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

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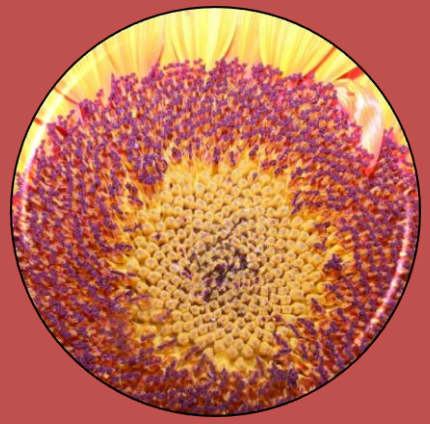
Objectives

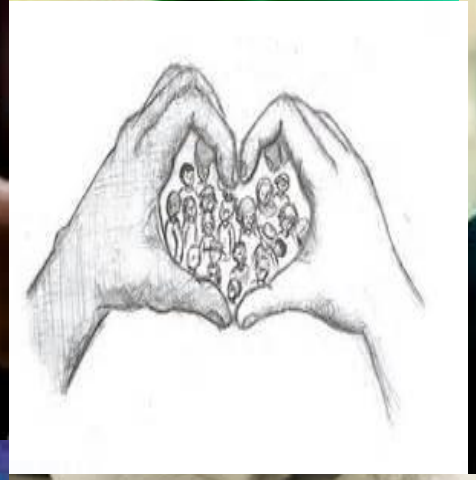


To describe the importance of spirituality, religiosity, and spiritual distress in the palliative care setting.

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.











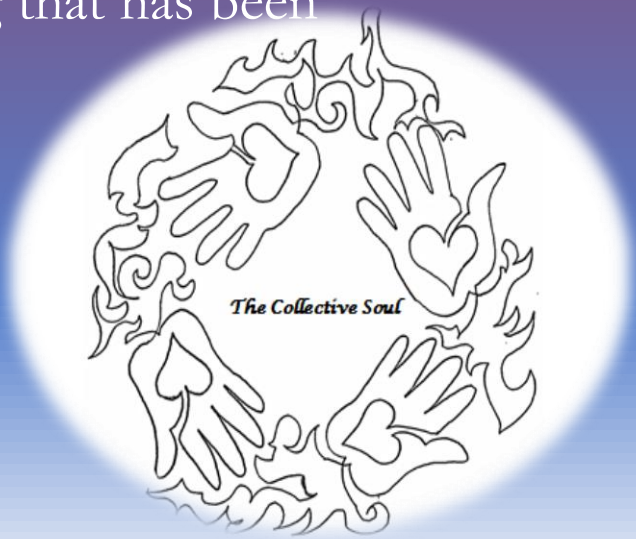






THE PATIENT

- 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?

  It is just horrible…

- What do you think is causing you that pain?

  I feel I have lost everything… I can't control it…

  I have failed to my family…and too my self…

  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…

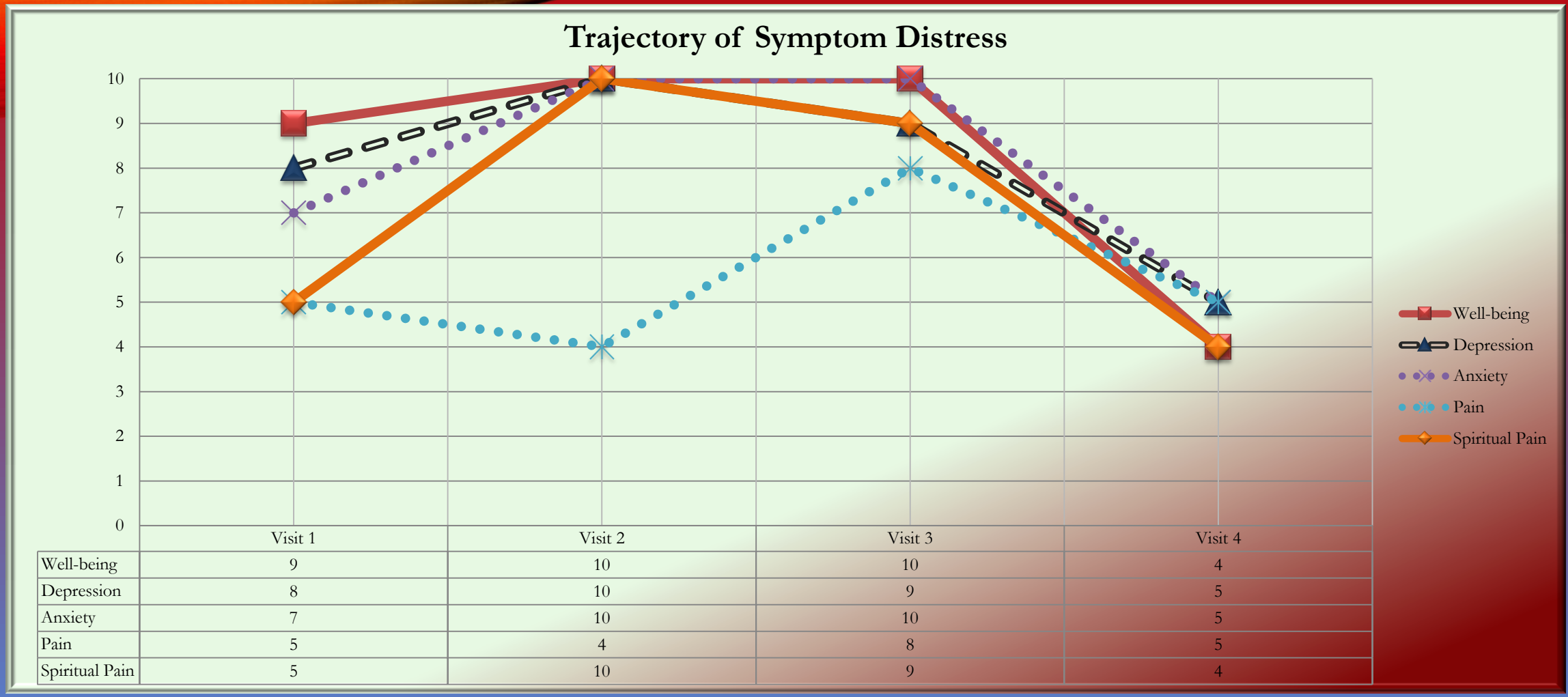
Life Review: identifying what has helped him in difficult moments also.

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.



	Visit 1	Visit 2	Visit 3	Visit 4
Well-being	9	10	10	4
Depression	8	10	9	5
Anxiety	7	10	10	5
Pain	5	4	8	5
Spiritual Pain	5	10	9	4

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.

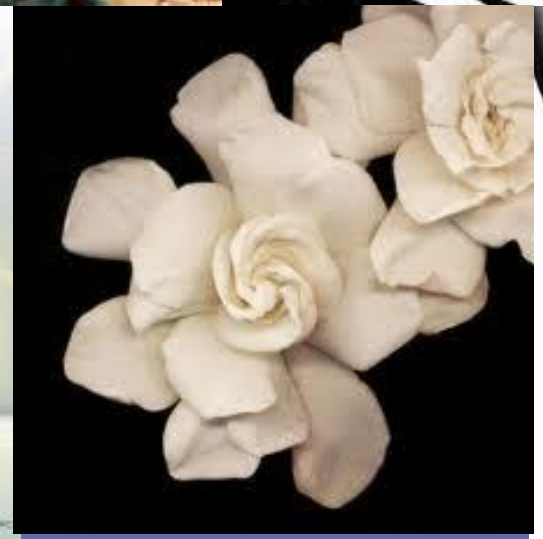
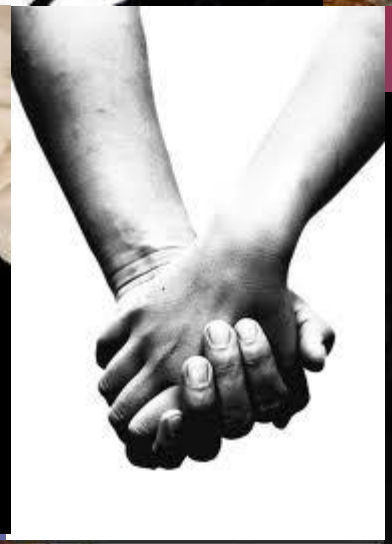
- It is a process, and you are doing a great job for being here.

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.





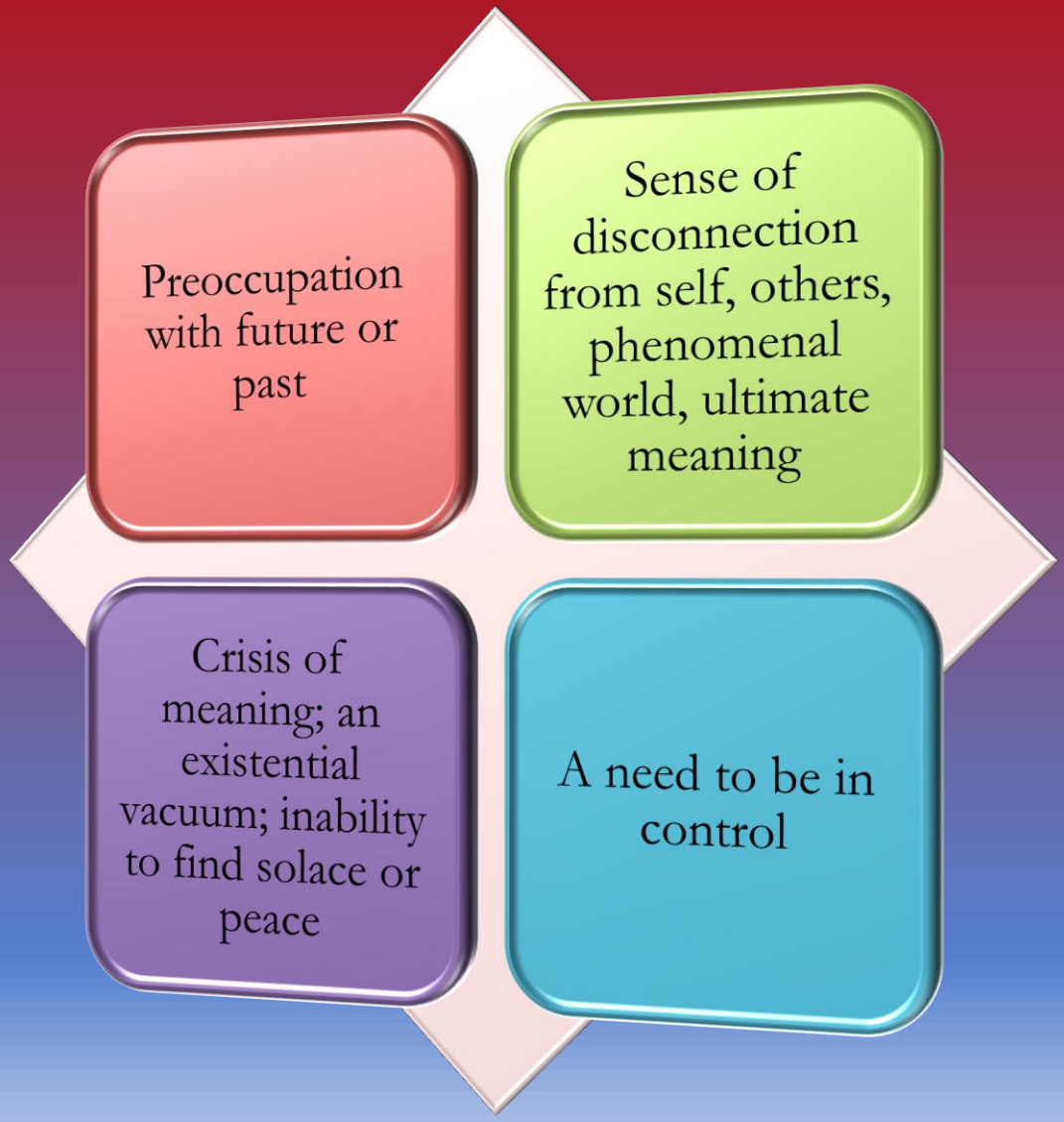






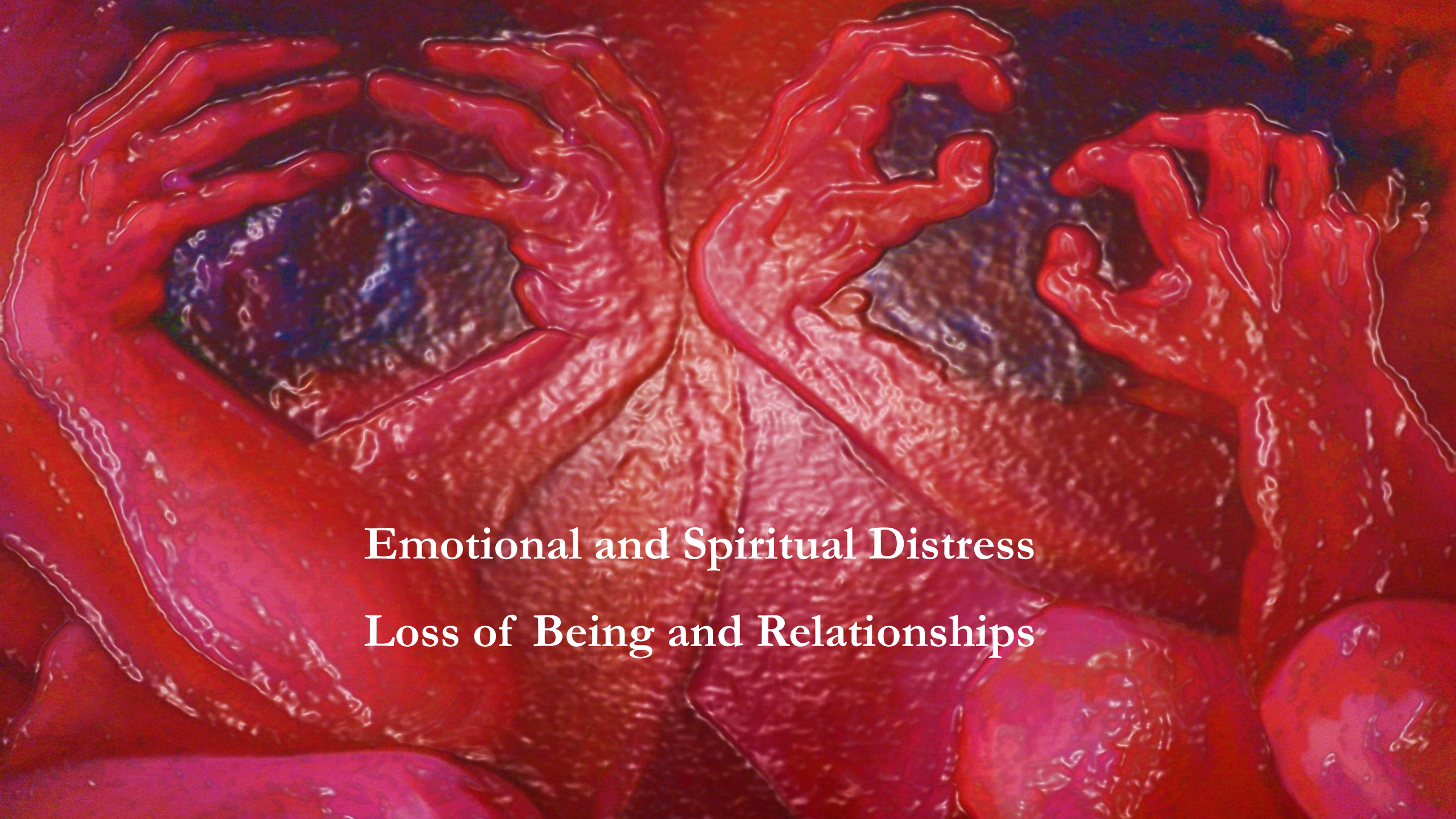

Symptom Distress

Delgado-Guay M, Bruera E. *Oncology* 2008; 22:56-61

SUFFERING/ANGUISH

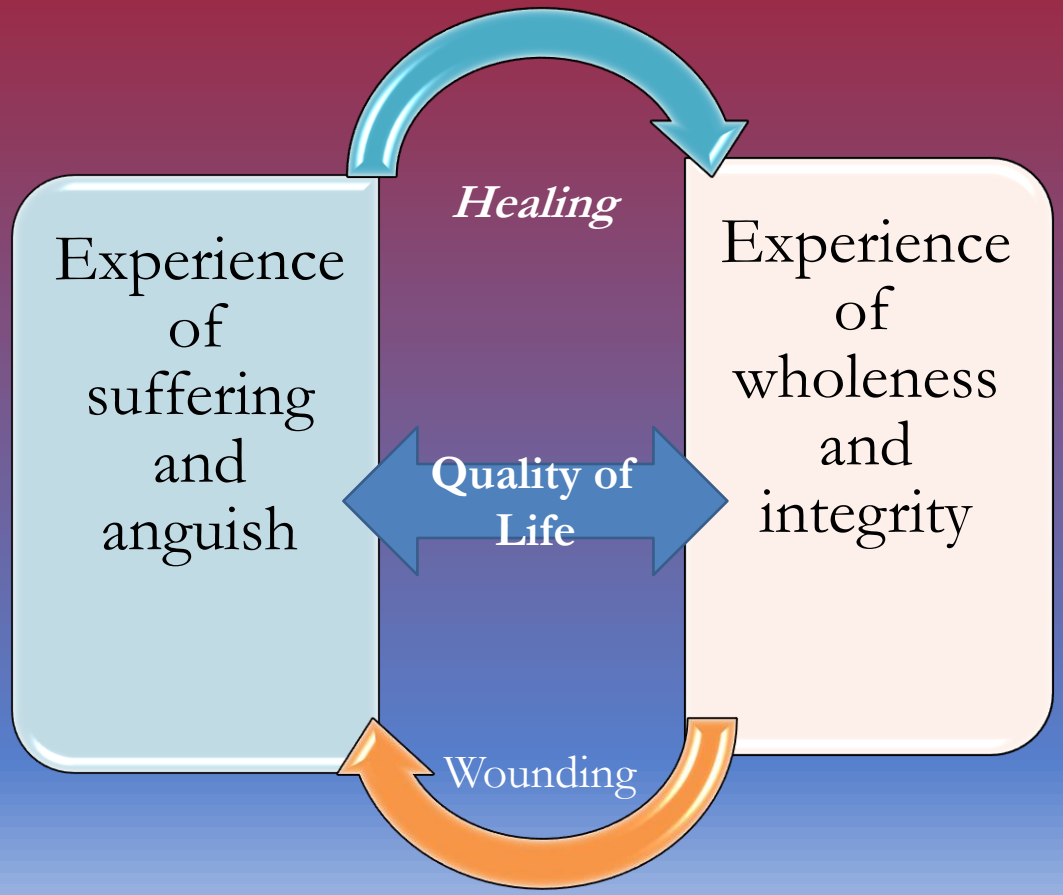


Mount BM, Boston PC, Cohen SR. J Pain Symptom Manage 2007;33:372e388.


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.



Mount BM, Boston PC, Cohen SR. J Pain Symptom Manage 2007;33:372-388.

