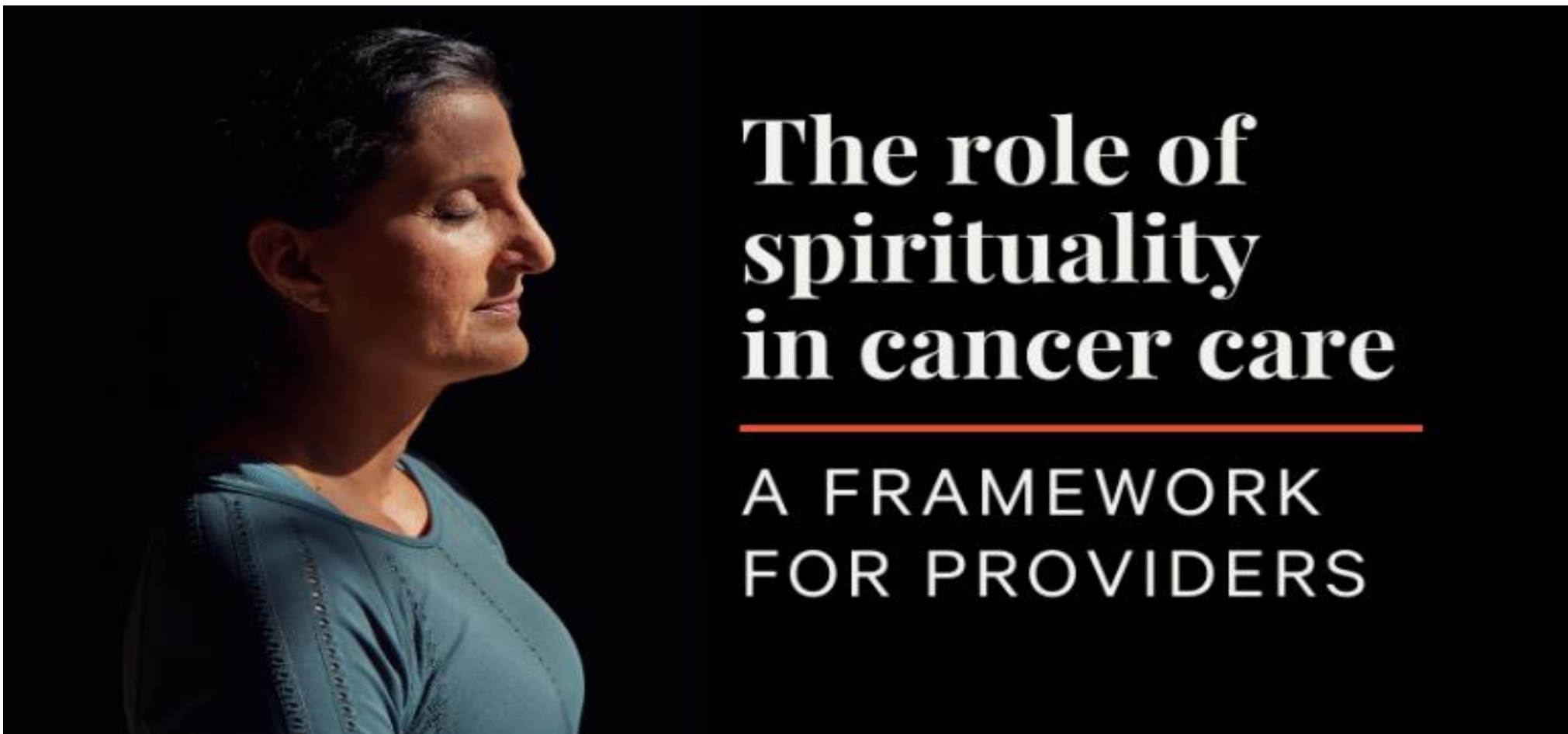




The role of spirituality in cancer care

A FRAMEWORK
FOR PROVIDERS



Tracy Balboni MD, MPH
and
Rev. Saneta Maiko PhD



LIVING BEYOND
BREAST CANCER®

The role of spirituality in
cancer care:
A framework for providers

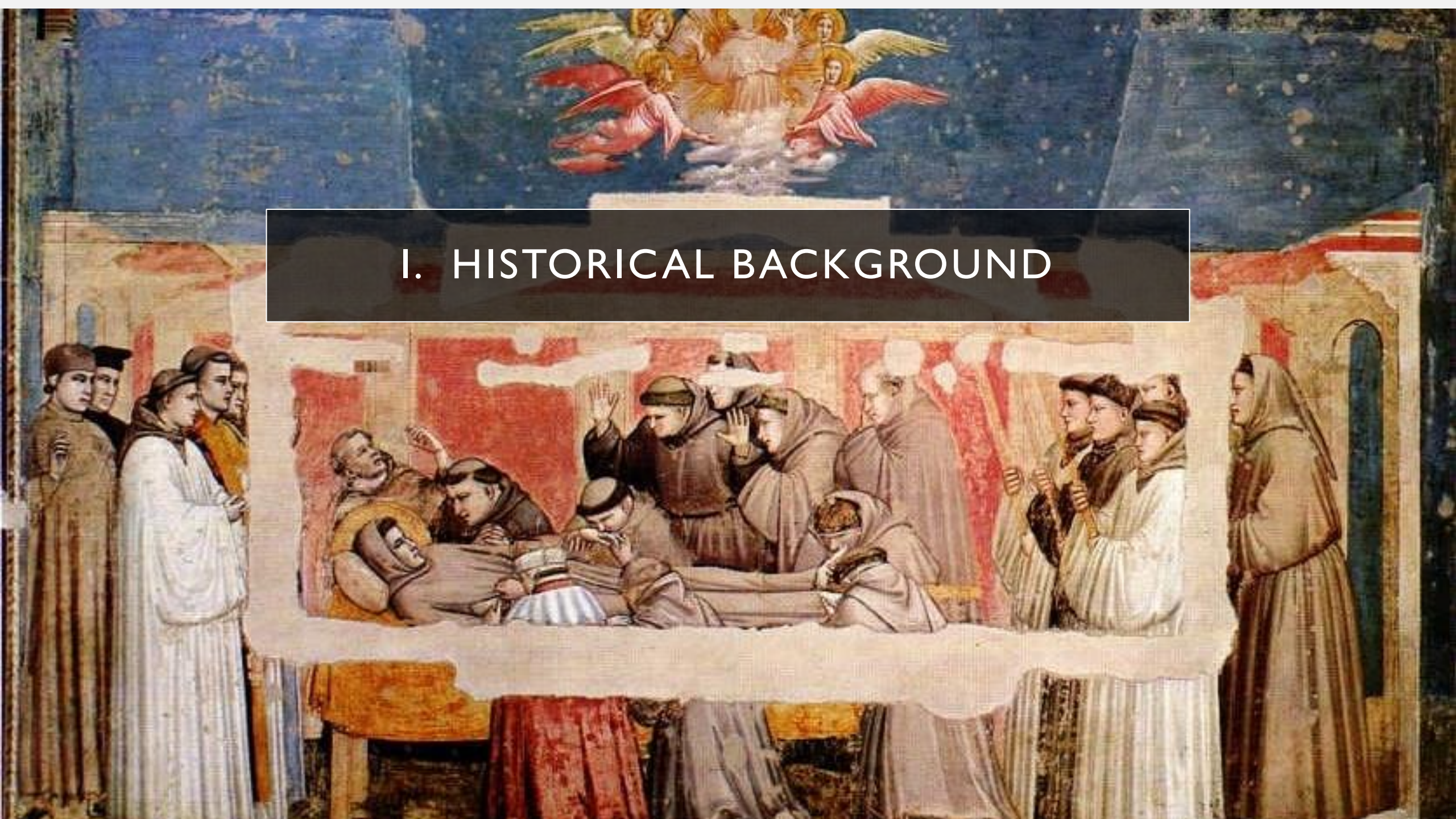
1. Tracy Balboni MD, MPH

- Historical and empirical background
- Basic spiritual care framework

2. Rev. Saneta Maiko PhD

