Spiritual Issues in the Care of Dying Patients
“... It’s Okay Between Me and God”

Daniel P. Sulmasy, OFM, MD, PhD

THE PATIENT’S STORY

Mr W is a 54-year-old man with a history of hypertension, bronchitis, and nephrolithiasis who presented 3 months prior to admission with increasing pain in his upper back. A magnetic resonance imaging study revealed a T7 vertebral body lytic lesion, suggesting malignancy. He was admitted to the neurosurgical service of a university hospital in late June 2005 for resection of the lesion, which proved to be adenocarcinoma. Further evaluation revealed a 2.8-cm lesion in the tail of the pancreas, multiple lung nodules, and rib lesions. Immediately following his T7 corpectomy and fusion, his course was relatively uneventful. The oncology and general internal medicine services were consulted.

One week after the operation, during preparation for discharge to a rehabilitation facility, Mr W’s respiratory status began to worsen. A pleural effusion was noted and a chest tube placed, draining 2 L of fluid. Despite drainage, however, the patient’s oxygen requirements increased rapidly from 2 L/min of oxygen to 80% oxygen by facemask plus 6 L/min via nasal cannula. He was transferred to the medical service for further management.

The medicine team was made aware of Mr W’s wishes that he not be intubated or resuscitated and attempted to treat the possible underlying causes for his rapidly worsening respiratory status. Although he showed some improvement with bilevel positive airway pressure (BiPAP), it was extremely uncomfortable for him.

After continued chest tube drainage, broad-spectrum antibiotic coverage, and diuresis, computed axial tomography showed no pulmonary emboli, stable parenchymal nodules, improving effusion, and possible pleural metastasis. He experienced minimal improvement in his dyspnea. Eventually, however, his condition stabilized with 30 L/min of high-flow, vapor-phased, humidified oxygen by nasal cannula, which allowed him to talk, eat, and interact.

After consulting with the oncology team, the medical team determined that Mr W would be a candidate for chemotherapy only if he were discharged successfully to home (that is, if his oxygen requirements could be reduced substantially from his inpatient requirements, and if he could undergo rehabilitation). This information combined with consistent inability to wean Mr W’s oxygen left the medical team with few treatment options. At this juncture, the team initiated discussions with Mr W regarding his ultimate goals of care. He was very clear that he wanted to pursue all options available to him. The palliative care consultation service team was called in for consultation and assistance with end-of-life discussions and discharge options. Mr W stated 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 preclude referral to hospice care.

JAMA. 2006;296:1385-1392 www.jama.com

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Perspectives on Care at the Close of Life is produced and edited at the University of California, San Francisco, by Stephen J. McPhee, MD, Michael W. Rabow, MD, and Steven Z. Pantilat, MD; Amy J. Markowitz, JD, is managing editor.
Perspectives on Care at the Close of Life Section Editor: Margaret A. Winker, MD, Deputy Editor, JAMA.
that he expected God to miraculously extend his life for many years, and the consultation team interpreted that belief to indicate that hospice was not an appropriate option for him. Ultimately, Mr W’s oxygen requirement was tapered to 12 L/min via nasal cannula, and he was discharged to a skilled nursing facility.

A Perspectives editor interviewed Mr W, his attending physician Dr D, and Rev S, the palliative care service chaplain, in July and August 2005.

**PERSPECTIVES**

**Mr W:** I believe in the God of the Bible and that he is the God of miracles. When I say that I mean that I could, 5 minutes from now, stand up completely healed and walk out of here because I believe that He can do instantaneous healing. But I also know that it’s no less a miracle if 3, 6, or 9 months from now, I realize that everything is gone and I’m . . . fully functional. . . . I don’t know if they’ve incorporated my beliefs into planning for my future. . . . A couple of days ago when the palliative care team was here, the social worker heard me saying things about living for many more years, and she came in the next day and told me that things had changed. . . . She told me that she had been looking for hospice care for me, which is just to take care of me for the last 6 months of my life. She said that since I was planning on living longer than 6 months, she needed to look for something else for me. So, my beliefs did affect her outlook on things.

**Dr D:** I assumed that he wasn’t giving me the details of what he believed in. He wasn’t necessarily comfortable talking about it. . . . I had deep conversations with him, but we never spoke explicitly about what we believed in, because I didn’t feel that opening with him. But, I did talk about issues in a more general fashion. . . . You tread the line between being respectful of others’ wishes to share them with you and probing to a certain extent. I wonder why I didn’t ask this patient those questions.