Areas of Relationship

~ To Self

~ To the other

~ To the Holy

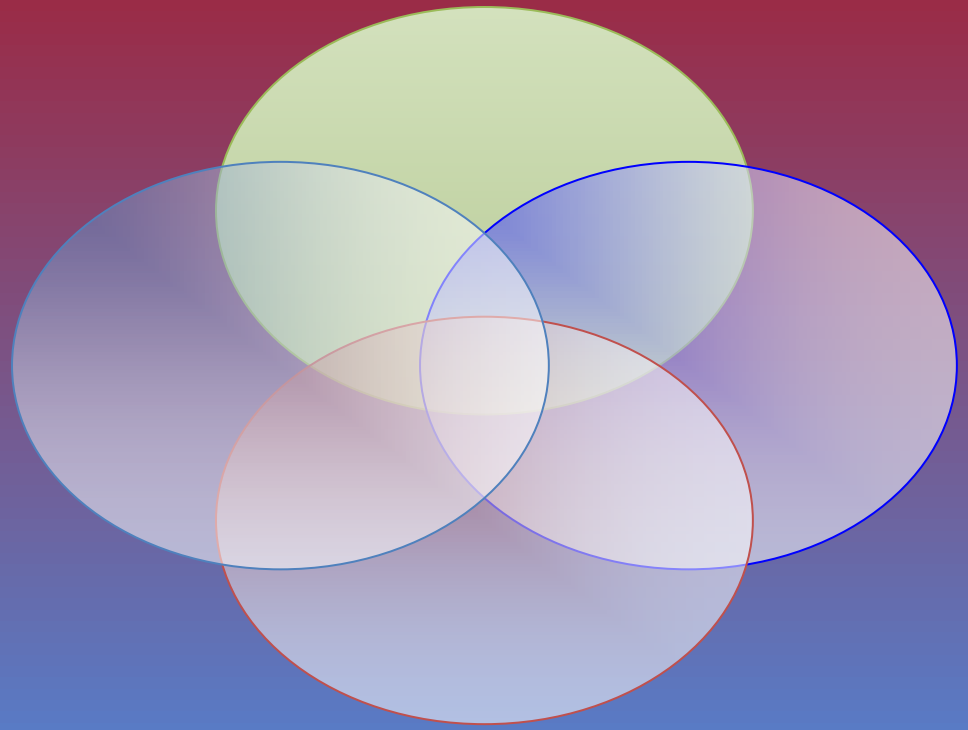
~ To the environment

~ To the Evil

SPIRITUALITY… A PART OF THEIR TOTAL EXISTENCE

Communion with Self

Communion with a higher being



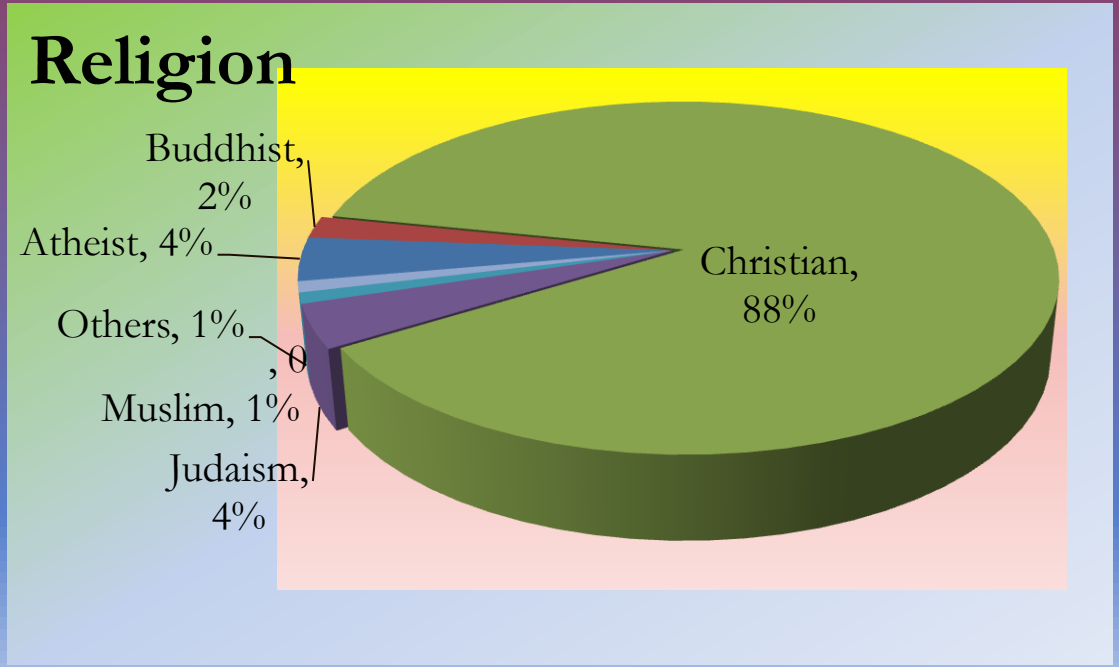
Communion with others

Communion with Nature

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%
  - Lung: 15%
  - Sarcoma: 13%
  - Gastrointestinal: 11%
  - Gynecologic: 10%
  - Genitourinary: 9%
  - Head and Neck: 9%
  - Hematologic: 5%
  - Other: 9%



Delgado-Guay MO, et al. J Pain Symptom Manage. 2011:41;986-994.

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

* [0 to 10 (max) scale]

Delgado-Guay MO, et al. J Pain Symptom Manage. 2011:41;986-994.

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

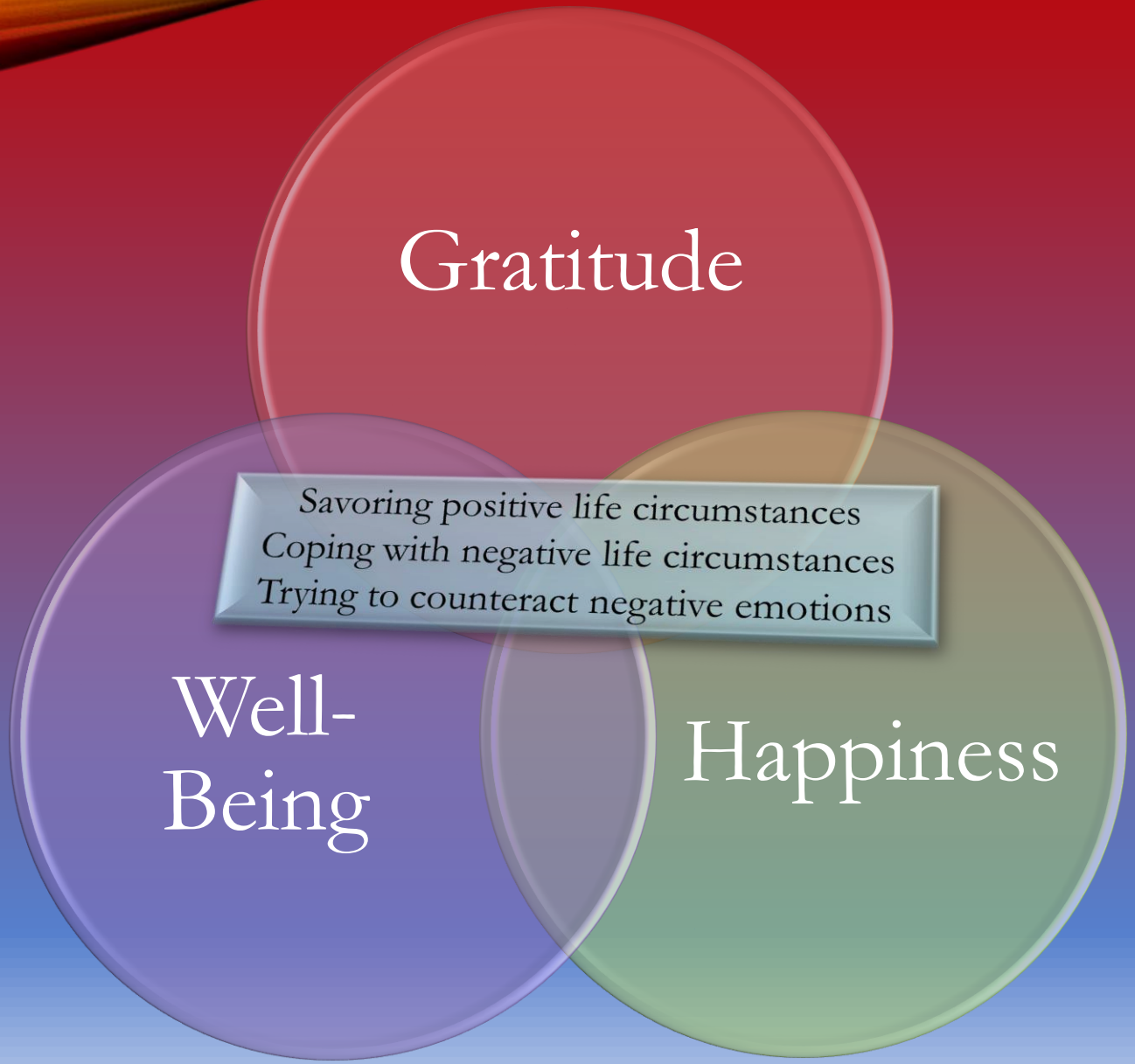
The relationships as a Blessing

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)*

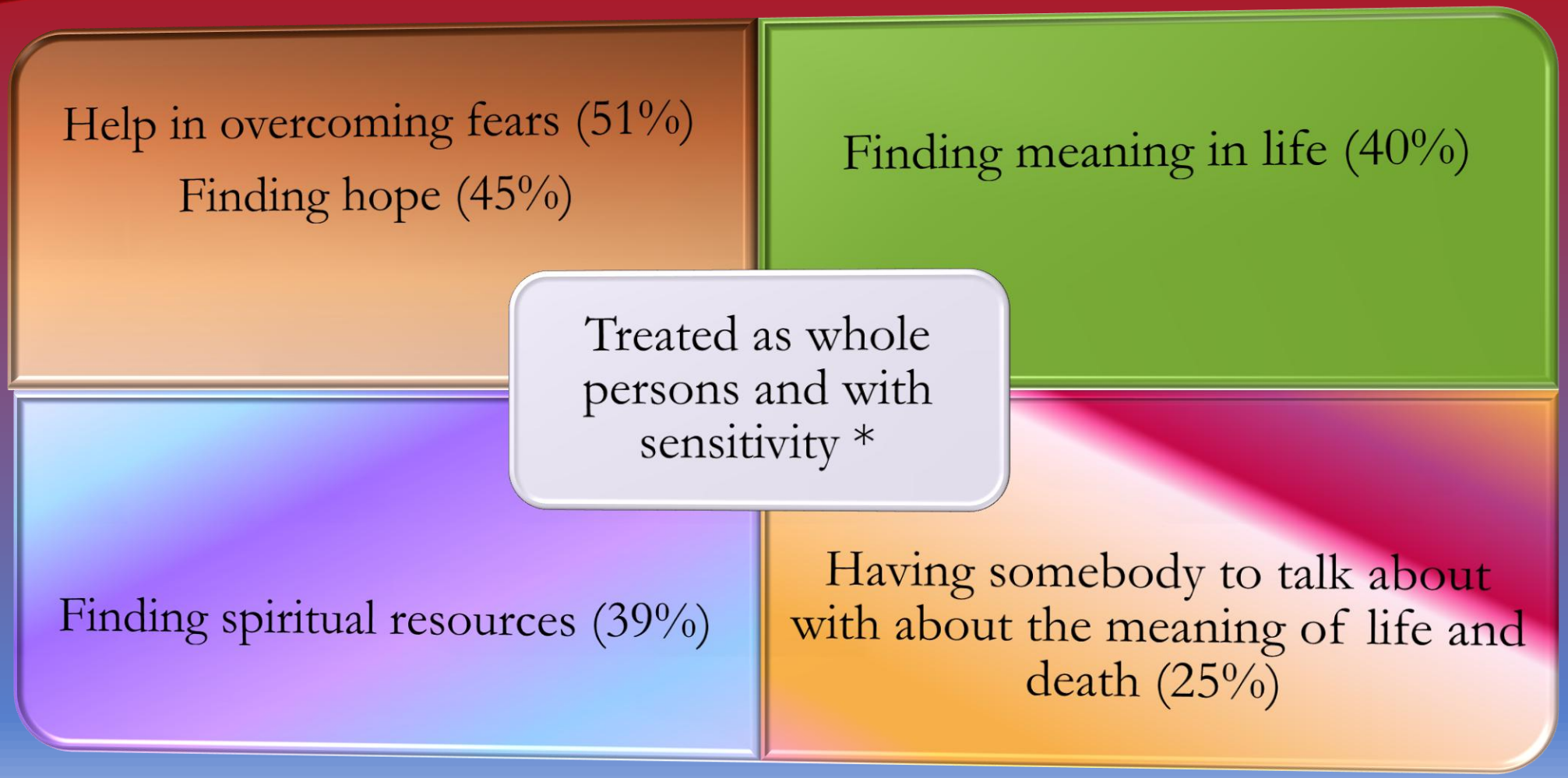
Palliative care clinicians who are continually exposed to others' emotions without actually receiving adequate support themselves may well end up experiencing emotional exhaustion and, eventually, burnout.

Nyatanga B. British Journal of Community Nursing 2013



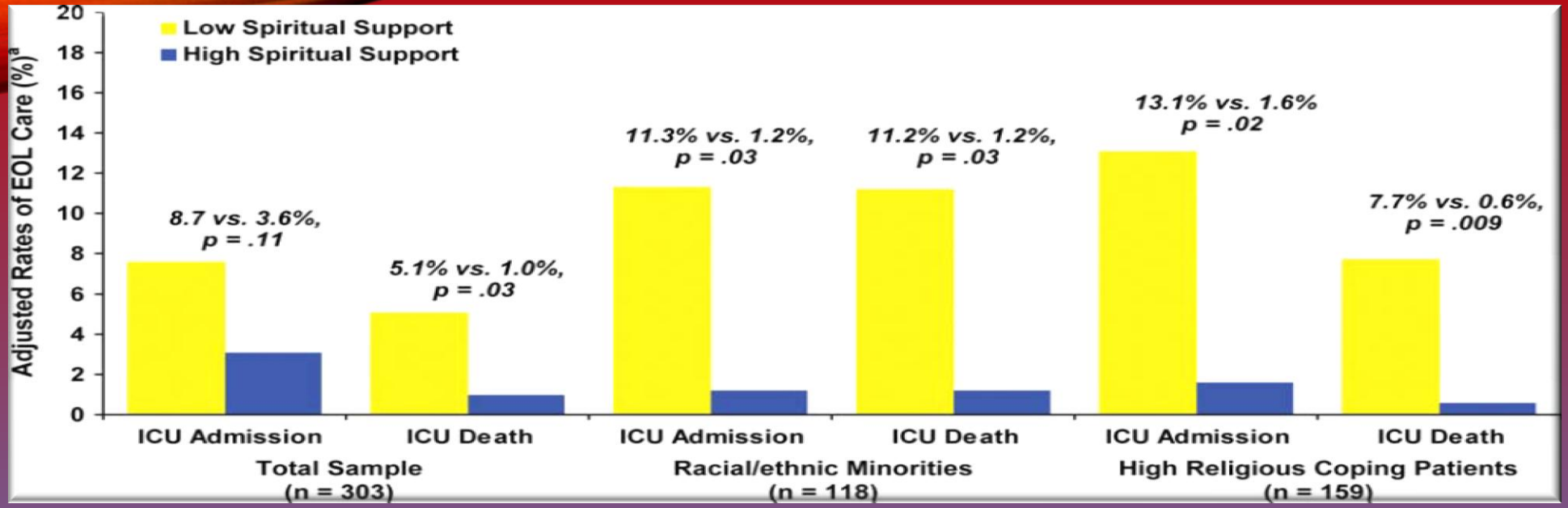
Emmons RA, McCullough ME. Journal of Personality and Social Psychology 2003,Vol.84,No.2,377–389

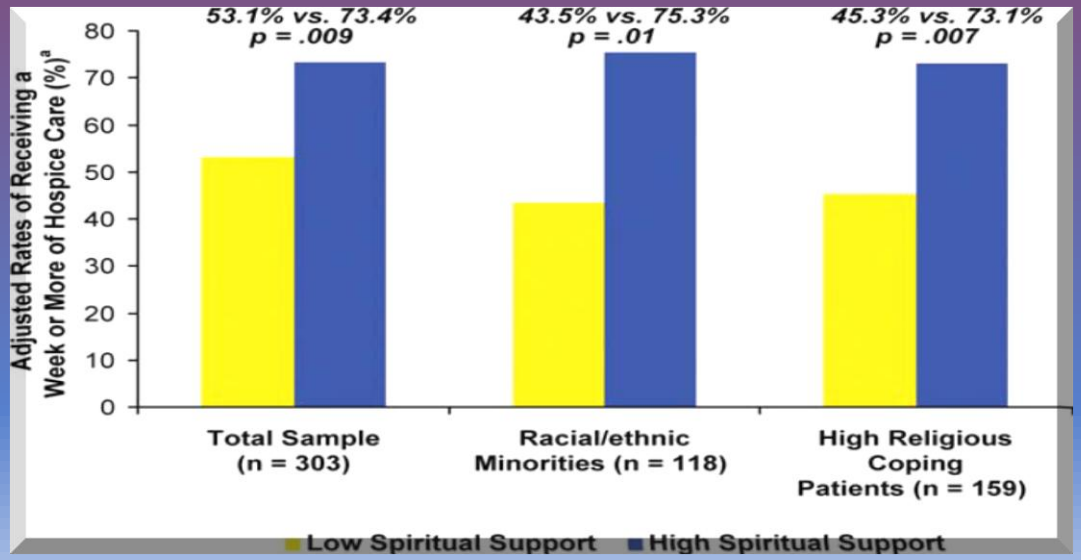
PATIENTS' SPIRITUAL NEEDS AND CLINICIANS

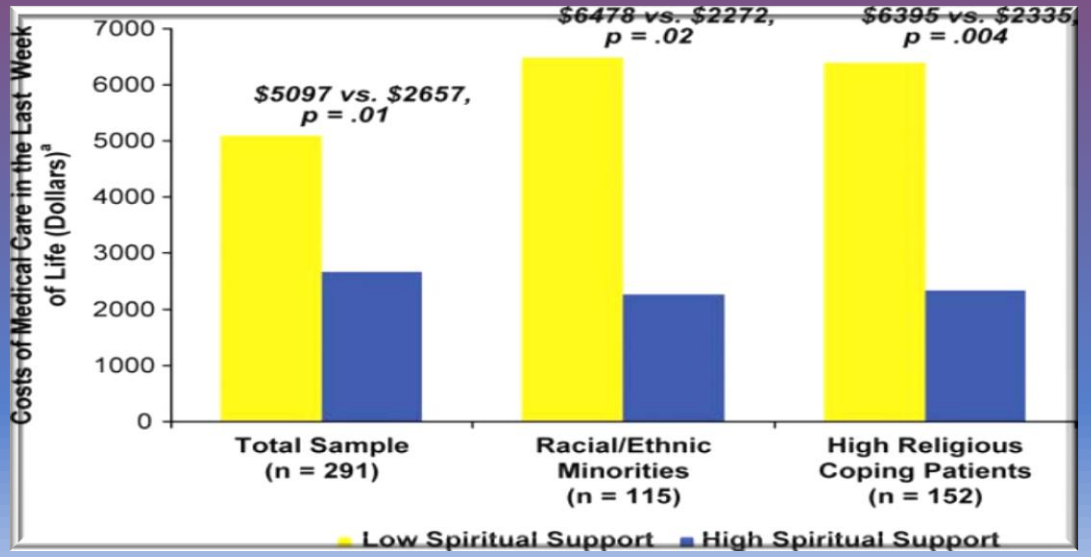


* Moadel A, et al. Psycho-Oncology 1999;8:378-85

SPIRITUAL NEEDS IN PATIENTS WITH ADVANCED ILLNESS







Balboni T, et al. Cancer 2011;117:5383–91.

