

The Role of Deferring to God's Control in Disparities in Colon Cancer: Evidence and Proposed Solutions

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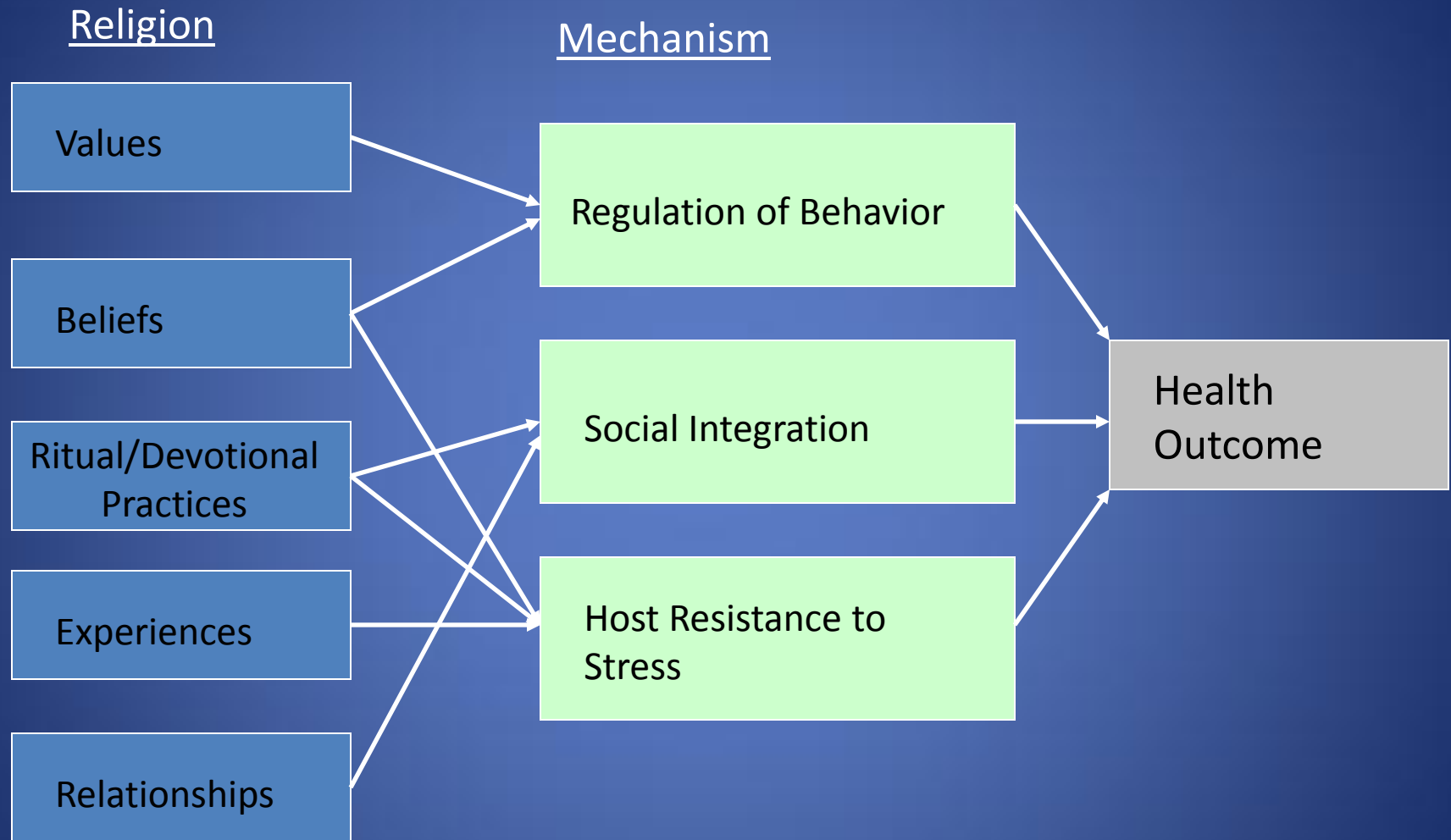
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How Does Religion Influence Health?



Worship Attendance and Health-Related Behavior

| Worship Attendance | Non-smoking | Moderate drinking | Fiber intake | Mammogram - ever | Breast self-exam - ever |
|--------------------|-------------|-------------------|--------------|------------------|-------------------------|
| Never | 1.00 | 1.00 | 1.00 | 1.00 | 1.00 |
| < weekly | 1.41 | 1.35 | 1.08 | 1.34 | 1.14 |
| weekly | 1.76 | 1.60 | 1.16 | 1.41 | 1.33 |
| >weekly | 2.27 | 2.19 | 1.31 | 1.33 | 1.25 |

Values are Odds Ratios adjusted for demographic and health factors.

71,000 women in WHI

Salmoirago-Blotcher et al., 2011

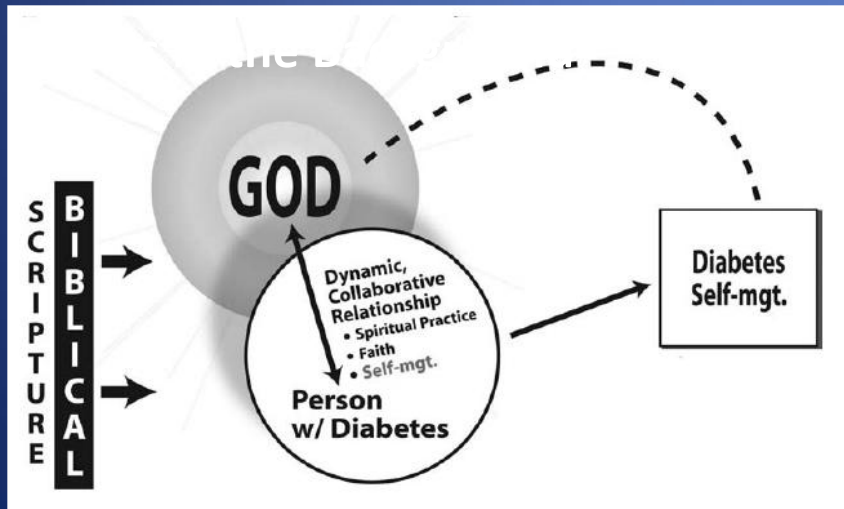
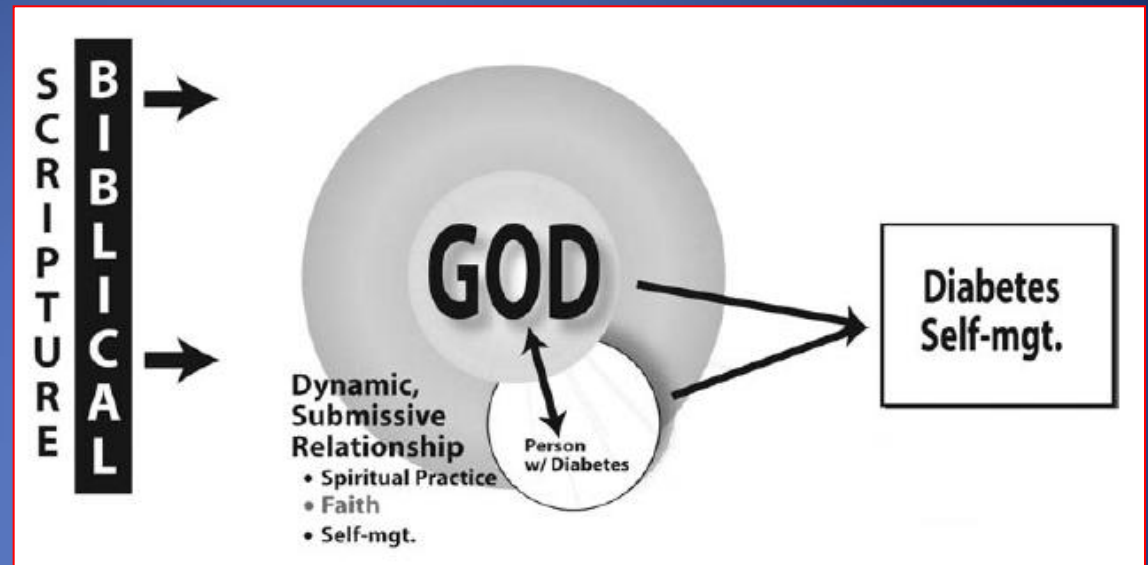
Religious Beliefs & Practices Related to Healing

| | Black (n=120) | White (n=94) |
|--|---------------|--------------|
| Ever prayed for healing your medical problems | 98% | 78% |
| Daily prayer for healing medical problems | 72% | 52% |
| Believe in religious miracles a great deal or a lot | 82% | 39% |
| Believe God acts through religious healers to cure illness a great deal or a lot | 71% | 36% |
| Believe God acts through medical doctors to cure illness a great deal or a lot | 82% | 42% |
| The most important factor in whether people get well from illness | | |
| having a good doctor | 21% | 49% |
| God's will | 65% | 22% |