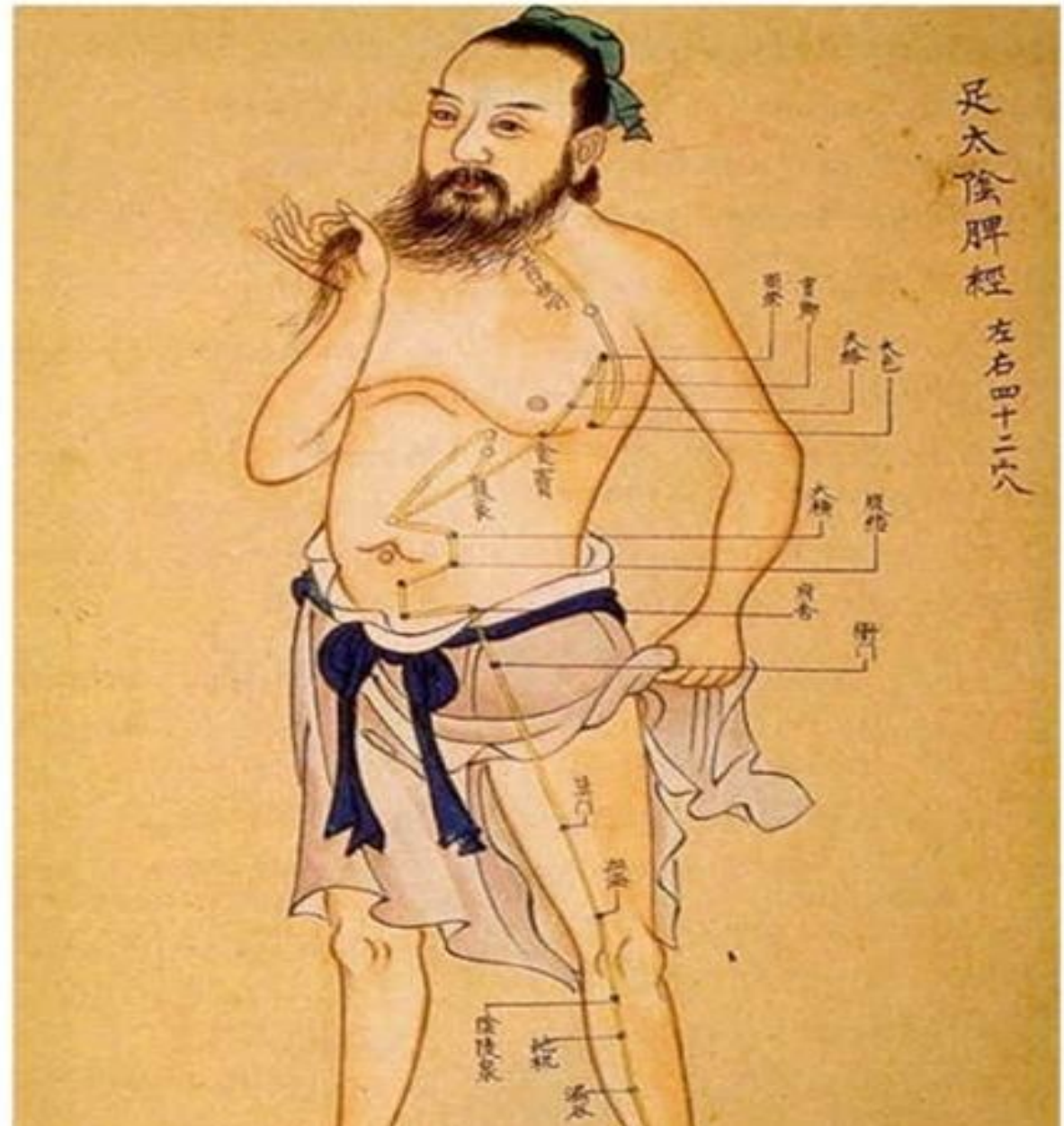
- Key domains of spirituality for assessment
- Work of chaplains





I. HISTORICAL BACKGROUND

HEALING TRADITIONS WITH INTEGRATED CONCEPTIONS OF BODY AND SPIRIT



SPIRITUALITY AND MEDICINE: ENLIGHTENMENT TO POST- MODERNISM (1700S-PRESENT)

- Growth of materialism and reductionism
- Empirical method is the primary source of truth for humanity
- Medicine grows in material focus





