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February 2013 Article of the Month

This month's article selection is by Chaplain John Ehman,
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Elliott, B. A., Gessert, C. E., Larson, P. and Russ, T. E. "**Religious beliefs and practices in end-stage renal disease: implications for clinicians**." *Journal of Pain & Symptom Management* 44, no. 3 (September 2012): 400-409.

SUMMARY and COMMENT: This month's article addresses a population frequently encountered by chaplains: patients with End-Stage Renal Disease; but is also written largely with chaplains and community clergy in mind, even though it appears in a non-pastoral care journal, and the title refers only to "clinicians." The lead author, Barbara A. Elliott, PhD, is a long-time professor at the University of Minnesota School of Medicine, but she also is an alumna of Clinical Pastoral Education, has been an on-call chaplain for 10 years at St. Mary's Medical Center in Duluth, and in January 2013 was ordained an Episcopal priest.

The authors explain at the outset that "[t]he findings reported here emerged from a qualitative study designed to investigate decision making at end of life among patients with end-stage renal disease (ESRD)" [p. 400]. In the course of that original qualitative research,

> The interviews revealed how some of the patients' and family members' religious practices and beliefs provided meaning for their experiences and guidance in their decision making regarding ESRD and its management. The themes and findings related to the religious beliefs and practices are reported here. [p. 401]

A total of 31 interviews with patients and family members were conducted over a two-year period, at which point the authors felt that they had achieved a saturation of data. The method is well described [pp. 401-403]. The guide used for the interviews is helpfully given in a table [p. 402], and it is worth noting that religion/spirituality is *not* emphasized in any of its seven main questions, only figuring into two follow-up questions: "Tell us about your personal outlook or values; the role of family and social relationships; and religion and spirituality," and "Are there issues with family burden or family conflict; finances; religion, faith; treatment burden; symptoms; and control?"

Among the results: "five themes pertaining to religious beliefs and practices were identified" [p. 403]. These were...

> ...two that are used in decision making: their faith-based beliefs and the meaning that emerges from these beliefs; two that describe how their coping is impacted: the participants' religious practices and their perceived support from the church community; and one that describes the participants' spiritual distress, which was based in dilemmas at the interface of their beliefs and religious experiences. [p. 403]

The authors explicate each of these themes. For example.

- BELIEFS: "Several patients described dialysis as a gift from God. ...However, having these gifts is not seen as implying or demanding that they be used..., [and though]...several participants discussed the availability of dialysis in religious terms, a sense of religious obligation to continue dialysis was not evident" [p. 403]. The theme of *beliefs* also involved the notion that "there is a time to die" [p. 403] as well as "references to what comes after death, including the afterlife, heaven, and specific events that can occur after death" [p. 404].

- MEANING: "[T]he meaning that they found in their dialysis experiences was grounded in their beliefs about God's role in their continued survival and in their dying. Some were very clear that their illness and suffering had resulted in new insights. ...Some participants explained how their relationship with God enables them to create meaning. ...They also interpreted the outcomes and experiences that occurred as God's work. ...Several participants described the role of spiritual beliefs in decisions to continue or discontinue dialysis" [p. 404]. "Faith also offered hope and countered fear in these patients and family members" [p. 405].

- RELIGIOUS PRACTICES: "[R]eligious practices also were important in managing their day-to-day lives on dialysis... [and] helped them cope with their circumstances as well as maintain their contact with God and with other people. One important practice was prayer, which was mentioned by most of the participants as a means of accomplishing a variety of desired outcomes. ...[P]rayer helped maintain a sense of community... [and was] a special way to honor the relationship with [family].... There also were those who described how answers to prayers reduced the patient's suffering.... In addition to prayer, liturgical and traditional rituals were important in managing their lives and relationships" [p. 405].

- COMMUNITY SUPPORT: "Participants also commented on the value of church connections in providing social support in their lives. ...Participants also described how regularly they were or had been attending church, commenting that they continued for as long as possible" [p. 405]. ...When some dialysis patients could no longer get to church, the church came to them.... Clergy presence was especially important at the time of death, as reported by surviving family members..." [p. 406].

