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## March 2015 Article of the Month

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

Scott, L. O., Law, J. M., Brodeur, D. P., Salerno, C. A., Thomas, A., and McMillan, S. C.

**"Relationship with God, loneliness, anger, and symptom distress in patients with cancer who are near the end of life."** *Journal of Hospice and Palliative Nursing* 16, no. 8 (December 2014): 482-488.

**SUMMARY and COMMENT:** This month's article reports research by five CPE residents from the James A. Haley Veterans' Hospital in Tampa, Florida, working with [Susan C. McMillan](#), PhD, ARNP, FAAN, Distinguished University Professor and Thompson Professor of Oncology Nursing at the College of Nursing of the University of South Florida, Tampa. It is of interest not only in terms of the particular topic but also as an example of a CPE program's partnership with an experienced researcher to mentor chaplains in a residency project. Four of the five residents have offered their personal reflections on the experience [--see below].

The study analyzed data from previous research [see Related Items of Interest, §III (below)], regarding 354 cancer patients in home hospice care, to explore two questions:

1. What are the levels of satisfaction with relationship with God, symptom distress, anger, and loneliness among cancer patients who are near the end of life?
2. What are the relationships between hospice patients' satisfaction with their relationship with God and the variables of anger, loneliness, and symptom distress?

The authors focus on *relationship with God* in light of there being "very limited research" [p. 482] on that factor in the healthcare literature. Assessments of relationship with God, as well as those for anger and loneliness, were made through the Hospice Quality of Life Index (developed by Dr. McMillan, et al.; see Related Items of Interest, §I (below)). The study sample was predominantly Christian.

Among the findings: "Scores on satisfaction with relationship with God in this group... were very high (mean, 9.2 on a 0- to 10-point scale)" [p. 484]; there was "relatively little loneliness" [p. 485], though the authors comment that their sample may have had stronger than typical support systems for cancer hospice patients; and, contrary to other research in the field, "relatively little anger" [p. 485]. Weak but significant relationships were found between the lack of loneliness and relationship with God, and between the lack of anger and the relationship with God. Also, "[p]atients who perceived a satisfactory relationship with God reported less symptom distress" [p. 486]; however, there was a positive correlation between reports of greater loneliness and symptom distress, and greater anger and symptom distress [--see p. 487]. While younger age was associated with greater anger, loneliness, and symptom distress, "age did not seem to have any association with the

patients' satisfaction with their relationship with God" [p. 487; and see also Items of Related Interest, §II (below)].

The authors speculate on the associations and, in so doing, suggest areas for further research. For example, regarding the sample's satisfaction with relationship with God:

This high satisfaction score may be related to the fact that because these patients were facing death, they might have been actively working on improving their relationships with God, although we cannot know that for certain. Although most patients were satisfied, it must be acknowledged that some patients were not. More research is needed about patients' relationships with God and whether they might be different as they get closer to death. [p. 484]

And, regarding the report of relatively little anger in the sample, the authors wonder whether "patients did not feel comfortable admitting to anger, especially if that anger was directed at God" [pp. 485-486]. The point implies both a patient's psychological dynamic of resistance and a researcher's methodological challenge of detection in this context.

Regarding methodology, the way that *relationship with God* was conceived and applied in the study should be noted.

...[T]he patients were asked about their relationships with God allowed even nonbelievers to rate themselves as satisfied because the question stated: "How satisfied are you with your relationship with God (however you define that relationship)?" The item was worded like this so that the subset of patients who did not believe in God could respond to that item and still have a range of satisfaction scores. They were told that if they did not believe in God and they were satisfied with that belief, they should score the item accordingly. [p. 487]

Whether "nonbelievers" would really feel at ease in responding to such a question, even with a proviso aimed at inclusivity, might be debated, but it raises the broad topic of how inclusive measures can be when employing religious language.

