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February 2004 Articles of the Month

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

Peterman, A. H., Fitchett, G., Brady, M. J., Hernandez, L. and Cella, D. "Measuring spiritual well-being in people with cancer: the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp)." *Annals of Behavioral Medicine* 24, no. 1 (January 2002): 49-58.

Fisch, M. J., Titzer, M. L., Kristeller, J. L., Shen, J., Loehrer, P. J., Jung, S.-H., Passick, S. D. and Einhorn, L. H. "Assessment of quality of life in outpatients with advanced cancer: the accuracy of clinician estimations and the relevance of spiritual well-being--a Hoosier Oncology Group study." *Journal of Clinical Oncology* 21, no. 14 (July 15, 2003): 2754-2759.

SOME BACKGROUND TO *SPIRITUAL WELL-BEING*: The idea of *spiritual well-being*, as a scientifically measurable sociological concept, developed in relation to public policy in the late 1960s and the 1970s, to a large extent through the work of sociologist David O. Moberg. In 1971, Moberg was the principal author of a report, *Spiritual Well-Being: Background and Issues*, which was part of a White House initiative. This report now seems very dated in many ways, but it is striking in its treatment of spirituality vis-a-vis religion.

...[W]e shall consider "the spiritual" as pertaining to man's inner resources, especially his ultimate concern, the basic value around which all other values are focused, the central philosophy of life-whether religious, anti-religious, or nonreligious--which guides a person's conduct, the supernatural and nonmaterial dimensions of human nature. We shall assume, therefore, that all men are "spiritual," even if they have no use for religious institutions and practice no personal pieties. [Moberg, D. O. and The Technical Committee on Spiritual Well-Being (Hess T. Sears, chairman), *Spiritual Well-Being: Background and Issues* (White House Conference on Aging, February 1971), p. 3.]

Later, Moberg noted in relation to the White House Conference that focusing on *spiritual well-being* rather than on *religion* allowed participants to "overcome" certain "constitutional and other barriers to investigation." [Moberg, D. O. and Brusek, P. M., "Spiritual well-being: a neglected subject in quality of life research," *Social Indicators Research* 5, no. 3 (July 1978): 313.] The White House Conference report indicated a desire to transcend the traditional language and perceived limits of religion, but in the end it was a report that talked about churches and Biblical teachings and even decried what it called "institutionless religion" [p. 42 of the report]. Spirituality itself does not seem to have been dealt with very practically apart from religion, in spite of intentions to the contrary.

The concept of spiritual well-being proved convenient for the purpose of public policy consideration, but there were many problems from an investigational standpoint, not the least of which was the design of measures for something so broad and varied as spirituality. Yet in 1982, the Spiritual Well-Being Scale was published by Raymond F. Paloutzian and Craig W. Ellison, consisting of two subscales for Existential Well-Being and Religious Well-Being. This 20-item measure became attractive for its relative brevity, in addition to its attention to existential issues implicit in the concept of spirituality going beyond religion per se. It became widely used, more than Moberg's own 1984 Spiritual Well-Being Questionnaire--a 96-item comprehensive questionnaire, requiring 30-60 minutes to complete. [See Moberg, D. O., "Subjective measures of spiritual well-being," *Review of Religious Research* 25, no. 4 (1984): 351-359.]

Paloutzian and Ellison's Spiritual Well-Being Scale will be the subject of the March 2004 Articles-of-the-Month page, but those immediately interested in the measure may consult Paloutzian, R. F. and Ellison, C. W., *Manual for the Spiritual Well-Being Scale* (Nyack, NY: Life Advance, Inc., 1991), or visit their web site at www.lifeadvance.com. For the present purpose, however, it is worth noting that the Spiritual Well-Being Scale includes items referring to prayer and a personal relationship with God--items which may problematically limit the use of the scale because they work out of specific religious practices and beliefs.