Items from Mansfield et al 2002; data from P60; all racial differences significant $p < .001$

Religion & Self-Management of Disease

God is in the
Forefront



Polzer & Miles, 2007, 29 African-Americans with diabetes

Religious Beliefs & Stage of Disease

| If a person prays about cancer, God will heal it without medical treatments | | 1.9 (1.1, 3.3) |
|---|-------------------------------|----------------|
| | | |
| Model | Variables in Model | OR (95% CI) |
| Model 1 | Race | 3.0 (1.9, 4.7) |
| Model 2 | Race + SES | 1.8 (1.1, 3.2) |
| Model 3 | Race + Cultural Factors | 1.8 (1.0, 3.2) |
| Model 4 | Race + SES + Cultural Factors | 1.2 (0.6, 2.5) |

540 women newly dx with breast cancer in E No Carolina
17.4% presented with Stage III or IV disease

Lannin et al 1998

Worship Attendance and Breast Cancer Screening

| | Frequent Worship Attendance (weekly or more) | | |
|----------------------------|---|--------------------|-------------|
| | Odds Ratio | 95% CI | p |
| White women (N=177) | 2.61 | 1.12 - 6.06 | 0.03 |
| Black women (N=145) | 0.49 | 0.19 - 1.31 | 0.16 |

Odds Ratios for the likelihood of breast cancer screening among those with frequent worship attendance adjusted for demographic, medical, and health behavioral factors.

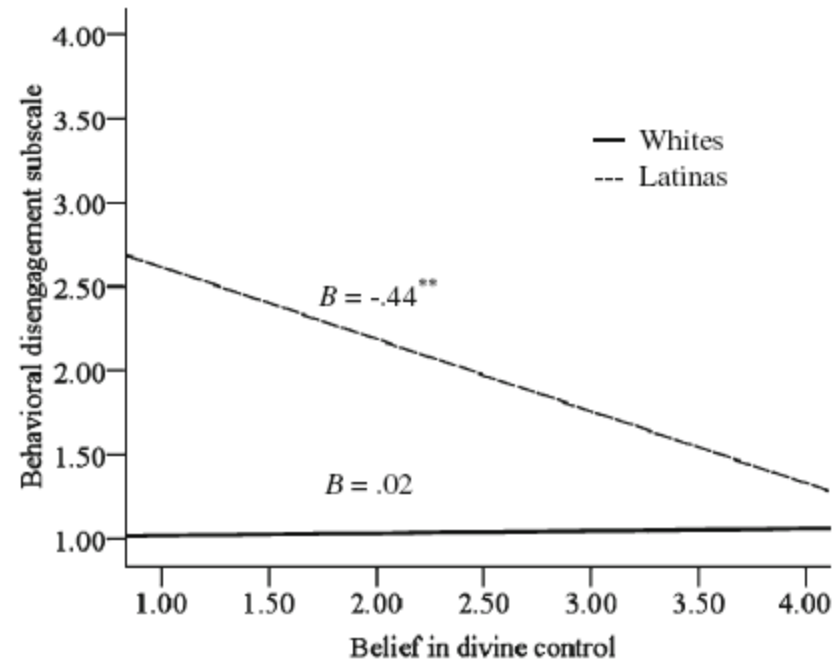
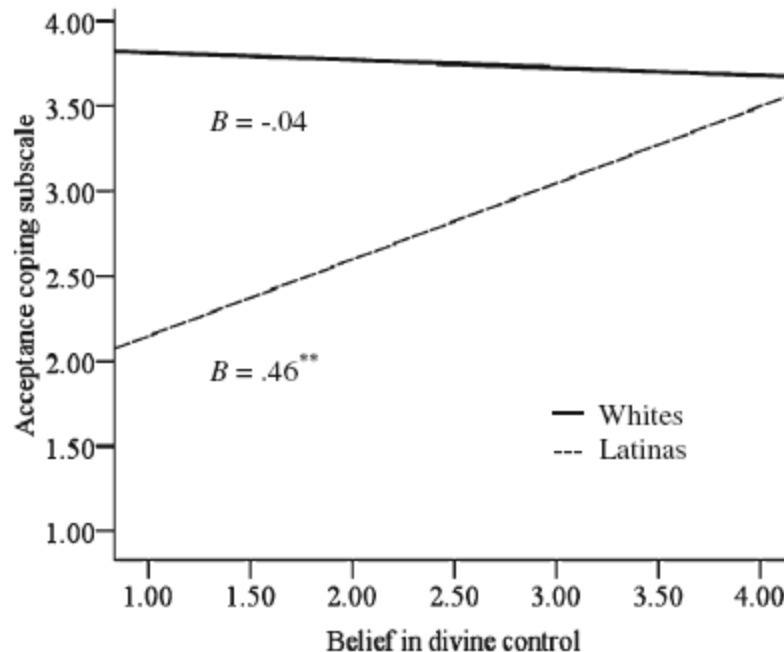
N=322 women in CT newly dx with breast cancer 1987-89

Van Ness et al, 2002

Religious Beliefs, Health Knowledge and Behavior

| Study, sample | Religious belief | Health knowledge, behavior |
|---|---|---|
| Mitchell et al., 2002 608 women (41% AA) in E No Car, in home interviews | Believe God works through doctors to cure breast ca (82%) | OR = 1.12* for mammogram in past year |
| | Trust God more than doctors to cure breast ca (44%) | OR = 1.24** for intention to delay presentation of self-discovered breast lump |
| Holt et al., 2007 108 AA women recruited from churches | Passive spirituality •No point in taking care of myself when it's all up to God •Won't seek medical attention because God will heal me | Significant negative bi-variate associations with: •Mammogram knowledge (r = -.35)* •Breast ca knowledge (r = -.30)* •Breast ca tx knowledge (r = -.25)* •Ever had mammogram (r = -.20)* |

Belief in Divine Control and Coping Strategies



- Older women with newly dx breast cancer
- Latina n=99, White n=92, Black n=66
- Differences between White and Black ns
- Among Latinas significant interactions by acculturation

