Spiritual Assessment and Intervention Model (AIM) in Outpatient Palliative Care for Patients with Advanced Cancer

University of California, San Francisco

Caring for the Human Spirit
New York, NY

Acknowledgements

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- UCSF Helen Diller Family Comprehensive Cancer Center
- Mt. Zion Health Fund
- Our patients
- Our departments
- Our families

Outline:

- Overview of project
- Description of Spiritual AIM
- Results of study
- Case presentations
- Conclusions

Project Team

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Rationale for Study (1)

- Minimal description of what chaplains actually DO with patients
  - How do chaplains assess patients' spiritual needs?
  - How do chaplains intervene to address these needs?
  - What outcomes do chaplains seek?
  - How can chaplains tell if these outcomes are achieved?

Rationale for Study (2)

- Need for patients' own voices in descriptions of chaplains' work with them
- Quantitative description of impact of spiritual care on patients seen in outpatient palliative care setting
- Fostering chaplains' as researchers and research collaborators

Spiritual Assessment and Intervention Model (Spiritual AIM)

- Background (rationale/evolution)
- Theology/Philosophy
- Psychology
- Core Spiritual Needs
- Spiritual AIM: How does it work
- Distinctiveness

Shields M, Kestenbaum A, Dunn LB. Spiritual AIM and the work of the chaplain: A model for assessing spiritual needs and outcomes in relationship. Palliative and Supportive Care. 2014 Mar 10:1-15. [Epub ahead of print]

Spiritual AIM: Background

- Developed during 21 yrs of Spiritual Care/ Clinical Pastoral Education (CPE) focused on what occurs between the patient and chaplain
- Begun in chaplaincy mentorship in a CPE supervisory training group with Rev. Dennis Kenny, D.Min. for first 2 yrs
- Developed with theological reflection and psychological theory, plus critique from professional peers and students
- Refinement with the Spiritual AIM Research Team during this study for last 1.5 years

Spiritual AIM: Theology/Philosophy

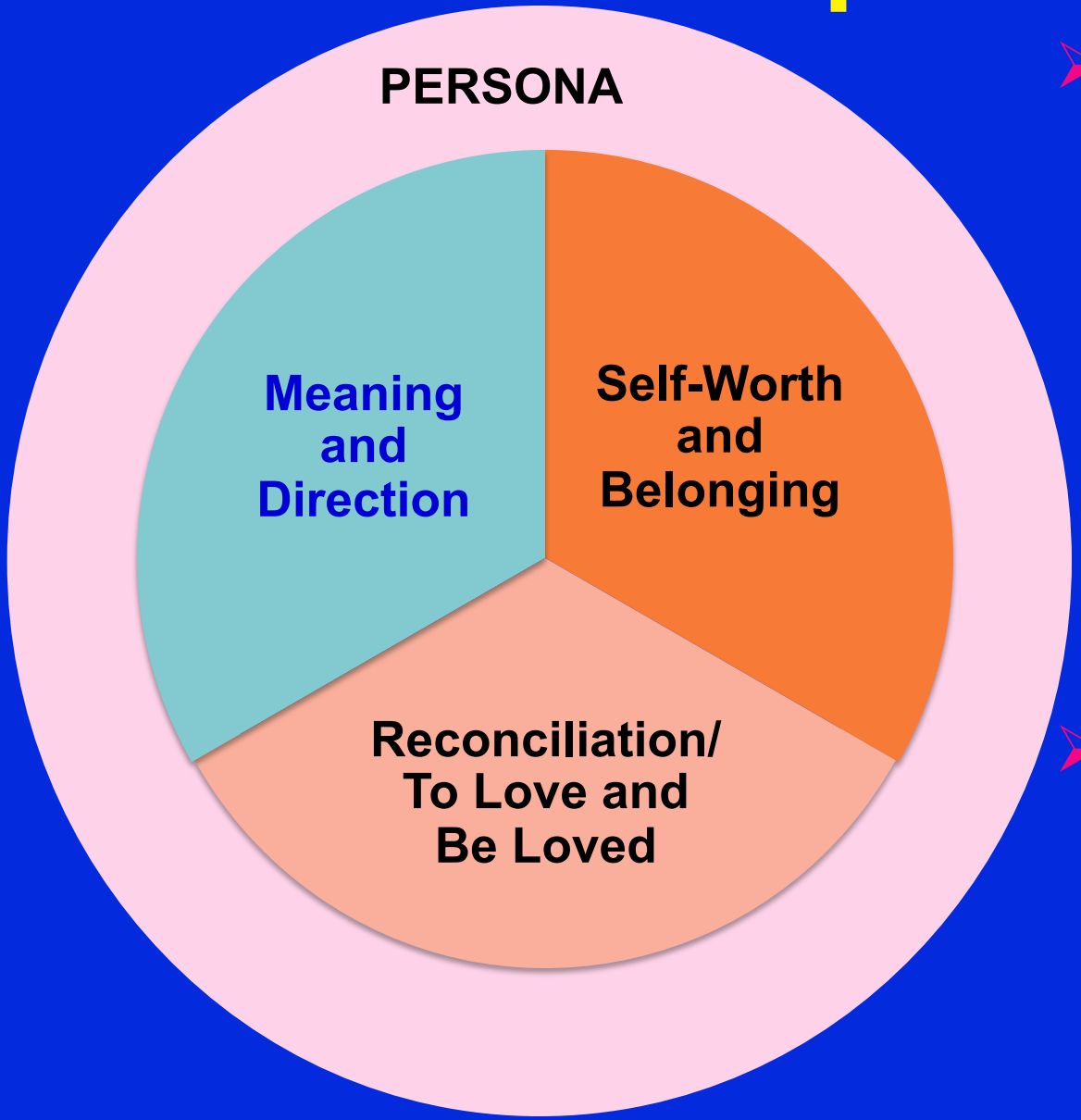
- The Golden Rule or Ethic of Reciprocity:
  - "Treat others as you wish to be treated." "Love your neighbor as yourself." (Lev. 18:18, Matt. 22:37-40)
  - "What you do not wish for yourself, do not impose on others." (Confucianism)
- Spiritual maturity requires autonomy enough to love oneself and connection enough to achieve fairness in balancing love for oneself, others and God (if one's belief includes God).