“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

PALLIATIVE CARE

- …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)

MULTICULTURAL PALLIATIVE CARE

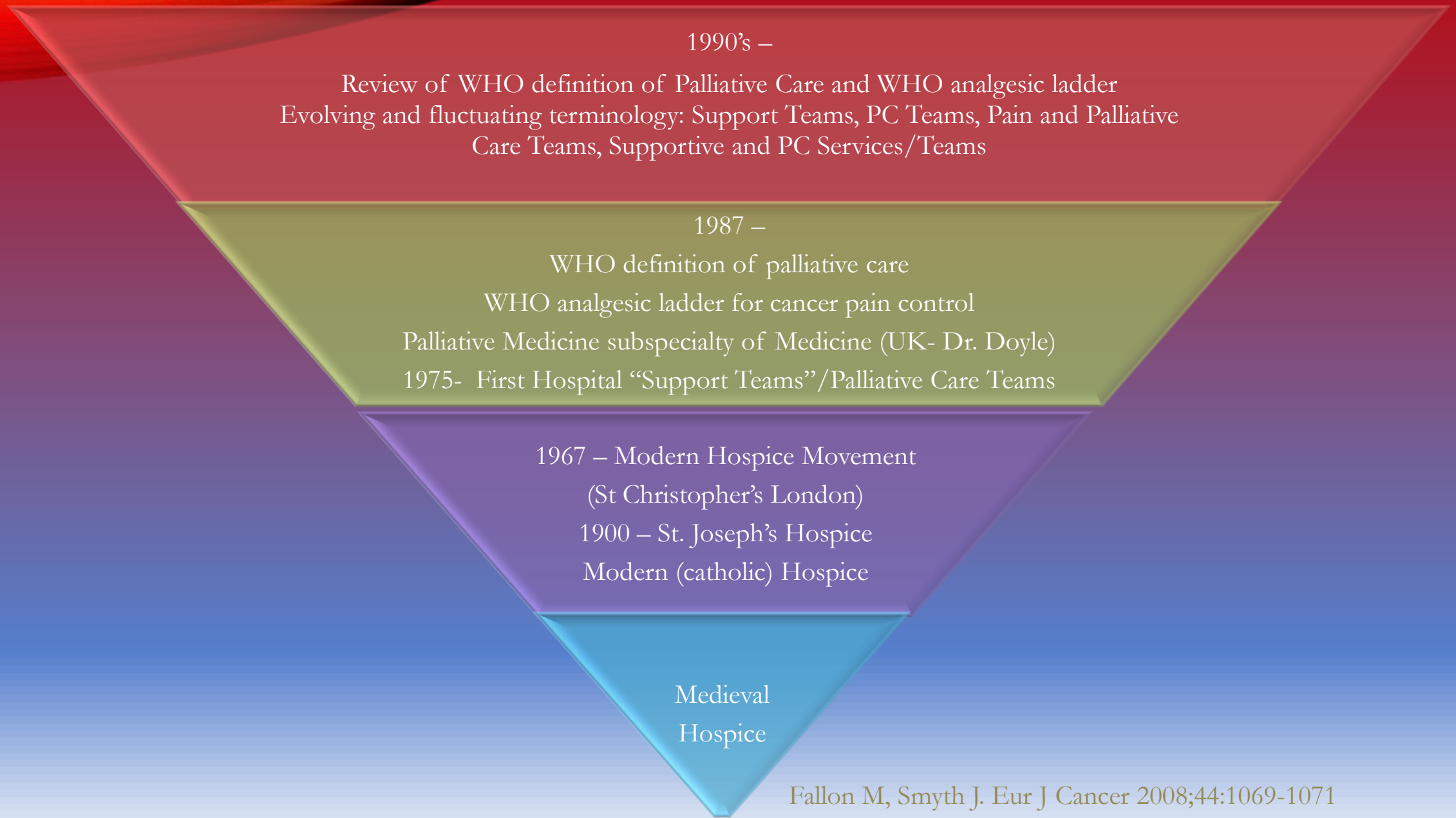
Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.

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

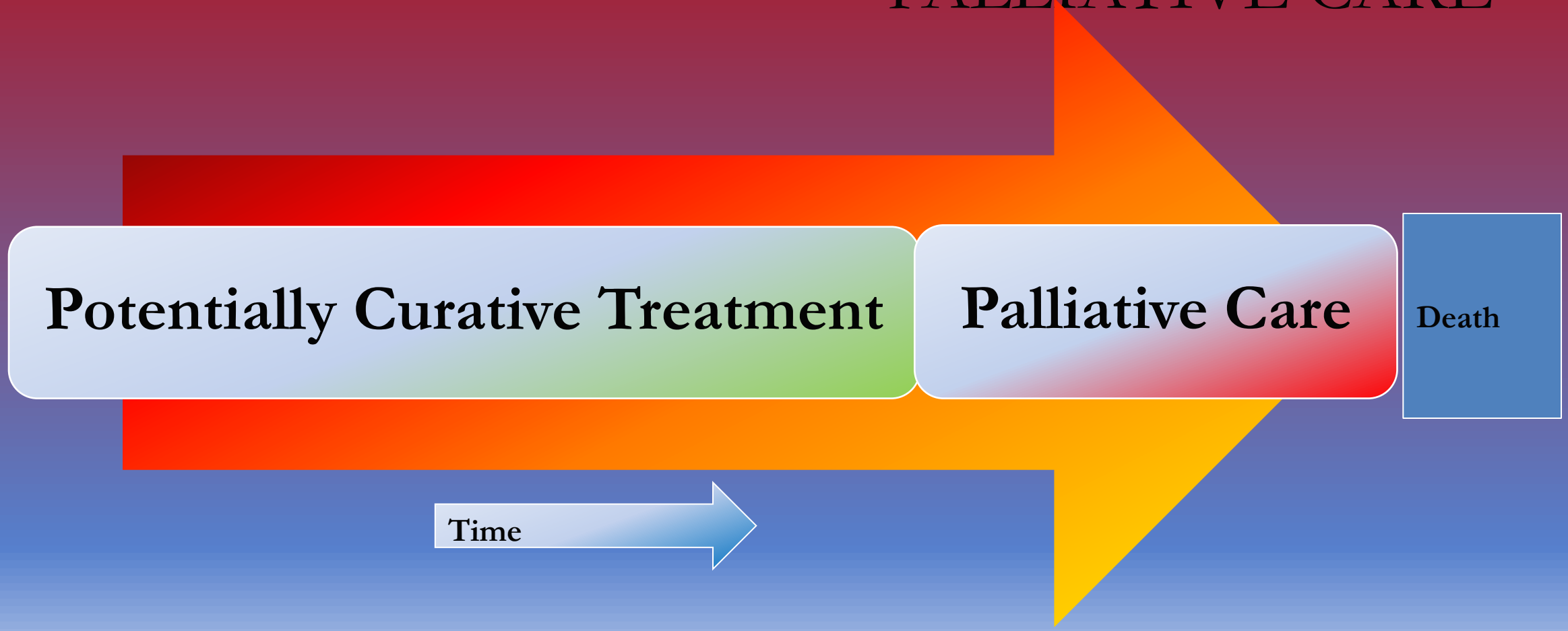
Medicare Hospice Conditions of Participation – Final Rule

EVOLUTION OF PALLIATIVE CARE



Fallon M, Smyth J. Eur J Cancer 2008;44:1069-1071

TRADITIONAL CONCEPT OF PALLIATIVE CARE



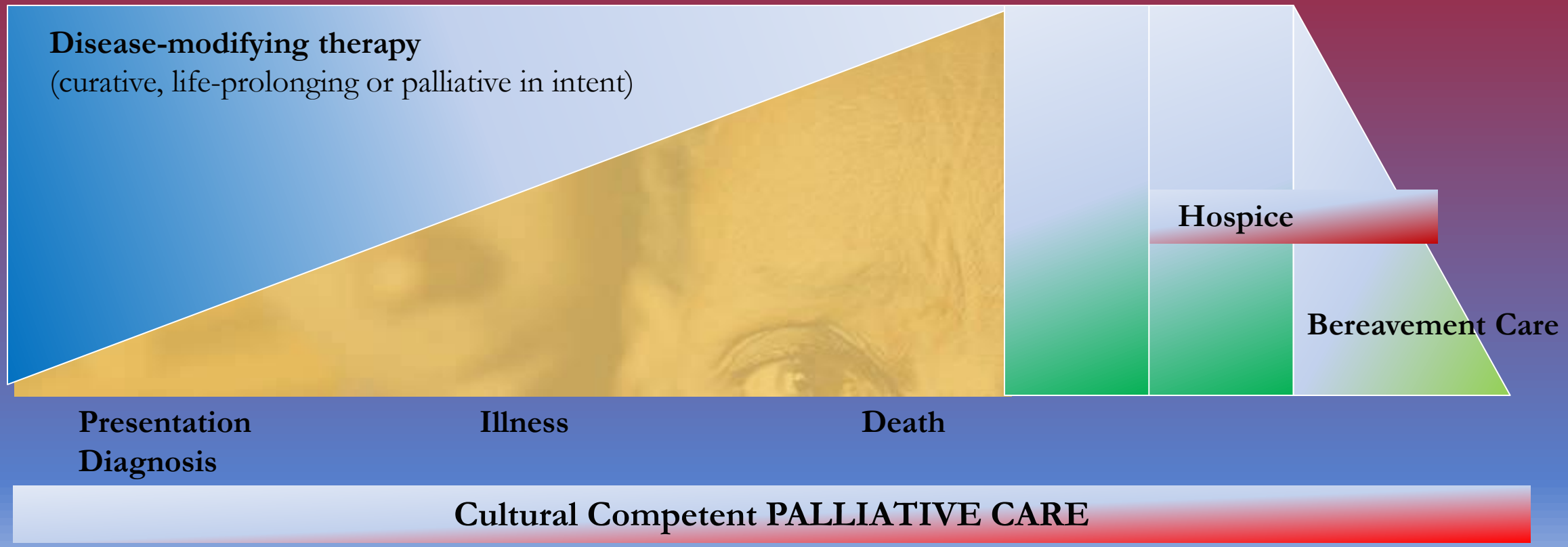
KEY ELEMENTS OF PALLIATIVE CARE

- 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.

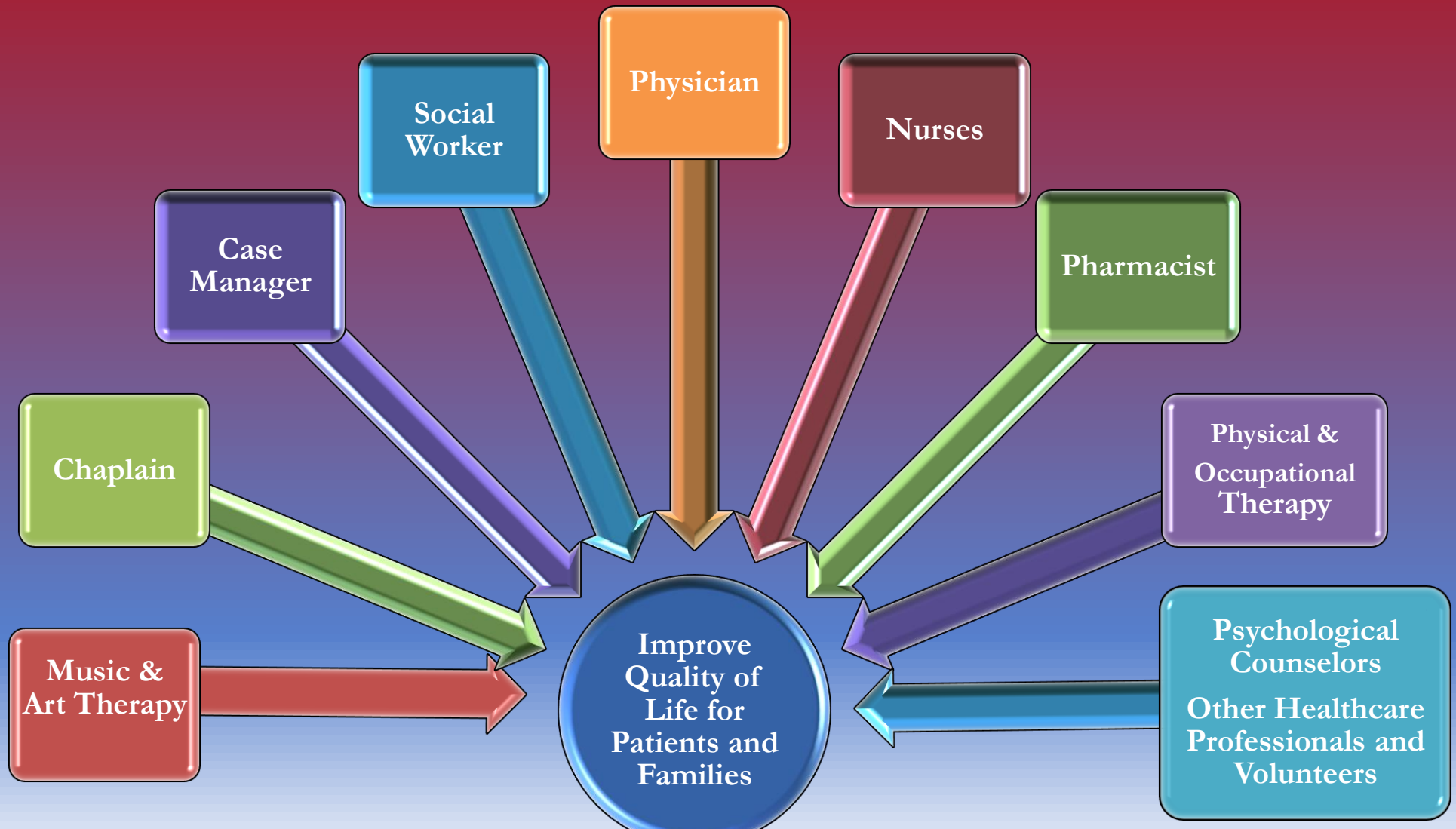
PALLIATIVE CARE

- …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

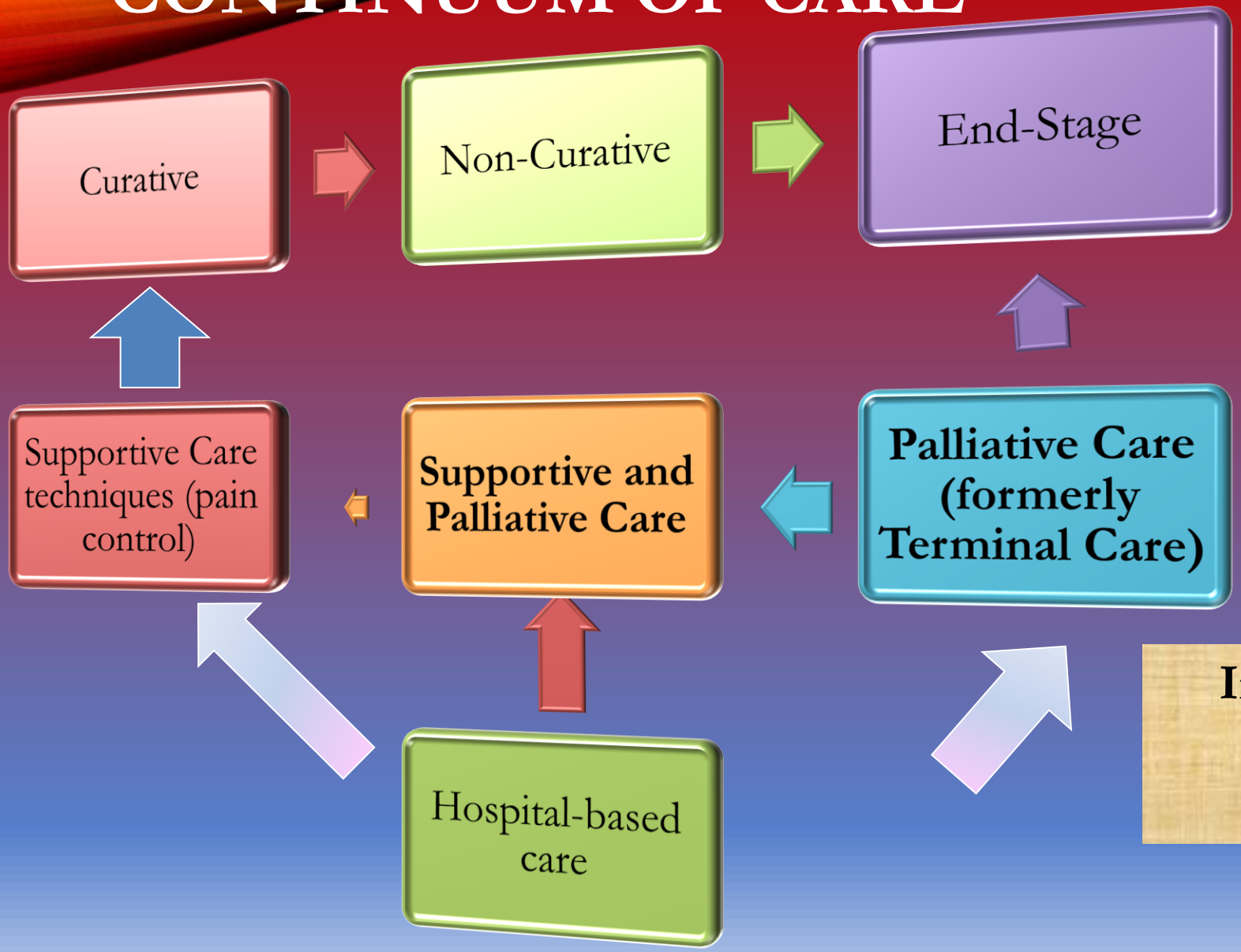
INTEGRATED MODEL OF CURATIVE AND PALLIATIVE CARE FOR CHRONIC PROGRESSIVE ILLNESS



