

Annotated Bibliography of Articles on Spirituality at the End of Life

The Duke Institute on Care at the End of Life is committed to improving how spiritual care is provided to those who are seriously ill, dying and grieving. The study of spirituality and health at the end of life is an emerging discipline, with a growing body of literature. ICEOL staff and colleagues compiled the following annotated bibliography of articles related to this topic drawing from academic and clinical journals from 1998 – 2008. The abstracts were taken directly from the journals where the articles were published. This bibliography is not all inclusive; it is a starting point. To submit an article for inclusion, please email us at us at iceol@div.duke.edu.

Anandaraja, G. “Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment.” *American Family Physician* 63, no. 1 (2008): 81-88.

The relationship between spirituality and medicine has been the focus of considerable interest in recent years. Studies suggest that many patients believe spirituality plays an important role in their lives; there is a positive correlation between a patient’s spirituality or religious commitment, and health outcomes, and patients would like physicians to consider these factors in their medical care. A spiritual assessment as part of a medical encounter is a practical first step in incorporating the consideration of a patient’s spirituality in medical practice. The HOPE questions provide a formal tool that may be used in this process. The HOPE concepts for discussion are as follows: H—sources of hope, strength, comfort, peace, meaning, peace, love, and connection; O—the role of organized religion for the patient; P—personal spirituality and practices; E—effects on medical care and end-of-life discussions.

Barham, D. “The Last 48 Hours of Life: a Case Study of Symptom Control for a Patient Taking a Buddhist Approach to Dying.” *International Journal of Palliative Nursing*, no. 6 (2003): 245-251.

Caring for a patient dying of cancer can be extremely difficult. Sarah was 39 years old when she died; she is survived by her husband and two children, ages 6 and 4 years. During the weeks leading up to her death, Sarah held extensive discussions with family and the multidisciplinary team. Her goal was to live the remainder of her last few hours as comfortably as possible and to die a “peaceful death.” Terminal care is an important phase of life; one in which individuals have the right to expect quality of care to ensure

that their death occurs with dignity. Sarah practiced Buddhism on a daily basis; issues of spirituality, serenity, and peacefulness in dying were very important to her to ensure a good rebirth.

Breitbart, W. "Spirituality and Meaning in Supportive Care: Spirituality-and Meaning-Centered Group Psychotherapy Interventions in Advanced Cancer." Support Cancer Care 10, no. 4 (2002): 272-280.

Existential and spiritual issues are at the frontier of a new clinical and research focus in palliative and supportive care of cancer patients. As concepts of adequate supportive care expand beyond a focus on pain and physical symptom control, existential and spiritual issues (such as meaning, hope, and spirituality in general) have received increased attention from supportive care clinicians and clinical researchers. This paper reviews the topics of spirituality, and suggests measures of spirituality that deal with two of its main components: faith/religious beliefs and meaning/spiritual well-being. These two constructs of spirituality are reviewed in terms of their role in supportive care. Finally, a review of existing psychotherapeutic interventions for spiritual suffering are reviewed and meaning-centered group psychotherapy for advanced cancer patients is described.

Breitbart, W., Gibson, C., Poppito, S. and Berg, A. "Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality." Cancer Journal of Psychiatry 49, no. 6 (2004): 366-372.

Medical and psychological discourse on end-of-life care has steadily shifted over the years from focusing primarily on symptom control and pain management to incorporating more person-centered approaches to patient care. Such approaches underscore the significance of spirituality and meaning-making as important resources for coping with emotional and existential suffering as one nears death. Though existential themes are omnipresent in end-of-life care, little has been written about their foundations or importance for palliative care practitioners and patients in need. This article explores the existential foundations of meaning and spirituality in light of terminal illness and palliative care. Existential themes (i.e. patients' awareness of death and search for meaning) and practitioners' promotion of personal agency and responsibility are discussed. Viktor Frankl's existential logotherapy is discussed in light of emerging psychotherapeutic interventions. Meaning-centered group therapy is one such novel modality that has successfully integrated themes of meaning and spirituality into end-of-life care. Spiritual and existential themes run through this meaning-oriented approach that encourages dying patients to find meaning and purpose in living until their death.

Byrne, M. "Spirituality in Palliative Care: What Language Do We Need?" International Journal of Palliative Nursing 8, no. 2 (2002): 67-74.

Spirituality can be described as a search for meaning. In the time of a significant life crisis, such as is experienced by patients in palliative care, this search necessarily becomes more urgent. Patients and their families describe times of questioning and loss of faith as well as discovery, growth, and a deepening of inner peace. Because spirituality has an increasingly wide range of interpretations, the delivery of spiritual care can be equally diverse. This article has its limitations in that it concentrates on Christianity, partly because it is a known starting place from the experience of the author and still is relevant for many patients in the West. The holistic/whole person approach to nursing care has helped to refocus on the spiritual dimension of care. However, nurses require support and guidance as to how to approach spiritual care and understand its concept, which appears resistant to language—their basis for communication.

Cairns, A. "Spirituality and Religiosity in Palliative Care." Home Healthcare Nurse 17, no. 7 (1999): 450-455.

Positive spirituality preserved through religiosity can be a useful tool in the care of people who are dying. Spirituality concerns the connectedness of self, others, environment, and Other. Religiosity described postures and acts done alone or in company with others that preserve practices and spiritual understandings for the good of the terminally ill. The home care and hospice nurse must understand these principles and act in concert with the care team to accomplish care goals. By understanding various principles of palliative and spiritual care the home care and hospice nurse can become an effective participant, and direct provider, in the care team. The insight and introspection that study of this subject provides is helpful to all health providers as they minister to patients and their families, their personal network of family and friends as well as discover their own thoughts and approaches to spirituality and religion.

Catholic Health Association, "Health Progress, May – June 2006." Catholic Health Association of the United States, <http://chausa.org>.

The relationship between medicine and spirituality has been the focus of considerable interest in recent years. Studies suggest that many patients believe that spirituality plays an important role in their lives. On the one hand there needs to be a positive relationship that exists between their spiritual (or religious) commitment and health outcomes; on the other hand, physicians and other caregivers should consider these factors in their medical fields. Just as patients' spiritual needs are important, so too are those from the other half in the patient-physician relationship. Physicians increasingly seek contact with and guidance from their own spirituality. Physicians and Catholic health care organizations alike are answering the call to increase focus on personal spirituality as a way of coping with the challenges the current medical climate presents for those practicing medicine. The articles in this special section outline some of those initiatives.

Cavendish, R., Naradovy, L., Como, J. and Mitzeliotis, C. "Patients' Perceptions of Spirituality and the Nurse as a Spiritual Care Provider." Holistic Nursing Practice 20, no. 1 (2006): 41-47.

This qualitative study explores patients' perceptions of spirituality and of the nurse as a spiritual care provider. Semi-structured interviews were conducted with 8 adults older than 21, who were living at home, and had been discharged from the hospital within the past 3 months having had a least a 5-day length of stay. Participants agreed that during their hospitalization, nurses were kind and caring but these behaviors were not perceived as spiritual care. Study findings suggest that patients do not perceive spiritual care within the role of nursing and therefore they did not share their spiritual concerns with the nurses. Study findings are limited by sample size; however, implications for practice are that nurses need to be aware of a patient's spiritual needs in order to provide spiritual care.

Chao, C., Chen, C. and Yen, M. "The Essence of Spirituality of Terminally Ill Patients." Journal of Nursing Research 10, no. 4 (2002): 237-245.

The purpose of this hermeneutical study was to investigate the essence of spirituality within terminally ill patients. In-depth unstructured interviews were used as the method for data collection. The researcher was in the role of a hospice palliative care consultant who directly took care of the subject patients in a hospice ward of a teaching hospital. The six subjects were suggested purposefully according to various demographic backgrounds. Interview transcripts provided the data for analysis. The results were composed of four constitutive patterns and ten themes. The first constitutive pattern was "Communion with Self" which included three themes: (1) Self-identity—spirituality is the discovery of the authentic self; (2) Wholeness—a human being is full of contradictions but still in wholeness; (3) Inner peace—spirituality is negotiating conflicts for self-reconciliation. The second constitutive pattern was "Communion with others" which included two themes: (1) Love—spirituality is a caring relationship but not an over-attachment to others; (2) Reconciliation—spirituality is to forgive and be forgiven. The third constitutive pattern was "Communion with Nature" which included two themes: (1) Inspirations from the nature—spirituality is the resonance of the marvelous beauty of nature; (2) Creativity—spirituality is conceiving imaginatively. The fourth constitutive pattern was "Communion with Higher Being" which included three themes: (1) Faithfulness—spirituality is keeping the trust dependably; (2) Hope—spirituality is claiming possibilities; (3) Gratitude—spirituality is giving thanks and embracing grace. The scientific rigor of this qualitative research as well as the strength and limitations of the study are reported. Implications for hospice palliative care and future research are recommended.

