower</td>
</tr>
<tr>
<td>Zimmermann et al. 2012 (110) PC team intervention in OP clinics</td>
<td>Improved ($p = 0.05$)</td>
<td>Improved ($p = 0.007$)</td>
<td>NR</td>
<td>Improved ($p &lt; 0.001$)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
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</tbody>
</table>

Healthcare professionals need to be aware of how cultural determinants influence a person’s role within their family structure, their health beliefs, and how a diagnosis of cancer may affect decisions regarding life planning, life goals, and end-of-life preferences.

The cultural context of communication is an important aspect in palliative care.

Best practices in communication skills can promote comfort and hope while diminishing suffering and distress.
Ethical principles, healthcare decision-making, truth telling, role expectations, life values, medical terminology, and disclosure are culturally interpreted.

Cultural beliefs: Patient preferences; to understand individual decision-making preferences.

Influence on the meaning and experience of death and dying

Impact on symptom management (eg, pain control and feeding), advance care planning, and grief and bereavement counseling.

Sharma RK, Dy SM. *Am J Hosp Palliat Care* 2011 28: 437
Palliative care has generated the evidence that dramatically changed the care of patients and their families facing incurable diseases.

(Bruera E. and Hui D. Palliat Med 2013)

Ability to understand the emotional state of another person, i.e. ‘putting yourself in another’s shoes’.

When offered appropriately, empathy can help others to continue living their lives with enhanced quality of life and dignity in dying.
EARLY PALLIATIVE CARE INTERVENTIONS AND CLINICAL OUTCOMES

Early, Integrated PC Model Practices and Processes
- Team approach
- Decision-making
- Educational support

Patient-level Targets
- Physical
- Psychological
- Sociocultural
- Spiritual/Existential
- Ethical/legal

Caregiver Support

Quality of Life
Physical Symptoms
Mood

Illness knowledge
And understanding

Health Behaviors:
Anticancer therapies
End-of-life care

Coping behaviors

Survival

BARRIERS TO PALLIATIVE CARE ACCESS

Perceived Barriers to Palliative Care Access According to Cancer Center Executives

- Limited Palliative Care Needs
- Limited Institutional Budget
- Poor Reimbursement
- Limited Trained Palliative Care Staff
- Lack of Evidence for Palliative Care
- Palliative Care May Increase Hospital Mortality
- Palliative Care May Affect National Rating
- Palliative Care Available But Not Utilized
- Other

NCI indicates National Cancer Institute. Perceived barriers to palliative care access were based on the question “Irrespective of whether palliative care is offered at your institution, what in your opinion, are some of the potential barriers to palliative care access for your institution? (check all that apply).” Error bars indicate 95% confidence intervals.

Hui D, et al. JAMA 2010;303 (11):1054-1061
TRAJECTORIES OF ILLNESSES OVER THE TIME


Selwyn P. J of Palliat Med 2003;6:475-487
NO CLEAR DEFINITION OF END-OF-LIFE

Life-limiting disease with irreversible decline and expected survival in terms of months or less.

1) place of care (e.g., hospital to home)
2) level of professions providing the care (e.g., acute care to hospice)
3) goals of care (e.g., curative to palliative).

“hours or days of survival.”
Palliative Care: Ongoing Research. Research Topics. Number Of Groups

pan-European survey

66 out of 89 groups reported conducting clinical trials

The most common study design for the clinical trials was the randomized controlled trial (65% of the groups), followed by observational studies (61%) and prospective nonrandomized trials (58%)
Research Opportunities at this stage of life

More observational studies conducted by following up patients close to the end of their lives.

Different patient populations (CHF, COPD, CKD, Cancer, Neurological diseases) and in different settings

Identify risk factors for the most common complications such as infection, thromboembolic disease, or sudden death.

Randomized, controlled trials of different communication interventions will help us improve the effectiveness of our psycho-educational interventions with patients and families.

Interventions aimed at minimizing the emotional impact of preparation for end of life both in patients and families. Socio-demographic characteristics, underlying disease, and different settings of care.
WHAT WE HAVE LEARNED…

Assessment tools need to have clinically actionable items. Asking questions that do not have clinical utility is impractical.

The assessment tools should be easy to use, without requiring extensive training.

All assessment tools need to be short, and all of them need to be free since the vast majority of palliative care programs have very limited budgets.

Education

Bruera E. and Hui D. Palliat Med 2013
• Studies should ideally be designed by investigators rather than drug companies to minimize bias.

• A crossover study design improves power and allows patients and investigators to provide a global blinded choice.

