Northwestern Medicine®
Buehler Center on Aging, Health & Society
Northwestern University Feinberg School of Medicine

The Role of the Chaplain in Medical Decision Making

HCCN CARING FOR THE HUMAN SPIRIT
ANNUAL CONFERENCE MARCH 2017

Rebecca Johnson, PhD & M. Jeanne Wirpsa, MA BCC

Research Partners

Joan Bieler, MS MA
Lara Boyken
Patricia Murphy, PhD BCC
Edward Penate, MDiv
Karen Pugliese, MA BCC
Emily Rosencrans, MDiv MFT

1

Disclosures

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

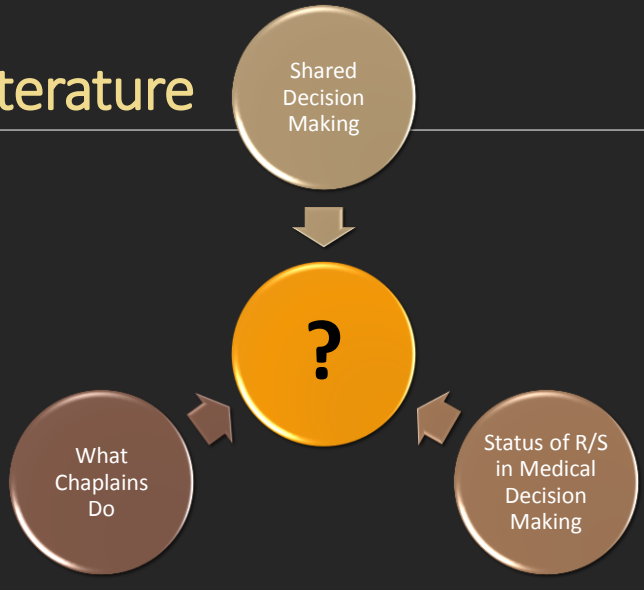
2

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

3

Background Literature



Carey, 2008; Clemm, 2015; Grant, 2015; Johnson, 2016, Massey 2015, Simmonds, 1994

Balboni, 2013 & 2015; Ernecoff, 2015

4

Shared Decision Making

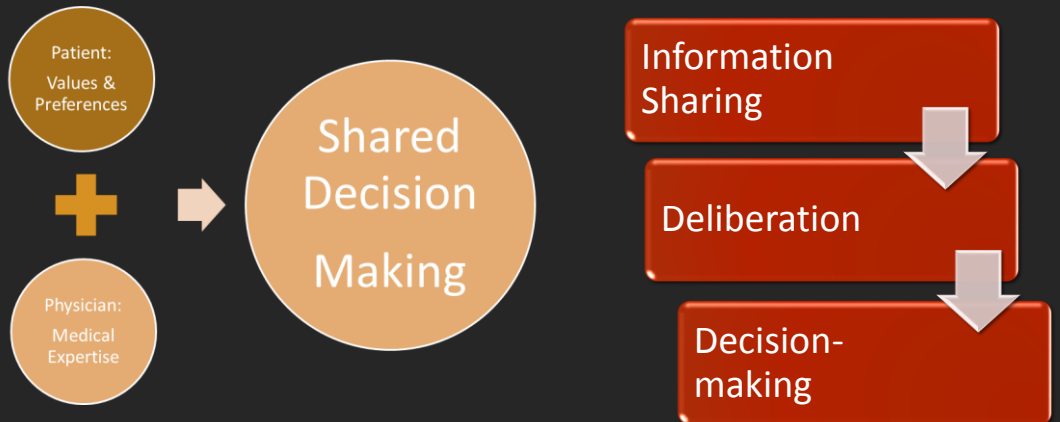
Shared Decision Making (SDM)

"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

5

SDM: Models



Charles, 1999

6

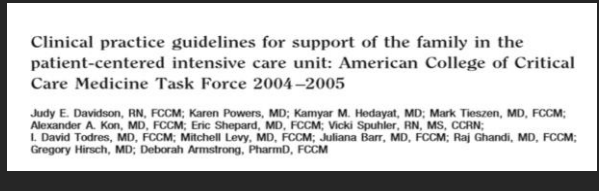
SDM: Barriers

- 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

7

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

Judy E. Davidson, RN, FCCM; Karen Powers, MD; Kamyar M. Hedayat, MD; Mark Tieszen, MD, FCCM; Alexander A. Kon, MD, FCCM; Eric Shepard, MD, FCCM; Vicki Spuhler, RN, MS, CCRN; I. David Todres, MD, FCCM; Mitchell Levy, MD, FCCM; Juliana Barr, MD, FCCM; Raj Ghandi, MD, FCCM; Gregory Hirsch, MD; Deborah Armstrong, PharmD, FCCM

ELSEVIER

Patient Education and Counseling

How is shared decision-making defined among African-Americans with diabetes?

