September 2015 Article of the Month

This month's article selection is by Chaplain John Ehman,
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Leeson, L, A., Nelson, A. M., Rathouz, P. J., Juckett, M. B., Coe, C. L., Caes, E. W. and Costanzo, E. S. "**Spirituality and the recovery of quality of life following hematopoietic stem cell transplantation**." *Health Psychology* 34, no. 9 (September 2015): 920-928.

SUMMARY and COMMENT: The practical task of research is less about providing definitive answers than deepening the questions that move our understanding closer to some reality. This month's study explores changes in spirituality in patients receiving hematopoietic stem cell transplantation (HSCT) and the extent to which domains of spirituality prior to transplant may predict domains of quality of life during the first year after transplant. The data here suggest the importance of a sense of *meaning & peace* and also support the idea of giving special attention to spirituality as a resilience factor affecting quality-of-life at a most critical time of treatment and recovery. For chaplain readers, this article -- especially the Discussion section -- may help stir thinking about meaning & peace vis-à-vis religious faith as dimensions of spirituality, about spiritual assessment that is mindful of health outcomes, and about spirituality-related patterns during a patient's course, in addition to possibilities for further research.

This prospective, longitudinal study was pursued in light of the "significant psychological and physical effects of HSCT" (e.g., fatigue, depressed mood, heightened anxiety, pain, and diminished functioning) and its "life-threatening context" [p. 920]. Data were analyzed from 220 patients who were part of a larger study at the University of Wisconsin Carbone Cancer Center, with measures completed prior to transplant and at 1, 3, 6, and 12 months after transplant. Attrition, missing data, and death reduced the sample size to 68% by the 12-month mark, but a total of 86% did accomplish four of the five data points. The key measure of spirituality was the Functional Assessment of Chronic Illness Therapy Spirituality (FACIT-Sp) questionnaire [--see Items of Related Interest, §I (below)], interpreted here according to two subscales: 1) meaning & peace and 2) religious faith. The authors state, "While past studies have measured spiritual well-being several months to years after HSCT, we focused on changes earlier in recovery that are more likely to be directly affected by transplant and its physical and emotional sequelae" [p. 921]; and they characterize this early period as potentially "both a critical and an opportune time for addressing patients' spiritual and existential needs" [p. 926]. Other measures addressed emotional well-being, physical well-being, fatigue, and pain.

Results are presented in data tables and, very helpfully, in graphs that suggest patterns/trajectories in patient experience. Among the findings:

- Participants in our study experienced a slight decline in the meaning and peace dimension of spiritual well-being during the first month following transplant. …Findings suggest that patients' inner sense of peace and purpose in life may be vulnerable in the first few weeks and months of recovery after

transplant. [p. 925]

- On average, participants' sense of meaning/peace had returned to pretransplant levels by 6-months posttransplant. Religious faith increased slightly during this time frame. …Taken as a whole, the data suggest that spirituality is a largely resilient domain, with no persisting declines. This is notable considering deficits in other areas of physical and emotional well-being are typically more persistent. [p. 925]

- Participants with a greater sense of meaning and peace prior to transplant were less likely to experience depression, fatigue, and anxiety, and more likely to report better physical and functional well-being during the first year after transplant. These effects were seen above and beyond the effects of time on the recovery. Findings further suggested that meaning/peace had the most salient effect during the most rigorous period of early recovery from HSCT. [p. 925]

- A notable finding was that patients high in meaning/peace were more resilient to depression, and this buffering effect appeared to be particularly true early after transplant. …There may be special clinical relevance for HSCT patients given the high prevalence of depression and potential link to mortality following transplant. [p. 925]

- [A] sense of meaning and peace, but not religious faith per se, was related to better adjustment and functioning among HSCT recipients. [p. 926]