• Our studies emphasize that palliative care research needs to include placebo whenever possible since expectations of improvement can have a dramatic effect on subjective outcomes. Placebo is scientifically and ethically justified in this population.

• Most symptom problems in cancer patients are multidimensional.

• A better understanding of cachexia and fatigue helped move research from single intervention to multimodal interventions aimed at reducing the false-negative rate of these studies.

Bruera E. and Hui D. Palliat Med 2013
LESSONS LEARNED ABOUT PC RESEARCH

• Patient-reported and family caregiver–reported outcomes are useful. Efforts to include family caregivers’ observations are likely to improve the accuracy of our diagnosis and monitoring, care delivery, and perhaps even the bereavement process.

• Clinicians frequently underestimate symptom burden in palliative care patients.

• Underdiagnosis of delirium by clinicians results in undertreatment of this devastating syndrome. Further efforts are needed to improve the detection and treatment of delirium.

Bruera E. and Hui D. Palliat Med 2013
Palliative care programs can decrease physical and emotional distress as well as change the place and cost of death.

Regularly measuring and reporting the impact of our programs, clinical and financial outcomes are crucial to the maintenance and growth of our field.

**LESSONS LEARNED ABOUT PC RESEARCH**

Bruera E. and Hui D. Palliat Med 2013
### Research Opportunities in Palliative Care Study Design

<table>
<thead>
<tr>
<th>Issues</th>
<th>Problems</th>
<th>Potential Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topics</td>
<td>Nebulous Orphaned</td>
<td>Research opportunities Research opportunities</td>
</tr>
<tr>
<td>Randomization</td>
<td>Relatively few new treatments Tx Accessible without clinical trials</td>
<td>Multimodal interventions, programs Compare to gold standard Clinician education</td>
</tr>
<tr>
<td></td>
<td>Perceived lack of equipoise</td>
<td>Wait list design, open label phase, cluster randomization</td>
</tr>
<tr>
<td>Blinding</td>
<td>Devices, procedures, counseling cannot be blinded easily</td>
<td>Innovative research designs Not essential for objective outcomes</td>
</tr>
</tbody>
</table>
## Research Opportunities in Palliative Care

### Patient Enrollment and Retention

<table>
<thead>
<tr>
<th>Issues</th>
<th>Problems</th>
<th>Potential solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frail Patients</td>
<td>Low interest in symptom research</td>
<td>Generally favorable</td>
</tr>
<tr>
<td></td>
<td>Short survival, too tired</td>
<td>Limit study burden and duration</td>
</tr>
<tr>
<td></td>
<td>Low recruitment</td>
<td>Incentives</td>
</tr>
<tr>
<td></td>
<td>High attrition</td>
<td>Multicenter study</td>
</tr>
<tr>
<td>Patient consent</td>
<td>Delirium</td>
<td>Consent in advance</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>Surrogate consent</td>
</tr>
<tr>
<td>Clinicians</td>
<td>Too busy</td>
<td>Encouraging boss, invested resources</td>
</tr>
<tr>
<td></td>
<td>Lack of training and interest</td>
<td>Education and incentives</td>
</tr>
<tr>
<td>Ethical concerns</td>
<td>Vulnerable patients?</td>
<td>Careful study design (equipoise)</td>
</tr>
<tr>
<td></td>
<td>Not giving “best” treatment?</td>
<td>Wait list design</td>
</tr>
<tr>
<td></td>
<td>Placebo?</td>
<td>Informed consent (risk vs. benefits)</td>
</tr>
<tr>
<td></td>
<td>Harm?</td>
<td>Safeguard with ethics review board</td>
</tr>
<tr>
<td></td>
<td>Taking precise time away?</td>
<td>and data safety and monitoring board</td>
</tr>
</tbody>
</table>
BARRIERS TO RESEARCH IN PALLIATIVE CARE

- Funding
- Institutional Capacity
- Research workforce
- Challenging nature of population and topic
- Public and professional misunderstanding and discomfort with palliative care

Barriers In General for PC research. Number Of Groups

- Pan-European Survey

Research Challenges
Funding Sources

542/848 (59%) original palliative oncology studies reported no funding sources
43% of randomized controlled trials did not report no funding sources
Palliative Care Research Challenges

Hui et al. JAMA 2010

Hui et al. JAMA 2010
Research Challenges

Personnel

Limited number of research staff

- Research chairs
- Research MDs
- Research RNs
- Research data Coordinators
- Research data analysts

Difficult to recruit and retain

- What is “palliative care”
- Stress
- Funding

Research Challenges

Infrastructure

- Research Staff
- Biostatistical support
- Administrative staff
- Databases
- Equipment
- Space
- Collaborators (institutional, national, international)
Professions
- Medicine
- Nursing
- Psychology
- Social Work
- Rehabilitation
- Chaplains
- Complementary medicine