Monica E. Peek, Michael T. Quinn, Rita Gorawara-Bhat, Angela Odoms-Young, Shannon C. Wilson, Marshall H. Chin

Curtis, 2008; Davidson, 2005; Kon, 2016; Osborn, 2012; Peek, 2009; Sohi, 2015

8

THE BASICS OF THE STUDY

Aims

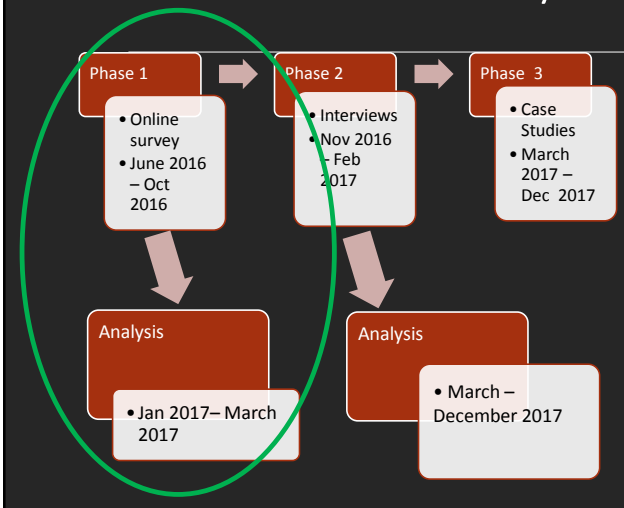
- To explore the extent to which chaplains are involved in medical decision making with adult patients and their families with a serious or life limiting illness.
- To improve understanding of how chaplains perceive their role in medical decision making.
- To understand how chaplains contribute to the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

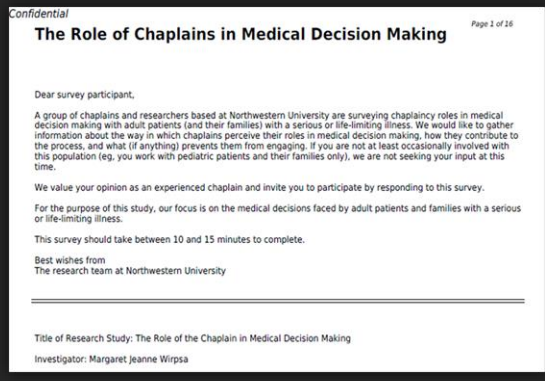
Objective

- 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.

9

Study Plan & Survey





Confidential

The Role of Chaplains in Medical Decision Making

Page 1 of 16

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 the way in which chaplains perceive their roles in medical decision making, how they contribute to the process, and what (if anything) prevents them from engaging. If you are not at least occasionally involved with this population (eg, 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.

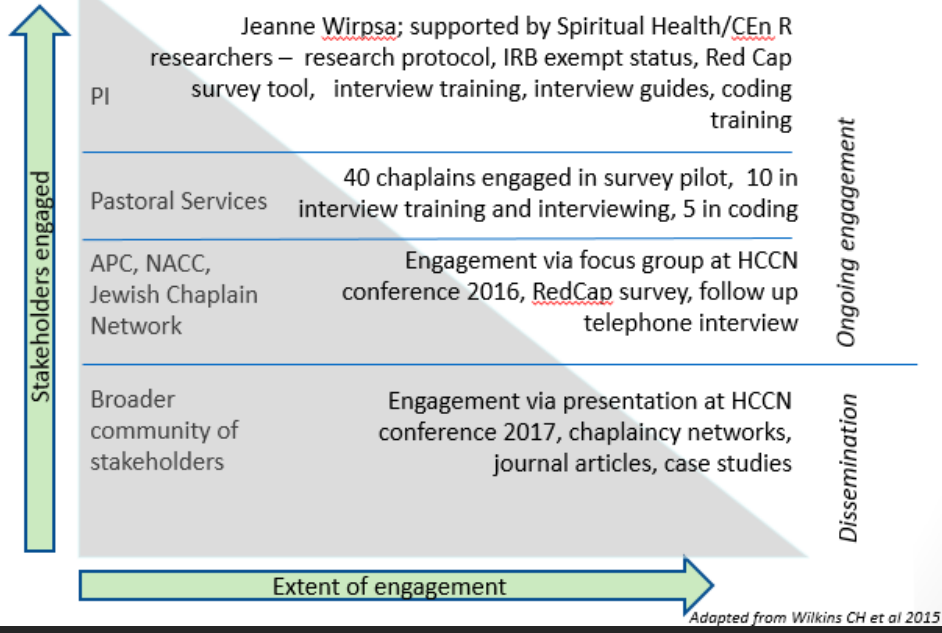
Best wishes from
The research team at Northwestern University

