

# **Spirituality and Palliative Care: Putting the Pieces Together**

**Tracy A. Balboni, MD, MPH**  
**15<sup>th</sup> Annual Spirituality Research  
Symposium**



**HARVARD MEDICAL  
SCHOOL**

**University of Pennsylvania**



**DANA-FARBER  
CANCER INSTITUTE**

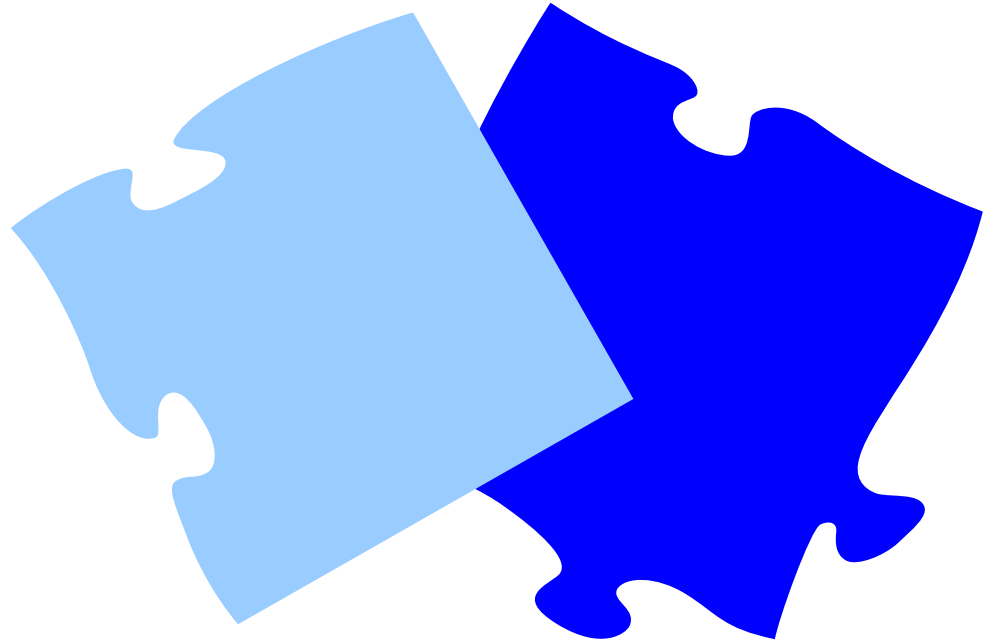


# Talk Outline

- 1. Role of Pt Spirituality**
  - 2. Pt Spirituality and QOL**
  - 3. Pt Spiritual Needs**
  - 4. Pt Preferences for Spiritual Care**
  - 5. Influence of Spiritual Care on QOL and Medical Care**
  - 6. Pt, MD, nurse perceptions of spiritual care**
- Putting the pieces together and next steps...**

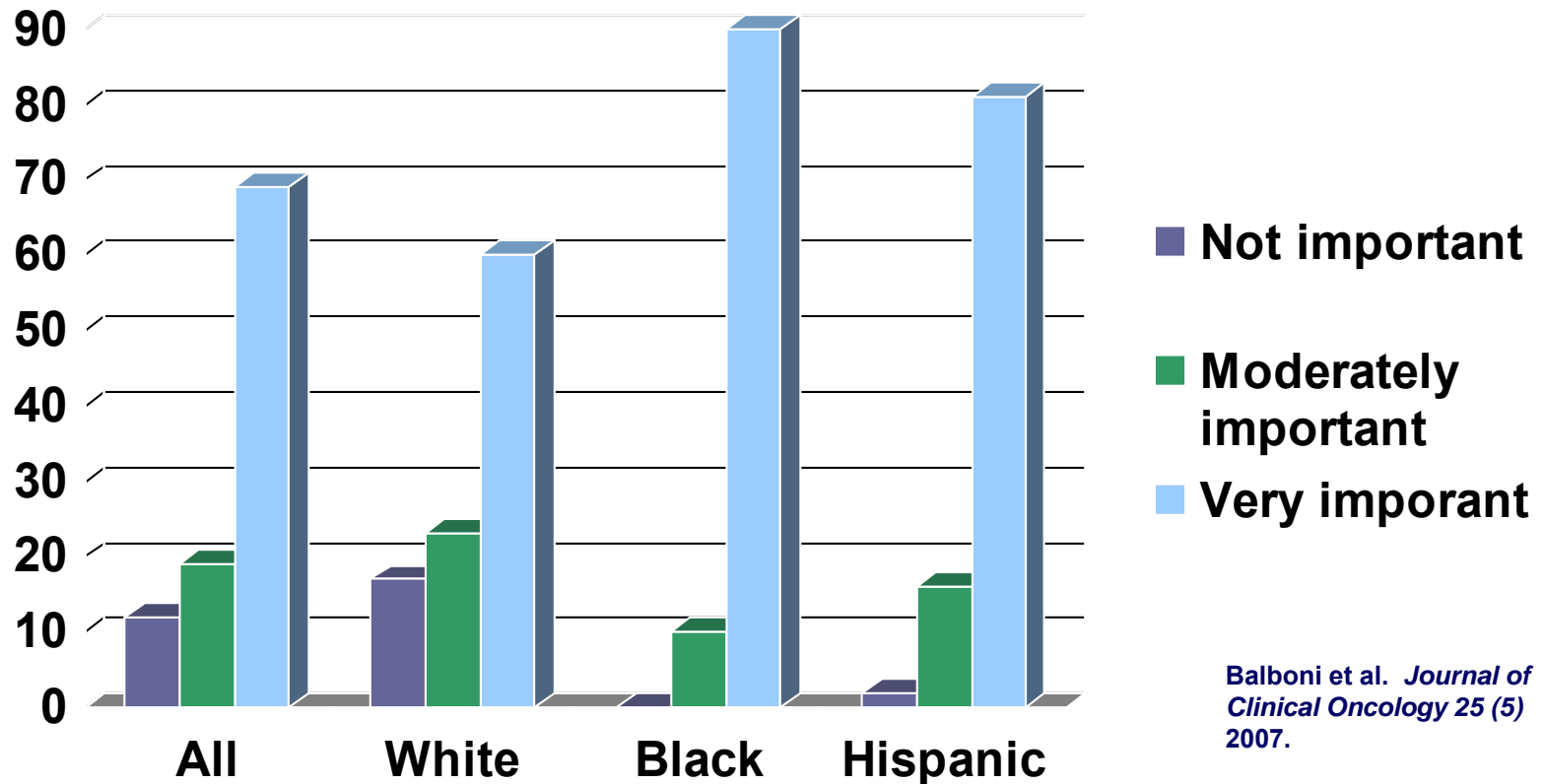
# Question 1:

**What role does patient religion/spirituality play in the experience of advanced illness?**



# Patient Religion/Spirituality

“How important is religion to you?”



Balboni et al. *Journal of Clinical Oncology* 25 (5) 2007.

