

EMORY



Impact of Hospital-Based Chaplain Support on Decision-Making During Serious Illness in a Diverse Urban Palliative Care Population



Specific Aims

Using a mixed-methods approach, we specifically aim to:

1. Explore in depth chaplains' work-related daily activities and experiences in palliative care through diary-based methods.
2. Document the impact chaplains make on patients' and families' decision-making during serious illness with a specific focus on decisions to use hospice care.
3. Involve hospital-based chaplains as active participants in the research process and develop their research skills through a collaborative community-based participatory research (CBPR) approach

Roadmap

I. Project Development

II. Quantitative Data

III. Qualitative Data

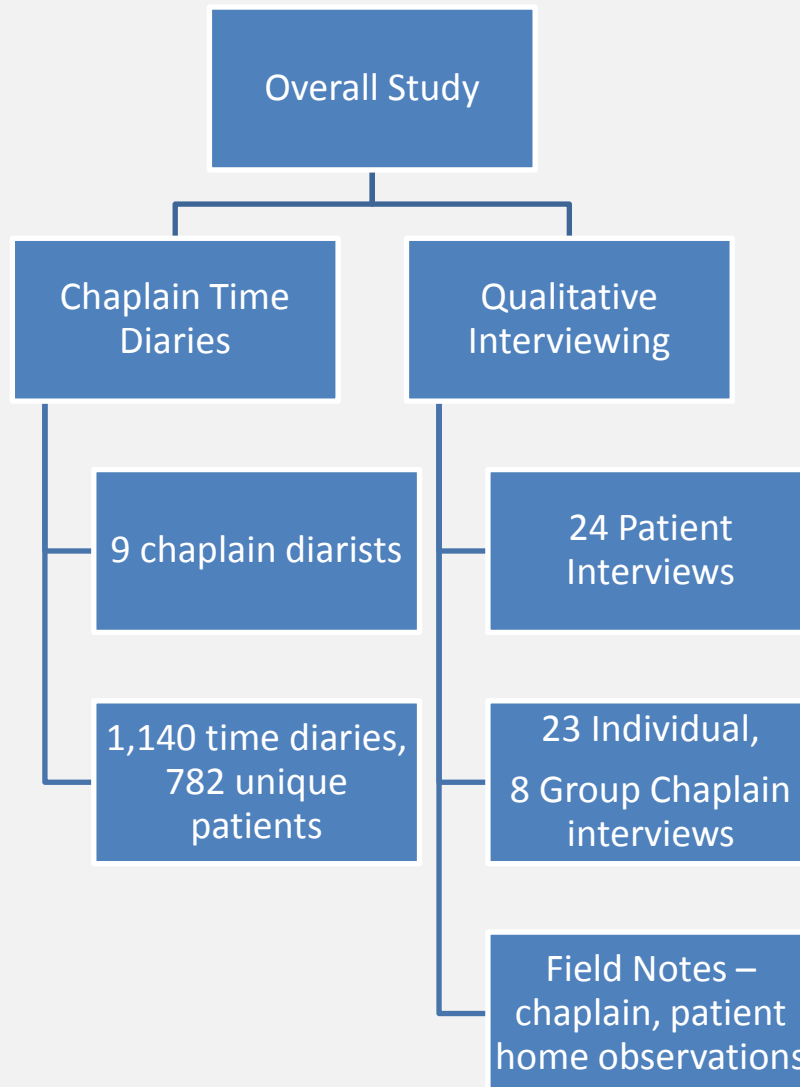
Study Setting

- Emory University Hospital Midtown (EUHM): 511-bed community-based full-service hospital located in metropolitan Atlanta.
 - Atlanta is the second largest majority African-American city in the U.S.
 - African-Americans are 70% of the total EUHM patient population
 - Similar end-of-life decision making patterns among whites, African Americans (SEE Table 1 below)
- Palliative care team: 2.0 FTE physicians, 2.0 FTE nurse practitioners, 1.0 FTE palliative care chaplain.
- Chaplain services are provided by 5.0 FTE staff chaplains (that vary in their ethnicity, faith community and gender), 1.0 FTE palliative care chaplain and 5.0 FTE chaplain residents.

Table 1: Palliative Care Consultation Service – Emory University Hospital Midtown

	Total Palliative Care Consults	% of Consults African-American	ICU	Non-Cancer/Cancer	Average Hospital LOS (d)	Time of admit to consult (d)	Time of consult to discharge (d)	% Hospice Discharge (all consults)
FY 11	743	73%	44%	58%/42%	15.9	6.8	7.8	37%
FY 12	1110	70%	58%	61%/39%	13.7	6.3	7.3	34%

Study Design



Interview candidates drawn from patients with Time Diaries who a.) consented and b.) were hospice-eligible

Project Schematic - Interviews

Patients seen by Chaplains
(~7,500 encounters; 5,000 patients)

Diary completed
(N = 1,140; 782 patients)

Consented
(N = 153 to study, 116 for F/U
interview)

Charts reviewed for
hospice eligibility
(N = 62)

Interviews
(N = 24)

Add'l interviews:
23 individual and
8 group chaplain
interviews

Required Resources - Diaries

Personnel:

9
chaplains



Time – Chaplains:

15
min/Diary
→ 285 hrs



Time – Study:

10
months

1,140
Diaries

Required Resources – Consents

Personnel:

4 RAs



Time:

3 hrs/day
5 days/wk
→ 600 hrs



782 patients
visited → 153
patient
consents
(20%)



Dollars:

\$12/hr →
\$7,200

116
consented
for
interviews



Required Resources – Chart Review and Outreach

Personnel:

3 MDs +
2 RAs



Time - Physicians:

15 min/chart x
116 charts →
29 hours



Time – RAs:

30
mins/outreach
x 62 eligible
→ 31 hours

62 Eligible
patients,
24
interviews

Required Resources – Interview Conduct, Transcription

Personnel:

3 RAs +
outside
transcription
agency



Time:

Conduct: 100
hours
Transcription
: 300 hours



50 hours of
interviews
→ ~900
pages



Dollars:

Conduct:
\$1,500
Transcription
: \$9,000

Roadmap

I. Project Development

II. Quantitative Data

III. Qualitative Data

Diary Study (Aim 1)

Explore in depth chaplains' work-related daily activities and experiences in palliative care through diary-based methods.

What happens during encounters of chaplains with seriously ill patients?

Who is there besides the patient?

How long do encounters last?

What are the topics of conversation?

What activities are performed?

How do chaplains feel about these encounters?

Do they perceive that the encounter has an impact?

How do they evaluate their own response?

Diary Study Background

- Religion and spirituality have historically been part of the founding of hospitals, and the role of the chaplain is part of this history (Cadge, 2012)
- Chaplains occupy an important social role in the institution of the hospital and are recognized by other health professionals as a care team member, particularly palliative care teams (Cadge, Calle, Dillinger, 2011)
- There are calls to professionalize and modernize this role (Proserpio, Piccinelli, Clerici, 2011)
- There are also calls for chaplains to identify best practices and the unique contributions of chaplains (Jankowski, Handzo, Flannelly, 2011)
- AND YET, there are few observational studies of chaplain activities, and these are based on medical records (thus limited to administrative data) (Galek, Flannelly, Jankowski, Handzo, 2011)

Diary Study Methods - Background

Extant diary methods	Ideas we used from these methods	Ways in which our diary approach differs
<p>Experience Sampling (Csikszentmihalyi and Larson, 1987)</p> <ul style="list-style-type: none"> • Participants are notified at random times during the day to record their activities at that moment. • Uses digital equipment for data input. • All types of experiences are included. 	<ul style="list-style-type: none"> • Near “in real time” recording of information. • Use of digital equipment for data input. • Chaplains report their emotional response to the event. 	<ul style="list-style-type: none"> • Chaplains know they will be collecting diary data. • Only professional work experiences are included.
<p>Day Reconstruction Method (Kahneman, Krueger, Schkade, Schwarz, Stone, 2004)</p> <ul style="list-style-type: none"> • Participants are notified randomly to record all events of the previous day. • Paper and pencil method. 	<ul style="list-style-type: none"> • Chaplains identify discrete events to record. • Chaplains report their emotional response to the event. • Initial draft of diary contained DRM descriptors (was revised). 	<ul style="list-style-type: none"> • Chaplains know they will be collecting diary data. • Same day recording. • Only professional work experiences are included. • Use of digital equipment for data input.

Diary Study Methods

Survey Development

- Draft diary survey approved by IRB.
- RED Cap Survey tool used to format survey for iPad and provide web-based data entry platform.
- Data collected “in real time” – shortly following each visit.
- Draft diary instrument fielded with 7 chaplains in training at a university hospital other than the study hospital.
- Study team (GG, ZB, EI) met with chaplains biweekly for three months to get feedback on survey.
- Community Advisory Board added interpretation and context.
- “I was one of the CPE resident chaplains who worked on the project with you, George, and Zach. I learned a lot about paying attention to patients, families, and myself while working on that project. I hope the data has been helpful for you and your team. I enjoyed being with you and witnessing your enthusiasm and energy for your work.” *BC, chaplain in pretest phase of project*

Diary Study Methods

Data Collection

- Data were collected at a large urban academic hospital with a diverse patient (and chaplain) population.
- Chaplains were issued iPads and given training on completing the survey.
- Chaplains were instructed to record encounters with “seriously ill patients” in most units of the hospital (not only palliative care).
- Diaries to be completed ASAP after each encounter.
- Chaplains could record more than one encounter with a patient/family.
- More than one chaplain could record an encounter with a patient.
- The unit of analysis is the encounter.

Diary Study Methods

Sample

- The chaplain is the study subject as well as the data collector for the diary phase of the project.
- Each chaplain provided informed consent.
- N = 9 chaplains
 - 4 staff chaplains, 5 chaplain residents
 - 5 females, 4 males
 - 3 white, 4 African American, 2 Hispanic

Diary Study Results

Characteristics

Number of encounters recorded from 1/2013 to 10/2013	1140 encounters
Number of unique patients having recorded chaplain encounters	782 patients
Mean encounter length (minutes)	22.6 minutes
Mean number of participants present	3.87 participants
Percent of chaplain encounters with:	
1 person	27.3 %
2 persons	29.5 %
3 or more persons	43.2 %
Percent of encounters in which _____ was present:	
Patient	75.6 %
Spouse	21.9 %
Daughter(s)	19.7 %
Son(s)	12.5 %
Other family	29.0 %
Friend/significant other	6.0 %