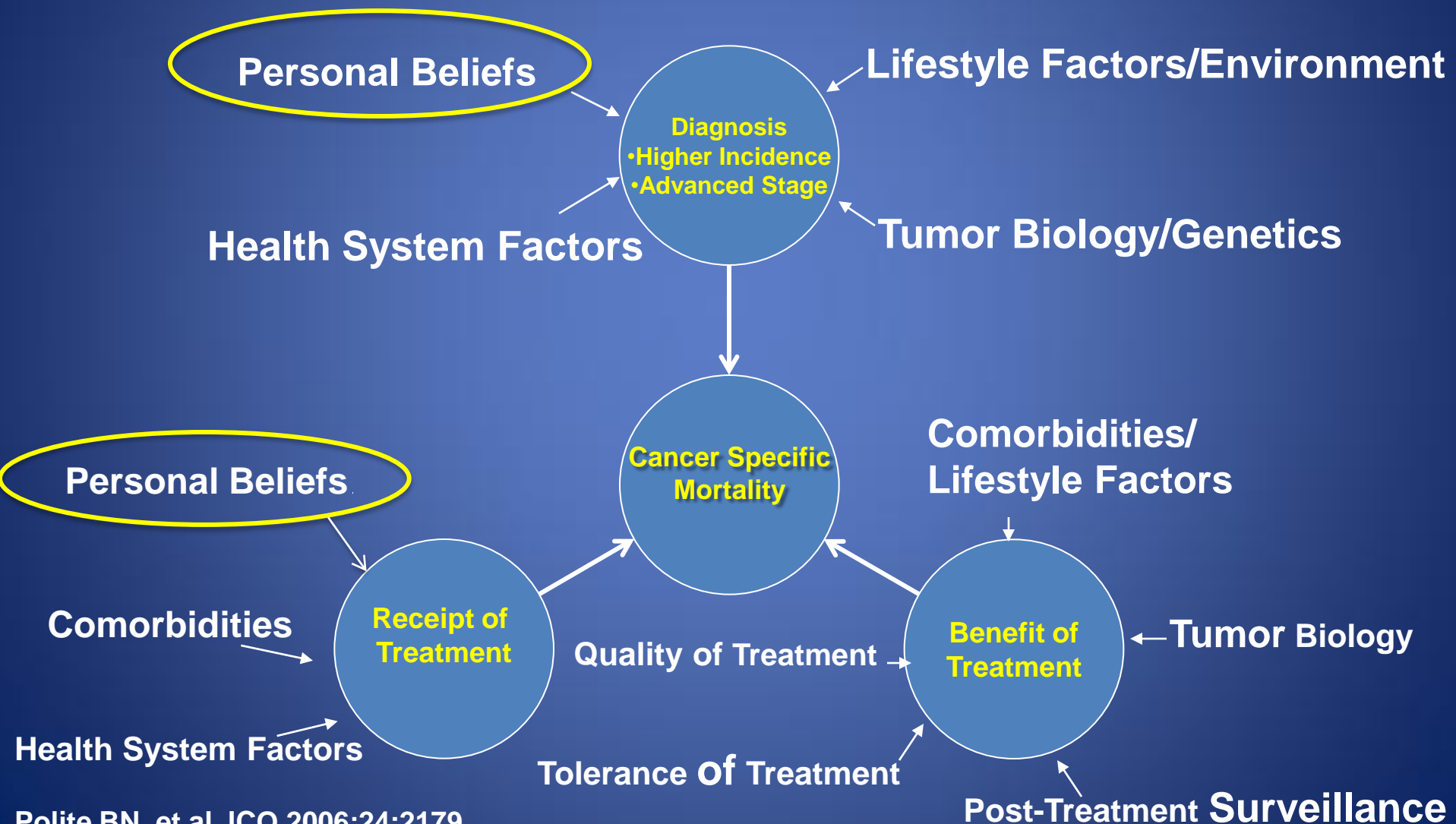
Umezawa et al., 2012

God Locus of Health Control

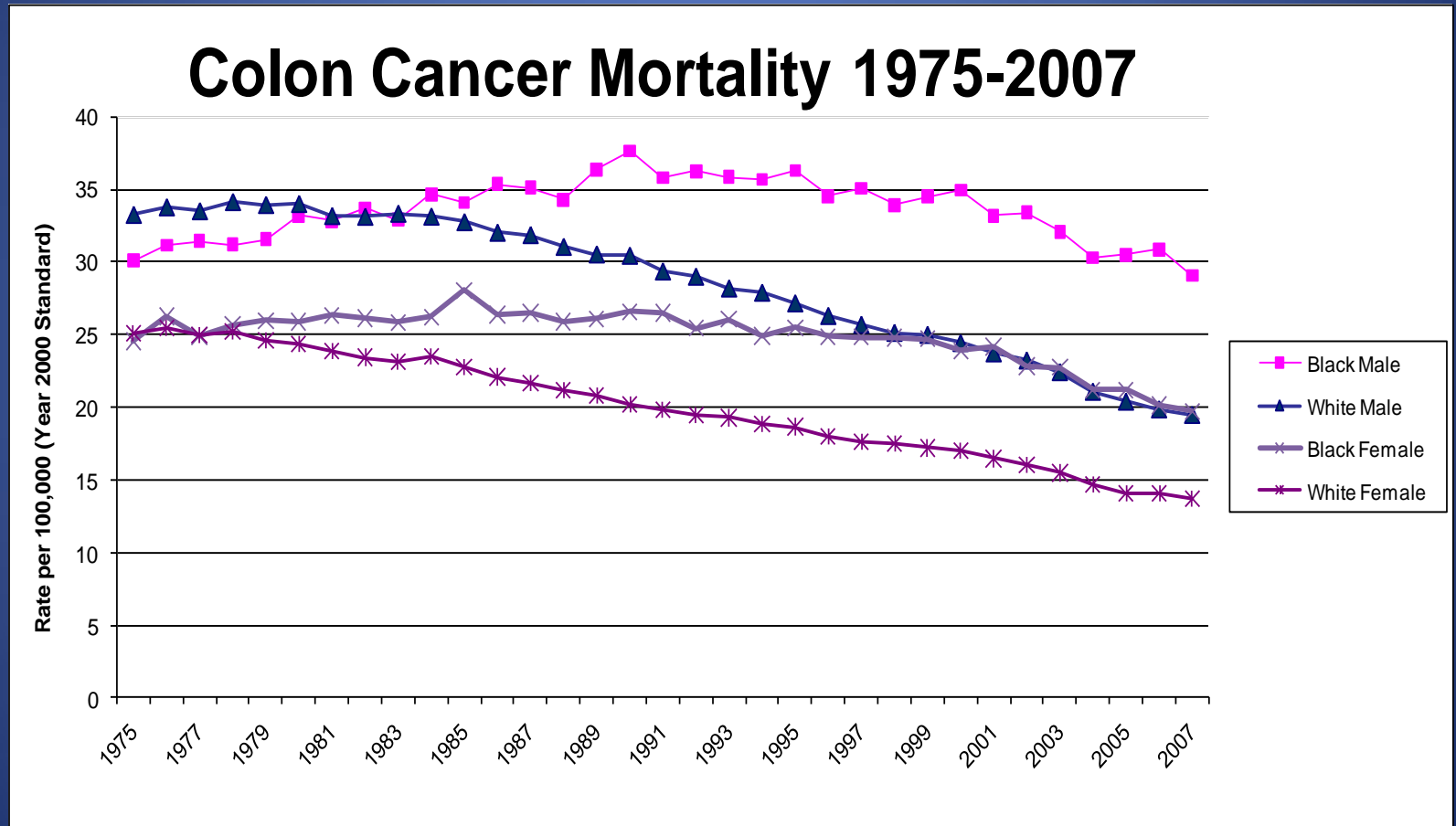
| % Agree a great deal or a lot | African-American (N=213) | White (N=194) |
|--|-------------------------------------|--------------------------|
| Most things that affect my health happen because of God | 30% | 10% |
| If my health condition worsens, it is up to God to determine whether I will feel better again | 73% | 24% |
| God is directly responsible for my health getting better or worse | 64% | 22% |
| Whatever happens to my health is God's will | 73% | 33% |
| Whether or not my health improves is up to God | 71% | 24% |
| God is in control of my health | 79% | 23% |

Patients in Chicago with new diagnoses of colon cancer
 All racial differences are significant $p < .001$

