

A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life

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Purpose: This article presents a model for research and practice that expands on the biopsychosocial model to include the spiritual concerns of patients. **Design and Methods:** Literature review and philosophical inquiry were used. **Results:** The healing professions should serve the needs of patients as whole persons. Persons can be considered beings-in-relationship, and illness can be considered a disruption in biological relationships that in turn affects all the other relational aspects of a person. Spirituality concerns a person's relationship with transcendence. Therefore, genuinely holistic health care must address the totality of the patient's relational existence—physical, psychological, social, and spiritual. The literature suggests that many patients would like health professionals to attend to their spiritual needs, but health professionals must be morally cautious and eschew proselytizing in any form. Four general domains for measuring various aspects of spirituality are distinguished: religiosity, religious coping and support, spiritual well-being, and spiritual need. A framework for understanding the interactions between these domains is presented. Available instruments are reviewed and critiqued. An agenda for research in the spiritual aspects of illness and care at the end of life is proposed. **Implications:** Spiritual concerns are important to many patients, particularly at the end of life. Much work remains to be done in understanding the spiritual aspects of patient care and how to address spirituality in research and practice.

Key Words: Religion, Spirituality, Quality of life, Questionnaires, Health surveys

It can be said that the fundamental task of medicine, nursing, and the other health care professions is to minister to the suffering occasioned by the necessary physical finitude of human persons, in their living and in their dying (Sulmasy, 1999a). Death is the ultimate, absolute, defining expression of that finitude.

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Today's health professions seem to have become superb at addressing the physical finitude of the human body. Previously lethal diseases have either become curable or have been transformed into the chronic. The Vice-President of the United States has his fourth myocardial infarction and has an automatic, implantable, cardioverter defibrillator inserted, and now the public only yawns (Walsh & Vedantam, 2001).

However, contemporary medicine still stands justly accused of having failed to address itself to the needs of whole human persons and of preferring to limit its attention to the finitude of human bodies (Ramsey, 1970). The purpose of this article is to advance a more comprehensive model of care and research that takes account of patients in the fullest possible understanding of their wholeness—as persons grappling with their ultimate finitude. One may call this a biopsychosocial-spiritual model of care.

More Inclusive Models

George Engel (1977) laid out a vast alternative vision for health care when he described his biopsychosocial model. This model, not yet fully realized, placed the patient squarely within a nexus that included the affective and other psychological states of that patient as a human person, as well as the significant interpersonal relationships that surround that person. At about the same time, White, Williams, and Greenberg (1996) were introducing an ecological model of patient care that included attention to their environment as well—a public health model of primary care. Neither of these models had anything to say about either spirituality or death. Although both models asserted certain truths about patients as human persons, neither provided any genuine grounding for these theories in what might be called a philosophical anthropology. That is to say, neither attempted to articulate a metaphysical grounding for their notions of patients as persons, although both seemed to depend on such a notion.

Both of these models have struggled to find a place in mainstream medicine. In large measure, this is because the successes of medicine have come about by embracing exactly the opposite model. Rather than considering the patient as a subject situated within a

nexus of relationships, medical science has often considered the person as an object amenable to detached, disinterested investigation. Through the scientific reduction of the person to a specimen composed of systems, organs, cells, organelles, biochemical reactions, and a genome, medicine has made remarkable discoveries that have led to countless therapeutic advances. No one disputes that these advances have been good. But the experience of both patients and practitioners at the dawn of the 21st century is that the reductivist, scientific model is inadequate to the real needs of patients who are persons. Having cracked the genetic code has not led us to understand who human beings are, what suffering and death mean, what may stand as a source of hope, what we mean by death with dignity, or what we may learn from dying persons. All human persons have genomes, but human persons are not reducible to their genomes. To paraphrase Marcel (1949), a person is not a problem to be solved, but a mystery in which to dwell. To hold together in one and the same medical act both the reductivist scientific truths that are so beneficial and also the larger truths about the patient as a human person is the really enormous challenge health care faces today.