Diary Study Results

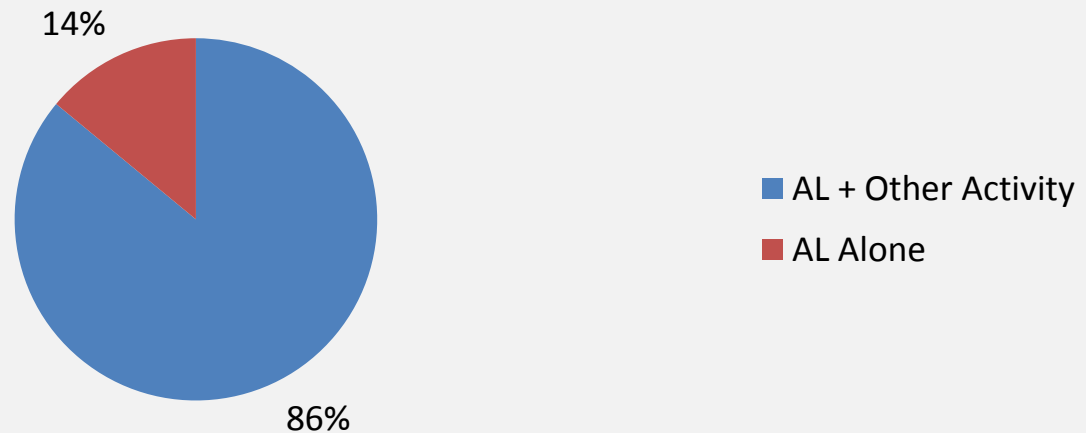
Characteristics, cont.

Chaplain characterization of encounter conversation as:	
Surface conversation	32.6 %
Extensive care response	67.4 %
Percent of encounters in which chaplain reports familiarity with:	
Patient's chart	69.3 %
Patient's diagnosis	82.5 %
Patient's prognosis	68.2 %
Percent of chaplain encounters with this patient that were _____:	
Initial encounters	72.7 %
Second encounters	14.0 %
Third or more encounters	13.4 %
Percent of encounters chaplain evaluated overall as:	
Excellent	57.0 %
Very good	22.3 %
Good	16.3 %
Fair or poor	4.4 %

Diary Data – Chaplain Activities

Chaplain Activity	Number of Diaries
All	1,140
Active Listening (Any)	1,049 (92.0%)
Active Listening (Alone)	147 (14.0%)
<i>Most popular companion activities...</i>	
AL + Spiritual Assessment	421 (40.1%)
AL + Prayer (Any)	279 (26.6%)
AL + Touch	225 (21.4%)
AL + Ministry of Presence	536 (51.0%)

Encounters that Included Active Listening (AL) Consisted of...



Diary Study Results

Chaplain Evaluation Scale

“Feeling Wheel” Descriptors

Positive Feelings	Negative Feelings
Confident	Confused
Stimulated	Irritated
Thankful	Sad
Optimistic	Tired
Content	Frustrated
Appreciated	Anxious

- Each adjective scored 0-4 (negative items reverse-coded), so could range from 0-48
- Cronbach’s $\alpha = .749$
- Mean score = 39.31, s.d. 8.78
- Chaplains most often felt “confident”
- Chaplains least often felt “irritated”
- Overall chaplains endorsed positive feelings much more often than negative feelings

Diary Study Results

Activities Cluster Analysis

Frequencies and Cluster Analysis for
Activities that Occurred during Chaplain Encounters (N = 1140)

Activities during Encounter	Percent of Encounters with this Activity	Results of Cluster Analysis
Religious practice (formal religious ritual such as performing sacrament, sacred text/scripture reading, anointing)	3.2	"Doing" activities characterize 603 (52.9% of encounters)
Prayer (praying during visit, request for later prayer)	28.3	
Touch (brief or extended physical contact)	21.5	
Advance Directive (requested, delivered, discussed, or completed)	11.1	
Other (provided food or personal items)	10.1	
Spiritual assessment	38.9	"Being" activities characterize 537 (47.1% of encounters)
Ministry of presence	48.1	
Active listening	92.1	

Diary Study Results

Conversation Topics Cluster Analysis

Frequencies and Cluster Analysis for
Topics of Conversation in Chaplain Encounters (N = 1140)

Topics of Conversation during Encounters	Percent of Encounters with this Topic of Conversation		Results of Cluster Analysis
	Patient topics	Family topics	
Work (function, employment)	3.9	-	"Practical matters" characterize 822 (72.1% of patient encounters)
Financial concerns	1.7	-	
Hospice care	6.1	14.6	
Advance directives	13.6	8.7	
Family concerns	17.8	19.6	
Life review	16.3	19.8	
Diagnosis	13.9	-	
Prognosis	13.2	-	
Medical care	15.7	20.0	
Emotions (expressed, openly displayed)	24.8	29.2	"Ultimate concerns" characterize 318 (27.9% of patient encounters)
Existential matters	25.2	30.0	
Spiritual/religious matters	29.6	28.8	
Physical symptoms	30.6	20.4	"Ultimate concerns" characterize 332 (29.1% of family encounters)

Diary Study Results

Time and Chaplain Evaluation Differences by Visit Activities and Topics of Conversation

T-tests for Mean Differences in Encounter Length and Chaplain Evaluations for Encounter Activities and Topics of Conversation with Patients and Family (N = 1140)