The early sociological use of the concept of *spiritual well-being*—as evidenced in the White House Conference report—seems to have indicated at least a general interest in expanding what had been conceptualized as *religion*, and measures like the Spiritual Well–Being Scale offered some practical means for doing this, but religious language remained the parlance for discussion and for instruments. In the years since, as spiritual well-being has become more and more a concept for research into spirituality and health, the language of spirituality has continued to evolve. The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp), common to the articles in this month's selection, attempts to measure spiritual well-being in a way that accommodates religious perspectives without being limited by them, so as to be useful with diverse populations.

ARTICLE SUMMARIES AND COMMENTS: The two articles featured this month are a report of the development and testing of the FACIT-Sp and a report of an implementation of the instrument (that may possibly suggest a future study for chaplains). Both articles present the actual 12-item instrument, but the FACIT-Sp may also be downloaded directly as a PDF file from www.facit.org for free (though registration is required). It should be noted that the FACIT-Sp consists of two subscales: the Meaning and Peace Subscale (items 1-8) and the Faith Subscale (items 9-12).

The article by **Peterman, et al.** presents two studies of the FACIT-Sp itself. The first "demonstrates good internal consistency reliability and a significant relation with quality of life in a large, multiethnic sample" [p. 49, abstract]. Participants (n=1,617) had current or past diagnoses of cancer or AIDS/HIV infection and were given, in addition to the FACIT-Sp, the Functional Assessment of Cancer Therapy--General (FACT-G) scale, which is a staple of quality of life research; the Marlowe-Crowne Social Desirability Scale (MCSDS), and the Profile of Mood States--Short Form (POMS-FS). Participants' functional status was also assessed using the Eastern Cooperative Oncology Group Performance Status. Results are detailed well in the narrative and in tables, including slight trends relating to age, education, sex, ethnic and religious groups, and type of disease, in terms of both the Peace and Meaning and the Faith subscales, though no such trends could be seen to compromise the instrument's soundness overall (--however, this reader was somewhat troubled that Jewish participants had lower FACIT-Sp scores). The use of the MCSDS is especially noteworthy, as social desirability is a perennial concern in religious/spiritual research.

The second study described in this same article "was undertaken to further validate the FACIT-Sp by examining its relation to existing measures of religion and spirituality" [p. 54]. Participants (n=131) were part of a larger, longitudinal study of fatigue and quality of life of cancer patients beginning chemotherapy. The FACIT-Sp was found to be moderately correlated with other measures, including the Spiritual Beliefs Inventory (SBI), the Coherence subscale of the Reker Life Attitude Profile--Revised (LAP-R), the Cancer Patient Behavior Survey (CAPB) and items relating to organizational and nonorganizational religious activity and intrinsic religiousness. The study is a fine example of the process of instrument validation.

In light of these findings, the authors discuss the strengths of the instrument, including:

this measure appears to be a good choice for assessing spirituality across a range of religious traditions and for respondents who identify themselves as spiritual but not religious. ...In addition, the items in the scale make no reference to specific religious beliefs or practices, such as belief in God or use of prayer. [p. 56]

Hence the contrast to earlier measures as illustrated in the BACKGROUND comments, above. The authors of the FACIT-Sp have sought to use careful language that may speak to religious individuals but without using traditional religious terminology which may be potentially delimiting. So, there is emphasis on peacefulness, harmony, and meaning and purpose, and the use of the only slightly awkward phrase, "my faith or spiritual beliefs." The language of the items of the measure seem, to this reader, to flow from a genuine a sense of spirituality and not from a mere desire to avoid religious expressions. The instrument's Faith subscale shows moderate to strong association with traditional religious dynamics without implying a very particular religious perspective, and it appears that the Meaning and Peace subscale may bring out "a dimension that is more independent [of religion] and is not assessed by [other] existing instruments" [p. 56].