**Rev S:** When I look at a patient, in this case a dying patient, I really look at the primary core spiritual need that they are presenting to me. Is it a quest for meaning to try to determine what their life meant or what their faith means? Or, are they presenting a need for affirmation, support, and community, a kind of valuing from the people around them? Or, are they looking for reconciliation in relationships—they’re presenting broken relationships with people that they can’t say goodbye to because they can’t let go in good conscience and they are carrying resentment about the past.

**Overview**

Spirituality and religion are complex topics, and these matters have become especially delicate in public discussions in the Western world, in academic circles, and in medicine. This article cannot begin to address every aspect of so vast a field, but instead will present some overarching concepts of spirituality and religion, describe the spiritual and religious needs of patients approaching the end of life, and delineate how physicians might play a role in ascertaining and responding to those needs. It then focuses on the clinical situation that arises when patient and/or family prayers for miracles affect medical decision making at the end of life. Although many of the themes discussed have broad applicability across religions and cultures, the nature of the case requires specific focus on Judeo-Christian religious themes.

**Text and Subtext**

This case is presented as a crisp, technical summary of the biomedical problems encountered in caring for the patient. The interview excerpts, by contrast, demonstrate Mr W’s deeper levels of personal and spiritual concern. Dr D, the attending physician, is hesitant to ask about Mr W’s spiritual and religious needs. In today’s medical culture, even a deeply concerned clinician might tend to “problematize” the spiritual aspects of a patient’s care, casting them as ethical problems (eg, “code status” and “futility”) or as psychosocial problems (eg, “denial” and “disposition”). Spirituality cannot be reduced to these categories, however. The spiritual aspects of this case are distinguishable yet inextricably bound up with its biomedical, psychosocial, and ethical aspects. Spiritual and existential well-being are major components of health-related quality of life, especially at life’s end. Overall quality of life is highly correlated with spiritual well-being among dying patients and among patients living with cancers of variable prognoses. Religions have a great deal to say about care at the end of life, and numerous studies have demonstrated that religious denomination and religiosity are correlated in complex ways with patients’ attitudes about various aspects of care at the end of life. For example, religiosity (as defined by strength of belief or by frequency of religious practices) is inversely correlated with fear of death. Religious independence of denomination, is also associated with opposition to the deliberate hastening of death. Catholics are less likely than Protestant Christians to pursue life-prolonging treatment. Among Jews, more religiously observant practice is associated with a greater preference for the use of feeding tubes. African Americans show consistently greater resistance to limits on life-sustaining treatments and advance directives compared with other racial groups, and these attitudes are linked to spiritual and religious concerns. Clearly, if physicians are committed to treating patients as whole persons in the 21st century, spirituality and religion cannot be ignored. A bio-psychosocial-spiritual model of care will be required.

**Spiritual Issues in the Care of Dying Patients**

Spirituality is about one’s relationship with the transcendent questions that confront one as a human being and how one relates to these questions. A religion, by contrast, is a set of texts, practices, and beliefs about the transcendent, shared by a particular community. Spirituality, in this respect, is broader than religion. While not everyone has a religion, spiritual issues, in this wider sense, arise for almost all dying persons.

Despite increasing evidence that patients would like their physicians to do so, spiritual issues are rarely addressed by
21st-century Western physicians. In one survey of outpatients, 52% believed that a physician had the right to inquire about a patient’s religious beliefs, but a majority could not recall any physician ever having inquired about religious beliefs. In a survey of inpatients, 77% believed physicians should consider their spiritual needs and 48% wanted their physicians to pray with them, but 68% said no physician had ever inquired about their spiritual or religious needs. In another survey of outpatients, 94% thought it appropriate for physicians to inquire about their spiritual beliefs were they to become gravely ill.

In the case presented, Rev S has named all 3 of the most pressing categories of spiritual questions that serious illness raises—questions of meaning, value, and relationship (Box 1). These are the deep-seated spiritual needs of dying persons, as affirmed by thousands of years of wisdom accumulated by the world’s great religions, and reinforced by recent qualitative research even among largely non-religious Westerners.