Title of Research Study: The Role of the Chaplain in Medical Decision Making

Investigator: Margaret Jeanne Wirpsa

10

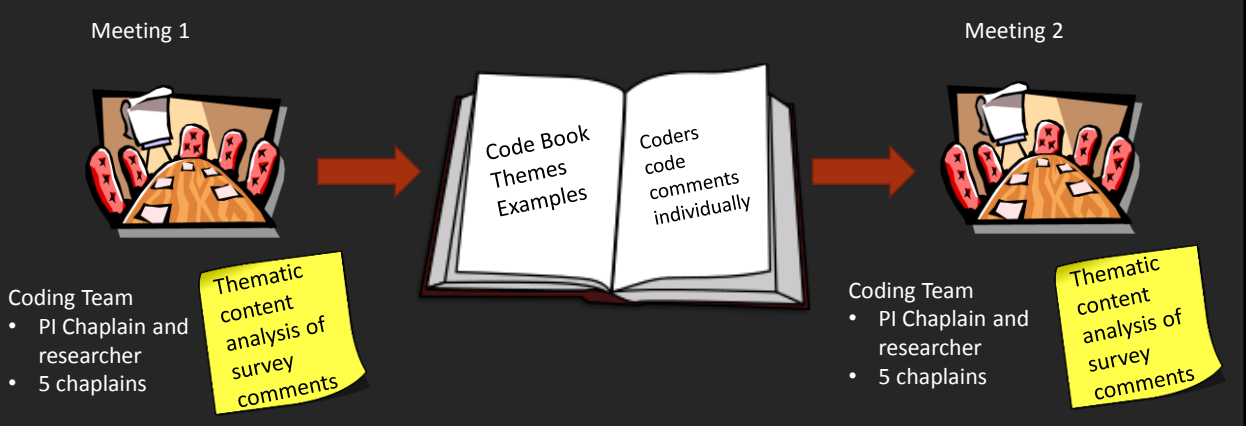
Research Engagement Continuum



Adapted from Wilkins CH et al 2015

11

Qualitative coding team, Inter-rater reliability and conflict resolution process



12

Survey Participants: Characteristics of Chaplains

13

Demographic Characteristics of Sample, N = 463	
Gender (n=462)	
Male	237 (51.3%)
Female	225 (48.7%)
Race	
Caucasian	404 (87.3%)
African American	26 (5.6%)
[a]Other	33 (7.1%)
Religion (n=453)	
Protestant	311 (67.2%)
Catholic	120 (25.9%)
Jewish	17 (3.7%)
[b]Other	5 (1.1%)
[a]Asian, 13 (2.8%); Hispanic, 8 (1.7%); Other, 11 (2.4%) [b]Islam, 1 (.2%); Buddhist 1 (.2%); Spiritual/not religious. 1 (.2%); Ethical culture, 1 (.2%)	

14

Chaplain's Background

Chaplain is Board certified (n = 460)	426 (92.4%)
Chaplain's Certifying Organization (n=425)	
APC	319 (68.9%)
NACC	96 (20.7%)
NAJC	4 (.9%)
[a]Other	6 (1.3%)
Years of professional experience as a chaplain	
1 to 5	73 (15.8%)
6 to 10	103 (22.2%)
11 to 16	97 (21.0%)
16 to 20	74 (16.0%)
21 or more	116 (24.1%)
[a]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%.	

15

Work Characteristics

Work setting (n = 422)	
Academic medical center	102 (24.2%)
Community hospital	208 (49.3%)
VA or military hospital	11 (2.6%)
Specialty hospital (Oncology, rehabilitation, psychiatric)	12 (2.8%
Inpatient or home hospice	20 (5.0%)
Other or combination	15 (16.1%)
Work at Religiously affiliated medical institution (n=460)	202 (43.6%)
Special Designations	
Palliative care chaplain (n=458)	116 (25.1%)
ICU chaplain (n=453)	170 (36.7%)
Oncology chaplain (n = 454)	78 (16.8%

