

**A Select Bibliography of Spirituality and Health Research Articles by
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John Ehman, 4/24/12

Alcorn, S. R., Balboni, M. J., Prigerson, H. G., Reynolds, A., Phelps, A. C., Wright, A. A., Block, S. D., Peteet, J. R., Kachnic, L. A. and Balboni, T. A. [Center for Psycho-Oncology and Palliative Care Research, Dana-Farber Cancer Institute, Boston, MA]. **"If God wanted me yesterday, I wouldn't be here today': religious and spiritual themes in patients' experiences of advanced cancer."** *Journal of Palliative Medicine* 13, no. 5 (May 2010): 581-588.

[Abstract:] BACKGROUND: This study sought to inductively derive core themes of religion and/or spirituality (R/S) active in patients' experiences of advanced cancer to inform the development of spiritual care interventions in the terminally ill cancer setting. METHODS: This is a multisite, cross-sectional, mixed-methods study of randomly-selected patients with advanced cancer (n = 68). Scripted interviews assessed the role of R/S and R/S concerns encountered in the advanced cancer experience. Qualitative and quantitative data were analyzed. Theme extraction was performed with interdisciplinary input (sociology of religion, medicine, theology), utilizing grounded theory. Spearman correlations determined the degree of association between R/S themes. Predictors of R/S concerns were assessed using linear regression and analysis of variance. RESULTS: Most participants (n = 53, 78%) stated that R/S had been important to the cancer experience. In descriptions of how R/S was related to the cancer experience, five primary R/S themes emerged: coping, practices, beliefs, transformation, and community. Most interviews (75%) contained two or more R/S themes, with 45% mentioning three or more R/S themes. Multiple significant subtheme interrelationships were noted between the primary R/S themes. Most participants (85%) identified 1 or more R/S concerns, with types of R/S concerns spanning the five R/S themes. Younger, more religious, and more spiritual patients identified R/S concerns more frequently (beta = -0.11, p < 0.001; beta = 0.83, p = 0.03; and beta = 0.89, p = 0.04, respectively). CONCLUSIONS: R/S plays a variety of important and inter-related roles for most advanced cancer patients. Future research is needed to determine how spiritual care can incorporate these five themes and address R/S concerns.

Balboni, T., Balboni, M., Paulk, M. E., Phelps, A., Wright, A., Peteet, J., Block, S., Lathan, C., Vanderweele, T. and Prigerson, H. [Center for Psycho-Oncology and Palliative Care Research, and the Department of Palliative Care, Dana-Farber Cancer Institute; Harvard Medical School Center for Palliative Care; and Department of Radiation Oncology, Dana-Farber Cancer Institute, Boston, MA]. **"Support of cancer patients' spiritual needs and associations with medical care costs at the end of life."** *Cancer* 117, no. 23 (Dec 1, 2011): 5383-5391.

[Abstract:] BACKGROUND: Although spiritual care is associated with less aggressive medical care at the end of life (EOL), it remains infrequent. It is unclear if the omission of spiritual care impacts EOL costs. METHODS: A prospective, multisite study of 339 advanced cancer patients accrued subjects from September 2002 to August 2007 from an outpatient setting and followed them until death. Spiritual care was measured by patients' reports that the health care team supported their religious/spiritual needs. EOL costs in the last week were compared among patients reporting that their spiritual needs were inadequately supported versus those who reported that their needs were well supported. Analyses were adjusted for confounders (eg, EOL discussions). RESULTS: Patients reporting that their religious/spiritual needs were inadequately supported by clinic staff were less likely to receive a week or more of hospice (54% vs 72.8%; P = .01) and more likely to die in an intensive care unit (ICU) (5.1% vs 1.0%, P = .03). Among minorities and high religious coping patients, those reporting poorly supported religious/spiritual needs received more ICU care (11.3% vs 1.2%, P = .03 and 13.1% vs 1.6%, P = .02, respectively), received less hospice (43.3% vs 75.3% \geq 1 week of hospice, P = .01 and 45.3% vs 73.1%, P = .007, respectively), and had increased ICU deaths (11.2% vs 1.2%, P = .03 and 7.7% vs 0.6%, P = .009, respectively). EOL costs were higher when patients reported that their spiritual needs were inadequately supported (\$4947 vs \$2833, P = .03), particularly among minorities (\$6533 vs \$2276, P = .02) and high religious copers (\$6344 vs \$2431, P = .005). CONCLUSIONS: Cancer patients reporting that their spiritual needs are not well supported by the health care team have higher EOL costs, particularly among minorities and high religious coping patients.