Spirituality and the Medical Model

Toward this end, some are now calling for a model that goes even further—a biopsychosocial-spiritual model of health care (King, 2000; McKee & Chappel, 1992). Yet, on a closer reading, these authors, much as Engel and White before them, have merely asserted the need for this expanded model without doing much more than assigning a name to it. They have not founded it upon a philosophical anthropology and have not shown how this new model can be integrated with the reductivist, scientific conception of the patient or how it can be integrated into a more general metaphysics of life and death. Furthermore, an entire “movement” has arisen promoting the integration of spirituality into medicine. This movement is split into two camps, neither of which appears adequate to the task. One camp discounts the reductivist, scientific model of medicine as “rational,” “Western,” “biased,” “narrow,” “chauvinistic,” and perhaps even toxic, seeking either to replace it or, at the very least, to complement it as a parallel universe of medical practice and discourse (Chopra, 2001; Myss, 1997; Weil, 1995). The other camp thoroughly accepts the reductivist, scientific model, and although it might extend the boundaries of the scientific model of the patient to include the psychological and the epidemiological, nonetheless it almost appears to advocate the reduction of the spiritual to the scientific (Benson, Malhotra, Goldman, Jacobs, & Hopkins, 1990; Matthews & Clark, 1998). Furthermore, these scientific models of spirituality in health care have now produced a startling array of measurement techniques with very interesting results, but have engendered significant confusion over what is being measured, why it is being pursued, and what it means.

Therefore, I wish to propose some elements of a

philosophical anthropology adequate to the task of providing a foundation or groundwork for a biopsychosocial-spiritual model of health care. Only then will I suggest an empirical research agenda regarding spirituality and health care at the end of life—one that will acknowledge and be informed by its limitations.

Spirituality and Religion

First, a word about the distinction between spirituality and religion. On this point, many contemporary scholars have achieved a fair consensus. Spirituality is a broader term than religion (Astrow, Puchalski, & Sulmasy, 2001). Spirituality refers to an individual’s or a group’s relationship with the transcendent, however that may be construed. Spirituality is about the search for transcendent meaning. Most people express their spirituality in religious practice. Others express their spirituality exclusively in their relationships with nature, music, the arts, or a set of philosophical beliefs or relationships with friends and family. Religion, on the other hand, is a set of beliefs, practices, and language that characterizes a community that is searching for transcendent meaning in a particular way, generally on the basis of belief in a deity. Thus, although not everyone has a religion, everyone who searches for ultimate or transcendent meaning can be said to have a spirituality.

The Human Person: A Being in Relationship

Having said this, the cornerstone of the philosophical anthropology proposed here is that human persons are intrinsically spiritual. This is based on a notion of the human person as a being in relationship.

From a philosophical point of view, Bernard Lonergan (1958) has argued that when one knows (literally) any “thing,” what one is really grasping is a complex set of relationships, whether that thing is a quark, a virus, a galaxy, or a patient. Sickness, rightly understood, is a disruption of right relationships. It is not “looking at a bad body inside an otherwise healthy body.” As Frank Davidoff has asked, “Who has seen a blood sugar?” (Davidoff, Deutsch, Egan, & Ende, 1996). Diabetes is not a bad body that one sees, but a disturbance in that set of right relationships that constitute the homeostasis of the thing we call a human being.

Ancient peoples readily understood sickness as a disturbance in relationships. Because these peoples had a keen sense of the relationship between human beings and the cosmos, the task of the shaman was to heal by restoring the relationship between the sick person and the cosmos. Thus, healing was a religious act. It consisted in the restoration of right relationships between people and their gods.

Contemporary scientific healing also consists of the restoration of right relationships. However, scientific healing heretofore has understood this as limited to the restoration of the homeostatic relationships of the patient as an individual organism. Thus, scientific healing means restoring the balance of blood sugar in

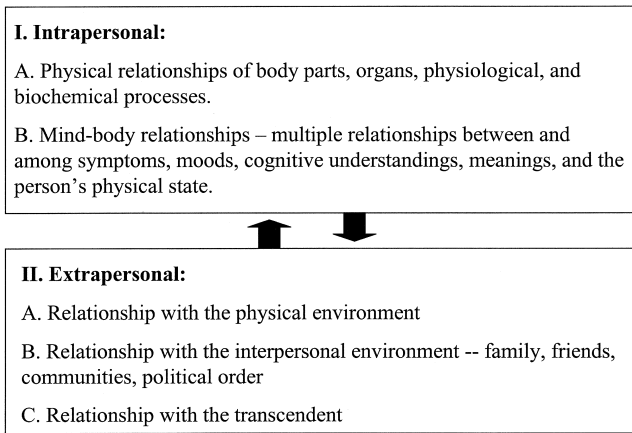


Figure 1. Illness and the manifold of relationships of the patient as a human person.

relation to other biochemical processes, restoring the due regard that growing cancer cells ought to have for their border with other cells, restoring the proper temporal relationship between the pacemaker cells of the heart and other physiological processes, or restoring blood pressure to the level that allows the heart and lungs to maintain their proper relationships with the other vital organs.

But illness disturbs more than relationships *inside* the human organism. It disrupts families and workplaces. It shatters preexisting patterns of coping. It raises questions about one’s relationship with the transcendent.