Disease Groups
- Cancer
- Kidney disease
- Heart Failure
- COPD
- Cystic fibrosis
- Liver Failure
- AIDS
- Neuromuscular disease
- Dementia
- Pediatric diseases
- Frailty

Settings
- Inpatient
- Outpatient
- Palliative Care Units
- Consult teams
- ICU
- Hospice
- Home

Research Topics
- Physical Symptoms (53%)
- Health services (13%)
- Communication (4%)
- Psychosocial (9%)
- Quality of life (6%)
- Research methodology (5%)
- Decision Making (4%)
- Complementary medicine (2%)
- Spiritual/Existential issues (2%)
- Education (2%)

Study Design
- Retrospective case report (30%)
- Retrospective case series (20%)
- Cohort study (9%)
- Cross sectional study (18%)
- Population based study (3%)
- Qualitative study (11%)
- RCT (6%)

Study Populations
- Patients (84%)
- Caregivers (9%)
- Health Care professionals (10%)

Research Challenges
Diversity needed.
Pan-European survey

Priorities for the field concerning future research on adults with cancer in their last year of life.

## SPIRITUALITY/SPIRITUAL CARE RESEARCH PRIORITIES

<table>
<thead>
<tr>
<th>Priority</th>
<th>Rank</th>
<th>Sum Score (Number Prioritizing)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluate screening tools used to identify patients with spiritual needs</td>
<td>1st</td>
<td>1243 (449)</td>
</tr>
<tr>
<td>Develop and evaluate conversation models for spiritual conversations with palliative patients</td>
<td>2nd</td>
<td>1219 (470)</td>
</tr>
<tr>
<td>Evaluate the effectiveness of spiritual care</td>
<td>3rd</td>
<td>1194 (394)</td>
</tr>
<tr>
<td>Develop and evaluate spiritual interventions, e.g., pastoral counseling, interventions by nonspecialist spiritual care providers (e.g., physicians, nurses)</td>
<td>4th</td>
<td>1185 (411)</td>
</tr>
<tr>
<td>Determine the prevalence of spiritual distress among people with incurable progressive illness in different cultural and religious populations</td>
<td>5th</td>
<td>1102 (401)</td>
</tr>
<tr>
<td>Conduct longitudinal studies to understand how patients’ spiritual needs change</td>
<td>6th</td>
<td>870 (287)</td>
</tr>
<tr>
<td>Develop spiritual care for palliative care staff</td>
<td>7th</td>
<td>845 (261)</td>
</tr>
<tr>
<td>Determine the best spiritual outcome measures for research and audit purposes in palliative care</td>
<td>8th</td>
<td>817 (254)</td>
</tr>
<tr>
<td>Develop and evaluate models of spiritual care, e.g., community engagement, spiritual care in palliative homecare</td>
<td>9th</td>
<td>791 (253)</td>
</tr>
<tr>
<td>Develop spiritual care for family carers</td>
<td>10th</td>
<td>726 (216)</td>
</tr>
<tr>
<td>Determine clinical factors potentially associated with spiritual distress, e.g., cancer types, cancer vs. noncancer diagnoses</td>
<td>11th</td>
<td>608 (185)</td>
</tr>
<tr>
<td>Determine demographic factors potentially associated with spiritual distress, e.g., age, gender, socioeconomic status</td>
<td>12th</td>
<td>486 (145)</td>
</tr>
<tr>
<td>Develop spiritual care for patients with dementia</td>
<td>13th</td>
<td>359 (107)</td>
</tr>
<tr>
<td>Evaluate the cost-effectiveness of spiritual care</td>
<td>14th</td>
<td>339 (100)</td>
</tr>
<tr>
<td>Develop spiritual care in pediatric palliative care</td>
<td>15th</td>
<td>321 (102)</td>
</tr>
</tbody>
</table>

SPIRITUALITY AND PALLIATIVE CARE RESEARCH

Variables

Religious affiliation
Socioeconomical and Cultural and philosophical differences

Sexual identity

Gender
Age
Language

Disease Performance Status Settings

Caregivers

Health care providers

Patients with advanced illnesses could describe and respond questions and instruments intended to capture Spiritual Aspects of their Experience.

There are patients in Palliative Care with spiritual needs for whom Spiritual Beliefs and practices are meaningful and active.

Patients want to be known as individuals and able to share their journey.