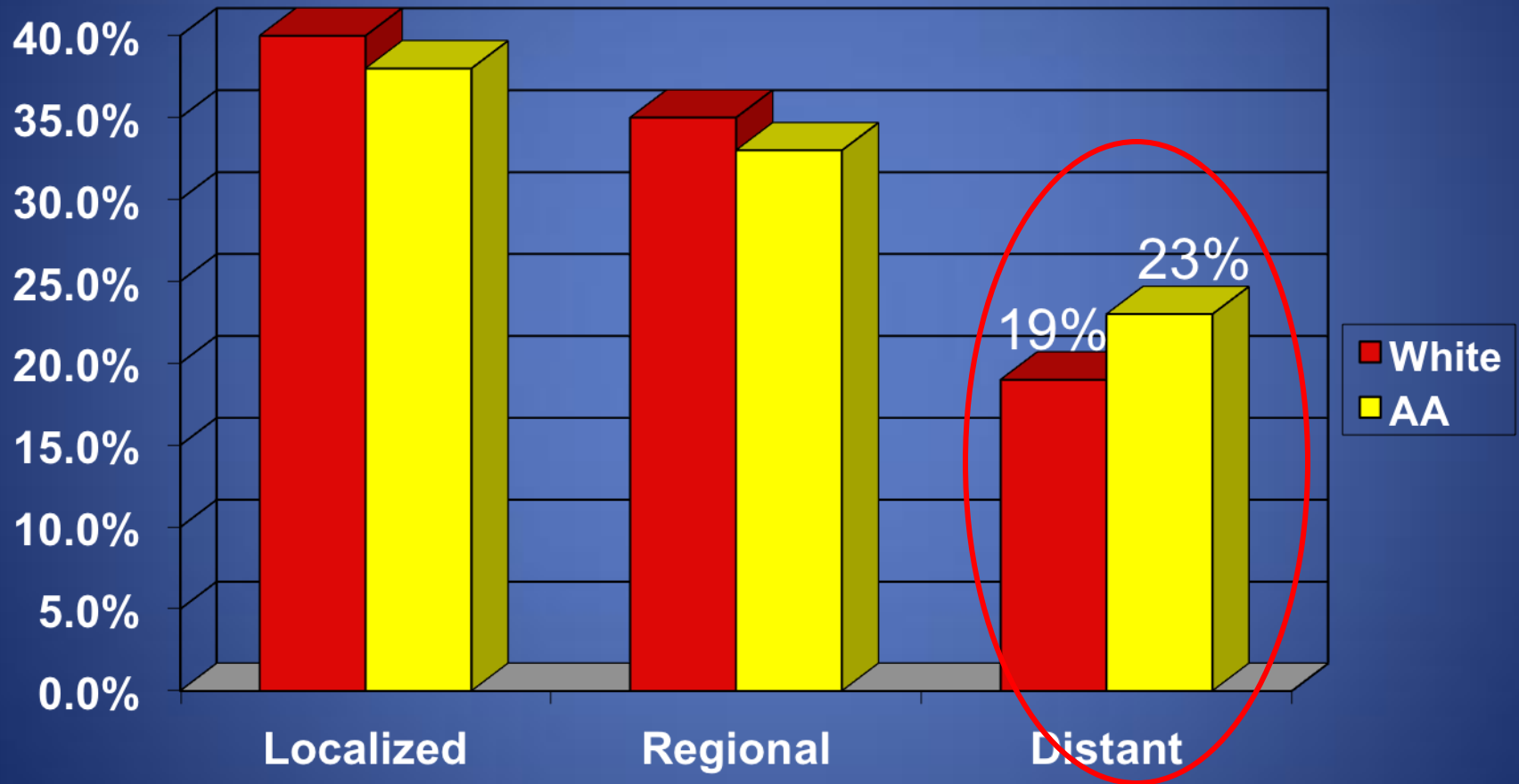
An Oncology Health Disparities Model



Colorectal Mortality Rates: 1975-2007



Stage at Diagnosis 2002-2011



The Importance of Stage, SES, Tumor Biology in Explaining Survival Differences

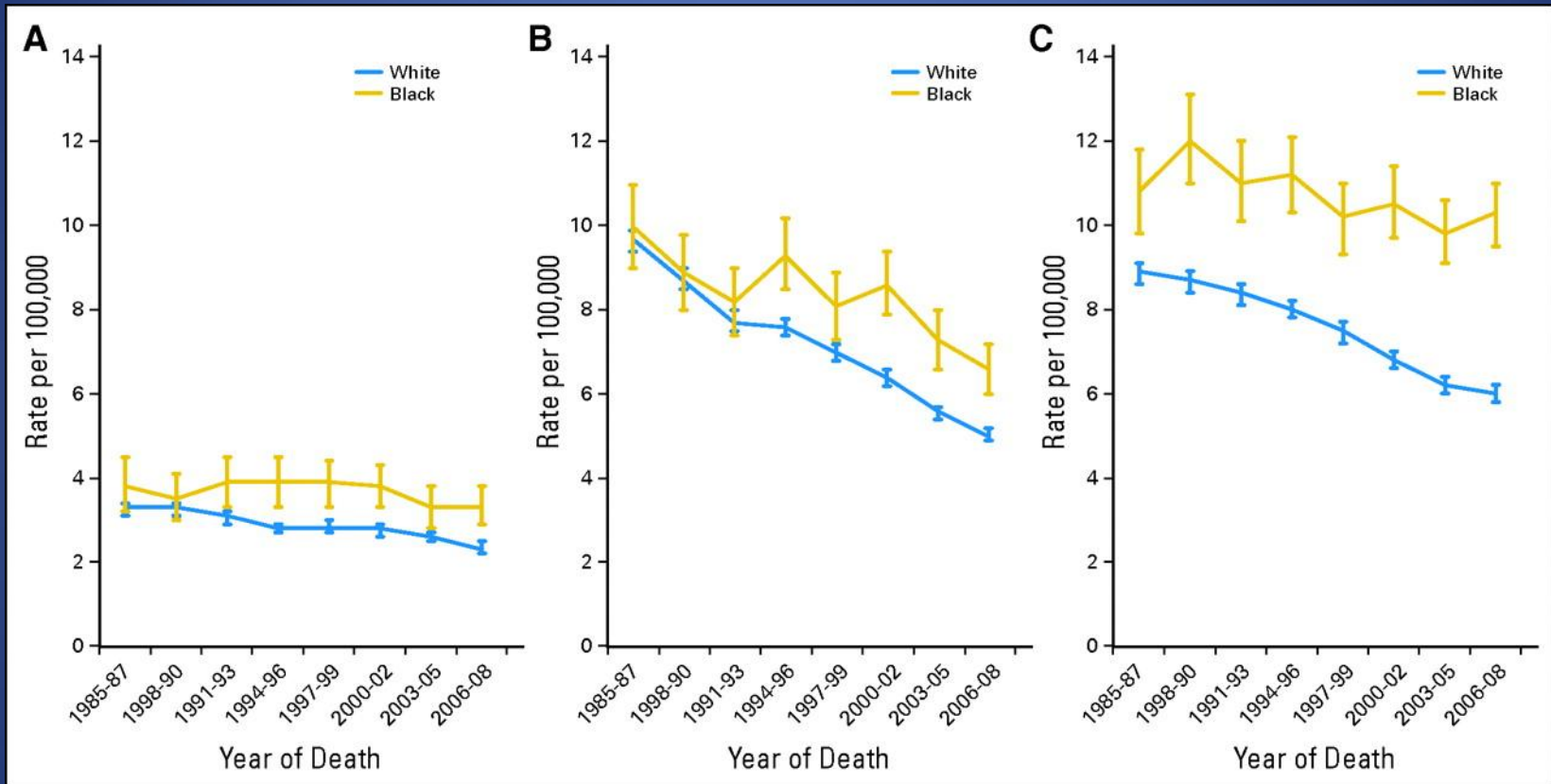
| Variables | Colon Cancer Deaths HR (95% CI) |
|---|--|
| Race | 1.5 (1.2-1.9) |
| Race and Stage | 1.2 (1.0-1.5) |
| % Explained by Stage | 60% |
| Race and SES | 1.4 (1.1-1.9) |
| Race, Stage, SES | 1.2 (0.9-1.6) |
| Race, Stage, Tumor characteristics | 1.3 (1.0-1.8) |

Even When Stage Controlled AA doing worse

Localized

Regional

Distant



Rate Ratio (RR):
1.4 (1.2-1.6)

RR: 1.3(1.2-1.4)

RR: 1.7(1.6-1.9)

Religious and Spiritual Beliefs

Chicago Black/White Colon Cancer Study

- 5 year study to discover the causes of Black-White disparity in Colon Cancer Diagnosis and Outcome
- Recruiting newly diagnosed colon cancer patients from 8 Chicago Hospitals (UIC, Rush, Stroger, NW, U Chicago, Advocate Christ, Advocate Illinois Masonic, Ingalls)
- Recruitment Completed on May 1, 2014
 - N=407
 - Black: 213 (52%)
 - White: 194 (48%)

Sample Characteristics

| | |
|---|-------------|
| Age (mean, SD) | 59.9 (10.7) |
| Female | 52% |
| Black | 52% |
| <HS education | 62% |
| Income <=\$20k | 34% |
| Income \$20-50k | 28% |
| Income >\$50k | 38% |
| | |
| Late stage at presentation (stage III or IV) | 62% |

Current Religious Preference

| | African-American (n=213) | White (n=192) |
|----------------------------------|-----------------------------|------------------|
| Catholic | 2% | 48% |
| Protestant | 88% | 22% |
| Baptist | 53% | 1% |
| Pentecostal | 7% | 1% |
| Protestant, Christian, Non-Denom | 24% | 13% |
| Other mainline Protestant | 4% | 7% |
| Other | 6% | 10% |
| None | 3% | 19% |

Religiosity Measures

- God Locus of Health Control
- RCOPE (positive and negative)
- Religious Problem Solving Scale (collaborative and deferring)
- Doctor as God's Mechanic
- Religious Comfort and Strain (fear and Anger)