The article's closing sections (Implications of the Study and Conclusions) encourage nurses to use chaplains and other clergy in the care of patients, supporting a general advocacy for chaplaincy; and in the Discussion section the authors write: "Even patients who are satisfied [with their relationship with God] may find a visit from a chaplain or their own clergy person to be affirming and encouraging" [p. 485]. Overall, one message to the target audience of hospice nurses is to pay ever closer attention to patient spirituality.

### **Chaplain Co-Authors' Personal Reflections:**

*At the invitation of the Network, Chaplain Resident co-authors of this month's article offered personal reflections on their experience of participating in the study, with the hope of helping other chaplains to identify with the research process.*

### **From Chaplain Linda Olson Scott:**

Statistics and I never made friends in college. Researching any topic, however, was a joy. I spent hours in the seminary library opening worlds previously unknown to me. So when our resident group at the James A. Haley VA Medical Center in Tampa was offered the opportunity to learn about and do some research (with statistics) in the area of end-of-life and spiritual issues, I was both excited and horrified. It was the old "I don't understand these statistics" message playing in my head. But when our group met with Dr. Susan McMillan, I was

reassured. She assured us that we could do it and gain an understanding of how to do proper research on behalf of the hospital chaplaincy.

We dove in, with her expertise guiding our formulation of questions, discovery, and ultimately the statistical proofs that are essential for the medical world. We focused on end-of-life concerns of people dying of cancer. There was a statistical base already in place, and we used measuring instruments that were tried and true. This helped to establish credibility and our need to narrow down from the bigger and myriad questions we students had swimming in our minds. The stats were gathered and processed by people who are professionally trained to do that work – phew!

My research was focused on a person's relationship with God at end of life. This, combined with the interests of the other students, gave us a focus that was narrow yet broad enough to dive into. Dr. McMillan taught us to look for research with statistical measures, not just articles on spiritual issues. "The articles," she said, "won't give us proof that spirituality has an impact. It's the numbers, verifiable numbers that we need."

This task was both arduous and exciting. The process unfolded, and Dr. McMillan was a superb mentor and teacher. We were fed a semester's worth of statistical know-how in a few short weeks. And, we wrote and rewrote and rewrote again with her guidance. Amazingly to us (Dr. McMillan was certain all the time), we were published.

Thanks to Dr. Susan McMillan and my fellow residents, my fear of statistics is gone, and my love of research has been enhanced. I hope to do more in the future, now that I'm settled in my work at the Salem VA Medical Center. I might even try a stats course again – just maybe.

#### **From Chaplain Christopher A. Salerno:**

Initially, I was inspired simply to be introduced to research in the health care field, but I was uncertain that we as a group could devote the time necessary to come to an agreement on our topic and produce findings worthy of publication. But, with the help of Dr. Susan McMillan's didactics on topic selection, research writing, and a statistical analysis refresher, we began to formulate a course of action. In some respects, Dr. McMillan could have been listed first in authorship given her extensive contribution in shepherding us through the process but she graciously deferred, insisting that this was a Resident driven study. Given that none in our group could have shouldered the breadth of the work alone with our other responsibilities, we had to define our roles and coalesce as a team. As things began to fall into place, we found a synergy, and our collaborative efforts were under way. Chaplain Linda Scott's skills in editing served us well in shaping the written submissions of the group into a unified voice. In light of her help in this important area, we determined that she should be listed first among the contributors.

In addition to ministering to patients near end of life, during the course of this research the study took on a more personal note for me, particularly in my focusing on patient anger as it related to God, ultimately contributing to our research conclusions. I had just relocated from the West Coast and was near my 43 year old sister who suffers from a neurological illness that is expected to severely shorten her life span in spite of many corrective procedures and brain surgery. Reviewing the findings of our research often echoed weekend exchanges with my long-suffering sibling who spoke of God upholding her through bouts with pain and a continued diminished quality life as a wife and mother. She shared that reacting in anger would be akin to fighting against a rip tide and that acceptance was not giving up... moreover her faith sustained her as the Lord held her in his arms so far above the depths of possible suffering that she could not even see into the abyss. It was gripping that what I was hearing and understanding vicariously through a loved one's experience of affliction and faith response

was also playing out statistically in this study. My personal connection further distilled the point for me that a patient's relationship with God could have a profound effect on his or her symptom distress levels and that faith could become even more robust as a result. In the population studied, which was predominantly Protestant, those who believed in and put their trust in the Lord, generally experienced therapeutic benefits during times of intense pain and suffering.

