The Role of the Chaplain in Medical Decision Making

HCCN CARING FOR THE HUMAN SPIRIT
ANNUAL CONFERENCE MARCH 2017

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Disclosures

None of the presenters or research partners have anything to disclose.
Presentation Objectives

1. Discuss the concept of shared decision-making as well as the current state of research in this area.

2. Draw upon preliminary research results to identify how chaplains perceive themselves to contribute to medical decision-making with patients and families facing serious or life-limiting illness.

3. Explore models for shared decision-making that account for the unique role of chaplains in promoting patient-centered care.

Background Literature

Shared Decision Making (SDM)

“A collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences.”

Charles, 1977

SDM: Models

Charles, 1999
SDM: Barriers

- Disease focus of medicine
- Evidence based vs. value based Family-Physician Communication
- Physician Communication Style
- Traditional DPR? Increasingly fragmented and specialized health care system
- Family denial and conflict

Azoulay, 2014; Bernstein, 2015; Reuben, 2012; Visser, 2014

SDM: Opportunities

Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005

Curtis, 2008; Davidson, 2005; Kon, 2016; Osborn, 2012; Peek, 2009; Sohi, 2015
THE BASICS OF THE STUDY

Aims

 To explore the extent to which chaplains are involved in medical decision making with adult patients and their families with a serious or life limiting illness.
 To improve understanding of how chaplains perceive their role in medical decision making.
 To understand how chaplains contribute to the process of medical decision making and what (if anything) prevents them from engaging.

Objective

 Our overall objective is to improve practice and enhance positive effects of chaplains’ care for patients by publishing case study examples illustrative of key themes.

Study Plan & Survey

Phase 1
- Online survey
- June 2016 – Oct 2016

Phase 2
- Interviews
- Nov 2016 – Feb 2017

Phase 3
- Case Studies
- March 2017 – Dec 2017

Analysis
- Jan 2017 – March 2017

- Analysis
- March – December 2017

Confidential

The Role of Chaplains in Medical Decision Making

Dear survey participant,

A group of chaplains and researchers based at Northwestern University are surveying chaplaincy roles in medical decision making with adult patients and their families with a serious or life limiting illness. We would like to gather information about how chaplains perceive their roles in medical decision making, how they contribute to the process of medical decision making, and what (if anything) prevents them from engaging. As we are interested in the experiences of chaplains in this population (i.e., you work with pediatric patients and their families only), we are not seeking your input at this time.

We value your opinion as an experienced chaplain and invite you to participate by responding to this survey. For the purpose of this study, our focus is on the medical decisions faced by adult patients and families with a serious or life limiting illness.

This survey should take between 10 and 15 minutes to complete.

Best wishes from,
The research team at Northwestern University

Title of Research Study: The Role of the Chaplain in Medical Decision Making
Investigator: Margaret Jeanne Wroza
Qualitative coding team, Inter-rater reliability and conflict resolution process

Meeting 1

Coding Team
- PI Chaplain and researcher
- 5 chaplains

Thematic content analysis of survey comments

Code Book Themes Examples

Meeting 2

Coders code comments individually

Coding Team
- PI Chaplain and researcher
- 5 chaplains

Thematic content analysis of survey comments
Survey Participants: Characteristics of Chaplains

Demographic Characteristics of Sample, N = 463

<table>
<thead>
<tr>
<th>Gender (n=462)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>237 (51.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>225 (48.7%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>404 (87.3%)</td>
</tr>
<tr>
<td>African American</td>
<td>26 (5.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>33 (7.1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion (n=453)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant</td>
<td>311 (67.2%)</td>
</tr>
<tr>
<td>Catholic</td>
<td>120 (25.9%)</td>
</tr>
<tr>
<td>Jewish</td>
<td>17 (3.7%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (1.1%)</td>
</tr>
</tbody>
</table>

*Asian, 13 (2.8%); Hispanic, 8 (1.7%); Other, 11 (2.4%)

*bIslam, 1 (.2%); Buddhist 1 (.2%); Spiritual/not religious. 1 (.2%); Ethical culture, 1 (.2%)
### Chaplain’s Background