Dying persons want to know if there is any meaning in their suffering or in their dying. These questions are often framed in overtly religious terms, but qualitative research suggests that these are pressing questions for almost all dying patients. Despair is typically defined as the absence of hope, but another name for hopelessness may be meaninglessness. Mr W seems to have found meaning in his illness and dying. He said, “Through this process I have grown incredibly.”

Dignity is the word we use to describe the ultimate value of a human being. In its intrinsic sense, dignity refers to the value human beings have by virtue of being just what they are—human beings. Dying persons need to be assured that they have this value at a time when their reduced productivity, dependence, and altered appearance have called their ultimate value as persons into question and may even have caused them to doubt their own intrinsic value. During a visit, Rev S reported having paraphrased the Christian scriptures for Mr W, saying, “Nothing can separate us from the love of God, neither height nor depth, life or death.” Rev S then noted that Mr W “said that he believed that.” Regardless of religious affiliation, the need of the dying to understand that they are valued—cherished—is a powerful spiritual need.

Box 1. Assessing the Spiritual Issues Raised by Serious Illness, Especially at the End of Life

First, establish an empathic connection with the patient (or the patient’s family). Often, nothing more will be required to engage the patient in significant spiritual sharing. Only then, consider moving to more specific questions.

Opening

“It must be very hard for you to find yourself (your loved one) so sick. How are you holding up?”

Questions of Meaning

Patient/family questions

“What is the meaning of my illness?”

“What is the meaning of my suffering?”

“What is the meaning of my death?”

“Will any meaning persist beyond my death?”

Clinician questions

“Have you thought about what all this means?”

“Would there be anything for which you might hope even if you (your loved one) are not cured?”

“Do you attach any spiritual significance to the word ‘hope’?”

Questions of Value

Patient/family questions

“How does my value relate to my appearance?”

“... my productivity?”

“... my independence?”

“Is there anything about me that is valuable when these are threatened?”

“Is there anything valuable about me that will persist beyond death?”

Clinician questions

“Are you able to hold onto a sense of your own dignity and purpose?”

“Do you feel that people in the hospital/your family/your friends/your congregation really care about you (your loved one) as a person?”

“Are there any spiritual or religious resources upon which you can draw to help see you through this?”

Questions of Relationship

Patient/family questions

“Am I estranged from any family or friends?”

“Who have I wronged? Who has wronged me?”

“Am I loved? By whom?”

“Does love endure beyond the grave?”

Clinician questions

“How are things with your family and friends?”

“Is there anyone with whom you need to ‘make up’?”

“Is there anyone to whom you need to say ‘I love you’ or ‘I’m sorry’?”

“If you’re a religious person, how are things between you and God?”

Closing Comments

“I can’t do everything—that’s why we work as a team. I think we’ve covered some very important ground here, but there’s so much more to talk about. If it’s okay with you I’m going to send Rev S to see you later today. Also, I’d like to tell her a little about what you’ve just shared with me, so she can be better prepared. Would that be okay?”

Based on Sulmasy.
As their bodies bend and break, dying patients are somehow reminded of the brokenness in their relationships with others and of their deep need for the healing of reconciliation.

Rev S describes her encounter with Mr W: “The support that he felt in the community was his primary concern and his primary understanding of God’s presence came through the people that were supporting him and caring for him. He talked a lot about the relationships that were significant, in family and in church, and with his roommate.” In Eastern religions, this need for reconciliation extends beyond the interpersonal to take on a cosmic dimension.44 Pastoral care experts in the United States recommend a life review as a technique to assist in the spiritual healing of reconciliation for dying patients.23

It is not the task of the health care team to give patients meaning, value, or reconciliation, but to facilitate patients’ encounters with the meaning, value, and relationships that are already present as givens in the existential situations of their dying. It is in this sense that the clinicians in this case may have missed opportunities to make spiritual connections with Mr W and perhaps to have assisted him in his spiritual journey. Dr D came close to doing so, but backed away. “I didn’t expressly ask this patient about religion or faith; I asked him about his level of peace and where he was going and that sort of thing.” Even if physicians and patients can arrive at mutually acceptable biomedical plans of care without delving into spirituality, attending to patients’ spiritual needs gives physicians an opportunity to communicate to patients that they are truly respected as whole persons. A recent poll shows that 59% of the US population considers religion extremely or very important in daily life.26 Clinicians who ignore the spiritual concerns of patients are, in effect, asking many patients to isolate themselves from beliefs that deeply define them, at times of great vulnerability, as the price for receiving attention for their physical needs. The profession has an opportunity to offer patients more.