From a professional perspective, it was also encouraging to contribute in a small way toward promoting Evidenced-based Spiritual Care. I recall it being related as a final draft of our paper was being copied at USF, that a psychologist who happened to be nearby skeptically quipped, "Chaplains can't do research." While I don't know the full context of that statement, I took issue with the contention, although I was not really surprised. I believe there is a feeling in much of the medical community that spirituality and faith are too personally subjective to undergird with empirical data. And while the existential questions of life may be harder to quantify than subjects studied by other disciplines, these are the same questions that medical professionals feel most unqualified to speak to and why I believe chaplains should be most capable in addressing such matters. I would definitely encourage other Residents to take advantage of any opportunities to do research in our field, both to augment their professional development and to give traction to our craft, and ultimately increase our standing in the broader healthcare community.

#### **From Chaplain Johnathon M. Law:**

What the experience was like for me: I had been previously exposed to the process of research and publication during portions of business school. When I first heard the idea of jumping into a large research project while balancing clinicals, book studies, weekly reflections, and the rest of the CPE workload...I was a little worried that this might be a bit too much. The data crunching and the math alone could be enough to consume more time than I thought I had available. This quickly changed when I was able to see inside the world of "medical" research. The benefits of going through this process outweighed the extra time spent on brainstorming and gathering information on the topics we as a group decided to focus on.

The entire process brought our CPE resident team closer together, and I was able to see just how important it is for chaplains to be doing research. Research brings credibility and legitimacy to a discipline, and it is my opinion that research in our professional field of work will help the clinical chaplain become more of a value-added asset to the interdisciplinary team and to total patient care. It may be very difficult to quantify and measure the outcomes of the ministry we provide to our patient population, however, it can be done. With more medical research in our field of work, I feel that patterns will develop and the data will show how we as caregivers bring healing and recovery to the people we serve.

I discovered through the research process that the "raw data" aspect of chaplaincy research is very difficult to come across. There just are not a large number of chaplains or organizations out there collecting data on spiritual topics and other chaplain related information. We were very fortunate to have Susan McMillan lead the way and connect us to an already established data pool that contained topics such as "relationship with God" and symptom distress. Without a strong support system during this project, we could have never completed this during a residency. This entire project helped me become more aware and focused on "outcome oriented chaplaincy," it helped me to see the world of medical research, and it was an overall good learning experience.

#### **From Chaplain Anzette Thomas:**

As a Chaplain, I am very appreciative for the opportunity to work on my first research project along with my fellow CPE Residents at the James A. Haley Veterans' Hospital under the direction of Dr. Susan McMillan. Dr. McMillan graciously gave of her time and herself as she shared her wisdom and expertise to inspire us Chaplain Residents to embrace the importance of research in our discipline. The interconnectedness of holistic health across interdisciplinary interests was evident in the research findings. I look forward to future opportunities to engage in research to support evidence based interventions to improve the quality of life for patients and their caregivers.

[*Editor's Note: The ACPE Supervisor for the residents involved in this research, Martin Montonye, has long been a champion of research in chaplaincy.*]

### **Suggestions for the Use of the Article for Student Discussion:**

The article is very accessibly written, with special attention to clarify potentially confusing points for the lay reader (e.g.: "Loneliness and symptom distress scores also were significantly negatively correlated.... This result means that as loneliness got worse, symptom distress got worse also." [p. 487]). Moreover the introductory sections on Relationship with God, Symptom Distress, Anger, and Loneliness offer brief but good overviews of select research to provide context. Therefore, CPE students should be able to engage the material quite well. Perhaps, too, students' interest may be piqued by knowledge of the authorship by a group of CPE residents working with an expert. Discussion could take up the main findings and could be spurred on by the speculations of causation offered in each case. Are there theological implications in the speculation? Do the students believe that the predominantly Christian makeup of the sample affected the results in any special way? What might be the strengths and weaknesses of using the concept (and language of) "relationship with God"? Also, is the finding about the significance of *age* a surprise? Are students able to appreciate the fact that, while relationship with God was negatively correlated with anger, loneliness, and symptom distress; nevertheless, the sample still indicated anger, loneliness, and symptom distress? Discussion could include some attention to how statistical relationships are talked about in the scientific literature.

