April 2017 Article of the Month

This month's article selection is highlighted by John Ehman,
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Bandini, J. I., Courtwright, A., Zollfrank, A. A., Robinson, E. M., Cadge, W. "**The role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment**." *Journal of Medical Ethics* 43, no. 6 (June 2017): 353-358.

SUMMARY and COMMENT: Consultations by hospitals' Clinical Ethics Committees many times involve chaplains [--see Items of Related Interest, §I, below], because we may sit on the committees and perform ethics consultations or because ethics consultations may turn up religious/pastoral issues pertinent to our overall work with a case. The purpose of this month's featured study was "to examine the different ways religion was present in cases involving conflict around LST [Life-Sustaining Treatment], to consider when and how religion was a source of conflict in these situations, and to identify difference in sociodemographic and clinical characteristics and outcomes in conflicts over LST that were religiously centred versus non-religiously centred" [pp. 353-354]. One of the co-authors is Chaplain Angelika A. Zollfrank, ACPE Supervisor and Manager for Spiritual Care at Yale New Haven Hospital (New Haven, CT).

This was a retrospective cohort study analyzing 95 Ethics Committee cases at Massachusetts General Hospital between January 1, 2012 and December 31, 2014. About half of the patients in these cases (49.5%) were Catholic, though 16 other religious groups -- mostly Christian -- were also represented in the sample, along with patients who had no religious affiliation. "A majority of patients (61.1%) were hospitalized in an intensive care unit, and almost a third (31.6%) had an oncological diagnosis" Also, "[m]ost…lacked decision-making capacity (85.3%), but only 65.3% had a formal healthcare proxy" [pp. 354-355]).

Cases were categorized as *religiously centred* if they were ones "in which religion was centrally involved in the conflict or generating disagreement between the patient/family and clinicians" --in which "religion shaped the beliefs of the family and influenced them to take specific positions in the conflict regarding LST" [p. 354]. *Non-religiously centred* cases were those where "religion was not the primary reason for the conflict but was present in other ways in the conflict" [p. 354].

The authors have written to our Network the following note summarizing their core findings and offering background information:

> This study grew out of the work with the intense and relatively rare case in which ethics consultation is requested to help resolve conflict over life-sustaining treatment. The authors were curious about the impact or underlying motivational forces that religion and spirituality represent in cases like this, particularly given the public perception that religion or religious beliefs may drive end-of-life conflict. Ellen Robinson, RN, PhD, has been collecting data on ethics consultation cases at Massachusetts General Hospital for years

and was able to supply the demographic and quantitative data in this study. First author Julia Bandini, in collaboration with an interdisciplinary team that included nursing, physician, sociology, and chaplaincy representation, took the lead in analyzing the medical records in these cases. By analyzing inductively how religion was present in these cases, we identified three main ways which sometimes occurred simultaneously. These included religion 1) as a source of coping for patients and/or families, including through discussion or mention of miracles and through discourse around support and intervention from a higher being; 2) via the visits from chaplains; and 3) as central to conflict about life-sustaining treatment. Contrary to other studies, our exploration shows that religion and spiritual beliefs played a diversity of roles and was not always a driver of conflict. For patients and families who are served by the ethics consultation service, we found that excellent narrative notes of the chaplain at the bedside can make an important difference in highlighting the diverse aspects of religion in cases of disagreement about life-sustaining treatment.

Among the three ways in which religion was present in these cases:

1) **Religion as a Source of Coping for Patients and Families:** "Religion was often a source of coping for patients and families, providing hope, strength, and meaning in difficult situations around end-of-life treatment. These included cases in which religious or spiritual beliefs, practices, or communities were helpful for patients and families in getting through a difficult situation." [p. 355] Chaplaincy Note (example): "Mother and family has a deep faith in God's ability to perform miracles: 'God saved [patient] for a reason: he will bring her back to us I'm sure'" [p. 355].