SPIRITUALITY IN PALLIATIVE RESEARCH

Nature of the Spiritual Experience

Narratives Commentary Interpretative Explanations

Qualitative Methods Synopses Themes Schema

Illustrative schemas Theoretical Models

Understanding of provision of Spiritual Care Role of health care provider in Spiritual Care

Coping
Religious Coping
Symptom Distress
Relationship among Spirituality and other phenomena
Meaning of life
Existence/Essence
Spiritual Caregiving
> Satisfaction and value
Treatment options
Decision making
Emotional distress
Family distress
Quality of life
Spirituality And Religion

Spirituality
- Dimension of personhood
  - A part of our being
  - Broader than Religion

Religion
- Construct of human making
- Conceptualization and Expression of spirituality

Belief systems: address spiritual issues
codes of ethical behavior and philosophy

Choctinov HM, Cann BJ. J Palliat Med 2005;8S1:103-115
Religious Coping

Positive Religious Coping

~ “I think my life is part of a larger spiritual force…”
~ “I work together with God as partners to get through hard times?
~ “I try to find the lesson from God in crisis”
~ “I look to God for strength, support, and guidance in distress”
~ “I confess my sins and ask for God’s forgiveness”

Religious Coping

- Negative religious coping
  - Religious apathy
  - God’s Punishment
  - Anger at God
  - Religious doubts
- Interpersonal religious conflict
- Conflict with church dogma
- Religious denial, passivity
- Self-neglect

Spiritual Pain
Loss of Being and relationships
Essential dimension
Existential dimension
SPIRITUAL PAIN

Awareness of death +
Loss of Relationships +
Loss of Self

Loss of Purpose +
Loss of Control

Life Affirming and transcending purpose +
Internal sense of Control

Adapted from Millspaugh D, J of Palliat Med 2005; 6: 1110-1117
• “A deep pain in your being... in your soul, that is not physical”
• 57 pts with advanced cancer in a PC hospital
• Interviewed by chaplain
• 96% had Spiritual pain sometime in their life
• 61% had Spiritual Pain at the time of interview
• Mean of Spiritual Pain 4.6/10
Do you think you are experiencing **spiritual pain** now and how would you rate your overall spiritual pain?

<table>
<thead>
<tr>
<th>Do you think you are experiencing spiritual pain now and how would you rate your overall spiritual pain?</th>
<th>40 (44%)</th>
<th>Mean: 3 (1-6) (0-10 max)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Patient Characteristics (Age, Female sex, Christian, KPS)</th>
<th>No Spiritual Pain (N=51)</th>
<th>Spiritual Pain (N=40)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Reported Spirituality and Religiosity</td>
<td></td>
<td></td>
<td>NS</td>
</tr>
<tr>
<td>Do you consider yourself a spiritual person?</td>
<td>10 (7-10)</td>
<td>8 (6-10)</td>
<td>0.018</td>
</tr>
<tr>
<td>Do you consider yourself a religious person?</td>
<td>10 (7-10)</td>
<td>7 (5-9)</td>
<td>0.002</td>
</tr>
<tr>
<td>Is spirituality/religiosity a source of strength/comfort to you?</td>
<td>10 (9-10)</td>
<td>8.5 (7-10)</td>
<td>0.004</td>
</tr>
<tr>
<td>Does spirituality/religiosity help you cope with your illness?</td>
<td>10 (9-10)</td>
<td>9 (7-10)</td>
<td>0.03</td>
</tr>
<tr>
<td>Does spirituality/religiosity help your family member/caregiver cope with your illness?</td>
<td>10 (7-10)</td>
<td>8 (5-10)</td>
<td>0.04</td>
</tr>
</tbody>
</table>

Domains of Spiritual Pain in Adv. Cancer Patients

- **Intra-Psychic Dimension** 34.4%
  - expressed as despair, isolation, guilt, punishment, without faith, abandoned by the Divine

- **In Relation with the Divine** 49.2%
  - expressed as suffering loss, despair, regret, anxiety

- **Interpersonal Dimension** 16.4%
  - expressed as isolation and regret, disconnected from others

*Delgado-Guay MO, et al. EAPC 2010, Glasgow UK*
Health care providers and medical institutions often do not do a good job of attending to spiritual dimension of the patient's care.

Most importantly is that attention to religious/spiritual issues has been shown to have a significant influence on several important indicators of quality care.

Regular assessments of spiritual distress/spiritual pain in the SCOC setting are limited or no available. We modified the Edmonton Symptom Assessment Scale (ESAS-fs) adding two items following the same scale (0=best, 10=worst) to evaluate: Spiritual Pain (SP) and Financial-Distress (FD).