Spiritual AIM: Psychology

- Object Relations:
  - Personality takes shape through people's experiences of relationships and social context, specifically how a child appropriates, internalizes and organizes early experiences in the family.

- Spiritual AIM:
  - Spiritual dynamics and spiritual needs are shaped in a similar manner and may be changed or met in relationships, even in adulthood.

Core Spiritual Needs



- Spirituality encompasses the needs to **seek meaning and direction, to find self-worth and to belong to community, and to love and be loved,** often facilitated through seeking reconciliation when relationships are broken.
- When a person faces a crisis, 1 of 3 spiritual needs surfaces most urgently – referred to as the person's "core spiritual need"

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Spiritual AIM: How does it work?

- Assessment of spiritual need based upon:
  - comments
  - behavior
  - attribution of blame
  - questions
  - concerns
  - chaplain's own internal response to person
- Assessment of where person is along path to healing

Spiritual AIM: How does it work

- Embodiment: stance of
  - Guide
  - Valuer
  - Truth-teller
- Interventions in the process of healing
- Healing happens in relationship
- Desired outcomes to meet the spiritual need

Spiritual AIM: Distinctiveness

- Assessments, corresponding interventions, desired outcomes
- Psychological and theological/philosophical theory underpinnings
- Broad definition of "spirituality"
- Communicates well to the interdisciplinary team
- Inclusive of a variety of faith—or no faith—traditions
- Useful in fast-paced, clinical setting (it is not an interview approach)

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Spiritual AIM and the work of the chaplain: A model for assessing spiritual needs and outcomes in relationship

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ABSTRACT

Objective: Distinguishing the unique contributions and roles of chaplains as members of

Aims (1)

Aim 1. To describe the content and processes of spiritual **assessments** conducted by chaplains to identify core spiritual needs among patients with advanced cancer.

Aim 2. To describe the content and processes of spiritual care **interventions** developed based on these assessments.

Aims (2)

Aim 3. In order to calculate effect sizes for future intervention research, to **measure changes** in spiritual, psychological, and physical symptoms and to assess the value added to outpatient palliative care interdisciplinary teams by certified chaplains.

Aim 4. To evaluate the **feasibility** and **tolerability** of recruitment, assessment, and intervention research focused on evaluating Spiritual AIM in the outpatient palliative care setting.

Project Description

- Adults with advanced cancer (target n=30, recruited 31)
- Symptom Management Service (outpatient palliative care service of UCSF HDFCCC)
- Each participant is seen individually for three sessions with a chaplain; audiotaped and professionally transcribed
- Pre- and post-intervention booklet of self-report rating scales
- Exit interview with research coordinator
- Weekly team meetings (audiotaped, transcribed → auto-ethnography)

Study Measures (1)

- Symptoms (ESAS; 10 items) - e.g., fatigue, pain
- Spiritual well-being (1 item)
  - "I feel at peace"
- Overall quality of life (1 item)
- Spirituality (FACIT-Sp-12, 12 items)
  - "I find comfort in my faith or spiritual beliefs"
  - "I feel a sense of purpose in my life"
- Religious coping (Brief R-COPE; 14 items)
  - "Sought help from God in letting go of my anger"
  - "Wondered what I did for God to punish me."