THE PALLIATIVE CARE TEAM…
THE COLLECTIVE SOUL
OWN CULTURE AND SPIRITUALITY



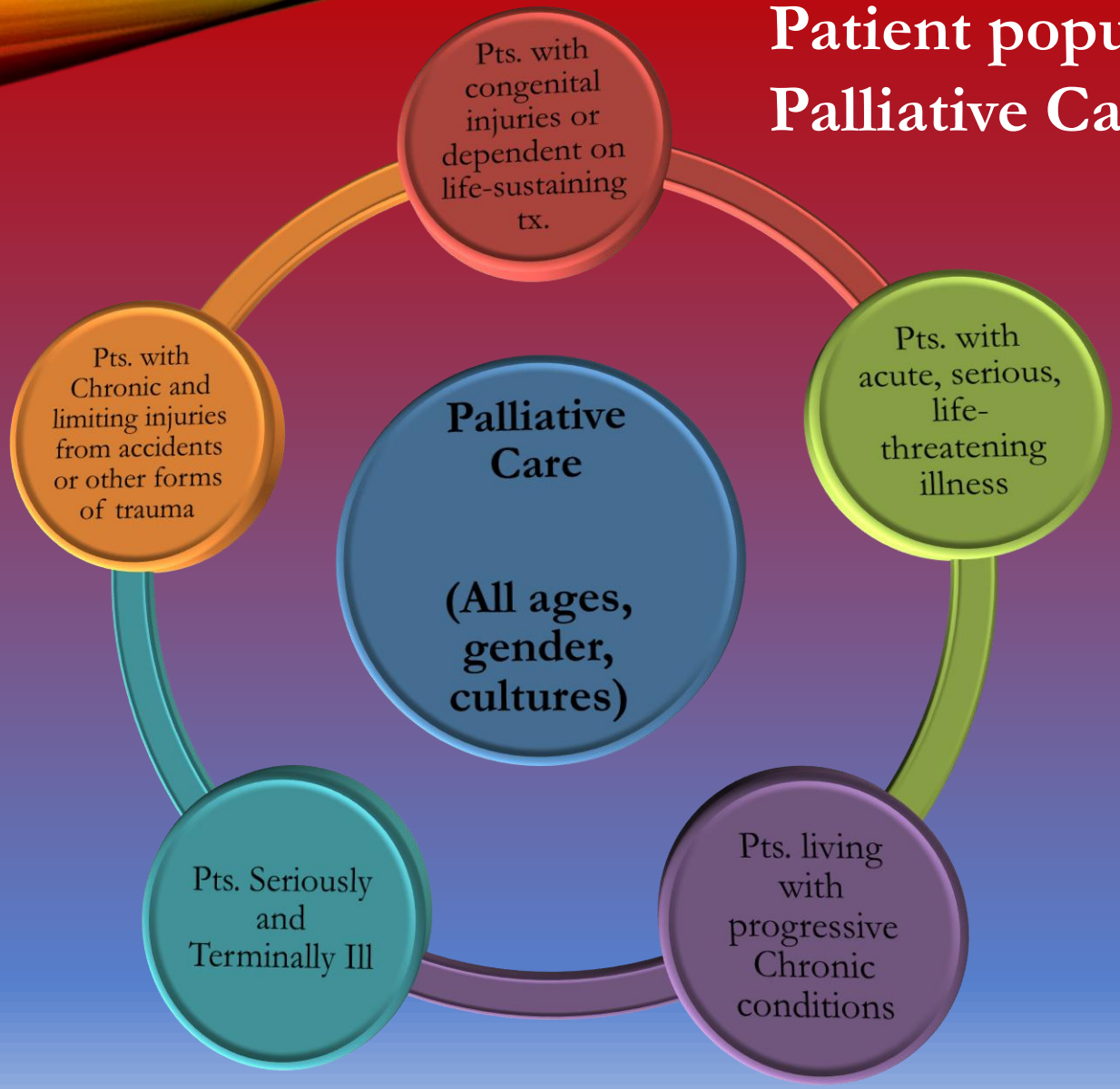
CONTINUUM OF CARE



In a Multicultural competent environment

Fallon M, Smyth J. Eur J Cancer 2008;44:1069-1071

Patient populations served by Palliative Care



Thomas J, J Palliative Medicine 2007, 10;S1-S18

CORE ELEMENTS OF PALLIATIVE CARE

OUTCOMES OF PALLIATIVE CARE INTERVENTIONS

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

Hughes MT, Smith TJ. Annu. Rev. Public Health 2014. 35:459–75

OUTCOMES OF PC INTERVENTIONS

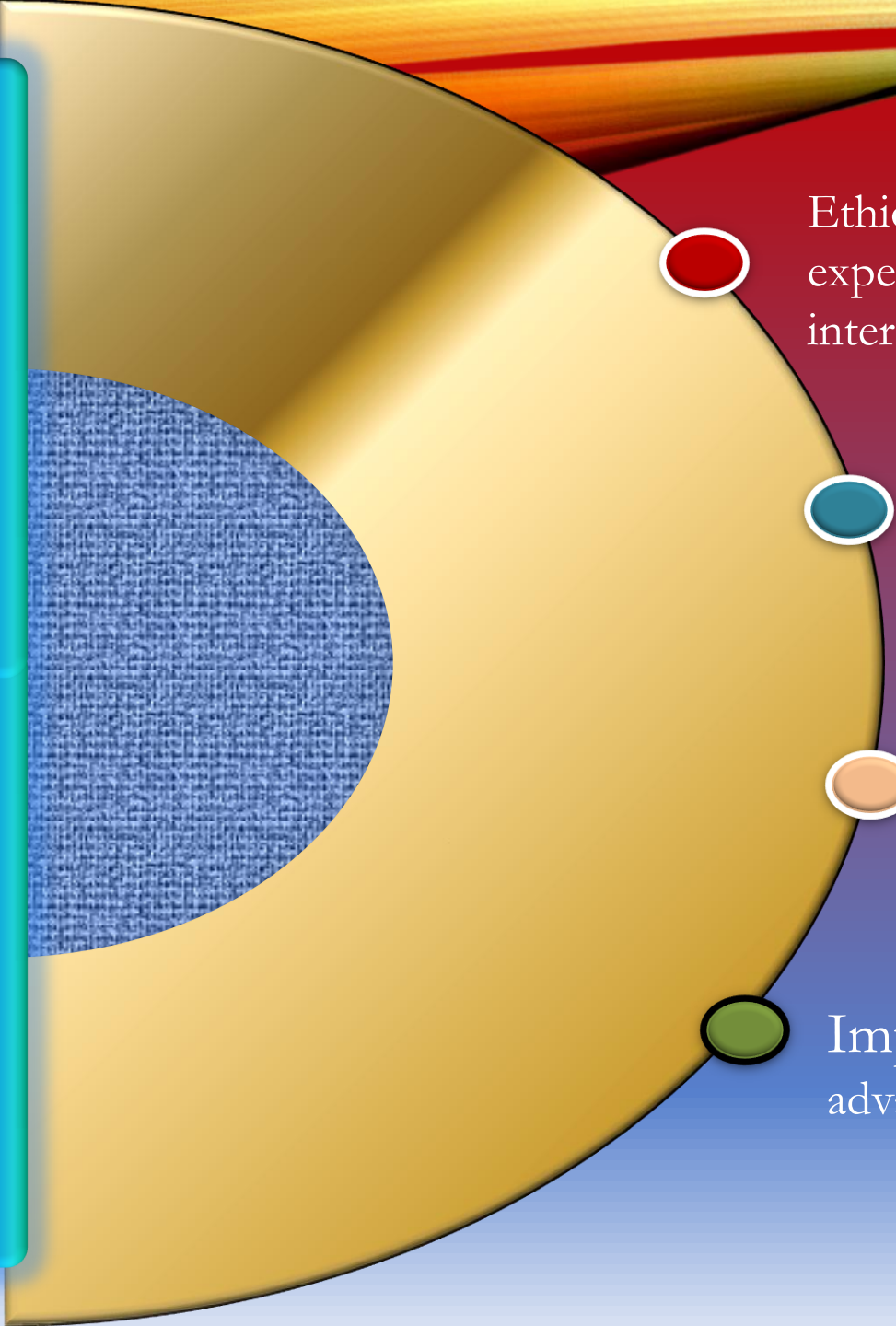
Citations	Outcomes							
	Symptoms	Quality of life	Mood	Satisfaction	Resource use	Advance care planning	Survival	Costs
Higginson et al. 2011 (45) PC team intervention in OP setting	Improved	Improved	NR	NR	Lower with PC	NR	NR	Lower
Temel et al. 2010 (97) PC team intervention	Improved $p = 0.04$	Improved $p = 0.03$	Less depression $p = 0.01$	Not measured	Less aggressive care $p = 0.05$, \$2,200 per-person savings	More ADs documented in PC group $p = 0.05$	11.6 versus 8.9 months $p = 0.02$	Lower
Zimmermann et al. 2012 (110) PC team intervention in OP clinics	Improved ($p = 0.05$)	Improved ($p = 0.007$)	NR	Improved ($p < 0.001$)	NR	NR	NR	NR

Hughes MT, Smith TJ. Annu. Rev. Public Health 2014. 35:459–75

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

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)

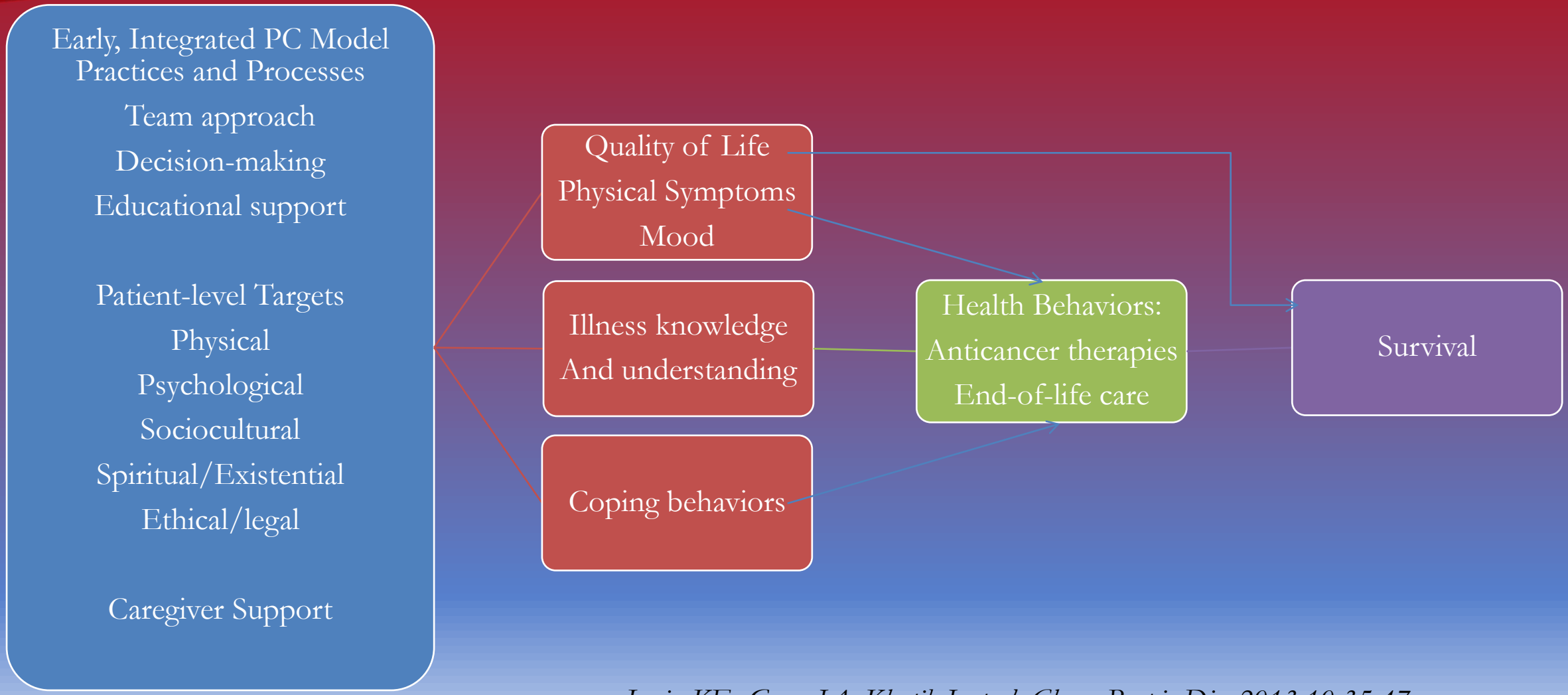
Ability to understand the emotional state of another person, i.e. 'putting yourself in another's shoes'.

When offered appropriately, empathy

can help others to continue living their lives with enhanced

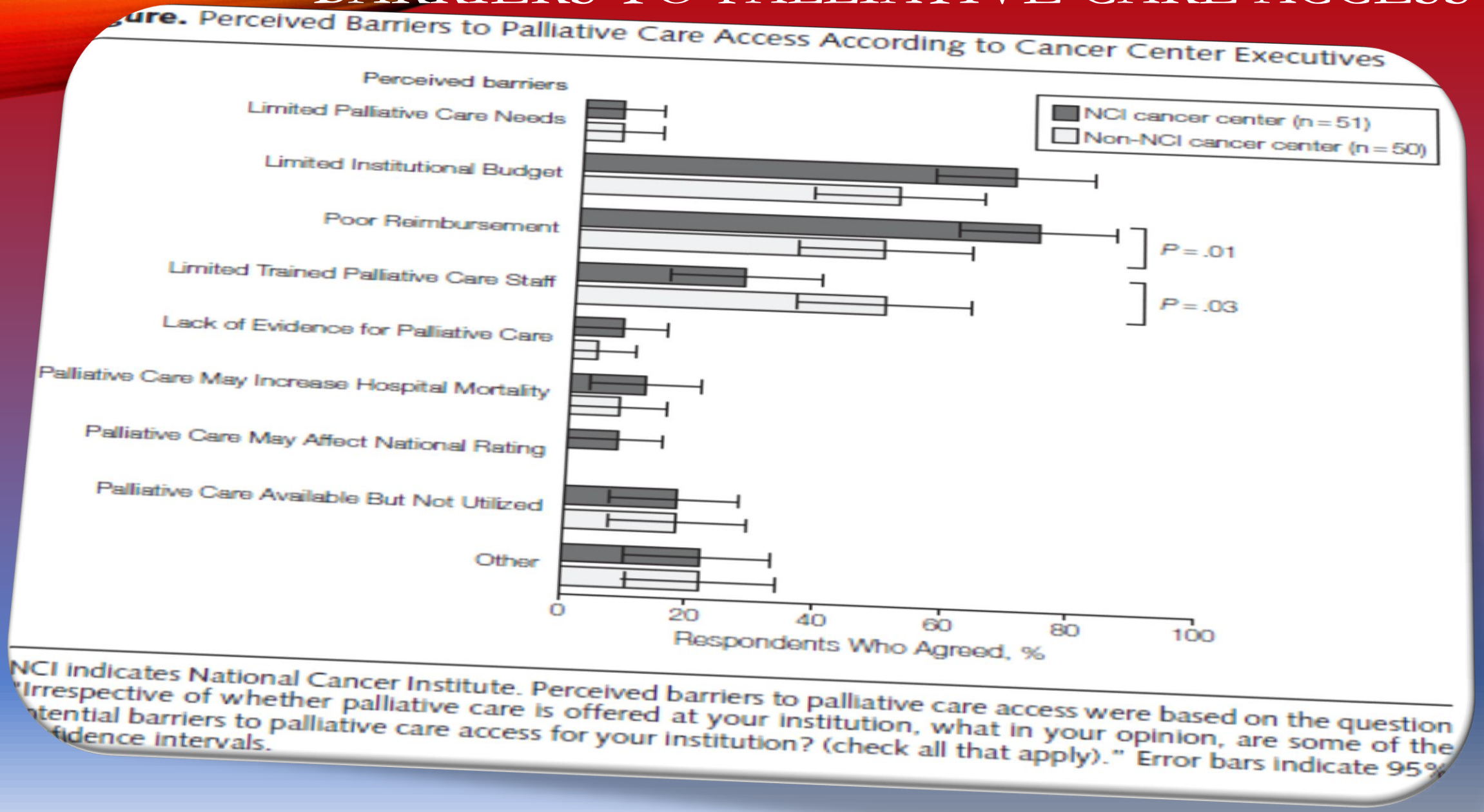
quality of life and dignity in dying.

EARLY PALLIATIVE CARE INTERVENTIONS AND CLINICAL OUTCOMES



Irwin KE, Greer JA, Khatib J, et al. Chron Respir Dis. 2013;10:35-47.
Greer JA, Jackson VA, Meier DE, Temel JS, Ca Cancer J Clin 2013;63:349–362

BARRIERS TO PALLIATIVE CARE ACCESS

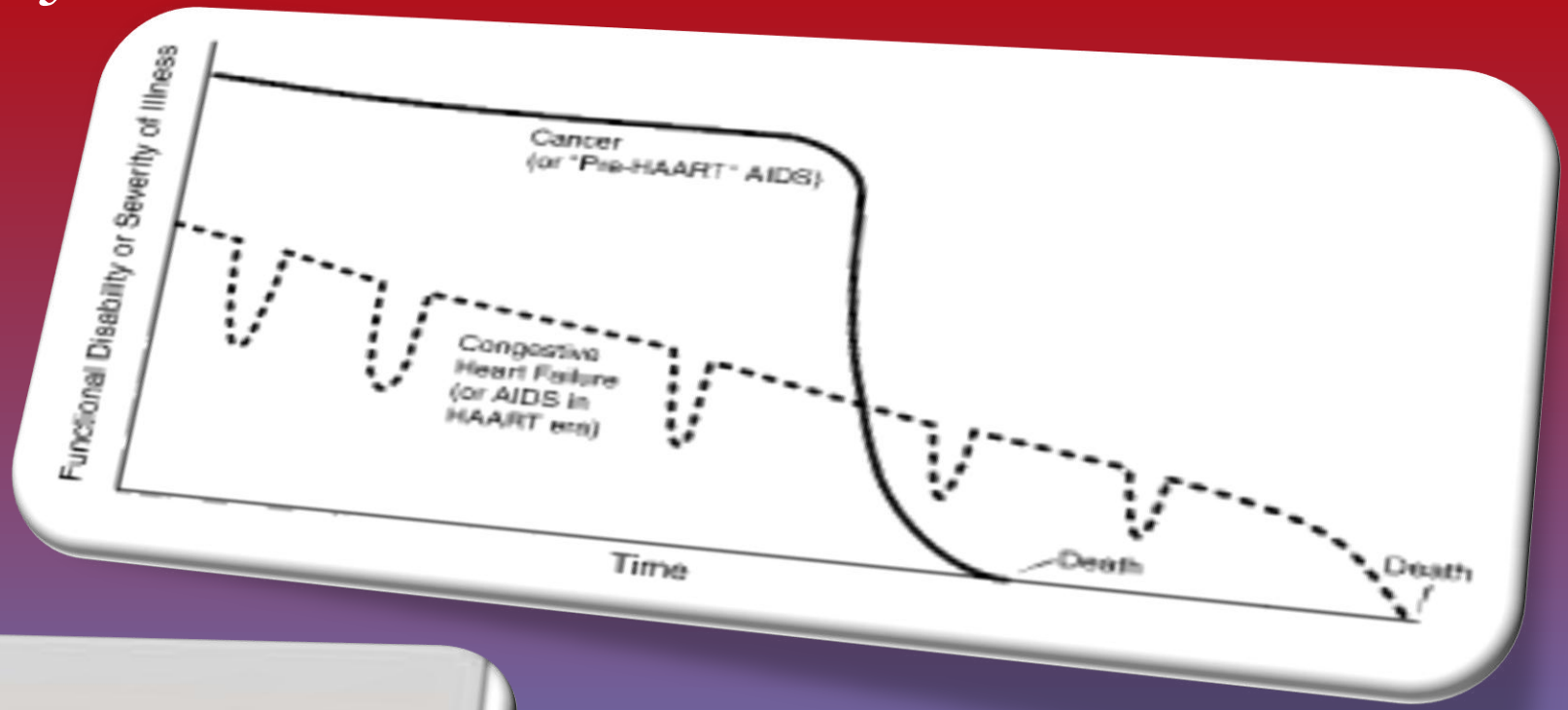


ure. Perceived Barriers to Palliative Care Access According to Cancer Center Executives