		Encounter minutes		Chaplain evaluation	
		Mean	p value for difference of means	Mean	p value for difference of means
Encounter activities	"Doing"	20.2	.000	36.2	.000
	"Being"	25.2		43.2	
Patient topics of conversation	"Practical matters"	21.2	.000	39.4	.531
	"Ultimate concerns"	26.1		39.8	
Family topics of conversation	"Practical matters"	18.7	.000	38.5	.000
	"Ultimate concerns"	31.9		42.0	

Diary Study Results

Adherence to National Consensus Project Guidelines for Palliative Care, Spiritual Care

NCP Criterion	Matching Diary Activity Category	% Completed... (N = 782 Patients)		
		At first visit	By second visit	After Second Visit
Interdisciplinary team includes trained spiritual professionals	N/A	-	-	-
Regular assessment of spiritual concerns documented: Life review	Talked with patient or family about life review, life completion	30.7%	33.5%	35.5%
Regular assessment of spiritual concerns documented: Life completion				
Standardized instrument used to assess religious background and preferences of patient/family	Activities performed: Spiritual assessment	48.8%	51.2%	51.7%
Facilitate contact with patient's own spiritual/religious communities	Activities performed: Facilitated contact with spiritual/religious communities, individuals, or clergy in patient's faith tradition	-	-	-
Referrals to specialized spiritual/existential practitioners when appropriate				
Encourage use of religious/spiritual symbols	Activities performed: Read scripture or sacred text OR provided sacred text	-	-	-
Ensure sensitive use of religious/spiritual symbols by professionals/institutions				
Periodic reevaluation of spiritual/existential interventions and preferences of patient/family	N/A	-	-	-
Regular assessment of spiritual concerns documented: Hopes and fears	Talked with patient or family about existential matters: hopes and fears, meaning and purpose	35.9%	40.3%	41.9%
Regular assessment of spiritual concerns documented: Meaning				
Regular assessment of spiritual concerns documented: Purpose				
Facilitate and advocate for religious/spiritual rituals, especially at time of death	Activities performed: Religious practice	2.8%	3.5%	4.1%
Regular assessment of spiritual concerns documented: Beliefs about afterlife	Talked with patient or family about spiritual/religious matters: testimony, beliefs, forgiveness	43.2%	47.3%	50.0%
Regular assessment of spiritual concerns documented: Guilt				
Regular assessment of spiritual concerns documented: Forgiveness				

Diary Study Conclusions

- Chaplains can collect data on their daily work and do not find it unduly burdensome.
- Chaplain encounters most often involved at least one other person besides the patient, and that person was most often the spouse or child.
- Chaplains evaluate their work very positively.
- The most frequent single activity in an encounter is “active listening”.
- Encounters can be characterized as “**doing**” encounters (religious practice, touch, prayer, or advance directives) or “**being**” encounters (active listening, spiritual assessment, ministry of presence).
- “**Being encounters**” are longer than “**doing encounters**”, and chaplains are more satisfied with them.

Diary Study Conclusions, cont.

- Conversation topics can be characterized as “**practical matters**” (work, family, finances, hospice care, diagnosis, prognosis, medical care) or “**ultimate concerns**” (expressed emotions, existential matters, spiritual/religious matters, physical symptoms)
- Conversations with **patients** are much more likely to be about “**practical matters**” than about “**ultimate concerns**”. “**Ultimate concerns**” encounters are somewhat longer, but chaplains are equally satisfied with both.
- Conversations with **family** are also much more likely to be about “**practical matters**” than about “**ultimate concerns**”. “**Ultimate concerns**” encounters with families are far longer, and chaplains are significantly more satisfied with them.

Diary Study Conclusions, cont.

- Chaplains perform a **wide variety of activities** in their encounters with patients, and engage in conversations across a broad range of topics, including, but not limited to spiritual matters.
- Chaplains care for the **whole person**, as evidenced by the length of time spent per encounter, the wide range of activities engaged in, and topics and seriousness of the conversations.
- A deeper understanding of the typical patterns of chaplain encounters with patients with serious illness and their families could enrich **chaplain practice and training**.

References

- Cadge, W. 2012. *Paging God: Religion in the Halls of Medicine*. Chicago: University of Chicago Press.
- Cadge, W., K. Calle, and J. Dillinger. 2011. What do chaplains contribute to large academic hospitals? The perspectives of pediatric physicians and chaplains. *Journal of Religion and Health* 50: 300-312.
- Csikszentmihalyi, M. and R. Larson. 1987. Validity and reliability of the Experience-Sampling Method. *Journal of Nervous and Mental Disease* 175:526
- Galek, K., K. Flannelly, K. Jankowski, G. Handzo. 2011. A methodological analysis of chaplaincy research: 2000-2009. *Journal of Health Care Chaplaincy* 17: 126-145.
- Jankowski, K., G. Handzo, and K. Flannelly. 2011. Testing the efficacy of chaplaincy care. *Journal of Health Care Chaplaincy* 17: 100-25.
- Kahnemann, D., A. Krueger, D. Schkade, N. Schwarz, and A. Stone. 2004. A survey method for characterizing daily life experience: The Day Reconstruction Method. *Science* 306: 1776-80.
- Proserpio, T., C. Piccinelli, C. Clerici. 2011. Pastoral care in hospitals: A literature review. *Tumori* 97: 666-71.
- Willcox, G. 2001. *Feelings: Converting negatives to positives*. Kearney, NE: Morris Publishing.