Thus, one can say (Figure 1) that illness disturbs relationships both inside and outside the body of the human person. Inside the body, the disturbances are twofold: (a) the relationships between and among the various body parts and biochemical processes, and (b) the relationship between the mind and the body. Outside the body, these disturbances are also twofold: (a) the relationship between the individual patient and his or her environment, including the ecological, physical, familial, social, and political nexus of relationships surrounding the patient; and (b) the relationship between the patient and the transcendent.

Healing the Whole Person

On this model, healing is not, as it is often characterized, a “making whole.” Rather, healing, in its most basic sense, means the restoration of right relationships. What genuinely holistic health care means then is a system of health care that attends to all of the disturbed relationships of the ill person as a whole, restoring those that can be restored, even if the person is not thereby completely restored to perfect wholeness. A holistic approach to healing means that the correction of the physiological disturbances and the restoration of the *milieu interior* is only the beginning of the task. Holistic healing requires attention to the psychological, social, and spiritual disturbances as well. As Teilhard de Chardin (1960) puts it, besides the *milieu interior*, there is also a *milieu divin*.

Furthermore, this means that at the end of life, when the *milieu interior* can no longer be restored, healing is still possible, and the healing professions still have a role. Broadly construed, spiritual issues arise naturally in the dying process. In a sense, these are the obvious questions—about meaning, value, and relationship (Sulmasy, 1999b, 2000, 2001b). No matter what the patient’s spiritual history, dying raises for the patient questions about the value and meaning of his or her life, suffering, and death. Questions of value are often subsumed under the term, “dignity.” Questions of meaning are often subsumed under the word “hope.” Questions of relationship are often expressed in the need for “forgiveness.” To die believing that one’s life and death have been of no value is the ultimate indignity. To die believing that there is no meaning to life, suffering, or death is abject hopelessness. To die alone and unforgiven is utter alienation. For the clinician to ignore these questions at the time of greatest intensity may be to abandon the patient in the hour of greatest need.

So, the appropriate care of dying persons requires attention to the restoration of all the intrapersonal and extrapersonal relationships that can still be addressed, even when the patient is dying. Considering the relationship between mind and body in its broadest sense, symptomatic treatment restores the human person by relieving him or her of the experiences of pain, nausea, dyspnea, fatigue, anxiety, and depression. Considering the relationship between the human person at the end of life and the environment, this means, for example, that the facilitation of reconciliation with family and friends is genuine healing within the biopsychosocial-spiritual model. For the dying individual to experience love, to be understood as valuable even when no longer economically productive, and to accept the role of teacher by providing valuable lessons to those who will survive, are all experiences of healing. Finally, to come to grips with the transcendent term of each of these questions about existence, meaning, value, and relationship is also an opportunity for healing for dying individuals.

If the human person is essentially a being in relationship, then even the person who has chosen to believe that there is no such thing as transcendence has made his or her choice in relationship to that question, which is put before each person. Each person must live and die according to the answer each gives to the question of whether life or death has a meaning that transcends both life and death. On this model, the facilitation of a dying person’s grappling with this question is an act of healing.

Clinicians, at a minimum, have an obligation to ensure that a spiritual assessment is performed for each patient. Those clinicians who are uncomfortable doing this may ensure that other members of the health care team perform this important function. It is also important to recognize the value of referral and that an assessment of spiritual needs does not imply that the physician or nurse must provide spiritual services in lieu of a chaplain or other clergy. Finally, it is important to understand that patients who refuse

spiritual assessment or intervention should be free to do so without any pressure or any detrimental effect on the rest of their care.

The Biopsychosocial-Spiritual Model of Care

Everyone, according to this model, has a spiritual history. For many persons, this spiritual history unfolds within the context of an explicit religious tradition. But, regardless of how it has unfolded, this spiritual history helps shape who each patient is as a whole person, and when life-threatening illness strikes, it strikes each person in his or her totality (Ramsey, 1970). This totality includes not simply the biological, psychological, and social aspects of the person (Engel, 1992), but also the spiritual aspects of the whole person as well (King, 2000; McKee & Chappel, 1992). This biopsychosocial-spiritual model is not a “dualism” in which a “soul” accidentally inhabits a body. Rather, in this model, the biological, the psychological, the social, and the spiritual are only distinct dimensions of the person, and no one aspect can be disaggregated from the whole. Each aspect can be affected differently by a person’s history and illness, and each aspect can interact and affect other aspects of the person.

Do Patients Want Clinicians to Address Their Spiritual Concerns?