Delgado-Guay MO, et al. MASCC 2014, Miami FL
Methods

We reviewed 282 consults of AdCa evaluated at our SCOC between October-2012 and January-2013.

Symptoms were assessed using ESAS-fs.

We determined the frequency, intensity and correlates of self-reported SP(pain deep in your soul/being that is not physical) among these AdCa.

Delgado-Guay MO, et al. MASCC 2014, Miami FL
Descriptive statistics were generated for demographic variables and both baseline and follow up clinical measures.

Spiritual Pain was defined as any ESAS Spiritual Pain score greater than 0.

Spiritual Pain at baseline and follow up were compared using a two-sided McNemar’s test.

Spearman correlations of continuous ESAS Spiritual Pain with other measures were calculated at both baseline and follow up.

Baseline ESAS variables were tested for association with change in intensity of Spiritual Pain using spearman correlations.

Delgado-Guay MO, et al. MASCC 2014, Miami FL
Mean age (range): 60 years (22-92). 53% were male.

189 (65%) were White, 45 (15%) African-American, and 34 (12%) Hispanic.

123/282 (44%) AdCa had Spiritual Pain. Mean (95% Confidence-Interval) 4 (3.5-4.4).
RESULTS

• AdCa with Spiritual Pain had
  • worse Pain [mean(95%CI) 5.3(4.8, 5.8) vs. 4.5(4.0, 5.0)] (p=0.03),
  • depression [4.2(3.7, 4.7) vs. 2.1(1.7, 2.6), p<0.0001],
  • anxiety [4.2(3.6, 4.7) vs. 2.5(2.0, 3.0), p<0.0001],
  • drowsiness [4.2(3.7, 4.7) vs. 2.8(2.3, 3.2), p<0.0001],
  • Well-Being [5.4(4.9, 5.8) vs. 4.5(4.1, 4.9), p=0.0136],
  • and FD [4.4(3.9, 5.0) vs. 2.2(1.8, 2.7), p<0.0001].
SP correlated (Spearman) with Depression \( r=0.45, p<0.0001 \); Anxiety \( r=0.34, p<0.0001 \); Drowsiness \( r=0.26, p<0.0001 \), and FD \( r=0.44, p<0.0001 \).

Multivariate-analysis showed association with FD [OR(95% Wald CI) 1.204 (1.104-1.313), \( p<0.0001 \)] and Depression [1.218(1.110-1.336), \( p<0.0001 \)].

The odds of patients with SP at baseline being also SP at follow up were 182% higher (OR=2.82) than for patients for SP-negative at baseline (\( p=0.0029 \)).

SP at follow up correlates with depression (\( r=0.35, p<0.0001 \)), anxiety (\( r=0.25, p=0.001 \)), Well-being (\( r=0.27, p=0.0006 \)), nausea (\( r=0.29, p=0.0002 \)), and FD (\( r=0.42, p<0.0001 \)).
Conclusion: Spiritual Pain was reported in more than 40% of AdCa. It correlates with physical and psychological distress. The use of ESAS-sf allows identifying AdCa with SP evaluated in a SCOC. More research is needed.
ADVANCED CANCER PATIENTS WITH SPIRITUAL DISTRESS IN PCU SETTING

<table>
<thead>
<tr>
<th></th>
<th>No Spiritual Distress (%)</th>
<th>Spiritual Distress Present (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 63</td>
<td>N = 50</td>
</tr>
<tr>
<td>Mean age, in years (standard deviation)</td>
<td>64 (14.3)</td>
<td>55 (14.6)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>28 (44)</td>
<td>17 (34)</td>
</tr>
<tr>
<td>Male</td>
<td>35 (56)</td>
<td>33 (66)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>11 (18)</td>
<td>10 (20)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7 (11)</td>
<td>9 (16)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>40 (64)</td>
<td>29 (58)</td>
</tr>
<tr>
<td>Asian</td>
<td>5 (8)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Median length of APCU stay in days (interquartile range)</td>
<td>8 (5-11)</td>
<td>7 (6-13)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>48 (76)</td>
<td>44 (81)</td>
</tr>
<tr>
<td>Jewish</td>
<td>3 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Buddhist</td>
<td>2 (3)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Hindu</td>
<td>2 (3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Muslim</td>
<td>1 (2)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Others</td>
<td>7 (11)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Median Edmonton Symptom Assessment scale (interquartile range)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>2 (1-4)</td>
<td>4 (1-7)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4 (1-7)</td>
<td>4 (1-7)</td>
</tr>
<tr>
<td>Nausea</td>
<td>1 (0-1)</td>
<td>1 (1-1)</td>
</tr>
<tr>
<td>Depression</td>
<td>1 (0-2)</td>
<td>2 (1-4)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1 (1-4)</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>1 (1-6)</td>
<td>4 (1-6)</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>2 (1-4)</td>
<td>2 (1-5)</td>
</tr>
<tr>
<td>Appetite</td>
<td>6 (3-8)</td>
<td>5 (2-8)</td>
</tr>
<tr>
<td>Sleep</td>
<td>3 (1-5)</td>
<td>4 (1-5)</td>
</tr>
<tr>
<td>Well-being</td>
<td>3 (1-5)</td>
<td>5 (1-5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domains</th>
<th>Number of Patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Despair</td>
<td>36 (32)</td>
</tr>
<tr>
<td>Dread</td>
<td>33 (29)</td>
</tr>
<tr>
<td>Broken</td>
<td>31 (27)</td>
</tr>
<tr>
<td>Helplessness</td>
<td>28 (25)</td>
</tr>
<tr>
<td>Alienation</td>
<td>18 (16)</td>
</tr>
<tr>
<td>Meaningless</td>
<td>17 (15)</td>
</tr>
<tr>
<td>Guilt/shame</td>
<td>10 (8)</td>
</tr>
</tbody>
</table>