Chochinov, H., Hack, T., Hassard, T., Kristjanson, L., McClement, S. and Harlos, M.
“Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End
of Life.” Journal of Clinical Oncology 23, no. 24 (2005): 5520-5525.

Purpose: This study examines a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter the most or they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study is to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress. **Patients and Methods:** Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and post-intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidal; and a post-intervention satisfaction survey. **Results:** Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement ($P= .023$) and reduced depressive symptoms ($P= .05$). Finding dignity therapy helpful to their correlated with life feeling more meaningful ($r= .0480$; $P=.000$) and having a sense of purpose ($r= 0.562$; $P=.0000$), accompanied by a lessened sense of suffering ($r= .0327$, $P=.001$) and an increased will to live ($r= .0387$; $P=.000$). **Conclusion:** Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

Chrymko, M. “Are Health Professionals Ministry?” Health Progress 85, no. 4
(2004): 48-54, 58.

Do those who practice in the health care professions minister to the people they serve? To answer this question, we must first define “health” and “ministry.” One writer has defined the latter as follows: “Christian ministry is the public activity of a baptized follower of Jesus Christ flowing from the Spirit’s charism and an individual personality on behalf of a Christian community to proclaim, serve, and realize the kingdom of God.” Not every positive act is necessarily ministry. People can do many good things without meeting these criteria. However, through baptism, every Christian is called into ministry. In this article, only those acts that meet the above criteria are described as ministry. There are many definitions of “health.” Today it is the most commonly defined in physical terms. However, the word was derived from one signifying holiness or wholeness, completeness. Health exists when physiological, psychological, spiritual, and social functions act cooperatively and harmoniously. “Health” will be understood here as a “dynamic process that embodies the spiritual, psychological, physical, and social dimensions of the person.” Many Catholic religious communities have continued their commitments to health care ministry in hospitals. This care embraces not only the physical but also the psychological, social, and spiritual dimensions of the person. It

incorporates both the medical and the pastoral aspects of care. "Pastoral care" includes a listening presence; helping in dealing with powerlessness, pain, and alienation; and assistance in recognizing and responding to God's will with greater joy and peace. Pastoral care focuses on a patient's spiritual dimension, but it also affects psychological and social dimensions, particularly when the pastoral care comes from the patient's own church community. When it does not come directly from the church community, the pastoral caregiver may yet represent the community. As the U.S. bishops have put it, "Catholic health care ministry is rooted in a commitment to promote and defend human dignity; this is the foundation of its concern to respect the sacredness of every human life from the moment of conception until death." A Catholic health care institution should be a community that provides healing and compassion.

Counsell, C., Adorno, G. and Guin, P. "Establishing an End of Life Program in an Academic Acute Care Hospital." SCI Nursing 20, no. 4 (2003): 238-249.

The primary goal of end-of-life (EOL) care is to relieve suffering through measures that improve comfort and address the psychological, social, and spiritual needs of the dying. This article discusses the components of a pilot project that focused on palliative EOL care at an academic, acute hospital. An interdisciplinary team of nurses, social workers, chaplains, patient care coordinators, and advanced practice nurses established a common vision for the care of patients who were "in the dying process," or were expected to die during their hospitalizations. A nurse-social worker "Care-Partner Team" completed a consistent interdisciplinary EOL care needs assessment when treatment goals became strictly palliative. Interventions were driven by a clinical pathway and a pre-printed physician's order set that continually clarified the goals of treatment. Key elements of the program included leadership support, advanced directives, education, communication, family involvement, symptom management, professional collaborations, and outcomes measurement.

Crawley, L., Marshall, P., Lo, B., and Koenig, B. "Strategies for Culturally Effective End of Life Care." Annals of Internal Medicine 136, no. 9 (2002): 673-679.

As a result of profound worldwide demographic change, physicians will increasingly care for patients from cultural backgrounds other than their own. Differences in belief, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients and families may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering. Good end-of-life care may be complicated by disagreements between physicians and patients, difficult interactions, or decisions the physician does not understand. Challenges may result from cultural differences between the patient's background and traditional medical practice. Values so ingrained in physicians as to be unquestioned may be alien to patients from different backgrounds. Physicians need to be sensitive to cultural differences and to develop the skills necessary

to work with patients from diverse backgrounds. Community and cultural ties provide a source of great comfort as patients and families prepare for death. This paper describes two cases that raise issues about cross-cultural end-of-life practice and suggests strategies for negotiating common problems. Physicians should assess the cultural background of each patient and inquire about values that may affect care at the end of life. They should become aware of the specific beliefs and practices of the population they serve, always remembering to inquire whether an individual patient adheres to these cultural beliefs. Attention to cultural difference enables the physician to provide comprehensive and compassionate palliative care at the end of life.

Daaleman, T., VandeCreek, L. "Placing Religion and Spirituality in End of Life Care." The Journal of the American Medical Association 284, no. 19 (2000): 2514-2517.

In 1995, the SUPPORT (study to understand prognoses and preferences for outcomes and risks of treatment) trial stimulated a reexamination of systems of care for seriously ill and dying patients. This study has accelerated efforts to improve end-of-life care and has indirectly promoted a rapprochement among religion, spirituality, medicine, and health care. The goal of a quality comfortable death is achieved by meeting a patient's physical needs and by attending to the social, psychological, and the now recognized spiritual and religious dimensions of care. This perspective is highlighted in a recent consensus statement that includes the assessment and support of spiritual and religious problems as core principles of professional practice and care at the end of life. Yet multiple ethical and pragmatic issues arise. For example, should physicians identify patient's spiritual and religious needs and intervene in clinical settings? The roles and responsibilities of patients and physicians in this scenario are unclear. An understanding of religion and spirituality within the context of end-of-life care, quality of life, and patient-clinician interactions may illuminate the problems and potentialities for both patients and clinicians.

Davidson, M. "Palliative Care Program Earns Circle of Life Citation Honor." Supportive Care Coalition 10, no.1 (2004): 19-21.

No abstract available.

Davies, B., Brenner, P., Orloff, S., Sumner, L. and Worden, W. "Addressing Spirituality in Pediatric Hospice and Palliative Care." Journal of Palliative Care 18, no. 1 (2002): 59-67.

Hospice and palliative care principles mandate clinicians to provide "total" care to patients and their families. Such care incorporates not only physical, emotional, and psychosocial care, but spiritual care as well. Even though considerable attention has been directed to spiritual issues for adult patients in hospice and palliative care, spirituality in

pediatric palliative care has been virtually neglected. The need for guidelines to assess spirituality in this population was identified as a priority issue by members of a subcommittee of the Children's International Project on Children's Palliative/Hospice Service, created under the auspices of the National Hospice Organization. Committee members, based on their clinical research and spiritual experiences, identified several aspects relevant to spirituality in general, and developed guidelines for clinicians in pediatric palliative care. The purpose of this paper is to share the results of this committee's work and, in particular, to present their guidelines for addressing spiritual issues in children and families in pediatric hospice and palliative care.

Dubose, Edwin R. "Preparing for Death: Linking Medicine, Spirituality, and End-of-Life Care." Park Ridge Center Bulletin 21, no. 5 (2001): 514, <http://www.parkridgecenter.org/Page514.Html>

No abstract available.

Ellis, M. & Campbell, J. "Patients Views about Discussing Spiritual Issues with Primary Care Physicians." Journal of Southern Medicine 97, no. 12 (2004): 1158-1164.

