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The Chaplain Family Project: A spiritual care intervention for family surrogates in the ICU

Alexia M. Torke, MD, MS
Beth Newton Watson, MDiv, BCC
Emily Burke, BA
Saneta Maiko, PhD

INDIANA UNIVERSITY
School of Medicine
Department of Medicine
Division of General Internal Medicine and Geriatrics
Center for Aging Research

Regenstrief Institute

Indiana University Health

The Team

The Evans Center, IU Health
- Steven Ivy, PhD
- Saneta Maiko, PhD
- Sarah Rush, BA

Spiritual Care and Chaplaincy Services, IU Health
- Beth Newton Watson, MDiv, BCC
- Kathryn Kozinski, MDiv

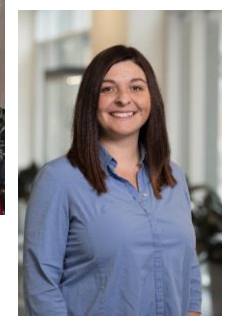
IU Center for Aging Research
- Annie Montz, MS
- Emily Burke, BA
- James Slaven, MS

Fairbanks Center for Medical Ethics, IU Health
- Robyn Axel-Adams, MDiv, BCC

Speakers

Alexia Torke

Beth Newton Watson



Emily Burke

Saneta Maiko

Workshop Schedule

- Introduction, Literature Review and the SCAI Framework—Alexia Torke
- Spiritual Care in the CFP--Beth Newton Watson
- Study Methods—Emily Burke
- The Chaplain's Experience—Saneta Maiko
- Study Results—Torke
- Discussion—Saneta Maiko

Spirituality

- Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.''
- Puchalski JPM 2014

Impact of religion on end of life care/preferences for patients

- Patients who endorse growing closer to God during illness want more aggressive care Van Ness Amer J Geriatr Psych 2002
- Patients with higher levels of religious practice are more likely to think DNR is immoral Sullivan Psychosomatics 2004
- Patients who rate religion as highly important want more aggressive care at EOL Balboni J Clin Oncol 2007
- Patient religious coping impacts aggressive care received at the end of life Phelps JAMA *2009;301(11):1140-1147*

Spiritual and Religious Coping

I know that without faith I couldn't have come this far . . . Faith is very important to me because of the simple fact that without faith I probably wouldn't be (here) right now, without hope and faith and trusting in the Lord.

- Branch, Torke Brown-Haithco JGIM 2006

Importance of Religion

- 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

Religious and Spiritual Support

- 88% of cancer patients considered religion to be at least somewhat important
- 47% reported their spiritual needs were minimally or not at all supported by their religious community
- 72% reported their spiritual needs were minimally or not at all supported by the medical system
  - Balboni et al J Clin Onc 2007

Support of Spiritual Needs

- Feeling support for spiritual needs
  - Cost of medical care
  - Preferences for end of life care
- Chaplain visits, including interventions specific to chaplain practice
  - Satisfaction with chaplain care
  - Overall satisfaction (HCAHPS and Picker patients surveys)

- Balboni T Cancer 2011, Balboni 2013, Flanelly 2009 Marin 2015, Sharma 2016

Few Chaplain Interventions

- Recent reviews identify a total of 7 interventions

Jankowski 2011, Pesut 2016,

- Effect of chaplain visits in COPD
  - Hospitalized patients with COPD
  - Received daily (unstructured) chaplain visits
  - Lower anxiety

Iler 2001

Chaplain Interventions

- Effect of pastoral care services on outcomes
  - Patients receiving CABG at Methodist
  - Structured intervention protocol
    - Five visits, each with a specific focus
  - Impact on positive and negative religious coping

» Bay J Rel Health 2008

Caregiver Outlook pilot study

- Caregivers of patients with advanced cancer or ALS
- Three chaplain-led sessions by telephone
  - Relationship review
  - Forgiveness
  - Legacy
- Results
  - Qualitative results showed value
  - No change in quantitative results
    - (anxiety, depression, spiritual well-being)
      - » Steinhauser PSC 2015

Surrogate Decision Making

- 40-47% of hospitalized adults rely on surrogates
  - Higher (over 50%) in the ICU
  - Higher at the end of life
- Surrogate decision making is different in key ways from patient decision making
  - Communication challenges
  - Decision making principles
  - Distress (grief, PTSD, anxiety and depression)

