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November 2013 Article of the Month

This month's article selection is by Chaplain John Ehman, University of Pennsylvania Medical Center-Penn Presbyterian, Philadelphia PA.

Garrido, M. M., Idler, E. L., Leventhal, H. and Carr, D. "Pathways from religion to advance care planning: beliefs about control over length of life and end-of-life values." *Gerontologist* 53, no. 5 (October 2013): 801-816.

SUMMARY and COMMENT: This month's article was chosen for the richness and explication of its involved concepts, hypotheses, and methodology as thought-provoking for future research. It attempts a fairly big-picture consideration of connections between religion and Advanced Care Planning (ACP), and in the process it illustrates both the significant sophistication of current spirituality & health research as well as the still-nascent state of the field overall. The findings are also a contribution to discussions within pastoral care about patients' sense of *control* in end-of-life care decision-making.

This research emerges, in part, from studies suggesting that "[s]elf-identified religious importance... religious service attendance, and positive religious and spiritual coping are negatively associated with ACP likelihood," raising the following question: "Why are highly religious people less likely to engage in ACP, particularly when ACP may specify treatment preferences consistent with one's religious beliefs, including preferences for intensive medical intervention?" [p, 802].

Data were analyzed from 305 outpatients (from a total sample of 575), aged 55 years and older, receiving treatment in New Jersey for colorectal cancer, type 2 diabetes, or congestive heart failure. Face-to-face interviews between 2006-2008 assessed for informal discussion of ACP, formal completion of a Living Will or other Advance Directive, self-rated health, sociodemographics, religious affiliation, importance of religion/spirituality and the degree of influence on medical decision-making, values about "physical and mental functioning, family and social functioning, and spirituality" [p. 805] around the end-of-life; and beliefs about God control [GC] and natural death [ND]. Regarding the latter: the GC score was assessed by three original items (i.e., "It is God's will when one's life will end"; "The length of one's life is determined by God"; and "I believe in turning my health problems over to God"); and the ND score by two items taken from the Death Attitude Profile-Revised (i.e., "Death should be viewed as a natural, undeniable and unavoidable event"; "Death is simply a part of the process of life") [p. 805, and see Related Items of Interest, §II (below)].

Results are given in detail in the narrative and in extensive tables. These express complex and varied relationships and require close reading. Among the findings:

Strong bivariate associations between religious affiliation and ACP were largely accounted for by beliefs and values about control in multivariate models. Beliefs about God's control over life length differed by affiliation, but...many values about control over the EOL were equally important across religious groups. Overall, beliefs in God's control over life length were associated with lower

likelihood of ACP (either informal or formal), whereas valuing individual control over EOL circumstances was associated with greater ACP likelihood. [p. 809]

Conservative Protestants were the least likely to engage in ACP.......[T]he relationship between conservative Protestantism and ACP...largely reflects differences by affiliation in beliefs about control over life length and in EOL values. ...The relationship between conservative Protestantism and lower rates of *informal* ACP discussions was accounted for by stronger beliefs in God's control over life length. ...Their lower *combined* [informal and formal] ACP likelihood also was partly accounted for by GC beliefs, but this relationship was not evident after controlling for health and sociodemographics. This may reflect the fact that African Americans are over-represented among conservative Protestants, and African Americans have lower ACP rates than Whites. ...The relationship between conservative Protestantism and lower rates of combined ACP was also accounted for by weaker beliefs in death as a natural part of life. Those endorsing this belief were more likely to engage in combined ACP. ...The association between conservative Protestantism and low discussion rates was accounted for by valuing having all available treatments. [p. 814]

The authors build upon a myriad of other research, well cited, to contextualize their findings. They also offer a good deal of speculation about larger dynamics at play. For instance: "Because conservative Protestants are more likely to believe that an outside entity controls life length, they may feel less of a need to plan for the EOL," and "Persons who do not believe that God controls life length might feel a need to appoint a specific person to take control in case they are incapacitated" [p. 814]. However, for this reader, the most practical and overarching proposition is that "individuals are more likely to engage in health-related actions when they perceive control over an illness or scenario" [p. 809]. This idea is guided by the Common Sense Model (CSM) of Illness Representations:

