Losing God

RICHARD T. PENSON, RUSHDIA Z. YUSUF, BRUCE A. CHABNER, JOANNE P. LAFRANCESCA, MICHAEL MCELHINNY, ALBERT S. AXELRAD, THOMAS J. LYNCH, JR.

Department of Medicine, Division of Hematology/Oncology, Massachusetts General Hospital, Boston, MA, USA

Key Words. Physicians · Spiritual · Psychosocial · Faith · Conflict · Crisis

ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

Nebulous language, distrust, and dogma confound spiritual aspects of cancer care. However, existential well being is an important determinant of quality of life: finding meaning and purpose make suffering more tolerable. The case presented is of a patient who experienced “losing God” as a Hodgkin’s disease survivor with metastatic prostate cancer and severe coronary artery disease. His caregivers were able to provide the sense of community in which he could re-establish his faith. Health care providers do not have to be religious in order to help patients to deal with a spiritual crisis. The clinical skills of compassion need to be deployed to diagnose and respond to spiritual suffering. Acknowledging and addressing anger or guilt, common sources of suffering, are essential to adjustment. Simply being there for the patient and being open to their hurt can help resolve their spiritual crisis, a responsibility that is shared by the whole health care team. The Oncologist 2001;6:286-297

PRESENTATION

Mr. A is a 57-year-old man with a very extensive medical history. He first noticed a mass in his right groin in 1966. Biopsy revealed mixed cellularity Hodgkin’s disease, and he received inverted Y field radiation therapy at Massachusetts General Hospital. Between 1968 and 1994 he developed eight nodal recurrences and required a splenectomy for idiopathic thrombocytopenic purpura which revealed Hodgkin’s disease. Treatment for recurrent disease included mantle radiation, mechlorethamine/vincristine/procarbazine/prednisone (MOPP) chemotherapy, left chest wall radiation therapy to the left axilla, and a second course of MOPP and adriamycin/bleomycin/vinblastine/dacarbazine (ABVD). Ultimately he was treated with stem cell supported high-dose chemotherapy, with busulfan and cyclophosphamide in 1994. Because of an elevated prostate-specific antigen (PSA) he underwent retropubic prostatectomy with bilateral pelvic lymphadenectomy and pelvic radiation therapy. Subsequently, he was diagnosed with bone metastases and treated with Lupron (leuprolide acetate). Other medical history included colonoscopic polypectomy for hematochezia and chronic anemia. He was also hearing impaired in the right ear. In recent years with problematic coronary artery disease he

Correspondence: Richard T. Penson, MRCP, Instructor in Medicine, Hematology-Oncology, Cox 809, 100 Blossom Street, Boston, Massachusetts 02114-2617, USA. Telephone: 617-726-5867; Fax: 617-724-3166; e-mail: rpenson@partners.org

Received May 29, 2001; accepted for publication May 29, 2001. ©AlphaMed Press 1083-7159/2001/$5.00/0

The Oncologist 2001;6:286-297 www.TheOncologist.com
had undergone aortic valve replacement with three-vessel coronary artery bypass grafting. He had hypercholes-
terolemia and had required insertion of a permanent pace-
maker for complete heart block. Most recently, he had
suffered with increasingly refractory congestive heart fail-
ure and chronic renal impairment, following an admission
for influenza A.

Infusion nurse: I first met Mr. A, approximately 8 years ago
at his fifth recurrence of Hodgkin’s disease. The incident
I’m going to relate happened last year. Mr. A came to the
clinic very distressed. One of his nurses came to find me
and said, “You have to come and see Mr. A. He’s really
upset.” So I said, “Okay” and walked into the room to see
Mr. A who looked straight at me and
said, “I’ve lost God, I’ve lost God.” My
first inclination was to laugh because I
just couldn’t believe
what I was hearing. But seeing the look of terror on his
face, I asked, “Mr. A, how did you lose God?” He replied,
“He’s always been there for me but I don’t seem to be
able to get in touch with him any longer.” Mr. A had
coped with Hodgkin’s disease, bone marrow transplan-
tation, prostate cancer, and managed to do that well but
was now faced with significant limitations from his car-
diac symptoms. He was distraught and I think he was
beginning to lose hope.