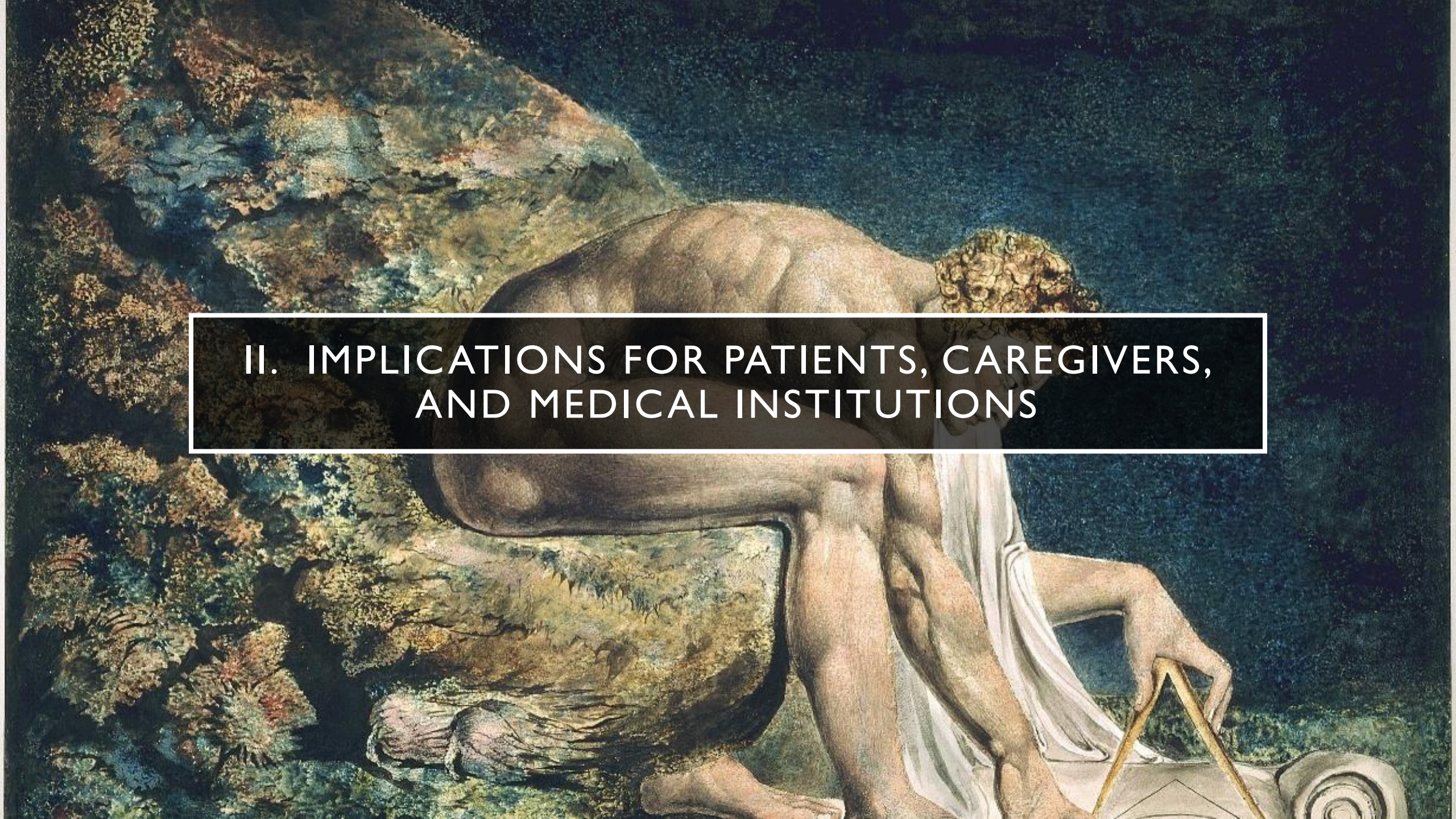
WILLIAM BLAKE.
NEWTON. 1795



Sir Luke Fildes' *The Doctor* (1891)



John Collier *The Sentence of Death* (1908)

The background of the slide is a reproduction of Michelangelo's famous fresco, "The Creation of Adam," from the ceiling of the Sistine Chapel. The image shows the reclining position of Adam on the left, with his body stretched out towards the right. The text is overlaid on the central part of the image, specifically over Adam's torso and the space between him and the right side of the frame.