Interviewed after the patient’s discharge, Dr D said, “This conversation makes me wonder why I didn’t ask those questions.” Although 74% of primary care physicians agree that physicians should ask dying patients about their religious or spiritual beliefs,27 the data in the patient surveys cited above suggest that physicians are not acting on this belief. Perhaps this hesitancy is true of US physicians because they are less likely than the general population to believe in God (76% vs 83%), and report that they are less likely to try to incorporate their religious beliefs into all aspects of their lives (58% vs 73%).28 Sometimes clinicians hesitate to inquire about patients’ spiritual and religious beliefs because of their own spiritual and existential struggles, not just with the idea of death, but also with the ultimate impotence of medicine as a cure for death. As Dr D describes it, “It’s an awful thing to come to the patient with your bag of tricks empty.” Sometimes clinicians fear that they might give offense, as did Dr D, who worried that she might be “probing.”29 But in one survey, even 45% of patients who professed no religious beliefs thought that physicians should inquire about their spiritual needs.17 In another survey, conducted at a New York City hospital, regression analysis showed that patients’ expressions of spiritual needs were independent of religious denomination, including those who reported no religious affiliation.30

Others hesitate because they believe they lack the time or the capability.31-33 One way to begin might be by asking, as did Dr D, “Are you at peace with all this?”43 As this case demonstrates, however, that question may be too vague for many patients. More probing follow-up questions might include, “Does that peace come from a spiritual or religious source?” or “Might spirituality or religion play a role in helping you find peace?” Multiple educational efforts, using both didactic and experiential learning methods, are under way to help clinicians better understand how to assess the spiritual needs of all patients, regardless of religious denomination or spiritual background.35-37

**Whose Job Is It, Anyway?**

Defining the clinician’s role in addressing the spiritual needs of dying patients is important. Physicians should not ignore the spiritual needs of their dying patients, but neither should they overestimate their skills in addressing these needs. What physicians should be able to do is to take a spiritual history, elicit a patient’s spiritual and religious beliefs and concerns, try to understand them, relate the patient’s beliefs to decisions that need to be made regarding care, try to reach some preliminary conclusions about whether the patient’s religious coping is positive or negative, and refer to pastoral care or the patient’s own clergy as seems appropriate.36-42 As with any other medical skill, the clinical situation will dictate the required depth to which these skills will be put to use.

Astute clinicians pick up clinical clues from patients. The Hindu amulet, copy of the Qur’an, rosary beads, or Shabbat candles on the nightstand next to the bed may be as much communication to the staff as they are spiritual aids to the patient. They are signs of what the patient holds most dearly.41 All that may be needed is a simple, open-ended question, such as, “Is that the Bible you’re reading there?” in order to engage the patient on a spiritual level. Showing respect for such defining features of a patient’s life may constitute a healing act and can be integral to the care of the “whole person.”

**What Can a Physician Do?**

The basic historical information physicians can garner from all patients has been summarized in useful acronyms for taking a spiritual history. A spiritual history provides information about the patient’s spiritual and religious background. BOX 2 presents 2 spiritual history tools: “FICA” as developed by Matthews, Puchalski, Sulmasy and Teno and published by Puchalski,44 and another called “SPIRIT” by Maugans.38 It is probably most helpful to use these acronyms as reminders of important information one should gather rather than as specific questions to be asked on a checklist. Most of this information flows naturally from open-
ended questions. A useful opening question might be, “What role does spirituality or religion play in your life?” If the patient responds narrowly, for example, saying, “I’m a woman of faith,” a useful follow-up comment might be, “Tell me about your faith.”

A spiritual history only provides a backdrop against which to understand the pressing spiritual questions that dying patients face. Physicians who are committed to the care of patients as whole persons have an obligation to ensure that the spiritual needs of their patients are met, either personally or by another member of the treating team. Simple screening may exclude the need for more detailed assessment. Box 1 provides the elements that might be involved in a detailed spiritual assessment of a dying patient. These questions often overlap, and spiritual conversations usually proceed in an organic rather than a mechanistic manner. The questions are thus only suggestions for assessing the spiritual concerns of patients. The primary spiritual act is the expression of empathic concern. If sincere, nothing more may be needed.