# Patient Religion/Spirituality

## Religion and Spirituality in Cancer Care Study

- 75 randomly selected patients receiving palliative RT (RR=73%) in 4 Boston centers
- 81% at least slightly religious (58% moderate to very religious)
- 93% at least slightly spiritual (74% moderate to very spiritual)
- 78% - religion and/or spirituality “important to advanced cancer experience.”

Alcorn S et al. “If God wanted me yesterday, I wouldn’t be here today”: Religious and spiritual themes in patients’ experiences of advanced cancer. *Journal of Palliative Medicine* 2010.

# Qualitatively-grounded religious/spiritual themes in patients' experiences of advanced cancer, n = 53\*

Theme	n (%)	Representative Quote
Coping through R/S	39 (74)	<i>I don't know if I will survive this cancer, but without God it is hard to stay sane sometimes. For me, religion and spirituality keeps me going.</i>
R/S practices	31 (58)	<i>I pray a lot. It helps. You find yourself praying an awful lot. Not for myself, but for those you leave behind. There will be a lot more praying.</i>
R/S beliefs	28 (53)	<i>It is God's will, not my will. My job is to do what I can to stay healthy—eat right, think positively, get to appointments on time, and also to do what I can to become healthy again like make sure that I have the best doctors to take care of me. After this, it is up to God.</i>
R/S transformation	20 (38)	<i>Since I have an incurable disease that will shorten my life, it has made me focus on issues of mortality and sharpened my curiosity on religion/spirituality and what the various traditions have to say about that. I've spent a lot of time thinking about those issues, and it has enriched my psychological, intellectual, and spiritual experience of this time.</i>
R/S community	11 (21)	<i>Well, I depend a lot upon my faith community for support. It's proven incredibly helpful for me.</i>

# Patient Religion/Spirituality

- **Silvestri et al. Journal of Clinical Oncology, 2003**
- **100 pts with advanced lung cancer, their caregivers, 257 medical oncologists**
- **Rank 7 factors important to patient in making treatment decisions**



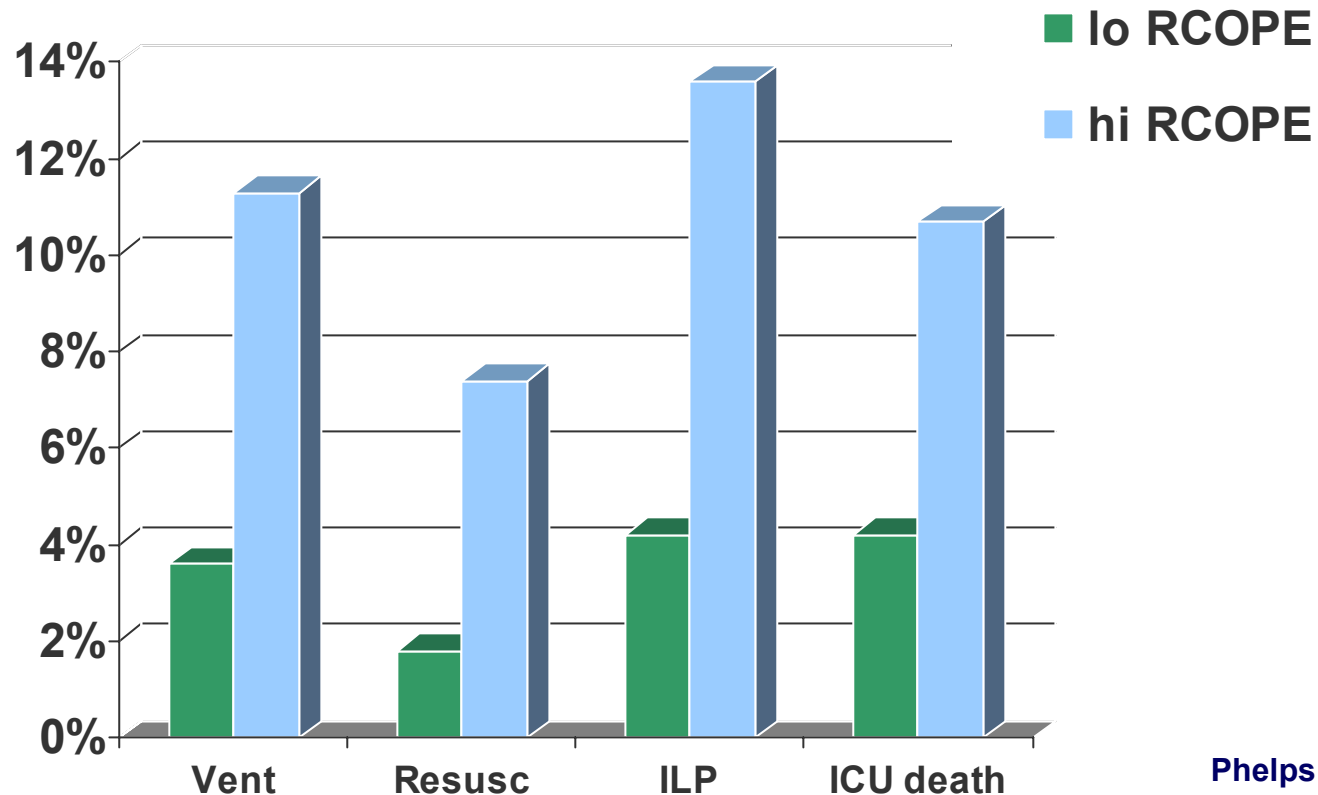
# Spirituality in Medical Decisions

## 7 factors ranked:

- Oncologist's treatment recommendation
- Ability of treatment to cure disease #1
- Side effects
- Family doctor's recommendation
- Spouse's recommendation
- Children's recommendation
- Faith in God #2 for pts/families, #7 MDs

# Spirituality in Medical Decisions

**CWC study: Relationship between religious coping and receipt of aggressive medical care at the EOL**



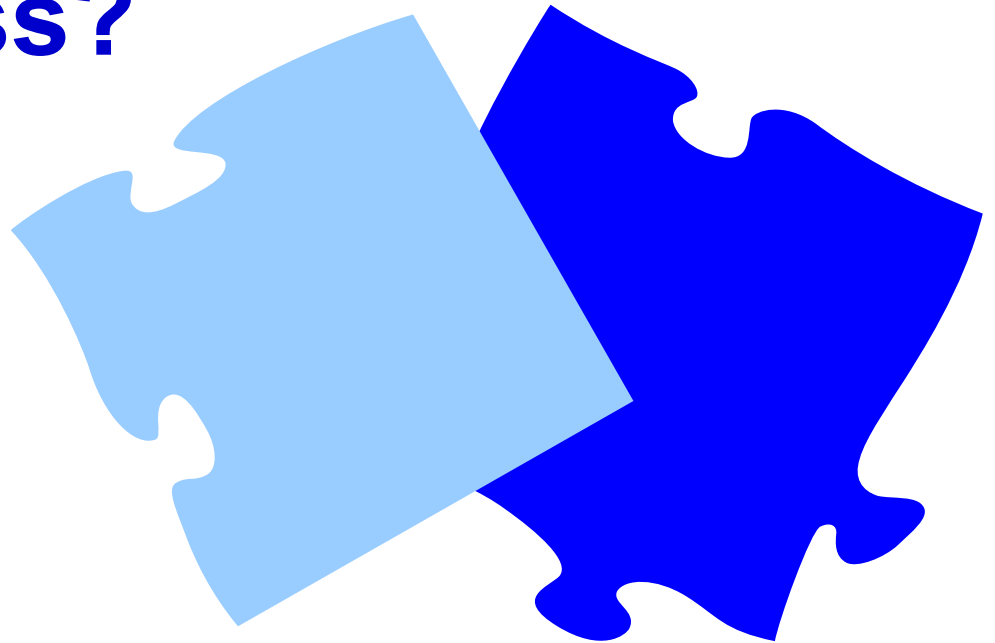
Phelps et al JAMA 2009;  
301(11): 1143-1147