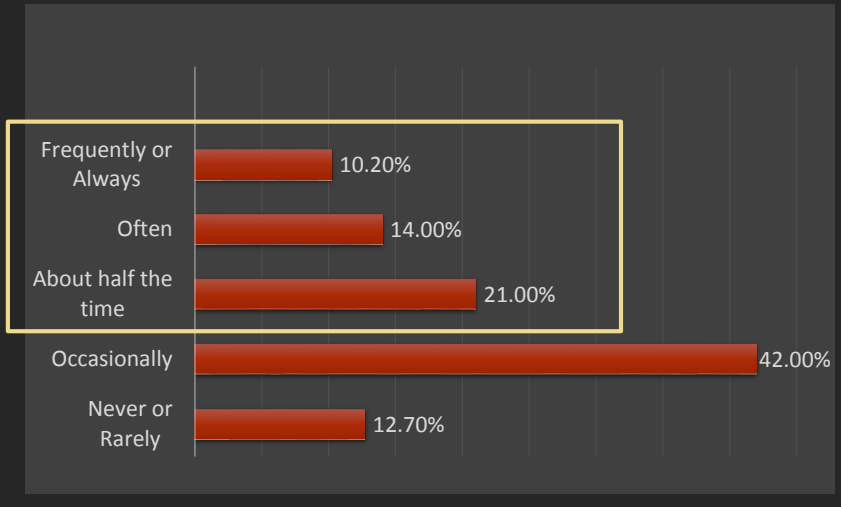
16

QUANTITATIVE ANALYSIS

17

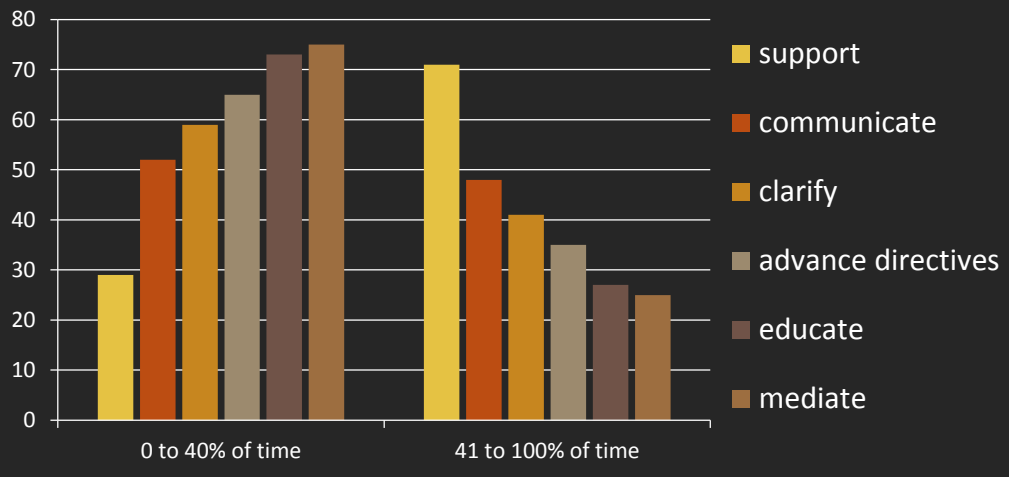
Quantitative Analysis: Frequencies
Percentage of Clinical Time in DM

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?



18

Percentage of Time - Specific Areas of DM



19

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%

20

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%

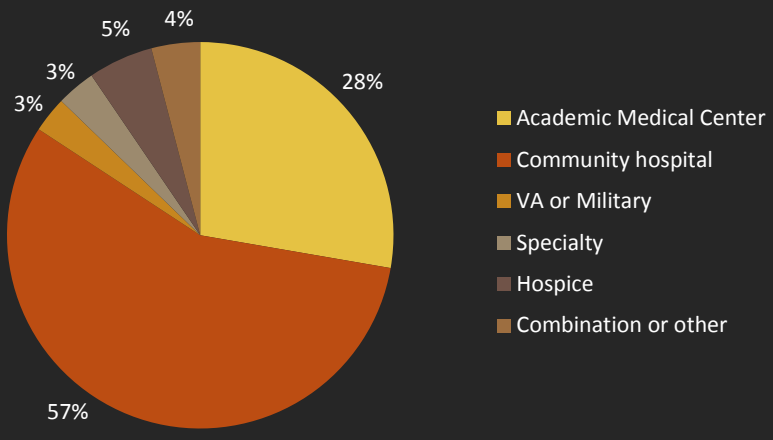
Disagree/Strongly Disagree: 24%

21

Quantitative Analysis: Associations

22

Frequency of DM & Inclusion in Team Discussions Work Setting



There was no difference between academic and community settings for inclusion in team discussions or overall time spent in decision making

23

Religiously affiliated vs. Non-religiously Affiliated Institutions

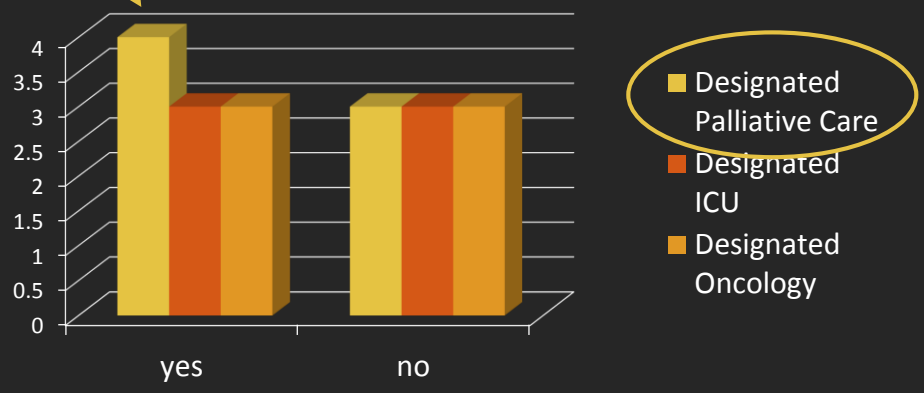
There is **NO** difference between religiously affiliated hospitals and other hospitals for overall time spent in DM, inclusion or welcome.