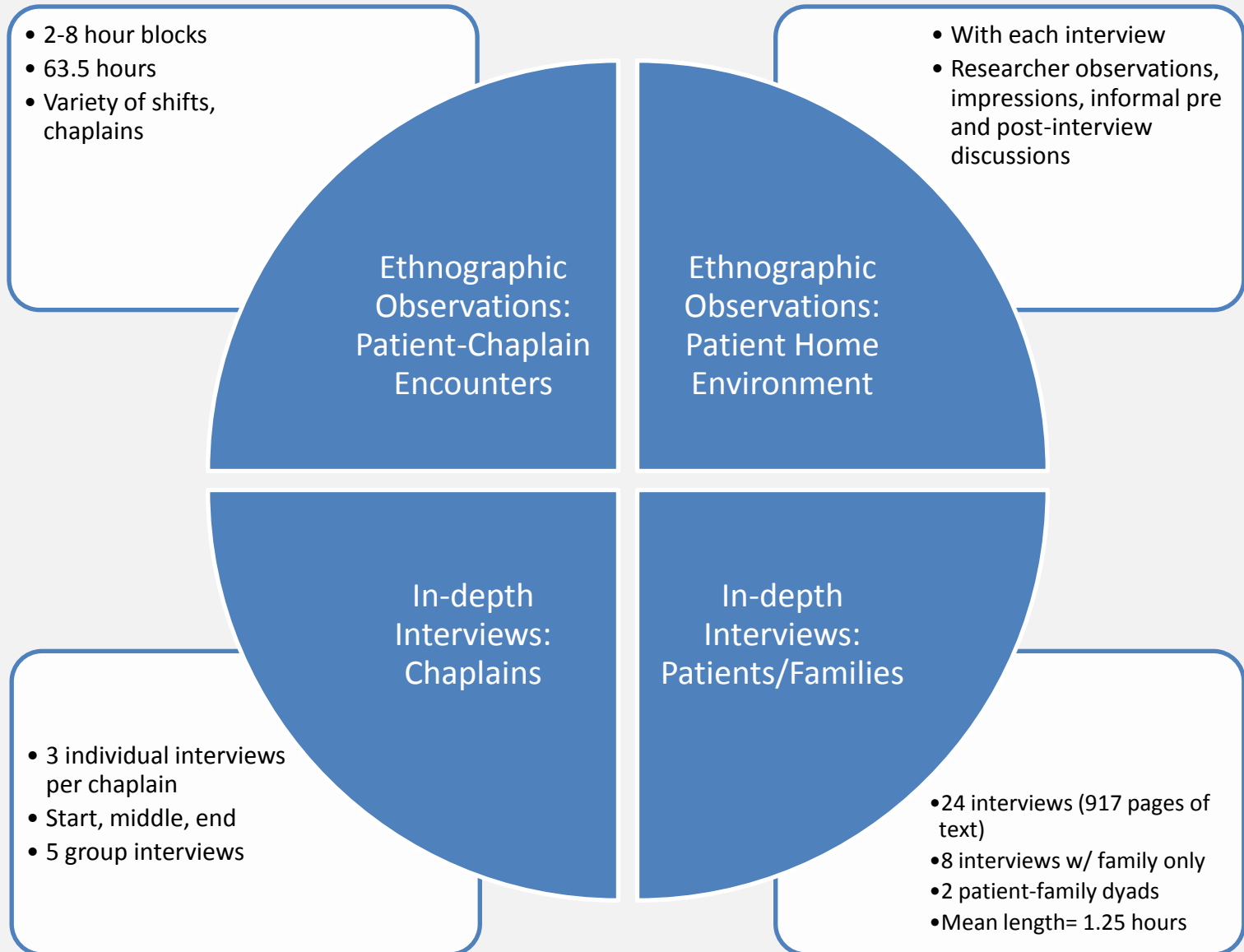
Roadmap

I. Project Development

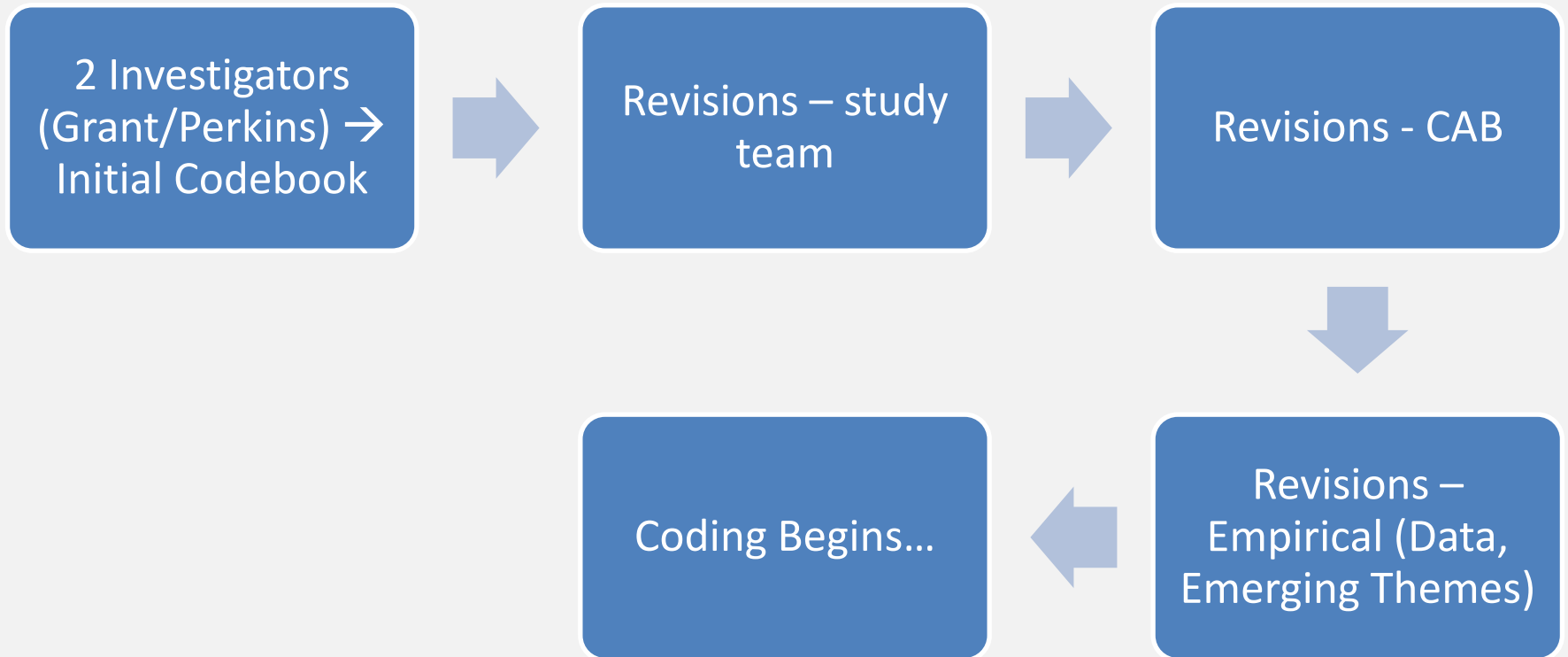
II. Quantitative Data

III. Qualitative Data

TYPES OF QUALITATIVE DATA

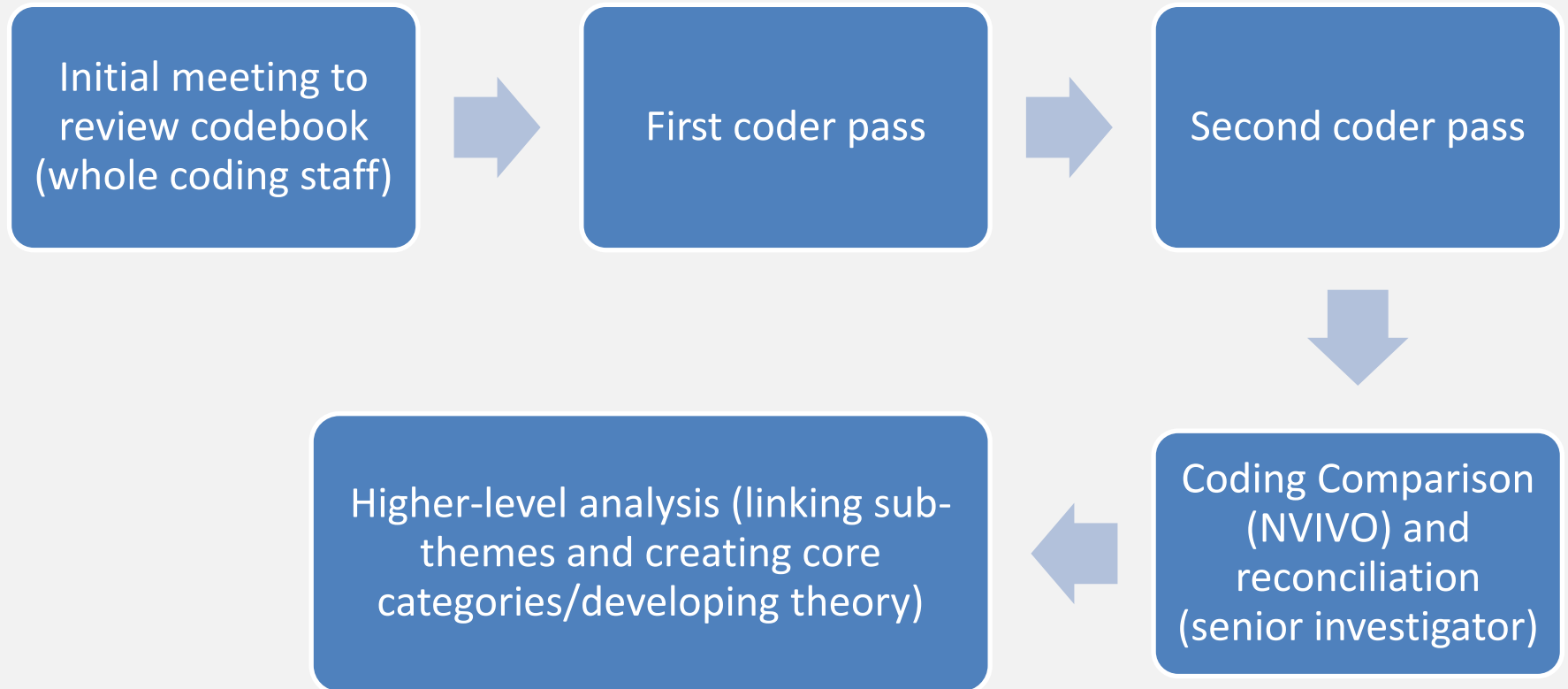


Codebook Development



Coding Process

- Coders: 3 RAs + 2 Investigators



Coding Screen in NVIVO

The screenshot displays the NVivo software interface. The top menu bar includes File, Home, Create, External Data, Analyze, Query, Explore, Layout, and View. The View menu is currently open, showing options like Navigation View, Find, Quick Coding, Detail View, Workspace, Dock All, Undock All, Close All, Close, Bookmarks, Layout, List View, Coding Stripes, Highlight, Annotations, See Also Links, Relationships, Node, Node Matrix, Framework Matrix, Classification, Report, Previous, Next, Reference, and Visualization.

The main window is titled "Lindsay2Templeton Chaplain Grant.nvp - NVivo". The "Sources" pane on the left shows a tree view with "Internals" expanded to "Chaplain Group Interviews", which includes "Family and Patient Interviews", "Home Observations (field n", "Individual Chaplain Intervie", and "Patient and Family Home O".

The central pane displays a table titled "Family and Patient Interviews" with the following data:

Name	Nodes	References	Created On	Created By	Modified On	Modified By
237_Interview	47	136	9/13/2013 11:02 AM	MMP	9/13/2013 11:02 AM	MMP
283_Interview	0	0	9/20/2013 1:04 PM	MMP	9/20/2013 1:04 PM	MMP
315_Interview	53	215	9/13/2013 11:03 AM	MMP	9/19/2013 9:12 PM	LFP
528_Interview	0	0	9/13/2013 11:01 AM	MMP	9/13/2013 11:01 AM	MMP
588_Interview	0	0	9/13/2013 11:02 AM	MMP	9/13/2013 11:02 AM	MMP

Below the table, the "315_Interview" source is selected, and the transcript text is displayed. The text includes a conversation between a researcher and a participant. A coding sidebar on the right shows a vertical bar for "315" with a purple segment, and a legend below it with categories: Coding Density, Patient, Religion, P-Faith, P-Health, and P-Personal Values.