# **Role of Patient Spirituality in Advanced Illness**

- **Important to most patients, particularly ethnic minorities**
- **Plays multiple roles**
- **Impacts medical care decision-making**

# Question 2:

**How does patient spirituality influence well-being in advanced illness?**



# Patient Spirituality and QOL

**Brady et al. *Psycho-Oncology* 1999**

- **Multi-institutional cross-sectional study of 1610 cancer patients.**
- **R/S (FACIT-Sp) → independent predictor of QOL (FACT-G)**
- **Controlled for physical well-being, emotional well-being, social well-being, disease, demographic variables**
- **R/S associated with improved symptom tolerance**

**Brady et al. A case for including spirituality in quality of life measurement in oncology. *Psycho-Oncology*. 1999; 8: 417-428.**

# Patient Spirituality and QOL

## Religion and Spirituality in Cancer Care Study

Associations of Spirituality With QOL Among  
Patients Receiving Palliative Radiation Therapy  
(n = 69)

	PATIENT SPIRITUALITY <sup>a</sup>			
	UNIVARIATE MODELS		MODELS ADJUSTED FOR KARNOFSKY PERFORMANCE STATUS	
	$\beta$	P	$\beta$	P
Physical QOL <sup>b</sup>	1.37	.03	1.11	.06
Psychological QOL <sup>b</sup>	1.66	.18	1.45	.24
Existential QOL <sup>b</sup>	5.81	<.001	5.50	<.001
Social Support <sup>b</sup>	1.56	<.001	1.49	<.001
Overall QOL <sup>b</sup>	11.55	<.001	10.57	<.001

# Patient Spirituality and QOL

## Steinhauser et al. JAMA 2000

- National survey of 1885 seriously ill patients, recently bereaved family, physicians, and other care providers
- Importance of 44 attributes of quality of life near death
- 9 major attributes ranked

Steinhauser et al. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *Journal of the American Medical Association*. 2000; 284(19): 2476-2482.

# Factors Considered Important to Patient QOL at EOL

**Table 5. Mean Rank Scores of 9 Preselected Attributes\***

Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

\*Attributes are listed in the mean rank order based on patient response. Numbers in parentheses are mean rank order, with lowest rank score (1) indicating most important attribute and highest rank score (9) indicating least important. Friedman tests were significant at  $P < .001$ , suggesting that rankings by each group were different than would be expected by chance alone.

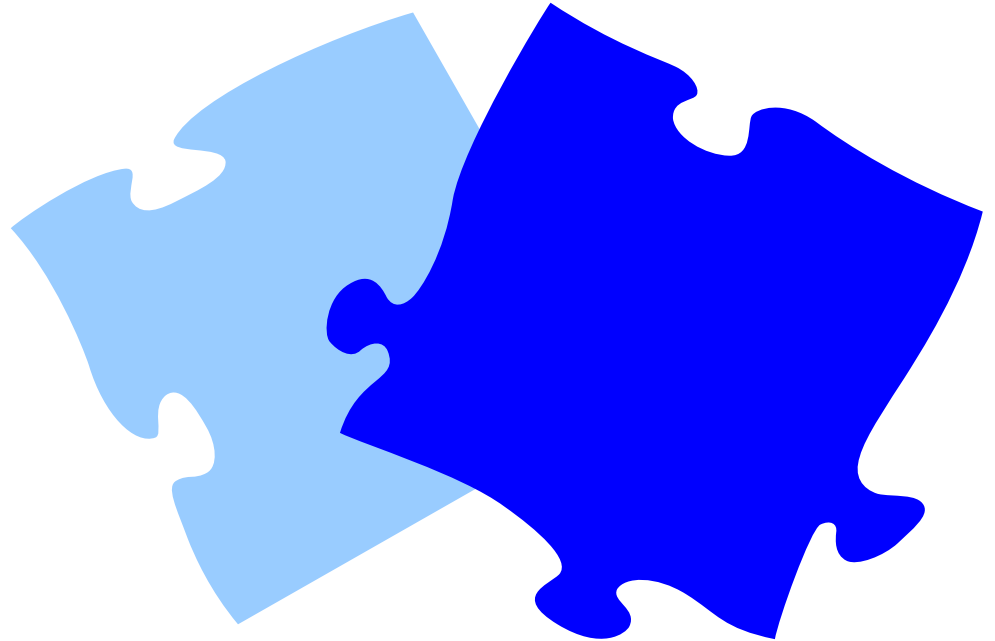


# **Question 2: How does patient spirituality influence well-being in advanced illness?**

- **Important to pt well-being**
- **One of the most important issues at the end of life**

# Question 3:

**Does advanced illness raise spiritual concerns or needs?**



# Spiritual Issues in Advanced Illness

## Religion and Spirituality in Cancer Care

- 75 randomly selected patients receiving palliative RT (RR=73%) in 4 Boston centers.
- 14 spiritual issues assessed
- 85% 1 or more spiritual issues
- Median of 4 spiritual issues

<b>Quantitatively-assessed religious/spiritual concerns in advanced cancer</b>	
<b>Religious/Spiritual Beliefs</b>	<b>n (%)</b>
Doubting one's belief in God or one's faith	13 (19)
Questioning God's love*	14 (21)
Questioning God's power*	14 (21)
Believing the devil caused the cancer*	6 (9)
<b>Religious/Spiritual community</b>	
Feeling abandoned by ones religious/spiritual community*	6 (9)
<b>Religious/Spiritual transformation</b>	
Seeking a closer connection with God or one's faith	36 (53)
Seeking what gives meaning to life	37 (54)
Seeking forgiveness (of oneself or others)	32 (47)
Feeling angry at God	17 (25)
Feeling abandoned by God*	19 (28)
Feeling punished by God*	15 (22)
<b>Religious/Spiritual coping</b>	
Seeking meaning in the experience of cancer	34 (50)

# Spiritual Issues and Patient QOL

## MVA of predictors of spiritual issues

- Younger age associated with greater burden of spiritual concerns ( $\beta = -0.01$ ,  $p = 0.006$ )