Leeson and her colleagues offer much thought-provoking speculation on what lay behind these findings: for instance, on the point cited immediately above, that in light of other research, "Religious faith may facilitate adjustment during the cancer experience only to the extent that it promotes a sense of inner peace and purpose in life" [p. 926]. Or, regarding the finding that "patients high in meaning/peace were more resilient to depression": "It is possible that this effect may be due in part to some conceptual and content overlap between the meaning/peace and depression measures" [p. 925]; and they note how "anhedonia and feelings of inadequacy captured by the depression measure may overlap with lacking a sense of meaning and purpose on the spirituality measure" [p. 925]. The authors show care in their effort to work as precisely as possible with the conceptual ambiguities prevalent in spirituality & health research, but this reader would note that the phrases "peace and purpose" [pp. 925 and 926], and "meaning and purpose" [esp. pp. 925 and 926] appear to be used interchangeably regarding findings from the FACIT-Sp's Meaning & Peace sub scale. More on how *purpose* figures into that measure's conceptualizations would have been useful. Also, the authors refer to the "religious faith" [pp. 922, 923, and 924] subscale of the FACIT-Sp, but the measure's subscale is officially only Faith, and no version of the FACIT-Sp explicitly mentions religion.

The authors ultimately venture the following in terms of clinical significance:

> Findings suggest that assessments of spirituality may provide an important perspective as part of the pretransplant psychosocial evaluations that are routinely performed by many HSCT programs during the clinical workup for transplant. Our findings further suggest that HSCT patients are likely to benefit from spiritual or psychological care that targets more global or existential concerns and cultivates a sense of meaning, rather than targeting specific religious tenants or practices. Enhancing this resilience factor could improve both psychological and physical functioning among individuals undergoing HSCT.

There is one reference to chaplains [--see p. 926].

Suggestions for the Use of the Article for Student Discussion:

This month's article peers into the world of patients undergoing a treatment that is not only highly stressful but quite particular, so any student who has worked with this population and procedure might lead off the group's discussion with a personal perspective, or perhaps an HSCT nurse or physician might be invited to participate. If there is no such resource for describing broadly the patient experience, a few points/quotes from a qualitative article on HSCT [e.g. Moira Stephens' "The lived experience post-autologous haematopoietic stem cell transplant…" --see Items of Related Interest, §II (below)] might be used to expand on our featured article's introductory section. *Spirituality* in the present study is delineated by the FACIT-Sp measure, so some review of that instrument, or at least a note of its twelve items, may also set the context for discussion [--see Items of Related Interest, §I (below)]. The group could talk especially about differences in findings for the Meaning & Peace subscale in contrast to the Religious Faith subscale. Should items from the FACIT-Sp be incorporated into a spiritual assessment process, or could they be used to inform a chaplain's practice? Students might also consider the patterns of change that are graphed by Leeson, et al. [pp. 924-925]. How might such patterns affect students' sense of *timing* in their care planning for patients, and how might a sense of typical patterns of patient experience be part of pastoral planning in general? What might it mean for spirituality to be both an area of need and a "resilience factor" [p. 926]? What pastoral interventions could help support HSCT patients, and how might an understanding of the HSCT population be useful for thinking about pastoral care with other populations? Finally, our authors mention the idea of "spiritual disposition" [p. 926, citing Gall, T. L. and Grant, K., "Spiritual disposition and understanding illness," *Pastoral Psychology* 53, no. 6 (July 2005): 515-533], and this passing reference could open a larger discussion about the significance of one's general spiritual *traits* in contrast to one's spiritual *state* at any single point in time, and how that distinction might affect the use and interpretation of measures in spirituality research. Is the FACIT-Sp being used by Leeson, et al., as a trait or state measure?

