November 2016 Article of the Month

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

King, S. D. W., Fitchett, G., Murphy, P. E., Pargament, K. I., Harrison, D. A. and Loggers, E. T. "**Determining best methods to screen for religious/spiritual distress**." *Supportive Care in Cancer* (2016): 9 pp., published online ahead of print, October 6, 2016.

[***Editor's Note:*** *Because this article is available ahead of print, no final page numbers can be cited. Quotations noted below are referenced by manuscript [MS] page numbers.*]

SUMMARY and COMMENT: This is an extraordinarily well-written article, from eminent researchers in the field of spirituality & health, on a topic of great practical value to most chaplains. "...[T]his study was designed to rigorously test for the first time a variety of methods of R/S [Religious/Spiritual] distress screening to identify the best very brief screening items" [MS p. 2]. In the process, it establishes an important baseline of results in relation to which further research can build a continually refined understanding of spirituality screening.

Data were collected as part of a larger survey of hematopoietic cell transplant (HCT) survivors at one major cancer center --that patient group being judged to "represent a reasonable sample for distress screening across the broader care continuum of cancer patients in treatment and cancer survivors because most HCT survivors do not return to their original baseline, continuing to face medical, physical, emotional, and existential threats increasing the likelihood of encountering R/S distress" [MS p. 2]. Mailed paper surveys included the 7-item Negative Religious Coping subscale of the popular Brief RCOPE measure along with six selected screening measures [--see MS pp. 2-3]:

- "Do you struggle with the loss of meaning and joy to your life?"
- "Do you currently have what you would describe as religious or spiritual struggles?"
- "Are you at peace?"
- "Does your religion/spirituality provide you all the strength and comfort you need from it right now?"
- "Do you have any spiritual/religious concerns?"
- the two-path Revised Rush Religious Struggle Protocol which asks about the importance of R/S in the patient's life and then, depending on the response, asks either how much their R/S is helping them now or whether R/S has been important previously. [See Items of Related Interest, below.]

The questions, choices for answering, and response data are reported in a table [MS pp. 5-6]. Using the Brief RCOPE's Negative Religious Coping subscale as the reference standard, the researchers set a threshold for the other measures of 85% for sensitivity to R/S distress and for specificity (i.e., "correctly identifying persons

without distress" [MS p. 3]). The final sample for analysis was 1449 patients [35.7% of all patients who were sent the survey]. Among the results:

- "The responses of the study participants to negative religious coping items indicated that 14% had some R/S distress." [MS p. 3]
- ...[T]hough two of the screeners had a specificity of at least 85%, none of the very brief screeners approached our pre-specified minimum of 85% sensitivity." [MS p. 3]
- ...[T]he simultaneous use of two screening items was assessed (the Rush Protocol was omitted...because it was not a single-item screener...). Combining the meaning/joy item with the self-described struggle produced the highest sensitivity (82% sensitivity) followed by the pair of meaning/joy and the peace item (78% sensitivity) in the whole sample...." [MS p. 4]. The sensitivity of those same pairs was also confirmed in an analysis of a subsample of patients within 2 years of transplant.
- Specificity was nevertheless low for the pairing of meaning/joy and self-described struggle (50%) and for meaning/joy and peace (54%) in the full sample, and even lower for the subgroup of patients within 2 years of transplant. [--See Table 4, MS p. 8 for all percentages]; "which may have important implications for resource use in cancer care organizations attempting to efficiently screen for R/S distress" [MS p. 4]. However, the authors caution against using the screeners that produced relatively higher specificity. For example, the dyad of peace and self-described struggle yielded a specificity of 64% in the full sample (and a sensitivity of 75%), but the authors' own clinical experience of using the peace item in particular leads them to suspect that it may over-assess R/S distress in the newly diagnosed [--see MS p. 4].

The authors acknowledge a number of limits to the study, among which are the limits of the Brief RCOPE which was used as the reference standard here, the fact that the "best single screening item, meaning/joy, is limited in that it measures two themes simultaneously" [MS p. 8], and the study population did not involve patients in active treatment. They affirm the need for replication, "including using clinical interviews by a chaplain or other professional with expertise in R/S distress as a reference standard" [MS p. 8], and suggest exploring the potential of the recently developed Religious and Spiritual Struggles Questionnaire which assesses more domains of R/S distress than the Brief RCOPE.

Nevertheless, the authors lift up the strengths of their study:

> Unlike many other studies, we identified clear cutoff values for each screening item and pre-specified our target sensitivity and specificity. Other strengths of the study include the large and geographically diverse sample used in the analyses and consistency of the findings in the full sample and the subsample. [MS p. 8]

Their conclusion is a rather bold recommendation, at least regarding cancer patients:

> While this study did not identify a valid single item screener for R/S distress, the simultaneous use of the meaning/joy and self-described distress items is currently the best choice for screening for R/S distress in cancer patients and survivors. Until further study identifies another method, we recommend this pair be considered for all clinical screening for R/S distress, even among cancer patients in active treatment, when only a minimal number of items are permitted.