- SPIRITUAL DISTRESS: "A person's faith base and experiences in church communities are not always supportive and positive, which leads to the experience of spiritual distress for the church member. Participants in these conversations described their experiences with spiritual distress clearly and honestly." [Examples given include turmoil in a church over a minister's firing for breaking confidences and tension with a clergy person over sexual orientation.]

Each theme is illustrated with quotes from participants.

The authors summarize the significance of the findings:

> First, the detailed comments from these participants describe how the clergy and chaplains specifically serve their needs and, in addition, offer suggestions regarding how chaplains and other clinicians can provide welcome and helpful support to this group (while being sensitive to the reality of spiritual distress). Second, the comments also specify how religious beliefs impact ethical decision making and indicate their relevance to discussions concerning goals of care that prolong living and dying.
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> This population described the importance of having the clergy and chaplains who served them with discussions about faith-based beliefs and traditions and provided prayer, ritual and sacraments, and continuing contacts. Patients and families valued continuing religious contact and support when they were no longer able to get to church activities. Clergy or chaplain presence at the time of death was noted to be especially important. Also, several participants clearly appreciated the

opportunities that they had had to discuss church doctrines and views regarding end-of-life care and decisions. [p. 406]

They additionally comment on the implications for "other clinicians" [non-clergy], who in their interactions with ESRD patients should consider these patients' beliefs in the discussions of goals of care and medical decisions and recognize of the role of religion in "coping with day-to-day dialysis and living" [p. 407].

A brief but valuable paragraph lists "[e]arlier research on the role of spirituality in the lives of people living with dialysis" [p. 407; and see Items of Related Interest, §I, below] and notes that the present study is distinguished by how it has added *spiritual distress* as a major theme for this population. While the earlier research that the authors cite indeed doesn't highlight spiritual distress, this reader does recall an article referenced in our Summer 2011 Newsletter: Davison, S. N. and Jhangri, G. S., "Existential and supportive care needs among patients with chronic kidney disease" [*Journal of Pain & Symptom Management* 40, no. 6, pp. 838-843], which addresses kidney disease essentially in the context of spiritual distress.

Generalizability of this research is limited by the sample, which is relatively small and comprised of Caucasians in Northern Minnesota and Wisconsin who were over 70 years of age and already in dialysis. Nevertheless, the qualitative analysis provides five basic themes that should be the bases for further research and, in the meantime, should be salient for chaplains or community clergy visiting ESRD patients.

Suggestions for the Use of the Article for Discussion in CPE:

This is a very accessible article and would be well suited for CPE students new to visiting with End-Stage Renal Disease patients, even more so if a CPE program included community clergy. The introductory section on ESRD [p. 401] makes clear the sheer incidence of kidney failure in our society. A nephrology physician or nurse might be invited to the discussion, yet a carefully chosen dialysis patient might make for an even richer conversation. The Results section lays out nicely the five themes, and students may want to think through each one. *Distress* is the fifth theme here, but discussion might relate it to the other four: for instance, the theme of *community support* includes a comment about how a patient could no longer attend religious services; so, might there be distress implicit in that circumstance? For students who have visited with dialysis patients, do the findings here ring true, and what kinds of distress have they discovered in these patients? Finally, the sample of patients is limited (i.e., Caucasians in Northern Minnesota and Wisconsin who were over 70 years of age and already in dialysis). It might be instructive for students to think about the dynamics of generalizability by naming demographic variations that they believe might have affected the findings.

Related Items of Interest:

I. Our authors this month cite several earlier studies (including one case report) about the role of spirituality in the lives of dialysis patients:

Cohen, L. M., Germain, M. J. and Poppel, D. M. "**Practical considerations in dialysis withdrawal: 'to have that option is a blessing'**." *JAMA* 289, no. 16 (April 23-30, 2003): 2113-2119. [(Abstract:) Cessation of life-support treatment is an appropriate option for situations in which the burdens of therapy substantially outweigh the benefits. Decisions to withdraw dialysis now precede 1 in 4 deaths of patients who have end-stage renal disease. Guidelines have been recently published to assist clinicians in making these complex and emotionally charged determinations, and they include: relying on shared decision making by all participants, obtaining informed consent, estimating the prognosis on dialysis, adopting a systematic approach for

conflict resolution of disagreements, honoring advance directives, and ensuring the provision of palliative care. These principles are discussed in relation to an elderly man with dementia whose family decided to terminate maintenance hemodialysis.]