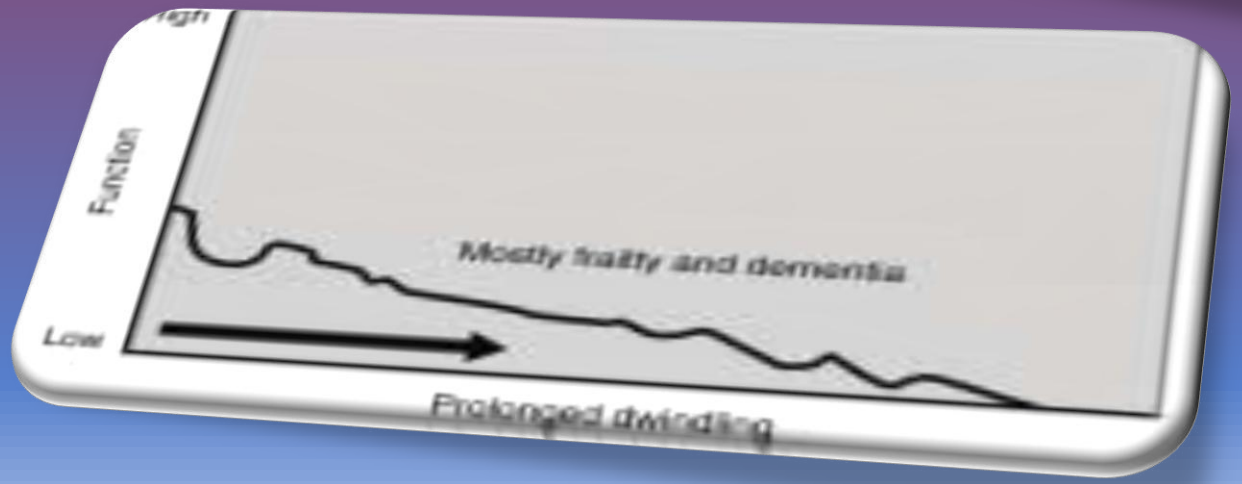
NCI indicates National Cancer Institute. Perceived barriers to palliative care access were based on the question "Irrespective of whether palliative care is offered at your institution, what in your opinion, are some of the potential barriers to palliative care access for your institution? (check all 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



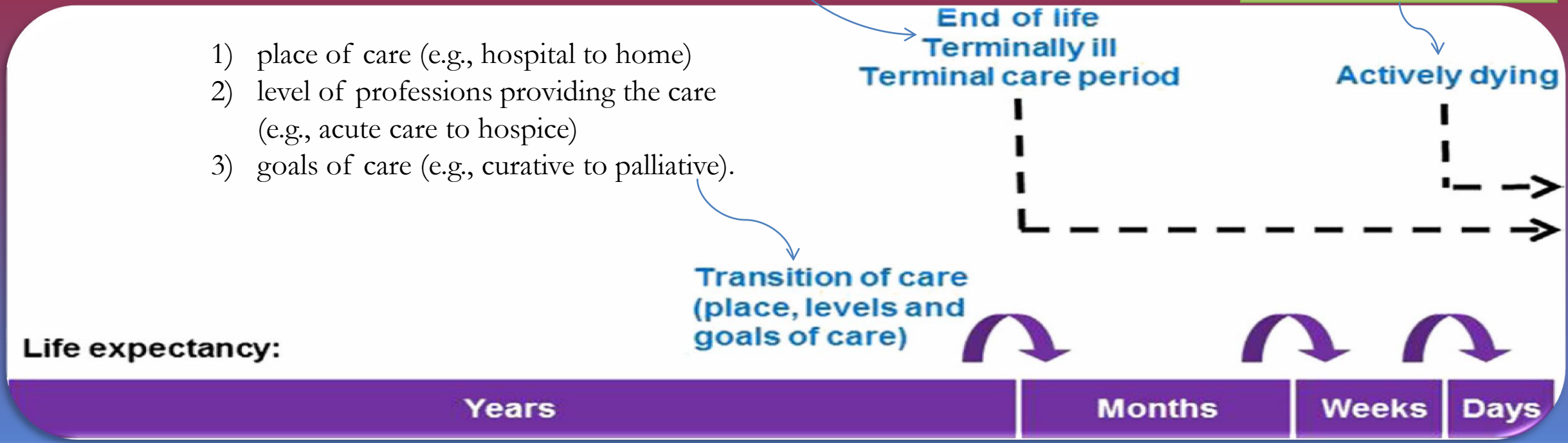
Lynn J, Adamson DM. *Living well at the end of life: adapting health care to serious chronic illness in old age. Arlington, VA, Rand* Health, 2003

NO CLEAR DEFINITION OF END-OF-LIFE

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

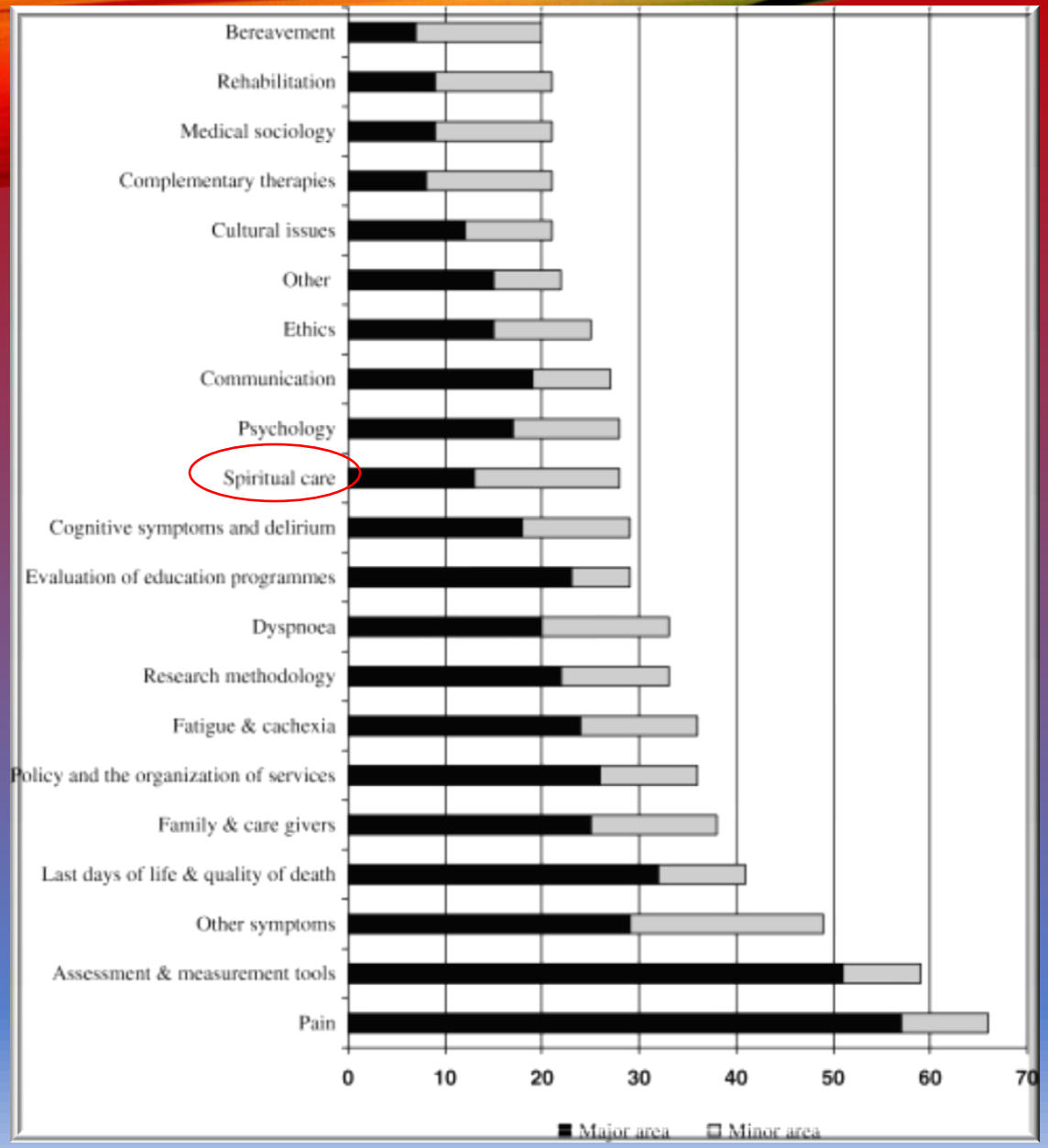
"hours or days of survival."

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).



Hui D, et al. J Pain Symptom Manage 2014;47:77-89.

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.

Bruera E. Palliative Medicine 2015, Vol. 29(2) 99– 100

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.

Education

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.

Bruera E. and Hui D. Palliat Med 2013

ABOUT SYMPTOM MANAGEMENT

- 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

LESSONS LEARNED ABOUT PC RESEARCH

- 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.

Bruera E. and Hui D. Palliat Med 2013
Dev R, et al. J Pain Symptom Manage 2013; 45: 261–271.

Research Opportunities in Palliative Care Study Design

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

Research Opportunities in Palliative Care
Patient Enrollment and Retention

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

BARRIERS TO RESEARCH IN PALLIATIVE CARE

Funding

Institutional Capacity

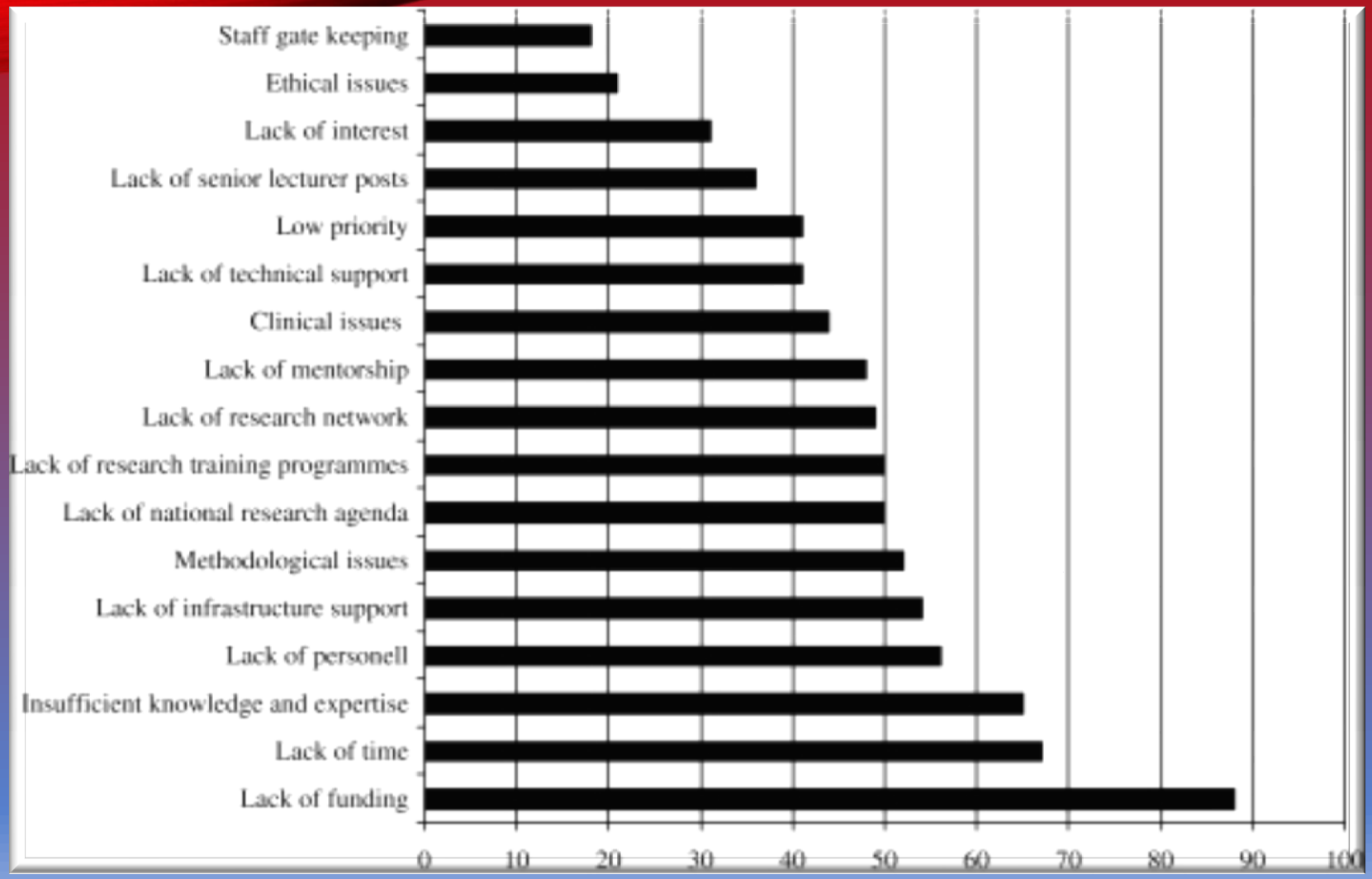
Research workforce

Challenging nature of population and topic

Public and professional misunderstanding and discomfort with palliative care

Chen EK, et al. J Palliat Med 2014;17:1-6

Barriers In General for PC research. Number Of Groups



- Pan-European Survey

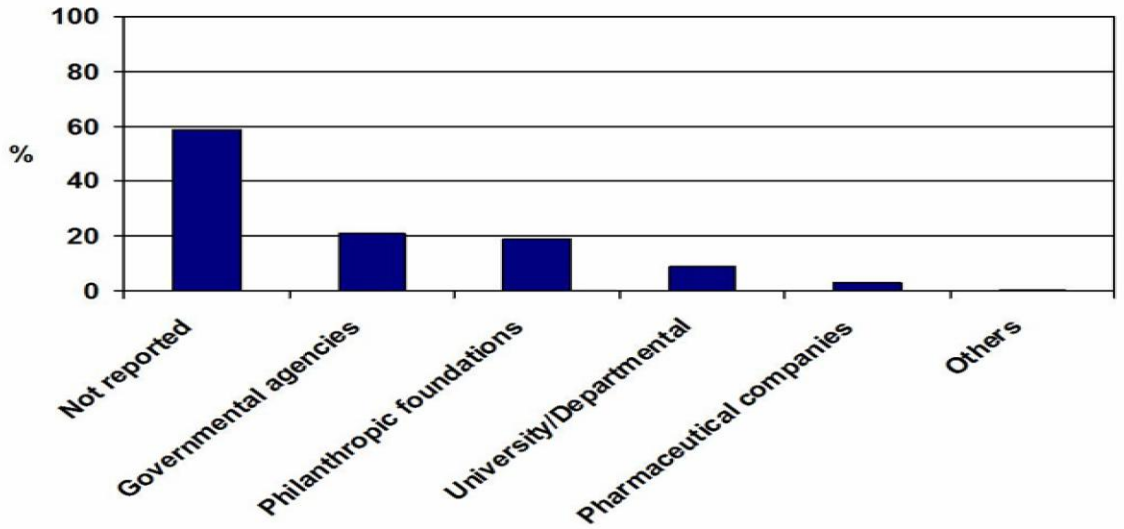
Sigurdardottir KR, et al. Support Care Cancer. 2012 Jan;20(1):39-48

Research Challenges

Funding Sources

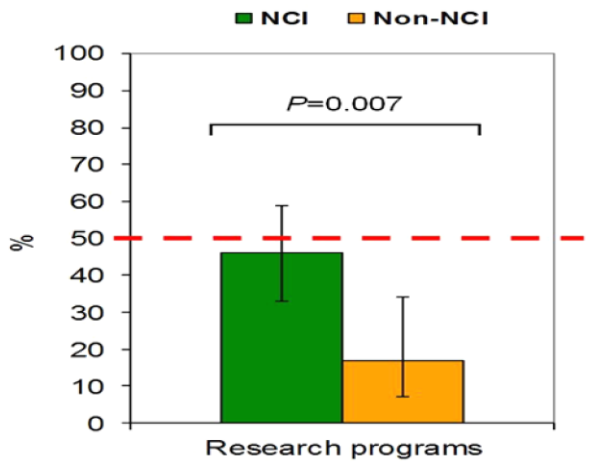
542/848 (59%) original palliative oncology studies reported no funding sources

43% of randomized controlled trials did not report no funding sources

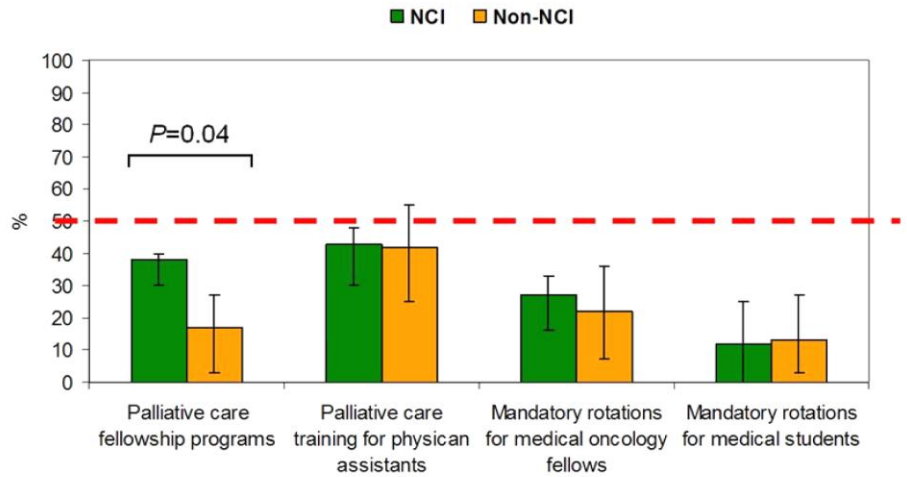


Hui et al. *J Pain Symp Manage* 20

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)

Research Challenges
Diversity needed.