A final thought: Since screening questions ultimately turn on the effectiveness of specific word choices, it is notable that the two top contenders out of this study -- Do you struggle with the loss of meaning and joy to your life?" and "Do you currently have what you would describe as religious or spiritual struggles?" -- both employ the word *struggle*. This reader wonders how that word in particular may be a key to opening up revealing responses about distress from HCT patients or patients in general. It is not a word that figures into any of the other assessments studied here, even the Brief RCOPE, but it may ring with a special clarity for many in the throes of healthcare crises. If so, then this raises a question of whether the term is as effective with patients in less severe circumstances and what analog terms in other languages are similarly effective.

Special comment to the Network from lead-author Stephen D. W. King, Manager: Chaplaincy, Child Life, and Clinical Patient Navigators at Seattle Cancer Care Alliance, Seattle, WA:

> There were several reasons for this study. There were too many patients for our chaplains to visit; we needed a way to prioritize patients beyond those referred by staff. Patients with religious/spiritual (R/S) struggle were being demonstrated in studies to have a number of other issues in addition to their spiritual pain: e.g., slower rehabilitations and longer hospitalizations, greater pain and depression, and poorer quality of life and coping. Furthermore, about 50% of cancer patients were identified in these studies as having sufficient RS struggle to have these associations. However, the studies used too many questions; we needed one or two screening items. We began to experiment with paper-and-pen screening of patients in certain service areas to see what items generated reasonable referrals. But we did not know how well "our best" items would identify those indicated by the "gold standard" in measuring RS struggle (i.e., the Brief RCOPE). I knew our Long Term Follow-Up program for survivors of hematopoietic cell transplant did an annual survey. As it turned out, they also added brief modules each year and had been asked by survivors to inquire about spirituality. After further conversation, we agreed to do a pilot study of the questions, and if there were no identified issues, to add an R/S coping module. I consulted with a number of experts in the field, and a plan was made for a study that would address a number of issues including determining the best screening items for R/S struggle. Collaboration with local and national researchers made the study possible. In 2015, the Commission on Cancer mandated screening all cancer patients for psychosocial distress, including spiritual. Thus, an issue that was important locally became an identified issue of national importance. Our study is just the first step in addressing this need …and through the collaboration a way for me to learn more about research --*SDK*

Suggestions for Use of the Article for Student Discussion:

This article should be engaging to chaplaincy students not only for the topic but as a result of the strength and clarity of the writing. While it focuses on specific screening questions, it broaches the wider issue of screening per se. What do students think of the idea of patients being screened for religious/spiritual distress by means of explicit questions? Do they imagine that this could be part of their pastoral practice, or would they prefer that the screening be done by someone else? If so, how would this bring the dynamics of *referral* into play? What might be the difference between asking explicit screening questions and a chaplain simply *listening* for the themes of certain screening questions during a pastoral conversation? What of the authors' point that, while the Negative Religious Coping subscale of the Brief RCOPE may be worthy of being a reference standard for the study, its "seven items...may be burdensome" [MS p. 2]? Our authors note the issue of screening for R/S distress in patients "with no explicit religious identity" [MA p. 2]. Is this a salient issue for students? And, how important is the timing of an assessment? It's not just about *what* to ask but *when* to do it [--see MS pp. 4 and 8]. Looking at the tested screening items themselves, do students have personal preferences that might not align with the findings of the article? If that's the case, then are they receptive to being swayed by the research? In light of the authors' comment about "balanc[ing] the value of sensitivity relative to that of specificity" [MS p. 4], students might consider closely the trade-offs implicit in Table 4 [MS p. 8] to see the practical compromises implicit in the various screening question combinations. What is the relationship between the empirical data here and the need for the authors to work with it in light of such factors as their "clinical experience" [--see MS

p. 4]? For students more versed in research, the data presented in the tables could be rich source for discussion [--especially Table 3 on MS p. 7].

Related Items of Interest:

I. For related research from our authors on hematopoietic cell transplant (HCT) survivors, see:

> King, S. D. W., Fitchett, G., Murphy, P. E., Pargament, K. I., Martin, P. J., Johnson, R. H., Harrison, D. A. and Loggers, E. T. "**Spiritual or religious struggle in hematopoietic cell transplant survivors**." *Psycho-Oncology* (2015): published online ahead of print. [(Abstract:) BACKGROUND: This study describes the prevalence of religious or spiritual (R/S) struggle in long-term survivors after hematopoietic cell transplantation (HCT), demographic and medical correlates of R/S struggle, and its associations with depression and quality of life. METHODS: Data were collected in conjunction with an annual survey of adult (age ≥18 years) survivors of HCT. Study measures included R/S struggle (negative religious coping, NRC, from Brief RCOPE), measures of quality of life (subscales from 36-item Short Form Health Survey and McGill), and the Patient Health Questionnaire 8. R/S struggle was defined as any non-zero response on the NRC. Factors associated with R/S struggle were identified using multi-variable logistic regression models. RESULTS: The study analyzed data from 1449 respondents who ranged from 6 months to 40 years after HCT. Twenty-seven percent had some R/S struggle. In a multi-variable logistic regression model, R/S struggle was associated with greater depression and poorer quality of life. R/S struggle was also associated with younger age, non-White race, and self-identification as either religious but not spiritual or spiritual but not religious. R/S struggle was not associated with any medical variables, including time since transplant. CONCLUSIONS: Religious or spiritual struggle is common among HCT survivors, even many years after HCT. Survivors should be screened and, as indicated, referred to a professional with expertise in R/S struggle. Further study is needed to determine causal relationships, longitudinal trajectory, impact of struggle intensity, and effects of R/S struggle on health, mood, and social roles for HCT survivors.]