Balboni, T. A., Paulk, M. E., Balboni, M. J., Phelps, A. C., Loggers, E. T., Wright, A. A., Block, S. D., Lewis, E. F., Peteet, J. R. and Prigerson, H. G. [Departments of Psycho-Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, MA; tbalboni@iroc.harvard.edu]. **"Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death."** *Journal of Clinical Oncology* 28, no. 3 (Jan 20, 2010): 445-452.

[Abstract:] PURPOSE: To determine whether spiritual care from the medical team impacts medical care received and quality of life (QoL) at the end of life (EoL) and to examine these relationships according to patient religious coping. PATIENTS AND METHODS: Prospective, multisite study of patients with advanced cancer from September 2002 through August 2008. We interviewed 343 patients at baseline and observed them (median, 116 days) until death. Spiritual care was defined by patient-rated support of spiritual needs by the medical team and receipt of pastoral care services. The Brief Religious Coping Scale (RCOPE) assessed positive religious coping. EoL outcomes included patient QoL and receipt of hospice and any aggressive care (eg, resuscitation). Analyses were adjusted for potential confounders and repeated according to median-split religious coping. RESULTS: Patients whose spiritual needs were largely or completely supported by the medical team received more hospice care in comparison with those not supported (adjusted odds ratio [AOR] = 3.53; 95% CI, 1.53 to 8.12, P = .003). High religious coping patients whose spiritual needs were largely or completely supported were more likely to receive hospice (AOR = 4.93; 95% CI, 1.64 to 14.80; P = .004) and less likely to receive aggressive care (AOR = 0.18; 95% CI, 0.04 to 0.79; P = .02) in comparison with those not supported. Spiritual support from the medical team and pastoral care visits were associated with higher QoL scores near death (20.0 [95% CI, 18.9 to 21.1] v 17.3 [95% CI, 15.9 to 18.8], P = .007; and 20.4 [95% CI, 19.2 to 21.1] v 17.7 [95% CI, 16.5 to 18.9], P = .003, respectively). CONCLUSION: Support of terminally ill patients' spiritual needs by the medical team is associated with greater hospice utilization and, among high religious copers, less aggressive care at EoL. Spiritual care is associated with better patient QoL near death.

Balboni, T. A., Vanderwerker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S., Peteet, J. R. and Prigerson, H. G. [Harvard Radiation Oncology Program, Dana-Farber Cancer Institute, Boston, MA]. **"Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life."** *Journal of Clinical Oncology* 25, no. 5 (Feb 10, 2007): 555-560.

[Abstract:] PURPOSE: Religion and spirituality play a role in coping with illness for many cancer patients. This study examined religiousness and spiritual support in advanced cancer patients of diverse racial/ethnic backgrounds and associations with quality of life (QOL), treatment preferences, and advance care planning. METHODS: The Coping With Cancer study is a federally funded, multi-institutional investigation examining factors associated with advanced cancer patient and caregiver well-being. Patients with an advanced cancer diagnosis and failure of first-line chemotherapy were interviewed at baseline regarding religiousness, spiritual support, QOL, treatment preferences, and advance care planning. RESULTS: Most (88%) of the study population (N = 230) considered religion to be at least somewhat important. Nearly half (47%) reported that their spiritual needs were minimally or not at all supported by a religious community, and 72% reported that their spiritual needs were supported minimally or not at all by the medical system. Spiritual support by religious communities or the medical system was significantly associated with patient QOL (P = .0003). Religiousness was significantly associated with wanting all measures to extend life (odds ratio, 1.96; 95% CI, 1.08 to 3.57). CONCLUSION: Many advanced cancer patients' spiritual needs are not supported by religious communities or the medical system, and spiritual support is associated with better QOL. Religious individuals more frequently want aggressive measures to extend life.

