

CULTURE AND CARE OF THE DYING

BRUCE A. HURWITZ, PH.D.

Director of Development, Aging in America, Inc., Bronx, New York

This article examines the need for cultural sensitivity in the care of palliative care patients. Focusing in particular on the Jewish contribution to the debate surrounding care of the dying, the article reviews the "Not on My Shift" training program developed for staff at Morningside House Nursing Home in the Bronx, NY.

The medical literature recognizes the importance of culture in the treatment of patients requiring and receiving palliative care. What has only recently become a topic of discussion, however, is the impact of the culture of professional caregivers on the palliative care process; specifically, how to deal with conflicts between the culture of professional caregivers, patients, and general society.

Nursing homes throughout the country generally, and in the state of New York in particular, are facing a severe shortage in available nurses and certified nursing assistants. As a result, nursing homes are looking to foreign markets to meet staffing shortages. In the past recruitment efforts were focused on India and Ireland. Today the Philippines, Guam and the Caribbean are the targets of recruitment campaigns.

Staff from these countries come with many assets. However, they arrive ignorant of the predominant cultures of the patient population with which they will interact. And there will be many. "In today's society it is highly likely that palliative care patients will be drawn from a cosmopolitan, multiethnic background and that in the major cities of the world many different cultural identities will be encountered" (Marks, 1999, p. 1).

In addition, "culture is subtle. Although learning about death and dying rituals, about ethnic and religious groups is important, finding the patient in their cultural context and being able to negotiate with them is even more so" (Oliviere, 1999).

Being caring individuals, nursing home staff, whether foreign or domestic raised, be-

come attached to patients in their charge. Even if the patient and family have accepted the inevitability of death, the staff may object and do all they can to postpone the inevitable. At best, they may begrudgingly accept the decision of the patient and family, thereby creating a tense atmosphere.

In a discussion on palliative care, one African-American nurse at Aging in America's nursing home, Morningside House, made it clear that she understood the inevitability of the death of a nursing home resident, but said that she would continue to provide the resident with the nutrition she needed to sustain her life. She maintained that the nurses on the next shift could refrain from feeding the resident. What was important for her was that the patient "not die on my shift."

That remark was made in a meeting with a funder of one of the nursing home's existing programs. It succinctly expressed the problem and the need for cultural sensitivity training of staff and ultimately for the "Not on My Shift" training program.

This article discusses the need for such a staff training program, with special emphasis on the contribution of Judaism to palliative care. It is hoped that this program will be adopted not only in the nursing home field but also as a model for social service agencies confronting the issue of palliative care.

REVIEW OF THE LITERATURE

In November 2000 the Greater New York Hospital Association sponsored a workshop entitled, "Perspectives on Quality: End-of-Life Care in a Cultural Context." Participants identified these cultural barriers to care:

- distrust by staff or by patients
- distrust of health care providers
- philosophy held by staff that all life is worth living
- belief in miracles
- feeling that death is "the enemy"
- problems in communication

In response, a Jewish hospice hired a rabbi who was a medical ethicist to teach its predominantly African-American staff about Jewish law and the Holocaust and to review case studies in a Jewish context.

STAFF TRAINING IN CULTURAL SENSITIVITY

Professor Betty Wolder Levin of the Department of Health Nutrition Services at Brooklyn College helped develop a cultural sensitivity curriculum for staff consisting of five modules: (1) Culture, Race, and Class; (2) Concepts of Illness, Pain, and Death; (3) Communication, Truth-Telling, and Decision-Making; (4) Social and Spiritual Environment; and (5) Implications for Clinical Practice.

Morningside House's "Not on My Shift" training program expands on this framework to meet the needs of the nursing home environment.

Session I: Understanding Palliative Care

The World Health Organization defines palliative care as "the active, total care of patients whose disease no longer responds to curative treatment, focusing on the quality of life and integrating physical, psychological, spiritual and social aspects of care." Its objectives are not to cure but to relieve symptoms and to improve the quality of life and of death of patients with chronic and terminal illnesses (Rhymes, 1996).

When talking about quality of life in the palliative care context we are really talking about the quality of death, or giving the patient the ability to determine when to accept death. A recent English case concerning a Jewish child is enlightening in this regard (Reuters Medical News, 2000):

A 3-year-old girl...was declared brain dead after being admitted to an intensive care unit. While the medical staff recommended discontinuation of life support, the child's family and their religious advisors insisted that treatment not be withdrawn because the child was not yet dead according to Jewish law. In fact, they argued, 'to withdraw or withhold care would be tantamount to murder.'