Objectives: The authors sought to explore patients' views about discussing spiritual issues with primary care physicians, including perceived barriers to and facilitators of discussion. **Methods:** The study was a qualitative, semi-structured interview of 10 chronically or terminally ill patients who were deliberately selected to represent a range of demographic factors (religious background, age, sex). We coded each interview and evaluated interviews for themes through content analysis. **Results:** Themes included rationale for addressing spiritual issues; prerequisites for these discussions; roles in spiritual discussions; principles of spiritual assessment; and barriers and facilitators of spiritual discussions. Patients justified spiritual assessment on the basis of importance of spirituality in life and health. They asserted that patients must feel honored and respected by their physicians to risk discussing spiritual issues. They affirmed that physicians are helpful when legitimizing their spiritual concerns. Citing physicians' neglect of spirituality as a barrier, they affirmed that spiritual assessment in the context of other life issues facilitates spiritual discussions. **Conclusions:** Patients' willingness to discuss spiritual issues may depend on their sense of physicians' respect for their spiritual views, attitudes about spiritual health, and qualities of openness and approachability.

Foley, Kathleen. "Dismantling the Barriers: Providing Palliative and Pain Care." Journal of the American Medical Association 282, no. 1 (2000): 115-118, <http://jama.ama-assn.org/cgi/content/full/283/1/115>

No abstract available.

Enyert, G. & Burman, M. "A Qualitative Study of Self-Transcendence in Caregivers of Terminally Ill Patients." American Journal of Hospice and Palliative Care 16, no. 2 (1999): 455-462.

Despite changes in social and cultural structure, the family has remained a consistent provider of in-home care needs for the chronically and terminally ill. The experience of a terminal illness is not limited to the individual patient and creates a myriad of challenges for the family, including the struggle to adjust and respond to the demands of the situation. The purpose of this study was to assess the caregivers' sense of emotional well being and their ability to transcend and find meaning in the care-giving experience. The participants in this study were all caregivers of a family member who had died 6 to 12 months prior to the interview. They were able to find meaning as a result of their care-giving experience within the context of supportive networks, care-giving actions, grief and loss, fatigue, financial burdens, and multiple challenges. Finding meaning involved "being with" or "doing for" their loved ones as death approached.

Galek, K., Flannelly, K., Vane, A. and Galek, R. "Assessing a Patient's Spiritual Needs." Holistic Nursing Practice 19, no. 2 (2005): 62-69.

Seven major constructs—belonging, meaning, hope, the sacred, mortality, beauty, and the acceptance of dying—were revealed in an analysis of the literature pertaining to patient's spiritual needs. The authors embedded these constructs within a 29-item survey designed to be inclusive of traditional religion, as well as non-institutional based spirituality. This article describes the development of a multidimensional instrument designed to assess a patients' spiritual needs. This framework for understanding a patient's spiritual needs hopefully contributes to the growing body of literature, providing direction to healthcare professionals interested in a more holistic approach to patient well-being.

Garces-Foley, Kathleen. "Hospice and the Politics of Spirituality." OMEGA 53, no. 1-2 (2006): 117-136.

Within the hospice literature, spirituality and religion are usually defined in opposition to one another, with 'religion' negatively associated with the external, authoritarian doctrines of Christianity, and 'spirituality' positively associated with the free search for truth, meaning, and authenticity. According to survey data, however, most Americans integrate spirituality and traditional religious commitments. The hospice literature is promoting spirituality to its own detriment by alienating potential patients and depriving religious patients of the resources that religious traditions and their affiliated religious communities have to offer.

Geerling, E. "CALL Care; One Year Down the Road." Supportive Care Coalition 10, no. 1 (2004): 11-18.

No abstract available.

Gibbs, H.W., Achterberg Lawiis, J.J. "Spiritual Values and Death Anxiety: Implications for Counseling with Terminal Cancer Patients." Journal of Counseling Psychology 26, no. 6 (1970): 563.

'Death fear' as a function of discomfort level, previous experience with death, and religiosity among indigent cancer patients in a country general hospital was investigated. The participants were those patients in the Cancer Rehabilitation Program at the University of Texas Health Science Center at Dallas who were judged closest to death. The Allport Religious Orientation Scale, Discomfort Indices, and the Templer Death Anxiety Scale were administered to each patient. Patients also participated in a structured interview which examined death fear at the conscious and imagery (unconscious) levels, and as affected by religious values, and support systems. The Death Anxiety Scale was also administered to a standardization sample of outpatients in the Eye Clinic of the same hospital. Results indicate that these patients depend strongly on perceived strength of religious belief and integral religious values in their coping with imminent death. Also highly associated with minimal or low fear of death was previous experience with a dying person with whom one had a close relationship. The Death Anxiety Scale mean score for the cancer patients was significantly lower than that obtained through the standardization population. These findings reveal the various sources of support that are very important to this population and are suggestive of untapped resources available as appropriate intervention avenues.

Groopman, Jerome. "God at the Bedside." New England Journal of Medicine 350, no. 12 (2004): 1176-1178.

No abstract available.

Gordon, T. and Mitchell, D. "A Competency Model for the Assessment and Delivery of Spiritual Care." Palliative Medicine 18, no. 1 (2004): 646-651.

The delivery of spiritual and religious care has received a high profile in national reports guidelines and standards since the start of the millennium, yet there is, to date, no recognized definition of spirituality or spiritual care or a validated assessment tool. This article suggests an alternative to the search for a definition and assessment tool, and seeks to set spiritual care in a practical context by offering a model for spiritual assessment and care based on the individual competence of all healthcare professionals to deliver spiritual and religious care. Through the evaluation of a pilot study to familiarize staff with the Spiritual and Religious Care Competencies for Specialist Palliative Care

developed by Marie Curie Cancer Center, the authors conclude that competencies are a viable and crucial first step in 'earthing' spiritual care in practice, and evidencing this illusive area of care.

Hamilton, D. "Believing in Patients' Beliefs: Physician Attunement to the Spiritual Dimension as a Positive Factor in Patient Healing and Health." The American Journal of Hospice and Palliative Care 15, no. 5 (1998): 276-279.

The spiritual dimension has been demonstrated by research to be an important and fundamental aspect of human functioning, one that positively affects healing and health and should be mobilized as an active part of the health care of persons. Moreover, physicians have an obligation to acknowledge the potential role of spirituality in the health and healing of patients and to form a therapeutic alliance with patients that takes their spirituality into account and affirms its importance. Questions about persons' spiritual beliefs and practices, their values, and what they consider meaningful in their lives should become part of the initial medical interview and an ongoing focus in the physician-patient relationship.

Handzo, G. & Koenig, H. "Spiritual Care: Whose Job is it Anyway?" Southern Medical Journal 97, no. 12 (2004): 1242-1244.

The use of spirituality and religion in coping with illness is widespread among primary care patients. Although the overwhelming majority of healthcare providers agree that they should be aware of patients' spiritual beliefs, that these beliefs may influence their healing, and that patients benefit from spiritual care, there remains considerable debate about who should inquire about spiritual beliefs and deliver spiritual care. The authors, a physician and a chaplain, propose that, in general, the role of the physician is to assess spiritual needs as they relate to healthcare (i.e. briefly screen) and then refer to a professional pastoral caregiver as indicated. The chaplain is the spiritual care specialist on the healthcare team and has the training necessary to treat spiritual distress. Seeing the physician as the generalist in spiritual care and the chaplain as the specialist is a helpful model.

Hanson, L., Dobbs, D., Usher, B., Williams, S., Rawlings, J. & Daaleman, T. "Providers and Types of Spiritual Care during Serious Illness." Journal of Palliative Medicine 11, no. 6 (2006): 907-914.

Objective: Patients and palliative care experts endorse the importance of spiritual care for seriously ill patients and their families. However, little is known about spiritual care during serious illness, and whether it satisfies patients' and families' needs. The objective of this study was to describe spiritual care received by patients and families during serious illness, and test whether the provider and the type of care is associated with satisfaction with care. *Methods:* Cross-sectional interview with 38 seriously ill

patients and 65 family caregivers about spiritual care experiences. *Results:* The 103 spiritual care recipients identified 237 spiritual care providers; 95 (41%) were family or friends, 38 (17%) were clergy, and 66 (29%) were health care providers. Two-thirds of spiritual care providers shared the recipient's faith tradition. Recipients identified 21 different types of spiritual care activities. The most common activity was help coping with illness (87%) and the least common intercessory prayer (4%). Half of recipients were very or somewhat satisfied with spiritual care, and half found it very helpful for facilitating inner peace and meaning making. Satisfaction with spiritual care did not differ by provider age, race, gender, role, or frequency of visits. Types of care that helped with understanding or illness coping associated with greater satisfaction with care. *Conclusion:* Seriously ill patients and family caregivers experience spiritual care from multiple sources, including health care providers. Satisfaction with this care domain is modest, but approaches that help with understanding and with coping are associated with greater satisfaction.