El Nawawi, N. M., Balboni, M. J., and Balboni, T. A. **"Palliative care and spiritual care: the crucial role of spiritual care in the care of patients with advanced illness."** *Current Opinion in Supportive & Palliative Care* (2012): online ahead of print from the journal website, as of March 3, 2012

Purpose of Review: Within the hospice and palliative care movement, patients' religion/spirituality (R/S) has been a core component of care incorporated within international and US palliative care guidelines. However, as the discipline of palliative care has been incorporated into the larger biomedical community, the inclusion of spiritual care has become controversial. This review summarizes key empirical research at the intersection of palliative care and R/S in order to assess its validity as a domain of end-of-life care. Recent Findings: Recent research shows that R/S and spiritual care are important components to the care of patients facing advanced illness. Patients – particularly ethnic minorities – rely upon R/S as an important means to interpret and cope with illness. Studies suggest that R/S plays an important role in coping with disease related symptoms, improves quality of life, and impacts medical decision-making near death. Patients largely desire medical caregivers to take an active role in providing spiritual care, and patients likewise frequently experience multiple spiritual needs arising in the face of life-threatening illness. Summary: Despite an empirical evidence for spiritual care as part of palliative care, R/S remains insufficiently addressed by the medical system. Further research is required in order to more clearly identify the roles of healthcare providers and standardize the provision of spiritual care within palliative care.

Maciejewski, P. K., Phelps, A. C., Kacel, E. L., Balboni, T. A., Balboni, M., Wright, A. A., Pirl, W. and Prigerson, H. G. **"Religious coping and behavioral disengagement: opposing influences on advance care planning and receipt of intensive care near death."** *Psychooncology* (2011): online ahead of print from the journal website as of March 29, 2011.

[Abstract:] Objective: This study examines the relationships between methods of coping with advanced cancer, completion of advance care directives, and receipt of intensive, life-prolonging care near death. Methods: The analysis is based on a sample of 345 patients interviewed between January 1, 2003, and August 31, 2007, and followed until death as part of the Coping with Cancer Study, an NCI/NIMH-funded, multi-site, prospective, longitudinal, cohort study of patients with advanced cancer. The Brief COPE was used to assess active coping, use of emotional-support, and behavioral disengagement. The Brief RCOPE was used to assess positive and negative religious coping. The main outcome was intensive, life-prolonging care near death, defined as receipt of ventilation or resuscitation in the last week of life. Results: Positive religious coping was associated with lower rates of having a living will (AOR = 0.39, p = 0.003) and predicted higher rates of intensive, life-prolonging care near death (AOR, 5.43; p<0.001), adjusting for other coping methods and potential socio-demographic and health status confounds. Behavioral disengagement was associated with higher rates of DNR order completion (AOR, 2.78; p = 0.003) and predicted lower rates of intensive life-prolonging care near death (AOR, 0.20; p = 0.036). Not having a living will partially mediate the influence of positive religious coping on receipt of intensive, life-prolonging care near death. Conclusion: Positive religious coping and behavioral disengagement are important determinants of completion of advance care directives and receipt of intensive, life-prolonging care near death.

Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, E. M., Trice, E., Schrag, D., Peteet, J. R., Block, S. D. and Prigerson, H. G. **"Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer."** *JAMA* 301, no. 11 (March 18, 2009): 1140-1147.

[Abstract:] CONTEXT: Patients frequently rely on religious faith to cope with cancer, but little is known about the associations between religious coping and the use of intensive life-prolonging care at the end of life. OBJECTIVE: To determine the way religious coping relates to the use of intensive life-prolonging end-of-life care among patients with advanced cancer. DESIGN, SETTING, AND PARTICIPANTS: A US multisite, prospective, longitudinal cohort of 345 patients with advanced cancer, who were enrolled between January 1, 2003, and August 31, 2007. The Brief RCOPE assessed positive religious coping. Baseline interviews assessed psychosocial and religious/spiritual measures, advance care planning, and end-of-life treatment preferences. Patients were followed up until death, a median of 122 days after baseline assessment. MAIN OUTCOME MEASURES: Intensive life-prolonging care, defined as receipt of mechanical ventilation or resuscitation in the last week of life. Analyses were adjusted for demographic factors significantly associated with positive religious coping and any end-of-life outcome at P < .05 (ie, age and race/ethnicity). The main outcome was further adjusted for potential psychosocial confounders (eg, other coping styles, terminal illness acknowledgment, spiritual support, preference for heroics, and advance care planning). RESULTS: A high level of positive religious coping at baseline was significantly associated with receipt of mechanical ventilation compared with patients with a low level (11.3% vs 3.6%; adjusted odds ratio [AOR], 2.81 [95% confidence interval {CI}, 1.03-7.69]; P = .04) and intensive life-prolonging care during the last week of life (13.6% vs 4.2%; AOR, 2.90 [95% CI, 1.14-7.35]; P = .03) after adjusting for age and race. In the model that further adjusted for other coping styles, terminal illness acknowledgment, support of

spiritual needs, preference for heroics, and advance care planning (do-not-resuscitate order, living will, and health care proxy/durable power of attorney), positive religious coping remained a significant predictor of receiving intensive life-prolonging care near death (AOR, 2.90 [95% CI, 1.07-7.89]; $P = .04$). CONCLUSIONS: Positive religious coping in patients with advanced cancer is associated with receipt of intensive life-prolonging medical care near death. Further research is needed to determine the mechanisms for this association.