So I talked with Mr. A that day about anger. And I
said to him “Mr. A, do you think you lost God because you
are angry with him?” And he said, “How could I be angry
with God?” To which I replied, “How could you not be
angry with God?” Yet he said, “Well, I just couldn’t
fathom being angry with God.” I then remembered hear-
ing a story on public radio that morning about a brother
and sister who were actually pleading for the life of a pris-
oner sentenced to be executed for the death of their father.
They talked about anger and what it had done to them and
that they wanted leniency for this man because they knew
that if he died they would never be able to resolve their
anger. They knew that before they could live in peace they
had to somehow come to terms with their anger. I told him
that story and I said, “Maybe you lost God because you
need to be angry enough with him first to come to peace
with him.” There was a knock on the door and I was so
glad, because it was the chaplain.

Chaplain: I’ve known Mr. A for 2 years. There were times
when he was depressed, but he always found a way to
make himself and people around him feel better. His
faith is what sustained him. He’s one of God’s messen-
gers. He makes rosary beads while stuck in traffic and
gives them to the hospital chaplain. I have a few to
prove it! Mr. A was someone who would say, “I know
God is with me. I trust God will lead me through this. I
know God loves me.” The temporary loss of that con-
nection with God, for someone with a strong faith,
brings on a powerful spiritual crisis. God, the rock of
the person’s life, is suddenly gone. Where do they turn?
I would humbly suggest they turn to people like us, the
whole team. You have gained the trust of your patients,
and they are going to look to you for help.

Usually patients are going to give you a pretty clear
signal about their spiritual distress. Questions
like, “Why did God do this to me? There is no
hope. I must have done something to get this dis-
ease,” are clues to their
spiritual suffering. If you’re comfortable with it, you
can follow up with a question like, “Do you really think
that?” or, “Do you really believe God did that to you?”
Questions like that may open patients up to say the
things they really need to say. Other patients may speak
about God a lot in a positive context and you may
almost get used to them doing it. Then they change.
People around the patient say, “So-and-so has begun to
close up.” A question from someone they trust asking,
“I haven’t heard you mention God lately, everything
going okay with that?” invites them to respond.
Hopefully what happens, and what happened that day
when Mr. A was here, is that the patients who are spir-
itually suffering will then identify the barrier that is
blocking them from their spiritual resource. They will
have a chance to admit that there is a barrier. You can
help them acknowledge that it’s okay to feel a block
and that hopefully by talking about it to someone like
you, and then bringing it to God, they can get rid of it.
That’s what happened to Mr. A. He was angry that day
at God and he finally admitted it. He was fearful about
dead and he got to talk about it and slowly but surely,
Mr. A’s faith, and Mr. A’s strength returned. I also want
to say that what Mr. A did that day was to give up the
idea that he was in control of his life and realize that
God was in control. He has since told me, “I’m at peace
with dying, although I don’t want to rush it.” He can
even wonder as he does some days, “I wonder why God
hasn’t taken me already,” but then he’ll stop and smile
and say, “Because I know he has to do more things for
me and for other people here on this earth through me.” Maybe the last comment I would make is that in the efforts you make to struggle with a patient in their spiritual crisis, you are showing that you care. The patient will see that you are concerned about taking care of the whole, the physical, the emotional, and the spiritual person.

**Infusion nurse:** Mr. A was really in despair. If you had seen his face that day, you’d understand. I think that mostly patients really want to talk about what they are going through. They want to find meaning in their illness and they want to be able to share that with people whom they trust. If in fact we’re uncomfortable with sharing their innermost feelings, they will know right away and they won’t disclose them. I think that one of the most beautiful pieces of our work happens when patients disclose their deepest concerns. We all experience God in a different way, yet that shouldn’t get in the way of our being able to help patients spiritually. Lastly, I thought it was ironic that Mr. A came to the hospital that day to find God. And I think that he did, because he was comfortable with the people he knew here. That day we gave him an IV (we rehydrated him because that’s what we do!) and we tried to help Mr. A find God again.

**Rabbi:** Well, I’ve yet to meet Mr. A so I’m speaking in somewhat more of a vacuum than the other speakers. I think on the whole when someone gives voice to the kinds of sentiments that have been described above, they are not intending to engage in a protracted theological discourse, but are expressing frustration, anger, despair, and real fear. I think that if someone is truly interested in a theological discussion, then I would give them *Harold Kushner’s* book or the text that led to *Harold’s* book, an extraordinary essay, by a thinker named Henry Slonimsky [1, 2].