Herring, M. & Rahman, J. "Physicians and Spirituality, St. Vincent Indianapolis Has a Program that Encourages Spiritual Development in Doctors." Health Progress 85, no. 4 (2004): 43-46.

No abstract available.

Hills, J., Paice, J., Cameron, J. & Shott, S. "Spirituality and Distress in Palliative Care Consultation." Journal of Palliative Medicine 8, no. 4 (2005): 282-288.

Background: One's spirituality or religious beliefs and practices may have a profound impact on how the individual copes with the suffering that so often accompanies advanced disease. Some previous studies suggest that negative religious coping can significantly affect health outcomes. **Objective:** The primary aim of this study was to explore the relationship between spirituality, religious coping, and symptoms of distress among a group of inpatients referred to the palliative care consult service. **Design:** Pilot study. **Setting:** The study was conducted in a large academic medical center with a comprehensive palliative care and home hospice program. **Measurement:** (1) National Comprehensive Cancer Network Distress Management Assessment Tool; (2) Pargament Brief Religious Coping Scale (Brief RCOPE); (3) Functional Assessment of Chronic Illness Therapy—Spiritual Well Being (FACIT-Sp); (4) Puchalski's FICA; and (5) Profile of Mood States-Short Form (POMS-SF). **RESULTS:** The 31 subjects surveyed experienced moderate distress, major physical and psychosocial symptom burden, along with reduced function and significant care-giving needs. The majority (87.2%) perceived themselves to be at least somewhat spiritual, with 77.4% admitting to being at least somewhat religious. Negative religious coping (i.e. statements regarding punishment or abandonment by God) was positively associated with distress, confusion, depression, and negatively associated with physical and emotional well-being, as well as quality of life. **CONCLUSIONS:** Palliative care clinicians should be alert to symptoms of spiritual

distress and intervene accordingly. Further research is needed to identify optimal techniques to address negative religious coping.

Hinshaw, D. "Spiritual Issues in Surgical Palliative Care." Surgical Clinics of North America 85, no. 1 (2005): 257-272.

No abstract available.

Holmes, S., Rabow, M., Dibble, S. "Screening the Soul: Communication Regarding Spiritual Concerns among Primary Care Physicians and Seriously Ill Patients Approaching the End of Life." American Journal of Hospice and Palliative Medicine 23, no.1 (2006): 25-33.

The purpose of this study was to explore the spiritual concerns of seriously ill patients and the spiritual care practices of primary care physicians (PCPs). Questionnaires were administered to outpatients (n=65, 90 percent response rate) with end stage illness and to PCPs (n=67, 87 percent response rate) in a diverse general medical practice. Most patients (62%) and PCPs (68%) considered it important that physicians attend to patients' spiritual concerns. However, few patients reported receiving such care, and most (62 percent) did not think it was the PCP's job to talk about spiritual concerns. Although both seriously ill outpatients and PCPs assert the importance of spiritual concerns, PCPs often do not provide spiritual care. Appropriate provisions of spiritual care within a diverse population of seriously ill outpatients is complex, necessitating appropriate and attentive screening.

Irshad, Tasneem. Review of "Recognizing Spiritual Needs in People who are Dying" by R.

Stanworth. Foundation for the Sociology of Health & Illness, (2006): 125-127.

No abstract available.

Jenkins, C., Lapelle, N., Zapka, J. & Kurent, J. "End of Life Care and African Americans: Voices from the Community." Journal of Palliative Medicine 8, no. 3 (2005): 585-592.

Background: In 1997, the Institute of Medicine called for reform, improved quality and expanded research in end-of-life care. Yet little empirical information about preferences of African Americans has been documented. A community-campus partnership was formed to guide needs assessment related to end-of-life care in a Southern, urban, African American community. This paper presents focus group findings related to end-of-life and palliative care. **Methods:** A qualitative design of multiple-meeting focus groups were

used to explore experiences, preferences, needs, and feelings expressed by family members with at least one relative who had died in a hospital (group 1) or at home (group 2). Sessions were taped and transcribed; themes were identified using systematic analytic procedures. **Results:** Thematic analysis revealed key concerns related to health care provider communications about end-of-life care and dying. Positive communications empowered and showed respect for patients and family members and recognized the importance of their spiritual beliefs; informed them about resources available to assist dying at home; and for patients dying in the hospital, treated them with nurturing, compassion, and diligent monitoring of the patient's medical status and needs. Other themes related to end-of-life care issues include preparation, planning, and access. A table of quotes from participants is available from the corresponding author. **Conclusions:** Findings suggest important clinical implications for clinicians and other health professionals. These voices from the community remind us of the heterogeneity in needs and preferences and challenge us to listen and tailor communication to each patient and their families.

Jones, L. Gregory "The 'Good Life' or a Life That Is Good? Aging, Death, and Christian Theology in American Culture." Word & World 8, no. 3 (1993): 284-292.

No abstract available.

Kaldjian, L.C., et. Al. "End-of-Life Decisions in HIV-Positive Patients: The Role of Spiritual Beliefs." AIDS, 12(1) (1998): 103.

Objective: To describe the role of spiritual beliefs in HIV-positive patients' end-of-life decisions. **Design:** In-person, cross-sectional survey. **Setting:** An HIV/AIDS floor of an urban, university teaching hospital. **Patients:** Ninety hospitalized HIV-positive patients. **Main Outcome Measures:** Prior discussions about advance directives, possession of a living will (written advanced directives), fear of death, professions of hope and purpose in life, religious beliefs and practices, guilt about HIV infection, and perception of HIV as punishment. **Results:** Of 104 eligible patients, 90 agreed to be interviewed. Twenty-four per cent of patients had discussed their resuscitation status with a physician and 17% possessed a living will; 44% of patients felt guilty about their HIV infection, 32% expressed fear of death; and 26% felt their disease was some sort of punishment. Prior discussions about resuscitation status were less likely in those who perceived HIV as punishment ($P=0.009$) and more likely in those who believed in God's forgiveness ($P=0.043$). A living will was more common in those who prayed daily ($P=0.025$) and in those whose belief in God helped them when thinking about death ($P=0.065$). Fear of death was more likely in those who perceived HIV as punishment ($P=0.01$) or felt guilty about having HIV ($P=0.039$) and less likely in those who read the Bible frequently ($P=0.01$) or attended church frequently ($P=0.015$). Outcome measures did not vary significantly according sex, race, HIV risk factors, or education level. **CONCLUSIONS:** In this HIV-positive population, spiritual beliefs and religious practices appeared to play a role in end-of-life decisions. Discussions about end-of-life decisions may be facilitated

by a patient's belief in a forgiving God and impeded by a patient's interpretation of HIV infection as punishment. Health care providers need to recognize patients' spiritual beliefs and incorporate them into discussions about terminal care.

Koenig, H. "Religion, Spirituality, and Medicine: Research Findings and Implications for Clinical Practice." Journal of Southern Medicine 97, no.12 (2004): 1194-1200.

A growing body of scientific research suggests connections between religion, spirituality, and both mental and physical health. The findings are particularly strong in patients with severe or chronic illness who are having stressful psychological and social changes, as well as existential struggles related to meaning and purpose. Recent studies indicate that religious beliefs influence medical decisions, such as the use of chemotherapy and other life-saving treatments, and at times may conflict with medical care. This article addresses the way physicians can use this information. Spirituality is an area that makes many physicians uncomfortable, since training in medical school and continuing medical education programs are limited. Not only do most physicians lack the necessary training, they worry about spending additional time with patients and overstepping ethical boundaries. While these concerns are valid, each can be addressed in a sensible way. Taking a spiritual history, supporting the patient's beliefs, and orchestrating the fulfillment of spiritual needs are among the topics this article will address. The goal is to help physicians provide medical care that is sensitive to the way many patients understand and cope with medical illness.

Klitzman, R., Daya S. "Challenges and Changes in Spirituality Among Doctors Who Welcome Patients." Social Science and Medicine 61, no. 11 (2005): 2396-2406.