In an attempt to reconcile the family's wishes with medical guidelines advising the withdrawal of life support in brain-dead patients, Dr. [David] Inwald [of the Institute of Child Health in London] and colleagues looked to the late Lord Jakobovits, an expert on Jewish medical ethics. According to his writings, while death is not official until the heart stops pumping and circulation ceases, 'one need not artificially prolong life.' While nutrition, hydration and oxygen should be continued in the brain-dead patient, by Jewish law, other interventions such as antibiotic therapy and resuscitation need not be administered.

Following this protocol, the child was maintained on artificial ventilation for 4 days, until asystole occurred. Dr. Inwald and his team concluded, 'In these unusual circumstances, it is more important to respect the cultural traditions of the family than to free a bed in the intensive care unit.'

According to the New York State Department of Health (1994, p. 162), "The provision of pain medication is ethically and professionally acceptable even when such treatment may hasten the patient's death, if the medication is intended to alleviate pain and severe discomfort, not to cause death." In justifying this conclusion the Task Force on Life and Law relied on D. M. Feldman and R. Rosner's *Compendium on Medical Ethics* (6th ed., New York: Federation of Jewish Philanthropies, 1984) and I. Jakobovitz, *Jewish Medical Ethics* (2nd ed., New York: Blich, 1975) stating, "A Jewish authority agrees that relief of pain is adequate reason to assure palliation therapy, even with attendant risk" (p. 163).

This dilemma, of choosing reduction of pain over continuation of life, is not unique to the physician. The patient must also make

similar decisions. "Patients resolve the tradeoffs between controlling pain and feeling alert; they choose whether to use a medical device that provides them with nutrients but causes swelling and congestion" (Laconte, 1998, p. 4).

Of course, pain management is only one component of palliative care. The importance of helping with grief and bereavement (that of the patient and family and friends) cannot be underestimated (see Session X). That said, a person who is in physical pain cannot be expected to be able to confront the psychosocial aspects of his or her condition. The same is true for relatives and friends who will demand an end to their loved one's suffering. Thus, the emphasis on pain management as a prerequisite to total palliative care.

Palliative care is, in essence, a balance between pain relief and life. Accordingly, as is explored in more detail below, it must be understood that if, for example, morphine is administered as a pain reliever, even though it will hasten death by retarding respiration, it is a legitimate form of care.

Session II: The Role of Culture

Different cultures relate differently to death. For example, as reported in the *Journal of the American Medical Association* (Carrese & Rhodes, 1995, p. 826). "In traditional Navajo culture, it is held that thought and language have the power to shape reality and to control events. Discussing the potential complication of diabetes with a newly diagnosed Navajo patient may, in the view of the traditional patient, result in the occurrence of such complications."

This view of language is not unique to the Navajo. According to the Palliative Care Council of South Australia, in dealing with Muslim patients it is taboo to use such words as "death, dying and cancer." Similarly, in Jewish culture, central to which "is a passion for life," caregivers "may be reluctant to tell a patient that they will die for fear that the patient will lose hope" (Neuberger, 1999, p. 5). Moreover, as a Hasidic man explained, "The word cancer was never spoken in my

house, yet it was referred to as the *richtiger peckel*, which is translated sarcastically as the right package. It was only when I was a teen that I learned that the *richtiger peckel* meant cancer" (Mark & Roberts, 1994, pp. 204–205).

Imagine not being able to say anything negative to a patient about his or her medical condition. This goes against the Patient Self-Determination Act that was passed into federal law effective December 1, 1991. "A major goal of this legislation was to increase patient participation in end-of-life decision making by encouraging adults to complete advance directive documents. To facilitate this goal, two of the law's major requirements are (1) providing all adult patients admitted to hospitals with written material, at the time of admission, summarizing state law and hospital policies addressing the patient's right to formulate advance directives, and (2) educating staff and the surrounding community about issues concerning advance directives" (Carrese & Rhodes, 1995, p. 828).

The Jewish approach to advance directives is evolving. "While Judaism may not have encouraged the proliferation of living wills and durable powers of attorney, it has come to terms with them and recognizes the opportunity that these documents offer to have Jewish law applied in end-of-life situations.... Both the Agudath Israel and the Rabbinical Council of America have drafted model living wills and powers of attorney that are intended to meet the needs of the Torah-sensitive Jew" (Eisenberg, 1999).