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chaplain is Board certified (n = 460)</td>
<td>426</td>
<td>(92.4%)</td>
</tr>
<tr>
<td>Chaplain’s Certifying Organization (n=425)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>APC</td>
<td>319</td>
<td>(68.9%)</td>
</tr>
<tr>
<td>NACC</td>
<td>96</td>
<td>(20.7%)</td>
</tr>
<tr>
<td>NAJC</td>
<td>4</td>
<td>(.9%)</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>(1.3%)</td>
</tr>
<tr>
<td>Years of professional experience as a chaplain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 5</td>
<td>73</td>
<td>(15.8%)</td>
</tr>
<tr>
<td>6 to 10</td>
<td>103</td>
<td>(22.2%)</td>
</tr>
<tr>
<td>11 to 16</td>
<td>97</td>
<td>(21.0%)</td>
</tr>
<tr>
<td>16 to 20</td>
<td>74</td>
<td>(16.0%)</td>
</tr>
<tr>
<td>21 or more</td>
<td>116</td>
<td>(24.1%)</td>
</tr>
</tbody>
</table>

*Other: ACPE, 1; ACPE and APC 1; American Board of Homeland Security, 1; APC and NAVAC, 1; APC and SCA, 1; NAVAC, 1; 1 = .2%.

### Work Characteristics

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work setting (n = 422)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic medical center</td>
<td>102</td>
<td>(24.2%)</td>
</tr>
<tr>
<td>Community hospital</td>
<td>208</td>
<td>(49.3%)</td>
</tr>
<tr>
<td>VA or military hospital</td>
<td>11</td>
<td>(2.6%)</td>
</tr>
<tr>
<td>Specialty hospital (Oncology, rehabilitation, psychiatric)</td>
<td>12</td>
<td>(2.8%)</td>
</tr>
<tr>
<td>Inpatient or home hospice</td>
<td>20</td>
<td>(5.0%)</td>
</tr>
<tr>
<td>Other or combination</td>
<td>15</td>
<td>(16.1%)</td>
</tr>
<tr>
<td>Work at Religiously affiliated medical institution (n=460)</td>
<td>202</td>
<td>(43.6%)</td>
</tr>
<tr>
<td>Special Designations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care chaplain (n=458)</td>
<td>116</td>
<td>(25.1%)</td>
</tr>
<tr>
<td>ICU chaplain (n=453)</td>
<td>170</td>
<td>(36.7%)</td>
</tr>
<tr>
<td>Oncology chaplain (n = 454)</td>
<td>78</td>
<td>(16.8%)</td>
</tr>
</tbody>
</table>
Quantitative Analysis: Frequencies
Percentage of Clinical Time in DM

In a typical week, what percentage of your clinical time is spent supporting patients and families with serious or life-limiting illness in medical decision making?

- Frequently or Always: 10.20%
- Often: 14.00%
- About half the time: 21.00%
- Occasionally: 42.00%
- Never or Rarely: 12.70%
**Percentage of Time - Specific Areas of DM**

- **support**
- **communicate**
- **clarify**
- **advance directives**
- **educate**
- **mediate**

![Bar chart showing percentage of time spent on different areas of DM](chart.png)

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**Readiness to Support: Ease of Communication, Inclusion, Welcomed**

I find it easy to communicate (in person, by phone, or electronically) with members of the health care team to support patient and family medical decision making.

- **Agree/Strongly Agree:** 86%
- **Neither Agree nor Disagree:** 8%
- **Disagree/Strongly Disagree:** 6%

I am always included in health care team discussions about patient and family medical decision making.

- **Agree/Strongly Agree:** 40%
- **Neither Agree nor Disagree:** 19%
- **Disagree/Strongly Disagree:** 41%

The health care teams in which I work welcome my contributions to patient and family medical decision making.