## MVAs examining spiritual issues and QOL

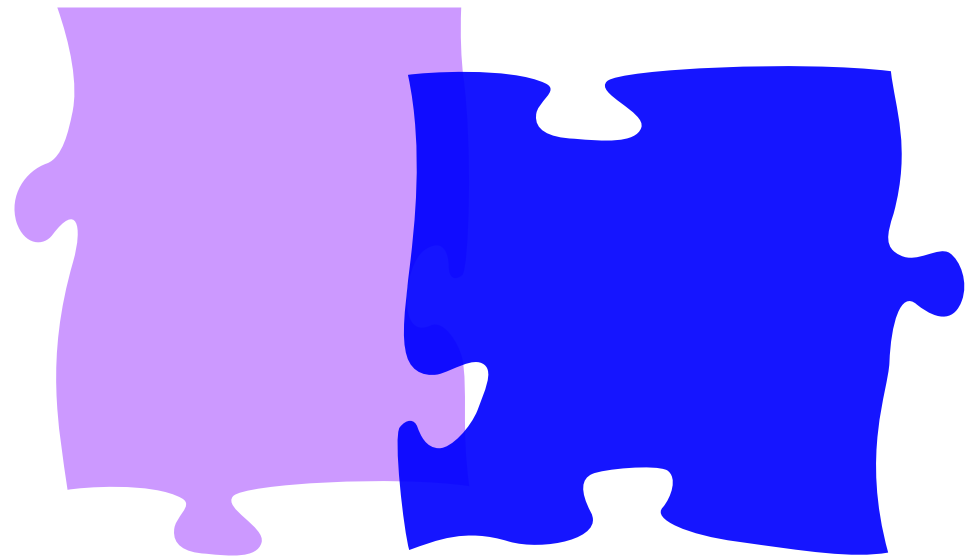
- Total spiritual concerns (as well as spiritual seeking/struggle) associated with worse psychological QOL ( $\beta = -1.11$ ,  $p = 0.01$ ;  $\beta = -1.67$ ,  $p < 0.05$ ; and  $\beta = -1.06$ ,  $p < 0.001$ )

# **Question 3: Does advanced illness raise spiritual concerns or needs?**

- Yes, for most**
- Most with multiple spiritual issues**
- May be associated with inferior well-being**

# Question 4:

**Do patients with advanced illness want their medical care to include attention to R/S dimensions?**



# Patients' Spiritual Care Preferences

- Ehman et al. Cross-sectional survey of pts seen at outpt clinic at Univ of Penn, N = 177**
- 66% agreed/strongly agreed they would like their MD to inquire about spiritual/religious beliefs if they were very ill**
  - 85% stated they had never had a physician ask about R/S**



# Patients' Spiritual Care Preferences

## Religion and Spirituality in Cancer Care Study

- Importance of oncology MDs/nurses “considering patients’ spiritual needs as part of cancer care”
- Four response options: not at all, mildly, moderately, and very important

# **Patient Preferences for Spiritual Care in Advanced Illness**

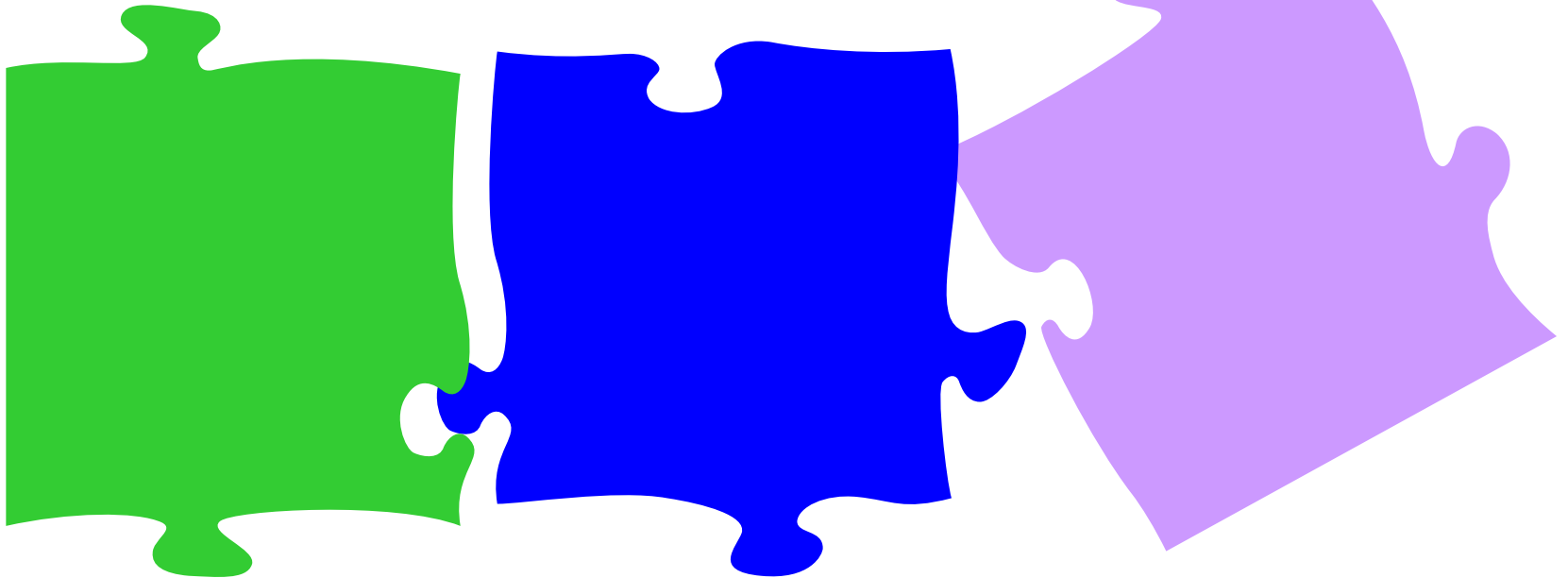
- MDs: 65% 'moderately' or 'very important' (89% at least mildly important)**
- RNs: 69% 'moderately' or 'very important' (87% at least mildly important)**
- 9% received spiritual care from MDs, 20% from RNs**
- 8 spiritual care types included: spiritual history, referrals to chaplains**

# **Do patients with advanced illness want medical care to include R/S?**

- **Most do**
- **Spiritual care is infrequent**

# Question 5:

**How does spiritual care influence patients' experiences of advanced illness?**



# Coping with Cancer (CwC) Study

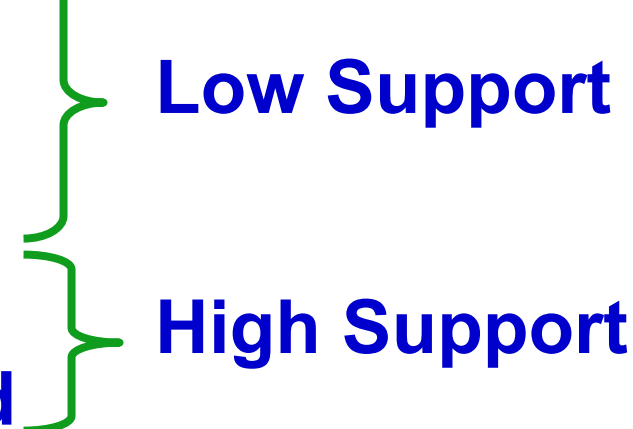
- **Multi-site, prospective cohort study of advanced, incurable cancer pts and caregivers, N=343**
- **Purpose: examine psychosocial/ spiritual factors and relationship to EOL and bereavement outcomes**

Balboni et al. "Provision of Spiritual Care to Advanced Cancer Patients: Associations with Medical Care and Quality of Life Near Death" *J Clin Oncol* 2010.