Patients of various faith traditions often have very specific religious needs that might not easily be met in the contemporary hospital environment. By inviting patients to express these needs, physicians may be able to locate the resources to meet these needs or to facilitate the patient’s efforts to meet these needs. Although it is obviously not intended as an exhaustive list, several examples are given in Box 3.

Physicians also need to have an “exit strategy.” The suggested closing comments in Box 1 may provide an easy way to break off the conversation when it has run its course or should the physician feel at any time overwhelmed by the content or the duration of the patient’s self-disclosure. Referral to a chaplain, the patient’s own personal clergy, a social worker, a psychiatrist, or some combination constitutes the next step, depending on the content of the assessment. For example, if a patient is both depressed and reporting a spiritual crisis, referral to both psychiatry and pastoral care would be indicated.

Religious beliefs can sometimes result in unwarranted suffering and distorted decision making at the end of life. Negative religious coping is associated with guilt, anxiety, fear, and denial (Box 4). Physicians are often in an excellent position to uncover these issues. By asking a patient who has previously disclosed religious belief, “How are you and God with this?” a physician may discover that the patient believes his/her illness is a punishment from God for a past sin. Negative religious coping warrants referral to pastoral care or the patient’s own clergy.

All patients are vulnerable, but perhaps none so much as those who are approaching the end of life. It is critical that no physician who undertakes a discussion of spiritual issues with dying patients misuse the power imbalance between physician and patient in order to proselytize. Patients must always be perfectly free to refuse to participate in such discussions and no aspect of care should be made beholden to denominationally “correct” responses.

Above all, clinicians can respond to the spiritual needs of patients by respectful attention to their patients’ ultimate concerns, by being present with them and demonstrating that they are worthy of time and attention, and by listening to what the dying have to tell about life and its meaning. If the patient and the physician are of the same faith, the shared language, tradition, and symbolism facilitates such interactions. But the ultimate questions about meaning, value, and relationship are questions for all patients, whether or not the patient or the physician subscribes to any specific creed. For example, a nonreligious physician might say to a devoutly Buddhist patient, “I do not share your faith, but I understand how important Buddhism is to you, especially at this time, as a source of hope, value, and strength. How can I help you live well as a Buddhist for as much time as remains for you?”

**MEDICINE AND MIRACLES**

Mr W raises one highly specific spiritual issue that sometimes arises in care at the end of life: when the prayers of patients and families for miracles lead them either to reject medical recommendations or to demand medical interventions that the treating team believes are inappropriate. Although the exact incidence of this specific kind of dilemma...
Physicians can, however, listen attentively and make appropriate interventions, such as referrals. Patients demanding futile care in the expectation of a miracle may really be expressing a sense of being out of control, interpreting discontinuation of a particular treatment as a sign of abandonment, or possibly experiencing guilt, denial, or even pathological ambivalence. Some may be expressing a culturally mediated suspicion, based on historical injustices, that the treatment may not actually be futile and that the suggestion to withhold treatment may be based on financial concerns. For still others, the issue is not a religious belief that God requires a physician to perform the miracle but rather a belief that assenting to a request to stop treatment amounts to giving up on God before God has given up on them. Astute clinicians can discern the scope of the problem and come to a deeper understanding of the issue in its actual spiritual and cultural complexity. Such understanding may help bring about a resolution. However, physicians should not extend their expertise beyond their capabilities. Discussions about scriptural exegesis, the theology of miracles, or the pastoral counseling of patients who are experiencing spiritual crises are best left to the experts. In this way, chaplains can play a direct and important role in providing good care to patients as part of the team.

**Miracles and Hospice**

Fortunately, in this case, Mr W did not appear to be in denial. He was praying for a miracle but he accepted the possibility that God’s answer to his prayers might not be the miracle he was seeking. He was not demanding that physicians enlist themselves as God’s agents for him. Here is how he describes his prayer:

**Mr W:** I always include in my prayers, “God, not as I would have it, but as you would have it.” I don’t think that’s a cop-out.

He even accepted a do not attempt resuscitation (DNAR) order.