The CSM states that individuals' perceptions of their own health and illnesses affect the decisions they make when seeking health care... Illness perceptions include perceived controllability of an illness or a scenario (here, EOL in general); those who believe their illness is controllable are more likely to seek treatment. Similarly, those who believe that the timing and nature of death are beyond one's own control may be less likely to engage in ACP. [p. 802, and see also Related Items of Interest, §III (below)]

The authors acknowledge the heterogeneity of beliefs within religious groups and the complexity in relationship between a religion's teachings and an individual's beliefs and how those beliefs are translated into decisions and actions. For some chaplain readers, the article might still seem to make too many assumptions about groups as a whole (e.g., "conservative Protestants"), but <u>Garrido</u>, <u>Idler</u>, <u>Leventhal</u>, and <u>Carr</u> bring considerable erudition to this study. If the article is a mix of both broad conceptualizations and minute statistical details, this may illustrate the state of the field of spirituality & health at this point, as the particulars of accumulated research are building a sense of connections but still require a wide view for interpretation.

There is much to stimulate thinking and debate in this article, especially for chaplain researchers, but there are practical implications as well. The authors conclude [p. 815] by encouraging educational initiatives in congregations to empower religious leaders to promote ACP (like the Robert Wood Johnson Foundation's "Compassion Sabbath" initiative), and this should resonate with chaplains in the frequent role as liaison between hospitals and community clergy. The authors also propose that some types of Advance Directives (like the Five Wishes document, which provides for statements about religious beliefs) could be more acceptable to some patients. Chaplains can, of course, also bring sensitivity to religious values -- and potentially "God control" beliefs in particular -- to the facilitation of Advance Directive completion and care plan decision-making for inpatients. In fact, chaplains may be ideally placed to help people better understand ACP as a process to ensure the consonance of one's beliefs and one's medical care and not a means merely to limit treatments [--see p. 803].

One final observation: The authors are exceptionally thorough in defining the key terms used in the study. This reader would note, however, the absence of the term *locus of control*, which is so much in the parlance of the

control literature; perhaps because that literature tends to be focused on health and not specifically on the end of life.

Suggestions for the Use of the Article for Student Discussion:

The article is geared for researchers and may be more difficult than usual for students without a solid sense of the spirituality & health literature, as the relationships between the study's variables are complex, and there is a concentration analytical details. The opening paragraphs, moreover, have an outsider-looking-in tone that may not entice chaplaincy students. Nevertheless, like any good article, this one should be accessible for thoughtful dialogue in CPE, and the Discussion section [pp. 809, 814-815] offers many intriguing ideas regarding the connection between beliefs about control and Advanced Care Planning. Students might think about the specific questions used here to assess for "God control" [--see p. 805]. They may want to talk about associations between "God control" and different theological/denominational traditions, especially in light of the finding that "many values about control over the EOL were equally important across religious groups" [p. 809]. Students might also be asked if they personally have Advance Directives and whether anything in the article touched upon their reasons for having or not having one. Finally, they should be interested in the authors' conjectures about the causes and mechanisms behind their findings, for instance, regarding beliefs about "natural death": "Individuals who believe that death is a natural part of life may engage in ACP because they want to ensure that they have an opportunity to die when nature -- not medicine -- intended.... Alternatively, individuals who believe that death is a natural event may be less fearful of discussing death, making them more likely to engage in ACP." [p. 814]

Related Items of Interest:

I. A related study by co-author Deborah Carr, analyzing a variation of the same overall patient sample:

Carr, D. "Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable?" *Omega - Journal of Death & Dying* 63, no. 1 (2011): 1-20. [(Abstract:) I evaluate the extent to which ethnic disparities in advance care planning reflect cultural and religious attitudes and experience with the painful deaths of loved ones. Data are from a sample of 293 chronically ill older adults who are seeking care at one of two large medical centers in urban New Jersey. Blacks and Hispanics are significantly less likely than Whites to have a living will, a durable power of attorney for health care (DPAHC), and to have discussed their end of life treatment preferences. Multivariate analyses reveal that the Black-White gap in advance care planning is largely accounted for by Blacks' belief that God controls the timing and nature of death. The Hispanic-White gap is partially accounted for by the belief that one's illness negatively affects one's family. Ethnic disparities are starkest for living will and DPAHC use, and less pronounced for discussions. Implications for policy and practice are discussed.]