Religion and Surrogate Decision Making

- Over 50% believes that divine intervention could save a family member from a major trauma when physicians have determined care is futile
  - Zier Crit Care Med 2008
- R/S and goals of care conversations
  - R/S raised in 16.1% of conversations
  - Clinicians further explored beliefs in 8/40 cases
    - » Ernecoff JAMA IM 2015
- Themes for surrogates (qualitative research)
  - The value of life
  - Religious coping
  - Religious community
  - Faith

» Braun et al JGIM 2008; Elliot J Gerontol Nurs 2007; Boyd Crit Care Med 2010

Faith and Religion Interviews

- Religion plays a role in the hardest decisions (life and death)
- Many surrogates desire guidance and support from spiritual leaders and chaplains
- Surrogates both accept and reject aggressive life sustaining care on the basis of faith

» Geros-Willfond et al JRH 2015

Chaplain Support

Chaplains came by and prayed her with her at times….God's healing touch was instrumental in her getting better. And also, you don't only ask for prayer for the patient, but you ask for prayer for the family as well because it was a really hard time.

To what extent are your religious/spiritual needs being supported by the medical system (eg, doctors, nurses, chaplain)?

- N=234
- Completely supported 16%
- To a large extent 8%
- To a moderate extent 22%
- To a small extent 18%
- Not at all 37%

Pilot Study Aims

1. Develop a chaplain-delivered intervention to provide spiritual support to surrogate decision makers of seriously ill older adults.
2. Pilot test the intervention in a single-arm pilot study to assess feasibility and acceptability.

Intervention Development

- Interdisciplinary team met regularly over several months (chaplains, healthcare leaders, physician, research staff)
- Developed and reviewed the intervention
- Pilot tested with 16 participants (to date)
- Refined by feedback from the team

The Spiritual Care Assessment and Intervention (SCAI)

- Proactive contact
- Semi-structured assessment of spiritual strengths and spiritual distress
- Spiritual care interventions
- Documentation

Proactive Contact

- Assigned study chaplain contacts surrogate as soon as possible and completes initial visit within 48 hours of enrollment
  - In person or by phone
- Follow-up visits every 2-3 days or more frequently as needed
- Further follow-up at chaplain's discretion
- All participants could receive additional chaplain support as needed from the unit or on-call chaplain

Semi-structured assessment

- Balance of structure and openness
- Identified dimensions of spiritual experience

Pruyser	Spiritual Needs Model/Spiritual Distress Assessment Tool		Spiritual AIM Shields	FACT LaRocca-Pitts	7X7 model Fitchett	SH4DI Fisher	SCAI
	Dimension	Need					
	Meaning	Need for life balance	Meaning and Direction	Faith (includes meaning and purpose)	Belief and meaning	Personal Domain: Meaning Purpose and Values; self-awareness, self-esteem and identity	Meaning and Purpose
Providence							
Communion		Need for connection	Learn to love others (God)		Community	Communal domain	Relationships
Awareness of the Holy	Transcendence					Transcendental Domain	Transcendence and Peace
Repentance							
Sense of Vocation	Values	Need for values acknowledgment/need to maintain control			Vocation and obligation		
	Psycho-social Identity	Need to maintain identity	Self-worth and Belonging to Community				Self-worth and identity
					Experience and Emotions		
					Courage and Growth		
				Active in your faith community, support and presence	Rituals and Practice		
				Coping/comfort			
				Treatment plan			
					Authority and Guidance		
Grace or Faith Gratefulness							

Semi-structured assessment

- Balance of structure and openness
- Identified dimensions of spiritual experience
  - Meaning and purpose
  - Relationships
  - Transcendence and peace
  - Self worth and identity
- Developed questions for each dimension
  - Initial interview: Ask one question from each dimension
  - Follow-up interview: Ask one question from any dimension

Semi-structured Assessment

Dimension 1: ***Meaning and Purpose- Values, beliefs, understanding of life events, the actions of God, others, and self***

- What does it mean for you to be here?
- What helps you understand what is going on now?
- What is the most powerful or important thing in your life?
- What happens when you feel helpless?
- When life is hard, what do you depend on to keep you going?
- What are your sources of strength?
- How do your values and beliefs help you make decisions?
- Are you struggling with any decisions right now?

Dimension 2: ***Relationships- Connection to community, family, others, and God***

- Who is there for you at a time like this one? How are they important?
- How are you connected to others during this health crisis?
- Are you experiencing any changes in how you are connected to others?
- Do you have any religious, spiritual, or communal support?
- How important is your relationship with God/ higher power?
- Who are you able to rely on?
- How are you feeling connected to them?