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. ($p<.10$)

24

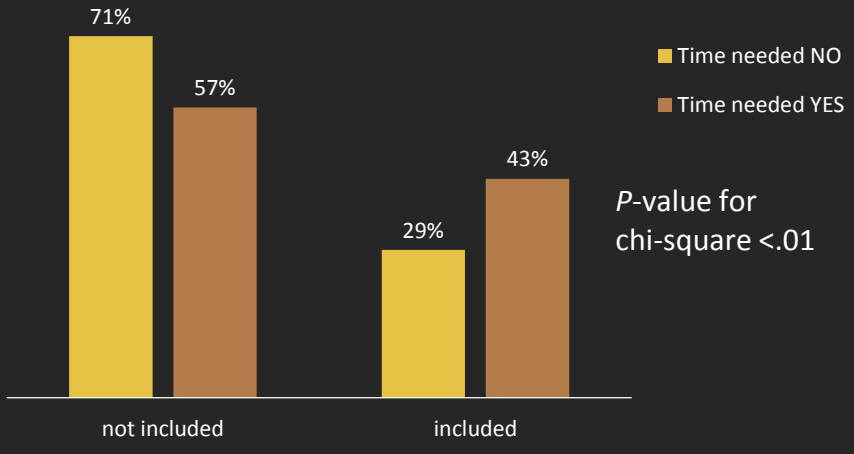
Inclusion in Team Discussions Designated Chaplain



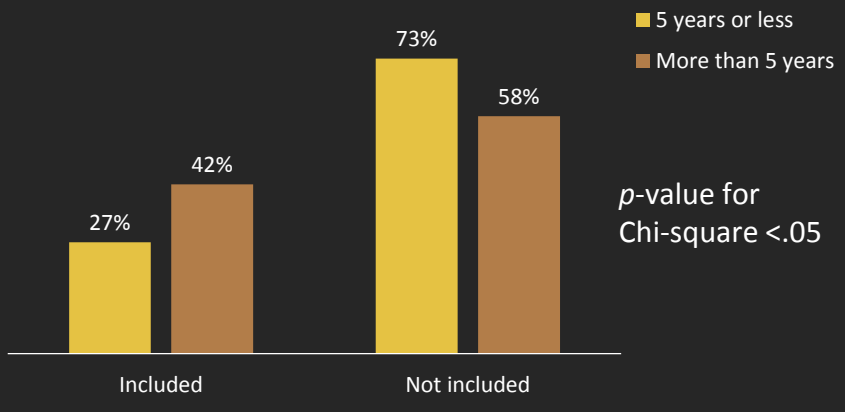
Based on the Mann-Whitney U Test, designated Palliative Care Chaplains rank significantly higher than those who are not palliative care chaplains, $p<.002$ on inclusion in team discussion.

25

Inclusion in Team Discussions Chaplain's Time



Included in Team Discussions Chaplain Years of Experience



p-value for Chi-square <.05

27

Inclusion in Team Discussions Readiness Variables & Years of Experience

"I am always included in health care team discussions about patient and medical decision making."	
The health care teams in which I work welcome my contributions to patient and family decision making.	**.546*** **
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.	**.398*** **
I am well-prepared to assist patients and families in medical decision making	.283***
I have all the time I need to assist patients and families in medical decision making.	.246***
Number of years as a professional chaplain.	.186***
****p*<.001; all correlations are Spearman's rho	

28

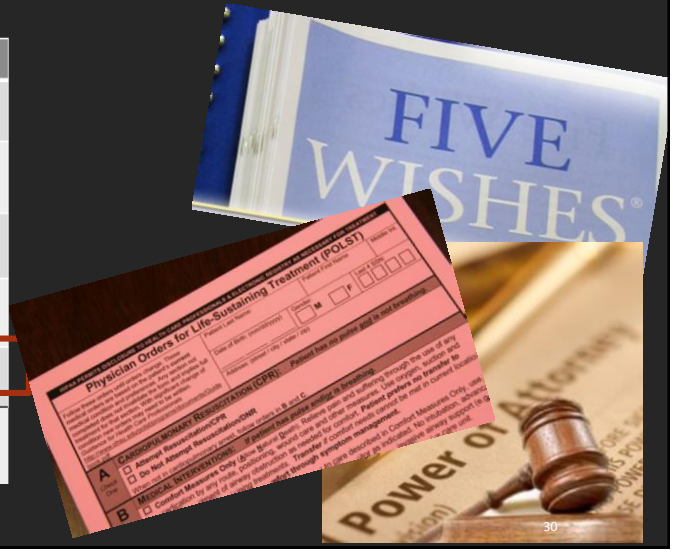
Chaplain Activities Team Response

Correlations of Team Response and Chaplain's Activities		
	Included in Team Discussions	Welcome my contribution
Clarify factors for choice	.294***	.158**
Communicate family values to team	.292***	.155**
Educate about procedure	.261***	ns
Mediate family conflict	.230***	ns
Support patient and family	.223***	.096*
Facilitate advance directives	.176***	ns
*p<.05; **p<.01; ***p<.001; There were no correlations with easy to communicate with team.		