All of this theorizing might be moot if patients were uninterested in medical attention to their spiritual concerns. However, initial research suggests that between 41% and 94% of patients want their physicians to address these issues (Daaleman & Nease, 1994; Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; King & Bushwick, 1994). In one survey, even 45% of nonreligious patients thought that physicians should inquire politely about patients’ spiritual needs (Moadel et al., 1999). This is particularly true if they are at the end of life (Ehman et al., 1999; Moadel et al., 1999) or more religious to begin with (Daaleman & Nease, 1994; Ehman et al., 1999). These results are also corroborated by surveys regarding patients’ desire for nursing attention to their spiritual concerns (Reed, 1991). Nonetheless, if patients reply that they do not have spiritual or religious concerns or do not wish them to be addressed in the context of the clinical relationship, the clinician must always respect the patient’s refusal (Sulmasy, 2001a).

Physicians have generally been reluctant to address patients’ spiritual concerns in practice (Ellis, Vinson, & Ewigman, 1999). In one study, oncologists rated spiritual distress low compared with 17 other clinical concerns they felt they were responsible for addressing (Kristeller, Zumbun, & Schilling, 1999). In addition, studies have shown that health care professionals fail to address the spiritual needs of patients with Do Not Resuscitate orders. Physicians make referrals to chaplains or otherwise address these patients’ spiritual issues less than 1% of the time (Sulmasy, Geller, Levine, & Faden, 1992; Sulmasy & Marx, 1997; Sulmasy, Marx, & Dwyer, 1996).

Can One Measure a Patient’s Relationship With the Transcendent?

Although it is a tautology, one must always remember that one can only measure what can be measured. Most believing religious persons understand God to be a mystery. They mean by this not that one cannot know God, but that the way in which one knows God transcends the spatiotemporal limits on which empirical measurement depends. In addition, most believing persons understand that the way God speaks to the human heart leaves ultimate judgments to God, not to other human beings. Thus, the very idea of measuring such things as spiritual awareness, spiritual need, spiritual distress, death transcendence, or religious coping poses a number of theological questions (Sulmasy, 2000). Nonetheless, patients and researchers will readily identify particular attitudes, aspects of human distress, ways of coping, and particular behaviors as religious or spiritual. These attitudes, beliefs, feelings, and behaviors are amenable to measurement. As long as investigators are careful to understand the extremely limited view, these measurements give of the spiritual life and as long as clinicians are properly reticent about using these measurements in the care of individual patients, these tools have their place. Above all, they can help institutions and programs determine, in a general way, whether they are responding appropriately to the needs of their patients.

What Domains Might Be Measured?

In measuring the measurable aspects of spirituality and religion, it is useful to distinguish which aspect is being assessed. I have suggested (Sulmasy, 2001a) the following four distinct categories: (a) measures of religiosity, (b) measures of spiritual/religious coping and support, (c) measures of spiritual well-being, and (d) measures of spiritual need (Table 1). Sometimes there can be a tendency to lump all of these categories together, but they all serve different purposes.

Religiosity

Religiosity has been the most extensively studied of the four domains. Religiosity is itself complex and can

Table 1. Classification of Spiritual and Religious Measurement Domains in Health Care

Measurement Domain	Example
Religiosity	Strength of belief, prayer and worship practices, intrinsic versus extrinsic
Spiritual/Religious Coping and Support	Response to stress in terms of spiritual language, attitudes, practices, and sources of spiritual support
Spiritual Well-Being	Spiritual state or level of spiritual distress as a dimension of quality of life
Spiritual Needs	Conversation, prayer, ritual; over what spiritual issues?

be said to consist of many dimensions, such as denominational preference, religious beliefs, values, commitment, organizational religiosity, private religious practices, and daily spiritual experiences. The report of the Fetzer Institute/National Institute on Aging Working Group (1999) on measures of religiosity provides a unique and important research resource, tabulating and evaluating multiple instruments, many of which have been extensively evaluated for validity, reliability, and other psychometric properties. This group has also proposed, in this same monograph, a single composite, multidimensional instrument to measure religiosity.

Among these many dimensions of religiosity, a patient's religious denomination has had the least predictive value in health care research. The most consistently predictive items have measured specific behaviors, such as church attendance, prayer, or the reading of sacred texts. Other dimensions that have been shown to correlate with health and health care include attitudes such as self-described strength of religious belief (Fetzer Institute/National Institute on Aging Working Group, 1999).

Religiosity has been shown to have significant predictive value in health care research. Multiple studies have linked religiosity to improved long-term health outcomes, even when controlling for smoking, alcohol and drug use, and other potential confounders (Hummer, Rogers, Nam, & Ellison, 1999; Koenig et al., 1999; McBride, Arthur, Brooks, & Pilkington, 1998; Oman & Reed, 1998; Strawbridge, Cohen, Shema, & Kaplan, 1997). However, there is little information about linkages between religiosity and end-of-life care.