Dimension 3: ***Transcendence and Peace- Experience of the divine, ability to be centered and aware, and practices and behaviors that increase or decrease transcendence and peace***

- Are you at peace?
- How do you experience peace?
- Is there anything you have faith in?
- Is there any moment when you can relax?
- Do you have any sense of a higher power or God?
- Can I pray for you? How shall I pray for you?

Dimension 4: ***Self-Worth- Sense of belonging, being loved, and capacity to be self-aware***

- What stresses are you experiencing?
- What is weighting on you right now?
- How do you feel about yourself right now?
- How are you taking care of yourself right now?
- When was the last time you got some sleep or had a meal?
- Are there times you feel like you have to choose someone else over yourself?

Spiritual Care Interventions

- Specific interventions (actions)
  - Developed by the interdisciplinary team
  - Review of the literature
- The content of each intervention
  - The spirituality dimension(s) addressed

Flannelly 2004, Handzo, 2008 (Massey 2015)

Interventions

- Prayer
- Reading the bible or other sacred text
- Faith affirmation
- Ritual or Sacrament
- Confession/amends
- Active Listening
- Non-anxious attending
- Emotional Support
- Explores behaviors that may be self defeating or harmful
- Naming behaviors that are beneficial or healthy
- Life review
- Crisis/Trauma Care
- Spiritual Counseling
- Bereavement Support
- Provision of Religious/Spiritual Resources
- Normalization
- Advance Care planning
- Referral to member(s) of interdisciplinary team
- Referral to other clergy/spiritual support
- Other

Outcome Measures

- Spiritual Well-being
  - FACIT-sp non-illness
- Religious Coping
  - Brief RCOPE
- Perceived spiritual support
  - Coping with Cancer
- Anxiety
  - GAD-7
- Depression
  - PHQ-9
- Posttraumatic stress
  - IES-R
- Communication Quality
  - Family Inpatient Communication Survey
- Decisional Conflict
  - Decision Conflict Scale
- Decision Regret
  - Decision Regret Scale

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Beth Newton Watson, MDiv, BCC

COLLABORATION AND SPIRITUAL CARE IN THE CHAPLAIN FAMILY PROJECT

The Framework

- From this chaplain's perspective, the development of the project took place with a series of theological reflection conversations, exploration of the elements of spiritual care/ pastoral experience, and a collaborative struggle to measure something akin to a work of art

The Framework

- No doubt the researchers thought something else was going on
- They worked gently with us to take something numinous and give it a form that could connect assessment, intervention and outcome consistently

Development of the Framework

- We chose our Four Dimensions after conversations about human concerns, what gives meaning to life, exploration of a chaplain's professional pastoral practice, and spiritual interventions guided by hope for healing

Professional Spiritual Assessment

- Four Dimensions were chosen for assessment. Chaplains were asked to recognize opportunities for conversation about Meaning and Purpose, Relationships of Connection, Transcendence and Peace, and Self-worth arising from belonging, being loved and capacity for self-awareness

Further thoughts: Chaplain Skills for Spiritual Assessment

- Essential skills:
- the ability to hear the surface meaning of words being spoken,
- to understand implications of particular words,
- to hear the emotions which filled the words
- to recognize theological implications of particular nuanced answers

Parallel Process in Spiritual Assessment

- They could assess those receiving their care, and hear the themes of the conversations, because they understood the importance of health in each of the dimensions—for themselves, as well as in those receiving their care.

Chaplains Ability to Assess

- Chaplains doing the assessment had demonstrated capacity for such reflection on a personal and professional level.

Connection between Theology and Pastoral Practice/ Interventions

- Careful listening to named issues
- Accurate empathy
- A kind of confrontation with acceptance
- Using oneself for resonance echoes that help us understand
- Recognizing where one's own issues arise
- Using what is good and gathering up their resources

Chaplains Ability to Intervene

- A kind of fearlessness is helpful
- Ability to lean in seize the moment at the same time

The Spiritual Connection between Interventions and Outcomes

- Chaplains believe in spiritual care
- They have received it
- They know its effectiveness
- They are able to hear and see critically
- They believe in the efficacy of their interventions
- They understand the process as love

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Emily Burke, BA, Research Specialist

STUDY METHODS

Methodology

- How did we choose patients?
- How did we enroll participants?
- How did we coordinate our effort between research and intervention?
- How did we collaborate with the ICU team- specifically the unit chaplain?

Building relationships and communication were at the foundation of our study!