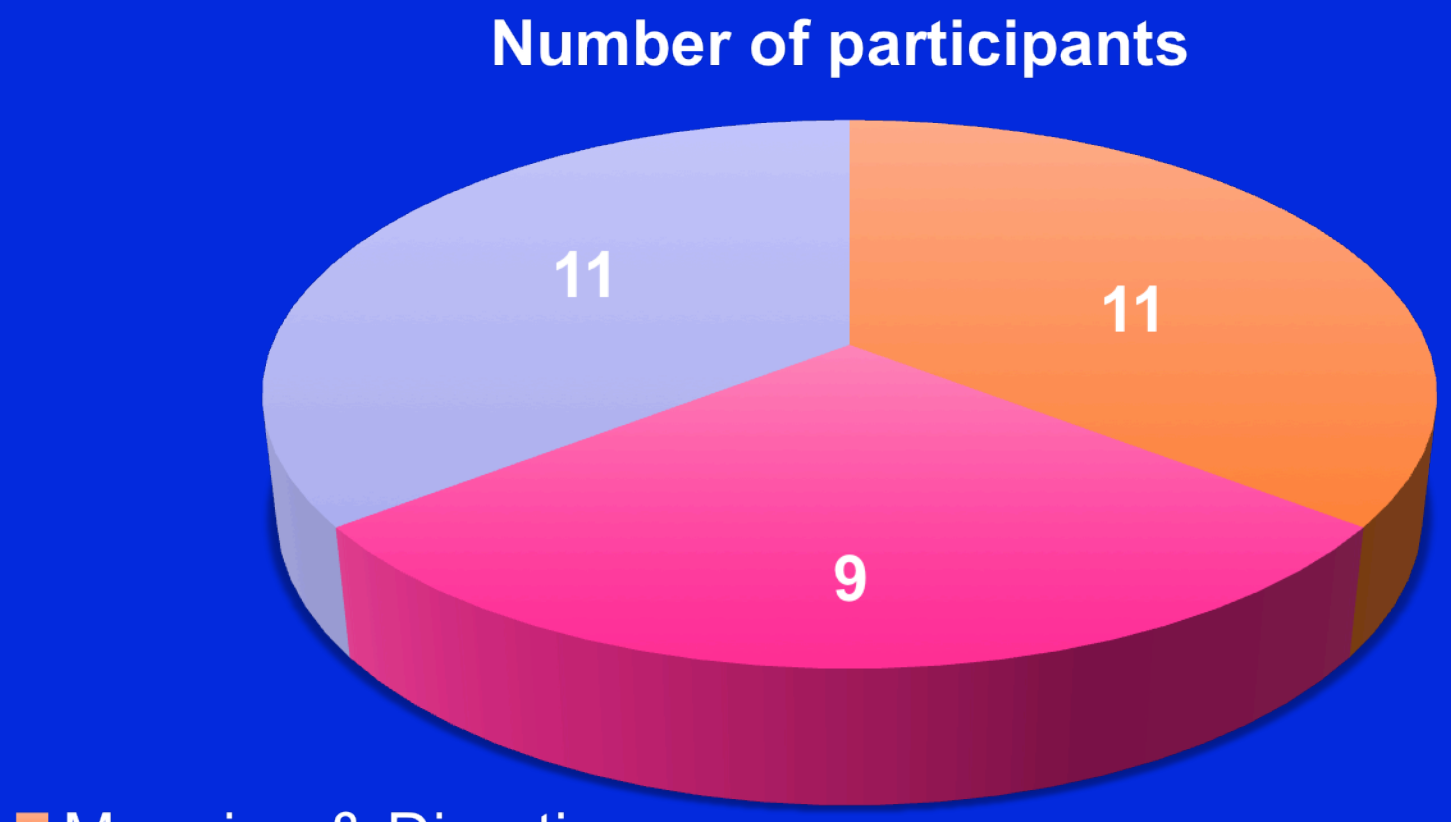
Study Measures (2)

- Dignity (Patient Dignity Inventory, 25 items)
  - "Feeling like I am no longer who I was."
- State anxiety (STAI-S, "now," 20 items)
  - "I feel at ease"
  - "I feel nervous"
- Depressive symptoms (CES-D, "past 7 days," 10 items)
  - "I felt sad"
  - "I could not get 'going'"