We’re not really dealing with theological discourse. These are sentiments that deserve identification. There is a story, and I think it’s not an apocryphal one, about a senior and very distinguished colleague of mine, who shall remain nameless. He is reputed to have said, in dealing with a patient who was very angry and who had lost faith in God, “I don’t blame you, I sure can identify with your loss of faith, after all God’s really f---ed you over, hasn’t He?” I think that my colleague actually said that word or something very close. But I can identify with that so I take the blame along with this very revered colleague of mine. Therefore, I think first of all one has to identify with the sentiment that the patient is expressing, not belittle it or ignore it, and I think all of us can engage in this practice. This is not just the domain for clergy or theologians. I think it is the domain of humans across the board. Secondly, an element that would be of concern to me is whether the patient is thinking that his or her disease is some kind of punishment; divine retribution for something that they did. I feel very secure about assuring the patient that no such thing is at play; that nothing that he or she has done would deserve or merit such a response from the Holy One. I would suggest to him or her that it’s something to be coped with courageously and with dignity and inner strength, drawing upon our unique gifts of spirit and soul and heart and character; but not something that one “deserves.” I would assure Mr. A that as I examine sacred writ, across the board, it is clear that shaking your fist at God is not a scurrilous thing to do; it’s not audacious irreverence, but rather a mark of piety. I would remind Mr. A of the story of Sodom and Gomorrah and Abraham bargaining for mercy [Genesis 18]. God doesn’t dismiss Abraham, God doesn’t get ticked off at Abraham; God takes it very seriously and deals with it and says, “Yes, I’ll spare the city if you find 50 righteous men.” Compare that with what Noah did. Noah did not quarrel with God. He built the Ark and saved his own hide and his family [Genesis 6]. Noah is described as “blameless in his generation.” However, there are biblical interpretations that suggest that this is faint praise of Noah and compared to others like Abraham, who fought with God, Noah was a nobody in moral and spiritual terms. Now would be the time to share that with our friend Mr. A and others like...
he. Finally, I would ask Mr. A, despite his crisis and despite his loss of faith, whether he would like to pray with me in a somewhat unusual vein. If he were to say yes, and I think he might, I would share with him a prayer that would go something like this: Today our faith is sorely tested. Serious illness has been thrust on Mr. A. We wonder about God’s role, doubts plague us, and yet we seek the divine presence. We ask for strength and loving kindness and let us say Amen. And then if Mr. A were of a mind, I would want to sing the prayer with him and teach it to him in song, and sing it with him again and again. And it would go something like this: We ask for strength and loving kindness and let us say, Amen. We ask for strength and loving kindness and let us say, Amen (repeat).

**The responsibility to help resolve a spiritual crisis rests with the whole team.**

**Oncologist:** The other day, one of the Chaplains, asked me if I would be comfortable praying with one of my patients before an operation. I was never in a situation like that, even though one of the Chaplains here was my patient for a number of years and my wife is a graduate of the Lay Minister Program of this Institution. Still I drew a blank. As I thought about it, I decided that I would be comfortable, but I would feel like I was the wrong guy to be doing it. I would be comfortable, personally, because of my own spiritual inclinations, but it would make me feel like a bit of a fraud. I wouldn’t know why the patient wanted me to pray with him, but I would do it and I would feel comfortable personally.

**Oncologist:** I noticed something recently. The Chaplains have been putting notes in the medical chart. I love it. It’s been really important to me to see the Chaplain putting these notes in because until a very short time ago, I could never find them. I could never catch up with the chaplains. They were there, but they were like phantoms. Now they’re on the scene and available. They used to stay in the background and now they’re stepping right up and they’re doing a great job.

**Assessment**

**Infusion nurse:** I think it’s really important to assess a patient’s spirituality and how they cope early on. If you gain that information from your interaction with the patient early on in their disease, then you can use it as their disease progresses. I don’t think that we do this well enough, because we’re not comfortable with the issue and we don’t know how to ask about a patient’s spirituality.

**Social worker:** I think you’re right. In my experience, spirituality evolves with time. Patients also get in touch with it themselves, as they go along. It’s not something you’re able to articulate or even let out right away. This is all about our readiness to meet them at a deeper level and it does start from our medical connection with them. I think, in fact, that getting in touch with a patient’s spirituality is about this connection. I’m struck by the fact that Mr. A came here to tell you he’s lost his connection with God. He counted on you to help make the connection with the deepest parts of himself, as one would on one’s family. It is important to realize, however, that it doesn’t always work when you confide in your family about your spirituality.

**Rabbi:** I think that if you listen to the hints that people give you, which they do to test if you are willing to listen to them, you will pick up what they are trying to say to you and that can open a detailed discussion.