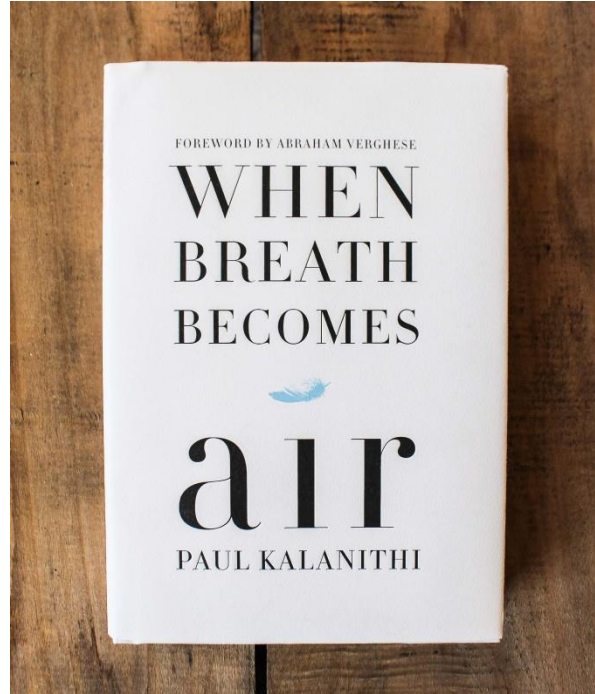
II. IMPLICATIONS FOR PATIENTS, CAREGIVERS, AND MEDICAL INSTITUTIONS



IMPLICATIONS
FOR PATIENTS:
KATE

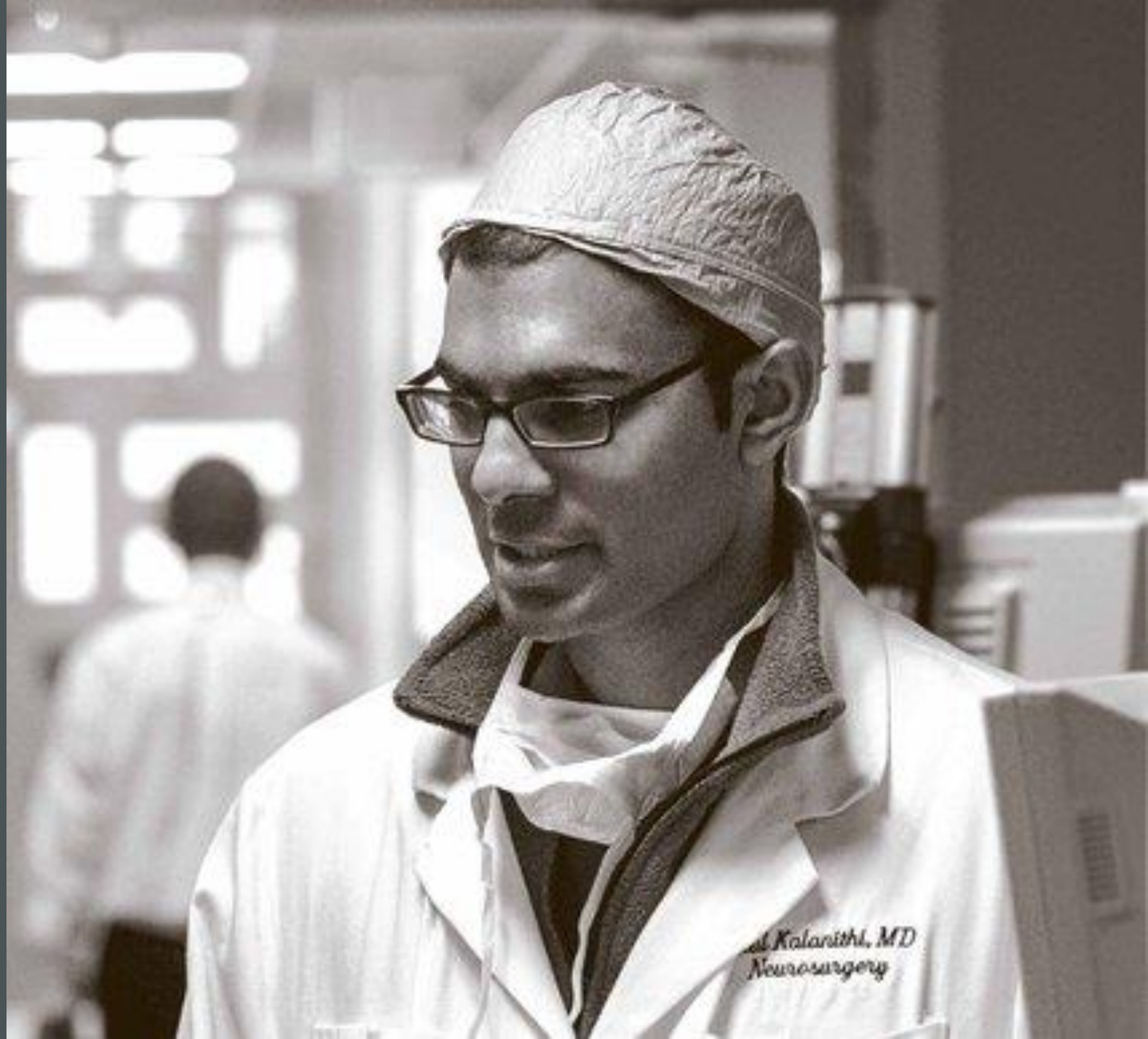
EVERY TIME I WALK INTO
THIS PLACE, IT FEELS
LIKE ALL MY ENERGY
HAS BEEN SAPPED OUT
OF ME. I CAN ALMOST
HEAR THIS PLACE
TELLING ME THAT ALL I
AM IS A BODY FULL OF
TUMORS THAT ARE
KILLING ME.





PAUL KALANITHI MD, NEUROSURGEON
AND AUTHOR

SOME DAYS, THIS IS HOW IT FELT
WHEN I WAS IN THE HOSPITAL:
TRAPPED IN AN ENDLESS JUNGLE
SUMMER, WET WITH SWEAT, THE
RAIN OF TEARS OF THE FAMILIES
OF THE DYING POURING DOWN....
I WAS LOSING SIGHT OF THE
SINGULAR IMPORTANCE OF
HUMAN RELATIONSHIPS, NOT
BETWEEN PATIENTS AND THEIR
FAMILIES, BUT BETWEEN DOCTOR
AND PATIENT.





IMPLICATIONS FOR RELATIONSHIPS OF PATIENTS AND MEDICAL CAREGIVERS

A photograph of a female doctor with dark hair, wearing a white lab coat over blue scrubs and a light blue surgical mask. She is holding a white tablet and looking down at it. A female patient with blonde hair, wearing a grey t-shirt and a light blue surgical mask, is sitting next to her, also looking at the tablet. The background is a bright, out-of-focus clinical setting. The text "III. Reintegrating Spirituality and Medicine" is overlaid in white on the left side of the image.

III. Reintegrating Spirituality and Medicine

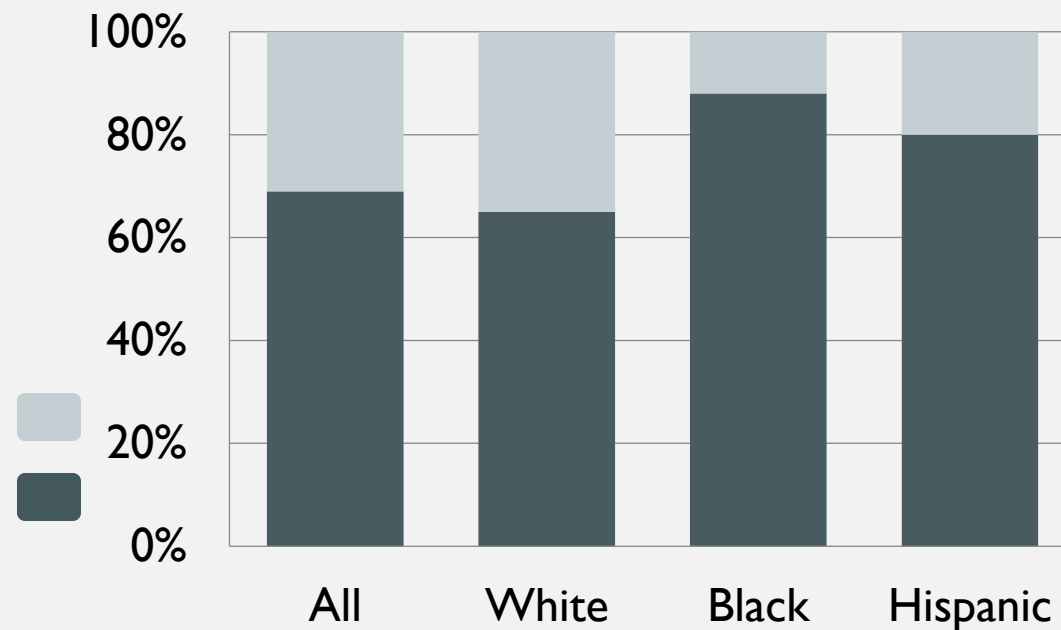
QUESTION 1: IS SPIRITUALITY IMPORTANT IN SERIOUS ILLNESS? HOW?