29

Advance Directives Chaplain Activities

Facilitate Advance Care Planning & Advance Directives	
Clarify factors that impact decision making	.360**
Mediate conflict between patient and family or between family members	.414**
Communicate patient/family values to the health care team	.417**
Support patient and family in the emotional processing of decisions	.335**
Educate patient/family about procedures (CPR, DNR, etc)	.529**
**Correlation is significant at the 0.01 level (2-tailed)- Pearson Correlation	



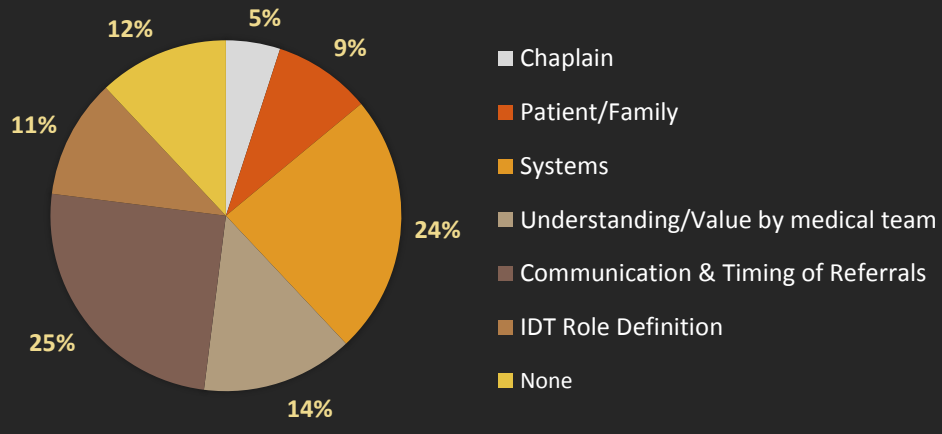
30

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?

31

Qualitative Findings: Text Analysis Barriers to Chaplain Participation in DM



32

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."

33

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."

34

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."

35

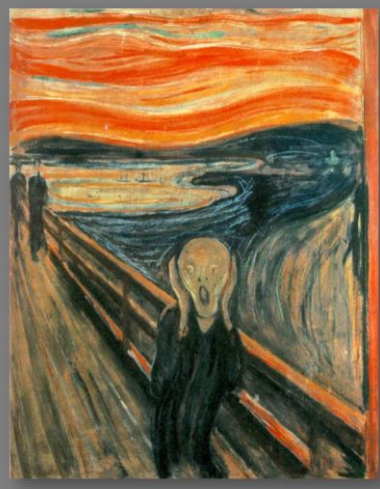
Qualitative Findings: Text Analysis
What Do Chaplains Uniquely Contribute?

- Spiritual Dimension & Authority
- Religious, Ethical and Cultural Frameworks
- Patient Story & Values
- Emotions
- Family Meditation
- Approach/Process
- Liaison/Communicator

36

"I am able to speak to how God will honor their decision making."

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



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

Spirituality: Space, Authority, Concerns

Integration of Prayer in decision making, attention to spiritual distress, holding sacred space, blessing the decisions

37

"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."

"If there are spiritual or cultural barriers to the communication and understanding, I can be a bridge to a successful solution."

"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

38

"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

39

"There is often a deeply ingrained belief that we must feed someone if we love them. If family think this true and don't understand the relative benefits and burdens, they may feel guilty forgoing a feeding tube."

"During the conversation, the chaplain can be a spiritual calming presence, supportive of patients and families as they struggle with these difficult decisions."

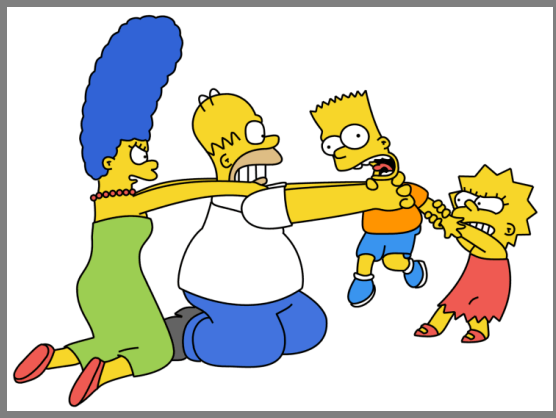
"I make judgments about the emotional and/or spiritual strength or readiness of the patient or family to hear and comprehend treatment options."

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

40

"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."

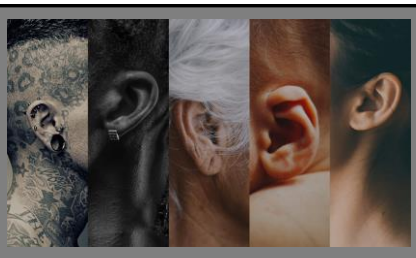


"I some instances I become a reconciler of family members to each other, especially in one case where one family member was accusing another of wanting to 'commit murder' in allowing their loved one to be taken off the ventilator."