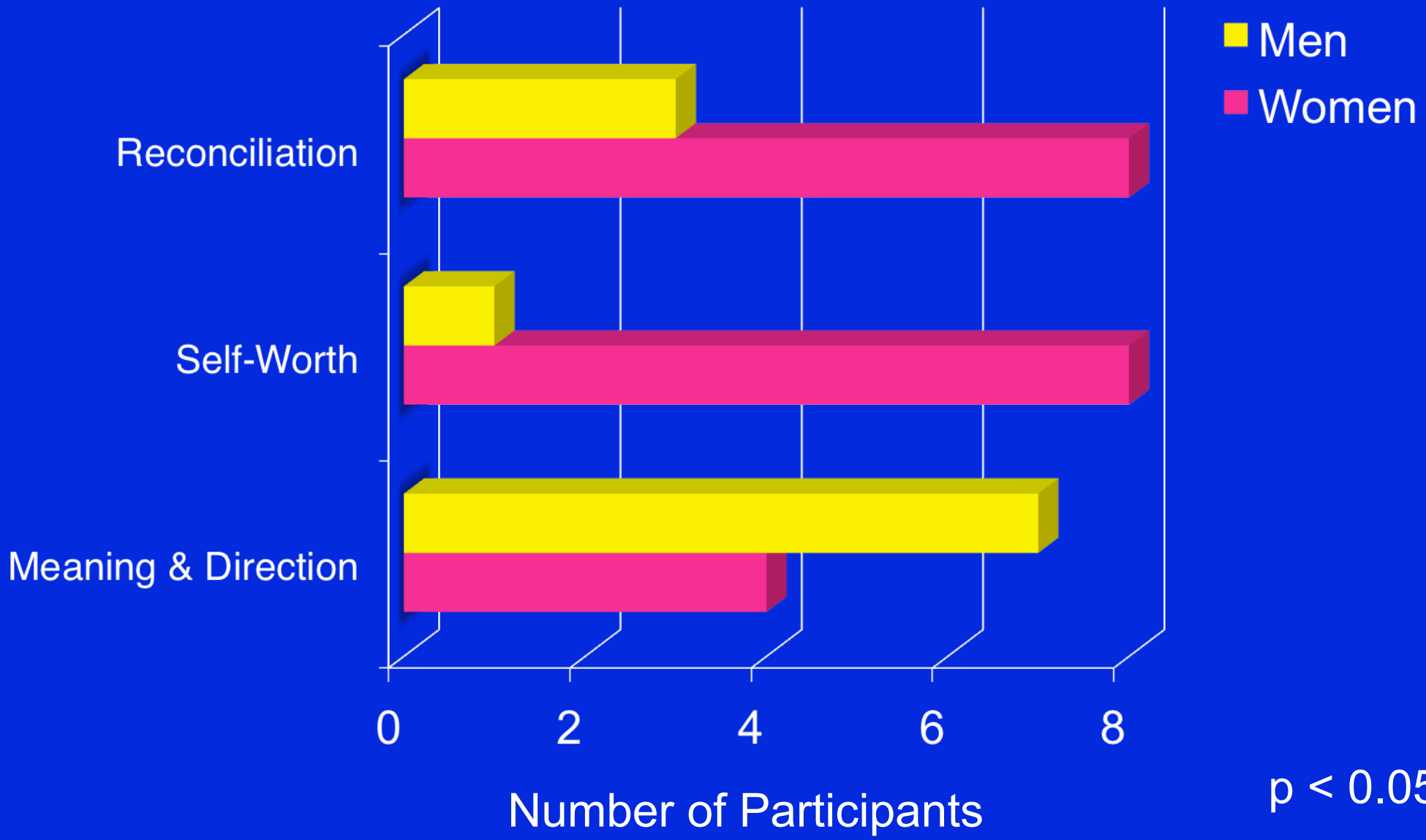
Demographic and Clinical Characteristics

	Mean (SD)	N (%)
Age (years)	59.4 (9.9)	
Female Male		20 (64%) 11 (36%)
Christian Jewish Buddhist None		18 (58%) 4 (13%) 3 (10%) 6 (19%)
White Asian Hispanic		27 (87%) 3 (10%) 1 (3%)
Breast cancer Gynecologic GI Prostate Head/Neck Other		6 (19%) 7 (23%) 5 (16%) 5 (16%) 3 (10%) 5 (16%)