2) **Chaplaincy Visits:** The purpose of these visits was to provide support and spiritual care to patients and families, often in the form of providing a religious ritual or to pray with patients and/or family members: "Prayed with the grieving family, offered patient the Sacrament of the Sick, end of life Catholic prayers and offered family spiritual support." Chaplains also assisted patients and families in understanding end-of-life care and discussed decisions around goals of care. [p. 355]

3) **Religion as Central to Conflict Over Life-Sustaining Treatment:** In a quarter of the cases reviewed, we found that religion shaped not only beliefs but also oriented families to their own positions in disagreements with clinicians. In some of these cases, there was a strong belief in miracles or insistence that decisions are "in God's hands," indicating a belief in God's power over and above the power of the medical team. However, there was no difference in the number for life-sustaining treatment, hospitalization in the intensive care unit, or utilization of artificial nutrition, hydration or mechanical ventilation in patients with religiously vs non-religiously centered conflict. [p. 356]

"The data from this study demonstrate that while religion can be a source of conflict over life-sustaining treatment, religion also plays a variety of roles in discussions in these situations. It is important for clinicians to recognize that religion can also be a source of support for patients and families through coping and making sense of the hospitalization." [p. 357]

--Sent by the article's authors to the ACPE Research Network, after invitation from the Network Convener, on 3/27/17 via co-author Angelika A. Zollfrank

In connection to the point made just above (#3):

> Patients who were among the group of religiously centred conflicts were more likely to be non-white, not speak English as a primary language, born outside the USA and be with low income, which may suggest a cultural component to the role of religion in conflict over LST, potentially mediated by distrust in the health system. It may also be possible that these patients and families who have concerns over withdrawal of LST are more likely to use religious language to express their discomfort or conflict. Alternatively, it may be that patients and families who are white and born in the USA may express their desire for ongoing LST in non-religious terms because of a

> perception that clinicians will be more responsive to non-religious requests. ...The data from this study may suggest that stated religious beliefs may be a mechanism for framing convictions and wishes in a way that surrogates believe is more likely to evoke a particular response among clinicians, although more detailed prospective work is needed to investigate this hypothesis. [p. 357].

The authors address limitations of the study [--see p. 357], cautioning against generalization, and then point up additional lines of investigation, as in the need for studies with other and larger populations, for interviews with consultation stakeholders, for attention to those who identify as *spiritual but not religious*, and for multivariate (instead of bivariate) analysis.

They state in closing: "[V]isits from chaplains may be helpful for patients and families in reaching an acceptance of the situation and also important for clinicians in understanding the perspectives of patient and surrogate viewpoints" [p. 357]. The article is aimed at non-chaplains, but it may well spark chaplains to think about how better to help Ethics Committees become attuned to religious/spiritual dynamics in case consultations.

Suggestions for Use of the Article for Student Discussion:

This relatively brief and straightforward article could be a general entrée to the activity of Ethics Committees and might be paired with a plan for students to attend a meeting of their institution's own Committee. Have students ever encountered a case that has been the subject of an ethics consultation, and what religious/spiritual dynamics do they remember? Our authors note, "Oftentimes, families invoked religious beliefs to assert power or to resist the medical model in situations in which they may have felt powerless" [p. 356]. Have students observed this? What about the observation that "death and dying is often experienced as a spiritual more than a medical event" [p. 356]? What might that mean for the role of a chaplain in relation to the activity of an Ethics Committee? Students could discuss what "in God's hands" could mean for families and how that connects with the idea of locus of control [pp. 355 and 356]. Also, can they see in this study an implicit argument for charting good notes of visits?

Related Items of Interest:

I. For more on the relationship between Ethics Committees and chaplains, see:

> Carey, L. B. and Cohen, J. "**Health care chaplains and their role on institutional ethics committees: an Australia study**." *Journal of Religion and Health* 49, no. 2 (June 2010): 221-232. [(Abstract:) This paper presents the results of the largest Australian pastoral study concerning the perceptions of health care chaplains about their involvement on hospital research ethics committees (also known in some contexts as institutional ethics committees). Survey results from over 300 Australian health care chaplains indicated that nearly 90% of chaplains believed there was merit in chaplains serving on hospital research ethics committees, yet only a minority (22.7%) had ever participated on such committees. Data from in-depth interviews is also presented exploring the reasons for the lack of participation and the varying opinions regarding the role, appropriateness, and value of chaplains on ethics committees. Some implications of this study with respect to chaplaincy, hospital research ethics committees, health care institutions, ecclesiastical institutions, and government responsibilities are discussed.]