Though spirituality can help patients cope with illness, several studies have suggested that physicians view spirituality differently than do patients. These issues have not been systematically investigated among doctors who become patients, and who may be able to shed critical light on this area. We interviewed fifty doctors from major urban US centers who had become patients due to serious illnesses about their experiences and views relating to religion and spirituality before and after diagnosis, and we explored the range of issues that emerged. These physician-patients revealed continua of *forms* and *contents* of spirituality. The *forms* ranged from being spiritual to start with, to being spiritual but not thinking of themselves as such; to wanting but being unable to believe. Some continued to doubt and, perhaps relatedly, appeared depressed. The *contents* of beliefs ranged from establishing religious traditions, to mixing beliefs, or having non-specific beliefs (e.g., concerning the power of nature). One group of doctors felt wary of organized religion, which could prove an obstacle to belief. Others felt that symptoms could be reduced through prayer. At times, self-assessments of spirituality were difficult to make or inaccurate. Questions surfaced concerning whether and how medical education could best address these issues, and how spirituality can affect clinical work. This study is the first that we know of to examine spirituality among physicians when they become patients. Obstacles to physicians' attentiveness to the potential role of

spirituality arose that need to be further explored in medical education and future research. Increased awareness of these areas could potentially have clinical relevance, strengthening doctor-patient relationships and communication, and patient satisfaction.

Last Acts “Religious Groups Tackle End of Life Issues.” Last Acts: Care and Caring at the End of Life 5, (1998): 1.

No abstract available.

Lo, Bernard, T. Quill, J. Tulsky “Discussing Palliative Care with Patients.” Annals of Internal Medicine 130, no. 9 (1999): 744-749.

Palliative care focuses on relief of suffering, psychosocial support, and closure near the end of life. Even experienced physicians often struggle when initiating complex, emotionally laden discussions about palliative care with seriously ill patients and their families. We use two hypothetical case scenarios to illustrate how physicians can initiate these discussions and to emphasize and illustrate several communication techniques. Physicians can elicit a patient’s concerns, goals, and values by using open-ended questions and following up on the patient’s response before discussing specific clinical decisions. Physicians should also screen for unaddressed spiritual and existential concerns. Some patients may make statements or ask questions that are difficult for physicians to respond to. We provide examples of responses that align the physician with patient’s wishes without reinforcing unrealistic plans. Exploring such difficult issues may lessen feelings of aloneness even when the physician cannot “fix” the problem, and it raises new opportunities for patients to find comfort. In addition to addressing physical suffering, physicians can extend their caring by acknowledging and exploring psychosocial, existential, or spiritual suffering. As patients struggle to find closure in their lives, active listening and empathy have therapeutic value in and of themselves.

Lo, Bernard, et al. “Discussing Religious and Spiritual Issues at the End of Life: A Practical Guide for Physicians.” JAMA 287, no. 6 (2002): 749-754.

As patients near the end of life, their spiritual and religious concerns may be awakened or intensified. Many physicians, however, feel unskilled and uncomfortable discussing these concerns. This article suggests how physicians might respond when patients or families raise such concerns. First, some patients may explicitly base decisions about life-sustaining interventions on their spiritual or religious beliefs. Physicians need to explore those beliefs to help patients think through their preferences regarding specific interventions. Second, other patients may not bring up spiritual or religious concerns but are troubled by them. Physicians should identify such concerns and listen to them empathetically, without trying to alleviate the patient’s spiritual suffering or offering premature reassurance. Third, some patients or families may have religious reasons for insisting on life-sustaining interventions that physicians advise against. The physician

should listen and try to understand the patient's viewpoint. Listening respectfully does not require the physicians to agree with the patient or misrepresent his or her own views. Patients and families who feel that the physician understands them and cares about them will be more willing to consider the physician's views on prognosis and treatment. By responding to patients' spiritual and religious concerns and needs, physicians may help them find comfort and closure near the end of life.

Lo, Bernard, et al. "Responding to Requests Regarding Prayer and Religious Ceremonies by Patients Near the End of Life and Their Families." Journal of Palliative Care 6, no. 3 (2003): 409-415.

Prayer and religious ceremonies may help patients near the end of life and their relatives find comfort and discover meaning in their lives. In this paper, we analyze how physicians might respond in two situations regarding prayer and religious ceremonies. First, how should physicians respond when such patients or their families ask physicians to pray for them or with them? Physicians' response to such requests will depend on their own religious and spiritual beliefs, the congruence of their beliefs with those of the patient and family, and the relationship with the patient. Many physicians may be willing to be present and stand silently while the patient prays. Second, how should physicians respond when such patients and families seek to carry out their religious and spiritual practices in the hospital? Religious ceremonies can provide meaning, hope, and solace to patients and families. Institutional guidelines regarding religious ceremonies should allow as much leeway as is compatible for good care both for the patient for whom the ritual is offered and also for other patients within the facility. Physicians should inquire whether there are religious and spiritual practices that patients and families would like to engage in. However, physicians should be cautious about recommending specific ceremonies or practices. Physicians can respond to requests and respect patients' spiritual needs in ways that may deepen the therapeutic doctor-patient relationship, without compromising their own religious and spiritual beliefs or professional roles.

Lunn, J. "Spiritual Care in a Multi-Religious Context." Journal of Pain and Palliative Care Pharmacotherapy 17, no. 3/4 (2003): 153-169.

Spiritual care is an essential component of palliative care because spirituality is an important part of suffering and the relief of pain and suffering. It is especially important in the developing world where medical and comfort resources are limited. Spiritual resources in the context of many religions are described. Understanding pain from a spiritual perspective and approaches when spiritual resources appear ineffective are discussed. The role of spiritual resources in end-of-life care is described in the context of taking a spiritual inventory. The importance of all palliative care clinicians understanding these concepts is emphasized.

Maugans, T. "The SPIRITual History." Archives of Family Medicine 5, no. 1 (1996): 11-16.

Spirituality can be defined as a belief system focusing on intangible elements that impart vitality and meaning to life's events. Often spirituality is expressed through formalized religions. Recently, the interplay of spirituality, religion, and health care has been explored in the medical literature as well as spiritual belief systems impact on the incidences, experiences, and outcomes of several common medical problems. Unfortunately, there is little recent literature addressing the process of conducting a medically oriented spiritual history. One approach to assisting the physician in spiritual history, taking a mnemonic, SPIRIT, is presented as a guide to identifying important components of the spiritual history. This article addresses the issues of when and who to interview, as well as specific professional and ethical issues related to the topic. Two case examples from my practice are presented to illustrate the utility of the SPIRITual history.

McClain, C., Rosenfeld, B. & Breitbart, W. "Effect of Spiritual Well Being on End-of-Life Despair in Terminally-Ill Cancer Patients." The Lancet 361, (2003): 1603-1607.

Background: The importance of spirituality in coping with a terminal illness is becoming increasingly recognized. We aimed to assess the relation between spiritual well-being, depression, and end-of-life despair in terminally-ill cancer patients. **Methods:** 160 patients in a palliative care hospital with a life expectancy of less than 3 months were interviewed with a series of standardized instruments, including the functional assessment of chronic illness therapy—spiritual well-being scale, the Hamilton depression rating scale, the Beck hopelessness scale, and the schedule of attitudes toward hastened death. Suicidal ideation was based on responses to the Hamilton expression rating scale. **Findings:** Significant correlations were seen between spiritual well-being and desire for hastened death ($r=0.51$), hopelessness ($r=0.68$), and suicidal ideation ($r=0.41$). Results of multiple regression analyses showed that spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates. Additionally, depression was highly correlated with desire for hastened death in participants low in spiritual well-being ($r=0.40$, $p<0.0001$) but not in those high in spiritual well-being ($r=0.20$, $p=0.06$). **Interpretation:** Spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent. Our findings have important implications for palliative care practice. Controlled research assessing the effect of spirituality-based interventions is needed to establish what methods can help engender a sense of peace and meaning.

