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 |
|---------------------------------|-----------------|--------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| FY 11  | 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

Overall Study

Chaplain Time Diaries
- 9 chaplain diarists
- 1,140 time diaries, 782 unique patients

Qualitative Interviewing
- 24 Patient Interviews
- 23 Individual, 8 Group Chaplain interviews

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

Field Notes – chaplain, patient home observations
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

Total: 1,140 Diaries
Required Resources – Consents

Personnel:

- 4 RAs

Time:

- 3 hrs/day 5 days/wk → 600 hrs

Dollars:

- $12/hr → $7,200

782 patients visited → 153 patient consents (20%)

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

<table>
<thead>
<tr>
<th>Extant diary methods</th>
<th>Ideas we used from these methods</th>
<th>Ways in which our diary approach differs</th>
</tr>
</thead>
</table>
| **Experience Sampling** (Csikszentmihalyi and Larson, 1987) | • Near “in real time” recording of information.  
• Use of digital equipment for data input.  
• Chaplains report their emotional response to the event. | • Chaplains know they will be collecting diary data.  
• Only professional work experiences are included. |
| • 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. | | |
| **Day Reconstruction Method** (Kahneman, Krueger, Schkade, Schwarz, Stone, 2004) | • Chaplains identify discrete events to record.  
• Chaplains report their emotional response to the event.  
• Initial draft of diary contained DRM descriptors (was revised). | • Chaplains know they will be collecting diary data.  
• Same day recording.  
• Only professional work experiences are included.  
• Use of digital equipment for data input. |
| • Participants are notified randomly to record all events of the previous day.  
• Paper and pencil method. | | |
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

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of encounters recorded from 1/2013 to 10/2013</td>
<td>1140 encounters</td>
</tr>
<tr>
<td>Number of unique patients having recorded chaplain encounters</td>
<td>782 patients</td>
</tr>
<tr>
<td>Mean encounter length (minutes)</td>
<td>22.6 minutes</td>
</tr>
<tr>
<td>Mean number of participants present</td>
<td>3.87 participants</td>
</tr>
<tr>
<td>Percent of chaplain encounters with:</td>
<td></td>
</tr>
<tr>
<td>1 person</td>
<td>27.3 %</td>
</tr>
<tr>
<td>2 persons</td>
<td>29.5 %</td>
</tr>
<tr>
<td>3 or more persons</td>
<td>43.2 %</td>
</tr>
<tr>
<td>Percent of encounters in which ____ was present:</td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>75.6 %</td>
</tr>
<tr>
<td>Spouse</td>
<td>21.9 %</td>
</tr>
<tr>
<td>Daughter(s)</td>
<td>19.7 %</td>
</tr>
<tr>
<td>Son(s)</td>
<td>12.5 %</td>
</tr>
<tr>
<td>Other family</td>
<td>29.0 %</td>
</tr>
<tr>
<td>Friend/significant other</td>
<td>6.0 %</td>
</tr>
</tbody>
</table>
## Diary Study Results

Characteristics, cont.

<table>
<thead>
<tr>
<th>Chaplain characterization of encounter conversation as:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Surface conversation</td>
<td>32.6%</td>
</tr>
<tr>
<td>Extensive care response</td>
<td>67.4%</td>
</tr>
</tbody>
</table>

### 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

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

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

- 86% AL + Other Activity
- 14% AL Alone
Diary Study Results
Chaplain Evaluation Scale

“Feeling Wheel” Descriptors

<table>
<thead>
<tr>
<th>Positive Feelings</th>
<th>Negative Feelings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confident</td>
<td>Confused</td>
</tr>
<tr>
<td>Stimulated</td>
<td>Irritated</td>
</tr>
<tr>
<td>Thankful</td>
<td>Sad</td>
</tr>
<tr>
<td>Optimistic</td>
<td>Tired</td>
</tr>
<tr>
<td>Content</td>
<td>Frustrated</td>
</tr>
<tr>
<td>Appreciated</td>
<td>Anxious</td>
</tr>
</tbody>
</table>

• 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)

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

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

<table>
<thead>
<tr>
<th>Topics of Conversation during Encounters</th>
<th>Percent of Encounters with this Topic of Conversation</th>
<th>Results of Cluster Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient topics</td>
<td>Family topics</td>
</tr>
<tr>
<td>Work (function, employment)</td>
<td>3.9</td>
<td>-</td>
</tr>
<tr>
<td>Financial concerns</td>
<td>1.7</td>
<td>-</td>
</tr>
<tr>
<td>Hospice care</td>
<td>6.1</td>
<td>14.6</td>
</tr>
<tr>
<td>Advance directives</td>
<td>13.6</td>
<td>8.7</td>
</tr>
<tr>
<td>Family concerns</td>
<td>17.8</td>
<td>19.6</td>
</tr>
<tr>
<td>Life review</td>
<td>16.3</td>
<td>19.8</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>13.9</td>
<td>-</td>
</tr>
<tr>
<td>Prognosis</td>
<td>13.2</td>
<td>-</td>
</tr>
<tr>
<td>Medical care</td>
<td>15.7</td>
<td>20.0</td>
</tr>
<tr>
<td>Emotions (expressed, openly displayed)</td>
<td>24.8</td>
<td>29.2</td>
</tr>
<tr>
<td>Existential matters</td>
<td>25.2</td>
<td>30.0</td>
</tr>
<tr>
<td>Spiritual/religious matters</td>
<td>29.6</td>
<td>28.8</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>30.6</td>
<td>20.4</td>
</tr>
</tbody>
</table>
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)