Tanyi, R. A. and Werner, J. S. "**Women's experience of spirituality within end-stage renal disease and hemodialysis**." *Clinical Nursing Research* 17, no. 1 (February 2008): 32-49. [(From the abstract:) The purpose of this descriptive, phenomenological qualitative study is to describe women's lived experiences of spirituality within end-stage renal disease (ESRD) and hemodialysis. The purposive volunteer sample of 16 women regularly attended two outpatient dialysis centers in a large Midwestern city. Audiotaped, transcribed interviews were analyzed using Colaizzi's method. These women affirmed that spirituality was extremely important in living with their illness and necessary treatment regime. Four major clusters of themes pertaining to the women's spiritual experience within their illness emerged: acceptance, understanding, fortification, and emotion modulation. Findings show that spirituality is of great importance in living with ESRD while receiving hemodialysis and suggest that spirituality may be a significant consideration in nursing and interdisciplinary health care.]

Tanyi, R. A., Werner, J. S., Recine, A. C. and Sperstad, R. A. "**Perceptions of incorporating spirituality into their care: a phenomenological study of female patients on hemodialysis**." *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* 33, no. 5 (September-October 2006): 532-538. [(Abstract:) This phenomenological study was aimed at understanding how women with end stage renal disease undergoing hemodialysis want nurses to address their spirituality. Interviews were conducted with 16 women from outpatient hemodialysis centers in a large Midwestern city. Eighty-three significant statements yielded meanings representing four theme clusters, highlighting how these women prefer nurses to incorporate spirituality into their care: (a) displaying genuine caring, (b) building relationships and connectedness, (c) initiating spiritual dialogue, and (d) mobilizing spiritual resources. Participants expressed that nephrology nurses are uniquely positioned to understand their individualized spiritual needs and implement spiritual care.]

Walton, J. "**Finding a balance: a grounded theory study of spirituality in hemodialysis patients**." *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* 29, no. 5 (October 2002): 447-456, with discussion on p. 457. [(Abstract:) The purpose of this study was to discover what spirituality means to hemodialysis patients and how it influences their lives. Grounded theory qualitative research method was used to discover meaning, provide understanding, and create a beginning substantive theory of spirituality. Four men and 7 women, 36 to 78 years of age, receiving outpatient hemodialysis in the northwestern United States, volunteered to participate in this study. Demographic data were collected and indepth interviews were completed. The Glaserian method of grounded theory was used for data collection and analysis. The central core category of this study was finding a balance, which occurred in the following four phases: (a) confronting mortality, (b) reframing, (c) adjusting to dialysis, and (d) facing the challenge. Categories of spirituality were faith, presence, and receiving and giving back. Participants described spirituality as a life-giving force from within, full of awe, wonder, and solitude, that inspires one to strive for balance in life. Participants validated the description of spirituality, categories, and phases to assure that it captured their person experiences. A focus group of hemodialysis staff validated the results for clarity, understanding, and application to clinical practice. The results of this study provide a theoretical

framework to guide nursing practice as well as an understanding of what spirituality means to hemodialysis patients and how it influences their lives.]

Weil, C. M. "**Exploring hope in patients with end stage renal disease on chronic hemodialysis**." *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* 27, no. 2 (April 2000): 219-224. [(Abstract:) The purpose of this qualitative study was to explore the definitions and sources of hope in patients with end stage renal disease (ESRD) receiving chronic hemodialysis. A convenience sample was recruited from a population of chronic hemodialysis patients from two dialysis centers in a rural area of the Pacific northwest. Study participants consisted of 9 men and 5 women between the ages of 43 and 81 (M = 62.5) who had been on chronic hemodialysis an average of 8.3 years. The data collection process consisted of an audiotaped interview guided by the pre-established research questions. The results of this study provide examples of the experience of hope in patients with ESRD on chronic hemodialysis. Hope is a multifaceted human response. The participants in this study were able to adapt to situational changes by attaching their hopes to reality consideration, therefore developing a cognitive process for maintaining hope.]