The bottom status bar shows "MMP 5 Items Nodes: 53 References: 215 Read-Only Line: 97 Column: 0" and the system clock indicates "6:16 PM 9/27/2013".

Memoing

- Methodological Notes
- Observational Notes
- Theoretical Notes

Methodological Note

- George asked the chaplains how the time diaries may have impacted their self-awareness. We don't have a code for “self-awareness,” so I coded it as “chaplain health” and “chaplain emotions.”
- Here (in this text) they are discussing the impact of the ipad equipment (portability etc). Later, they (the chaplains) talk about the problem with having to carry around a physical object and whether they should carry it into patients rooms or not, where to stash it while visiting the patient etc.

Observational Note

My understanding is that E. is showing the chaplain interns the ropes. The interns are new- it's their second week here. Throughout the day, I see her help them troubleshoot various issues and field their questions. I have a sense that the residents and interns get along well and work well as a team, even though they serve different parts of the hospital.

Analytical Note

Two chaplains mention feeling "disoriented," because in the event of their colleague's death there is a role reversal. Chaplains are usually providing care, but in this case, they become care-seekers. I think this situation contributed to feeling disoriented and not being sure what to do in the days following his death.

Patient and Family Decision-Making (Aim 2)

Document the impact of chaplains on patients' and families' decision-making during serious illness with specific attention to the choice of hospice care.

How do patients or family members describe their experiences with chaplains?