Determining Eligibility: Inclusion Criteria

- 18+ years of age
- English speaking
- Relying on a legally authorized surrogate decision maker
  - First degree relative (spouse, child, parent, sibling)
  - Or documented legal POA-HC
- Less than 3 days in the ICU
- Able to enroll within 3 days of admission to the ICU

Where did we recruit?

- Two intensive care units
  - Cardiovascular
  - Medical
- High likelihood of meeting our inclusion criteria
- Coordination with the unit chaplain was essential to our success!
  - Through coordination with the unit chaplain we gained valuable information about the floors, the patients, and the inpatient team
  - Participants still received the standard of care, which could (and often did) include visits from the hospital chaplaincy service

Assessing the Inpatient Census

- Each day we reviewed the patient list for each unit in the EMR for newly admitted patients
- For patients meeting basic criteria (>18 years, <3 days in ICU), we then looked for keywords and other indicators of eligibility

Chart Search Keywords and Indicators

- Ventilated
- Sedated
- Intubated
- Unresponsive
- Coma
- Advanced stage dementia/Alzheimer disease
- Delirium
- Note implying an authorized decision maker is involved
- Other statements implying patient cannot make their own decisions

Who did we exclude?

- Patients who are imminently dying
- Patients expected to transfer out of the ICU within 24 hours
- Patients who were expected to regain decision making capacity within 24 hours (ex: someone who consented for self and was vented for surgery, but had an LAR present in case decisions needed to be made)
  - In these cases we would check back the next day, in case decisional capacity had not been reached
- Non-English speaking decision maker
- No decision maker available
- Unique circumstances:
  - APS
  - Prisoners
  - Families with care contracts for behavior

Enrollment Procedure: First Steps

- Prioritize eligible patients
  - Who is going "off list"?
  - Who has a readily available decision maker?
- Ensure that decision maker is legally authorized
  - First degree relative
  - Documented legal POA-HC or hospital HCR
- Identify decision maker contact information
  - EMR
  - Inpatient healthcare team: typically the unit chaplain

Making Initial Contact

- Great care and sensitivity to each families individual circumstances is always a consideration:
  - The first impression is essential
  - Make specific note of known variables such as their availability, circumstances surrounding the patient and family, cues provided in the call (do they seem rushed, tired, frustrated, etc.)
- RA makes initial contact in person or by phone
- Gauge whether it is a good time?
  - "May I speak with you for a moment?"
  - "If not, when would be a better time?"

Making Initial Contact

- Review the study information sheet (informed consent)
- Obtain consent from the decision maker for participation
- The baseline research interview is ideally administered at the time of consent
  - 20-30 minutes

Enrollment: Next Steps

- Notify the unit chaplain
  - Email deidentified info to the unit chaplain
  - Page if necessary
- Notify the study chaplain
  - Study chaplains rotated based on availability and number of “active” participants

Who are our study chaplains?

- We had a team of 3 chaplains who provided the CFP intervention to surrogates
  - 1 board certified chaplain
  - 2 board eligible chaplains
- Our team was selected based on their reputations for having strong listening skills, needs assessment, and the ability for useful theological reflection

Initial Intervention

- Must be conducted within 2 days of enrollment
- Preferred in person whenever possible
- Must bring pocket card or intervention guide (long form)
- Aims:
  - Address ALL Dimensions
  - Ask at least 2 questions from each dimension
- Schedule first follow-up for 1-2 days later

Follow-Up Interventions

- Minimum of 2 more encounters
  - Total encounter goal= 3
- Goal of every 2-3 days or daily should the participant need more support
- Can be done by phone or in person
- Address any dimensions that were not addressed in the first meeting
  - Ask at least one question from each dimension
- Assess participants spiritual needs and tailor intervention to them

Discharge and Death

- Discharged patient
  - From unit: Follow to next area of hospital
  - From hospital: Discontinue interventions (even if 3 encounter minimum is not met)
- Deceased patient
  - Attempt bereavement contact: within 48 hours of patient's death