Mean Score on Religiosity Measures by Race

| Scale | Scale Range | Black | White | P-value | N |
|--------------------------|-----------------------|-------|-------|---------|-----|
| GLHC | 6-30 | 22.1 | 13.2 | <0.0001 | 372 |
| RCOPE-Positive | 7-28 | 24 | 15.4 | <0.0001 | 372 |
| RCOPE-Negative | 7-28 | 9.1 | 8.0 | 0.002 | 372 |
| RPS-Collaborative | 6-30 | 25.3 | 15.4 | <0.0001 | 372 |
| RPS-Deferring | 6-30 | 23.2 | 11.9 | <0.0001 | 372 |
| RCSS-Fear | 1-10 | 5.9 | 4.9 | 0.52 | 161 |
| RCSS-Anger | 1-10 | 2.5 | 2.5 | 0.966 | 163 |
| God Acts Through Doctors | % Great Deal or A lot | 82% | 44% | <0.0001 | 163 |

Racial Differences in Responses to God Locus of Health Control Items

| % Agree a great deal or a lot | African-American | White | P-value |
|--|-------------------------|--------------|------------------|
| Most things that affect my health happen because of God | 30% | 10% | <0.001 |
| If my health condition worsens, it is up to God to determine whether I will feel better again | 73% | 24% | <0.001 |
| God is directly responsible for my health getting better or worse | 64% | 22% | <0.001 |
| Whatever happens to my health is God's will | 73% | 33% | <0.001 |
| Whether or not my health improves is up to God | 71% | 24% | <0.001 |
| God is in control of my health | 79% | 23% | <0.001 |

Racial Differences in Religious Problem Solving

| % Always or Very Often | African-American | White | P-value |
|--|-------------------------|--------------|------------------|
| When it comes to deciding how to solve a problem, God and I work together as partners (C) | 81% | 33% | <0.001 |
| When I have a problem, I talk to God about it and together we decide what it means (C) | 78% | 30% | <0.001 |
| Together, God and I put my plans into action (C) | 79% | 31% | <0.001 |
| Rather than trying to come up with the right solution to a problem myself, I let God decide how to deal with it (D) | 71% | 23% | <0.001 |
| In carrying out solutions to my problems, I wait for God to take control and know somehow He'll work it out (D) | 74% | 17% | <0.001 |

Religiosity and Stage at Presentation

| Mean Scores | Early Stage | Late Stage | P-value |
|-------------------|-------------|------------|---------|
| GLHC | 16.19 | 18.32 | 0.016 |
| RPS-Deferring | 17.06 | 17.58 | 0.59 |
| RPS-Collaborative | 19.71 | 20.36 | 0.49 |
| RCOPE-Positive | 19.34 | 20.24 | 0.25 |
| RCOPE-Negative | 8.13 | 8.54 | 0.17 |

Multivariate Model and Late Stage

- GLHC , age and Advanced Stage (stage 34)
 - Age OR: 0.97, $p=0.019$
 - GLHC OR: 1.03, $p=0.014$
 - R-Square: 0.178
 - Race, income, education, sex not significant
 - Interaction between Race, GLHC, stage=0.238 (NS)

Racial Differences

Need, Receipt, and Desire for Spiritual Help

| % Some or a great deal | African-American | White | P-value |
|---|-------------------------|--------------|------------------|
| Since you were diagnosed with colon cancer, how much spiritual help or support have you needed? | 77% | 51% | <0.001 |
| How much spiritual help or support have you received, from anyone? | 82% | 65% | <0.001 |
| % Who received some or great deal if needed some or great deal | 93% | 96% | 0.045 |
| To what extent would you welcome religious or spiritual support from your doctor or health care team? | 75% | 42% | <0.001 |

Conclusions from our Quantitative Work

- There are large and statistically significant differences in how blacks and whites view the role of God in the care of their illness-
 - God is Clearly in the Forefront for Black Colon Cancer Patients and viewed as more important than doctors in patient getting better
 - The majority of black patients want to receive spiritual support from the health care system
- Patients with High God Locus of Health Control also are more likely to present with advanced disease regardless of race. No other religiosity measure showed this correlation
- Next step is to determine whether advanced stage and high GLHC is being mediated by another variable (such as regular care with primary care physician) or is just a result of advanced stage at presentation

Religion/Spirituality (R/S): An Adaptive Resource for Coping with Cancer

- R/S is identified as a protective mechanism that provides the pt with a sense of control in order to actively cope with a diagnosis across the cancer trajectory (Holt, 2009; Thune-Boyle 2006; Karkela 2010)
- Our quantitative data reveal preliminary evidence re pt dependency of R/S beliefs for coping with cancer for ethnically diverse cancer pts
- However, an in-depth exploration provides a greater understanding of how specifically R/S directly influenced pt's cancer experience, treatment decisions, and ability to cope across the cancer trajectory
- Further investigation is warranted identifying patient's desires for additional spiritual support services

Qualitative Portrayal of P60 Patient Perspectives on the Role of Religious Beliefs in Cancer Treatment Decision Making: *Two Approaches*

Focus Group Interviews

- Dynamic patient communication interaction enabling some patients to elaborate on their religious beliefs and coping and how they shape the patients' decisions about seeking treatment for their cancer

Cognitive Interview Inquiry

- In-depth comprehensive cognitive exploration of their understanding of spiritual support

Focus Group Ethnic and Religiousness

Patient Description (N=23)

| Group | Religion | Race | number of participants |
|-------|------------------------|-------|------------------------|
| 1 | trust God, defer cope | AA | 7 |
| 2 | any negative God | mixed | 3 |
| 3 | trust God, collab cope | W | 4 |
| 4 | hi collab, lo defer | AA | 2 |
| 5 | high def, Stage3/4 | AA | 2 |
| 6 | high def, Stage3/4 | AA | 2 |
| 7 | low def, Stage3/4 | mixed | 3 |

Focus Group Inquiry: Primary Domains

- **Religious beliefs and religious coping:** *“What have been some of the things that have led to your beliefs about God’s role in your health?”*
- **Role of God and Physician in Healing:** *“Some people believe that God holds to key to their life and their healing. For some people this means they should follow their doctor’s recommendations and trust God to take care of the rest. For other people this means they don’t need to follow their doctor’s recommendations because their life is in God’s hands. Tell us what you think?”*
- **Other Domains of Interest:** Discovery of Cancer; Religious/Spiritual Beliefs Use During Cancer Decision Making; Relationship with God; Existential Meaning/Suffering; Abandonment/Fatalism; Role of Evil/Satan; Religious Coping; God’s Role in Cancer Decision Making; Use of Spiritual Support Services
- **Quantitative Measures included:** Brief Symptom Inventory (BSI-18); The Functional Assessment of Chronic Illness Therapy-Colon (FACIT-Colon); Religious Coping (RCOPE)

Adapted from Franklin et al., 2008, Polzer and Miles, 2007, and Exline et al., 2010.

Framework Analyses

- Analytical approach provides for thematic identification and categorization deeply embedded in qualitative and narrative text.
- Through a five stage process of data analysis, data are indexed according to themes and corresponding secondary themes into organized charts with summaries of participant responses
- A glossary of terms was created in order to assist with thematic identification
 - Adapted from prior qualitative work: Hlubocky & Daugherty 2004; Polite, Hlubocky, Daugherty 2007

Focus Group 1-7 Demographics: N=23

| Demographics | Patients |
|------------------|------------------------------------|
| Age (years) mean | 57y* |
| median | 56y |
| range | 35-70y |
| Gender | |
| Male | 10(47%) |
| Female | 13 (53%)* |
| Race | |
| African American | 13 (64%)* |
| Caucasian | 10 (35%) |
| Marital Status | |
| Single | 6 (19%) |
| Married | 12 (47%)*--(length): 28 y (11-46y) |
| Divorced | 1 (18%) |
| Widowed | 2 (12%) |
| Education | |
| Some High School | 2(4%) |
| High School | 7(30%) |
| Some College | 6 (28%) |
| College Graduate | 6 (12%) |
| Trade | 2 (2%) |

Focus Group 1-7 Demographics: N=23

| Religion | |
|--|---|
| <u>Christian:</u> | 22 (94%)* |
| Catholic | 8 (35%) |
| Baptist | 1 (29%) |
| Orthodox | 1 (6%) |
| Seventh Day Adventist | 1 (6%) |
| Christian Non-Denominational | 1 (6%) |
| Bhuddist | 1 (6%) |
| <u>Jehovah Witness:</u> | 1 (6%) |
| Frequency of Religious Service Attendance | |
| 1-3x week: | 9 (35%) |
| 1-3x month: | 8 (29%) |
| Several times a year | 4 (23%) |
| Never | 2 (12%) |
| Do You Currently Receive Religious Counseling? | |
| Yes (frequency?) | 4 (23%)(2 every week; 2 once a month); |
| No | 19(76%) |
| If Yes, by whom? | |
| Church Pastor | 3 |
| Spiritual Counselor | 1 |
| How important are your religious beliefs to you? (Likert 1 "Not Very Important" to 5 "Very Important") | |
| | 100% Very Important |

Quantitative Measures: Distress, QOL, & RCOPE

| | |
|---------------------------|------------------------|
| Distress: BSI | 9.5 ± 8 (0-35) |
| QOL FACT-General | 84.6 ± 2.3 (26-103) |
| FACT-Colon | 103±20 (44-136) |
| Religious Coping RCOPE | |
| Positive R Coping | 24.0± 2.5 |
| Negative R Coping | 10.8 ± 4.3 |

Direct Inquiry: When you First Learned It Was Cancer, What was that Like?