How do race/ethnicity and other factors such as culture, gender, age, socioeconomic status, family structure, type of illness, or religious affiliation, shape participants' decision-making about advance care planning and hospice care specifically?

INTERVIEW DEMOGRAPHICS

For interviewees (patient and family)

In total, 24 participants were interviewed. This analysis includes 22 unique patient/ family units-- 13 patients and 9 family members. Two patient family dyads were interviewed; this analysis excludes the family member interviews from those dyads.

Age (Mean, SD)	60.0, 13.2
Gender (% Female)	63.6%
Race (% Black)	63.6%
Marital Status (% Married)	36.4%
Education (% graduated High School)	72.7%
Work Status	
Retired	27.3%
Unemployed on Disability	27.3%
Employed Full-Time	18.2%
Income (% < \$45,000/ yr)	66.7%* (30.0% < \$15,000/ yr)* *2 missing
Religion	
Baptist	31.8%
Non-Denominational Christian	13.6%
Other (Presbyterian, Methodist, African Methodist Episcopal, Holiness, Thelema, Swedenborgian.)	36.4%

Patient Health Characteristics

TABLE 2. Patient Health Status

	Total	Percent
Participants (excluding family dyads)	22	100
<i>Diagnosis Type</i>		
Cardiac	15	68.2
<i>Congestive Heart Failure</i>	11	50.0
<i>Cardiac Arrhythmia</i>	12	54.5
Pulmonary	6	27.3
<i>Chronic Pulmonary Disease</i>	3	13.6
<i>Pulmonary Circulation Disorder</i>	3	13.6
Renal	10	45.5
Cancer	7	31.8
Neurological	5	22.7
Mental Disorder	9	40.9

Factors Associated with Use

- Past experience with hospice
- Counseling / education from the palliative care team

Counseling /Education from the Palliative Care Team

“That was the biggest education that I got that ‘hospice’ means care and comfort as opposed to, you’re gonna die soon. I always thought that hospice [meant] this person’s gonna die soon as opposed to it’s making [patients] as comfortable as possible during their last few days. So that was one my largest educations that I’ve had this year.”