Interim and Follow-Up Research Interviews

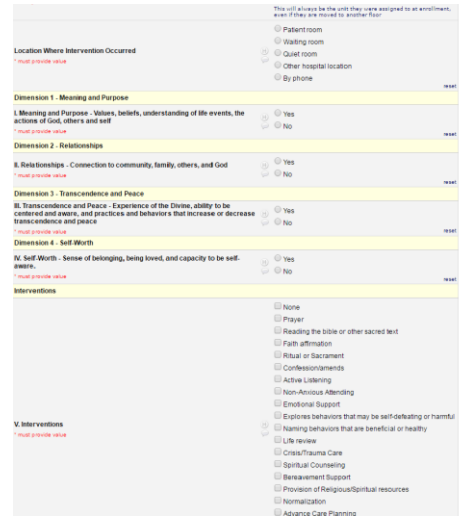
- Interim
  - 7-14 days after enrollment
  - If patient dies this interview is skipped
- Follow-up
  - 6-8 weeks after discharge
  - Special circumstances for patients who die during this time period
    - 1-7 days prior: always reschedule
    - 8-30 days prior: option to reschedule

Chaplain Documentation

- RedCap
- EMR (Cerner)
- Contact records (Excel)

RedCap CFP Database

- Designed for clarity
- Models our pocket card
- Clicking on each dimension will provide branching with the questions within that dimension
- Not pictured are items such as
  - MRN
  - Date
  - Start/Stop time
  - Chaplain Initials
  - Unit
  - Additional notes text box



So how did the research go? The Numbers:

- 25 enrolled
  - 14 from medical ICU
  - 11 from cardiovascular ICU
- Eligibility
  - 21 Vented and Unresponsive/Sedated
  - 4 AMS, Dementia, Altered Mental Status
- Interim
  - 15 completed interims
  - 5 Ineligible due to death (pt died before interview was completed during target window 7-14 days after enrollment)
  - 5 could not be reached
- Follow-up
  - 20 completed follow-up
  - 5 could not be reached
- 13/25 died
  - 8/25 during target hospitalization

Overall Impression

- The Good
  - People WANT to tell their story
  - Patient demographic typically made it easy to reach surrogates (e.g. often at bedside or a phone call away)
  - Relationship building hinged on communication and good study design
- The Bad
  - Data entry could be cumbersome for chaplains, using two systems
  - Timing of interventions sometimes challenging based on patient work-up, surrogate schedule, other commitments, weekends, and holidays

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Saneta Maiko, PhD

A CHAPLAIN RESEARCHER'S SCAI EXPERIENCE

Before I started using the SCAI model, four questions emerged:

- *Is this going to be different from the clinical method (action, reflection, application/integration) of chaplain training?*
- *How is this going to be different from a subjective assessment of our competencies?*
- *How am I going to remember measurable indicators that would support the care I provide.*
- *How will this be applicable in the real world?*

What was it like to use the SCAI framework?

- **After using the SCAI model I discovered the following:**
- *The clinical approach was enhanced.*
- *An excellent and easy to use (more structured) framework.*
- *A new outcome driven and clearly articulated way of doing clinical intervention and documentation.*

SCAI Model

- What are the downsides?

- *1. Chaplains are not trained to carry notes to an encounter. This could be initially be a challenge.*

- *2. Chaplains are not trained to do an intervention with hopes to assess outcomes. This approach may be misperceived by chaplaincy leaders as targeting outcomes and not professional care.*

- *3. A well thought out approach in using SCAI model may be misperceived as time consuming in care and documentation.*

SCAI model aligns with chaplaincy professional standards

- **Ten common standards of professional chaplaincy addressed in the SCI Model**

- **TPC1:** *Articulation of a theology of spiritual care that is integrated with a theory of pastoral practice*

- **TPC2:** *Incorporation of a working knowledge of psychological and sociological disciplines and religious beliefs and practices in the provision of pastoral care.*

- **TPC5:** *Articulation of a conceptual understanding of group dynamics and organizational behavior.*

- **IDC1:** *Functioning pastorally in a manner that respects the physical, emotional, and spiritual boundaries of others.*
- **IDC5:** *Communicating effectively orally and in writing.*

SCAI model aligns with chaplaincy professional standards

- **Ten common standards of professional chaplaincy addressed in the SCI Model**
- **PAS1:** *Establishing, deepening and ending pastoral relationships with sensitivity, openness, and respect.*
- **PAS6:** *Formulating and utilizing spiritual assessments in order to contribute to plans of care.*
- **PAS9:** *Facilitating theological reflection in the practice of pastoral care.*
- **PRO1:** *Promoting the integration of Pastoral / Spiritual Care into the life and service of the institution in which it resides.*
- **PRO5:** *Documenting one's contribution of care effectively in the appropriate records.*