Vallurupalli, M., Lauderdale, K., Balboni, M. J., Phelps, A. C., Block, S. D., Ng, A. K., Kachnic, L. A., Vanderweele, T. J. and Balboni, T. A. "**The role of spirituality and religious coping in the quality of life of patients with advanced cancer receiving palliative radiation therapy.**" *Journal of Supportive Oncology* 10, no. 2 (Mar-Apr 2012): 81-87.

[Abstract:] OBJECTIVES: National palliative care guidelines outline spiritual care as a domain of palliative care, yet patients' religiousness and/or spirituality (R/S) are underappreciated in the palliative oncology setting. Among patients with advanced cancer receiving palliative radiation therapy (RT), this study aims to characterize patient spirituality, religiousness, and religious coping; examine the relationships of these variables to quality of life (QOL); and assess patients' perceptions of spiritual care in the cancer care setting. METHODS: This is a multisite, cross-sectional survey of 69 patients with advanced cancer (response rate = 73%) receiving palliative RT. Scripted interviews assessed patient spirituality, religiousness, religious coping, QOL (McGill QOL Questionnaire), and perceptions of the importance of attention to spiritual needs by health providers. Multivariable models assessed the relationships of patient spirituality and R/S coping to patient QOL, controlling for other significant predictors of QOL. RESULTS: Most participants (84%) indicated reliance on R/S beliefs to cope with cancer. Patient spirituality and religious coping were associated with improved QOL in multivariable analyses ($\beta = 10.57$, $P < .001$ and $\beta = 1.28$, $P = .01$, respectively). Most patients considered attention to spiritual concerns an important part of cancer care by physicians (87%) and nurses (85%). LIMITATIONS: Limitations include a small sample size, a cross-sectional study design, and a limited proportion of nonwhite participants (15%) from one US region. CONCLUSION: Patients receiving palliative RT rely on R/S beliefs to cope with advanced cancer. Furthermore, spirituality and religious coping are contributors to better QOL. These findings highlight the importance of spiritual care in advanced cancer care.

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., Kachnic, L. A., VanderWeele, T. J. and Balboni, T. A. "**The relationship of spiritual concerns to the quality of life of advanced cancer patients: preliminary findings.**" *Journal of Palliative Medicine* 14, no. 9 (Sep 2011): 1022-1028.

[Abstract:] PURPOSE: Religion and/or spirituality (R/S) have increasingly been recognized as key elements in patients' experience of advanced illness. This study examines the relationship of spiritual concerns (SCs) to quality of life (QOL) in patients with advanced cancer. PATIENTS AND METHODS: Patients were recruited between March 3, 2006 and April 14, 2008 as part of a survey-based study of 69 cancer patients receiving palliative radiotherapy. Sixteen SCs were assessed, including 11 items assessing spiritual struggles (e.g., feeling abandoned by God) and 5 items assessing spiritual seeking (e.g., seeking forgiveness, thinking about what gives meaning in life). The relationship of SCs to patient QOL domains was examined using univariable and multivariable regression analysis. RESULTS: Most patients (86%) endorsed one or more SCs, with a median of 4 per patient. Younger age was associated with a greater burden of SCs ($\beta = -0.01$, $p = 0.006$). Total spiritual struggles, spiritual seeking, and SCs were each associated with worse psychological QOL ($\beta = -1.11$, $p = 0.01$; $\beta = -1.67$, $p < 0.05$; and $\beta = -1.06$, $p < 0.001$). One of the most common forms of spiritual seeking (endorsed by 54%)--thinking about what gives meaning to life--was associated with worse psychological and overall QOL ($\beta = -5.75$, $p = 0.02$; $\beta = -12.94$, $p = 0.02$). Most patients (86%) believed it was important for health care professionals to consider patient SCs within the medical setting. CONCLUSIONS: SCs are associated with poorer QOL among advanced cancer patients. Furthermore, most patients view attention to SCs as an important part of medical care. These findings underscore the important role of spiritual care in palliative cancer management.