National study of cancer survivors (n=8405):

“My faith or spirituality has helped me through my cancer experience?”

- Not at all, A little
- Quite a bit, Very much

Spirituality in Cancer Survivors



SPIRITUALITY IN SERIOUS ILLNESS

- Religion and Spirituality in Cancer Care Study
- 75 randomly selected patients receiving palliative RT (RR=73%) in 4 Boston centers
- 78%: religion and/or spirituality important to advanced cancer experience

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

Theme	n (%)	Representative Quote
Coping through R/S	39 (74)	<i>If it weren't for my faith, I don't know I would have kept my equilibrium through this process... Whenever I'm in my hardest places in life, God just sends his Holy Spirit, and it just takes over.</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>Based on my religious beliefs I think I was given a certain number of days on this earth from day one, and I don't think that changes with my diagnosis... It tells me that if God wanted me yesterday, I wouldn't be here today.</i>
R/S transformation	20 (38)	<i>It's a transformative experience to have an illness such as this, and when you have that you have to reevaluate all you've done in life, who you are, and who you are going to be."</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>

QUESTION 2: WHAT IS THE RELATIONSHIP OF PATIENT SPIRITUALITY TO QOL IN ILLNESS?

Brady et al. *Psycho-Oncology* 1999

- Multi-institutional cross-sectional study of 1610 cancer patients.
- R/S (measured by the FACIT-Sp) → independent predictor of QOL
- Controlled for physical well-being, emotional well-being, social well-being, disease, demographic variables

QUESTION 2: WHAT IS THE RELATIONSHIP OF PATIENT SPIRITUALITY TO QOL IN ILLNESS?

National survey of 1885 seriously ill patients on 44 attributes of quality of life near death, top 9 ranked:

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 3: DOES PATIENT SPIRITUALITY PLAY A ROLE IN MEDICAL DECISION-MAKING?

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

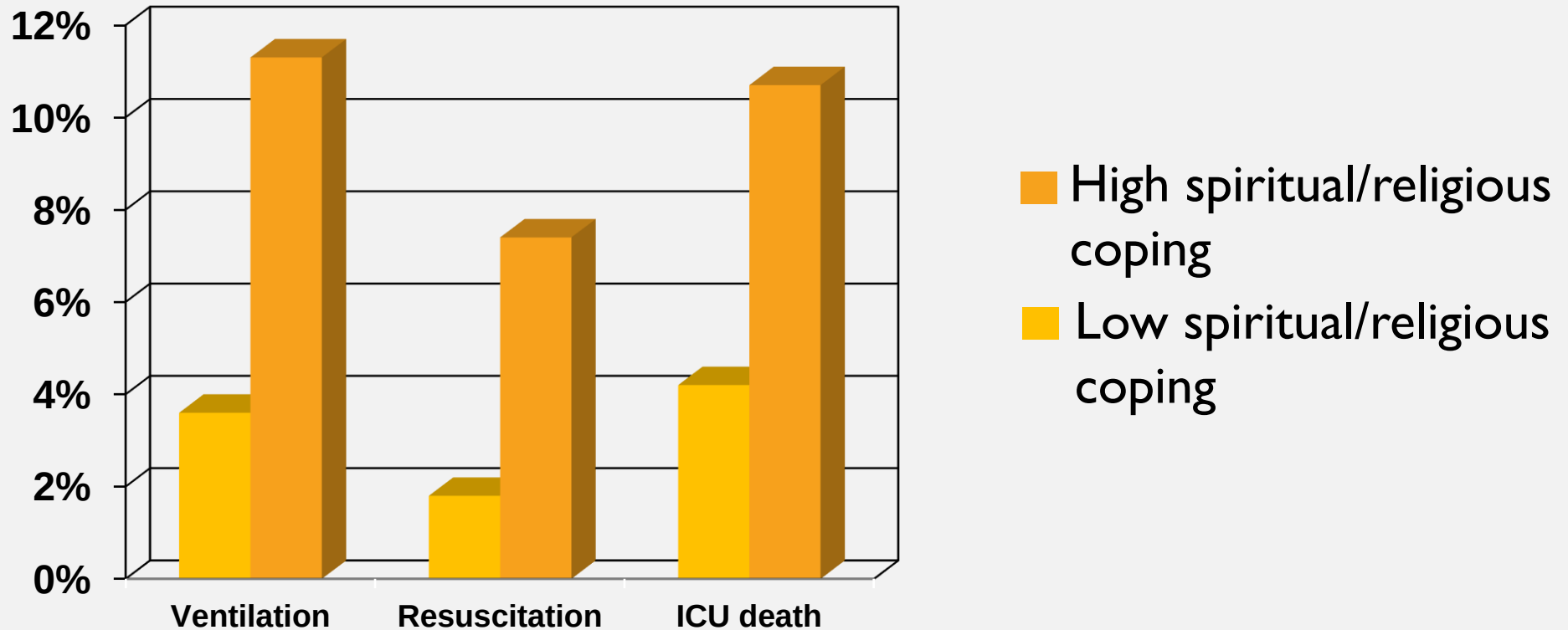
SPIRITUALITY AND MEDICAL DECISION-MAKING

7 factors ranked:

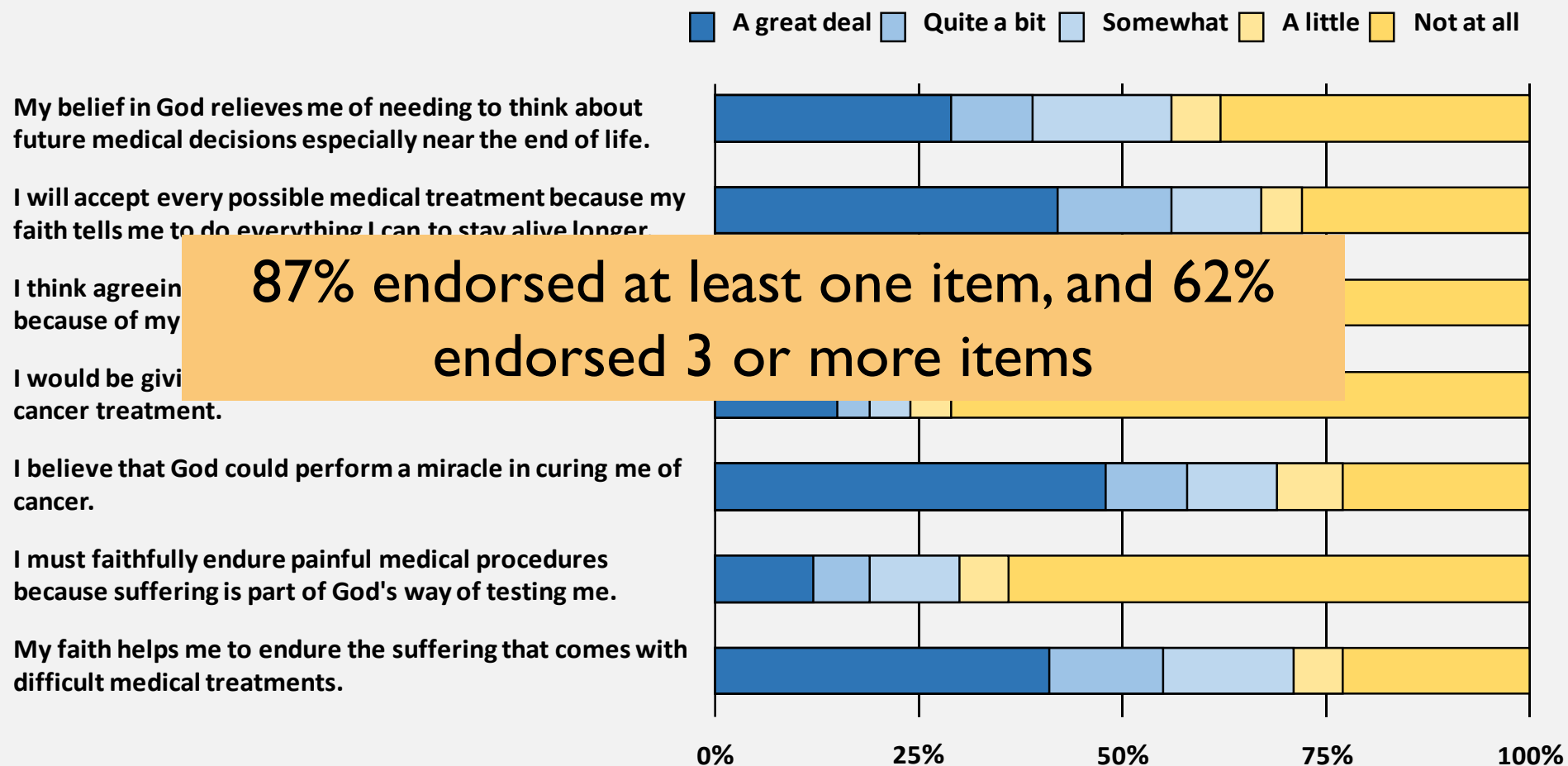
- Oncologist's treatment recommendation
- Ability of treatment to cure disease #1
- Side effects
- Family doctor's recommendation
- Spouse's recommendation
- Children's recommendation #2 for pts/families, #7 MDs
- Faith in God

SPIRITUALITY AND MEDICAL DECISION-MAKING

Coping with Cancer study (N=343): Relationship of baseline religious/spiritual coping and receipt of aggressive medical interventions in the last week of life



RELIGIOUS BELIEFS ABOUT END-OF LIFE CARE AMONG 275 ADVANCED CANCER PATIENTS



QUESTION 4: DOES PROVIDING SPIRITUAL SUPPORT TO PATIENTS INFLUENCE OUTCOMES IN ILLNESS?

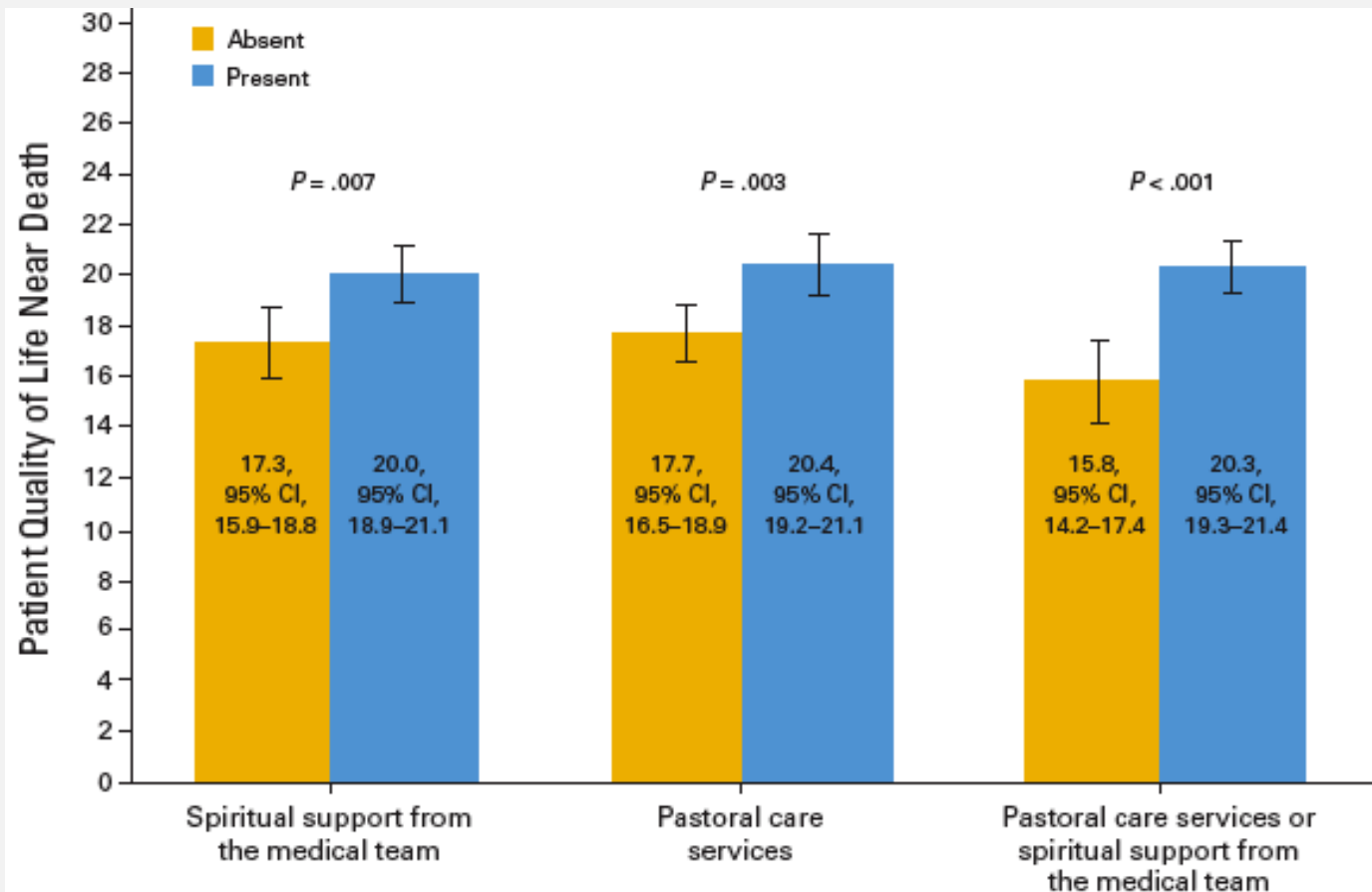
Multi-site, prospective study of advanced cancer pts, N=343, examining psychosocial/ spiritual factors and relationship to EOL outcomes