One promising new and unique measure is that of Daily Spiritual Experience (Underwood & Teresi, 2002). This instrument, which has undergone extensive psychometric study, asks subjects to quantify, from "never" to "many times a day," daily experiences such as closeness to God, gratitude to God, sense of religious peace, and dependence on God for assistance. Daily spiritual experience is related to decreased alcohol use, improved quality of life, and positive psychosocial state.

Researchers have also developed instruments to classify persons according to the important distinction between intrinsic and extrinsic religiosity. Intrinsic religiosity refers to "living" a religion—practicing and believing for the sake of the religion. Extrinsic religiosity refers to "using" a religion, that is, practicing and espousing beliefs for the sake of something else, such as getting a certain job or being seen as a certain type of person (Allport & Ross, 1967; Gorsuch & McPherson, 1989; Hoge, 1972). Intrinsic religiosity has been linked to lower death anxiety (Thorson & Powell, 1990). Many other useful studies might be undertaken to examine how religiosity affects a number of aspects of end-of-life care. But investigators should be cautious in asking about religiosity at the end of life. For example, intensely religious patients may have become too debilitated to attend religious services. Although prior religiosity might predict the

dying patient's present state, there are few data that would suggest fresh ideas about how knowing this might help in caring for patients.

Spiritual/Religious Coping and Support

Rather than assessing past religious beliefs, practices, and attitudes, perhaps more important in the care of dying persons is to understand their current manner of religious coping. Religious coping refers to how one's spiritual or religious beliefs, attitudes, and practices affect one's reaction to stressful life events. There are few instruments that measure this, but two with a track record are the RCOPE (Pargament, Koenig, & Perez, 2000) and the INSPIRIT (Vandecreek, Ayres, & Bassham, 1995). The former is more purely a measure of religious coping and the latter a measure of more general spiritual coping. It seems very relevant to the care of the dying to assess what sort of inner resources the patient has for dealing with the stress of terminal illness. Importantly, these instruments measure both positive (e.g., acceptance or peace) and negative (e.g., excessive guilt or anger) religious coping mechanisms. A measure of religiosity might or might not be associated with a person's religious coping style.

Religious *coping* measures the internal resources and reactions. Religious *support* measures the resources and reactions of the religious community that can be mustered on behalf of a patient. It can be considered a subset of social support (Krause, 1999). However, there are no validated instruments to measure this construct.

Spiritual Well-Being

The World Health Organization has declared that spirituality is an important dimension of quality of life (WHOQOL Group, 1995). Quality of life consists of multiple facets. How one is faring spiritually affects one's physical, psychological, and interpersonal states and vice-versa. All contribute to one's overall quality of life. Thus, it is particularly useful to try to measure spiritual well-being or its opposite, spiritual distress. These can be measured as discrete end points in themselves or as subscales contributing to one's quality of life. All of these spiritual well-being measures are descriptions of the patient's spiritual state of affairs, which can either function as an outcome measure or an independent variable potentially associated with other outcomes. Thus, for example, a patient's spiritual history, present religious coping style, present biopsychosocial state, plus any spiritual intervention all would combine to affect the present state of spiritual well-being, which in turn would contribute to overall quality of life.

Thus far, the most rigorously studied of the available instruments and the most applicable to dying patients appears to be the FACIT-SP (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999). Related instruments include the Spiritual Well-Being scale (Paloutzian &

Ellison, 1982) and the Meaning in Life scale (Warner & Williams, 1987). The McGill Quality of Life Questionnaire has a very useful spiritual well-being subscale and has the advantage of having been developed specifically for patients at the end of life (Cohen, Mount, Strobel, & Bui, 1995; Cohen et al., 1997). The Death Transcendence scale (VandeCreek & Nye, 1993) looks specifically at spiritual issues related to dying.

Some of these instruments have been criticized as confounding spiritual well-being with psychological well-being, but those who have made this criticism appear to have confounded for themselves the measurement of spiritual well-being and the measurement of religiosity (Sherman et al., 2000). All of these instruments have their pros and cons. Excellent reviews of these instruments have been prepared by Mytko and Knight (1999) and Puchalski (2001). Whereas the individual instruments vary quite a bit, one vitally important take-home message is that the phenomenon(a) that they measure account(s) for a substantial part of the variance in patients' overall quality-of-life ratings that cannot be reduced to other measures of psychosocial well-being and coping (Cohen et al., 1997).