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

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%)

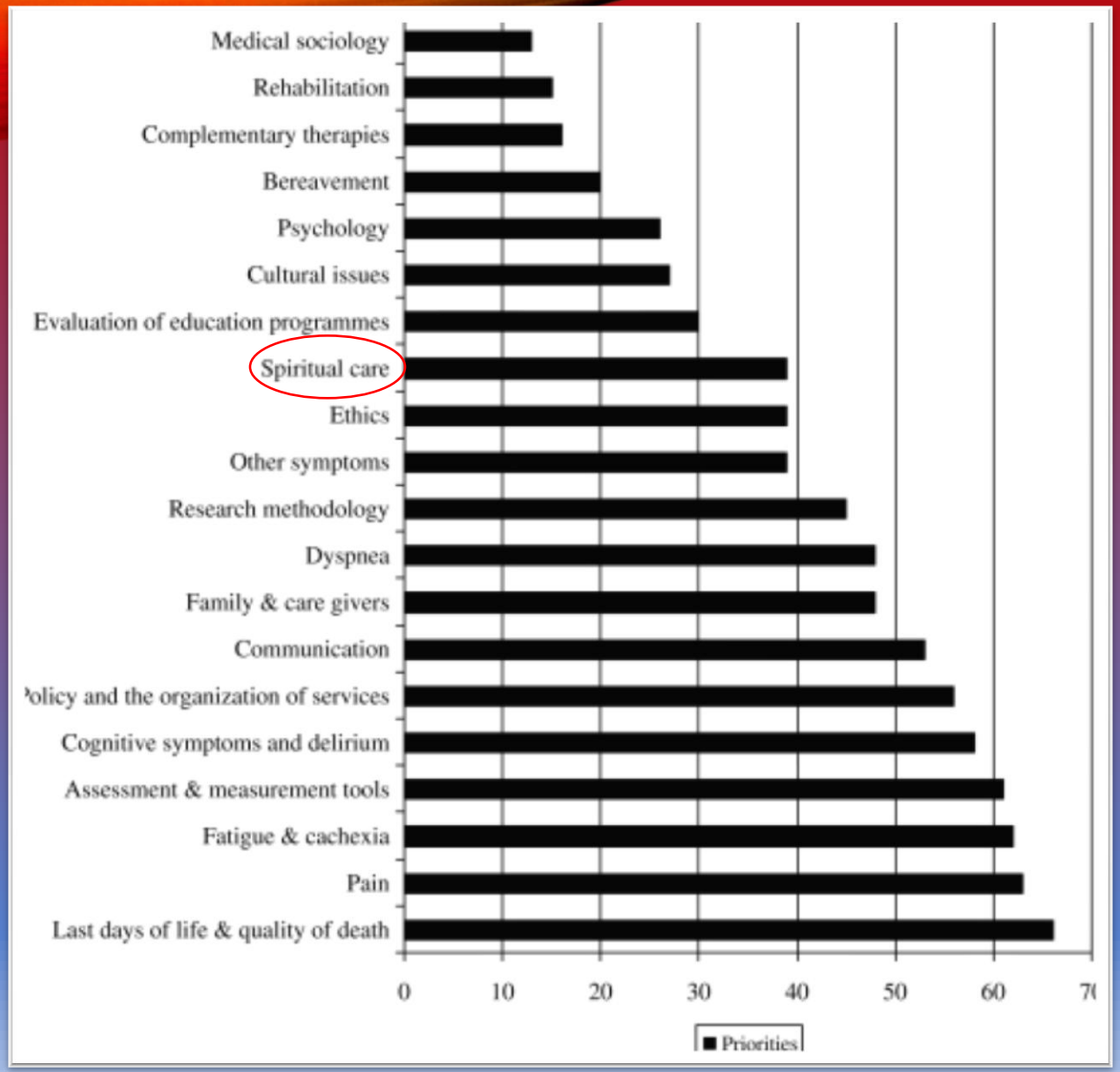
Study Populations
Patients (84%)
Caregivers (9%)
Health Care professionals (10%)

Settings

Inpatient
Outpatient
Palliative Care Units
Consult teams
ICU
Hospice
Home

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%)



Pan-European survey

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

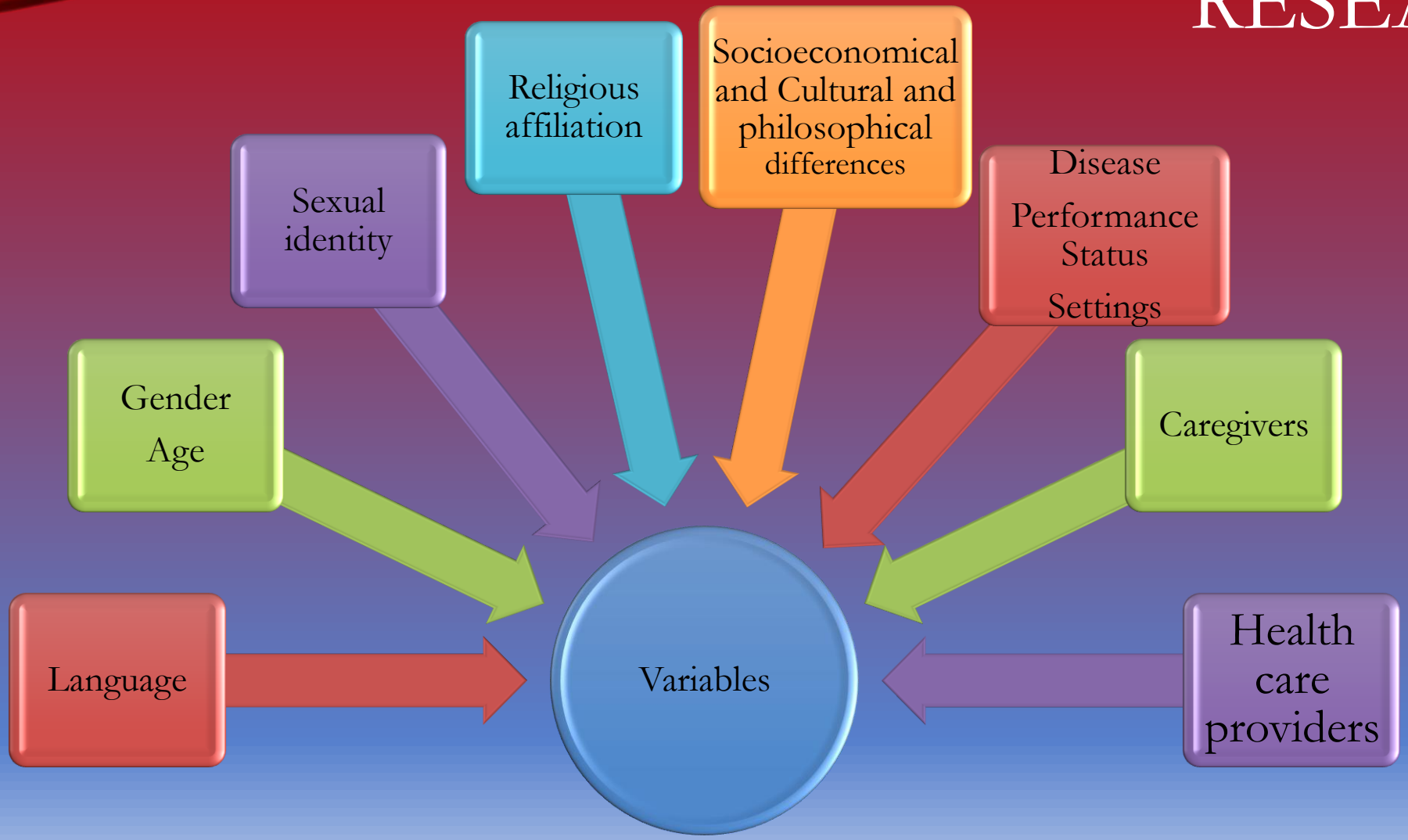
Sigurdardottir KR, et al. Support Care Cancer. 2012 Jan;20(1):39-48

SPIRITUALITY/SPIRITUAL CARE RESEARCH PRIORITIES

Research Priorities ($N = 807$)		
Priority	Rank	Sum Score (Number Prioritizing)
Evaluate screening tools used to identify patients with spiritual needs	1st	1243 (449)
Develop and evaluate conversation models for spiritual conversations with palliative patients	2nd	1219 (470)
Evaluate the effectiveness of spiritual care	3rd	1194 (394)
Develop and evaluate spiritual interventions, e.g., pastoral counseling, interventions by nonspecialist spiritual care providers (e.g., physicians, nurses)	4th	1185 (411)
Determine the prevalence of spiritual distress among people with incurable progressive illness in different cultural and religious populations	5th	1102 (401)
Conduct longitudinal studies to understand how patients' spiritual needs change	6th	870 (287)
Develop spiritual care for palliative care staff	7th	845 (261)
Determine the best spiritual outcome measures for research and audit purposes in palliative care	8th	817 (254)
Develop and evaluate models of spiritual care, e.g., community engagement, spiritual care in palliative homecare	9th	791 (253)
Develop spiritual care for family carers	10th	726 (216)
Determine clinical factors potentially associated with spiritual distress, e.g., cancer types, cancer vs. noncancer diagnoses	11th	608 (185)
Determine demographic factors potentially associated with spiritual distress, e.g., age, gender, socioeconomic status	12th	486 (145)
Develop spiritual care for patients with dementia	13th	359 (107)
Evaluate the cost-effectiveness of spiritual care	14th	339 (100)
Develop spiritual care in pediatric palliative care	15th	321 (102)

Selman L, et al. J Pain Symptom Manage 2014. Oct;48(4):518-31

SPIRITUALITY AND PALLIATIVE CARE RESEARCH



Cobb M, et al. J Pain Symptom Manage 2012;43:1105-1119

SPIRITUALITY IN PALLIATIVE CARE POPULATION

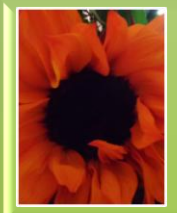
Patients with advanced illnesses could describe and respond questions and instruments intended to capture Spiritual Aspects of their Experience

The 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

Cobb M, et al. J Pain Symptom Manage 2012;43:1105-1119

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

Cobb M, et al. J Pain Symptom Manage 2012;43:1105-1119

SPIRITUALITY IN PALLIATIVE RESEARCH

Cobb M, et al. J Pain Symptom Manage 2012;43:1105-1119

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

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

Religious Coping

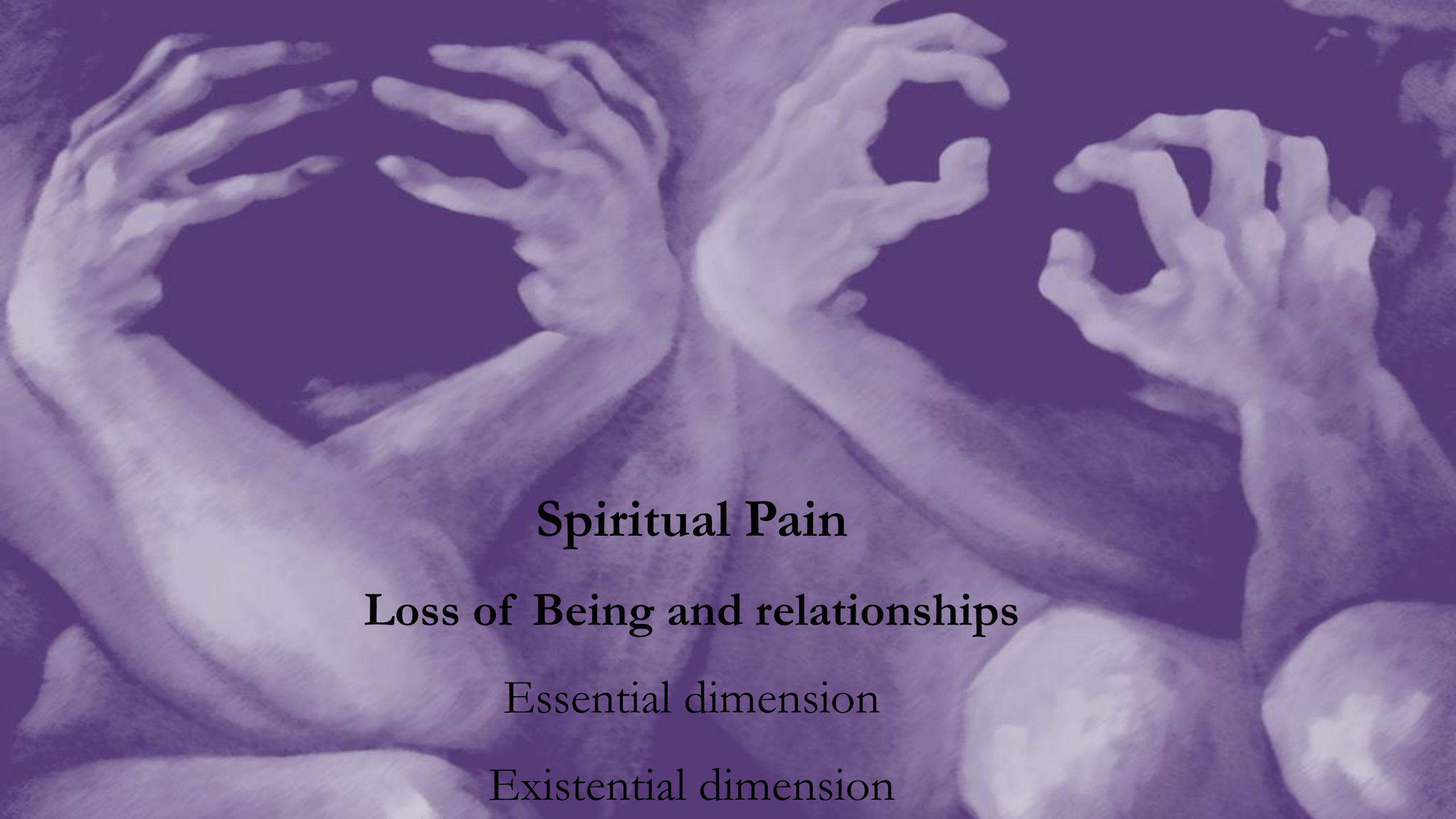
Positive Religious Coping

~ “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”

Pargament K, Zinnbauer BJ, Scott AB, et al J ClinPsych1998; Vol.54(1):77-89.

Religious Coping

Pargament K, Zinnbauer BJ, Scott AB, et al J ClinPsych1998; Vol.54(1):77-89.



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

Spiritual Pain

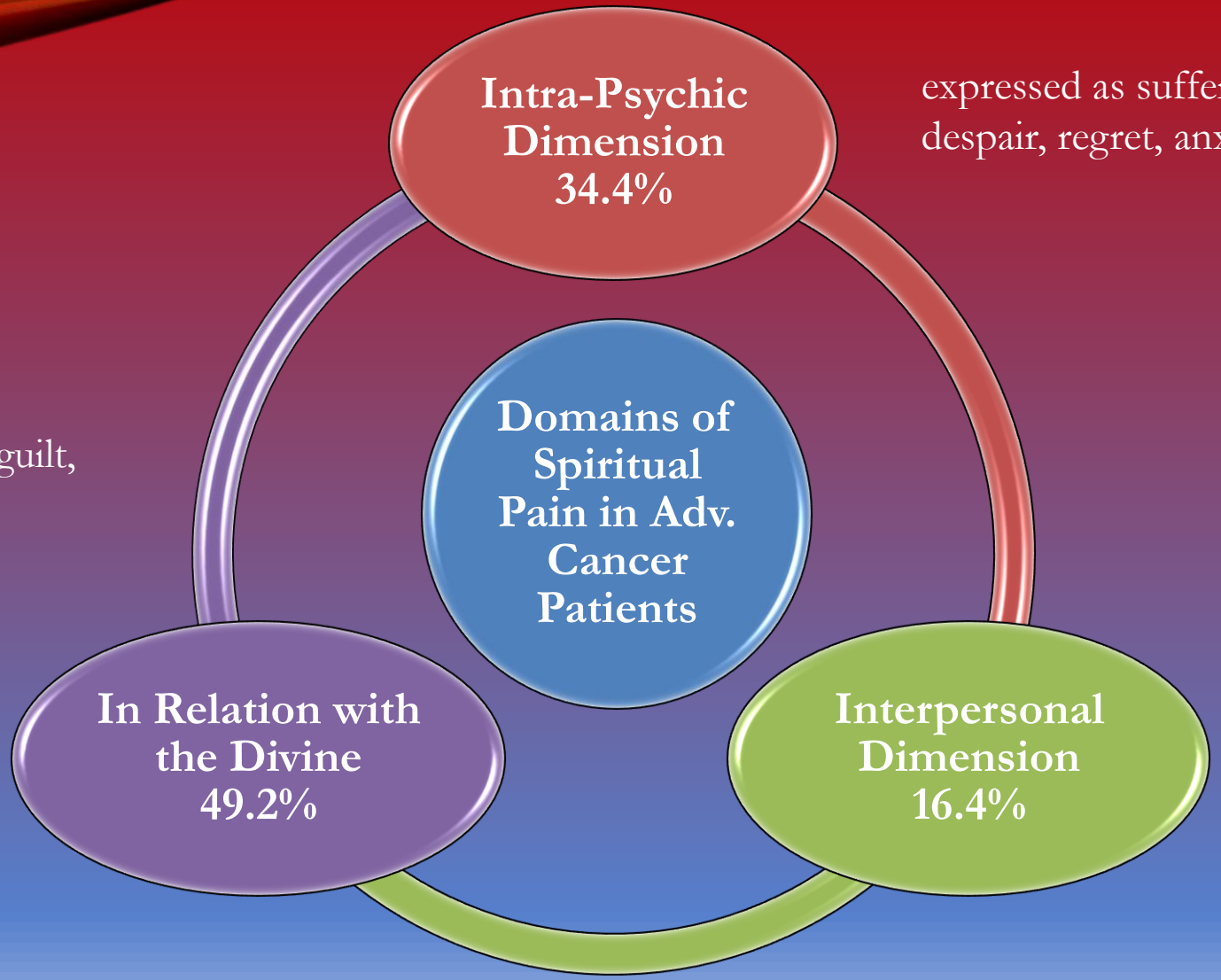
- "A deep pain in your being…in your soul, that is not physical"
- 57 pts with advanced cancer in a PC hospital
- Interviewed by chaplain
- 96% had Spiritual pain sometime in their life
- 61% had Spiritual Pain at the time of interview
- Mean of Spiritual Pain 4.6/10

Mako C, Galek K, Poppito SR. J Palliat Med 2006;9:1106-1112

Do you think you are experiencing **spiritual pain** now and how would you rate your overall spiritual pain?	**40 (44%)**	**Mean: 3 (1-6) (0-10 max)**

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

Delgado-Guay MO, et al. J Pain Symptom Manage. 2011:41;986-994.