- 49%- Emotional Feeling State (*Traumatized, anxiety/worry/fear, devastation, surprise/shock, grief/abandoned, dazed, depressed/saddened/worthless*)
- 22%-Emotional Physical Reaction (crying, punched a hole in wall, raised hands to God in prayer)
- 27%-God's providence (blessing, His Hand, punishment, torture)
- 2%-Illness Status (unable to process it due to illness/medications,

Direct Inquiry: How did you feel when you were told that you had cancer?

- 53% Negative Emotional Feeling State : *blue/hopeless/sad/depressed/down lonely; anxiety/worry/fear/nervous/tense/jittery; devastation, surprise/shock, grief/abandoned, , lack of control/ avoidant/avoidance; pessimism*
- 12% Positive Emotional Feeling State: *strength, comfort, hope, peace, fortunate/"lucky"/thankful, gratitude, joy, optimism, acceptance*
- 3.5% Mixed emotional state -*worried/comforted, sad/hope, don't' know,*
- 32% God's Providence (*God's will, God's love, hand, strength, God's help, peace and harmony, blessing, acceptance*)

Direct Inquiry: Who helped you the most during your Illness and

- 91% God and Physician
 - Shared Decision making:*
 - Patient, God and Physician—*team working together, God guides MD, Physicians Hands are Gods Hands*
- 9% Physician

Is religion or spirituality part of how you have coped with the news of your diagnosis?

- Yes-92%
- o **Active means of coping:** prayer, rituals, attending service/Mass, staying positive because God on side, Stay spiritual, need to act on punishment to be saved
- o **Significant Role/Contributor**—daily mental and spiritual well-being
- o **Religious Commitment**—Religious foundation since childhood-adulthood
- o **Private Religious Practices:**
 - 1. *Prayer; Frequency of Prayer—daily, morning*
 - ? *Specific Prayers—gratitude; ask (family, health, strength, instrument to cure); not ask God Knows gives all worries to HIM*
 - ? *Effect of Prayer, minimize fear and worry*
 - ? *Mediation Education-Religious*
 - ? *Scripture Bible*
- ? No-8% (need to act/do/get treatment without God)

Direct Inquiry: Does God play a role in making decisions about treatment for your disease?

- Yes—98%

-Passive Coping—*blind trust in Lord; dependence on one's willingness to accept, strength/comfort*

-Faith/Religious Commitment--*Belief-Test in Live; God's plan (to have cancer); Need to continue living*

-Sense of Wholeness/Peace

- No—2%

Direct Inquiry: Some people believe that God will heal them through their doctor; other people believe that God can heal them without conventional medical care. Some people believe in both of these things. Can you tell us what you think about this?

- **God works Through MD--** *God gave me the MD/MD mind for surgery, chemo and living*
- **Partnership with God and Me**
- **Partnership with God, Me and Physician—**God guides us
- **God/Faith Shapes Decision Regarding Medical Treatment**
- **Medicine Is God's Tool—***past family medical decisions; lack of trust in medical system alone; acceptance of Lord*
- **Longing for the Transcendent—***desire to be closer to God; Union with God*

Direct Inquiry: What has helped you make decisions about the best treatment for your cancer? Is it the recommendations from your doctors? Is it your prayers and beliefs about what God wants you to do?

- **Relationship with MD**
- **Belief in God's will**
- **Social Support** (family, friends, md, religious practices)
- **Private and Public Religious Practices:**
 - i. non-organizational religiosity/faith base;
 - ii. organizational community (Church, practices/services/Mass):
 - iii. Prayer—formal; informal, devotion, novena, rosary, Our Father, scripture, Bible, good Word
 - iv. Chant
 - v. In home v. In House of God
 - vi. Talk to God

Direct Inquiry: If spiritual support services were made available to you by your healthcare team, what would that look like and involve?

- **Chaplain/Priest/Clergy**—prayer, scripture reading, mediation,
- **Spiritual Counselor**-- prayer, scripture reading, mediation
- **Cancer Support Services**—group setting

Direct Inquiry: What type of spiritual support services would you like your health team to make available to you (prompt-hospital chaplains, support group of a similar faith group)

- Chaplain/Priest/Clergy/Counselor/Lay Person—
 - i. To give communion; support; active/passive prayer, scripture reading, mediation, therapeutic support*
 - ii. One hour sessions weekly in the clinic during MD visit*
 - iii. Group sessions weekly*
 - iv. By telephone*
- Biblical Scholar--*Ecumenical*
- Lay Religious Person
- Spiritual Counselor
- *Should be Christian; Same Faith*
- Cancer Support Services—group setting

Indirect Response: Role of God In End-of-Life Decision making

- Importance of Quality of Life
 - God Does Not Want Us To Suffer (ex. “be on Life support”, “become brain dead”)
 - God Does Not Want Family to Suffer
- Past Experience: God Selected
 - My Family Member to Be Decision-Maker For Me
 - Me to be DNR
- Family- Past Experience:
 - I don't want Prolongation of Family Member Life Waiting for God to Heal---bad death
- God's Ultimate Goal -Reach the Spiritual Home/Heaven

Example of Qualitative Responses

- **God's Role in Ca:** I know God is taking me thru this. I believe I can be a testimony to somebody, I believe it. I'm grateful. (Grp1, 6)
- **God Role-EOL:** "When the death is inevitable, why keep prolonging, why keep suffering? Right, yeah we can go ahead and meet up with God, you know instead of prolonging it. Have a, live a good quality of life, you know, because it makes it so hard on your loved ones, to see you suffering. It's not, it's not helping the family, you know. It's not. but you know that's just like being on life support, when you know brain dead, you know it's inevitable, why keep a person alive? I mean I don't think God wants us to suffer like that."
- **MD Guided by God Alone:** ".When you think about you know we all are getting God's gifts. We're all created by God, the good doctors, the good therapists, you focus your time and attention and God gave them talents on the physical world and then you interact with the physical world, you know, treatment. Hey you're there, do it. I think that's all again in the greater God's plan."
- **God Uses Medicine To Heal:** "God gives medicine as an instrument to heal you." (Grp 3, 9)

Qualitative Work: Specific Aim 3

Determine receptiveness of newly diagnosed colon cancer patients to a spiritual support intervention and evaluate whether this receptiveness differs by religious belief and coping styles and race.