Family: Roles, Dynamics, & Conflict

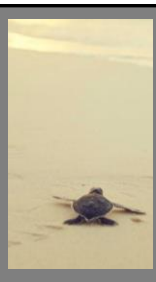
Mediate between family members or between patient and family; attention to relationship/family dynamics that impact decisions; focus family on what patient would want

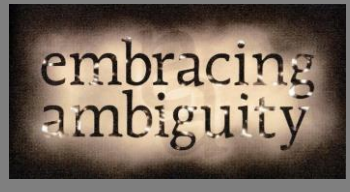
41



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."





Approach/Process

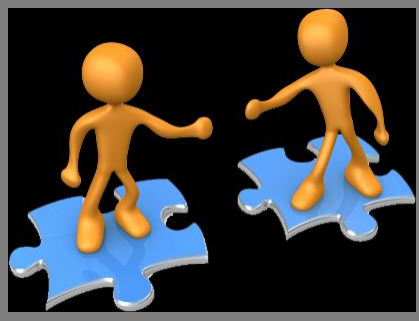
Chaplains have the time; Ability to listen, hear what is beneath the surface; Create safe space/build trust; Skill in questioning, opening up difficult conversation; Pace of decision making.

42

Advocate

Translator
Interpreter

Neutral Party,
Non-medical,
Impartial



Coach

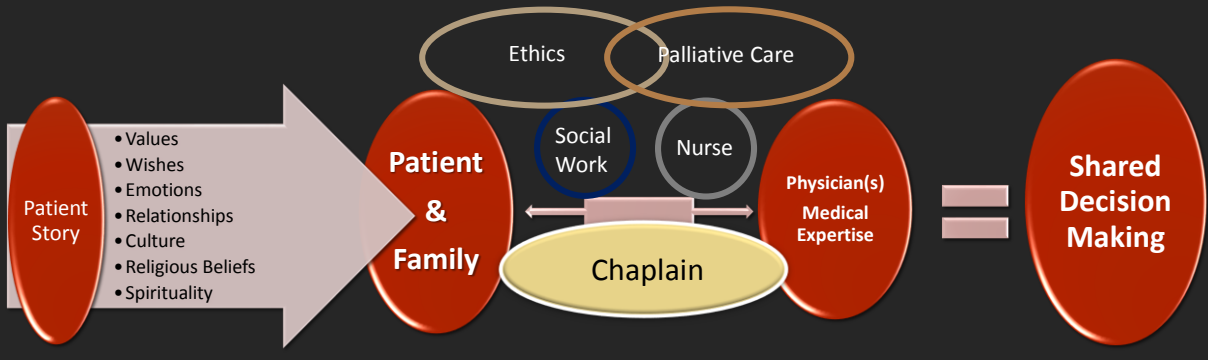
Bridge
Mediator
Liaison

Liaison/Communicator

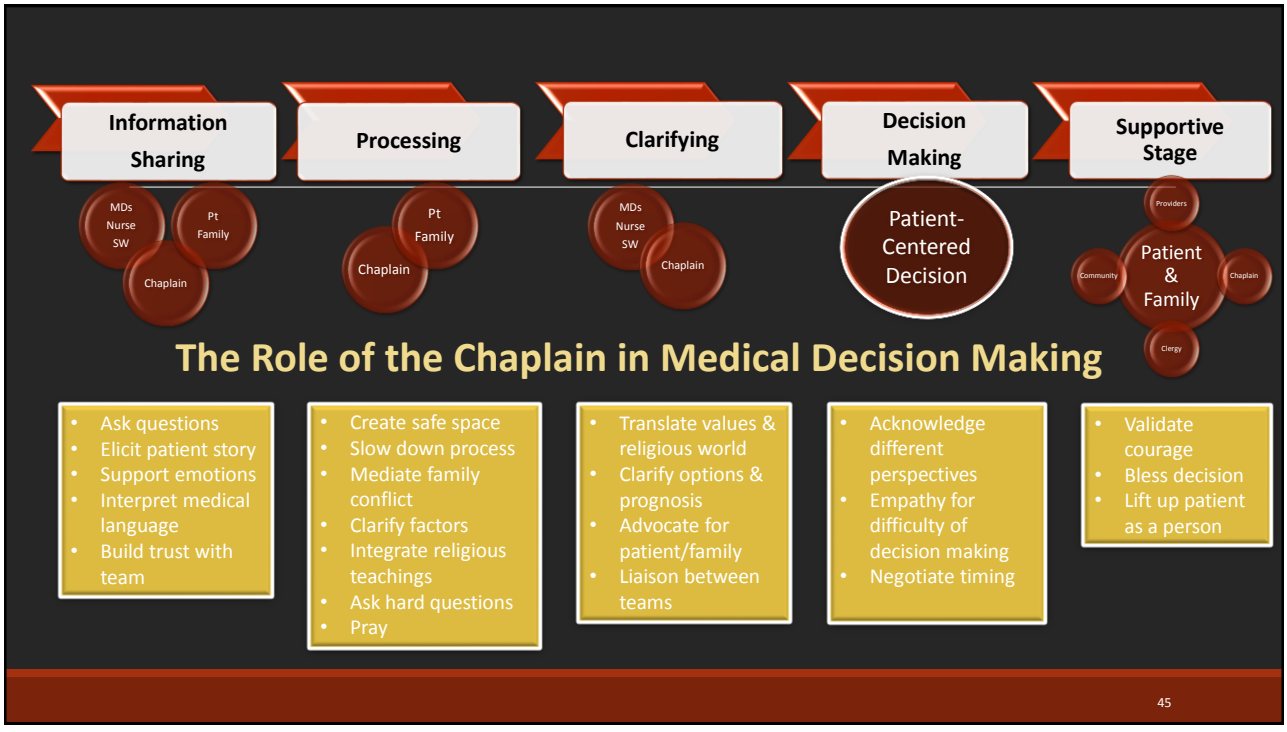
Bridge between patient/family and medical team; Speak both languages so can translate; Empower all to speak up, ask right questions; Advocate to the medical team so patient and family wishes are heard and respected.