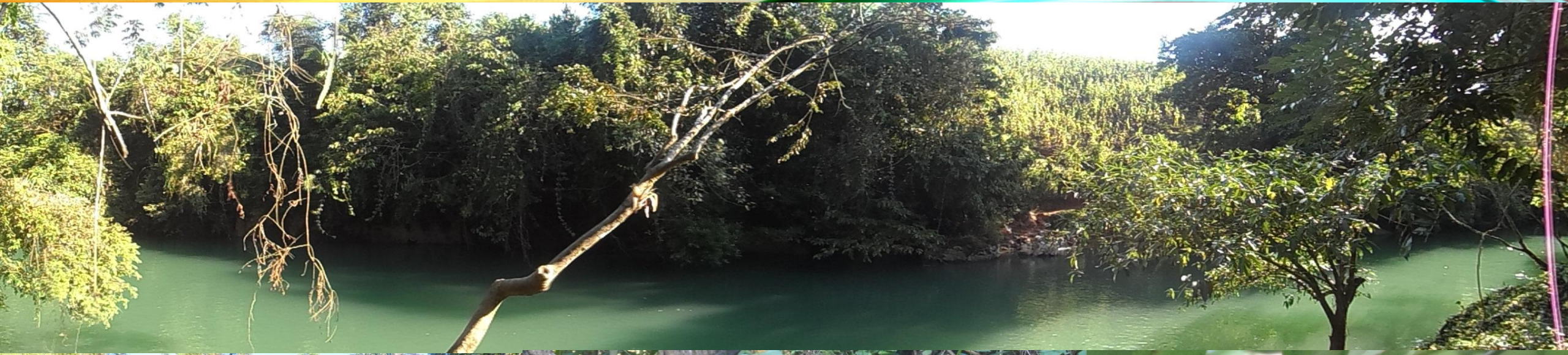


expressed as suffering loss, despair, regret, anxiety

expressed as despair, isolation, guilt, punishment, without faith, abandoned by the Divine

expressed as isolation and regret, disconnected from others

Delgado-Guay MO, et al. EAPC 2010, Glasgow UK



Frequency, Intensity and correlates of Spiritual Pain among Advanced Cancer Patients (AdCa) assessed in a Supportive Care Outpatient Center (SCOC).

- 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.

ANALYSIS

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

Results

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).

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

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), $p<0.0001$].

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

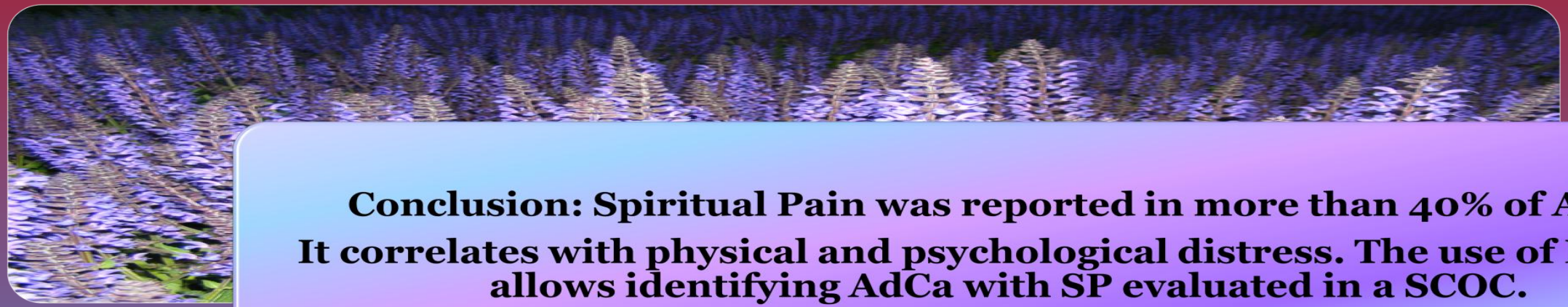
SP correlated (Spearman) with Depression r=0.45, p<0.0001; Anxiety r=0.34, p<0.0001; Drowsiness r=0.26, p<0.0001, and FD r=0.44, p<0.0001.

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).

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



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.

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

ADVANCED CANCER PATIENTS WITH SPIRITUAL DISTRESS IN PCU SETTING

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

Domains	Number of Patients (%)
Despair	36 (32)
Dread	33 (29)
Broken	31 (27)
Helplessness	28 (25)
Alienation	18 (16)
Meaningless	17 (15)
Guilt/shame	10 (8)

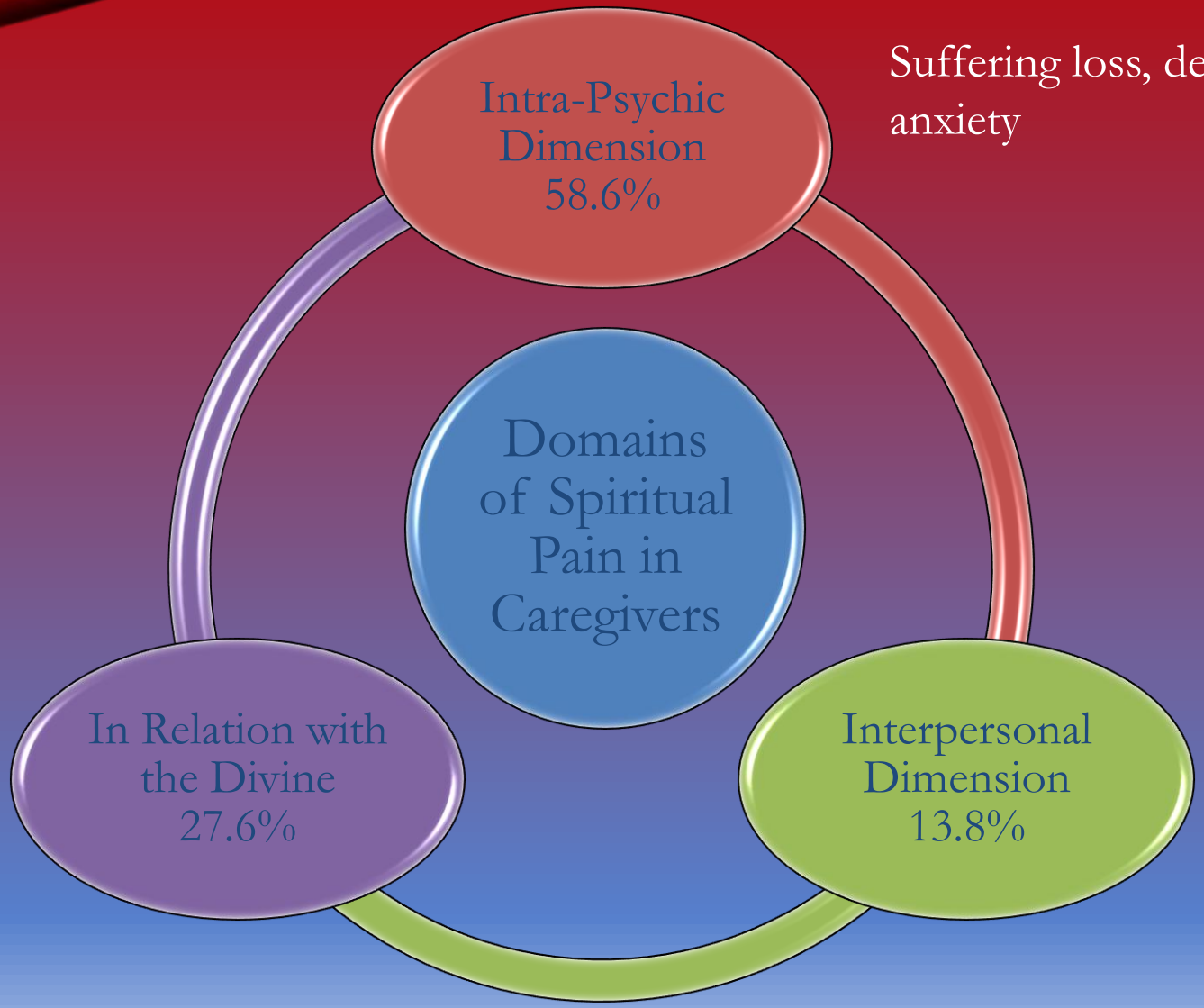
Hui D, et al. Am J Hosp Palliat Care 2011: 28;264-270

FAMILY DISTRESS AT THE END OF LIFE

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

SPIRITUAL PAIN IN CAREGIVERS: MULTIDIMENSIONAL



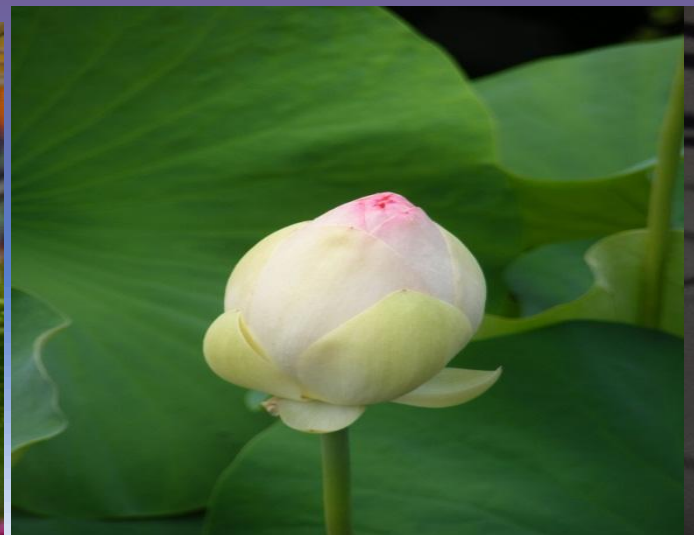
Suffering loss, despair, regret, or anxiety

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

Feeling disconnected from others and unwanted by family/friends

Delgado-Guay, MO, et al. Spiritual Pain as an expression of Suffering in Advanced Cancer Patients' Caregivers in the Palliative Care Setting. EAPC 2010.

PEACE TO YOU



THE PATIENT

- 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

Quill TE, Arnold A, Back AL. Ann Intern Med 2009;151:345-349

MEANINGS OF EVERYTHING

Affective Domain

Abandonment

Fear

Anxiety

Depression

- 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?

Cognitive Domain

Incomplete understanding

Reassurance that best medical care is given

All possible has been done

- 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 there 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.

- 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?

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

•Does your faith provide any guidance in these matters?

•How might we know when God thinks it is your time?

Quill TE, Arnold A, Back AL. Ann Intern Med 2009;151:345-349

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.

Quill TE, Arnold A, Back AL. Ann Intern Med 2009;151:345-349

BELIEF IN MIRACLES IS QUITE COMMON IN THE GENERAL POPULATION EVEN MORE SO AMONG PATIENTS AND FAMILIES THAN AMONG HEALTH PROFESSIONALS.

MIRACLES

- 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

MIRACLES

- 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."

Jacobs LM, Burns K, Bennett Jacobs B. Arch Surg 2008;143:730-735.

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.

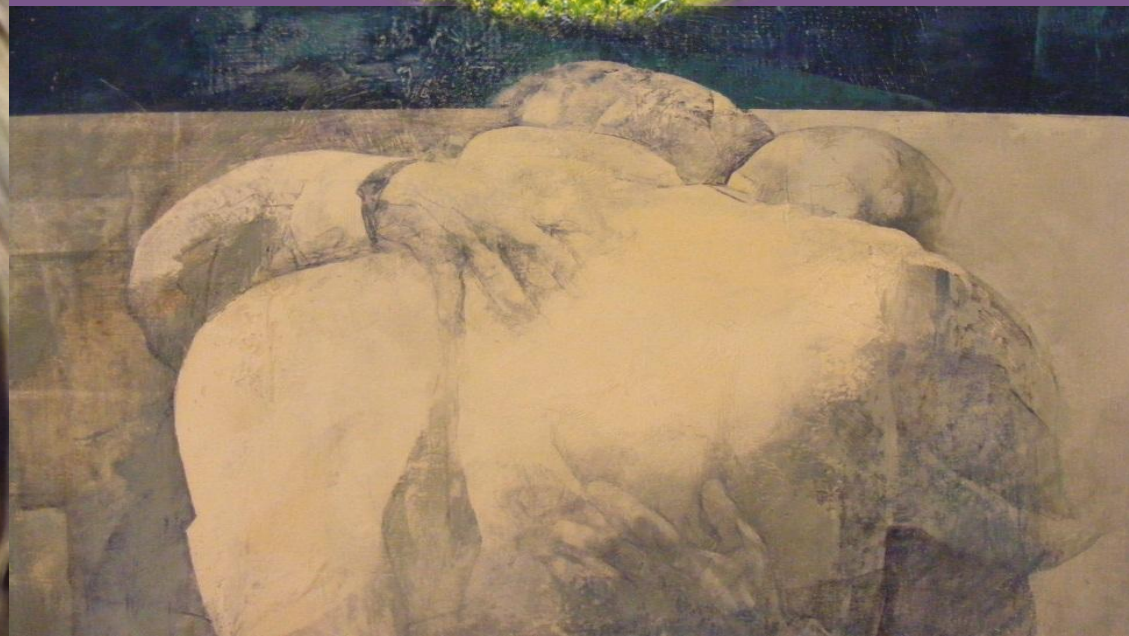
Mansfield CJ, Mitchell J, King DE. Soc Sci Med 2002;54:399-409.

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.

Zier LS, Burack JH, Micco G, et al. Chest 2009;136:110-117.

- 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.

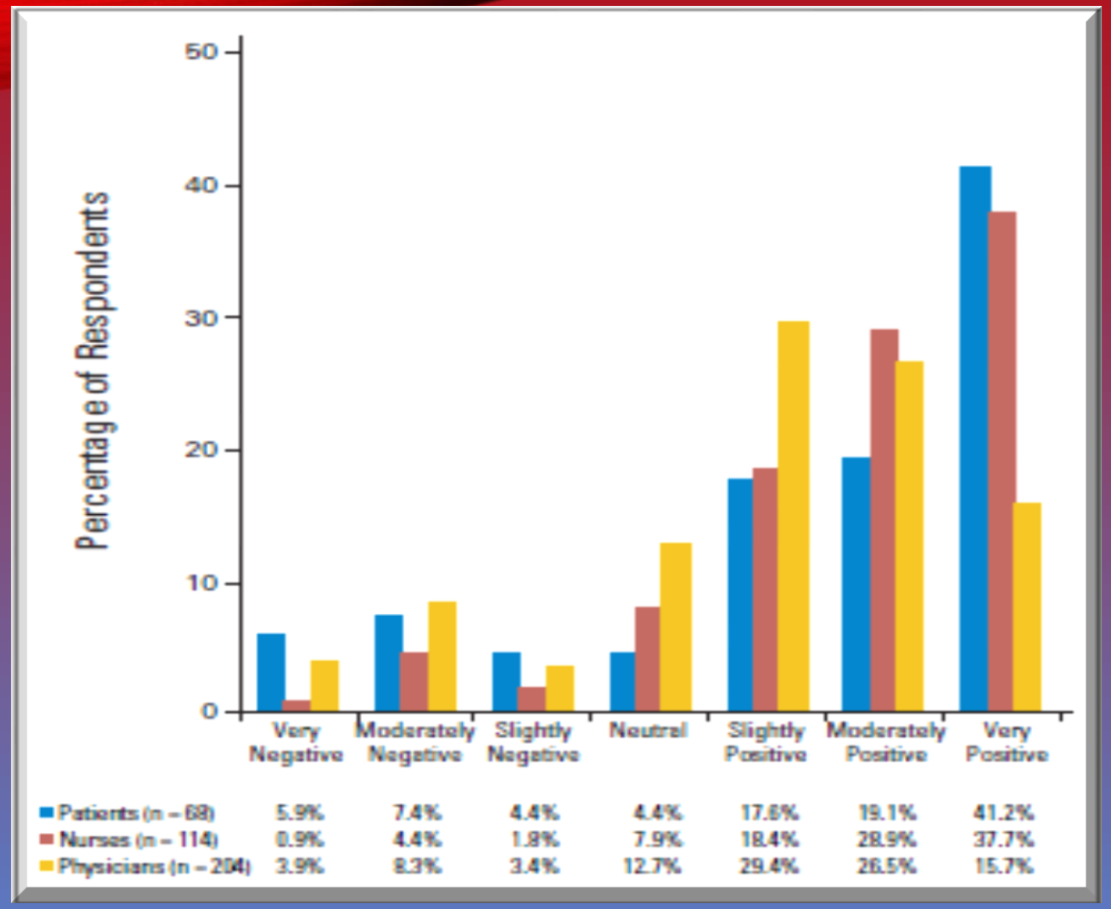
Feel comfortable talking about these issues. Explore those issues, do not Medicalized the issue. .

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

ATTITUDES ABOUT SPIRITUAL CARE



Multicenter
75 advanced cancer patients
339 cancer physicians and nurses

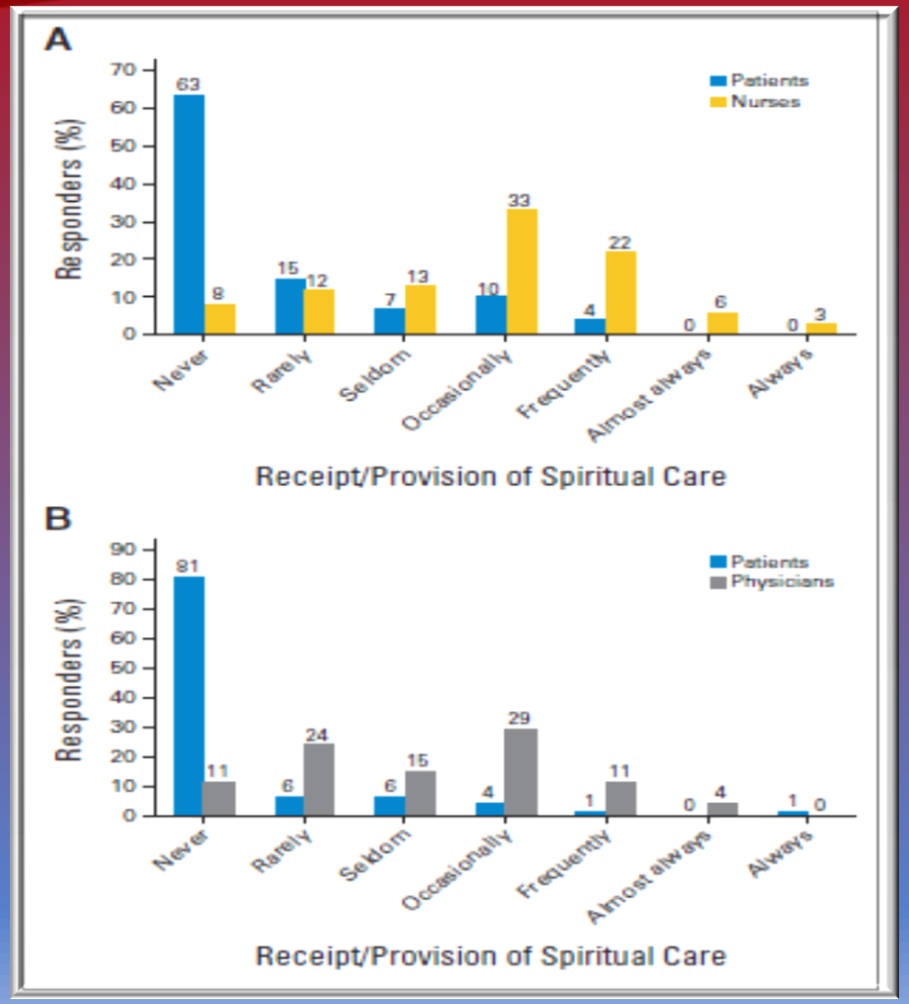
- Believe that routine spiritual care would have a positive impact on patients (77.9% patients, 71.6% physicians, 85.1% nurses)

- 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.