**Infusion nurse:** I feel that something should be said about the importance of consistency in care. I could have done on Mr. A’s problem immediately that day because I really knew him. Mr. A was approaching the terminal phase of his illness. With each visit, I felt his despair underneath the calm of his exterior. I wondered in what way and when it would surface. I knew that someday Mr. A was going to lose his ability to rationalize his situation. I knew how strongly he depended on his faith to get him through. If I was not allowed the opportunity to work with him over time, I could never have risked articulating what I instinctively understood the problem to be. If I had said what I said on any other day he probably would have been angry with me, but that day I knew I could raise the issue of being angry with God. If I hadn’t known Mr. A as well as I did, perhaps the outcome that day might have been different.

**Personal Discomfort**

**Social worker:** What responsibility does a medical person with no religious training have? Rabbi, you use the term
Different Views of God

Nurse: There are still people who hold tightly to a vengeful view of God and God’s will. Others will see God more as a loving and compassionate Being. We need to really explore with the person their concept of God, what they believe God does and does not do and the strength of their faith. Some people are rooted firmly in their beliefs. Other people may not be as religious.

Nurse: I once had a patient who wanted to pray before I started her i.v. I got really nervous and thought, “She doesn’t trust me.” It is uncomfortable when people ask you to pray with them, but you have to get over the discomfort, over the times when you want to run out of the room because you are not sure of what to say. If you can hold on through the discomfort, ultimately the right words come. I think for a lot of us it’s just easier to turn around and call a Chaplain “because that is their job” and because it saves us from having to deal with our insecurities.

Chaplain: The responsibility to help resolve a spiritual crisis rests with the whole team. The chaplain’s role is unique in being focused on issues of meaning. The chaplain is trained to have the language and emotional stamina for these searching conversations, and in carrying religious “authority” the chaplain’s care may be especially powerful in helping a patient toward resolution of a religious crisis. It is also the chaplain’s role to support other members of the team in their own struggles and search for meaning.

The issue of putting one’s life in perspective with one’s faith comes up often, and I think it is probably much more commonly addressed among our patients and caregivers than we realize.

The Carer’s Perspective

Oncologist: I’d imagine that if we did a poll in this room and asked people “What is your spiritual faith?” we’d get an individual answer from each person. I’m curious about how directly you can ask this question. I’m curious about...
how other people would respond to that very direct question in their own practices.

**Oncologist:** I know that from my perspective, one of the things that made me anxious about becoming an oncologist was whether people would turn to me as they were facing death and ask me somehow to add some kind of meaning to their life. Obviously that doesn’t happen nearly as much as I feared it would, but it happens to a certain extent. The issue of putting one’s life in perspective with one’s faith comes up often, and I think it is probably much more commonly addressed among our patients and caregivers than we realize.

**Infusion nurse:** Being in oncology for many years has allowed me to draw my own conclusions about my own spirituality, and I have a degree of comfort that when a patient brings it up, I’m not as afraid as I was.

**Psychiatrist:** I think I encourage children to legitimize the struggle rather than fix it. I tell them I don’t have a right answer. I don’t feel they’re truly asking for an answer. It is an issue they have to respond to in some way. I just recognize that it sounds like an important struggle, rather than try to fix it or get someone to help. Ultimately I think childhood rules.

**Nurse:** I’ve been asked about my faith several times by patients and I’ve had a very difficult time dealing with the question. I haven’t been trained for this and I start thinking, “How am I going to answer this?” I ask myself, “How do they want me to answer this?” I was with a woman who I knew was an Evangelical Christian from the South. I thought, “There is just no way we’re going to connect” and I didn’t want to spoil the relationship I had with her. It was a very hard situation, and I felt very uncomfortable about the way I handled it afterwards.

**Psychiatrist:** One of the things I’ve wondered about in my practice is whether the God of childhood abuts the God of adulthood in the crisis of cancer. In times of fear, there is a tension that “God won’t forgive me because I’m now an adult and I’ve done all these wrong things that in childhood would be in the ‘thou shalt not’ box.” I’m often asked to listen as people struggle to reconcile themselves with a particular belief system.

**Facilitator:** Could I ask how you deal with being the parental figure in the pediatric clinic. How do you respond?

Communicate that you care about them no matter what their religious belief is, or what yours is. Then they know you’re with them. In the end it really is all about sticking with your patients.