23/43 (53%) of the caregivers reported experiencing Spiritual Pain at the moment of the interview.

- Family manage multiple care giving tasks
- Including emotional task of preparing for the loss of a loved one
- Poor communication with health care providers can render the family helpless
- May feel selfish regarding their own needs
- Trigger thoughts of their own mortality
Intra-Psychic Dimension 58.6%

Suffering loss, despair, regret, or anxiety

Feeling disconnected from others and unwanted by family/friends

Domains of Spiritual Pain in Caregivers

In Relation with the Divine 27.6%

Being without faith and/or religious/spiritual community, feeling abandoned by God

Interpersonal Dimension 13.8%

PEACE TO YOU
Mr. OR is a 53-year-old farmer with Colorectal cancer metastatic to liver and bone. Poor performance status.

In talking about the future course of his illness, and that he is not candidate for chemotherapy, he begins to cry. His wife is also tearful.

He has strong faith, and tells you he is not ready to give up. Believes that God is going to cure him, he is praying for a miracle, and he wants everything to be done; only He can decide when it is time to stop.

The next most appropriate statement would be:
Besides be silent and then reassure them that you will be with them until the end. The next most appropriate statement/question would be:

A. Tell him you going to continue to talk with him at later time  
B. Tell him you understand the difficult situation and will do everything until the end  
C. Ask him: How might we know when God thinks it is the time?  
D. Tell him that “not even a miracle will cure you”  
E. Tell him you will send somebody else (a chaplain) to discuss about that issue  

(C)
MEANING OF “EVERYTHING”

Affective Domain
- Abandonment
- Fear
- Anxiety
- Depression

Cognitive Domain
- Incomplete understanding
- Reassurance that best medical care is given
- All possible has been done

Family Domain
- Differing perceptions
- Family conflict
- Children or dependents

Spiritual Domain
- Vitalism
  - Faith in God’s will

MEANINGS OF EVERYTHING

Affective Domain
- Abandonment
- Fear
- Anxiety
- Depression

Cognitive Domain
- Incomplete understanding
- Reassurance that best medical care is given
- All possible has been done

• Don’t give up on me
• Keep trying for me
• I don’t want to leave my family
• I’m scared of dying
• I would feel like I’m giving up

What worries you the most?
What are you most afraid of?
What does your doctor say about your prospects?
What is the hardest part for you?
What are you hoping for?

• I do not really understand how sick I am
• Do everything you think as a doctor is worthwhile
• Don’t leave any stone unturned
• I will go through anything, regardless of how hard it is.

What is your understanding of your condition/prognosis?
What have others told you about what is going on with your illness?
What have they said the impact of their treatments would be?
Tell me more about what you mean by “everything”
Family Domain
Differing perceptions
Family conflict
Children or dependents

- I cannot bear the thought of leaving my children (or spouse)
- My spouse will never let me go
- My family is only after my money
- I don’t want to bother my children with all this.

Spiritual Domain
Vitalism
Faith in God’s will

- I value every moment of life, regardless of the pain and suffering
- I will leave my fate in God’s hands; I am hoping for a miracle; only He can decide when it is time to stop

- How is your family handling this?
- What do your children know?
- Have you made plans for your children (other dependents)?
- Have you discussed who will make decisions for you if you cannot?
- Have you complete a will?