### **Related Items of Interest:**

I. For more on the Hospice Quality of Life Index, see:

McMillan, S. C. and Mahon, M. "**Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index.**" *Quality of Life Research* 3, no. 6 (December 2004): 437-447. [(Abstract:) The purpose of this study was to evaluate the validity and reliability of the newly developed Hospice Quality of Life Index (HQLI). Sixty-eight patient/caregiver dyads from one hospice were asked to fill out the HQLI on admission and after 3 weeks of hospice care. Hospice experts evaluated the items on the tool to assess content validity. The content validity index (0.83) and the alpha coefficients ( $r = 0.87$  and  $0.83$ ) supported the validity and reliability of the HQLI. Item analysis revealed items with which patients were most satisfied and aspects of quality of life that were considered to be most important.]

McMillan, S. C. and Weitzner, M. "**Quality of life in cancer patients: use of a revised Hospice Index.**" *Cancer Practice* 6, no. 5 (September-October 1998): 282-288. [(Abstract:) PURPOSE: Improving or maintaining the quality of life for persons with cancer is a major goal of end-of-life care; however, to measure quality-of-life outcomes, a valid and reliable measure is needed. The

purpose of this project was to report the psychometric properties of the revised Hospice Quality of Life Index (HQLI), including validity and reliability for hospice patients with cancer.

**DESCRIPTION:** Data were collected from home care hospice patients with cancer (n = 255) and a group of apparently healthy adults in the community (n = 32). The revised HQLI is a 28-item self-report instrument that includes three subscales: Psychophysiological Well-being, Functional Well-being, and Social/Spiritual Well-being. **RESULTS:** Evidence for validity was provided in three ways. First, factor analysis confirmed the three subscales (Psychophysiological, Functional, and Social/Spiritual Well-being). Second, a weak significant correlation was found between the Eastern Cooperative Oncology Group Performance Status Rating scores and HQLI scores ( $r = .26$ ;  $P = .00$ ). Third, the HQLI was able to discriminate between hospice patients with cancer and apparently healthy adults ( $\lambda = .34$ ;  $P = .00$ ). In addition, the mean scores of these two groups were significantly different ( $t = 6.64$ ;  $P = .00$ ). However, only a minimal difference in scores was found on the Social/Spiritual Well-being subscale between the cancer and healthy groups. Reliability for the revised HQLI was high for both the total scale ( $\alpha = .88$ ) and the subscales ( $\alpha = .82-.85$ ). **CLINICAL IMPLICATIONS:** Emphasis has been placed recently on understanding quality of life from the patient's perspective. The development of a valid and reliable tool can guide care givers in providing meaningful quality-of-life care. The HQLI provides patients the opportunity to express beliefs about quality-of-life issues and to maintain direction over a critical aspect of their care. Of note from this study, the significant difference between groups in functional well-being and minimal difference in social/spiritual well-being suggest that patients are able to appraise their functional abilities realistically and still maintain their social network and spiritual beliefs. Indeed, it may be that patients give family relationships and spiritual beliefs greater focus during a terminal illness.]

**II.** Regarding associations of *younger age* with spiritual distress, see our [September 2011 Article-of-the-Month page](#).