Value of the SCAI model of spiritual care

- Contribution to current literature:
- **1.** *There is not any other semi-structured intervention model like SCAI we are aware of.*
- **2.** *SCAI model is easy to use and assess effect on care recipient.*
- **3.** *There is no spiritual care intervention model like SCAI that enhances current ways of chaplain training.*

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Alexia Torke, MD, MS

RESULTS

IU Geriatrics

Results

Demographics	Patients	Surrogates
Sex		
- Female	48%	84%
Race		
- African American/Black	32%	32%
- White	68%	64%
Hispanic	4%	4%
Religion		
- None	8%	0
- Protestant	80%	84%
- Catholic	8%	12%
Relationship to Patient		
- Spouse/Partner		44%
- Son/Daughter		24%
- Other		32%
Deaths		
- In hospital	32%	
- By 6-8 week follow-up	52%	

Chaplain Visits

- Initial Visit
  - All 25 surrogates
    - (one bereavement)
- Follow-up visits
  - 19 received three visits
  - Range 1-6
- Bereavement calls
  - 7 surrogates
- Visit location
  - Waiting room 10%
  - Phone 40%
  - Quiet room 33%
  - Patient room 14%
- Visit Duration
  - Initial 40 min (3-130)
  - F/U 30 (10-135)
  - Bereavement 23 (3-75)

Dimensions of R/S

	Meaning & Purpose	Relationships	Transcendence & Peace	Self-Worth
Initial Visit N=25	100%	96%	96%	96%
Follow-up visits	75%	73%	73%	79%
Bereavement visits	60%	91%	64%	50%

Top 5 Interventions, by Visit

Intervention	Percent
Active listening	87
Emotional support	81
Non-anxious attending	74
Prayer	58
Spiritual counseling	55

Outcomes of Spiritual Care

Outcome	Percent
I. Meaning and Purpose	
Reaches greater clarity about the meaning and purpose of life	38.8
Reaches decisions about medical care or other concerns that reflect personal values	26.3
Reaches a clear understanding of how values and beliefs help or hinder coping	32.5
Other	15.0
II. Relationships	
Reports a greater sense of community	45.0
Recognizes impact of his or her behavior on others	25.0
Expresses or intends to express remorse and/or forgiveness	11.3
Other	27.5
III. Transcendence and Peace	
Feels a connection to the divine	46.3
Increases practices that foster connection with the divine or a sense of inner peace	36.3
Expresses a greater sense of peace or acceptance	38.8
Other	6.3
IV. Self-worth	
Demonstrates awareness of need for self-care	51.3
Balances self-care with care and concern for others	36.3
Other	13.8

Chaplain Family Experience Questions (n=20)

	Strong Agree	Agree	Neither A/D	Disagree	Strongly Disagree
The chaplains supported me during (patient's) hospital stay?	65%	35%	0	0	0
I would recommend the chaplains to other families.	80%	20%	0	0	0
The chaplains contacted me too often.	0	0	5%	50%	40%
The chaplains took up too much of my time.	0	0	5%	55%	40%
The chaplains provided spiritual support to me.	65%	30%	5%	0	0
The chaplains provided emotional support to me.	65%	30%	5%	0	0

Surrogate Interviews

They prayed over me, they prayed over my sister. Um, talked about our religion. …And they was very supportive of me. … that says a lot. Knowing that you have people that is supporting you. Especially the chaplain. And we didn't have that experience 4 years ago with our mom. But we had, I had it so much with my sister and I really commend that. And I love that.

Surrogate Interviews

The chaplain met me in the hallway and stopped me from going in the room when they were trying to resuscitate (patient) …so I didn't walk in on that. I was appreciative of that. And then when my loud-mouth granddaughter came in and said I'm an atheist, I don't need the chaplain. I just told her I do. And he was, he just kind of looked at me …He wasn't frightened off. So things went well there.

Study Outcomes

	Enrollment	Follow-up	P value
I wish I had gotten more religious/spiritual support from the hospital staff.*			
SD	0	0	0.85
D	20	5	
N	16	0	
A	44	55	
SA	20	40	
Spiritual support from the medical system			
Not at all	4	5	0.24
Small extent	20	5	
Moderate extent	12	30	
Large extent	16	25	
Completely	32	35	
Refused/DK	16	0	
Spiritual Well-Being (FACIT-sp-NI)	35 (21-42)	36 (24-41)	0.13
Anxiety (GAD-7)	4 (0-16)	0.5 (0-12)	0.21

Next Steps

- Randomized Controlled Trial of the Chaplain Family intervention
- Broader piloting of the semi-structured intervention for acceptability to chaplains