**Mr W:** Again, after talking with the doctors, I feel that if I do have a heart attack, it would be because the cancer has spread beyond . . . you know.

I have no regrets in making that decision. I feel that with prayer, and talking with the doctors, and talking to my family, that it was the right decision.

It was a decision that was made with prayer, and it’s okay between me and God.

Nevertheless, the treating team seems to have concluded that patients who believe they will live longer than 6 months are precluded from hospice. This may have been unfortunate for Mr W because enrollment in hospice often provides patients with resources that would not otherwise be available to them. It is uncertain why the team harbored this belief. No explanation is given in the case presentation, and it appears to have been an unchallenged assumption of all of the professionals involved in his care. Yet nothing in the federal regulations says that patients who believe in miracles are ineligible for the hospice benefit. The physician, not the
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September 20, 2006—Vol 296, No. 11

Box 4. Elements of Religious Coping

<table>
<thead>
<tr>
<th>Positive Religious Coping</th>
<th>Negative Religious Coping</th>
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<tbody>
<tr>
<td>&quot;I think my life is part of a larger spiritual force.&quot;</td>
<td>&quot;I feel that stressful situations are God's way of punishing me for my sins or lack of spirituality.&quot;</td>
</tr>
<tr>
<td>&quot;I work together with God as partners to get through hard times.&quot;</td>
<td>&quot;I wonder whether God has abandoned me.&quot;</td>
</tr>
<tr>
<td>&quot;I look to God for strength, support, and guidance in distress.&quot;</td>
<td>&quot;I try to make sense of the situation and decide what to do without relying on God.&quot;</td>
</tr>
<tr>
<td>&quot;I try to find the lesson from God in crises.&quot;</td>
<td>&quot;I question whether God really exists.&quot;</td>
</tr>
<tr>
<td>&quot;I confess my sins and ask for God's forgiveness.&quot;</td>
<td>&quot;I express anger at God for letting terrible things happen.&quot;</td>
</tr>
</tbody>
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From Pargament et al.47

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CONCLUSIONS

Increasingly, good spiritual care is recognized as an important part of high-quality care. Although spiritual issues arise in the settings of acute and chronic illness, spiritual issues assume a special salience in care at the end of life. The care of Mr W illustrates how the spiritual needs of patients are inextricably bound up with the “traditional” duties of physicians. Attending to these needs is integral to the job of being a good physician.

Financial Disclosures: None reported.

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the California Healthcare Foundation.

Role of the Sponsor: The funding source did not participate in the collection, analysis, and interpretation of the data or in the preparation, review, or approval of the manuscript.

Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at http://www.jama.com.

REFERENCES

9. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to eu-
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WEB SITES

The Association for Clinical Pastoral Education
http://www.acpe.edu
An organization that trains and certifies hospital chaplains to serve a religiously diverse patient population. Especially useful is the calendar of events with many local conferences on the spiritual care of patients.

Duke Institute on Care at the End of Life
http://www.iceol.duke.edu/index.htm
A joint effort between the Medical and Divinity Schools at Duke, with a special emphasis on spiritual aspects of care at the end of life. Special programs regarding end-of-life care and African Americans are a highlight.

George Washington Institute for Spirituality and Health (GWISH)
http://www.gwish.org
A clearinghouse for programs in spirituality and health care, with a very useful emphasis on the education of medical students and residents in spirituality.

The Healthcare Chaplaincy
http://www.healthcarechaplaincy.org/index.asp
An interfaith chaplaincy program with publication lists, conferences, and a consultation service for evaluating and improving pastoral care services.

Spirituality, Religious Wisdom, and the Care of the Patient
Yale Journal for Humanities in Medicine
An online journal that has published a series of talks by leading religious figures from 6 faith traditions, covering topics such as hope, guilt, anger, faith, denial, and love in the care of patients.

University of Virginia Health System, Chaplaincy Services and Pastoral Education.
“Religious Beliefs and Practices Affecting Health Care”
http://www.healthsystem.virginia.edu/internet/chaplaincy/rbpahc.cfm
A handy synopsis of the basic beliefs impacting health care of patients practicing Buddhism, Catholicism, Protestantism, Hinduism, Islam, and Judaism. Useful for a quick look for busy clinicians, but no issue is treated in depth. Hard copies can be purchased in booklet form.

BOOKS

Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research, by the Fetzer Institute