Related Items of Interest:

I. The Functional Assessment of Chronic Illness Therapy Spirituality (FACIT-Sp) questionnaire was a focus of our February 2004 Article-of-the-Month selection and was covered in our Fall 2008 *Newsletter* (item #6). The measure may be obtained from www.facit.org, which offers the 12-item version used in our featured article, plus an expanded 23-item version and a modified 12-item version for non-illness. See especially the following key articles (though remember that this month's study used the 2-factor instead of the 3-factor model):

> 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. [(Abstract:) OBJECTIVE: The 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp) is a popular measure of the religious/spiritual (R/S) components of quality of life (QoL) in patients with cancer. The original factor analyses of the FACIT-Sp supported two factors: Meaning/Peace and Faith. Because Meaning suggests a cognitive aspect of R/S and Peace an affective component, we hypothesized a 3-factor solution: Meaning, Peace, and Faith. METHODS: Participants were 240 long-term female survivors of cancer who completed the FACIT-Sp, the SF-12, and the BSI 18. We used confirmatory factor analysis to compare the 2- and 3-factor models of the FACIT-Sp and subsequently assessed associations between the resulting solutions and QoL domains. RESULTS: Survivors averaged 44 years of age and 10 years post-diagnosis. A 3-factor solution of the FACIT-Sp significantly improved the fit of the model to the data over the original 2-factor structure (Delta chi(2)=72.36, df=2, p<0.001). Further adjustments to the 3-factor model resulted in a final solution with even better goodness-of-fit indices (chi(2)=59.11, df=1, p=0.13, CFI=1.00, SMRM=0.05).The original Meaning/Peace factor controlling for Faith was associated with mental (r=0.63, p<0.000) and physical (r=0.22, p<0.01) health on the SF-12, and the original Faith factor controlling for Meaning/Peace was negatively associated with mental health (r=-0.15, p<0.05). The 3-factor model was more informative. Specifically, using partial correlations, the Peace factor was only related to mental health (r=0.53, p<0.001); Meaning was related to both physical (r=0.18, p<0.01) and mental (r=0.17, p<0.01) health; and Faith was negatively associated

with mental health (r=-0.17, p<0.05). CONCLUSION: The results of this study support a 3-factor solution of the FACIT-Sp. The new solution not only represents a psychometric improvement over the original, but also enables a more detailed examination of the contribution of different dimensions of R/S to QoL.]

Murphy, P. E., Canada, A. L., Fitchett, G., Stein, K., Portier, K., Crammer, C. and Peterman, A. H. "**An examination of the 3-factor model and structural invariance across racial/ethnic groups for the FACIT-Sp: a report from the American Cancer Society's Study of Cancer Survivors-II (SCS-II)**." *Psycho-Oncology* 19, no. 3 (March 2010): 264-272. [(Abstract:) OBJECTIVES: Recent confirmatory factor analysis (CFA) of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) Scale in a sample of predominantly white women demonstrated that three factors, Meaning, Peace, and Faith, represented a psychometric improvement over the original 2-factor model. The present study tested these findings in a more diverse sample, assessed the stability of the model across racial/ethnic groups, and tested the contribution of a new item. METHODS: In a study by the American Cancer Society, 8805 cancer survivors provided responses on the FACIT-Sp, which we tested using CFA. RESULTS: A 3-factor model provided a better fit to the data than the 2-factor model in the sample as a whole and in the racial/ethnic subgroups (Deltachi(2), p<0.001, for all comparisons), but was not invariant across the groups. The model with equal parameters for racial/ethnic groups was a poorer fit to the data than a model that allowed these parameters to vary (Deltachi(2)(81)=2440.54, p<0.001), suggesting that items and their associated constructs might be understood differently across racial/ethnic groups. The new item improved the model fit and loaded on the Faith factor. CONCLUSIONS: The 3-factor model is likely to provide more specific information for studies in the field. In the construction of scales for use with diverse samples, researchers need to pay greater attention to racial/ethnic differences in interpretation of items.]