McCord, G., et. al. "Discussing Spirituality with Patients: A Rational and Ethical Approach." Annals of Family Medicine 2, no. 4 (2004): 356-361, <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1466687>

Background: This study was undertaken to determine when patients feel that physician inquiry about spirituality or religious beliefs is appropriate, reasons why they want their physicians to know about their spiritual beliefs, and what they want physicians to do with this information. **Methods:** Trained research assistants administered a questionnaire to a convenience sample of consenting patients and accompanying adults in the waiting rooms of 4 family practice residency training sites and 1 private group practice in northeastern Ohio. Demographic information, the SF-12 Health Survey, and participant ratings of appropriate situations, reasons, and expectations for physician discussions of spirituality or religious beliefs were obtained. **Results:** Of 1,413 adults who were asked to respond, 921 completed questionnaires, and 492 refused (response rate=65%). Eighty-three percent of respondents wanted physicians to ask about spiritual beliefs in at least some circumstances. The most acceptable scenarios for spiritual discussion were life-threatening illnesses (77%), serious medical conditions (74%), and loss of loved ones (70%). Among those who wanted to discuss spirituality, the most important reason for discussion was desire for physician-patient understanding (87%). Patients believed that information concerning their spiritual beliefs would affect physician's ability to encourage realistic hope (67%), give medical advice (66%), and change medical treatment (62%). **Conclusions:** This study helps clarify the nature of patient preferences for spiritual discussion with physicians.

McEwen, M. "Spiritual Nursing Care." Holistic Nursing Practice 19, no. 4 (2005): 161-168.

Until recently, little attention has been given to spiritual dimensions in the nursing literature. This article reviews spiritual nursing care in the nursing literature, including basic concepts and current thoughts on spirituality-related research. In addition, it describes mechanisms that may be used to promote spiritual care and outlines the need to enhance research efforts in this vital area.

McSkimming, S., Super, A., Driever, M., Schoessler, M., Franey, S. & Fonner, E. "Living and Healing During Life-Threatening Illness." Focus Group Discussion by Supportive Care of the Dying: A Coalition for Compassionate Care, 1997.

No abstract available.

Meador, Keith G., Jones, L. Gregory "Bearing Witness in Life and Death." Christian Century, (2000): 830-832.

No abstract available.

Duke Institute on Care at the End of Life
Annotated Bibliography of Articles on Spirituality at the End of Life, Oct. 2008

Meador, K. "Spiritual Care at the End of Life: What Is It and Who Does It?" North Carolina Medical Journal 65, no. 4 (2004): 226-228.

No abstract available.

Miller, D., Chibnall, J., Videen, S. & Duckro, P. "Supportive-Affective Group Experience for Persons with Life-Threatening Illness: Reducing Spiritual, Psychological and Death-Related Distress in Dying Patients." Journal of Palliative Medicine 8, no. 2 (2005): 333-343.

Background: Attention to psych-socio-spiritual needs is considered critical by patients with life-threatening illnesses and their caregivers. Palliative care interventions that address these needs—particularly spirituality—are lacking. **Objective:** To evaluate the effects of an innovative program to address psycho-socio-spiritual needs in patients with life-threatening illnesses. **Design:** A group intervention entitled Life-Threatening Illness Supportive-Affective Group Experience (LTI-SAGE) was developed for reducing patient spiritual, emotional, and death-related distress. **Setting/Subject:** African American and Caucasian patients (N=69) from 2 hospitals in St. Louis, Missouri, with life-threatening medical conditions (cancer; HIV/AIDS; geriatric frailty; liver, kidney, pulmonary, or cardiovascular disease) were randomly assigned to intervention or control groups. Intervention patients participated in a maximum of 12 LTI-SAGE groups over a 12-month period. Control patients received standard care. **Measurements:** Outcome measures were depression symptoms anxiety, spiritual well-being, and death-related feelings of meaninglessness and significantly better spiritual well-being than did control patients. **Conclusions:** The use of the LTI-SAGE model for enhancing the end-of-life illness experience is promising.

Milstein, Jay M. "A Paradigm of Integrative Care: Healing with Curing Throughout Life, 'Being with' and 'Doing to.'" Journal of Perinatology 25, no. 9 (2005): 563-568.

We are presenting an integrative paradigm of care. We will review the basis for its evolution from prior series and parallel models. In this paradigm, healing and palliation (when indicated) are introduced in parallel with curative measures as soon as any diagnosis, especially a critical one, is made. Frequently, palliative measures address patient symptoms, such as pain, anxiety, delirium, or depression, and are geared towards comfort care at the end of life. Our view of healing care is that it actively addresses the cognitive, emotional, and spiritual needs of the patient and family, and includes the elements of palliative care as a complement. Because a loss is often experienced in many conditions, even in the absence of death, bereavement is represented in our model as an ongoing, continual process throughout a disease process. While we will be drawing mainly from experiences with children, the proposed model is applicable to all ages. In order to implement this model most effectively, it will be important to shift from our mindset of 'doing to' to one that includes 'being with' our patients and their families. The uniqueness of this paradigm, in contrast to other models, is its comprehensiveness and

universality. It is appropriate for patients of any age, at any stage of their disease or illness, regardless of the severity or duration of their condition.

Milstein, J. "Detoxifying Death in the Neonate: in Search of Meaningfulness at the End of Life." Journal of Perinatology 23, no. 4 (2003): 333-336.

At the end of life, when curative measures have failed to conquer the terminal nature of a disease, it is imperative to introduce healing measures that deal with the human suffering associated with illness. When dealing with critically ill neonates with lethal conditions, it may be necessary to institute healing measures at the beginning of life. In such cases, healing measures must incorporate customary palliative measures but should not be limited to them. The purpose of this paper is to describe the families' approaches to palliation at the end of life in their newborn infants with Trisomy 18, a genetic abnormality usually associated with a markedly decreased life expectancy. We shall consider the concepts of interference versus intervention as we examine subtle medical differences between the two cases. We will address medical, legal, and ethical issues in each case, but special attention will be given to the provision of compassionate care. People face physical, mental, emotional, and spiritual challenges as they go through life. The families' approaches with their infants at the end of their lives may support the premise that the latter two challenges, emotional and spiritual, confront us the most at the end. Encouraging families to engage with their dying infants helps to detoxify the experience and make it more meaningful.

Milstein, J., Raingruber, B. "Choreographing the End of Life in a Neonate." American Journal of Hospice and Palliative Care 24, (2007): 343-349.

As caregivers, we often have the privilege of accompanying patients and their families at the end of life. When the patients are newborn infants, the parents are totally unprepared cognitively, emotionally, and spiritually. Their experience represents uncharted territory. The concept of uncharted territory probably applies to everyone facing the death of a loved one for the first time for both the patients and their families. Providing some guidance to patient/family dyads, while simultaneously respecting their autonomy, may be helpful to facilitate healing and meaning construction during the process of bereavement. In applying an integrative universal paradigm of care when curative measures elude us, healing measures become of paramount importance. An exemplar involving a neonate is presented in this commentary; however, healing measures are relevant to patients of all ages as well as to their loved ones.

Murray, S., Kendall, M., Worth, A. & Benton, T. "Exploring the Spiritual Needs of People Dying of Lung Cancer or Heart Failure: A Prospective Qualitative Interview Study of Patients and their Carers." Palliative Medicine 18, (2004): 39-45.

Background: We set out to explore whether patients with life-threatening illnesses and their informal carers consider they experience significant spiritual needs, in the context of their overall needs, how spiritual concerns might vary by illness group and over the course of the illness, and how patients and their carers think they might be supported in addressing spiritual issues. **Methods:** Three-monthly qualitative interviews for up to one year with 20 patients with inoperable lung cancer and 20 patients with end-stage heart failure and their informal carers. **Results:** We conducted 149 in-depth interviews. Spiritual concerns were important for many patients in both groups, both early and later in the illness progression. Whether or not patients and carers held religious beliefs, they expressed needs for love, meaning, purpose, and sometimes transcendence. The different experiences of lung cancer and heart failure raised contrasting patterns of spiritual issues and needs. Carers voiced their own spiritual needs. Patients and carers were generally reluctant to raise spiritual issues, but many, in the context of a developing relationship with the researcher, were able to talk about such needs. **Conclusions:** Spiritual issues were significant for many patients in their last year of life and their carers. Many health professionals lack the necessary time and skills to uncover and address such issues. Creating the opportunity for patients and carers to discuss spiritual issues, if they wish, requires highly developed communication skills and adequate time.

Nathan Cummings Foundation "Spiritual Beliefs and the Dying Process."
http://www.ncf.org/ncf/publications/reports/fetzer/fetzer_keyfindings.html

No abstract available.