**Social worker:** I’m struck by people’s concerns about whether they’re going to use themselves appropriately when helping a patient in a spiritual crisis. I think the most important thing is not to leave the patient alone. They’ve opened up to you in some way. Don’t leave them. Don’t deflect them. Even if you say, “That is such an important, such a profound question, and I don’t know the answer to it,” it is better than running away. I think you’ve got to share with them who you are and let them know that they don’t have to think the way you do, in order for you to help them, care about them, pray for them, or hope for them. Communicate that you care about them no matter what their religious belief is, or what yours is. Then they know you’re with them. In the end it really is all about sticking with your patients.

**DISCUSSION**

**Spirituality**

While religion is a formal system of beliefs, values, and practices based on specific spiritual teachings, “spirituality” relates to the intangible mysteries of life and the quality of our relationships with ourselves, others, and God. Spirituality is the life principle that pervades a person’s entire being; volitional, emotional, moral, ethical, intellectual, and physical and
generates a capacity for transcendent values. Spirituality is the personal quest for meaning or purpose in life and the relationship to something of greater meaning than oneself. The spiritual dimension of a person integrates and transcends the biological and psychological nature of a person [3]. Religion comes from the Latin religare, to tie together, and for many people defines their spiritual frame of reference, God being the source of their religion. Hence, losing their spirituality means losing God [4]. Humanistic dimensions of spirituality relate to the quality of life, relationships, and deeds and the value of the personal legacy that is left. Our intention is to explore this fascinating and emotive interface in our relationships with our patients.

Health professionals tend to ignore issues of spirituality when dealing with patients, often floundering with the lack of a common language and dismissing how much they can contribute to their patients’ spiritual equanimity [5]. This latter attitude stems from modern bioscience being rooted in rational thinking and being honed by critical analysis. Indeed, concurrent with the evolution of science and technology has been the rise of secularism, which has challenged the role of faith and religion in postmodern lives [5]. By definition, transcendent phenomena cannot be made to fit Cox’s postulates.

Physicians are generally trained to seek objective evidence about physical aspects of disease. Objective, quantifiable, and reproducible data that can be used to derive hypotheses and test deductions are considered valuable in sharp contrast to subjective personal experience. By virtue of their training and experience they are more comfortable and confident when dealing with phenomena expressed in the universal language of science rather than questions concerned with existential experiences, personal worth, integrity, and suffering. All these concepts encourage treatment of disease as an object of science rather than the treatment of people with diseases [6].

Yet, to ignore spirituality when dealing with dying patients denies the mystery of life and prevents an adequate response to suffering. Many terminally ill patients operate with a spiritual frame of reference to avoid despair, and so spirituality is an important issue for them [7]. Such spirituality for many, like Mr. A, is informed by religion. For others it may simply be the acknowledgment that life is a mystery. For nearly all patients, reflection upon their spirituality in their last days is a quest for meaning [3, 8] or for community [9].

People experience God in different ways [4]. American notions of equality, autonomy, and egalitarianism may need to be tempered when dealing with Asian altruism or eastern stoicism [10]. To be ignorant or judgmental about the beliefs of other cultures or oblivious to the fact that dying patients reflect upon their spirituality or its loss and may need help to do so, is to ignore one of their fundamental needs.

A number of studies have demonstrated that strong religious and spiritual beliefs help terminally ill patients cope with their illness [11, 12]. Torbjornsen et al. reported that of 183 patients who had survived Hodgkin’s disease, 40 patients (38%) had changed their beliefs, and 33 of them had become more religious [12]. In the National Institutes of Health (NIH) Healthcare Research meta-analysis, religious involvement was significantly associated with lower overall cause mortality (odds ratio 1.29; 95% confidence interval: 1.20-1.39) [13]. Lastly, Balfour Mount has rigorously pursued the investigation of how existential issues impact quality of life. In a fascinating study, existential well-being scores were equivalent to physical well-being scores and more important determinants of health related quality of life, as formally assessed by the McGill Quality of Life Questionnaire, than support or emotional scores [14].