# Baseline Measure: Spiritual Care from the Medical Team

“To what extent are your religious/spiritual needs being supported by the medical system (e.g., doctors, nurses, chaplains)?”

## Response Options:

- Not at all
  - To a small extent
  - To a moderate extent
  - To a large extent
  - Completely supported
- Low Support
- High Support
- 
- A diagram consisting of two green curly braces on the right side of the list. The top brace groups the first three items: 'Not at all', 'To a small extent', and 'To a moderate extent'. The bottom brace groups the last two items: 'To a large extent' and 'Completely supported'. The text 'Low Support' is positioned to the right of the top brace, and 'High Support' is positioned to the right of the bottom brace.

# Baseline Measures: R/S Support from the Medical Team

*“Have you received pastoral care services  
within the clinic or hospital?”*

## Response Options:

- Yes
- No

# Baseline Measure: Spiritual Care from Religious Communities

“To what extent are your religious/spiritual needs being supported by your religious community (e.g., clergy, members of your congregation)?”

## Response Options:

- Not at all
  - To a small extent
  - To a moderate extent
  - To a large extent
  - Completely supported
- Low Support
- High Support
-



# Outcomes: QOL Near Death

**Caregiver-rated quality of death:**

**Sum (0-30) of assessments of:**

- 1. Psychological distress near death**
- 2. Physical distress near death**
- 3. Overall QoD**

# **EOL Medical Care Outcomes**

- 1. Hospice: Inpatient or outpatient hospice in last week of life**
- 2. Aggressive EoL care measures: ICU care, resuscitation, or ventilation in last week of life**
- 3. Death in an ICU**

# **Spiritual Care and EOL Well-being Multivariable Models**

## **Adjusted for:**

- **Race**
- **Religiousness**
- **Positive religious coping**
- **Baseline QOL**
- **Baseline existential well-being**
- **Baseline social support**
- **Recruitment site**
- **MD/patient relationship**

# **Spiritual Care and EOL Care Multivariable Models**

## **Adjusted for:**

- **Propensity score (demographic, psychosocial, other EOL care predictors, and R/S characteristics)**
- **Race**
- **Advance care planning**
- **Pt EOL treatment preferences**
- **EOL discussion**
- **Recruitment site**
- **MD/patient relationship**
- **Religious factors (religiousness, tradition, rel coping)**

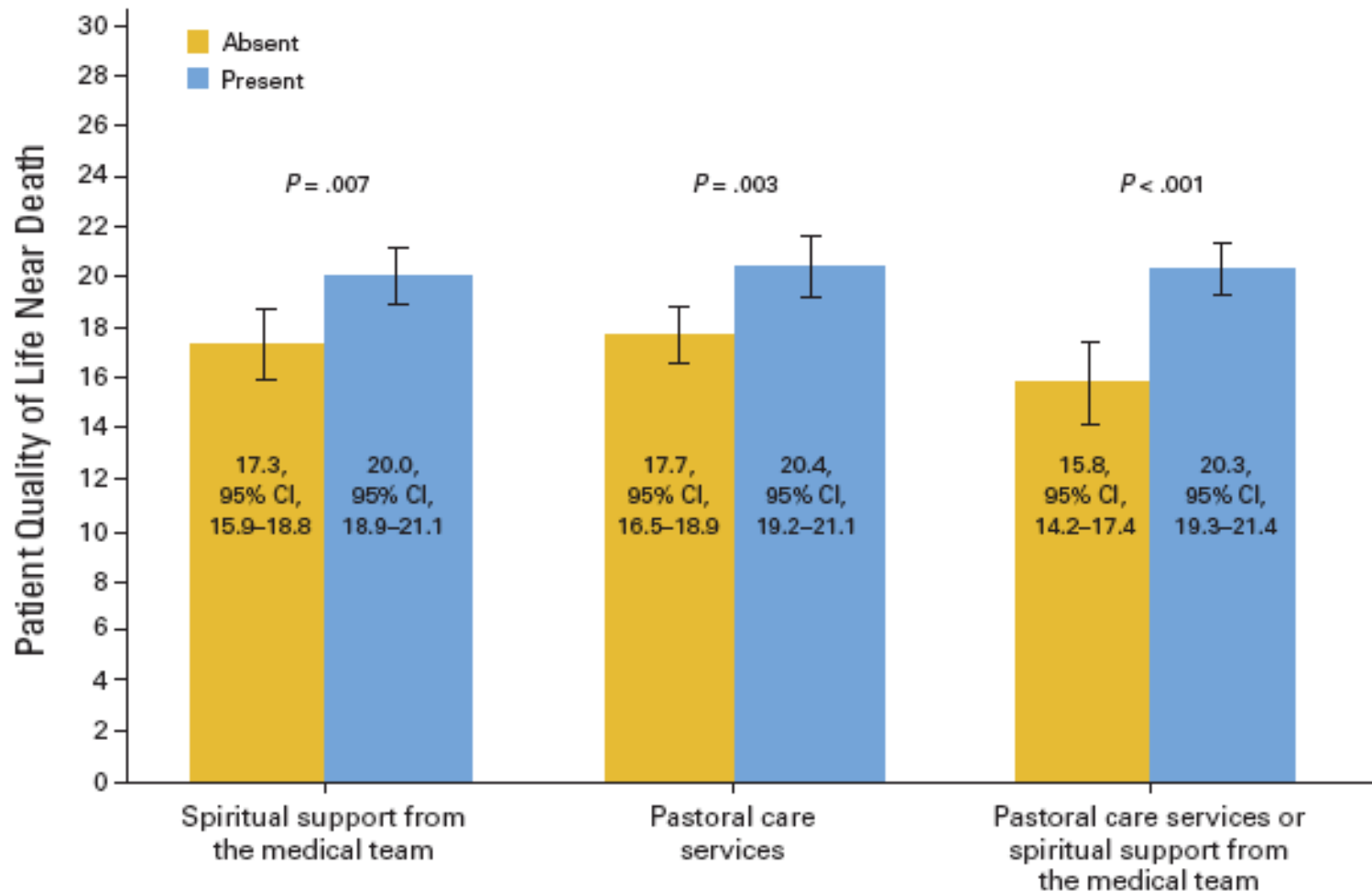
## Support of R/S needs by the medical team

Not at all	143 (42)
To a small extent	62 (18)
To a moderate extent	48 (14)
To a large extent	53 (15)
Completely supported	37 (11)