Core Spiritual Needs



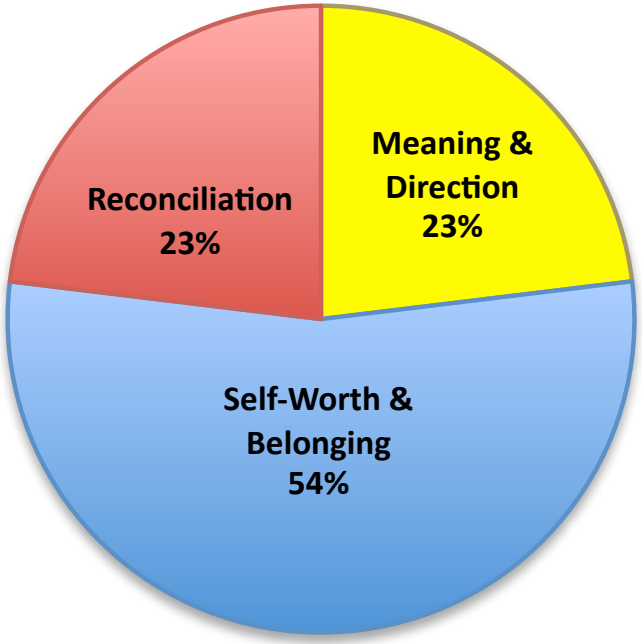
Core Spiritual Needs by Gender



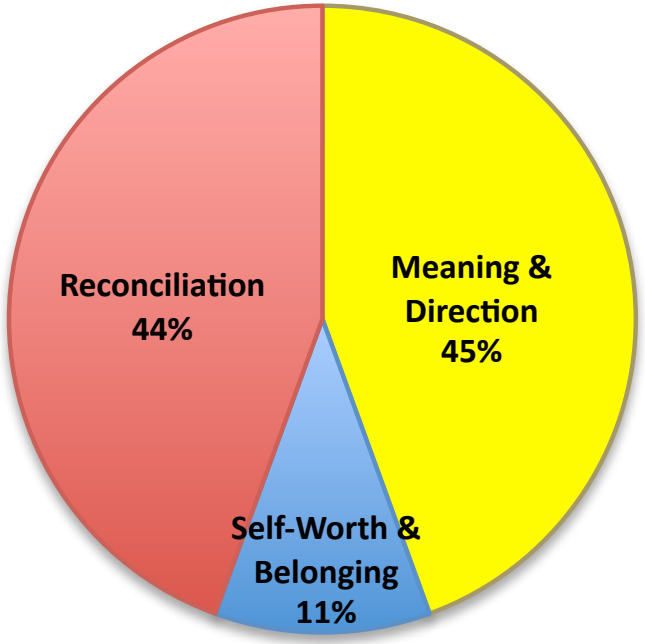
$p < 0.05$

Core Spiritual Needs by Age Group

Younger Patients (<60 yo)



Older Patients (>60 yo)



$p < 0.05$

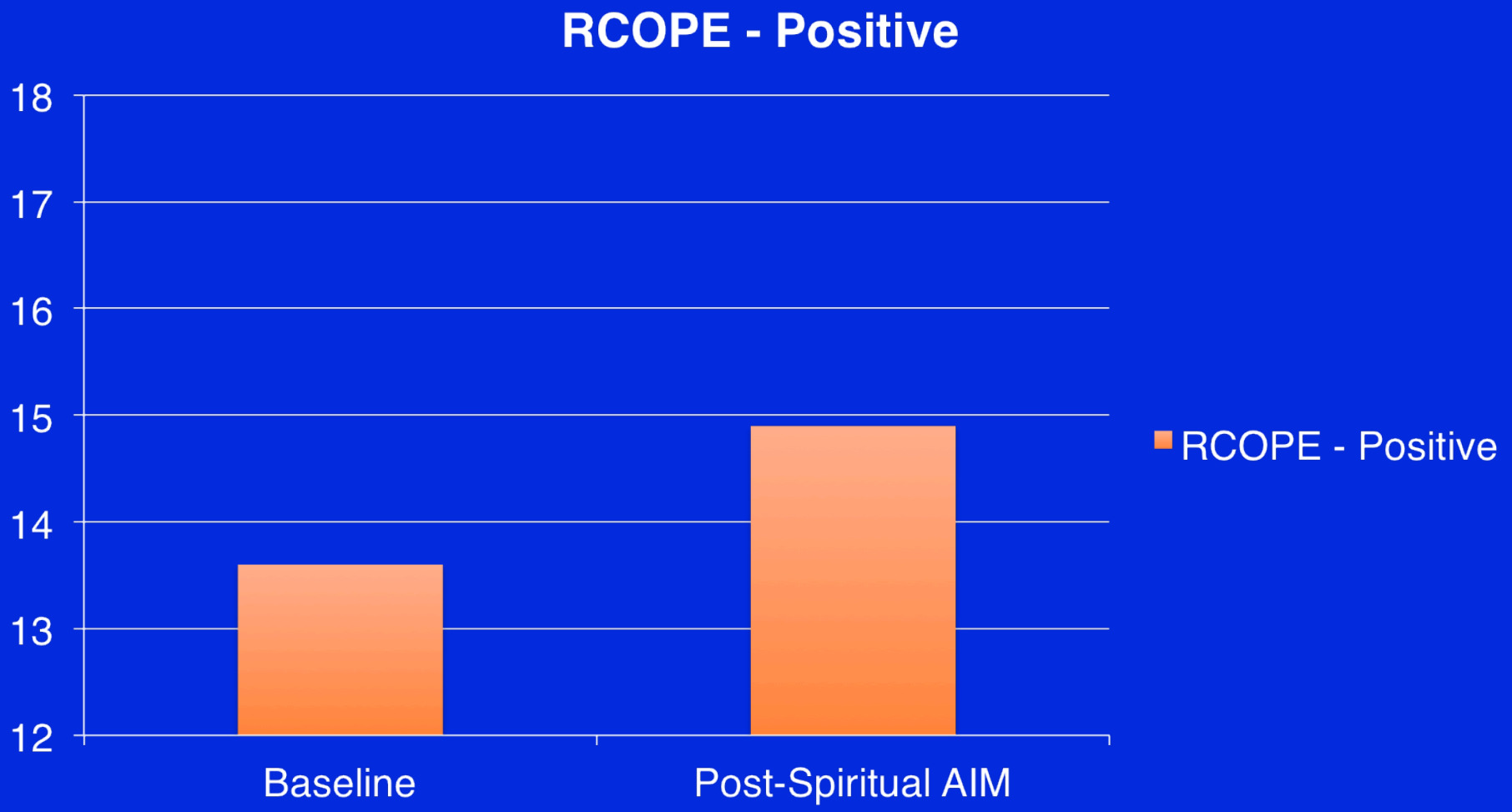
Baseline Symptom, QOL, Spiritual, and Psychological Measures