Existential Crisis

The wilderness experience, the “dark night of the soul,” is a common theme in mystical literature and perhaps characterizes the 20th Century in man’s search for truth and for God [15]. The famous eponymous metaphor that Camus used to explain existence is the myth of Sisyphus [16]. Sisyphus challenged the gods of Greek mythology and was sentenced to push a huge boulder up a hill every day, and every day as he reached the top, it would roll back down. This is perhaps a picture of patients’ experience of cancer. Camus draws an existential parallel to the human condition that we, like Sisyphus, toil away at senseless and ultimately futile tasks. Yet if there is no purpose to our existence, then why should we continue? If human life is purposeless, isn’t
it also valueless? A philosophy that denies the absolute permits suicide or murder, the criticism to which Camus was responding. And yet the absolute, by its very nature, assumes something—some being, some power, some law—external to man. Slonimsky builds on the heroic words of Job, “Though He slay me yet will I trust in Him” (Job 13:15), using the illustration of the Rabbi Akiba martyred by the same Roman executioners as Christ. Akiba, apparently abandoned by God, proclaimed, “Hear O Israel the Lord our God is one.” For the forsaken to proclaim their faith may be the ultimate validation of the concept of God [2]. A different dimension of faith is required to believe that Christ, who cried, “My God, My God, why have you forsaken me,” gave His life as a ransom for mankind: His life for ours, his death paying the penalty for our sins. If God is a righteous God of both justice and love, this faith requires that Christ’s salvation not end at the crucifixion. There has to be a resurrection. The historic and personal testimony that God has done the impossible is the greatest evidence for God. Similar personal testimony is told in the inspirational poem, Footprints, which relates the experience of walking with God on a beach: in the darkest times, when there is only one set of footprints—God is carrying you [17].

The Quran states that man is tested by being subjected to both good and bad conditions in this life, that death is inevitable and that the ultimate life is the life of the Hereafter where the deeds of this life will be rewarded or punished (from Al-Anbiyaa) [18]. Islam also stresses hope and the concept that Allah comes to the assistance of the believer no matter how forlorn the situation may seem. After the first revelation to the Prophet Muhammad, there was a gap of two and a half years. Towards the end of this period, the Prophet began to wonder whether God had forsaken him. Yet the next revelation, recorded in the chapter “Ad-Duha” of the Quran, was “In the name of Allah, the Compassionate… your Lord has not forsaken you” [18]. Other verses urge the believer to reflect upon the things with which he or she has been blessed during the course of their lifetime. Reading the Quran and reconnecting with God may enable the patient once again to draw strength from their spiritual resources. They may come to see Allah’s mercy not in the possibility of ultimate cure but in the dignity and grace with which they handle each passing day.

One remarkable insight is the contrast in C.S. Lewis’ commentary on suffering between his book, The Problem of Pain, an objective analysis, to A Grief Observed, as he relays the raw agony of his wife’s death from cancer and more poetically retold in the movie Shadowlands [19, 20]. Lewis describes going to God to seek relief from the agony he feels in his heart over the loss of his wife only to find the door slammed and the sound of the door being bolted and doubled bolted from the inside. He rails against God, his faith shaken, yet he finds his way back to God. The conclusion he draws? That to experience love in this world inevitably means that there will also be loss and pain and grief. One of the best-known biblical texts, Psalm 23, is a wonderful example. Until verse 4 the Psalmist, talks about God. Then in the “Valley of the shadow of Death” he is face to face with God and knowing that God is behind the ordeal (Thy Rod) and with him in the very midst of it (Thy staff), is his comfort (Nahchahm Hebrew: deep sighing).

Assessing Spiritual Suffering

Suffering is under diagnosed. In the context of end-of-life care, suffering occurs when a person fears the loss of dignity or integrity and that fear connects with previous painful experiences with no hope for relief. Eric Cassell has championed a logical approach to existential suffering that demands a compassionate and empathic response [21]. Suffering and perhaps particularly “spiritual” suffering need the “human” touch.

However, caregivers employ tactics that can emotionally distance themselves from their patients [22]. They seldom inquire directly about how the patient is coping emotionally with his or her illness and may ignore the issue of spirituality, tempted to prematurely close their assessment or offer unrealistic reassurances. Caregivers may fear that strong emotions such as guilt, anger, or anxiety will be unleashed by broaching the question of spirituality and that they may be unable to deal with these emotions. Some may fear that they will, as a consequence of unleashing anger or causing anxiety, be blamed for upsetting the patient. They also fear the time commitment [22]. However, the skills required to ask the relevant questions and listen empathetically to the answers improve with time, the exercise is of great help and the fear of being blamed for upsetting the patient can be diffused if
caregivers operate as a team [21]. Caregivers also fear that they may get too close to the patient and so be hurt when they die, yet the courage required to confront such fears itself renews one’s conviction that this is an important and rewarding aspect of clinical care [9].