## Support of R/S needs by religious communities

Not at all	110 (32)
To a small extent	43 (13)
To a moderate extent	43 (13)
To a large extent	55 (16)
Completely supported	92 (27)
Pastoral care services	158 (46)

# Results: Spiritual Care and Quality of Life Near Death



# **Results: Spiritual Care from Rel Communities and QOL Near Death**

**Though high spiritual support from religious communities associated w/ better QOL at baseline (McGill QOL), not associated w/ pt QOL near death**

# Results: Support of Spiritual Needs and Receipt of Hospice

High vs. Low Spiritual Support	Unadjusted OR [95% CI]	<i>p</i>	Adjusted OR [95% CI]	<i>p</i>
R/S Support from the Medical Team	1.65 [0.92-2.96]	.09	2.99 [1.45-6.17]	.003
R/S support from Religious Communities	0.53 [0.33-0.86]	.01	0.38 [0.20-0.72]	.003



# Results: Spiritual Support and Receipt of Aggressive EOL Care

High vs. Low Spiritual Support	Unadjusted OR [95% CI]	<i>p</i>	Adjusted OR [95% CI]	<i>p</i>
R/S Support from the Medical Team	0.67 [0.21-1.45]	.31	0.38 [0.15-0.98]	.04
R/S support from Religious Communities	1.63 [0.87-3.05]	.13	2.55 [1.10-5.93]	.03

# Results: Spiritual Support and Death in an ICU Setting

High vs. Low Spiritual Support	Unadjusted OR [95% CI]	<i>p</i>	Adjusted OR [95% CI]	<i>p</i>
R/S Support from the Medical Team	0.69 [0.25-1.88]	.46	0.23 [0.06-0.85]	.03
R/S Support from Religious Communities	3.77 [1.53-9.28]	.004	5.73 [1.74-18.93]	.004

# Study Limitations

- **Important confounding factors may not be included**
- **US population, only cancer patients**
- **Support of spiritual needs not well-characterized**

# How does spiritual care influence patients with advanced illness?

- **Spiritual support from medical team → better pt QOL at EOL**
- **Spiritual support from the medical team → less intensive medical care near death**
- **Spiritual support from religious communities → greater aggressive care near death**

# Question 6:

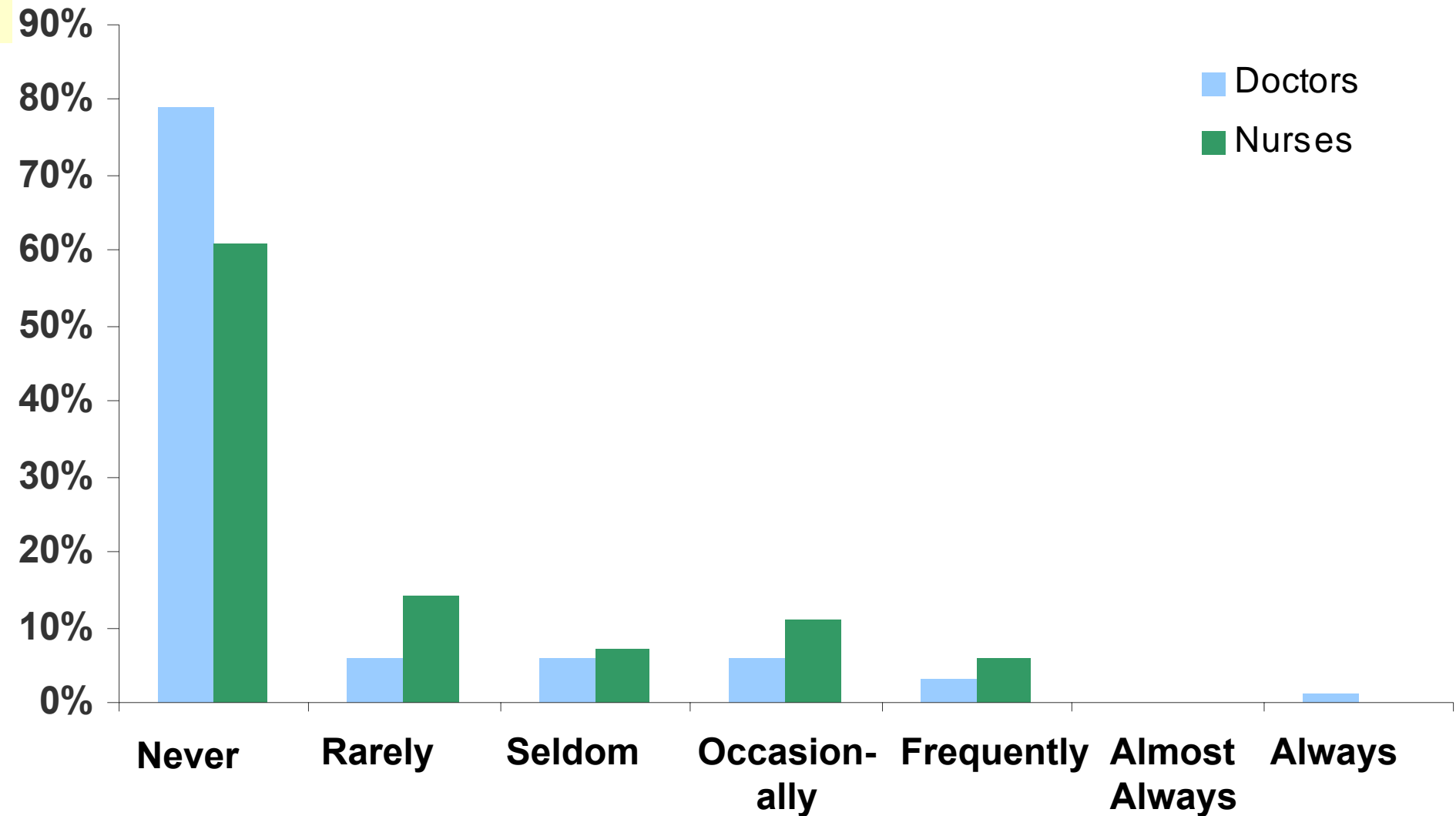
**How do patients, nurses, and physicians think about medical professionals providing spiritual care?**