	Mean (SD)	Range
ESAS - Total	25.0 (12.7)	2 - 52
"I feel at peace"	3.1 (1.1)	1 - 5
Overall Quality of Life	3.5 (0.8)	2 - 5
FACIT-Sp-12	29.2 (9.2)	1 - 48
RCOPE Positive RCOPE Negative	14.0 (5.7) 9.2 (2.6)	7 – 28 7 - 16
Patient Dignity Inventory	53.6 (14.4)	29 - 80
STAI - State	43.6 (12.5)	21 - 65
CES-D-10	4.2 (2.2)	0 - 8

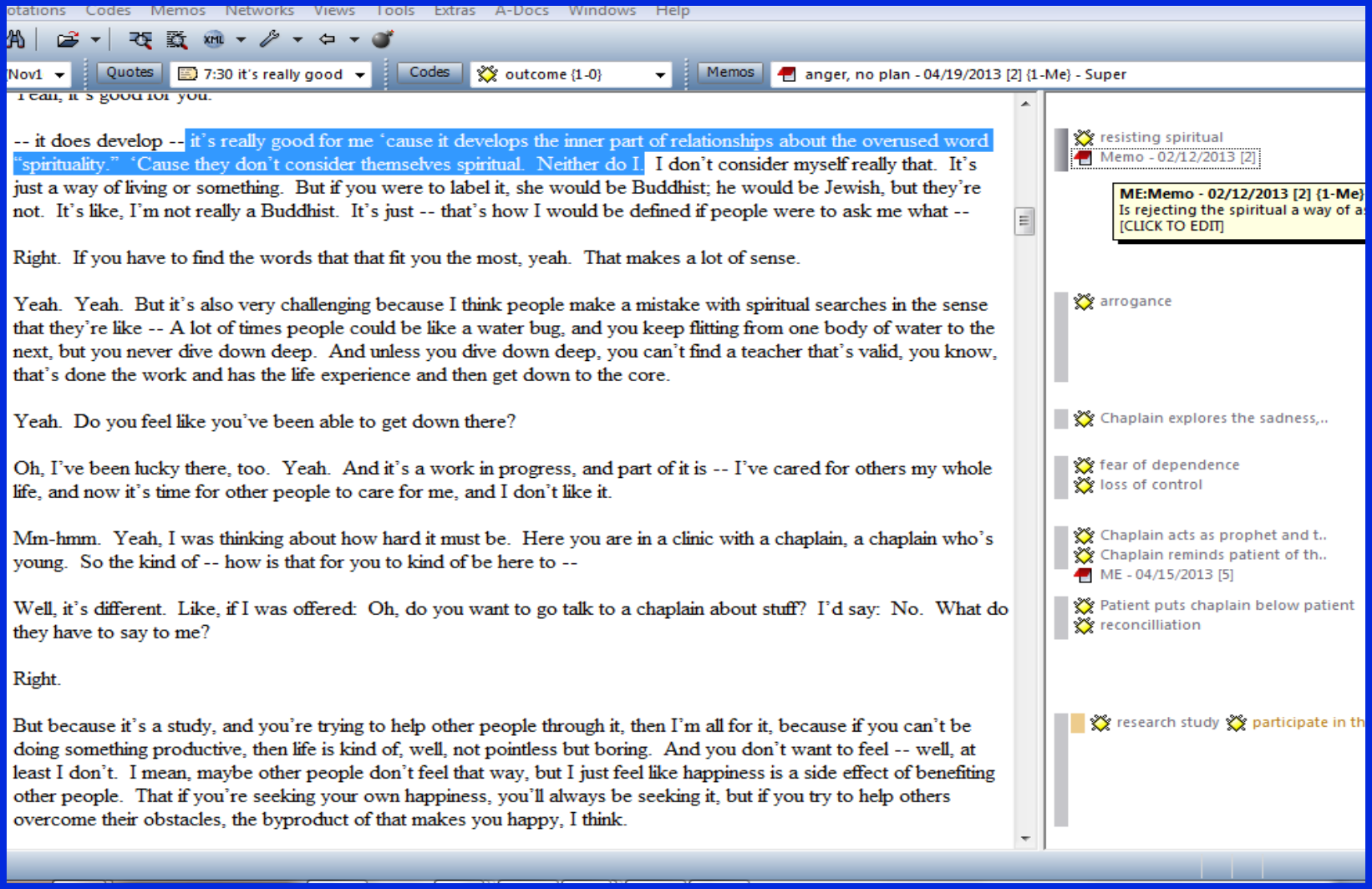
Changes in Symptom, QOL, Spiritual, and Psychological Measures from Baseline to Post-Spiritual AIM

	Change	p-value	Effect Size
ESAS - Total	-1.17	0.646	-0.09
"I feel at peace"	0.07	0.646	0.09
Overall Quality of Life	0.03	0.832	0.04
FACIT-Sp-12	-0.37	0.811	-0.14
RCOPE Positive	1.30	0.082	0.34
RCOPE Negative	-0.11	0.803	-0.06
Patient Dignity Inventory	-2.81	0.280	-0.21
STAI - State	-2.12	0.294	-0.20
CES-D-10	-0.28	0.502	-0.13