Question added to UIC/UC P60

To what extent would you welcome religious or spiritual support from your doctor or health care team?

| | RACE | |
|-------------------|-------------------------------|-------------------|
| Response Category | African American (%) N=120 | White (%) N=95 |
| None | 16 | 36 |
| A Little | 9 | 22 |
| Some | 25 | 23 |
| A Great Deal | 50 | 19 |

Cognitive Interviews (N=25) Demographics

| Demographics | Patients |
|------------------|----------|
| Age (years) mean | 61yrs |
| range | 26-79yrs |
| Gender | |
| Male | 16 (64%) |
| Female | 9 (36%) |
| Race | |
| African American | 12 (48%) |
| White | 11 (44%) |
| Marital Status | |
| Single | 1 (4%) |
| Married | 12 (48%) |
| Divorced | 7 (28%) |
| Widowed | 4 (26%) |
| Separated | 1 (4%) |
| Education | |
| No High School | 1 (4%) |
| Some High School | 2 (8%) |
| High School | 7 (28%) |
| Some College | 7 (28%) |
| College Graduate | 3 (12%) |
| Masters | 4 (16%) |

| Demographics | Patients |
|--|-----------------|
| Religious Denomination | |
| Catholic | 3 (12%) |
| Baptist | 8 (32%) |
| Non-Denominational | 4 (16%) |
| Christian-Reformed | 1 (4%) |
| Hindu | 1 (4%) |
| Lutheran | 4 (16%) |
| Jewish | 1 (4%) |
| Presbyterian | 1 (4%) |
| Methodist | 1 (4%) |
| Missing | 1 (4%) |
| Frequency of Religious Service Attendance | |
| 1-3x week: | 9 (36%) |
| 1-3x month: | 4 (16%) |
| 1-3x year | 8 (32%) |
| Never | 3 (12%) |
| Missing | 1 (4%) |
| Importance of Religious/Spiritual Beliefs | |
| Not Important | 1 (4%) |
| Slightly Important | 1 (4%) |
| Somewhat Important | 3 (12%) |
| Moderately Important | 3 (12%) |
| Very Important | 17 (68%) |

QUESTION 1

Some patients find it helpful to talk about their religious and/or spiritual needs and concerns when faced with a cancer diagnosis, would you be interested in having your health care team give you more information about services (such as hospital chaplains) that may be available?

Lexicon of Thematic Categories Response

| Category | Primary Themes (PR) | Secondary Themes (ST) |
|--|--|---|
| Desired Spiritual Support in the Medical Center | <p>Positive for spiritual support.</p> <p>Overarching theme:</p> <p>Coping with Illness</p> | <ul style="list-style-type: none"> • Perception of Doctor/Healthcare system as a Place of Spiritual Support During Times of Illness <ul style="list-style-type: none"> • Desire spir/sup through a spiritual counselor or physician • Doctor perceived as spiritual person, will do everything to help me • Pray with patient - during distress such as Bad News Delivery • Inquire into patient's spiritual needs • Mind and Body: Not just prescribing meds but treating whole person • Help me be at peace • Talk therapy <ul style="list-style-type: none"> • Discuss role of faith in illness • Read passages from Bible • Help with existential struggle • Acknowledge concerns through spiritual comfort • Compassionate care |

Lexicon of Thematic Categories Response

| Category | Primary Themes (PR) | Secondary Themes (ST) |
|--|---|---|
| Desired Spiritual Support in the Medical Center | <p>Negative for spiritual support.</p> <p>Overarching theme:</p> <p>Medicine and Religion Should Not Intersect</p> | <ul style="list-style-type: none"> • Religion in Private Life compared to Medicine as Public Life <ul style="list-style-type: none"> • Everybody should do their own jobs • Religion is your own business • Uncomfortable with doctor in spiritual role – stay separate • Would find other sources for spiritual comfort <ul style="list-style-type: none"> • Confident in own faith • Community Support <ul style="list-style-type: none"> •Family •Church Members •Friends |

Spiritual Care in the Medical Center

Positive

AA Female, 44 yrs, Raised a Baptist, Occasionally Attends Service

“I’m always interested in finding peace within . . . within Christianity. I want to be at peace with where I am, with my diagnosis – I want to have a greater faith and I need to – I want to ask those questions about how to build that, how to stay the course, how to pray even.”

Negative

White Male, 51 yrs, Non-practicing Catholic

“It’s my own personal experience. I guess I view religion a little more privately [...] it’s something between myself and what I believe. For instance, Dr. [so and so] - I never knew him and now all of a sudden he’s my Doctor – well I needed an oncologist...so now do I need a spiritual person to come in and be anointed by my healthcare provider? I guess one could say yeah, maybe I need that, but I doubt this would be the direction I would go to find a person for that.”

Positive

AA Female, 53 yrs, Practicing Baptist

“Well, I’d like to know if the doctor...is he spiritual? - and who can he refer me to if I don’t have anyone that I can go to right away? If he could refer someone to me that would be important because for me to feel that my doctor is a spiritual person, I would then feel that he would probably do the best that he can to help me out and see me through my situation.”

Lexicon of Thematic Categories Response

| Category | Primary Themes (PR) | Secondary Themes (ST) |
|-------------------|---------------------|--|
| Role of Chaplains | Positive View | <ul style="list-style-type: none"> •Helpful to those unaware of spiritual need <ul style="list-style-type: none"> •Provides comfort; Pray for all who suffer •Find peace within Christianity <ul style="list-style-type: none"> •Increase faith; Teach how to pray for comfort •Help to find a path to peace with where I am in life <ul style="list-style-type: none"> •With diagnosis; Stay the course •Past “Talk” with chaplains <ul style="list-style-type: none"> •Helpful; Contribute to well-being; Help to not feel self-pity; •Suggested Help from Chaplains <ul style="list-style-type: none"> • Guided/Focused; Expert in Providing Spiritual Guidance; Provide readings •Devastating news, might ask for a chaplain <ul style="list-style-type: none"> •Could stabilize you •Give perspective in face of bad news delivery •Someone familiar with hospital area <ul style="list-style-type: none"> •Hospital-based service; Aware of stress within hosp environment; Know what patients and families need in terms of support and comfort |

Lexicon of Thematic Categories Response

| Category | Primary Themes (PR) | Secondary Themes (ST) |
|-------------------|---------------------|---|
| Role of Chaplains | Negative View | <ul style="list-style-type: none"> • Would find other sources for spiritual comfort • Chaplain as religion specific <ul style="list-style-type: none"> • Must have similar set of beliefs • Only if Chaplain was same religion • Provide answers within particular faith • Last resort: Would talk to Chaplain if no one else available <ul style="list-style-type: none"> • Prefer own pastor: Not due to different beliefs but level of comfort • Chaplain unaware of patient needs <ul style="list-style-type: none"> • Does not understand patient needs/fears <p>Chaplains are Catholic</p> <ul style="list-style-type: none"> • Lack of Understanding of What a Chaplain Is • Chaplain seen as “Catholic” • Chaplain = Dying, Last Rites • Never offered Chaplain Support • Chaplain Service Only for Hospital Stays |

Role of Chaplain - Positive

Female, AA, 44 years

Attends 1-3 times per year; Baptist

“It’s hard to say since I’ve not had the total relationship – I think it would be ... I think it would be challenging for me. I think they would give me something to think about – hopefully, it will be guided – something that they’ll ask me to read - something that we can talk about later on, or during the course of our conversation. I think ... that’s what I think....In an institution like this... [the chaplain] would give me something to think about... where to go for guidance in the Bible to discover... what would be better for my soul.”

Role of Chaplain - Negative

Male, White, 67 years

Attends 1 time per wk; church elder, Presbyterian

“I think sometimes a title like a hospital chaplain will put people off. The thought of going to hospital chaplain carries to me, some dire connotations; like I’m checking out of this world and I gotta talk to somebody now.”

Male, AA, 78 years

Attends 1 time per year; Baptist

They (chaplains) all Catholic they all Catholic yes ma’am and to me they crooked now don’t misunderstand now they crooked they living too high....I don’t have too much faith in Catholic people because to me. . . they crooked. . . they living too high. Priests, he can’t be God - they treat him like God you know he not God.

Question 2: Scenario

What if cancer DOCTORS and NURSES regularly provided spiritual care. Assume the spiritual care is done in an appropriate, sensitive way.

For example, for a patient who is not religious or spiritual, the only spiritual care that might be given is the doctor or nurse asking about their religious/spiritual background and whether or not this type of care would benefit them in dealing with their cancer.

For a patient who is very religious/spiritual, the doctor or nurse might frequently provide spiritual care over the course of the relationship.

Rating Spiritual Support in Medical Setting

AA Male, 26 yrs, Non-denominational, Non-Practicing

“I think 1, yes 1 for most positive, because a lot of times especially with people who are dealing with situations you don’t wanna go to you know your church where everybody’s gonna be in your business you know or sometimes you want to feel a little more private so to have someone come in and offer you something. It might be something that you’re thinking about and don’t know where to go and to have somebody offer you help could be just a step in the right direction or you to have the resources available to say if I do need help, I know it’s there. I think it would be a great help and I think it’s very positive. A lot of times people don’t feel comfortable going to talk the neighborhood pastor - the churches business gets out there you know people wanna stand up and say oh we’re gonna stand today and pray for you and it makes you feel uncomfortable.”

Rating Spiritual Support in Medical Setting
White Male, 43 yrs, Christian-Reformed
Attends 1-3 times per month

Subject: “I believe it would be a **positive so I would give it a 1** as the most positive thing. My view would be that it would be very positive yes.”