**III.** The previous study from which the current article's data were gleaned:

McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L. and Haley, W. E. "**Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial.**" *Cancer* 106, no. 1 (January 1, 2006): 214-222. [(Abstract:)  
**BACKGROUND:** Family caregivers for cancer patients experience high levels of stress and burden and diminished quality of life (QOL). Interventions to improve coping skills of caregivers have been shown to be effective with other populations, but their impact has not been assessed in the difficult context of hospice care. The purpose of this study was to determine whether hospice plus a coping skill training intervention improved family caregivers' QOL, burden, coping, and mastery, compared with hospice plus emotional support, and usual hospice care. **METHODS:** A three group randomized controlled trial was conducted including baseline, 16 day, and 30 day assessments conducted from March 1999 to May 2003. The sample consisted of 354 family caregivers of community dwelling hospice patients with advanced cancer. Patient/caregiver dyads were randomly divided into three groups, including a control group (n = 109) who received standard hospice care, a group (n = 109) who received standard hospice care plus three supportive visits, and a group (n = 111) who received standard care plus three visits to teach a coping skills intervention. Primary outcomes included caregiver QOL, caregiver burden due to patient symptoms, caregiver burden due to tasks, and caregiver mastery. **RESULTS:** At the 30-day follow-up, the coping skills intervention led to significantly greater improvement in caregiver QOL (estimate = -0.16, standard error [SE] = 0.07,  $P = 0.03$ ), burden of patient symptoms (estimate = 0.28, SE = 0.07,  $P < 0.001$ ), and caregiving task burden (estimate = -0.01, SE = 0.01,  $P = 0.038$ ) than did the other two conditions. None of the groups showed significant change in overall caregiving mastery, caregiver mastery specific to caregiving tasks, problem-focused or emotion-focused coping.

CONCLUSIONS: The coping skills intervention was effective in improving caregiver QOL, reducing burden related to patients' symptoms, and caregiving tasks compared with hospice care alone or hospice plus emotional support. Structured caregiver skill-training interventions for caregivers are promising even in the difficult environment of end-of-life care and for families already receiving benefits of hospice care.]

#### IV. Other articles by Dr. Susan C. McMillan that may be of particular interest:

Buck, H. G. and McMillan, S. C. "**A psychometric analysis of the spiritual needs inventory in informal caregivers of patients with cancer in hospice home care.**" *Oncology Nursing Forum* 39, no. 4 (July 2012): E332-339. [(Abstract:) PURPOSE/OBJECTIVES: To test the validity and reliability of the Spiritual Needs Inventory (SNI) in measuring the spiritual needs of informal caregivers of patients with cancer in hospice home care. DESIGN: A subanalysis of a longitudinal, randomized hospice clinical trial. SETTING: Two hospices in the southwestern United States. SAMPLE: 410 informal caregivers of patients with cancer in hospice home care. METHODS: To test the hypotheses, Pearson and Spearman correlations, principal factor analysis with oblique rotation, and coefficient alpha were conducted. MAIN RESEARCH VARIABLES: Spiritual needs, depression, social support. FINDINGS: The SNI showed a small but significant positive correlation with the social support ( $p = 0.003$ ). A three-factor solution of the SNI accounted for about 55% of the variability. The first factor captured a traditional religious measure, with the original patient-reported subscales of inspiration, spiritual activities, and religion collapsing into this one factor. The second and third factors were similar to the original patient study. Cronbach alpha for the total scale was 0.88. The factor alphas ranged from 0.68-0.89. CONCLUSIONS: The current study provides early evidence for the validity and reliability of the SNI in informal caregivers of patients with cancer in hospice home care. Additional testing in other populations is recommended. IMPLICATIONS FOR NURSING: Use of the SNI with hospice caregivers could aid nurses in the identification of spiritual needs, enabling the development of plans of individualized, high-quality care.]