II. The individual assessments tested here are each worthy of a closer look. For more on the Rush Protocol, see our January 2013 Article-of-the-Month page. The question "Are you at peace?" was the focus of our February 2006 Article-of-the-Month. And, the NCCN Distress Thermometer and Problem List, may be found on the National Comprehensive Cancer Network website.

III. Our article references a joint position statement on screening for distress from the American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society [MS p. 2], including a recognition of R/S distress. The definition for distress given there comes from the National Comprehensive Cancer Network (NCCN): "unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment." The link to that joint statement, given in the bibliographical notes does not seem to work, though the document appears to be available from the Association of Oncology Social Work. For more on this, however, see:

> Pirl, W. F., Fann, J. R., Greer, J. A., Braun, I., Deshields, T., Fulcher, C., Harvey, E., Holland, J., Kennedy, V., Lazenby, M., Wagner, L., Underhill, M., Walker, D. K., Zabora, J., Zebrack, B. and Bardwell, W. A. "**Recommendations for the implementation of distress screening programs in**

cancer centers: report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force." *Cancer* 120, no. 19 (October 1, 2014): 2946-2954. [(Abstract:) In 2015, the American College of Surgeons (ACoS) Commission on Cancer will require cancer centers to implement screening programs for psychosocial distress as a new criterion for accreditation. A joint task force from the American Psychosocial Oncology Society, the Association of Oncology Social Work, and the Oncology Nursing Society developed consensus-based recommendations to guide the implementation of this requirement. In this review, the authors provide recommendations regarding each of the 6 components necessary to meet the ACoS standard: 1) inclusion of psychosocial representation on the cancer committee, 2) timing of screening, 3) method/mode of screening, 4) tools for screening, 5) assessment and referral, and 6) documentation.]

IV. The popular Brief RCOPE, used as the reference standard in this month's study, was developed from a longer RCOPE instrument, which is described in detail by Kenneth I. Pargament, Harold G. Koenig, and Lisa M. Perez in "**The many methods of religious coping: development and initial validation of the RCOPE**" [*Journal of Clinical Psychology* 56, no. 4 (April 2000): 519-543] (available online). For a tabular summary of the Brief RCOPE, pairing its 14 items with religious coping methods and key religious functions, click **HERE**. For a formal and detailed introduction to, and explanation of, the measure, see:

Pargament, K., Feuille, M. and Burdzy, D. "**The Brief RCOPE: current psychometric status of a short measure of religious coping**." *Religions* 2, no. 1 (2011): 51-76. [The Brief RCOPE is a 14-item measure of religious coping with major life stressors. As the most commonly used measure of religious coping in the literature, it has helped contribute to the growth of knowledge about the roles religion serves in the process of dealing with crisis, trauma, and transition. This paper reports on the development of the Brief RCOPE and its psychometric status. The scale developed out of Pargament's (1997) program of theory and research on religious coping. The items themselves were generated through interviews with people experiencing major life stressors. Two overarching forms of religious coping, positive and negative, were articulated through factor analysis of the full RCOPE. Positive religious coping methods reflect a secure relationship with a transcendent force, a sense of spiritual connectedness with others, and a benevolent world view. Negative religious coping methods reflect underlying spiritual tensions and struggles within oneself, with others, and with the divine. Empirical studies document the internal consistency of the positive and negative subscales of the Brief RCOPE. Moreover, empirical studies provide support for the construct validity, predictive validity, and incremental validity of the subscales. The Negative Religious Coping subscale, in particular, has emerged as a robust predictor of health-related outcomes. Initial evidence suggests that the Brief RCOPE may be useful as an evaluative tool that is sensitive to the effects of psychological interventions. In short, the Brief RCOPE has demonstrated its utility as an instrument for research and practice in the psychology of religion and spirituality.] [This is an Open Access article.]

V. For more on the American College of Surgeons' Commission on Cancer standards see the organization's website, which gives both the 2012 standards and the new ones for 2016. The 2012 standards address [pp. 76-77] the phase-in of the Psychosocial Distress Screening cited in our article and further mention spirituality on pp. 38 and 70. The 2016 standards covers the distress screening on pp. 56-57 and in the glossary on p. 80, and also mentions spirituality on pp. 25 and 53. [Note, however, that the explicit mention of *chaplains* occurs only in the 2012 standards (p. 70).]

VI. Participants in our featured research were survivors of hematopoietic cell transplantation. For more on such patients, see our September 2015 Article-of-the-Month page.