Chaplains should consider using the FACIT-Sp in research, especially inasmuch as it is well suited for a diverse population. What is not known, however, is how well the instrument may be employed to measure *change* in spiritual well-being. Subjects are asked to assess how questionnaire items apply to their experience of the "past 7 days," but might the measure be sensitive to changes over, say, a two-week period? Also, on a very pragmatic level (but not unrelated to research), chaplains may want to think about how the language of the instrument may model a general strategy for spiritual discussion and spiritual assessment in a diverse institutional setting. If the validity testing in the article is accurate--and there's no immediate reason to suspect that it isn't, even in light of the authors enumeration of study limitations (see p. 56)--the instrument may work well in research precisely because it engages individuals about their spirituality in profound ways. [Note: One of the authors is Network member George Fitchett, CPE Supervisor, Rush University Medical Center, Chicago IL.]

Turning now to the second featured article, the study by **Fisch**, **et al.** uses the FACIT-Sp in an assessment of how well clinicians estimate patients' own sense of their quality of life, since clinicians do often rely on subjective analyses of patients' quality of life rather than on a formal and validated assessment. A total of 163 patients with advanced, incurable cancer were enrolled from 15 sites (3 academic medical centers and 12 community sites) and were given the Functional Assessment of Cancer Therapy--General (FACT-G) scale and the FACIT-Sp. Among the results: clinicians were found to have "only modest success...in accurately estimating the level of QOL impairment of their patients, with an overall accuracy rate of approximately 60%" [p. 2758]. Moreover, the sicker the patient, the less likely the clinician was found to be accurate in assessing QOL, however, "higher levels of SWB [spiritual well-being] were associated with less risk of clinician underestimation of impairment" [p. 2758]. On this latter point, the authors speculate:

One reason why higher SWB might reduce the risk of clinician underestimation of QOL impairment is that clinicians may feel more comfortable spending additional time and communicating with patients whose SWB is high, thus improving the quality of their assessments. Alternatively, it could be that patients with adequate or high levels of SWB do not need thick smokescreens to preserve their dignity. [p. 2758]

This research primarily compares a subjective assessment to an assessment by means of a validated instrument-in this case looking at clinicians' assessments of patients' quality of life, which itself may be influenced by patients' spiritual well-being. From this, it is possible to imagine another study using the FACIT-Sp that would focus on chaplains' own subjective assessments of patients' spiritual well-being and perhaps quality of life. Might chaplains' subjective assessments in these areas be more or less accurate than those of clinicians? Might chaplains benefit from using some formal assessment or at least some standard assessment strategy that may be inspired by the FACIT-Sp? Again, a close look at that instrument's language may be profitable. Like so many studies in the health care literature, this one by Fisch, et al. does not concentrate on chaplains but yet may model a study that could be adapted for explicitly pastoral research.

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

These two articles contain a great many statistical details, and students should be cautioned--as has been said in a number of these Article-of-the-Month pages--not to get "bogged down" in statistics if that becomes a problem. Students can bring much critical thinking to the non-statistical sections of these reports. The article by Peterman, et al. is a good illustration of the process of instrument validation, and students may want to discuss especially the idea of guarding against "social desirability" in questionnaire items or in typical pastoral interaction with patients. As suggested already, students may also want to think at length about the properties and dynamics of the language used in the FACIT-Sp and how such relates to their own sense of spiritual and/or religious language. Finally, both articles connect spiritual well-being to quality of life, and students might be challenged to explore that latter concept and how it may be a *bridge* concept between pastoral care and other health care disciplines.

Other Items of Interest:

I. [ADDED 9/23/08]: See: Canada, A. L., Murphy, P. E., Fitchett, G., Peterman, A. H. and Schover, L. R., "A 3-factor model for the FACIT-Sp," *Psycho-Oncology* 17, no. 9 (September 2008): 908-916; noted in our <u>Fall 2008 Newsletter</u> (§6).