43

SHARED DECISION MAKING: A NEW MODEL?



44



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?

46

Questions & Discussion

M. JEANNE WIRPSA, MA BCC

JWIRPSA@NM.ORG (312) 472-1559

47

References

Azoulay, E, et al. Involvement of ICU families in decisions: fine-tuning the partnership. Annals of Intensive Care 2014; 4:37.

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.

Balboni, T. A., Balboni, M. J., & Fitchett, G. (2015). Religion, Spirituality, and the Intensive Care Unit: The Sound of Silence. *JAMA Intern Med, 175*(10), 1669-1670. doi:10.1001/jamainternmed.2015.4471

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

Carey, LB & Cohen J. Religion, spirituality and health care treatment decisions: The role of chaplains in the Australian clinical context. Journal of Health Care Chaplaincy 2008 15: 25-39.

Charles C et al. "Shared decision making in the medical encounter: what does it mean" Soc Sci Med 1977; 44-681-92.

Charles, C et al. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model . Soc Sci Med 1999; 49:651-66.

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.

48

Curtis, JR & White, DB. "Practical Guidance for Evidence-Based ICU Family Conferences". CHEST 2008; 134:835-843.

Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB. Health Care Professionals' Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions. JAMA Internal Medicine 2015; 175:1662-1669.

Grant, G., Perkins, M., Binney, Z., Idler, E., & Quest, T. (2015). Chaplains' Role in End-of-Life Decision-Making: Perspectives of African American Patients and Their Family Members (S711). *J Pain Symptom Manage, 2*(49), 412-413.

Johnson, R., Wirpsa, M. J., Boyken, L., Sakumoto, M., Handzo, G., Kho, A., & Emanuel, L. (2016). Communicating Chaplains' Care: Narrative Documentation in a Neuroscience-Spine Intensive Care Unit. *J Health Care Chaplain*, 1-18.

Kon, A et al. Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement." Society of Critical Care Medicine, 2016, 44(1)

Massey, K., Barnes, M. J., Villines, D., Goldstein, J. D., Pierson, A. L., Scherer, C., . . . Summerfelt, W. T. (2015). What do I do? Developing a taxonomy of chaplaincy activities and interventions for spiritual care in intensive care unit palliative care. *BMC Palliat Care, 14*, 10. doi:10.1186/s12904-015-0008-0

Osborn, T. R., Curtis, J. R., Nielsen, E. L., Back, A. L., Shannon, S. E., & Engelberg, R. A. (2012). Identifying elements of ICU care that families report as important but unsatisfactory: decision-making, control, and ICU atmosphere. *Chest, 142*(5), 1185-1192. doi:10.1378/chest.11-3277

Peek, M et al. How is shared decision-making defined among African Americans with diabetes/ Patient Education and Counseling 2009; 72: 450-458.

49

Reuben, DB and Tinetta, ME. "Goal-Oriented Patient Care – An Alternative Health Outcomes Paradigm." New England Journal of Medicine 2012, 366;9

Simmonds, AL. The Chaplain's Role in Bioethical Decision-Making. Healthcare Management FORUM 1994; Vol 7(4)

Simmonds, AL. The Chaplain as Spiritual and Moral Agent. Humane Medicine 1994; 10(2)

Sohi, J et al. "improving health care professionals' collaboration to facilitate patient participation in decisions regarding life-prolonging care: An action research project." Journal of Interprofessional Care 2015; 29(5): 409-414

Visser, M., Deliens, L., & Houttekier, D. (2014). Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. *Crit Care, 18*(6), 604. doi:10.1186/s13054-014-0604-z

Visor, M et al. "Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. Critical Care 2014; 18(6): 604.

50