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. [(Abstract:) A significant relation between religion and better health has been demonstrated in a variety of healthy and patient populations. In the past several years, there has been a focus on the role of spirituality, as distinctfrom religion, in health promotion and coping with illness. Despite the growing interest, there remains a dearth of well-validated, psychometrically sound instruments to measure aspects of spirituality. In this article we report on the development and testing of a measure of spiritual well-being, the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp), within two samples of cancer patients. The instrument comprises two subscales--one measuring a sense of meaning and peace and the other assessing the role of faith in illness. A total score for spiritual well-being is also produced. Study 1 demonstrates good internal consistency reliability and a significant relation with quality of life in a large, multiethnic sample. Study 2 examines convergent validity with 5 other measures of religion and spirituality in a sample of individuals with mixed early stage and metastatic cancer diagnoses. Results of the two studies demonstrate that the FACIT-Sp is a psychometrically sound measure of spiritual well-being for people with cancer and other chronic illnesses.]

II. For more on the general patient of experience of HSCT, see:

Anderson, K. O., Giralt, S. A., Mendoza, T. R., Brown, J. O., Neumann, J. L., Mobley, G. M., Wang, X. S. and Cleeland, C. S. "**Symptom burden in patients undergoing autologous stem-cell transplantation**." *Bone Marrow Transplantation* 39, no. 12 (June 2007): 759-766. [This study gives a picture of the types of symptom burdens that patients experience from pre-transplant to a month post-transplant and offers graphs that may complement the graphed data in our Article-of-the-Month. The study does *not* consider spirituality. (Abstract:) Patients who undergo autologous peripheral blood stem cell (PBSC) transplantation experience multiple symptoms that adversely

affect quality of life. We assessed symptoms during the acute phase of autologous PBSC transplantation to determine the severity of individual symptoms and to determine overall symptom profiles in 100 patients with multiple myeloma or non-Hodgkin's lymphoma. Study subjects completed the blood and marrow transplantation module of the M. D. Anderson Symptom Inventory before hospitalization, during conditioning, on day of transplantation, at nadir (the time of lowest white blood cell count) and on day 30 post-transplantation. Additional symptom, quality-of-life and medical status measures were collected. Symptom means were mild at baseline, intensified during conditioning, peaked at nadir and decreased by day 30. At nadir, the most severe symptoms for the entire patient sample were lack of appetite, fatigue, weakness, feeling sick, disturbed sleep, nausea and diarrhea. Cancer diagnosis was a significant predictor of changes in symptoms over time. The patterns of fatigue, pain, sleep disturbance and lack of appetite were significantly different for patients with multiple myeloma as compared with patients with non-Hodgkin's lymphoma.]

Stephens, M. "**The lived experience post-autologous haematopoietic stem cell transplant (HSCT): a phenomenological study**." *European Journal of Oncology Nursing* 9, no. 3 (September 2005): 204-215. [Though there have surely been advances in treatment since this Australian study was conducted, it remains a useful entrée to the world of the HSCT patient. (From the abstract:) Autologous haematopoietic stem cell transplant (HSCT) has a high physical and emotional morbidity. This study using Husserlian phenomenological methodology and using Giorgi's …method of analysis was undertaken to attempt to gain some understanding of the patient's experience. Five adult patients who had previously undergone autologous transplantation for a haematological malignancy at least 6 months before participated in the study. Interviews with the participants were audio taped and then transcribed verbatim. Nine themes emerged from the participants' stories and included psychological cost, physical and psychological adaptation, reprioritisation and a sense of isolation. The transplant experience can be separated into a discrete period of time and the findings illustrate that the experience of transplantation impacts on the life of the person for an undetermined period of time. The changes experienced may be permanent and the post-transplant person, emotionally, psychologically and physically, is not the same person who entered into transplant….]