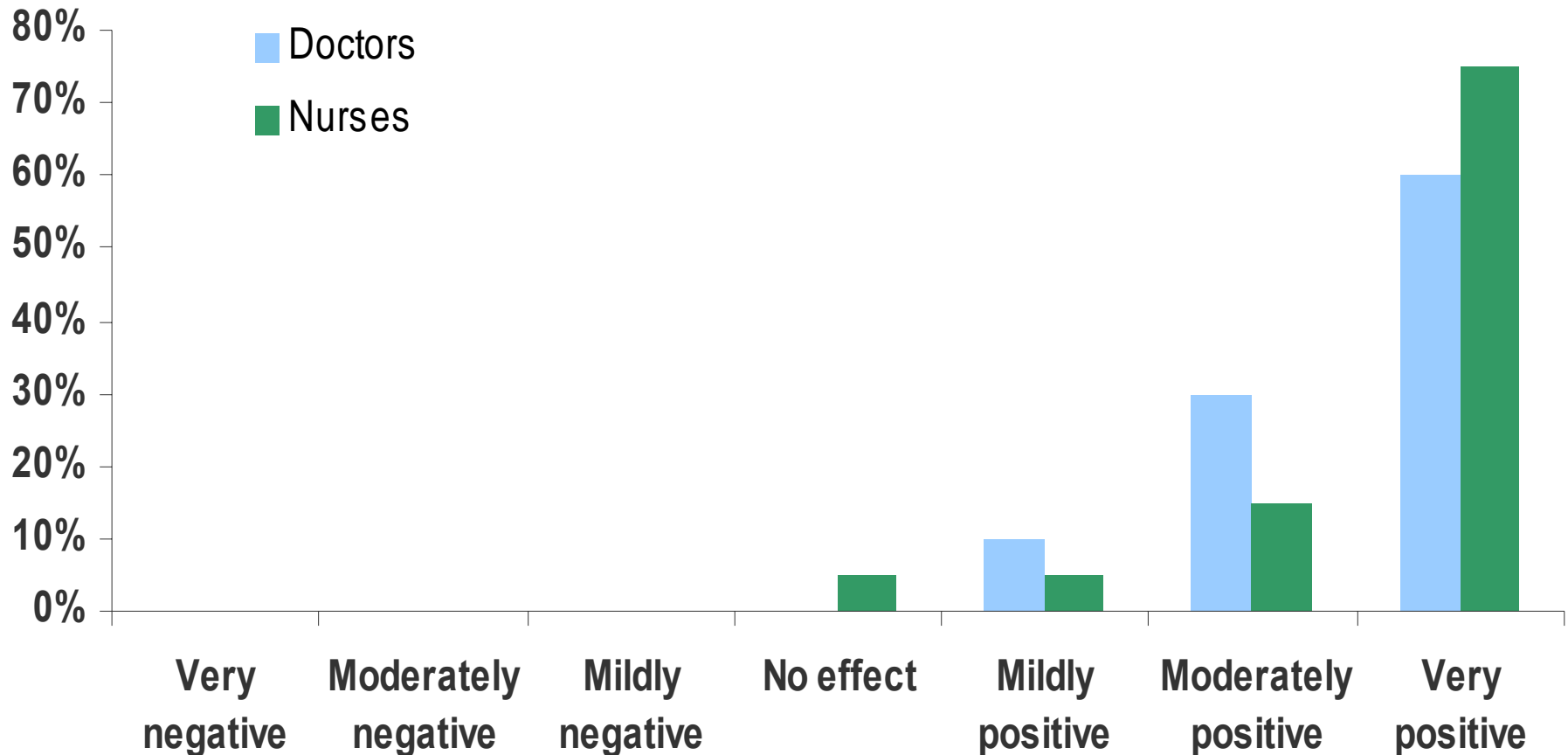
# **National Consensus Project Domains of Quality Palliative Care**

- 1. Structure and processes of care**
- 2. Physical aspects of care**
- 3. Psychosocial and psychiatric aspects of care**
- 4. Social aspects of care**
- 5. Spiritual, religious, and existential aspects of care**
- 6. Cultural aspects of care**
- 7. Care of the imminently dying patient**
- 8. Ethical and legal aspects of care**