- **Agree/Strongly Agree:** 84%
- **Neither Agree nor Disagree:** 11%
- **Disagree/Strongly Disagree:** 5%
**Readiness to Support: Preparedness & Time**

I am well prepared to assist patients and families in medical decision making  

**Agree/Strongly Agree:** 91%  
Neither Agree nor Disagree: 6%  
Disagree/Strongly Disagree: 2%

I have all the time I need to assist patients and families in medical decision making  

**Agree/Strongly Agree:** 58.5%  
Neither Agree nor Disagree: 17%  
Disagree/Strongly Disagree: 24%

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**Quantitative Analysis: Associations**
Religiously affiliated vs. Non-religiously Affiliated Institutions

There is NO difference between religiously affiliated hospitals and other hospitals for overall time spent in DM, inclusion or welcome.

Those who work in religiously affiliated hospitals more often endorse frequently or very frequently in clarifying factors impacting treatment options than those who do not work in religiously affiliated hospitals. (p<.05)

There is a trend for those who do not work in religiously affiliated hospitals to communicate values more frequently to the medical team. (p<.10)
Based on the Mann-Whitney U Test, designated Palliative Care Chaplains rank significantly higher than those who are not palliative care chaplains, $p<.002$ on inclusion in team discussion.
Included in Team Discussions
Chaplain Years of Experience

<table>
<thead>
<tr>
<th></th>
<th>Included</th>
<th>Not included</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 years or less</td>
<td>27%</td>
<td>73%</td>
</tr>
<tr>
<td>More than 5</td>
<td>42%</td>
<td>58%</td>
</tr>
</tbody>
</table>

*p*-value for Chi-square <.05

Inclusion in Team Discussions
Readiness Variables & Years of Experience

“*I am always included in health care team discussions about patient and medical decision making.*”

<table>
<thead>
<tr>
<th>Statement</th>
<th><em>p</em>-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>The health care teams in which I work welcome my contributions to patient and family decision making.</td>
<td>.546***</td>
</tr>
<tr>
<td>I find it easy to communicate (in person, by phone, or electronically) with members of the health care team I need to support patient and family medical decision making.</td>
<td>.398***</td>
</tr>
<tr>
<td>I am well-prepared to assist patients and families in medical decision making</td>
<td>.283***</td>
</tr>
<tr>
<td>I have all the time I need to assist patients and families in medical decision making.</td>
<td>.246***</td>
</tr>
<tr>
<td>Number of years as a professional chaplain.</td>
<td>.186***</td>
</tr>
</tbody>
</table>

***p<.001; all correlations are Spearman’s rho
### Chaplain Activities  
#### Team Response

<table>
<thead>
<tr>
<th>Correlations of Team Response and Chaplain’s Activities</th>
<th>Included in Team Discussions</th>
<th>Welcome my contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clarify factors for choice</td>
<td>.294***</td>
<td>.158**</td>
</tr>
<tr>
<td>Communicate family values to team</td>
<td>.292***</td>
<td>.155**</td>
</tr>
<tr>
<td>Educate about procedure</td>
<td>.261***</td>
<td>ns</td>
</tr>
<tr>
<td>Mediate family conflict</td>
<td>.230***</td>
<td>ns</td>
</tr>
<tr>
<td>Support patient and family</td>
<td>.223***</td>
<td>.096*</td>
</tr>
<tr>
<td>Facilitate advance directives</td>
<td>.176***</td>
<td>ns</td>
</tr>
</tbody>
</table>

* p<.05; ** p<.01; *** p<.001; There were no correlations with easy to communicate with team.

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### Advance Directives  
#### Chaplain Activities

<table>
<thead>
<tr>
<th>Facilitate Advance Care Planning &amp; Advance Directives</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clarify factors that impact decision making</td>
<td>.360**</td>
</tr>
<tr>
<td>Mediate conflict between patient and family or between family members</td>
<td>.414**</td>
</tr>
<tr>
<td>Communicate patient/family values to the health care team</td>
<td>.417**</td>
</tr>
<tr>
<td>Support patient and family in the emotional processing of decisions</td>
<td>.335**</td>
</tr>
<tr>
<td>Educate patient/family about procedures (CPR, DNR, etc)</td>
<td>.529**</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed)- Pearson Correlation**
QUALITATIVE ANALYSIS: TEXT ANALYSIS

➢ What, if anything, prevents you from being involved in the medical decision making process for patients and their families with a serious or life-limiting illness?