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., Herr, K., Joseph D. Rotella, J. D. and Casarett, D. J. "**Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association.**" *Journal of Pain and Symptom Management* (2015): article in press; available online from the journal website as of 2/16/15. [(Abstract:) CONTEXT: Measuring quality of hospice and palliative care is critical for evaluating and improving care, but no standard U.S. quality indicator set exists. OBJECTIVES: The Measuring What Matters (MWM) project aimed to recommend a concise portfolio of valid, clinically relevant, cross-cutting indicators for internal measurement of hospice and palliative care. METHODS: MWM was a sequential consensus project of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA). We identified candidate indicators mapped to National Consensus Project (NCP) Palliative Care Guidelines domains. We narrowed the list through a modified Delphi rating process by a Technical Advisory Panel and Clinical User Panel and ratings from AAHPM and HPNA membership and key organizations. RESULTS: We narrowed the initial 75 indicators to a final list of 10. These include one in the NCP domain Structure and Process (Comprehensive Assessment), three in Physical Aspects (Screening for Physical Symptoms, Pain Treatment, Dyspnea Screening and Management), one in Psychological and Psychiatric Aspects (Discussion of Emotional or Psychological Needs), one in Spiritual and Existential Aspects (Discussion of Spiritual/Religious Concerns), and three in Ethical and Legal Aspects (Documentation of Surrogate, Treatment Preferences, and Care Consistency with Documented Care Preferences). The list also recommends a global indicator of patient/family perceptions of care, but does not endorse a specific survey instrument. CONCLUSION: This consensus set of hospice and palliative care quality indicators is a foundation

for standard, valid internal quality measurement for U.S. settings. Further development will assemble implementation tools for quality measurement and benchmarking.]

McMillan, S. C., Small, B. J. and Haley, W. E. "**Improving hospice outcomes through systematic assessment: a clinical trial.**" *Cancer Nursing* 34, no. 2 (March-April 2011): 89-97. [(Abstract:)  
BACKGROUND: Systematic assessment is vital to palliative care, but documentation confirming completion of systematic assessment in hospice settings is often inadequate or absent.  
OBJECTIVE: The objective of the study was to determine the efficacy of systematic feedback from standardized assessment tools for hospice patient-caregiver dyads in improving hospice outcomes compared with the usual clinical practice. INTERVENTIONS/METHODS: The sample of patients (n = 709) newly admitted to hospice home care in 2 hospices had designated family caregivers. The interdisciplinary teams (IDTs) caring for these dyads were randomly assigned to either experimental (n = 338) or control (n = 371) conditions. Data were collected from both groups of dyads using standardized assessments on admission and 1 week after each of the first 2 IDT meetings in which these dyads were discussed. The experimental intervention consisted of reporting data from the standardized assessments to the IDTs. RESULTS: Results showed improved patient depression (P < .001) as a result of the intervention and improvement in both groups in patients' quality of life (P < .001). No other patient outcomes (symptom distress, spiritual needs) or caregiver outcomes (depression, support, spiritual needs) were significantly different. CONCLUSIONS: Assessment of depression added to usual care probably had an effect because it is not normally a focus of hospice staff. Hospice care was so good during the study that overall quality of life improved as a result of standard care and left little room for improvement in other variables. IMPLICATIONS FOR PRACTICE: Systematic assessment of depression is needed in hospice patients. No caregiver variables changed, which may indicate a need for a focus on caregivers.]

McMillan, S. C and Weitzner, M. "**How problematic are various aspects of quality of life in patients with cancer at the end of life?**" *Oncology Nursing Forum* 27, no. 5 (June 2000): 817-823. [(Abstract:)  
PURPOSE/OBJECTIVES: To identify aspects of quality of life (QOL) in patients receiving end-of-life care that are most and least problematic for patients. DESIGN: Descriptive using secondary analysis of data from an earlier QOL study. SETTING: A large not-for-profit hospice that primarily provides home care in southwest Florida. SAMPLE: 231 homecare hospice patients with cancer. METHODS: Item analysis of items on the Hospice Quality-of-Life Index. MAIN RESEARCH VARIABLES: Psychophysiologic, functional, and social/spiritual well-being. FINDINGS: Patients had the most problems in the area of functional well-being and the least problems with social/spiritual well-being. Most common physical problems included constipation and dyspnea. CONCLUSIONS: Patients with end-stage cancer are able to maintain their relationships with God and with family and friends even in the face of marked functional difficulties and troublesome physical symptoms. IMPLICATIONS FOR NURSING PRACTICE: A continued focus on the patient and family by the interdisciplinary healthcare team is warranted.]