Norris, K., Strohmaier, G., ASP, C. & Byock, I. "Spiritual Care at the End of Life, Some Clergy Lack Training in End of Life Care." Health Progress 85, no. 4 (2004): 34-39, 58.

No abstract available.

O'Connell, Laurence J. "The American Way of Death: Gallup Poll Results." The Park Ridge Center Bulletin 3, no. 2 (1998): 150-153,
www.parkridgecenter.org/page150.html

No abstract available.

Okon, T. "Palliative Care Review, Spiritual, Religious, and Existential Aspects of Palliative Care." Journal of Palliative Medicine 8, no. 2 (2005): 392-414.

No abstract available.

Park, C. "Religiousness/Spirituality and Health: a Meaning Systems Perspective." Journal of Behavioral Medicine 30, no. 4 (2007): 319-328.

The existence of links between religion and spirituality (R/S) and health appear to be firmly established, but much less is known about *how* these various aspects of R/S are translated into health outcomes. Within a meaning systems framework, this article reviews and integrates findings regarding the many pathways through which R/S may influence physical health and well-being. In particular, evidence for the pathways of body sanctification, meaning in life, social support, health locus of control, health behaviors, positive and negative affect and stress moderation, treatment adherence, and coping is examined. The article concludes with suggestions for future research.

Peay, Pythia "A Good Death." Common Boundary, (1997): 32-41.

No abstract available.

Plotnikoff, Gregory A. "Should Medicine Reach Out to the Spirit? Understanding a Patient's Spiritual Foundation Can Guide Appropriate Care." Postgraduate Medicine Online 108, no. 6 (2000).
http://www.postgradmed.com/issues/2000/11_00/editorial_nov.shtml

No abstract available.

Puchalski, Christina. "Forgiveness: Spiritual and Medical Implications." The Yale Journal for Humanities and Medicine (2002).

No abstract available.

Puchalski, C., Larson, D. "Developing Curricula in Spirituality and Medicine." Academic Medicine 73, no. 9 (1998): 970-974.

In recent years patients and some members of the medical community have expressed the concern that doctors have forgotten about compassion and too often ignore their patients' spiritual concerns. Patients can and should expect their physicians to respect their beliefs and be able to talk with them about spiritual concerns in a respectful and caring manner. Medical schools must teach their students how to meet these expectations, and health care

systems need to provide practice environments that foster compassionate care-giving. Medial educators are recognizing the need to bring the art of compassionate care-giving back into the medical school curriculum. This paper focuses on one approach to achieving this goal, the study of spirituality and medicine. The authors discuss the relationship of spirituality and healing, and describe studies that have shown patients' desire to have spiritual issues addressed by their physicians and the potential health benefits of spiritual beliefs. Finally, they describe common elements of the spirituality courses offered by approximately 50 U.S. medical schools, including 19 schools that have been awarded grants from the National Institute for Healthcare Research for the development of curricula in spirituality and medicine.

Puchalski, C., Kilpatrick, S., McCullough, M. & Larson, D. "A Systematic Review of Spiritual and Religious Variables in *Palliative Medicine, American Journal of Hospice and Palliative Care, Hospice Journal, Journal of Palliative Care, and Journal of Pain and Symptom Management.*" *Palliative and Supportive Care* 1, (2003): 7-13.

Objective: There has been increasing recognition and acceptance of the importance of addressing existential and spiritual suffering as an important and necessary component of palliative medicine and end-of-life care in the United States. This paper seeks to empirically and systematically examine the extent to which there is an adequate scientific research base on spirituality and its role in palliative care, in the palliative care and hospice literature. **Methods:** We sought to locate all empirical studies published in 5 palliative medicine/hospice journals from 1994 to 1998. The journals included: *American Journal of Hospice and Palliative Care, Journal of Palliative Care, Hospice Journal, Palliative Medicine, and The Journal of Pain and Symptom Management.* Journal contents were searched to identify studies that included spiritual or religious measures or results. Case studies, editorials, and theoretical or descriptive articles were not included in the search. **Results:** During the years 1994-1998, 1,117 original empirical articles were published in the 5 journals reviewed. Only 6.3% (70 articles) included spiritual or religious variables. This percentage, while low, was better than the 1% previously reported in an examination of studies published in *Journal of the American Medical Association, the Lancet, and New England Journal of Medicine.* **Significance of Results:** While researchers in the field of palliative care have studied spiritual/religious variables more than other areas of medicine, the total percentage for studies is still low at 6.3%. To move the field of palliative medicine forward so appropriate guidelines for spiritual care can be developed, it is critical that good research be conducted upon which to base spiritual care in an evidence-based model. Recommendations are made for future studies in spiritual care within palliative medicine.

Puchalski, Christina "Reconnecting the Science and Art of Medicine." *Academic Medicine* 76, no. 12 (2001): 1224-1225.

No abstract available.

Puchalski, Christina “Spirituality and End-of-Life Care: A Time for Listening and Caring.” Journal of Palliative Medicine 5, no. 2 (2002): 289-294.

No abstract available.

Puchalski, C., Dorff, E. & Hendi, I. “Spirituality, Religion and Healing in Palliative Care.” Clinical Geriatric Medicine 20, (2004): 659-714.

No abstract available.

Puchalski, Christina. “Taking a Spiritual History Allows Clinicians to Understand Patients More Fully.” Journal of Palliative Medicine 3, no. 1 (2000): 129-138.

Dr. Christina Puchalski is an internist and geriatrician who has recently designed a Spiritual Assessment consisting of four basic questions that physicians or others can integrate into patient interviews. The assessment is remembered by the acronym FICA, for the domains it touches on: Faith, Importance, Community, and Address. In this interview with Innovations associate editor Anna L. Romer, Dr. Puchalski explores how she came to develop the spiritual history, how she sees it as distinct from a careful psychosocial history, and what she has learned as she has trained physicians across the United States to incorporate it into their medical interviews. This interview is excerpted from a thematic issue, “Spirituality and End-of-Life Care,” vol. 1, no. 6, 1999 of the online journal Innovations in End-of-Life Care at <http://www.edc.org/lastacts/>.

Puchalski, Christina. “The Role of Spirituality in Health Care: Person-alizing Medicine.” The Maryland Family Doctor, (2000): 9-10.

No abstract available.

Puchalski, Christina. “Touching the Spirit: The Essence of Healing.” Spiritual Life (1999): 154-159.

No abstract available.

Rumbold, B. "Caring for the Spirit: Lessons from Working with the Dying." Medical Journal of Australia 179, (2003): 511-513.

- Spiritual care is integral to palliative care, and palliative care experience in offering spiritual care can be a resource for the emerging healthcare interest in spirituality.
- Spirituality is best understood in terms of the web of relationships that give coherence to our lives, uniquely identifying each person.
- In palliative care, responsibility for spiritual care is shared by the whole team, with leadership given by specialist practitioners such as pastoral care workers. The palliative care approach to spiritual care may, however, be transferred to other contexts and to individual practice.
- Spiritual care encourages and supports people in a quest for meaning and personal autonomy. It is offered, not imposed.

Sinclair, S., Pereira, J. & Raffin, S. "A Thematic Review of the Spirituality Literature Within Palliative Care." Journal of Palliative Medicine 9, no. 2 (2006): 464-479.

Research related to spirituality and health has developed from relative obscurity to a thriving field of study over the last 20 years, both within palliative care and within health care in general. This paper provides a descriptive review of the literature related to spirituality and health, with a special focus on the spiritual within palliative and end-of-life care. CINAHL and MEDLINE were searched under the keywords "spirituality" and "palliative." The review revealed five overarching themes in the general spirituality and health literature: (1) conceptual difficulties related to the term spirituality and proposed solutions; (2) the relationship between spirituality and religion; (3) the effects of spirituality on health; (4) the subjects enrolled in spirituality-related research; and (5) the provision of spiritual care. While the spirituality literature within palliative care shared these overarching characteristics of the broader spirituality and health literature, six specific theme areas transpired: (1) general discussions of spirituality in palliative care; (2) the spiritual needs of palliative care patients; (3) the nature of hope in palliative care; (4) tools and therapies related to spirituality; (5) effects of religion in palliative care; and (6) spirituality and palliative care professionals. The literature as it relates to these themes is summarized in this review. Spirituality is emerging largely as a concept void of religion, an instrument to be utilized in improving or maintaining health and quality of life, and focused predominantly on the "self," in the form of the patient. While representing an important beginning, the authors suggest that a more integral approach needs to be developed that elicits the experiential nature of spirituality that is shared by patients, family members, and health care professionals alike.