Spiritual Needs

Clinically, measures of the religious/spiritual needs of patients at the end of life may be more important than measures of religiosity or religious coping, and these avoid all potential controversy about the meaning of a patient's spiritual state as an outcome measure. Qualitative studies have suggested that patients have many such spiritual needs (Hermann, 2001). Unfortunately, there are few available instruments. Moadel and coworkers (1999) have developed such an instrument, but it has yet to undergo psychometric testing. Pastoral care professionals have also taken some steps toward constructing measures of spiritual need that might be of help to physicians (Hay, 1989).

The Complex Interaction of These Domains

For both clinical and research purposes, it is important to see how various measurement domains regarding spirituality interact and which of these might serve as dependent or independent variables. As depicted in Figure 2, this new model suggests that the patient comes to the clinical encounter with a spiritual history, a manner of spiritual/religious coping, a state of spiritual well-being, and concrete spiritual needs. Some of these states serve as independent variables predicting how the patient will fare spiritually in the face of illness. In addition, according to this model, this spiritual state may in turn be modulated by the biopsychosocial state of the person, and the spiritual state may also modulate the biopsychosocial state. The composite state—how the patient feels physically, how the patient is faring psychologically and interpersonally, as well as how the patient is progressing spiritually—constitutes the substrate of the construct called quality of life. Although quality of life might be measurable, it is also important to un-

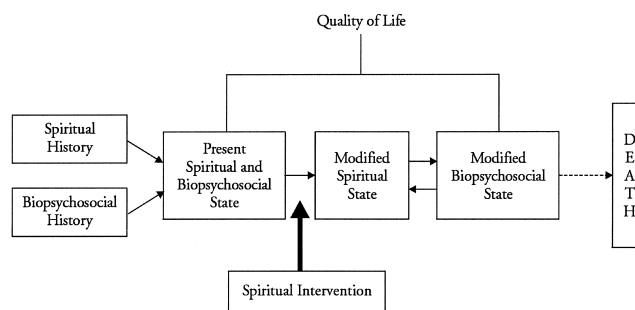


Figure 2. The biopsychosocial-spiritual model of the care of dying persons.

derstand that, as Eric Cassel (2001) once put it, "Quality of life is not just a variable. It is where we live." In the care of the dying, the biopsychosocial-spiritual state of the patient is the ground on which that patient lives until death and the ground from which that person posits himself or herself into whatever there is after death—whether absolute annihilation or beatific bliss.

For research purposes, either quality of life or the spiritual component of quality of life (spiritual well-being) might be the outcome variable of interest in an intervention study. For example, as shown in Figure 2, an experimental spiritual intervention (e.g., a new, standardized spiritual assessment of each patient by clergy) might modify the spiritual well-being of the person. But, in studying this outcome, one might also need to control for spiritual history, religious coping, and physical and psychological states. Or, one might be interested in studying the effects of a spiritual intervention on the biopsychosocial state of the patient. Figure 2 provides a framework for examining these complex interactions.

A Research Agenda

Although more has been accomplished in this field than most investigators realize, much work remains to be done. The following are areas that I believe are important topics for further research in the nexus of spirituality and end-of-life care.

Measuring Value and Meaning (Dignity and Hope)

There appear to be no well-developed measures of patients' own sense of either dignity or hope. Nonetheless, measures of spiritual well-being (as well as measures of quality of life that include a spiritual dimension) almost always include items referring to these concepts. It would not seem proper for investigators to have preconceptions about dignity or hope to which the patient must conform. Even among patients with the same religion, the particularity of individual spiritualities would preclude this sort of preconceptualizing. Some preliminary work using semantic differential technique to develop an empirical model for hope has recently been undertaken (Nekolaichuk, Jevne, & Maguire, 1999). Harvey Chochinov (2002) has begun

similar work regarding an empirical construct for dignity. Because these are key features of the spiritual growth that is open to dying patients, more work should be done to refine these constructs and to create new instruments that might concentrate on these dimensions.

Whose Role?

It is not at all certain who should facilitate the patient's spiritual healing. The fact that patients have said in surveys that they want doctors to be involved does not mean that the proper roles have been assigned. What are the proper roles of family and friends? What is the proper role of clergy and pastoral care? What is the proper role of the nurse or physician? What are the views of believing and nonbelieving patients about these roles? How should all these parties interact, if at all? More needs to be known about what all of these prospective agents believe, what they might be capable of accomplishing, and what will be most effective for patients.

