Most people cannot control the exact circumstances of their dying—when they die, where they die, how they die, how people treat them when they are dying, and so forth. They cannot be sure that they will die in “a sanctuary imbued with one’s own order” (Kayser-Jones, 2001, p. 3). This is particularly true in the days ahead as limits on health care expenditures become more and more constraining. The fact is that doctors and nurses will be responsible for more and more patients and have less and less time with each patient. This trend is inevitable when one considers the future costs of financing health care and the changing U.S. population demographics up ahead.

Medicare expenditures will double in less than a decade ($220 billion/year in 1998 to more than $415 billion by 2007), even before a cohort of 75 million “baby boomers” reaches age 65 and begins to expand the current 35-million-member elderly population to more than 80 million by midcentury (Smith, Freeland, Heffler, McKusick, & Health Expenditures Projection Team, 1998). Moreover, after 2011, the need for health services will increase astronomically as the aging population grows and life expectancy increases with advances in medicine. Within the first half of this century, the ratio of the number of working persons ages 15–64 to the number of persons older than age 65 will drop from 3:1 in developed countries around the world in 1999 down to 2:1 (United Nations, 1999). This means that instead of five working persons for every one retired person, there will be only two working persons for every one person requiring support. What will our health care look like in the decades ahead?

The picture is not a pleasant one (Schneider, 1999). Acute care hospitals will be able to treat only the most severely ill patients (this trend is already occurring) and will come to look like today’s intensive care units. After stabilization, sick patients will quickly be discharged to nursing homes, which will start to resemble acute care hospitals. Waiting lists to get into nursing homes will grow longer and longer, forcing the health care of aged and dying patients back into the community, back into people’s homes—with most of the burden falling not on health care providers, but on family members. Lacking family members or the ability to pay for private care, many aging baby boomers could be forced to spend their last days “on city streets and in parks” (Schneider, 1999, p. 797). The bottom line is that dying patients will become less and less able to control the circumstances of their dying in the years ahead.

I agree with Kayser-Jones (2002) that we health care providers must do everything possible to learn about and train doctors, nurses, and family about how to enable and empower dying patients to control the circumstances of their death. However, we health care providers must also consider the changing health care system ahead and identify internal resources and community resources that could help them achieve a “good death,” regardless of external circumstances over which they have no control.

Religion and Spirituality

Rather than desperately seek to control external circumstances, some persons have attitudes and viewpoints toward death and dying that make the need for such control less urgent. It is often religious faith and support from their spiritual community that give these people greater internal control over the dying process. (The example I use here, and the views I express throughout the article, are from a Judeo-Christian religious slant; examples from other traditional religious belief systems would work just as well, because all major religions provide solutions to the problem of death.) Rather than trying to control everything, faith allows them to give up the need for control and instead to trust that God will control their circumstances based on God’s love, wisdom, and unique knowledge about their situations. They say, “It’s all about letting go and letting God, not hanging on and holding tight to that which on this earthly plane is passing away.”

These people are not trying to find a sense of home here on earth. Instead, they are looking forward to going back home, returning to their real home—to join loved ones who have already died and with the
knowledge that loved ones still alive will soon join them. Dying is mainly about saying a temporary goodbye to loved ones and comforting them in their loss. It is a return to a place where they will no longer have pain or suffering, but rather have new bodies that will never become sick again. To those who believe, death is a time of true healing and wholeness like never before. For most of the rest of us, however, issues of controlling the external environment are more urgent and necessary, as is the need to create a home here on earth during the last remaining days of life.

The challenge, of course, is that most people do not have the kind of faith described herein. Instead, they have a combination of faith and lack of faith that make physical, psychological, social, and spiritual issues of great importance. Kayser-Jones (2002) has done a marvelous job of discussing the physical, psychological, and social aspects of dying. Spiritual struggles and needs also play a prominent role in the business of dying.

How common are religious or spiritual needs in older patients who are dying? Although few data are available, religious needs are widely prevalent even among nonterminal patients who are sick enough to be admitted to the hospital. Fitchett, Burton, and Sivan (1997) found that 76% of medical-surgical inpatients at a Chicago hospital had three or more religious needs (the figure was 88% for psychiatric inpatients). In another study of 330 consecutively admitted medical inpatients older than age 60, nearly 90% indicated they used religion to at least a moderate extent to help them cope, half of whom indicated that religion was the most important factor that kept them going (Koenig, 1998). Health care providers must provide dying patients with every opportunity to finish the psychological, social, and spiritual tasks of dying so that they and their families can ultimately experience a good death.

I now examine the physical, psychological, social, and spiritual needs of five groups: the dying person, the family, the health care provider, the nonreligious dying person, and the dying person without family.