Steinhauser, K., Voils, C., Clipp, E, Bosworth, H., Christakis, N. & Tulsky, J. “Are You at Peace?” Archives of Internal Medicine 166, (2006): 101-105.

Background: Physicians may question their role in probing patients’ spiritual distress and the practicality of addressing such issues in the time-limited clinical encounter. Yet, patients’ spirituality often influences treatment choices during a course of serious illness. A practical, evidence-based approach to discussing spiritual concerns in a scope suitable to a physician-patient relationship may improve the quality of the clinical encounter.

Methods: Analysis of the construct of being “at peace” using a sample of patients with advanced cancer, congestive heart failure, or chronic obstructive pulmonary disease.

Descriptive statistics were used to compare response distributions among patient subgroups. Construct validity of the concept of being “at peace” was evaluated by examining Spearman rank correlations between the item and existing spirituality and quality-of-life subscales. **Results:** Variation in patient responses was not explained by demographic categories or diagnosis, indicating broad applicability across patients. Construct validity showed that feeling at peace was strongly correlated with emotional and spiritual well-being. It was equally correlated with faith and purpose subscales, indicating applicability to traditional and nontraditional definitions of spirituality.

Conclusion: Asking patients about the extent to which they are at peace offers a brief gateway to assessing spiritual concerns. Although these issues may be heightened at the end of life, research suggests they influence medical decision making throughout a lifetime of care.

Sulmasy, Daniel P. “It’s Okay Between Me and God.” JAMA 296, no. 11 (2006): 1385-1392.

Spiritual issues arise frequently in the care of dying patients, yet health care professionals may not recognize them, may not believe they have a duty to address these issues, and may not understand how best to respond to their patients' spiritual needs. The case of a patient with a strong religious belief in a miraculous cure of metastatic pancreatic cancer is used to explore how better understanding of this belief and more explicitly spiritual conversation with the patient by his treating team might have provided opportunities for an improved plan of care. This article distinguishes spirituality from religion; describes the salient spiritual needs of patients at the end of life as encompassing questions of meaning, value, and relationship; delineates the role physicians ought to play in ascertaining and responding to those needs; and discusses the particular issue of miracles, arguing that expectations of miraculous cure ought not to preclude referral to hospice care.

Tamura, K., Kikui, K., Watanabe, M. "Caring for the Spiritual Pain of Patients with Advanced Cancer: A Phenomenological Approach to the Lived Experience." Palliative and Supportive Care 4, (2006): 189-196.

Objective: The aim of this research was to reveal, from the perspective of the "lived experience" shared by cancer patients and their nurses, how patients facing death create lived experience in the context of palliative care. This research also aims to elucidate the meaning nurses find in patients' experiences while caring for their patients. **Methods:** The participants in this study were cancer patients who were given opportunities to discuss events and concerns in their daily lives, with the interactions guided by the researchers. Transcriptions of conversations with the patients were analyzed using the method for empirical data classification set forth by Giorgi (1985) with appropriate modification. **Results:** This study found that when the nurse correctly interprets the meaning of the patient, fundamental questions naturally arise for the patient. Answering these questions becomes possible only through interactions that require the reexamination of the values of the patient and the nurse. **Significance of Research:** This research elucidates the spiritual pain experienced by cancer patients and discusses opportunities for nurses to address the spiritual care of these patients.

Underwood, Sandra Millon. "Religion and Spirituality: Influence on Health/Risk Behavior and Cancer Screening Behavior of African Americans." The Association of Black Nursing Faculty (2006): 20-31.

In spite of the diversity in the principles, expression, and practice, it is believed that significant improvements can occur in the health status of African Americans if promoted through religious, spiritual, and faith-based venues. Several reports published in the peer-reviewed literature address issues related to religion, spirituality, and cancer control among African Americans. This growing body of literature describes outcomes of several cancer prevention and control programs designed for, and conducted within, the African American faith community. However, few efforts have been undertaken to examine the influence of religion and spirituality on health/risk behavior and cancer screening practices of African Americans within the faith community. This report presents the outcomes of exploratory study undertaken to examine the influence of religion and spirituality on the health/risk behavior and cancer screening practices of African American congregants. Data suggest a need for tailored and targeted health education, outreach and programming among the targeted group of congregants focused specifically on tobacco control, diet and nutrition, exercise and physical activity, weight management, and cancer screening. The same appears to be the case relative to the need for education, outreach and programming focused on communication with primary care providers.

VandeCreek, Larry “Spiritual Assessment: Six Questions and an Annotated Bibliography of Published Interview and Questionnaire Formats.” Chaplaincy Today 21, no. 1 (2005): 11-22.

No abstract available.

Wasner, M., Longaker, C., Fegg, M. & Borasio, G. “Effects of Spiritual Care Training for Palliative Care Professionals.” Palliative Medicine 19, (2005): 99-104.

Little is known about the effects of spiritual care training for professionals in palliative medicine. We therefore investigated prospectively the effects of such training over a six-month period. All 63 participants of the three and a half-day training were asked to fill out three questionnaires; before and after the training, as well as six months later. The questionnaires included demographic data, numeric rating scales about general attitudes towards the work in palliative care, the Self-Transcendence Scale (STS), the spiritual subscale of the Functional Assessment of the Chronic Illness Therapy (FACIT-Sp) and the Idler Index of Religiosity (IIR). Forty-eight participants (76%) completed all three questionnaires (91% women, median age 49 years; 51% nurses, 16% hospice volunteers, 14% physicians). Significant and sustained improvements were found in self-perceived compassion for the dying, compassion for oneself, attitude towards ones family, satisfaction with work, reduction in work-related stress, and attitude towards colleagues, as well as in the FACIT-Sp. Our results suggest that spiritual care training had a positive influence on the spiritual well-being and the attitudes of the participating palliative care professionals which was preserved over a six-month period.

Weaver, A. & Flannelly, K. “The Role of Religion/Spirituality for Cancer Patients and Their Caregivers.” Journal of Southern Medicine 97, no. 12 (2004): 1210-1214.

Research has shown that religiosity and spirituality significantly contribute to psychosocial adjustment to cancer and its treatments. Religion offers hope to those suffering from cancer, and it has been found to have a positive effect on the quality of life of cancer patients. Numerous studies have found that religion and spirituality also provide effective coping mechanisms for patients as well as family caregivers. Research indicates that cancer patients who rely on spiritual and religious beliefs to cope with their illness are more likely to use an active coping style in which they accept their illness and try to deal with it in a positive and purposeful way. Faith-based communities also offer an essential source of social support to patients, and religious organizations can play a direct and vital role in cancer prevention by providing screening, counseling, and educational programs, especially in minority communities.

White, G. "An Inquiry into the Concepts of Spirituality and Spiritual Care."
International Journal of Palliative Nursing 6, no. 10 (2000): 479-484.

The requirement of healthcare professionals to consider the whole person, including spirituality, is hampered by a lack of clarity about the nature of spirituality and spiritual care. A multidisciplinary cooperative inquiry group met during 1997 and 1998 to explore this issue. The aim of the group was to 'explore spirituality with a view to how that informs our work.' Group members understood spirituality to be a unique potential which forms an integral part of every human being. Key themes through which spirituality may be expressed are the search for meaning or purpose and a sense of connection. Outcomes of the inquiry included personal and professional development, increased recognition of spirituality, and further training opportunities for other staff.

Wintz, S.K., Handzo, G.F. "Pastoral Care Staffing and Productivity: More than Ratios."
Chaplaincy Today 21, no. 1 (2005): 3-9.

One of the leading areas of interest and concern for professional chaplains is staffing and productivity. Administrators are increasingly requiring pastoral care departments to justify their staffing levels. How is a chaplain's work described and determined? How is the work of chaplaincy interpreted to administrators and other members of the interdisciplinary team? What practices are considered "productive" and how can they be measured? The authors provide an overview of the history of ratios within professional chaplaincy, identify important issues that impact staffing and productivity, and provide a process to assist chaplains in determining and articulating their department's needs.