The question really is, when may a patient refuse treatment? According to Rabbi Moshe Feinstein, it is permissible for "the terminally ill patient in intractable pain to refuse life-prolonging treatment that will neither cure him, nor relieve his pain.... A non-terminally ill patient may refuse treatment if the proposed therapy is sufficiently dangerous and unproven" (Eisenberg, 1999).

Do Not Resuscitate orders are acceptable under Jewish law as long as they do not hasten death but only recognize its inevitability. In a sermon on the topic, Rabbi Barry Block (1996)

concluded, "We are permitted to remove impediments to God's final decree. We must seek to provide comfort for the dying, and alleviate suffering, even if an unintended result is a slightly sooner death. But we are forbidden from taking God's power into our own hands. Only God may decree the hour of our death, and our entrance to life everlasting."

Session III: The Pharmacology of Palliative Care

Understanding medication is key to good palliative care. As stated by the Task Force on Life and Law (New York State Department of Health, 1994, p. 165), "The education of health care professionals about pain relief and palliative care must be improved. Training in pain relief and palliative care should be included in the curriculum of nursing schools, medical schools, residencies, and continuing education for health care professionals. In addition, biomedical research facilities should engage in further research in the physiology of pain and its appropriate relief, both at the basic and the clinical levels."

The most common auspices for palliative care is the hospice. "Hospice care is consistent with Catholicism and most mainstream Protestant traditions, as well as Reform and Conservative Judaism. In some Orthodox interpretations of Jewish law, death cannot be hastened (e.g., through withdrawing or withholding artificial nutrition and hydration or other treatment that may prolong life); however the dying process need not be prolonged. Therefore, if a therapy is not effective in prolonging life, it need not be offered, and palliative care, including hospice care, is acceptable" (Rhymes, 1996, p. 3).

This is especially relevant to the nursing home setting where a common dilemma is posed by an Alzheimer's patient who, as the disease progresses, forgets how to eat. He is neither hungry nor is his body capable of digesting food. Feeding, therefore, results in needless pain and discomfort that only prolongs life, not its quality. While denying nutrition will result in death, in this case it

merely allows the disease to take its natural course.

Session IV: Understanding Dying

The Western concept of dying was perhaps best explained by Dr. Bruce Mills (1994) at a Department of Justice Canada conference,

While the fear of death is universal it is in suffering or in the perception of suffering where fear of death gestates. I am reminded of a patient, who at late-stage disease states that his fear of death arises from images of the afterlife, hell and torment, when in fact he is speaking of his current state of suffering and chronic pain. His metaphors for death extend from a trajectory of abuse, neglect, and impoverishment to hell and torment. He cannot conceptualize the difference between his suffering and death. Our work often involved liberating death from the biopsychological experience of suffering and pain: Death is not like life; it is different; death is not like suffering, it is different.

A different perspective on death is held by the Hasidim. They "believe that God, a benevolent and omniscient figure, rules the world, so the challenges of life often are seen as reflecting God's will. However, there is a strong emphasis and belief in human free will and the power to influence fate through prayer.... The refusal to give up in the face of tragedy is encouraged. Through prayer, charity and repentance, it is hoped one can change one's divine sentence" (Mark & Roberts, 1994, p. 203).

While illness is deemed to be a decree from God, Hasidic Jews will do whatever they can to save their lives, even breaking commandments if necessary. This is acceptable because "a basic principle of Jewish law is the supremacy of *pikuach nefesh* or saving a life. When one's health is threatened, Jewish law mandates that one do whatever possible to increase one's chances of survival, even if it temporarily requires violation of other commandments. The rationale behind this is that more years of life can bring more service of

God" (Mark & Roberts, 1994, p. 206).

"Nevertheless, Judaism—acutely linked to the reality of the human condition—realizes there are circumstances in which a person might long for death. The Talmud reports of Rabbi Judah the Prince suffering great pain from an illness and his righteous maidservant praying for his death as an end to his suffering. At least one commentator cites this passage as an approbation of praying for the merciful death for one suffering pain from illness" (Diament, 2000, p. 8).

A high proportion of the Hasidic population are either Holocaust survivors or the children of survivors. As Mark and Roberts (1994, p. 206) note, "Memories of the Holocaust seem to figure considerably for a Hasidic patient in the treatment for cancer. The images alone—the shaved head, the number on the arm (on an identification bracelet), the sense of being trapped in an institutional setting, the wearing of the hospital gown or uniform—and the sense of being helpless, the worries about survival, and the sense of having research done on them can bring back suppressed memories."

Jewish rituals surrounding death and dying become important even for non-observant Jews.