Phelps AC, et al. J Clin Oncol 2012;30:2538-2544

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.

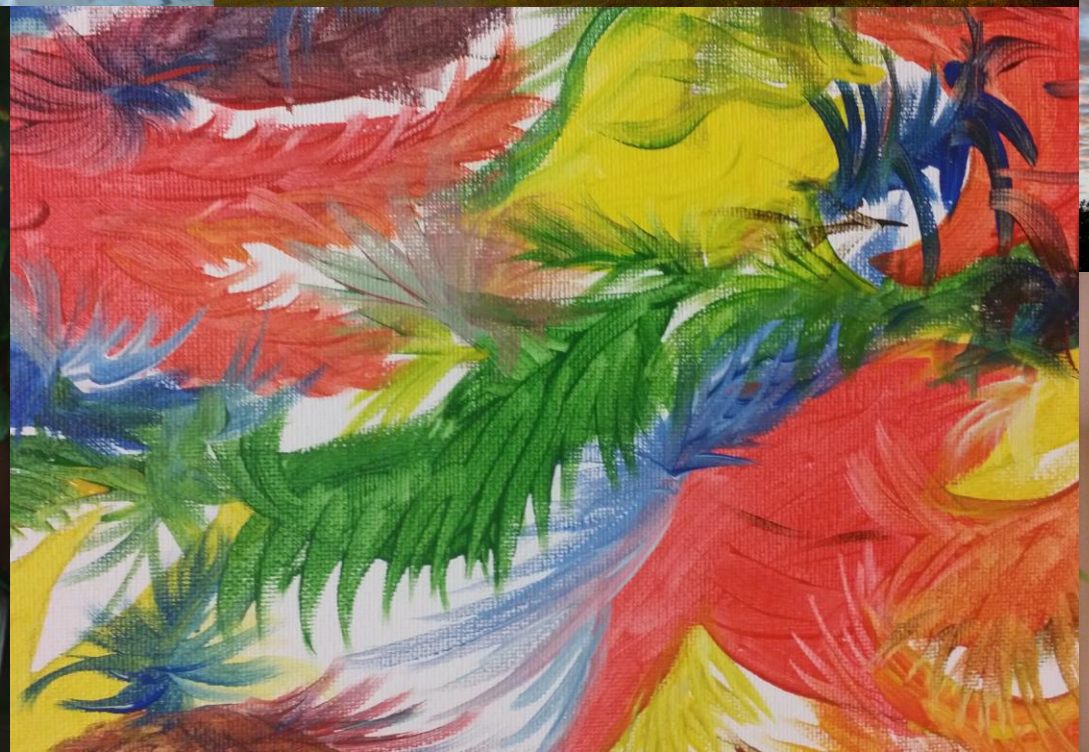
Balboni MJ, et al. J Clin Oncol 2013;31:461-467.

BARRIERS TO PROVIDE SPIRITUAL CARE

Nurse ($N=112$)[a] and Physician ($N=195$)[b] Perceptions of Barriers to Providing Spiritual Care to Patients With Advanced Cancer

Rank Order[c]		Nurse Barriers, *n* (%)[d]	Physician Barriers, *n* (%)[e]	*P*values[b]
#1	Not enough time	79 (71)	142 (73)	0.39
#2	Lack of private space to discuss these matters with my patients	83 (74)	76 (39)	<0.001
#3	I have not received adequate training	67 (60)	121 (62)	0.94
#4	I believe that spiritual care is better done by others on the health care team	35 (31)	120 (62)	<0.001
#5	I am worried that patients will feel uncomfortable	50 (45)	86 (44)	0.12
#6	I feel uncomfortable engaging these issues with patients whose religious/spiritual beliefs may differ from my own	37 (33)	94 (48)	0.04
#7	I am personally uncomfortable discussing spiritual issues	37 (33)	91 (47)	0.03
#8	I do not believe it is my professional role to engage patient spirituality	26 (23)	87 (45)	<0.001
#9	I am worried that the power inequity between patient and (nurse/doctor) makes spiritual care inappropriate	27 (24)	84 (43)	<0.001
#10	Religion/spirituality is not important to me personally	23 (21)	54 (28)	0.40
#11	I do not believe cancer patients want spiritual care from (nurses/doctors)	16 (14)	39 (20)	0.04

Balboni MJ, et al. J Pain Symptom Manage 2013



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

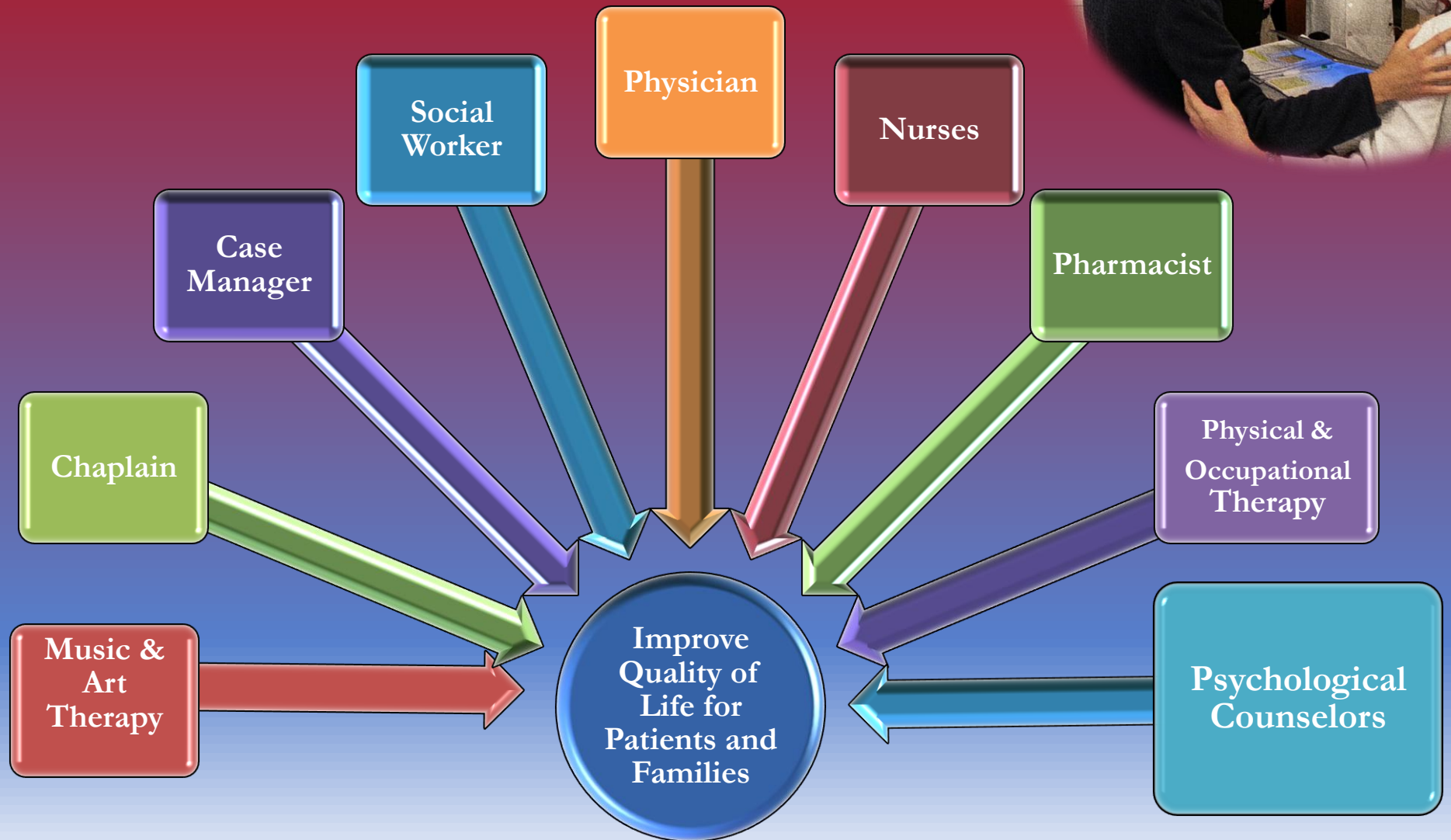
LeMay K, Wilson KG. Clin Psych Rev. 2008;28:472-493

SPIRITUAL INTERVENTIONS AND RESEARCH

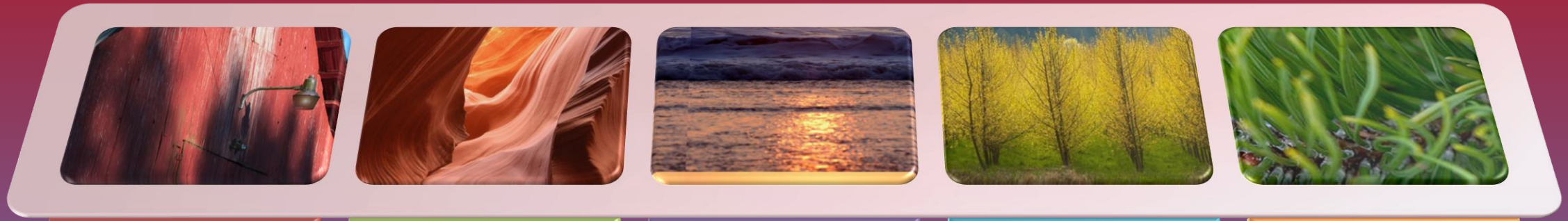
- Five RCTs (1130 participants) were included.
- Two studies evaluated meditation, the others evaluated multi-disciplinary palliative care interventions that involved a chaplain or spiritual counsellor as a member of the intervention team.
- The studies evaluating meditation found no overall significant 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.

Candy B, et al. Cochrane Database Syst Rev. 2012 May 16;5:CD007544.

THE PALLIATIVE CARE TEAM… THE COLLECTIVE SOUL



Healing Connections



With Self

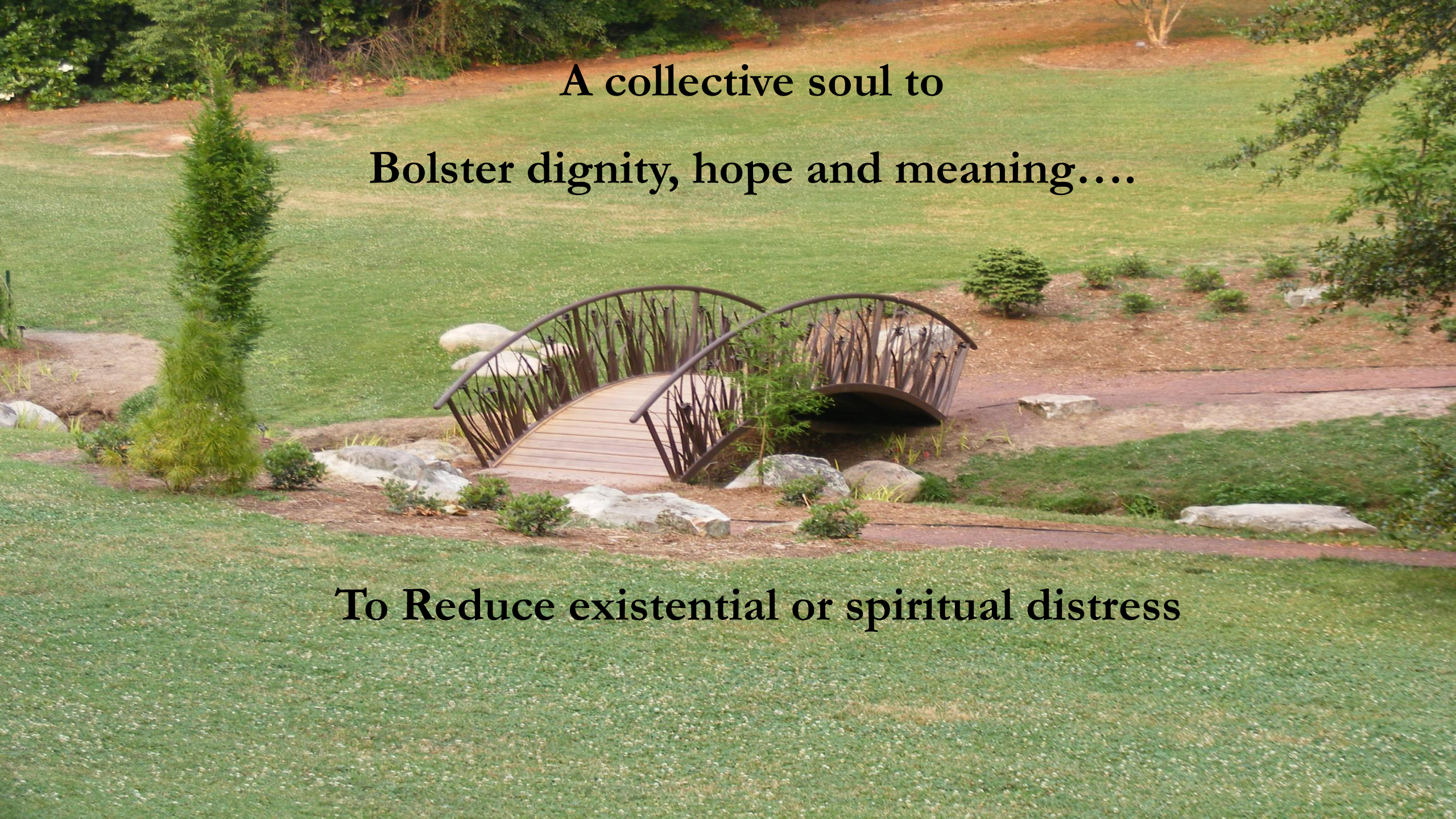
With Others

With Ultimate Meaning

Significance of the Present Moment

Letting Go

Mount BM, Boston PC, Cohen SR. J Pain Symptom Manage 2007;33:372e388.


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

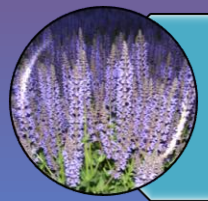
Palliative Care Investigators and Institutional Review Board (IRB)

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.

xplicitly 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.

Abernethy AP, et al. J Pain Symptom Manage. 2014.

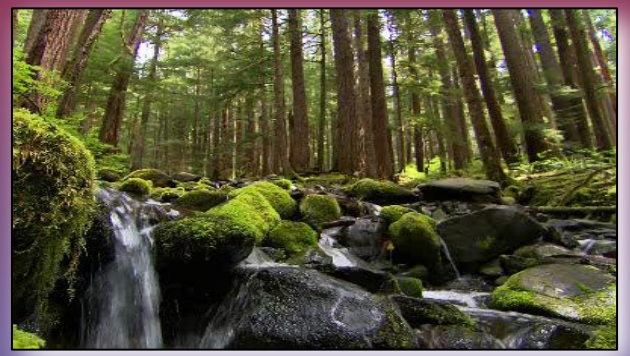
Palliative Care Investigators And IRB

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).

Abernethy AP, et al. J Pain Symptom Manage. 2014.



"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."*

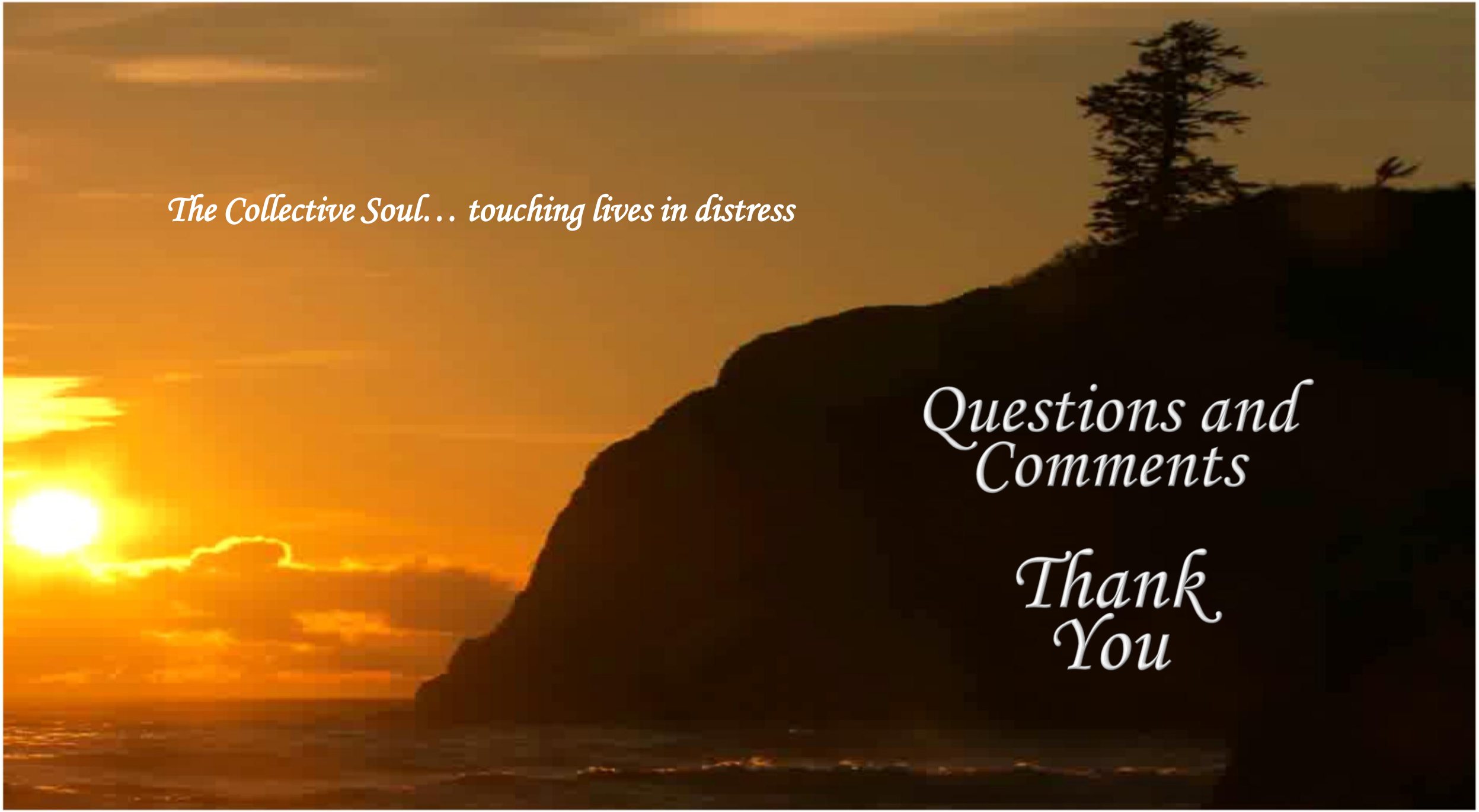
~ ~ We all are part of the collective soul…
Integrative care with multidisciplinary approaches…to provide a touch of hope… a touch of love… to decrease suffering and to improve the quality of life of patients and families/caregivers in distress.

We are actively working to develop research infrastructure, methodology, and portfolio.

SAVE THE DATE

Fifth Annual
Collective Soul Symposium
February, 2016

More Information:
Deanna Cuello: dcuello@mdanderson.org


The Collective Soul… touching lives in distress
Questions and Comments
Thank You