II. Other recent research of interest:

Davison, S. N. and Jhangri, G. S. "**The relationship between spirituality, psychosocial adjustment to illness, and health-related quality of life in patients with advanced chronic kidney disease**." *Journal of Pain & Symptom Management* 45, no. 2 (February 2013): 170-178. [(Abstract:) CONTEXT: Spirituality may promote psychosocial adjustment to illness, and this may be a mechanism by which patients with greater existential well-being (EWB) experience better health-related quality of life (HRQL) in the context of life-limiting illness. OBJECTIVES: This study explored the relationship between psychosocial adjustment to illness, EWB, and HRQL in patients with advanced chronic kidney disease and sought to determine whether adjustment to illness mediates the relationship between EWB and HRQL. METHODS: This was a cohort study of 253 prevalent Stage 4 or 5 chronic kidney disease and dialysis patients. Participants completed the Spiritual Well-Being Scale, the Psychological Adjustment to Illness Scale (PAIS)-Self-Report, and the Kidney Dialysis Quality of Life Short Form. RESULTS: Psychosocial adjustment to illness was highly correlated with HRQL, accounting for 29% and 27% of the variance in physical and mental HRQL scores, respectively. Although PAIS domains were associated with EWB, EWB remained a significant predictor of HRQL after all PAIS domains were considered. Adjustment in the domains of psychological distress and extended family relationships did appear to mediate some of the relationship between EWB and HRQL. CONCLUSION: Adjustment in the domains of psychological distress and extended family relationships appears to mediate some of the beneficial effect of EWB on HRQL. Spirituality, however, provides unique variance in patients' HRQL, independent of their psychosocial adjustment. This study testifies to the importance of targeting both psychosocial adjustment to illness and spirituality as ways to preserve or enhance HRQL of predialysis and dialysis patients.]

Molzahn, A., Sheilds, L., Bruce, A., Stajduhar, K., Makaroff, K. S., Beuthin, R. and Shermak, S. "**People living with serious illness: stories of spirituality**." *Journal of Clinical Nursing* 21, nos. 15-16 (August 2012): 2347-2356. [(From the abstract:) AIMS AND OBJECTIVES: To examine stories of spirituality in people living with serious illness. BACKGROUND: Although knowledge about the experience of people with various chronic illnesses is growing, there is little known about peoples' beliefs and perspectives relating to spirituality where there is a diagnosis of a serious chronic

and life-limiting illness. DESIGN OF THE STUDY: A social constructionist approach to narrative inquiry was used. METHODS: In-depth narrative interviews were conducted on one occasion with 32 participants. This included 10 people with cancer, 14 people with end stage renal disease (ESRD) and eight people with HIV/AIDS. They ranged in age from 37-83 and included 18 men and 14 women. RESULTS: The themes were reflecting on spiritual religious and personal beliefs, crafting beliefs for their own lives, finding meaning and transcending beyond words. Participants melded various belief systems to fit their own lives. They also looked to find meaning in their illness experience and described what gave life meaning. For some aspects of these belief systems, participants could not or would not express themselves verbally, and it seemed that aspects of their experience were beyond language. CONCLUSIONS: The stories revealed considerable depth relating to perspectives on life, illness and existential questions, but many participants were not comfortable with the term 'spirituality'.]

Ramirez, S. P., Macedo, D. S., Sales, P. M., Figueiredo, S. M., Daher, E. F., Araujo, S. M., Pargament, K. I., Hyphantis, T. N. and Carvalho, A. F. "**The relationship between religious coping, psychological distress and quality of life in hemodialysis patients**." *Journal of Psychosomatic Research* 72, no. 2 (February 2012): 129-135. [This is a Brazilian study, with Kenneth I. Pargament as a co-author. (Abstract:) OBJECTIVE: No studies have evaluated the relationship among religious coping, psychological distress and health-related quality of life (HRQoL) in patients with End stage renal disease (ESRD). This study assessed whether positive religious coping or religious struggle was independently associated with psychological distress and health-related quality of life (HRQoL) in hemodialysis patients. METHODS: This cross-sectional study recruited a random sample of 170 patients who had ESRD from three outpatient hemodialysis units. Socio-demographic and clinical data were collected. Patients completed the Brief RCOPE, the Hospital Anxiety and Depression Scale (HADS) and the World Health Organization Quality of Life instrument-Abbreviated version (WHOQOL-Bref). RESULTS: Positive or negative religious coping strategies were frequently adopted by hemodialysis patients to deal with ESRD. Religious struggle correlated with both depressive ($r=0.43$; $P<.0001$) and anxiety ($r=0.32$; $P<.0001$) symptoms. These associations remained significant following multivariate adjustment to clinical and socio-demographic data. Positive religious coping was associated with better overall, mental and social relations HRQoL and these associations were independent from psychological distress symptoms, socio-demographic and clinical variables. Religious struggle was an independent correlate of worse overall, physical, mental, social relations and environment HRQoL. CONCLUSION: In ESRD, religious struggle was independently associated with greater psychological distress and impaired HRQoL, while positive religious coping was associated with improved HRQoL. These data provide a rationale for the design of prospective and/or intervention studies targeting religious coping in hemodialysis populations.]