- Does your faith provide any guidance in these matters?
- How might we know when God thinks it is your time?
MEANING OF “EVERYTHING”

• Reluctance to face painful emotions connected with the patient’s loss of health, potential impending death.
• Painful spiritual or religious issues: “How a caring God could allow such a tragedy to happen?” “why God is doing this to me?”
• Questioning about existence and essence of life
MEANING OF “EVERYTHING”

Our main goal: Explore about these concerns and help them in their physical, emotional and spiritual issues.

• Do not assume that “everything” means any and all invasive treatments

• Neglecting to explore the meaning of this request:
  • reinforce patients’ denial in how critical ill is and close to death may be.
  • Depriving the opportunity to grief properly.

BELIEF IN MIRACLES IS QUITE COMMON IN THE GENERAL POPULATION EVEN MORE SO AMONG PATIENTS AND FAMILIES THAN AMONG HEALTH PROFESSIONALS.
• Prevalence of the Belief in Miracles or Divine Intervention

• Seventy-nine percent of 35,556 surveyed agreed that miracles still occur, with little difference based on the respondent’s age.

• Most respondents for every major religion and those unaffiliated with any religion agreed that miracles still occur

• Except for members of Jehovah’s Witnesses, of which only 30% agreed.

Pew Research Center. Religion among the millennials. 2010
• 1006 adult Americans and 774 trauma professionals
• Preferences for care when a life-threatening or fatal injury occurs.
• Most of the public respondents (61.3%) believed that a person in a persistent vegetative state could be saved by a miracle, as compared with only 20.2% of trauma professionals.
• 57.4% believed that divine intervention from God could save a person even if the physician told them “futility had been reached.”

MEANING OF "HOPING FOR A MIRACLE" WHEN USED IN MEDICAL DECISION MAKING AMONG PATIENTS WITH ADVANCED ILLNESS AND THEIR CAREGIVERS

Belief in a divine supernatural intervention that supersedes the laws of nature

An expression of hope or optimism about the possibility of unexpected recovery

A manifestation of denial of impending loss

An expression of anger, frustration, or disappointment over certain aspects of medical care
PHYSICIANS AS INSTRUMENTS OF GOD’S ACTS

- Telephone survey 1033 individuals
- 87.5% believed in religious miracles, with 62.6% responding “definitely” in their belief.
- 80% believed God acts through medical doctors to cure sickness.
- The belief that God acts through physicians was more common in African Americans than in whites, as well as in those older than 55 years of age.

BELIEFS AND DECISION MAKING
DO SURROGATES BELIEVE PHYSICIANS COULD PREDICT FUTILITY? (N=50)

- 64% expressed reluctance or unwillingness to believe predictions
- Skepticism about physicians’ prognostic abilities
- A need to see for themselves that a patient was incapable of recovery
- A need to triangulate multiple sources of information
- A belief that God could intervene to change the course of a hopeless situation.

• Most surrogate decision makers do not solely rely on physicians’ prognostications to develop their idea of their loved ones’ prognosis.

• Religious beliefs, including that of a belief in miracles, may indeed trump a physician’s opinion.
THE INTERVENTION

Open dialogue
Be empathetic
Help to control physical, emotional, and spiritual distressful symptoms

Safe environment to talk about emotional, spiritual, sexual issues.
Feel comfortable talking about these issues. Explore those issues, do not Medicalized the issue.
Involving the interdisciplinary team.
How to help patients with spiritual distress?

Spiritual well-being... a buffer against depression, hopelessness, and desire for death in patients with advanced cancer
Multicenter
75 advanced cancer patients
339 cancer physicians and nurses

- Believe that routine spiritual care would have a positive impact on patients (77.9% patients, 71.6% physicians, 85.1% nurses)
- Only 25% of patients have previously received spiritual care.
- Physicians held more negative perceptions of spiritual care than patients (p<0.001) and nurses (p=0.008)

Individualized, voluntary, inclusive of chaplains/clergy, based on assessing and supporting patient spirituality.

WHY IS DIFFICULT TO PROVIDE SPIRITUAL CARE?

Multisite survey: 4 North East USA
75 patients
339 nurses and physicians

87% of patients had never received spiritual care from their nurses
94% of patients had never received spiritual care from their physicians

Most (>80%) of physicians and nurses thought Spiritual Care should at least occasionally be provided by them.

Spiritual Care infrequency may be primarily due to lack of training

Spiritual Care training is critical to meeting national EOL care guidelines.