Interviewer: “Why do you answer that way?”

Subject: “Because in my belief it’s a very necessary thing from my standpoint that somebody have a religion or a support network. Religion can be very necessary for people to go through [painful experiences], for example September 11 the whole country turned religious because it was a tragedy and people had needed to go somewhere for some sort of moral support.

Rating Spiritual Support in Medical Setting

**White Female, 59 yrs, Practicing Catholic
(decreased attendance since CRC DX: 1 time per
week to zero)**

“I guess I have to say **probably about between a 5 and 6** because it is possible that a nurse could access a patient who initially said, for the first treatment, I’m very spiritual but might be having an awful time going through it and may be turning away from that aspect you know. Maybe they’re angry about it so I guess it would have to be reassessed but obviously some assessment is better than no assessment at all when offering help. As long as it’s done in that manner and it sounds like some thought has been given, as opposed to providing the same thing for each person.”

Rating Spiritual Support in Medical Setting
AA Female, 57 yrs, Practicing Baptist
(decreased attendance since CRC DX: 2 times per month to zero)

(Rating 1)

“Because you need to know that your doctor - I mean, you have people that don't believe, you know Atheists, you have Jehovah Witnesses, you have all different kind of religions - but we all serve the same God, but, so, but my doctors, they always have, and I'm surprised you asked me that, because my colon, the person who operated on me, his name is Dr....., he's very religious, and he always talks about religion. And when he came in he said, somebody's praying for you Ms. ...and he is very spiritual, he believes in God. So it's good to know that your doctor believes in God, and people that don't believe in God needs to hear that, you know, through medicine. And I think the doctor would be good, cause when people come here they is sick and they [need healing].”

What Does the Qualitative Data (Focus Group & Cognitive Interview) Tell Us About Cancer Patient's Desire for Spiritual Support Services Made Available by Healthcare Team?

- Cancer Pts **DO** Desire Spiritual Support Services
 - Based upon own current and/or past experiences
 - Unable to describe the type of support (Ex. Chaplain? Clergy? Spiritual Counselor?)
 - Unable to describe the frequency of support (Ex. weekly, monthly, group setting, in person, telephone)
- **SOLUTION?**: A Spiritual Care Advocate (SCA) Intervention Project is being developed as a complimentary solution to meet needs

The Vision: Spiritual Care Advocates in the Oncology Clinic Setting

**A liaison in the outpatient oncology clinic
between...**

- Patients**
- Local faith community**
- Healthcare team**
- Chaplains**

Identifying Partners and Relationship Building

- Community Pastors
- Chaplains
- Bishop Andersen House
- UC Researchers

Finding a Community Partner to Support Our Vision

A.C.T.S. of F.A.I.T.H.

**Actions Connected To Spirituality: Forming
Alliances In Transforming Health**

“A non-profit organization that works to improve health outcomes of African Americans, and to reduce and eliminate racial health disparities experienced on Chicago’s South Side and beyond.”

Creating the SCA Position

All partners have a
voice...and after
several iterations....

Position Description

Position Title: Spiritual Care Advocate (SCA)

Facility/Location: The University of Chicago

Department: Chaplaincy Services

Reports To: Manager of Chaplaincy Services at the University of Chicago Medicine & Biological Sciences

Date of original Position Description: TBD

Position Purpose/Job Summary

This role is responsible for the provision of effective spiritual care support services (emotional and spiritual understanding and support) to cancer patients facing a terminal cancer diagnosis. Specifically, this person will help cancer patients cope with their diagnoses through respect for and understanding of patients' individual religious values and beliefs. This person will also identify religious resources/faith-based to support their shared decision-making in an effort to enhance cancer patients' understanding of the palliative end of life (EOL) care options available to them.

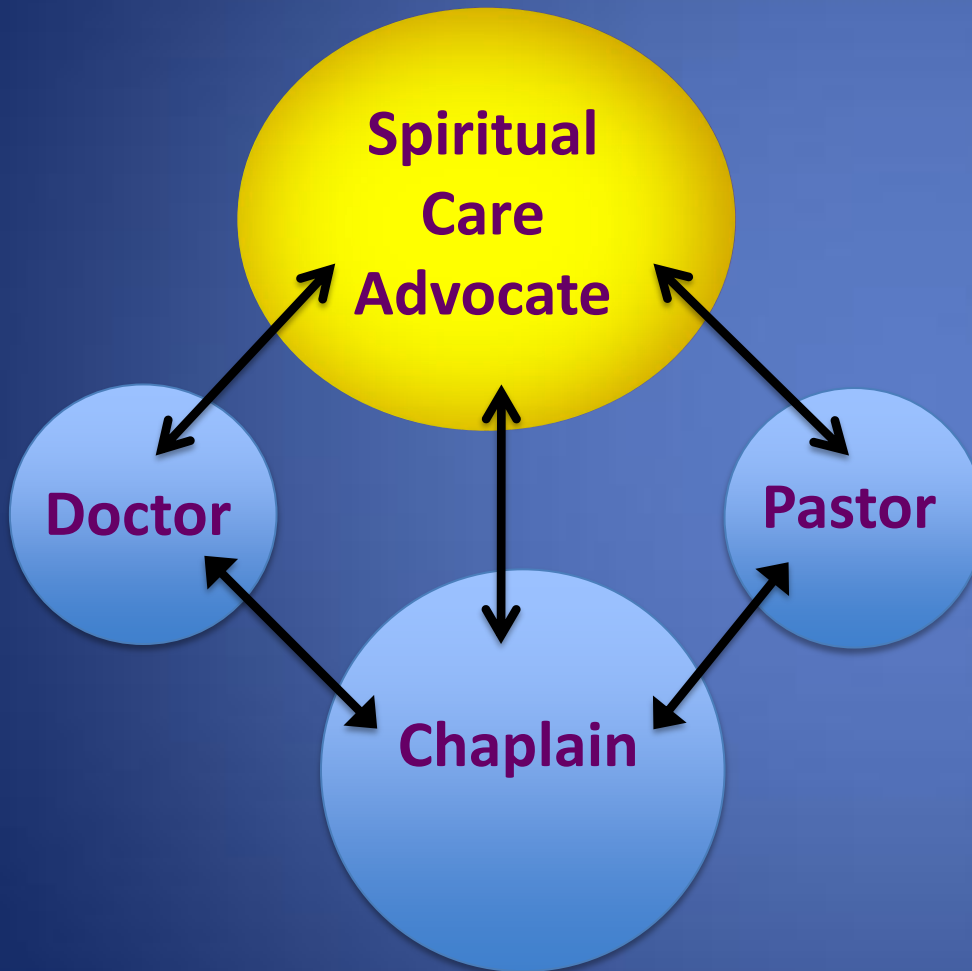
The role ensures that a reliable and flexible service is provided in accordance with the client's individual need for spiritual support during their terminal cancer diagnosis, taking into account individual client differences, preferences and their right to self-determination.

Role Description:

INITIAL MEETING In an initial meeting with patients and their loved ones the Spiritual Care Advocate will describe the program, determine interest and needs, and respond as indicated.

Spiritual Support The Spiritual Care Advocate will determine the patient and/or family's interest in and access to spiritual support. As indicated by this process the

SCA Support Model



- 3-WAY SUPPORT
- SCA TO REPORT TO UNIVERSITY OF CHICAGO MEDICINE'S HEAD CHAPLAIN
- ONCE A MONTH PROGRESS MEETINGS WITH CHAPLAIN, DOCTOR, PASTOR TO DISCUSS CASES, ISSUES, CONCERNS, NEEDS, ETC.

Developing the SCA Training

- **Cancer Care 101: Blase Polite**
- **EOL Care 101: Monica Malec**
- **Psychosocial Issues and Patient Communication at the EOL: Fay Hlubocky/Toni Cipriano**
- **Chaplain Care 101: Marsha Sumner/Sharyon Cosey**
- **Pastor Care 101: Pastors/Acts of Faith**

Thank You

- ✧ John Templeton Foundation (Polite PI, Fitchett, Cipriano, Hlubocky co-Is)
- ✧ UIC P60 (Raucher and Calhoun)
- ✧ UC Chaplains
 - Marsha Sumner
 - Sharyon Cosey
- ✧ UC Medicine
 - Monica Malec
- ✧ Acts of Faith
 - Herbert Lassiter
 - Marie Gilliam