II. While the three "God control" assessment items are original to the study, the two "natural death" items are taken from the 32-item Death Attitude Profile-Revised, available through its developer's website. For more, see Wong, P. T., Reker, G. T. and Gesser, G., "Death Attitude Profile-Revised: a multidimensional measure of attitudes toward death," in Neimeyer, R. A., ed., Death Anxiety Handbook: Research, Instrumentation and Application (Washington, DC: Taylor & Francis, 1994): 121-128.

III. Co-author Howard Leventhal was a principal developer of the Common Sense Model (CSM) of Illness Representations [--see p. 802], which guided this month's study. Our article gives as a reference for the CSM:

Leventhal, H., Diefenbach, M. and Leventhal, E. A. "Illness cognition: using common sense to understand treatment adherence and affect cognition interactions." Cognitive Therapy and Research 16, no. 2 (April 1992): 143-163. [(Abstract:) We summarize basic empirical themes from studies of adherence to medical regimens and propose a self-regulatory model for conceptualizing the adherence process. The model posits that self-regulation is a function of the representation of health threats and the targets for ongoing coping (symptom reduction, temporal expectancies for change) set by the representation, the procedures to regulate these targets, and the appraisal of coping outcomes. The underlying cognitive mechanism is assumed to function at both a concrete (symptom-based schemata) and abstract level (disease labels), and individuals often engage in biased testing while attempting to establish a coherent representation of a health threat. It also is postulated that cognitive and emotional processes form partially independent processing systems. The coherence of the system, or the common-sense integration of its parts, is seen as crucial for the maintenance of behavioral change. The coherence concept is emphasized in examples applying the model to panic and hypochondriacal disorders.]

However, a couple of other basic introductions to the CSM can be found in:

Diefenbach, M. A. and Leventhal, H. "The common-sense model of illness representation: theoretical and practical considerations." *Journal of Social Distress and the Homeless* 5, no. 1 (January 1996): 11-38. [(Abstract:) This article focuses on several areas. After reviewing the most commonly used approaches in the study of health behaviors, (e.g., the medical model, the health belief model, and the theory of reasoned action) the common-sense model is presented as an alternative. By presenting evidence across a wide range of illness domains, we demonstrate the usefulness of the common-sense, self-regulatory approach. We then discuss the importance of the common-sense model for health research among minorities. We conclude the article with examples of the operationalization of illness representations in past research and directions for future research.]

Hagger, M. S. and Orbell, S. "A meta-analytic review of the Common-Sense Model of Illness **Representations.**" *Psychology and Health* 18, no. 2 (2003): 141-184. [(Abstract:) A meta-analysis of empirical studies (N 1/4 45) adopting Leventhal, Meyer and Nerenz's (1980) Common Sense Model (CSM) of illness representations is presented. The average corrected intercorrelation matrix for the sample of studies showed that the CSM illness cognition dimensions of consequences. control/cure, identity and timeline followed a logical pattern supporting their construct and discriminant validity across illness types. A content analysis classified coping strategies into seven distinctive categories and health outcomes into six categories. Examining the average corrected correlation coefficients across the studies revealed that perceptions of a strong illness identity were significantly and positively related to the use of coping strategies of avoidance and emotion expression. In addition, perceived controllability of the illness was significantly associated with cognitive reappraisal, expressing emotions and problem-focused coping strategies. Perceptions of the illness as highly symptomatic, having a chronic timeline and serious consequences was significantly correlated with avoidance and expressing emotions coping strategies. Further, perceptions that the illness was curable/controllable was significantly and positively related to the adaptive outcomes of psychological well-being, social functioning and vitality and negatively related to psychological distress and disease state. Conversely, illness consequences, timeline and identity exhibited significant, negative relationships with psychological well being, role and social functioning and vitality. The analyses provide evidence for theoretically predictable relations between illness cognitions, coping and outcomes across studies.] [NOTE: This article is available on the Internet from the University of Nottingham.]

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 .

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