III. Our featured article provides a brief but good overview of studies relating to spirituality and HSCT patients [pp. 920-921]. In addition, chaplains may be interested in the following:

Adelstein, K. E., Anderson, J. G. and Taylor, A. G. "**Importance of meaning-making for patients undergoing hematopoietic stem cell transplantation**." *Oncology Nursing Forum* 41, no. 2 (March 1, 2014): E172-184. [This literature review underscores a need for spiritual intervention with HSCT patients but focuses on the patient-nurse relationship and does not consider chaplains. Nevertheless, the article should be useful in highlighting themes pertinent to chaplains, especially the potential importance of the patients *story*. (From the abstract:) PURPOSE/OBJECTIVES: The purpose of this integrative literature review of hematopoietic stem cell transplantation (HSCT) for hematologic malignancies was to determine whether meaning-making might be helpful to improve coping and psychological adaptation as patients navigate HSCT. DATA SOURCES: CINAHL, MEDLINE, and PsychINFO databases, and ancestry searches. Search terms included bone marrow transplant, hematopoietic stem cell transplant, hematologic malignancy, quality of life, lived experience, psychosocial, psychological, isolation, and social support. DATA SYNTHESIS: Twenty-four research articles published from 1989-2012 were included. Five major themes emerged: (a) lived experience, (b) coping style, (c) quality of life, (d) psychological morbidity, and (e) potential for post-traumatic growth. Meaning-making was a thread that ran through each of the key areas of the HSCT experience. CONCLUSIONS: Physical, psychosocial, and spiritual issues arise during HSCT that are unique among patients diagnosed with cancer. Meaning-making is key to adaptive coping and helps to reduce physical, psychosocial, and spiritual challenges, as well as

assists patients in experiencing positive personal growth. Interventions focused on meaning-making should be tested in this population.]

King, S. D., Fitchett, G. and Berry, D. L. "**Screening for religious/spiritual struggle in blood and marrow transplant patients**." *Supportive Care in Cancer* 21, no. 4 (April 2014): 993-1001. [(Abstract:) PURPOSE: A growing body of research documents the harmful effects of religious/spiritual (R/S) struggle (e.g., feeling abandoned or punished by God) among patients with a wide variety of diagnoses. Documented effects include poorer quality of life, greater emotional distress, poorer recovery, and increased disability. This study reports the use of a screening protocol that identified patients who may have been experiencing R/S struggle. We also examined the prevalence and correlates of possible R/S struggle, its association with quality of life, pain, and depressive symptoms and compared the results from the screening protocol with social workers' assessments. METHODS: One hundred seventy-eight blood and marrow transplant patients completed the Electronic Self-Report Assessment--Cancer (ESRA-C) which included the Rush Religious Struggle Screening Protocol and other measures of quality of life, pain, and depressive symptoms prior to transplant therapy. All participants were assessed by a social worker, 90 % within 2 weeks of the ESRA-C assessment. RESULTS: Using the Rush Protocol, 18 % of the patients were identified as potentially experiencing R/S struggle. R/S struggle was not reported in any social work assessments. In a multivariable model, potential R/S struggle was more likely in patients who were more recently diagnosed, male, and Asian/Pacific Islanders. There were no significant associations between potential R/S struggle and quality of life, pain, or depressive symptoms. CONCLUSIONS: Early identification of patients with R/S struggle will facilitate their referral for further assessment and appropriate intervention. Further research is needed to identify the best methods of screening patients for R/S struggle.]

Ragsdale, J. R., Hegner, M. A., Mueller, M. and Davies, S. "**Identifying religious and/or spiritual perspectives of adolescents and young adults receiving blood and marrow transplants: a prospective qualitative study**." *Biology of Blood and Marrow Transplantation* 20, no. 8 (August 2014): 1242-1247. [(Abstract:) The potential benefits (or detriments) of religious beliefs in adolescent and young adults (AYA) are poorly understood. Moreover, the literature gives little guidance to health care teams or to chaplains about assessing and addressing the spiritual needs of AYA receiving hematopoietic stem cell transplants (HSCT). We used an institutional review board-approved, prospective, longitudinal study to explore the use of religion and/or spirituality (R/S) in AYA HSCT recipients and to assess changes in belief during the transplantation experience. We used the qualitative methodology, grounded theory, to gather and analyze data. Twelve AYA recipients were interviewed within 100 days of receiving HSCT and 6 participants were interviewed 1 year after HSCT; the other 6 participants died. Results from the first set of interviews identified 5 major themes: using R/S to address questions of "why me?" and "what will happen to me;" believing God has a reason; using faith practices; and benefitting from spiritual support people. The second set of interviews resulted in 4 major themes: believing God chose me; affirming that my life has a purpose; receiving spiritual encouragement; and experiencing strengthened faith. We learned that AYA patients were utilizing R/S far more than we suspected and that rather than losing faith in the process of HSCT, they reported using R/S to cope with illness and HSCT and to understand their lives as having special purpose. Our data, supported by findings of adult R/S studies, suggest that professionally prepared chaplains should be proactive in asking AYA patients about their understanding and use of faith, and the data can actively help members of the treatment team understand how AYA are using R/S to make meaning, address fear, and inform medical decisions.]