➢ As a chaplain, what do you feel you uniquely contribute to the medical decision making process for patients and their families with a serious or life-limiting illness?

Qualitative Findings: Text Analysis

Barriers to Chaplain Participation in DM

- Chaplain: 24%
- Patient/Family: 14%
- Systems: 11%
- Understanding/Value by medical team: 5%
- Communication & Timing of Referrals: 12%
- IDT Role Definition: 25%
- None: 14%

3/28/2017
Barriers to Chaplain Participation in DM
Communication & Timing of Referrals (25%)

- Not included: not invited, not consulted, no notification

  “I am not asked for input by the medical team.” Clinical staff does not always notify me when decisions are being made.”
  “Not knowing when family meeting or care conferences are taking place.”

- Late Referrals
  “In many cases, decisions are already made by the time I am part of the conversation.”
  “Too often the process happens late in illness and patients/families are overwhelmed.”
  “Often times the chaplain is not thought of until right before the event or after the fact.”

Barriers to Chaplain Participation in DM
Systems & Administration (24%)

- Limited time due to large census:
  “I am one chaplain covering three hospital facilities so cannot be physically present to assist.”
  “I am only one chaplain in a 300 bed hospital.”  “Chaplains cut from 11 to 4 with 750 beds.”

- On-call or crisis pages interrupt longer meetings:
  “I am called to another emergency when interdisciplinary meeting is being conducted.”
  “Due to cost-cutting and management expectations that only one chaplain will be on duty at a time, we are frequently called away to other emergencies and then have to triage or ‘shuttle’ between critical and emergent cases.”

- Coverage area/Not being integrated:
  “I cover so many different areas of the hospital that I do not always learn of medical decisions being made until after the fact. If I were embedded, for instance in the Medical Intensive Care Unit that I cover, I would be involved most of the time in such decisions because I would be there and be available.”
Barriers to Chaplain Participation in DM
Understanding/Value of Chaplain Role (14%)

- Spirituality absent from care and medical decisions
  “Practioners who strongly emphasize the medical evidence of the decision making process over the emotional and spiritual components are less likely to utilize chaplaincy services.”

- Health care team not recognize chaplain skill in this area – Physicians and Social workers
  “Health care professionals persist in either compartmentalizing the work that chaplains do, or may not be comfortable working closely with health care chaplains.”
  “Majority of medical staff still view chaplains as just ‘pastors’ who have no knowledge of medical decision making.”

- Narrowing of Chaplain Role to Prayer, Ritual, Religion
  “Team members who do not understand my role. They don’t call me soon enough. The belief that all I do is pray once the person is dead.”
  “Oncologist believes I need not be involved unless the patient is religious or specifically ask for a chaplain.”

Qualitative Findings: Text Analysis
What Do Chaplains Uniquely Contribute?

- Spiritual Dimension & Authority
- Religious, Ethical and Cultural Frameworks
- Patient Story & Values
- Emotions
- Family Meditation
- Approach/Process
- Liaison/Communicator
“I am able to speak to how God will honor their decision making.”

“I believe a spiritual connection is important in medical decision making and often that takes the form of prayer.”

“The role of the chaplain carries with it an aura of spirituality that makes the discussion less threatening to some people.”

SPIRITUALITY: SPACE, AUTHORITY, CONCERNS
Integration of Prayer in decision making, attention to spiritual distress, holding sacred space, blessing the decisions

“I was able to provide the ‘official’ teaching (of the church) to the family, and they were then able to peacefully, and in good conscience allow nature to take its course and not prolong the patient’s dying.”

“We are well trained in advance care planning and well educated and prepared to listen to patients and families and participate in these challenging discussions.”