Active Listening

Having asked patients if they are suffering spiritually, the next step is to listen to the answers. For the caregiver, this involves listening not only to the words but also to the feelings behind those words [3, 21]. This art of empathic listening can be taught [22, 23]. According to Carl Rogers, the first step is to connect with one’s inner intuitive self for our attention to become therapeutic [24]. Equally important is to have “positive regard” for what the patient is saying and to respect his or her point of view, even if it is contrary to one’s own; respect requiring an appreciation without having to accept the other person’s views. Dying patients, like children, are sensitized to rejection and prejudice; personal bias and judgmental attitudes are, hence, significant blocks to open relationships with patients [25]. They will pick up nonverbal cues and resist entering into the trusting relationship so crucial to the spiritual care of dying patients. It is therefore essential to have insight into our personal biases and overcome them. A helpful way of doing this is to acknowledge both our own crude frailties and acquire a capacity for the sublime and for wonder. Only when we get over any aesthetic distaste for particular people can we help them feel that God loves them. We have to be brave enough to take off protective armor and make ourselves vulnerable to the feelings which opening up to people may give rise to. This is part of a professional’s responsibility, if he or she is completely committed to every aspect of their patients’ care [9]. So, an important step towards being able to help a patient who has lost touch with their spirituality is to know and own one’s own spirituality [26]. The exploration of one’s own spirituality is essential even if one realizes at the end of the search that one does not have strong religious affiliations. It is not necessary for the caregiver to be religious in order to help a patient regain lost spirituality [27] and find meaning in the midst of suffering [8].

Truly terminally ill patients are often not afraid to die as much as they are exhausted with ill health. They are afraid of being left alone, of being untouchable or have more specific concerns such as being in intolerable pain [9]. They need their community, it’s solidarity and camaraderie, to be able to deal with these concerns [3]. Several authors have stressed the principle of non-abandonment [28]. The feeling of being loved by other human beings or God gives meaning to life even in the worst situations [8, 9, 29]. The mere presence of a person who is willing to listen, raises the threshold for pain to where it is tolerable [9]. In a recent study Lang et al. studied non-pharmacological behavioral adjuncts for reducing discomfort during medical procedures in a randomized trial [30]. Patients received standard intraoperative care, structured attention, or self-hypnotic relaxation therapy. Patients who received structured attention and hypnosis therapy required significantly less analgesia (42% and 47% respectively) than those who received standard intraoperative care (p < 0.0001). Patients who underwent hypnosis therapy also had significant reduction in anxiety and pain.

Anger with God

Anger is a strong feeling of displeasure or hostility. Cognitive theorists formulate that anger is caused by a belief that someone is acting unfairly or by an injustice towards the person who is angry. For some it is immediate and autonomic. Anger is difficult to handle creatively and prone to distortion by displacement away from the source or by escalation to aggression. Blocks to expressing anger include suppression, replacement by anxiety or fear, passive-aggressive self-destructive behavior, denial, and repression [26].

Anger towards God is common. Patients often try to repress their feelings of anger towards God. Christianity has historically been used to reject an individual’s complaints about misfortune and used as an opioid to maintain wishful thinking as opposed to Judaism that permits greater expression of anger against God, embodied in the Yiddish poems of Aharon Zeitlin [31]. Patients and professionals, both religious and otherwise, have been culturally programmed to suppress the experience of anger in dying patients and seek to instill faith and hope [32]. However, it is essential to let dying patients express and not repress their anger towards God [33]. The release that comes from expressing anger as a natural emotion frees people to experience other emotions such as love, joy, and compassion and helps patients connect with God [26]. Spiritual anger can be constructively expressed in rituals and laments [3]. Soeken and Carson encourage caregivers to make their own spiritual resources available in order to aid patients’ expression of anger even across cultural
Health care providers with no religious inclinations, yet with an appreciation of aspects of another’s faith and a comfortable knowledge of ritual and religious language, can significantly contribute to holistic care. In the Schwartz Rounds, the Rabbi sang a prayer to demonstrate how song can be used to soothe. The Shiite Muslim tradition of waiting to mourn the martyrdom of Imam Hussain during the Islamic month of Moharram exemplifies the use of song to express loss and sadness and has many parallels in Jewish and Christian traditions [3]. Peterson describes the patient population most likely to benefit from religious laments as those who will feel that the laments are speaking to their experience of anger, powerlessness, and isolation; those who are exhausted by their disease, or have translated their anger towards God into guilt towards themselves [35]. Laments should clearly not be used to challenge a person’s lifetime denial of the existence of God. People should be allowed to die as they have lived. John Graham-Poll in his book, Illness and the Art of Creative Self-Expression, comments upon how children suffering from terminal cancer tum instinctively to art, painting or song, poetry or dance, whenever they need to make sense of scary or confusing things [36]. In the same way, music can replace words as a profound companion. The patient may choose a song with religious content such as “etz chaim hi lamahazikim bah” (the melody sung by the cantor as the Torah scroll is returned on the Sabbath), Miserere Mei by Gregorio Allegri, or something with a tinge of humor such as “2 kool 2 be 4gotten” [37]. Worship, prayer, religious ritual, and meditation are important ways of helping people cope with feelings of loss and anger. They give dying patients the strength to move the question “Why me?” to “Now that this has happened, how do I deal with it?,” instead of struggling with the futile and importantly, moving from “God loves me” to “God is with me.” Interestingly, Shechinah, the presence of God, is the only biblical name of God that is feminine. Whatever the method, the most important part of helping the patient express anger is being there with the patient and providing adequate information [38]. Confucius stresses going beyond what is needed to help and Buddha’s teachings stress the flow of compassion, or “Namo Amidabutsu,” through which life is supported [4]. The presence of the caregiver at the time of expression of anger also provides boundaries and limits, a safe space in which a person can be out of control. The act of being there with the patient and the exercise of empathic listening will require that the caregiver experience or “live” some of the hurt personally [21]. This is the sort of altruism which fosters our own growth as human beings and in turn helps the patients maintain their integrity; heroism in the face of horror.