At baseline patient assessed:

- Support of spiritual needs by medical team (e.g., doctors, nurses, chaplains)
- Support of spiritual needs by spiritual communities
- Receipt of pastoral care visits

Outcomes: QOL (caregiver assessed) and medical care in last week of life

QUESTION 4: DOES PROVIDING SPIRITUAL SUPPORT TO PATIENTS INFLUENCE OUTCOMES IN ILLNESS?



SPIRITUAL SUPPORT AND EOL MEDICAL OUTCOMES

- High Spiritual Support from Medical Team (26%)
 - Greater hospice (OR = 2.99, $p=0.003$)
 - Less aggressive interventions (OR = 0.38, $p=.04$)
 - Less ICU deaths (OR = 0.23, $p=0.03$)
 - Impact of med team spiritual support on EOL care largely seen in high religious coping patients
- High Spiritual Support from Religious Communities (43%)
 - Less hospice (OR = 0.38, $p=.03$)
 - Greater aggressive interventions (OR = 2.55, $p=.03$)
 - More ICU deaths (OR= 5.73, $p=0.004$)
 - Findings stronger high religious coping patients

A STORY UNFOLDING THROUGH RESEARCH

- Spirituality important within illness, functions multiple ways
- Spirituality influences QOL and medical decision-making
- Religious beliefs about end-of-life care are common
- Spiritual care appears to influence QOL and medical decision-making

NATIONAL CONSENSUS PROJECT DOMAINS OF QUALITY PALLIATIVE CARE

Spiritual Care Framework:

- Generalist – specialist model: non-chaplains healthcare workers are generalists, chaplains are specialists
- Generalist's primary role is spiritual history-taking
- Spiritual history guides subsequent conversations and referrals to spiritual care professionals

SPIRITUAL CARE FRAMEWORK: SPIRITUAL CARE GENERALIST'S ROLE

1. Do screening spiritual history as part of a social history, examples include:
 - Do you consider yourself a spiritual or religious person, both or neither?
 - Do you have a faith or spirituality that's important to you?
 - What are some primary sources of meaning and hope for you?
2. Apply that information to guide future questions conversations, either at that time or at future visits.

SPIRITUAL CARE FRAMEWORK

1. Spiritual history opens a door:
 - Implicitly says, “your medical care includes attention to all of you... It’s ok to talk about your spirituality/core values here.”
 - Gives you key information about the patient – though just an initial glimpse.
2. Next steps – Rev. Saneta



Cancer Patients: Do we really know what their spiritual needs are?

Saneta M. Maiko, PhD., MS., BCC
Faculty, Dan Evans Center, Indiana University Health
Affiliate Research Scientist, Indiana University
Center for Aging Research, Regenstrief Institute, Inc.



Indiana University Health





Cancer Impact

During moments of psychological, emotional, physical and spiritual distress, patients use religion or spirituality to cope.

(Bussing and Koenig, 2010; Murray et al., 2004; & Grant et al., 2004)

Cancer affects, family, caregivers, and others close to patient.

(Clarke, T.C.. 2015, Russell, B. et al., 2015)

Spiritual and religious concerns are important to cancer patients and caregiver

(Bovero et al 2015; Jim, H.S. et al 2015; Wilkelman, et al 2011 & Astraw, et al., 2007)

Preferences for care, quality of life, cost of healthcare and care at the end of life are impacted by spiritual and religious discomforts

(Balboni, et al 2011; Kernohan, et al 2007 ; Herman, et al 2007 & Moadel, et al 1999,)





Research Findings

Spiritual needs for cancer patients

➤ Creating the opportunity for patients and carers to discuss spiritual issues, if they wish, requires highly developed communication skills and adequate time.

- Murray, Scott A., et al. Palliative medicine 2004.

➤ Patients were best able to engage their personal resources to meet their spiritual needs when affirmed and valued by health professionals.

- GRANT, ELIZABETH, et al. Palliative & Supportive Care, 2004





Role of Religion in coping

- 80% of persons with serious mental illness in Los Angeles used religious activity or religious belief to cope.
- 30% reported that religious beliefs or activities “were the most important things that kept [them] going”
 - Tepper Psychiatric Services 2001





Chaplain Training, Role, and Referrals

- Chaplain Training (Board Certifications)
- Professional role of chaplains (listening, reflection, response)
- When is best to refer patients to chaplains?



Dimension # 1 Meaning and Purpose

- **Meaning and Purpose** – Values, beliefs, understanding of life events, actions of God, others, and self
- ☐ 1. Tell me what this hospitalization (or illness) has been like for you.
- ☐ 2. How do you make sense of what is going on right now?
- ☐ 3. What is the most powerful or important thing in your life?
- ☐ 4. What happens when you feel helpless?
- ☐ 5. When life is hard, what do you depend on to keep going?
- ☐ 6. What are your sources of strength?
- ☐ 7. What role do your values and beliefs play in the decisions you are facing in the hospital?
- ☐ 8. Are you facing any decisions right now?
- ☐ 9. What is your purpose in life (right now)?
- ☐ 10. What gives your life meaning?