Interactions Between the Four Domains of Spirituality and Other Measures

Although I have set forth a classification scheme of measures of patient spirituality, almost nothing is known of the interactions among these domains. For example, does prior patient religiosity (presumably intrinsic) predict better spiritual well-being at the end of life? Does better spiritual coping predict less spiritual distress? Does better spiritual well-being predict more or less spiritual need? Which of the many dimensions of religiosity are most important? Furthermore, whereas large population-based outcome studies have associated religiosity with mortality, there would appear to be a wide-open field in looking at the relationship between these four domains of spirituality and such phenomena as ethical decision making, symptom severity, site of death, and more.

Effectiveness of Spiritual Interventions for Dying Patients

As one might imagine, there are almost no data regarding the "effectiveness" of spiritual or religious interventions in the care of patients, either terminally ill or not. One British survey of a random sample of relatives of deceased patients did show that 63% of these survivors stated that their loved one's religious faith was of help to the patient at the time of death, regardless of belief in an afterlife (Cartwright, 1991). However, this does not answer the question of whether spiritual or religious interventions by health care professionals might make a difference. There is one randomized controlled trial under way that integrates attention to spiritual issues in the psychotherapeutic care of patients with cancer, but the results have not yet been published (Pargament & Cole, 1999).

It would be a serious mistake to think that any spiritual intervention could ever give a dying patient

either a sense of dignity or a sense of hope (Sulmasy, 2000). Rather, the health professions must come to understand that the value and the meaning are already present as given in every dying moment, waiting to be grasped by the patient. The professional's role is to facilitate this spiritual stirring, not to administer it.

Several studies have been conducted investigating whether prayer at a distance or other nonphysical interventions of a spiritual, complementary, or alternative nature can affect health care outcomes (Byrd, 1988; Harris et al., 1999). These studies have been highly controversial (Cohen, Wheeler, Scott, Edwards, & Lusk, 2000), and the efficacy of these interventions has not been either firmly established or disproved (Astin, Harkness, & Ernst, 2000). These studies will not be discussed further in this review. One might also ask, as a theological matter, whether a search for "proof of efficacy" is necessary or even appropriate with respect to prayer.

Spiritual Significance of Patient-Professional Relationships

Research should pay attention to the importance of the relationship between the health professional and the patient as a possible context for the patient to work out and express spiritual concerns and struggles. For example, Rachel Remen (1996) tells the story of a patient who admits not wanting any more chemotherapy, but of enjoying the support of his oncologist so much that he kept asking for more chemotherapy because he feared losing that relationship if he "stopped the chemo."

Again, this would seem to be a wide-open field. Are better relationships associated with better spiritual well-being scores or spiritual coping? Does the relationship with the health care professional affect spiritual needs? These and other related questions would be interesting ones for research.

Tools for Taking Spiritual Histories

Numerous acronyms have been developed for clinicians who are inexperienced at taking a spiritual history. The purpose of these acronyms is to help clinicians remember what questions to ask patients regarding spirituality, and how to ask them, similar to the CAGE questions for screening for alcoholism (Mayfield, McLeod, & Hall, 1974). The acronym "HOPE" (Anandarajah & Hight, 2001) stands for H: sources of hope, O: role of organized religion, P: personal spirituality and practices, and E: effects on care and decision making. The acronym "FICA" (Astrow et al., 2001; Post, Puchalski, & Larson, 2000), stands for F: faith and beliefs, I: importance of spirituality in your life, C: spiritual community of support, and A: how does the patient wish these addressed. A third acronym "SPIRIT" (Maugans, 1996) stands for S: spiritual belief system, P: personal spirituality, I: integration with a spiritual community, R: ritualized practices and restrictions, I: implications for medical care, and T: terminal events planning. My personal

practice is to allow much of this to unfold by using a simple open-ended question, "What role does spirituality or religion play in your life?"

All these history-taking tools are strikingly similar, even though they have all been developed independently. However, none has undergone any serious psychometric testing. The questions are relevant to understanding the lives and spiritual needs of patients, and one might argue that this sort of testing is no more required than it is required to validate how to ask questions about past medical history, occupation, sexual practices, and hobbies. Still, having valid and predictive instruments for clinicians would be a useful field of study.

For research purposes, George (1999) has proposed a measure of spiritual history in the sense of spiritual development and life history, a construct that is distinct from, although closely related to, the clinical sense of the word, "history." This instrument is based on previously developed questionnaires, none of which have been extensively validated, and there is ample opportunity for work in this area as well.

Role of the Professional's Own Spirituality

Clinicians should pay attention to the spiritual lessons that the dying can teach them (Byock, 1997; Kearney, 1996; MacIntyre, 1999; Sulmasy, 2000). Because the word "doctor" means "teacher," this is a bit of a role reversal. But it can be critical to a dying person to understand his or her value. Dying patients have this role of teaching us, even when they have become "unproductive."