> Fox, E., Myers, S. and Pearlman. R. A. "**Ethics consultation in United States hospitals: a national survey**." *American Journal of Bioethics* 7, no. 2 (February 2007): 13-25. [Working from a

random sample of hospitals in the US, researchers used a protocol to identify the "best informant" about each hospital's ethics consultation service. A "best informant" was defined as "the person most actively involved in ethics consultation" (p. 15). Among the findings of this slightly old study: chaplains constituted 13% of "best informants," and 70% of hospitals used chaplains on their ethics consultation services.]

II. The following recent study found that ethics consultations led to a greater incidence of chaplaincy referrals.

Voigt, L. P., Rajendram, P., Shuman, A. G., Kamat, S., McCabe, M. S., Kostelecky, N., Pastores, S. M. and Halpern, N. A. "**Characteristics and outcomes of ethics consultations in an oncologic Intensive Care Unit**." *Journal of Intensive Care Medicine* 30, no. 7 (Oct 2015): 436-442. [(Abstract:) OBJECTIVE: To evaluate the frequency, characteristics, and outcomes of ethics consultations in critically ill patients with cancer. DESIGN, SETTING, AND METHODS: This is a retrospective analysis of all adult patients with cancer who were admitted to the intensive care unit (ICU) of a comprehensive cancer center and had an ethics consultation between September 2007 and December 2011. Demographic and clinical variables were abstracted along with the details and contexts of the ethics consultations. MAIN RESULTS: Ethics consultations were obtained on 53 patients (representing 1% of all ICU admissions). The majority (90%) of patients had advanced-stage malignancies, had received oncologic therapies within the past 12 months, and required mechanical ventilation and/or vasopressor therapy for respiratory failure and/or severe sepsis. Two-thirds of the patients lacked decision-making capacity and nearly all had surrogates. The most common reasons for ethics consultations were disagreements between the patients/surrogates and the ICU team regarding end-of-life care. After ethics consultations, the surrogates agreed with the recommendations made by the ICU team on the goals of care in 85% of patients. Moreover, ethics consultations facilitated the provision of palliative medicine and chaplaincy services to several patients who did not have these services offered to them prior to the ethics consultations. CONCLUSION: Our study showed that ethics consultations were helpful in resolving seemingly irreconcilable differences between the ICU team and the patients' surrogates in the majority of cases. Additionally, these consultations identified the need for an increased provision of palliative care and chaplaincy visits for patients and their surrogates at the end of life.]

III. The Association of Professional Chaplains offers "Guidelines for the Chaplain's Role in Health Care Ethics". Note especially the six guidelines under Principle III: Chaplains Participate in the Health Care Ethics Consultation Services of the Facility or Organization.

IV. Regarding the ways that religion/spirituality may play into health care *decision-making*, the following recent study out of Indianapolis, IN, should be a good introduction to the literature. It includes a useful bibliography. One of the authors os ACPE Supervisor Steven S. Ivy.

Geros-Willfond, K. N., Ivy, S. S., Montz, K., Bohan, S. E. and Torke, A. M. "**Religion and spirituality in surrogate decision making for hospitalized older adults**." *Journal of Religion and Health* 55, no. 3 (June 2016): 765-777. [(Abstract:) We conducted semi-structured interviews with 46 surrogate decision makers for hospitalized older adults to characterize the role of spirituality and religion in decision making. Three themes emerged: (1) religion as a guide to decision making, (2) control, and (3) faith, death and dying. For religious surrogates, religion played a central role in end of life decisions. There was variability regarding whether God or humans were perceived to be in control; however, beliefs about control led to varying perspectives on acceptance of comfort-focused treatment. We conclude that clinicians should attend to religious considerations due to their impact on decision making.]

If you have suggestions about the form and/or content of the site, e-mail Chaplain John Ehman (Network Convener) at john.ehman@uphs.upenn.edu .