Change in Positive Religious Coping

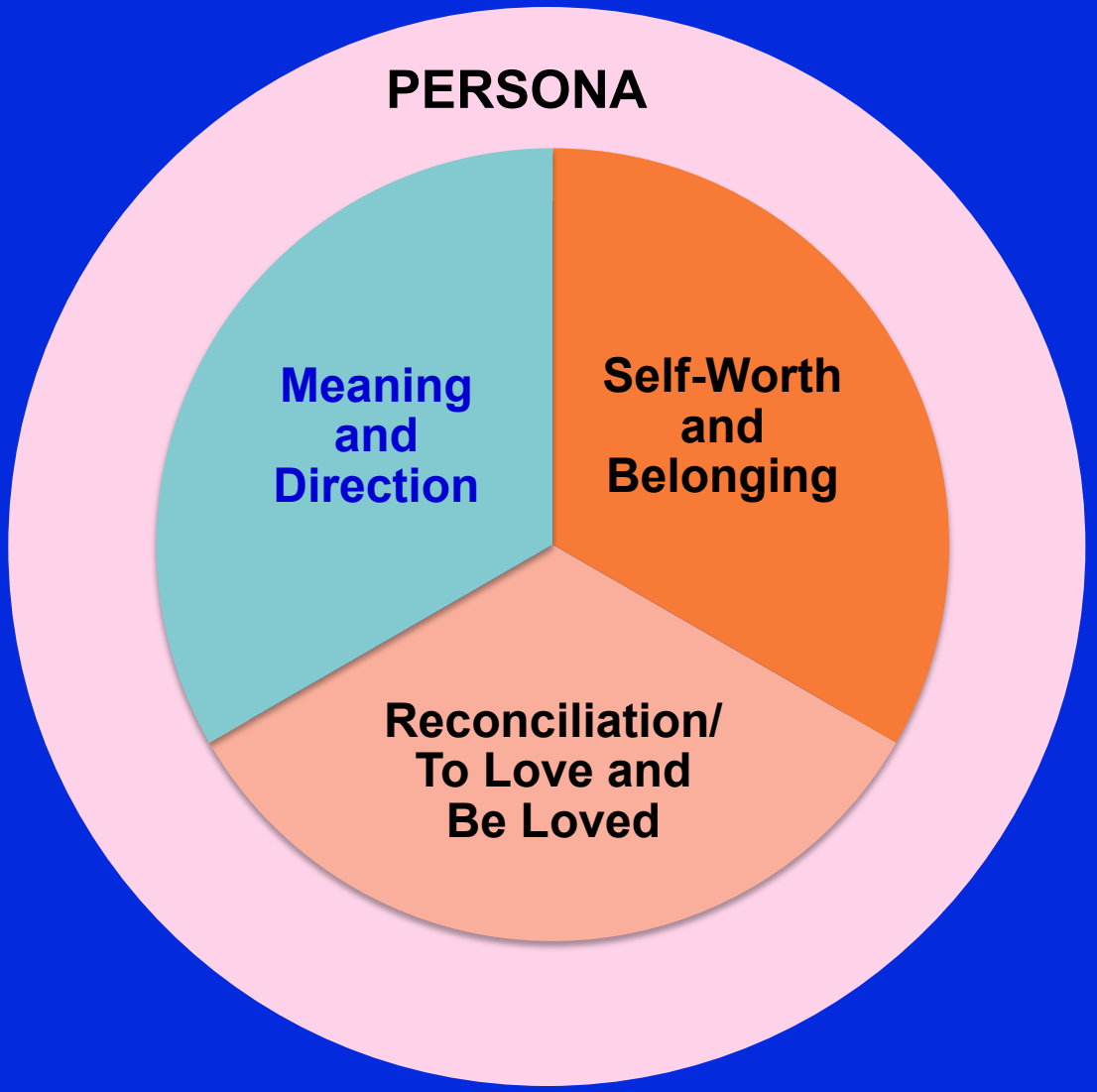


Qualitative Analysis



- Atlas.ti
- *a priori* coding (from model)
- inductive coding (based on themes emerging in team discussions)
- Reflexive memoing throughout analysis

Core Spiritual Needs



Case 1: Self-Worth and Belonging

Carol is a 60 year-old woman with metastatic solid tumor cancer.

She is married, has two children.

She identifies as Evangelical Christian.

Case 1: Self-Worth and Belonging

Chaplain's Assessment – "It's my fault."

- **Blames self** - "When I step away from that routine, I feel like a failure…I'm a quitter, like I've always thought of myself all my life. So I'm just going back into old patterns."

- **Guilt** - "Well, I feel [grief and sadness], and I feel bad that I do feel that way, 'cause I feel like I shouldn't feel that way."

Case 1: Self-Worth and Belonging

Chaplain's Assessment (continued)

- **Fear of burdening** - "My husband, he tries to help and I'm not one to ask for help a lot and there's certain things that I feel that it's easier for me to do..."

- **Blames self** - "I probably don't recognize it as 'God is speaking to me' rather than just coincidence or good things happening. I'm not giving praise where I should be."