The Dying Person

Relieving agonizing physical symptoms must be the first priority—otherwise, it will be impossible for the dying person to focus on the work that needs to be done. Although controlling physical pain is most important, I agree with Kayser-Jones (2002) that other physical symptoms need to be addressed as well: breathlessness, constipation, insomnia, and so forth. A second focus of care needs to be on enabling the patient to remain as alert and conscious as possible during those last days, while at the same time achieving physical comfort. A third focus needs to be on relieving depression, anxiety, or psychotic symptoms that may hinder the dying person from being fully conscious, and attending to relationships with others and with God. I agree again with Kayser-Jones (2002) that this should address feelings of loneliness, isolation, and abandonment, including spiritual abandonment.

A fourth focus of care, and one of the most important in this author’s opinion, is on meeting spiritual needs—where spiritual needs are defined broadly in terms of both religious and nonreligious spiritual needs. Religious needs involve making peace in one’s relationship with God and with others and readying oneself for the life to come. Spiritual needs not restricted to religion involve finding purpose and meaning in one’s remaining days, forgiving others and receiving forgiveness, accepting what one has accomplished and become during one’s life, and saying goodbye. These are sometimes called the “tasks” of dying, whose successful completion leads to a good death.

Besides being supportive and life enhancing, as the vast majority of the literature suggests (Koenig, McCallough, & Larson, 2001), religious or spiritual beliefs may for some dying persons and their families create turmoil and distress (Franks, Templer, Cappelletty, & Kauffman, 1990–1991; Fry, 1990). Fearing judgment or punishment, and perhaps eternal damnation, these persons wrestle with their religious beliefs and relationship with God. We recently reported that hospitalized patients age 55 or older who experience religious turmoil have a significantly higher mortality rate during the 2 years after hospital discharge (Parmegian, Koenig, Tarakeshwar, & Hahn, 2001). Although this religious struggle may somehow increase the risk of dying, another interpretation of the finding is that such struggle increases as patients approach nearer to death. Patients experiencing religious struggles were those who felt punished or abandoned by God, questioned God’s love for them and power to help them, felt abandoned by their religious community, or believed the devil caused their illness. Regardless of direction of causation, such patients need help from religious professionals to help them work through the religious distress.

Finally, devoutly religious and concerned family members and sometimes even well-meaning health professionals may fear that the dying person is not “saved” and place pressure on him or her (who may be of a different religious faith) to get saved. How often does this occur? What are the negative (and positive) consequences of such interactions? What are sensitive ways that professionals can deal with such issues? These questions remain unanswered because of a void of research in this area.

The Family

What about families and their needs? The family needs education and direction on how to help the patient successfully complete the tasks of dying. The family needs emotional and spiritual support to enable them to meet the dying patient’s needs, as well as physical support in terms of equipment and respite from the caregiver role. They also need support in letting go of the patient and coping with the grief of the expected loss and the guilt over imagined or real failings in their relationship with the patient. These unresolved psychological struggles can be a cause for a family’s inability to accept the patient’s poor prognosis.
or their becoming angry and requesting more technical treatment than is either indicated or the patient wants. It is perhaps also a cause for the inability of some family members to come physically and emotionally close to dying loved ones. Their guilt and grief serve as an insurmountable barrier between them and the person who is dying.

Does spirituality play a role in family members’ ability to cope with the dying and death of loved ones? The research done thus far suggests it does. In a prospective study of a cohort of 62 family caregivers of persons with either endstage Alzheimer’s disease or recurrent metastatic cancer, Rabins, Fitting, Eastham, and Zabora (1990) at Johns Hopkins examined baseline characteristics of family caregivers that predicted adaptation 2 years later. Nearly 30% of the variance in positive adaptation was explained by the number of social contacts and a further 13% by self-reported religious faith (p < .0001 for religious faith). Investigators concluded that a strong religious faith, along with frequent social contacts, were the two best predictors of positive adaptation in this group. At least three other studies have reported similar findings (Burgener, 1994; Keilman & Given, 1990; Wright, Pratt, & Schmall, 1985).

After the patient’s death, the emotional and spiritual needs of family need to remain a focus—even the increasing morbidity for family members in the year after bereavement. This is where the religious community can assist health care providers. The religious community could be involved at every step along the way—supporting both the patient and the family during the dying process and afterward. The fact is that the religious community will be called on in the days ahead to take on more and more of the responsibility that formal health care providers now have for dying patients and families (not by choice, but by default because of reasons discussed previously).

Given that 80% of older Americans are church members, what is the religious community doing now that facilitates dying and death besides conducting funeral services? How might the religious community play a greater role in this process? What are some of the barriers that religious communities face in meeting the physical, emotional, and spiritual needs of dying members and their families? Again, the research is nonexistent.

**The Health Care Provider**

Providing a nurturing and caring environment for the dying is even more important for we the living than it is for those who are dying. It is important that pain and suffering in others should evoke in us a compassion and desire to meet the physical, emotional, and spiritual needs of those who are dying and of grieving families. What do we health care providers need to help those who are dying to complete the tasks of dying and achieve healing during those final days?