III. To get a better sense of the overall *lived experience* of dialysis patients, see:

Clarkson, K. A. and Robinson, K. "**Life on dialysis: a lived experience**." *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* 37, no. 1 (January-February 2010): 29-35. [(Abstract:) The objective of this study was to explore the lived experience of patients with ESRD to determine if they are adequately educated about their illness so as to avoid the possible complications associated with the disease. Three pertinent conceptual categories emerged that described the concern

in the life of patients on dialysis: 1) life changes on dialysis with sub-themes of restricted life, limitations, and hard on body; 2) coping; and 3) areas lacking with sub-themes of health management, education, and preparing the next generation. Identified deficits among this study group will help healthcare professionals fill in the gaps in the delivery of healthcare service, which when addressed, would ultimately ease the burden of this disease on patients and their families.]

IV. Other articles we've cited on our website relating to renal disease and dialyais:

Davison, S. N. and Jhangri, G. S. "**Existential and supportive care needs among patients with chronic kidney disease**." *Journal of Pain & Symptom Management* 40, no. 6 (December 2010): 838-843. [Noted in our Summer 2011 Newsletter, §12. (Abstract:) CONTEXT: Living with chronic kidney disease (CKD) is associated with spiritual distress and frequently precipitates a search for meaning and hope; yet, very little is known about these patients' spiritual needs. OBJECTIVES: To describe the nature, prevalence, and predictors of spiritual and supportive care needs in CKD. METHODS: Prospective cohort study of 253 CKD patients who completed a seven-item spiritual and seven-item supportive care needs assessment. RESULTS: Patients reported a mean (standard deviation [SD]) number of 2.9 (2.6) spiritual needs, with 69.1% of patients reporting at least one spiritual need. The mean (SD) number of supportive care needs was 3.5 (2.1), with 91.4% of patients reporting at least one of these needs. Thirty-two percent of the patients had high spiritual needs (defined as reporting >=5 of the seven needs). Similarly, 37% of the patients reported high supportive care needs. Neither spiritual nor supportive care needs were associated with age, gender, race, marital status, dialysis modality, time on dialysis, or comorbidity. CONCLUSION: These patients had substantial spiritual and supportive care needs. There were no clear predictors of high spiritual or supportive care needs, highlighting the importance of evaluating all CKD patients for unmet needs. Health professionals will need to better understand and attend to CKD patients' spiritual needs to optimize quality care.]

Walton, J. "**Prayer warriors: a grounded theory study of American Indians receiving hemodialysis**." *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* 34, no. 4 (July-August 2007): 377-386. [Featured as our December 2007 Article-of-the-Month --and see the Items of Related Interest section. (Abstract:) The purpose of this classic grounded theory study was to explore what spirituality means to individuals who are American Indians receiving hemodialysis. Twelve women and 9 men ages 24 to 62, volunteered for this study. Informed consent was obtained, and in-depth interviews, field notes, and theoretical memos were completed. The metaphor "Prayer Warriors" described the core category of this study. Praying played a major role in the following categories: (a) suffering, (b) honoring spirit, (c) healing old wounds, and (d) connecting with community. Praying involved hard work, suffering, sweating, hunger, and passion, and was a powerful way to cope with the stress of hemodialysis.]

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