Case 1: Self-Worth and Belonging

Interventions

- Chaplain
  - Acts as a valuer for the patient, e.g. affirming her for caring for self.
  - challenges patient's beliefs about husband/God's expectations.
  - explores anger at feeling burdened by husband's expectations/God's desire for her.
  - emphasizes Jesus as source of support as she begins to pursue her own desires—such as spending quality time with her mother.

Case 1: Self-Worth and Belonging

Outcome

Patient named how she was working to…

Address her own needs

Find community

Case 2: Meaning and Direction

Gina is a woman in her 50's who has received extensive treatment for leukemia.

She is married, Jewish, and has 2 children.

Case 2: Meaning and Direction

Chaplain's Assessment – "Why did I survive?"

- Patient speaks in **monologues** and tries to **make sense of her illness**,
- Patient employs **imagery**
- Patient gravitates towards **possibilities**
- Patient expresses **curiosity** and **intellectualization** about the research study.

Case 2: Meaning and Direction

Chaplain's Interventions

- **Past decisions/coping** – "So have there been other times in your life where you needed to reintegrate in some way? You had been taking all these classes, which sounds amazing. Is that kind of how you've done it in the past?"
- **Sources of support** – "Oh, you've got quite an advocate in your husband."
- **Rejoicing** - "That's not something that everyone would be able to do or everyone would think that way. It sounds like you're really making a commitment to live in that way."

Case 2: Meaning and Direction

Chaplain's Interventions (continued)

- **Sources of support** – "How does that feel when you let yourself remember how supportive your family was [during illness]? How does that feel for you?
- **Blessing** - I'm thinking of the expression in our tradition, "from strength to strength;" it's a blessing. And I have an image of you being a strong link in the chain….We don't know why this has happened and it's been so, so heavy, but I have this image of the generations and how you're linked in that with those who have come before and after."

Case 2: Meaning and Direction

Outcome

- Patient reports that session with chaplain "brings you to realize what's important in your own life" and focus in more on her heart's desire.
- Pt reports that when she went to Hawaii…

  "I wanted to make sure I got in the water because we talked a lot about water and I love both looking at the water and also being in the water, feeling the water. I wanted to make sure I had that experience and I did. That got me to focus in on that a little bit."

Case 3: Reconciliation/To Love and Be Loved

Janice is a woman in her 60's with a gynecologic cancer.

She is married, has 2 children and is Episcopalian.

She is a survivor of sexual abuse.

Case 3: Reconciliation/To Love and Be Loved

Chaplain's Assessment – Tense relationships

- Patient presents with anger and discusses broken relationships

Chaplain's Interventions

- Chaplain acknowledged brokenness in important relationships
  Chaplain challenges patient to take responsibility

Case 3: Reconciliation/To Love and Be Loved

Outcomes

Confession –

"I tend to get angry with people for not being there; I don't remember that other people have lives too…"

Case 3: Reconciliation/To Love and Be Loved

Outcomes (continued)

Forgiveness of self and others

"And throughout this time, I had a personal change that triggered a complete reversal in my life in a lot of ways….You know, I would've sworn it would've taken years of drudgery to affect this kind of change…"

Case: Reconciliation/To Love and Be Loved

Outcomes (continued)

Intimacy:

"I feel like I finally let my husband in after all these years. It made this big shift inside where I try to let go of all this shame and self-hatred that I carried around for so long that was really eating me up… And that's really different for me to think that."

Love/Be Loved: "What I've learned to believe in is loving other people; that goes a long way."

Case: Reconciliation/To Love and Be Loved

Outcomes (continued)

Reconciliation:

"When I was in the hospital for the internal radiation and I had all that pain, I knew that the people around me were trying to do whatever they could to make that better....

I could feel that by the way that they treated me...that made a huge difference in how I got through it."

Chaplains Contributions -

Ch1: "Yeah, I wanted to give her permission to air that grievance because there is a biblical tradition for speaking back and saying, 'Wait a minute. You know, what you like and what's going on with you, God, is not what I like…'"

PI: "…it occurs to me that what you're saying is not something that an uninformed person like myself would know, would have any idea is part of what chaplains do, namely give people permission to have this kind of – "

Ch1: "Dialogue with God?"

Chaplains Contributions -

PI: "Yeah…I think the ignorant view is that…you come in and pray with people or encourage people to…be at peace with God…I think an uninformed view would be that."

Ch1: "Right. And her own faith gives her options to have a broader expression – a broader emotional expression -- which is what she's already saying here to God. You know, 'What you think is best is not maybe what I think is best for me, God.' And that is a genuine prayer of her heart and she's already said it and she's laughing, you know."

Conclusions

- Recruitment
  - Feasibility, tolerability of spiritual care research in patients with advanced cancer receiving palliative care
- Pre/post data on spiritual, psychological, physical and quality of life characteristics
- Generated a richly descriptive qualitative database
  - 93 chaplain-patient encounters
  - 30 exit interviews
  - 25 team meetings

Conclusions

- Evolution in articulation of Spiritual AIM
- Development of chaplains as researchers
- Deep description of chaplains' work: assessments, interventions, and outcomes
- New research questions

Thank you!!