60 year-old African American Family Member

Factors Associated with Non-Use

- Misperceptions or negative perceptions regarding hospice
- No knowledge about hospice
- Lack of knowledge/misperceptions regarding the seriousness of one's illness
- Does not think one's condition qualifies for hospice (e.g., belief that death will come much later than six months)
- Fear is an additional barrier

Misperceptions or Negative Perceptions Regarding Hospice

“I wouldn’t want that (hospice). I’ve read and heard too many stories about those places that are mean to people like that a lot of times. Not all cases but a lot of cases where, you know, you’re old and you can’t do for yourself or whoever the care giver is, they’re getting paid and they’re getting your check or whatever, and they treat you mean.”

74 year-old African American male patient

No Knowledge of Hospice

“What’s that? I do not know what you mean by ‘hospice.’”

60 year-old African American male patient

Does Not Think One's Condition Qualifies for Hospice

- “She kept talking about, ‘I don’t want no hospice because I’m going to be here longer than 6 months!’”

51-year old African American family member

- At the time of the interview, he understood that he had relatively few months to live, and he was receiving nursing care from a relative several times a week. According to the patient, the physician had not discussed hospice eligibility, and he was under the impression that he didn’t need it yet.

Excerpt from Field Notes

Lack of Knowledge/ Misperceptions Regarding the Seriousness of One's Illness

“I think it was good that they (the chaplain and palliative care team) came down and they shared who they were, what they stood for, but, like I said, I don't think that was my need right then.”

60 year-old African American male patient

Fear is an Additional Barrier

- J. introduces himself as the chaplain and says that he is just checking on everyone in the ED to see if anyone needs anything. Outside the room, J. tells me that some patients and families get scared when they hear the word “chaplain” because they think it means bad news is being delivered. He sensed that was the case in this situation, so we didn’t stay long.

Observation from Field Notes

- “[The discussions with the palliative care team] are kind of frightening me a little bit about the [need for] palliative care.”

51 year-old African American male patient

Key Findings Regarding Chaplains' Role

- **Chaplain's Role in Decisions to Use Hospice**
 - Counsel /educate as a member of the palliative care team (e.g., at patient's bedside, in family meetings).
 - Relieve spiritual distress, ease guilt, and comfort patients and family members in their decision.
 - Meeting patients and family members where they are at the time.

Role as a Member of the Palliative Care Team

The chaplain seemed to quietly insert himself into the care process and work around other [palliative care] team members. He used a variety of different counseling techniques, depending on the specific needs and personality of the patient/family member (e.g., listening, providing prayer, humor, and patient advocate). He was thoughtful about non-aggressively approaching patients and “feeling things out” as to whether or not they wanted spiritual support (like a prayer).

Observation from Field Notes

Relieve Spiritual Distress, Ease Guilt, and Comfort

“We had to make decisions to put [my mother] in hospice care. I was dealing with depression really bad. By listening and being there. The things [the chaplain] said to me, I felt better about my decisions. I believe it was something only the chaplain could offer.”

51 year-old African American family member

Relieve Spiritual Distress, Ease Guilt, and Comfort

“ It wasn’t proselytizing. It was just really supportive. [The chaplain] didn’t really talk a lot. He didn’t talk about religion at all. He just listened. He actually listened more than he talked. I was under a lot of stress. I can’t remember exactly what we spoke about it. It was just very comforting. Just in the moment, I remember being very comforted.”

40 year-old white family member

Meeting Patients and Family Members Where They Are

The patient looks in bad shape. He appears to be sleeping or sedated and there is a bandage across his forehead. His eyes are slightly open but all I can see are whites. J. asks the wife how she is doing and if she needs any support. He acknowledges that [her situation] is difficult. There is a short silence. It seems like J. is doing the silent probing technique, to give her space and time to speak about her feelings, without pressuring her.

Observation from Field Notes

Conclusions and Implications (Aim 2)

- Findings illuminate the crucial role chaplains play in the care of seriously ill patients and their family members.
- Key barriers to end-of-life planning include participants' low health literacy and misperceptions regarding hospice and palliative care.
- Results point to the need for interventions to mitigate the effects of low health literacy in certain at-risk palliative care populations.

Chaplaincy Research (Aim 3)

- Major study conducted with chaplains as subjects and researchers
- 22 chaplains engaged in design, execution and analysis of the study
- Data resulting from mixed-method to generate multiple publications
- Success of study culminates in the formation of a strong interdisciplinary research team with current submission to PCORI and the goal of an NIH RO1

Chaplain Reflection

“I guess I would say one of the most satisfying thing about this job is being able to spend time with patients and family members as they’re going through some of life’s most difficult transitions. Both in the going from being well to being sick as well as transitioning from life to death. Providing people with space to hear their feelings and emotions that these situations can kick up as patients, as family members, as caregivers is a very powerful and sacred time in peoples’ lives. It’s a pleasure for me to bear witness to that.”

Acknowledgements

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& all of our chaplain-researchers!