The emotional and spiritual needs of health care providers must be addressed so they are better able to meet the physical, spiritual, and emotional needs of dying patients and family members. It is difficult for health care providers to take care of those who are suffering and, regardless of what they do, will soon die. Health care providers who spend 24 hours a day, 7 days a week fighting disease and death may have a difficult time accepting when death is the necessary and preferred outcome. Instead, they see death as a reminder of their failure and inability to help the patient. Consequently, many feel guilty, and seeing the patient or family only increases that guilt. In addition, health care providers may have had negative experiences with their own family members in terms of dying that influence their responses to patients. There may be a reluctance to become attached to dying patients, thereby exposing themselves to the emotional pain of separation when death occurs. Furthermore, lack of spiritual beliefs or spiritual conflicts on the part of health care providers can make it difficult to care for religious patients or meet their spiritual needs.

Thus, the unmet emotional or spiritual needs of health professionals will serve as barriers that prevent them from being fully present with the dying person and family. Such unmet needs may cause health professionals to abandon patients and families or reduce their willingness to interact with them and form bonds that are necessary for compassionate, meaningful care. Psychological and spiritual conflicts of providers will certainly prevent them from allowing dying patients to define their own dying experience.

Although it is almost silly to say this, it is important to remember that health professionals are human, too. They have many of the same vulnerabilities, neurotic needs, and unfulfilled hopes and dreams as patients who are dying. Some health professionals have strengths in dealing with dying patients, and others do not. Each will deal with dying patients in their own unique way. Those without strengths in this area will probably choose a specialty or specialized area that minimizes their contact with the dying. If forced into contact with dying persons and their families, they will put up emotional barriers to protect themselves and avoid becoming too attached or involved in the lives of such patients.

For some providers, such barriers are necessary to allow them to function; otherwise they would become emotionally overwhelmed from the pain that repeated contact with dying patients would evoke. Other health professionals with the type of personality and life experience that makes them feel comfortable with those who are dying will choose areas like oncology or hospice, in which their personal strengths and skills can be utilized. Because in the days ahead most health professionals will need to care for and address the needs of dying persons and their families, it is essential that health professionals receive counseling, training, and ongoing resources that will enable them to improve their competency in this area.

What role does the spirituality of health care providers play in helping them meet the physical, emotional, and spiritual needs of patients? Does spirituality enable providers to be more “present” with patients, because
death is not as threatening or as final to them? Are there educational or training interventions that could be designed to help health care providers enhance their own spirituality in a way that would enable them to better meet the needs of dying patients? Almost no research has been done in this area.

The Nonreligious Dying Person

The nonreligious patient (about 10%–15% of Americans) is similar to the religious patient in needing physical symptoms controlled and consciousness preserved to do the work of dying. Again, however, little research exists on how nonreligious patients cope with death. Focus on emotional needs will probably have to be greater because of the absence of support from religious beliefs and absence of support from a religious community (30% of Americans are not members of religious communities). Attention to the needs of family members will also be greater both in education about delivering patient-centered care and in the meeting of emotional needs, particularly if the family is religious and the dying person is not. If the family is not religious, then other sources of community support besides the religious community will need to be sought. Thus, there is greater burden on the health care provider to meet the needs of both dying persons and their families to compensate for lack of religious resources.

Finally, whereas the dying person and/or family’s lack of religious beliefs must be accepted, respected, and honored, spiritual needs (perhaps even spiritual struggles) arise in nonreligious persons just as they do in religious persons. Spiritual resources need to be made available to these persons in a nonthreatening way and at their own pace. The spiritual needs of patients who are not specifically religious include finding purpose and meaning, forgiving and receiving forgiveness, maintaining hope, saying goodbye, and coming to terms with whatever they perceive may occur after they die.

The Dying Person Without Family

The dying person without family will require more attention by health care providers in the emotional and spiritual areas, because there will be no one else to help the patient complete the tasks of dying. This is particularly true for the dying person who is not religious or does not have a spiritual community that can compensate for the lack of family. In these cases, health care providers may need to identify and mobilize the dying person’s friends in the community to assist. Unfortunately, friends may be less reliable than family or the religious community (although not necessarily so, and this could be a topic for systematic study).

Conclusions

Patients who are dying and their families need to have physical, psychological, social, and spiritual needs comprehensively addressed during their final days of life. None of these areas should be neglected either in clinical care or in scientific research. When they are addressed in a compassionate, sensitive, and patient-centered way, this increases the likelihood that the dying process will be experienced as both comfortable and meaningful for patient, family, and health care providers. More research is needed to better understand the spiritual needs of dying persons, determine when religion contributes positively and when it contributes negatively to the dying process, and decide what role the religious community can play in providing the kinds of support that patients and families need as they depend less and less on the formal health care system.

References