BARRIERS TO PROVIDE SPIRITUAL CARE

<table>
<thead>
<tr>
<th>Rank Order</th>
<th>Nurse Barriers, n (%)</th>
<th>Physician Barriers, n (%)</th>
<th>P-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Not enough time</td>
<td>79 (71)</td>
<td>142 (73)</td>
<td>0.39</td>
</tr>
<tr>
<td>#2 Lack of private space to discuss these matters with my patients</td>
<td>85 (74)</td>
<td>76 (39)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>#3 I have not received adequate training</td>
<td>67 (60)</td>
<td>121 (62)</td>
<td>0.94</td>
</tr>
<tr>
<td>#4 I believe that spiritual care is better done by others on the health care team</td>
<td>35 (31)</td>
<td>120 (62)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>#5 I am worried that patients will feel uncomfortable</td>
<td>50 (45)</td>
<td>86 (44)</td>
<td>0.12</td>
</tr>
<tr>
<td>#6 I feel uncomfortable engaging these issues with patients whose religious/spiritual beliefs may differ from my own</td>
<td>37 (33)</td>
<td>94 (48)</td>
<td>0.04</td>
</tr>
<tr>
<td>#7 I am personally uncomfortable discussing spiritual issues</td>
<td>37 (33)</td>
<td>91 (47)</td>
<td>0.03</td>
</tr>
<tr>
<td>#8 I do not believe it is my professional role to engage patient spirituality</td>
<td>26 (23)</td>
<td>87 (45)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>#9 I am worried that the power inequity between patient and (nurse/doctor) makes spiritual care inappropriate</td>
<td>27 (24)</td>
<td>84 (45)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>#10 Religion/spirituality is not important to me personally</td>
<td>23 (21)</td>
<td>54 (28)</td>
<td>0.40</td>
</tr>
<tr>
<td>#11 I do not believe cancer patients want spiritual care from (nurses/doctors)</td>
<td>16 (14)</td>
<td>39 (20)</td>
<td>0.04</td>
</tr>
</tbody>
</table>

OTHER INTERVENTIONS

• Supportive expressive group therapy
• “The Healing Journey”
• Life threatening illness- supportive affective group experience
• Cognitive existential group therapy
• Meaning Making interventions
• Dignity therapy

SPIRITUAL INTERVENTIONS AND RESEARCH

• Five RCTs (1130 participants) were included.
• Two studies evaluated meditation, the others evaluated multi-disciplinary palliative care interventions that involved a chaplain or spiritual counsellor as a member of the intervention team.
• The studies evaluating meditation found no overall significant difference between those receiving meditation or usual care on quality of life or well-being.
• Inconclusive evidence that interventions with spiritual or religious components for adults in the terminal phase of a disease may or may not enhance well-being.

THE PALLIATIVE CARE TEAM…
THE COLLECTIVE SOUL

Improve Quality of Life for Patients and Families

- Physician
- Nurses
- Pharmacists
- Physical & Occupational Therapy
- Psychological Counselors
- Music & Art Therapy
- Social Worker
- Case Manager
- Chaplain
Healing Connections

A collective soul to
Bolster dignity, hope and meaning....

To Reduce existential or spiritual distress
DOMAINS OF THE COLLECTIVE SOUL

• 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 COLLECTIVE SOUL

• To assess and treat the complex needs of seriously ill patients and their family
• Leadership, cooperation, organization, frequent communication
• Continuity of care
• Education
• Research
Clear Communications with IRB And Expedient Conduct of Ethically Sound Palliative Care Research

- Frame the discussion when designing clinical study protocols.
- Clearly defining their study population and terms used in the application.
- Explicitly identifying areas of potential concern and proposing ways in which these concerns will be addressed.
- Quality assurance processes: plans to measure patient safety, inconvenience, or data quality into the conduct of the study.
- Clear, proactive, and precise communication between investigators and the IRB is essential to preventing misunderstandings before, during, and after the initial IRB review.

Palliative care clinicians and investigators to become active on IRBs, providing expert review and insight, and offering ongoing education to IRB members.

Palliative care investigators must maintain integrity in their research methods, including the use of approaches that minimize bias and maximize generalizability of results.

Study terms, funding plans, and budgets may need to be tailored to reflect realities faced by palliative care studies (e.g., time necessary for IRB review, realistic enrollment time frames).

“Our intactness as persons, our dignity and integrity, come not only from intactness of the body but from the wholeness of the web of relationships with self and others, and the Divine.”
We all are part of the collective soul… Integrative care with multidisciplinary approaches…to provide a touch of hope… a touch of love… to decrease suffering and to improve the quality of life of patients and families/caregivers in distress.

We are actively working to develop research infrastructure, methodology, and portfolio.
Fifth Annual
Collective Soul Symposium
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The Collective Soul... touching lives in distress

Questions and Comments
Thank You