Death: Reconciliation with Life

It is important for patients to reconcile with the past [39]. People who are religious need to face the parts of their life they are uncomfortable with, acknowledge guilt if it is justified, give and accept forgiveness, and have their faith in a caring and loving God reaffirmed by their care providers [3]. Rabbi Kushner in his 1998 address at the American Society of Clinical Oncology, related the story of a patient with AIDS who said to him “…no matter what a mess you’ve made of your life, you haven’t estranged yourself from the love of God” [9]. Finding meaning in life is equally important for the atheist who will find peace in knowing that his/her life has been valuable. One of the biggest fears of people who are dying is that they will be forgotten and they need “immense and repeated” assurances that their life is too precious to be forgotten [9].

An important step in helping patients come to terms with their death and resolve any spiritual conflict they may be facing is to help them realize that death is inevitable. This realization in terminally ill patients can trigger anticipatory grief or sadness as described by Elizabeth Kübler-Ross [40]. People don’t want to live forever, but long enough to “get it right” [9], a profound lesson for the living.

People from different cultures and religions find meaning in death in different ways. The Chinese and Japanese consider afterlife a continuation of worldly life [4]. Many other religions hold that life is transcendent. People find meaning in refusing to confine themselves to the narrow limits of time or the conditions of finitude [3]. This is exemplified in the Buddhist teachings of life and death being the continuum of one process [4] and in the concept of Hereafter, which is cardinal to the teachings of Islam and Christianity. All these religions stress that death is not the opposite of life but the opposite of birth.
Caring for a dying patient and his or her family should affirm the meaning and the value of life. Attention to the spiritual dimension becomes essential to such holistic care. It is important to deliver the message to the patient that he or she is something special and very important in his or her own right. Caring requires that the caregiver connect with the patient and with a team. The goal is not to make the patient live but to help him or her achieve wholeness; the integration of body, emotions, reason, imagination, and will. Sir William Osler captured this in one of his aphorisms, “Care more particularly about the patient than for the special features of the disease” [6]. This goal cannot be achieved by any one professional working alone. Physicians, nurses, clergy, and chaplain are all complementary. They need to acquire an understanding of each other’s professions and area of expertise [3, 26]. This is because patients and families in search of acceptance, guidance, spiritual well being, or shalom often turn to and will continue to turn to religious representatives with the hopes of spiritual healing through people they trust.

CONCLUSION
Ill patients can lose touch with their spirituality, which for religious patients translates into losing God. Health care providers need not necessarily be religious in order to help patients to deal with their spiritual crisis. The clinical skills of compassion need to be deployed to diagnose and respond to spiritual suffering. Acknowledging and addressing anger or guilt as the source of a lot of suffering is essential to adjustment. Simply being there for the patient and being open to their hurt can help resolve their spiritual crisis, a responsibility that is shared by the whole health-care team.

ACKNOWLEDGMENT
We very much wish to thank this wonderful gentleman and his wife for the many ways in which they have enriched the MGH Cancer Center.

REFERENCES


35 Peterson EA. The physical, the spiritual: can you meet all of your patient’s needs? J Gerontol Nurs 1985;11:23-27.