Sirilla, J. and Overcash, J. "**Quality of life (QOL), supportive care, and spirituality in hematopoietic stem cell transplant (HSCT) patients**." *Supportive Care in Cancer* 21, no. 4 (April 2014): 1137-1144. [(Abstract:) For many patients, a hematopoietic stem cell transplant (HSCT) can be challenging to physical and emotional health. Supportive care needs can be overwhelming for many patients and families. The purpose of this study was to evaluate the effect

of quality of life (QOL), spiritual well-being, and supportive care resources post-HSCT. This descriptive, repeated-measures study included people over the age of 18 years undergoing HSCT for any cancer diagnosis. The Functional Assessment in Cancer Therapy--Bone Marrow Transplant scale, the Functional Assessment of Chronic Illness Therapy--Spiritual--12 scale, and a resource questionnaire were administered prior to HSCT and following HSCT at 30, 60, 90, and 180 days. Three groups of HSCT patients were examined: allogeneic, autologous, and overall. Data analysis included descriptive statistics and correlations. In the sample (n=159), the autologous HSCT group reported the highest QOL scores. Spirituality scores increased for the autologous HSCT group at 90 days, but decreased for the overall and allogeneic groups. The type of supportive care resources most used were information from the physician and nurse, the Leukemia and Lymphoma Society Support as the most used form of support group, and Faith, Prayer and Spiritual Healing. QOL and spiritual well-being scores correlated best at 180 days (6 months) for autologous and allogeneic patients.]

Williams, B. J. "**Self-transcendence in stem cell transplantation recipients: a phenomenologic inquiry**." *Oncology Nursing Forum* 39, no. 1 (January 2012): E41-48. [(Abstract:) PURPOSE/OBJECTIVES: To understand the meaning of self-transcendence, or the ability to go beyond the self, for patients who have had a stem cell transplantation. RESEARCH APPROACH: A phenomenologic investigation guided by the interpretive philosophy of Heidegger. SETTING: A cancer center in a major urban academic medical center. PARTICIPANTS: 4 men and 4 women ages 45-63 who had received a stem cell transplantation in the previous year. METHODOLOGIC APPROACH: Two or three unstructured, open-ended interviews were conducted with each participant. Data were extracted, analyzed, and interpreted according to the Colaizzi method. MAIN RESEARCH VARIABLES: Self-transcendence. FINDINGS: Self-transcendence emerged as a process that was triggered by the suffering the participants experienced as they lived through the physical effects of the treatment, faced death, drew strength from within themselves, and perceived a spiritually influenced turning point. The experience of a human connection lessened their feelings of vulnerability in the process. As the participants recovered, they described being transformed both physically and personally. CONCLUSIONS: The findings from this study highlight the power inherent in patients to not only meet the challenges they face, but to grow from their experiences. The findings also highlight patients' deep need for a human connection and the power that nurses and other healthcare professionals have to provide that connection. INTERPRETATION: The caring connections established by health-care professionals can ease the ability of patients to access the inner resource of self-transcendence and reduce their feelings of vulnerability.]