<table>
<thead>
<tr>
<th>Encounter activities</th>
<th>Encounter minutes</th>
<th>Chaplain evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>p value for difference of means</td>
</tr>
<tr>
<td>&quot;Doing&quot;</td>
<td>20.2</td>
<td>.000</td>
</tr>
<tr>
<td>&quot;Being&quot;</td>
<td>25.2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient topics of conversation</th>
<th>Encounter minutes</th>
<th>Chaplain evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Practical matters&quot;</td>
<td>21.2</td>
<td>.000</td>
</tr>
<tr>
<td>&quot;Ultimate concerns&quot;</td>
<td>26.1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family topics of conversation</th>
<th>Encounter minutes</th>
<th>Chaplain evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Practical matters&quot;</td>
<td>18.7</td>
<td>.000</td>
</tr>
<tr>
<td>&quot;Ultimate concerns&quot;</td>
<td>31.9</td>
<td></td>
</tr>
</tbody>
</table>
### Diary Study Results

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

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


Roadmap

I. Project Development

II. Quantitative Data

III. Qualitative Data
TYPES OF QUALITATIVE DATA

- 24 interviews (917 pages of text)
- 8 interviews w/ family only
- 2 patient-family dyads
- Mean length= 1.25 hours
- 3 individual interviews per chaplain
- Start, middle, end
- 5 group interviews
- 2-8 hour blocks
- 63.5 hours
- Variety of shifts, chaplains
- With each interview
- Researcher observations, impressions, informal pre and post-interview discussions
- 24 interviews (917 pages of text)
- 8 interviews w/ family only
- 2 patient-family dyads
- Mean length= 1.25 hours
- Ethnographic Observations: Patient-Chaplain Encounters
- Ethnographic Observations: Patient Home Environment
- In-depth Interviews: Chaplains
- In-depth Interviews: Patients/Families
Codebook Development

2 Investigators (Grant/Perkins) → Initial Codebook → Revisions – study team → Revisions - CAB

Coding Begins... → Revisions – Empirical (Data, Emerging Themes)
Coding Process

- Coders: 3 RAs + 2 Investigators

  - Initial meeting to review codebook (whole coding staff)
  - First coder pass
  - Second coder pass
  - Higher-level analysis (linking sub-themes and creating core categories/developing theory)
  - Coding Comparison (NVIVO) and reconciliation (senior investigator)
Coding Screen in NVIVO

Researcher: You haven’t had to go back since the last time at Midtown?
Participant: Yeah.
Researcher: And the last time was... In April? When was it?
Participant: Um... Yeah, April. It must have been April.
Researcher: Oh! That’s good, great!
Participant: Yeah, so I haven’t been back since then.
Researcher: And you said you’ve been feeling better, so you haven’t had any breathing problems since then?
Participant: Right.
Researcher: And you’re taking your meds to keep your blood pressure stabilized and everything?
Participant: Yeah.
Researcher: Any other issues been going on?
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.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Mean, SD)</td>
<td>60.0, 13.2</td>
</tr>
<tr>
<td>Gender (% Female)</td>
<td>63.6%</td>
</tr>
<tr>
<td>Race (% Black)</td>
<td>63.6%</td>
</tr>
<tr>
<td>Marital Status (% Married)</td>
<td>36.4%</td>
</tr>
<tr>
<td>Education (% graduated High School)</td>
<td>72.7%</td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>27.3%</td>
</tr>
<tr>
<td>Unemployed on Disability</td>
<td>27.3%</td>
</tr>
<tr>
<td>Employed Full-Time</td>
<td>18.2%</td>
</tr>
<tr>
<td>Income (% &lt; $45,000/ yr)</td>
<td>66.7%* (30.0% &lt; $15,000/ yr)*</td>
</tr>
<tr>
<td>Religions</td>
<td></td>
</tr>
<tr>
<td>Baptist</td>
<td>31.8%</td>
</tr>
<tr>
<td>Non-Denominational Christian</td>
<td>13.6%</td>
</tr>
<tr>
<td>Other (Presbyterian, Methodist, African Methodist Episcopal, Holiness, Thelema, Swedenborgian.)</td>
<td>36.4%</td>
</tr>
</tbody>
</table>

*2 missing
Patient Health Characteristics

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

Study Team:

Tammie Quest, MD (PI)
George H. Grant, MDiv, PhD
Molly M. Perkins, PhD
Ellen L. Idler, PhD
Zachary O. Binney, MPH
Krisha A. Arvin, MDiv
John S. Schumacher, MDiv

Research Assistants
Lindsey P. Prizer, PhD student
Joanna M. Jungerman, MPH
Nancy Tourk, MPH Candidate
Broderick McBride, MDiv Candidate
Meaghan Hart, MPH Candidate

Community Advisory Board:

Eddie L. Bright (Minister)
Robert Brown (Chaplain)
Gary Batchelor (Chaplain)
Reggie Avant (Chaplain)
Mark LaRocca-Pitts (Chaplain)
Wayne Ingle (Patient-Family Advisor)
Trypehnia Speed (Patient-Family Advisor)
Betsy Styles (Patient-Family Advisor)

& all of our chaplain-researchers!