“Religious, Ethical and Cultural Frameworks & Teachings
Clarification and integration of specific religious beliefs and teachings, cultural competence and respect for diverse views, integration of ethical frameworks, advance care planning/advance directives

“If there are spiritual or cultural barriers to the communication and understanding, I can be a bridge to a successful solution.”
“Chaplains take a broader views of the lives and identity of patients and families, so we bring a robust narrative competence into the process that invites people to more fully articulate their values and wishes.”

“An ability to speak to patients and families in a way that takes into account the whole person, not just the illness or disease process.”

“Connecting the decision making to the consistent threads of meaning making throughout their lives.”

**Patient Story: Goals, Values, Wishes**

Narrative competence, whole person/patient-centered care, attention to values, wishes and goals, quality of life focus

“Chaplains take a broader views of the lives and identity of patients and families, so we bring a robust narrative competence into the process that invites people to more fully articulate their values and wishes.”

“An ability to speak to patients and families in a way that takes into account the whole person, not just the illness or disease process.”

“Connecting the decision making to the consistent threads of meaning making throughout their lives.”

**Attention to Emotions & the Emotional Burden of DM**

Calming, empathetic presence so decisions can be made; process emotions of guilt, anger, fear that impact decision making; support for weight of dm
“We ask the questions – what is the loving thing to do in this situation for the patient? Not what they want, but what the patient wants.”

“I some instances I become a reconciler of family members to each other, especially in one case where one family member was accusing another of wanting to ‘commit murder’ in allowing their loved one to be taken off the ventilator.”

Family: Roles, Dynamics, & Conflict
Mediate between family members or between patient and family; attention to relationship/family dynamics that impact decisions; focus family on what patient would want

Approach/Process
Chaplains have the time; Ability to listen, hear what is beneath the surface; Create safe space/build trust; Skill in questioning, opening up difficult conversation; Pace of decision making.

Patients and families need someone with ‘unlimited’ time to deeply listen to them. Doctors and nurses are focusing on providing specific care, which they believe is congruent with the family’s wishes. However, very rarely do they ask, “is that what you want? Or “what are your goals for your health and your life?”

“Help them step away from the frenetic, the pressure, the pressing need for a decision, help slow down the process so that a family can be present to themselves and their spiritual home, so they can make decisions that honor the participation of whoever needs to contribute.”
Liaison/Communicator

Bridge between patient/family and medical team; Speak both languages so can translate; Empower all to speak up, ask right questions; Advocate to the medical team so patient and family wishes are heard and respected.

SHARED DECISION MAKING: A NEW MODEL?

- Values
- Wishes
- Emotions
- Relationships
- Culture
- Religious Beliefs
- Spirituality

Patient & Family

Ethics

Palliative Care

Social Work

Nurse

Physician(s)

Medical Expertise

Chaplain

Shared Decision Making
The Role of the Chaplain in Medical Decision Making

- Ask questions
- Elicit patient story
- Support emotions
- Interpret medical language
- Build trust with team

- Create safe space
- Slow down process
- Mediate family conflict
- Clarify factors
- Integrate religious teachings
- Ask hard questions
- Pray

- Translate values & religious world
- Clarify options & prognosis
- Advocate for patient/family
- Liaison between teams

- Acknowledge different perspectives
- Empathy for difficulty of decision making
- Negotiate timing

- Validate courage
- Bless decision
- Lift up patient as a person

Challenge for our Profession

- Education about Chaplain Role in DM
  - Chaplain Training
  - Administrators
  - Members of the Health Care Team
  - Shared Decision Making – Inter-professional Shared Decision Making

- Staffing Ratios and Assignments
- Pro-active or Wait to be Invited to the Table?
Questions & Discussion

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References


Balboni, T, et al. “Provision of Spiritual Support to Patients with Advanced Cancer by Religious Communities and Associations with Medical Care at the End of Life” JAMA Internal Medicine 2013, 173(12):1109-1117.


Bernstsen, GKR et al. “How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care.” BMJ Open 2015;5


Clemm, S et al. The role of chaplains in end-of-life decision making: Results of a pilot survey. Palliative and Supportive Care 2015; 13: 45-51.