# **Pts – In your experience with cancer, how often do your cancer doctors/nurses perform any type of spiritual care?**

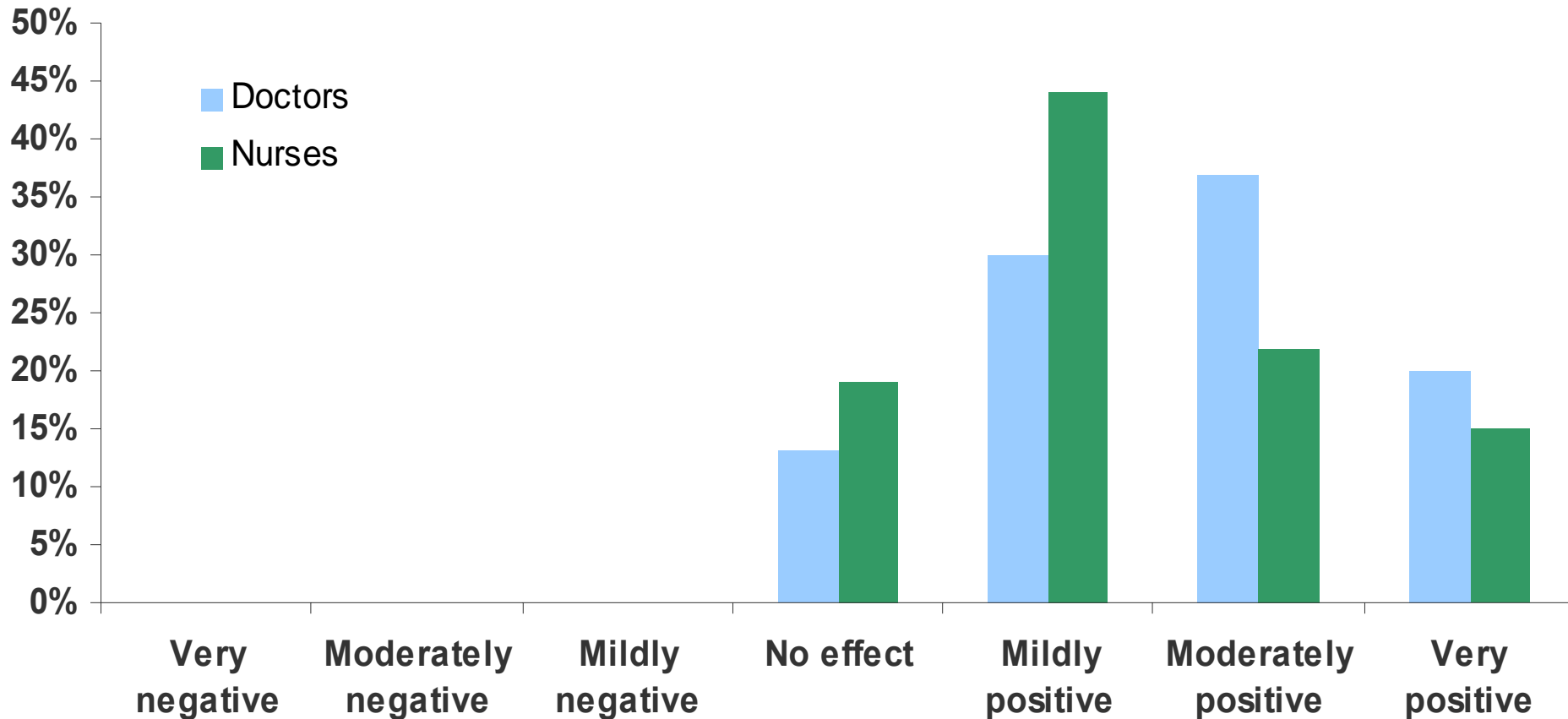


# Pts – How positive or negative was the spiritual care experience(s) for you?

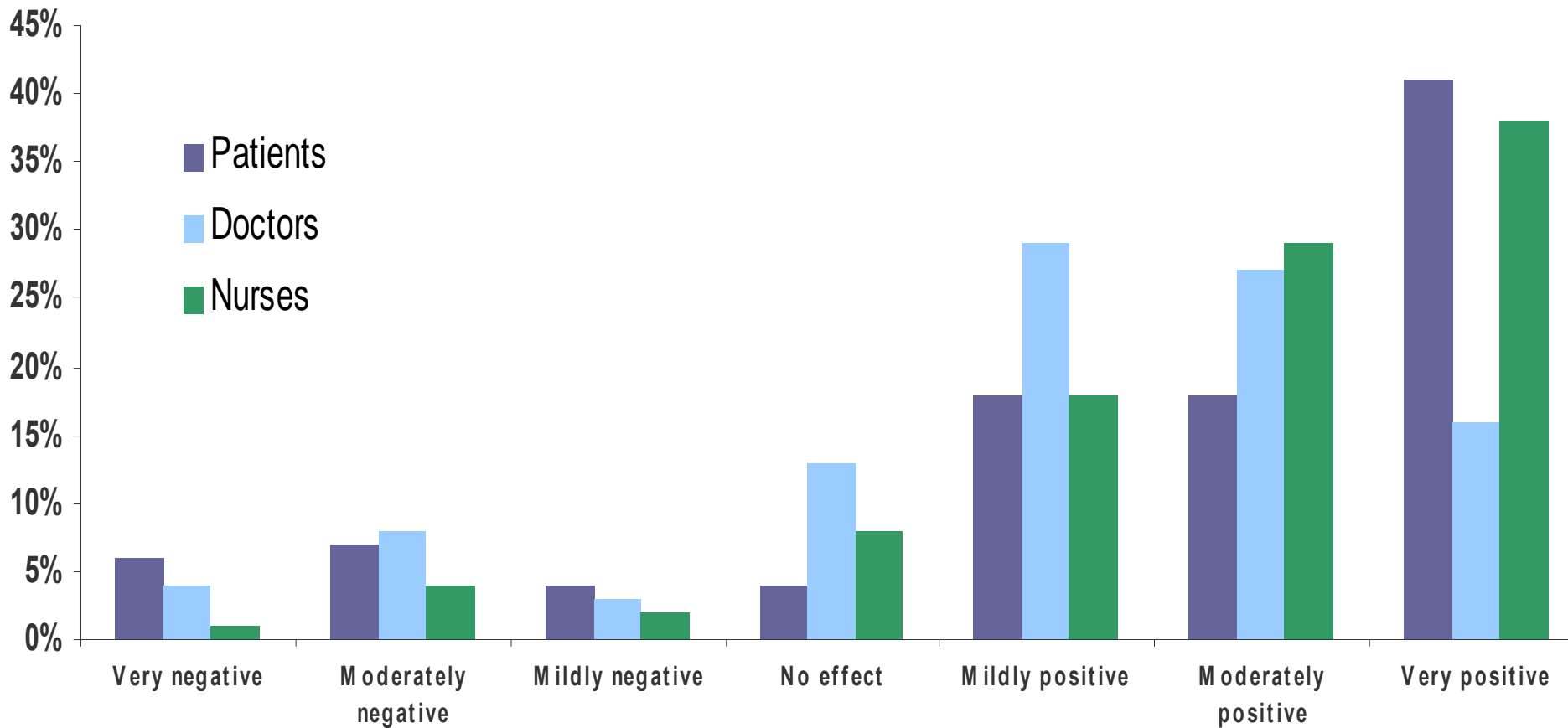




# MD & Nurses – How positive or negative was the spiritual care experience?



# Pt/MD/Nurse Perceptions of the Regular Provision of Spiritual Care



# Perceptions of the Regular Provision of Spiritual Care

## Patients:

- 78% positive
- 4% neutral
- 18% negative

## Nurses:

- 85% positive
- 8% neutral
- 7% negative

## MDs:

- 72% positive
- 13% neutral
- 15% negative

# **Qualitative themes of Positive Perceptions of Spiritual Care**

## **Positive:**

- **Positive effects on patient well-being**
- **Benefits to patient-practitioner relationship**
- **Part of holistic care**

# Representative Quotes: Patient Well-Being

***Patient – “I think that doctors, if they cared about spirituality, would encourage the patients to express their spiritual problems and especially the fear of death and the other side, and patients wouldn’t feel so afraid and that stuff wouldn’t be untouched.”***

# Qualitative Themes of Negative Perceptions of Spiritual Care

## Negative:

- **Professional role/Imposition**
- **Time**
- **Training**

# **Negative Perceptions of Regular Spiritual Care: Role and Training**

***Physician – “It's not really our role to provide this care. We're not trained in it and there are others available who would be better.”***

# **Perceptions of Spiritual Care among Pts, Nurses, Physicans?**

- **Spiritual care infrequent, including key elements of spiritual care: spiritual history, referrals to chaplaincy**
- **Spiritual care provided is viewed positively**



# **Perceptions of Spiritual Care among Pts, Nurses, Physicians?**

- Regular spiritual care viewed positively: pt well-being, holistic care, pt-practitioner relationship**
- Important minority view regular spiritual care negatively: role violations, training, time etc**
- Barriers to spiritual care provision: e.g., time, training, professional role**

**Interaction  
with R/S  
Communities**

**MEDICAL SC TEAM  
Structure of SC Provision  
Chaplains, MDs, Nurses,  
SWs, etc**

**Supporting Pt  
R/S &  
Meeting R/S  
Needs**

**R/S  
COMMUNITY  
& ILLNESS:  
Beliefs  
Support**

**PATIENTS**

**Pt R/S &  
ILLNESS:  
Coping  
Transform  
Beliefs  
Needs**

**PATIENT R/S  
BACKGROUND**

# What Are Next Steps??

## Spiritual Care Provision:

- What is the team model of care?
- What is provided to patients, to religious communities?
- How do we interface with important barriers to spiritual care?

# Acknowledgements

**Holly Prigerson, PhD**

**Michael Balboni, PhD**

**Andrea Phelps, MD**

**Tyler VanderWeele, PhD**

**Susan Block, MD**

**John Peteet, MD**

**Adam Sullivan, MS**

# Relevant Definitions

- **Spirituality:** the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.
- **Religion:** a set of spiritual beliefs shared by a community, often associated with common writings and practices.

# Propensity Score Spiritual Support from Rel Communities

## Demographic factors

- Age
- Gender
- Race
- Education
- Health insurance status
- Recruitment site

## Psychosocial factors

- MD/patient relationship
- Baseline existential well-being
- Baseline social support

## EOL care predictors

- Advance care planning
- EOL preferences
- EOL discussion
- Religious coping
- Med Spiritual Support

## Other R/S factors

- Religiousness
- Religious tradition