It has been suggested that clinicians need to pay attention to their own spiritual histories and to be conscious of how this affects the care they give their patients (Sulmasy, 1997). This seems especially true at the end of life (Chambers & Curtis, 2001; Sulmasy, 2000). However, there are no studies to support this. It would be interesting to administer instruments measuring the four domains described previously to physicians and other health care professionals and explore how their scores affect the care they deliver.

Spirituality After Death

Grieving families and friends have spiritual needs, spiritual/religious coping mechanisms, and measurable degrees of religiosity. How these affect bereavement would be a fascinating topic for study. It would also be interesting to begin to understand more about the role of spiritual well-being in the bereavement processes and its role within the overall quality of life of those who survive their loved ones. Finally, it would be interesting to study how the spirituality of the deceased patient affects the bereavement of those who survive him or her. Little work has been done in this area.

Humanities Research

As discussed previously, empirical studies, including qualitative empirical studies, give only a very limited

view of spirituality. The fields of philosophy of religion, theology, comparative religions, history, literature, and the arts have far more to say about the core of spirituality than do descriptive studies. One excellent way to begin to bridge the gap between 21st century medicine and the world of spirituality and religion might be to advance a research agenda that was open to funding the investigation of spirituality and end-of-life care using the techniques of these disciplines in the humanities.

Should It Be Done at All?

Despite all of the previously described, it remains controversial whether health care professionals should attempt to address the spiritual needs of patients, even at the end of life (Relman, 1998; Sloan, Bagiella, & Powell, 1999; Sloan et al., 2000). These critics, above all, fear inappropriate proselytizing of patients or the replacement of well-established, scientific Western medicine with quackery. Both of these types of concerns are well placed. Both proselytizing and quackery can do severe harm to patients. However, the approach advocated by responsible proponents of clinician involvement in spirituality and end-of-life care avoids both of these pitfalls (Astrow et al., 2001; Post et al., 2000). Clinicians should never use their power over patients to proselytize, but this does not imply that they must ignore the genuine spiritual concerns raised by patients. Medicine must also eschew quackery, but it is mere prejudice to assert that all spirituality in health care is quackery. The vast majority of patients and practitioners recognize that any dichotomy between healing the body and attending to the needs of the spirit is false. One needs only to avoid the extremes, rejecting both a reductionistic, positivistic approach to medicine as pure applied science as well as an other-worldly, spiritualistic approach to medicine as a matter of incantations and herbs. Those with the greatest experience in caring for the needs of terminally ill patients, hospice workers, have always attended to the spiritual needs of patients, and the movement was rooted in spirituality (Bradshaw, 1996). Likewise, the European Palliative Care approach, more securely placed within the mainstream of medicine, has also emphasized the spiritual aspects of caring for the dying (Kearney, 1996). This hospice approach has been suggested as a model for all of medicine in attending to the spiritual needs of patients at the end of life (Daaleman & VandeCreek, 2000).

Above all, however, the main reason for addressing the spiritual concerns of patients at the end of life is that these concerns affect them as whole persons, not simply in their moral decision making, but in their overall sense of well-being. To ignore these concerns at the end of life is to remove from the patient-physician interaction a significant component of the patient's well-being precisely at the time when standard medical approaches have lost their curative, alleviating, and life-sustaining efficacy.

At the end of life, the only healing possible may be spiritual. A biopsychosocial-spiritual model of

health care is necessary to accommodate such an approach.

Conclusions

A human person is a being in relationship—biologically, psychologically, socially, and transcendently. The patient is a human person. Illness disrupts all of the dimensions of relationship that constitute the patient as a human person, and therefore only a biopsychosocial-spiritual model can provide a foundation for treating patients holistically. Transcendence itself, by definition, cannot be measured. However, one can measure patients' religiosity, spiritual/religious coping, spiritual well-being, and spiritual needs. A research agenda in this area would include (a) improving measurements of spiritual states; (b) better defining who is best to address these issues with patients; (c) studying the interactions between the measurable dimensions of spirituality and more traditional health measures; (d) designing and measuring the effectiveness of spiritual interventions; (e) assessing the spiritual significance of patient-professional relationships; (f) refining and testing tools for taking spiritual histories; (g) assessing the impact of the health professional's own spirituality on end-of-life care; (h) developing measurement tools for assessing the religious coping, spiritual well-being, and spiritual needs of those who mourn the dead; and (i) encouraging scholarship in the humanities about these issues. The biopsychosocial-spiritual model proposed in this article appears rich enough to accommodate this ambitious and exciting research agenda.

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