Dimension # 2 Relationships

Relationships – Connection to community, family, others, and God

- ☐ 1. Who is there for you at a time like this one? How are they important?
- ☐ 2. How are you connected to others during this health crisis?
- ☐ 3. Are you experiencing any changes in how you are connected to others?
- ☐ 4. Are you troubled by conflict with anyone?
- ☐ 5. Do you have support from a faith community?
- ☐ 6. Do you have support outside of your family?
- ☐ 7. Tell me about your experience with the health care team here in the hospital.
- ☐ 8. Tell me about your relationship with God, a higher power, or the sacred.
- ☐ 9. Who is your “go to” person?
- ☐ 10. Do you have family nearby?
- ☐ 11. Do you ever feel lonely?



Dimension # 3 Transcendence and Peace

Transcendence and Peace- Experience of the divine, ability to be centered and aware, and practices and behaviors that increase or decrease transcendence and peace

- ☐ 1. Are you at peace?
- ☐ 2. How do you experience peace?
- ☐ 3. What do you have faith in?
- ☐ 4. Do you believe in a higher power, God, or the sacred?
- ☐ 5. Can I pray for you? How shall I pray for you?
- ☐ 6. Can you describe a time when you experienced peace?
- ☐ 7. What makes you feel peaceful or centered?
- ☐ 8. Tell me how you find balance in this situation.
- ☐ 9. What helps you when you need to calm down?
- ☐ 10. What is the hardest thing about this situation?





Dimension # 4 Self-Worth and Identity

Self-Worth and Identity- Sense of belonging, being loved, and capacity to be self-aware

- ☐ 1. What is weighing on you right now?
- ☐ 2. How do you feel about yourself?
- ☐ 3. How are you taking care of yourself right now?
- ☐ 4. Are there times you feel like you have to choose someone else over yourself?
- ☐ 5. How has the experience of this illness or hospitalization changed the way you feel about yourself (your sense of identity)?
- ☐ 6. Do you feel valued?
- ☐ 7. Everyone is known for something. What are you known for?
- ☐ 8. How are you handling this hospitalization?



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Stories from cancer patients

Family is the most important thing to every patient.

- Patients were asked, *what is the most important thing in your life now?*

my grandchildren and my daughter and my husband and my little critters....my friends, my church.

On an earthly level it's my family, period dot. It's my family, my children, my grandkids. They make me smile and nervous all at the same time. On a spiritual level it's got to be my faith.



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Patient's meaning of religious

- When asked whether they were religious, spiritual, both, or neither:

I'm religious because I believe that there is a man upstairs (God) and He loves us more than we could ever begin to think.





Patient's meaning of spiritual

- When asked whether they were religious, spiritual, both or neither:

I'm spiritual because I think it's important to pray. I think it's important to have quiet time and hopefully to conduct yourself like there's goodness inside with people so you're kind.



Patient's meaning of both religious and spiritual

- When asked whether they were religious, spiritual, both or neither:

Maybe both. I do believe in God. I'm probably more of a Christian and believe in Jesus but I'm not very much of a denominational and I don't, so not standard I could say.



Patient's meaning of Neither religious nor spiritual

- When asked whether they were religious, spiritual, both or neither:

Neither. I'm not a religious, I respect and appreciate religion, and at time find comfort in sitting in a church or talking to people of faith, but it's not a big, it's not a part of my life.





Impact of Illness on Family

- Cancer impacts Family in many ways :
 - Love for one another verbally expressed (50% of the participants)

I try to tell them all the time how much I love them and everything and make sure they know.

- High degree of closeness (85% of the participants)

We are a lot closer. Can't go through this without but yeah, I would say we're a lot closer. We know a lot more about each other because we sit in here. The last time it was every two weeks and we have all kinds of conversations.





Impact of Illness on Faith

- Expressions of anger toward God

At first I was kind of angry. ...I thought we made a covenant, God, and now You've just let me down.



Impact of Illness on Faith

- Expressions of how faith helps

God gives us no more than we can handle. I love crosses and crucifixes and I said everybody has got a cross they must bear. Well, I'm bearing mine and have for quite a while. My faith brings me through it.



Impact of Illness on faith and community

- Strong faith in God was the most important thing in life (75% of the participants).

“My God....My Jesus. It’s my faith in God. I’ve depended upon that since I’ve been struck with this illness.”



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Faith Coping Strategies



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Emotional Responses: Scared

- One patient expressed a conviction of acceptance even though scared:

At first it was kind of scary and then you just accept it. It is what it is and you can't get yourself down because that's probably the worst thing you can do. So just do what you've got to do and move on





Emotional Responses: Scared

- Not scared of dying but rather leaving her children without a mother even though fear:

I used to be scared of dying and everything but now I'm not scared of dying. I'm scared of them having to live without a mother at a young age.





Emotional Responses: Reality

- One patient expressed acceptance of reality this way:

It just causes you to accept reality of what it is... at first you think, well, you can beat it but the more treatments I get and the more things that go on you kind of discover you really can't cure it. You can delay it. So at some point you just accept that there is a stopping point somewhere. You just don't worry about it





Emotional Responses: Worry

- One patient expressed her worry this way:

I worry about....what if I'm not here during this time. What do I do with my children that I'm leaving behind?





Emotional Responses: Why Me?

- Expression of confusion, why me?

I do question a lot of times too. I've always tried, even thought I don't go to church or anything, to live my life as straight laced and how I think that I am supposed to in God's eyes....Then I think, why do I still get this awful disease when there's other people out there that have smoked and drank their entire lives and done bad things and here I am trying to be the best persona that I can and I get this."





Emotional Response: Guilt

- Expression of feeling guilt was shared this way:

I'm so tired all the time that I don't have the energy to do things like I want to do them....So that makes me feel guilty





Summary

- Most cancer patient heavily rely on faith practices to cope with the illness
- Family and other significant relationships are most important to patients who are spiritual, religious, both, or neither.
- There is inadequate spiritual care in cancer patients.
 - Allowing spiritual care may be a major therapeutic resource to such patients and their families.
- Patients (religious) have an expectation that staff will be open to share their own faith with them.
- Patients who identified as “neither” expressed a strong bond to family, work and philanthropy as a source of meaning.





Conclusions

- Educational, advocacy, and flexible interventions are needed to modify expectations in favor of spiritual care provision especially in outpatient cancer clinics.





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Questions?



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