II. The following is a sample of studies that utilize the FACIT-Sp.

[ADDED 2/16/05]: Andrykowski, M. A., Bishop, M. M., Hahn, E. A., Cella, D. F., Beaumont, J. L., Brady, M. J., Horowitz, M. M., Sobocinski, K. A.; Rizzo, J. D. and Wingard, J. R. "Long-term health-related quality of life, growth, and spiritual well-being after hematopoietic stem-cell transplantation." *Journal of Clinical Oncology* 23, no. 3 (January 20, 2005): 599-608.

Brady, M. J., Peterman, A. H., Fitchett, G., Mo. M. and Cella, D. "A case for including spirituality in quality of life measurement in oncology." *Psycho-Oncology* 8, no. 5 (September-October 1999): 417-428.

Cotton, S. P., Levine, E. G., Fitzpatrick, C. M., Dold, K. H. and Targ, E. "Exploring the relationship among spiritual well-being, quality of life, and psychological adjustment in women with breast cancer." *Psycho-Oncology* 8, no. 5 (September-October 1999): 429-438.

[ADDED 2/16/05]: Daugherty, C. K., Fitchett, G., Murphy, P. E., Peterman, A. H., Banik, D. M., Hlubocky, F. and Tartaro, J. "Trusting God and medicine: spirituality in advanced cancer patients volunteering for clinical trials of experimental agents." *Psycho-Oncology* 14, no. 2 (February 2005): 135-46.

[Added 11/14/07:] Kruse, B. G., Ruder, S. and Martin, L. "**Spirituality and coping at the end of life**." *Journal of Hospice & Palliative Nursing* 9, no. 6 (November/December 2007): 296-304.

[ADDED 9/23/08]: Mack, J. W., Wolfe, J., Grier, H. E., Cleary, P. D. and Weeks, J. C. "Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information." *Journal of Clinical Oncology* 24, no. 33 (November 20, 2006): 5265-5270.

[ADDED 9/23/08]: Martensson, G. Carlsson, M. and Lampic, C. "**Do nurses and cancer patients agree on cancer patients' coping resources, emotional distress and quality of life?** " *European*

Journal of Cancer Care 17, no. 4 (July 2008): 350-360.

McClain, C. S., Rosenfeld, B. and Breitbart, W. "Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients." *The Lancet* 361, no. 9369 (May 10, 2003): 1603-1607.

[ADDED 4/3/05]: McClain-Jacobson, C., Rosenfeld, B., Kosinski, A., Pessin, H., Cimino, J. E. and Breitbart, W. "Belief in an afterlife, spiritual well-being and end-of-life despair in patients with advanced cancer." *General Hospital Psychiatry* 26, no. 6 (November-December 2004): 484-486. [This article is featured as the April 2005 Article-of-the-Month.]

Nelson, C. J., Rosenfield, B., Breitbart, W. and Galietta, M. "Religion, spirituality, and depression in the terminally ill." *Psychosomatics* 43, no. 3 (May-June 2002): 213-220.

[ADDED 2/5/06]: Steinhauser, K. E., Voils, C. I., Clipp, E. C., Bosworth, H. B., Christakis, N. A. and Tulsky, J. A. "'Are you at peace?': one item to probe spiritual concerns at the end of life." *Archives of Internal Medicine* 166, no. 1 (January 9, 2006): 101-105.

[ADDED 9/23/08]: Szaflarski, M., Ritchey, P. N., Leonard, A. C., Mrus, J. M., Peterman, A. H., Ellison, C. G., McCullough, M. E. and Tsevat, J. "Modeling the effects of spirituality/religion on patients' perceptions of living with HIV/AIDS." *Journal of General Internal Medicine* 21 Suppl. 5 (December 2006): S28-S38.

III. A longer (23-item) version of the FACIT-Sp, called the FACIT-Sp-Ex, is also be available from www.facit.org. Regarding this, see: Brady, M. J., Peterman, A. H., Fitchett, G. and Cella, D., "The expanded version of the Functional Assessment of Chronic Illness Therapy--Spiritual Well-Being Scale (FACIT-Sp-Ex): initial report of psychometric properties." Annals of Behavioral Medicine 21 (1999): 129.

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