Jews who have not been near a synagogue for 50 years often want a Jewish burial with a *kaddish* (the mourner's prayer) said for them, just as much as a professing and active Jew. Whether it is fear of the unknown that compels people to resume their religious and cultural observances when they are dying, we will never know. For it is confused by the fact that most people die at a relatively old age and there is a tendency to return to religious belief and cultural practice in later years, although this appears to have little to do with faith. Certainly, the Jews that I have spent much time with in the final weeks and months have been quite frank about their lack of belief in a personal God. They have, nevertheless, wanted a 'proper' Jewish funeral, and their family to sit *shiva* (going through the mourning ritual) for them (Neuberger, 1999, p. 5).

This return to the faith at the end of life appears to be motivated by a desire for "comfort, security and community." What the patient wants is a "good death" like that of "Abraham or Moses, one that occurs in generational order, when the person is in peace, under no emotional or physical pain, and when the person has said his or her farewells to family and friends" (Neuberger, 1999, p. 5).

Session V: Communication

The ability to listen to the patient and to provide information to him or her to enable informed decision making are perhaps the two most important attributes of staff delivering palliative care. According to New York's Task Force on Life and Law (1994), "Patients' participation in treatment decisions contributes to their sense of self and well-being. Physicians should seek patients' participation in decisions about withdrawing or withholding life-sustaining treatment early enough in the course of illness to give patients a meaningful opportunity to have their wishes and values respected."

Simon Wein of Shaarei Zedek Medical Center, wrote (2000), "Before instituting any intervention at relieving refractory symptoms, it is crucial to involve the patient or surrogate in informed decision-making. Detailed information should be provided, including therapeutic alternatives, risks, and complications. It should be clearly stated that none of these interventions is expected to prolong the patient's survival."

That said, the right to know needs to be balanced against the need to know. In her experience, Rhymès (1996, p. 6) has found that most patients want to be told of their condition. Sometimes however, discussions about death and dying "can be carried to the point of rigidity or discomfort for their patients. To quote a hospice patient, 'They keep wanting to talk about death; I'd rather talk about how the Cubs are doing.'"

Cultural differences can negatively affect care. "Afraid of stepping into dangerous territory, or of mistakenly offending the Hasid, staff often can withdraw. Consequently,

Hasidic patients may be at high risk for isolation when undergoing cancer treatment" (Mark & Roberts, 1994, p. 206).

Moreover, cultural differences can exist within the same culture. For example, there is the case of two Chinese women suffering from similar terminal illnesses who acted in diametrically opposed manners. One chose to be uninvolved with the decision-making process, allowing family members to speak and decide on her behalf. The other was intimately involved with all aspects of her care. No generalizations can be made about how members of a culture will react to death (Hern et al., 1998).

Session VI: The Relationship between Patient/Family and Staff

Sometimes staff have moral objections to withholding care, which is what the patient wants. For example, a nurse believes that all life has value and must be preserved. To preserve the patient's quality of life, the nurse may be asked to withhold treatment that might prolong the patient's life, but at great pain and suffering to the patient.

Session VII: The Relationship between Staff

There can be tensions and conflicts among the palliative care team members. One Morningside House social worker who reviewed an early draft of the "Not on My Shift" grant wrote, "There needs to be sensitivity to the cultural differences and 'clinical culture' existing among the team members, particularly in relation to the physician. This is an important component in the delivery of services. The team, physician and the client can easily fall into looking toward the physician as having the right answer."

The physician is the team leader. As noted by the New York State Department of Health (1994, p. 164), "Society has granted physicians the authority to evaluate the risks and benefits of treatment, to recommend a course of treatment, and to provide treatments chosen by a patient or a surrogate in pursuit of

accepted medical goals. Judgments about potentially risky and life-threatening interventions undertaken to cure the patient or relieve pain fall squarely within the scope of the physician's professional role."

Nurses usually serve as program coordinators. They are the ones who actually carry out the physician's instructions. Social workers, chaplains, therapists and volunteers do not have firsthand knowledge of giving a patient morphine to combat pain or of withholding nutrition or hydration, knowing that it will also hasten death.

Turf issues can be overcome by successful teams. Commenting on the palliative care program at Northwestern Memorial Hospital, von Gunten (2000, p. 106) notes, "The most rewarding aspect of the program's development has been the collegial relationships that develop around the care of patients—relationships among students, residents, fellows, attending physicians, nurses, people in other medical disciplines, patients and families."

Session VIII: The Institutional View

At this session, participants are informed of Morningside House's philosophy on palliative care (i.e., when to allow death to occur) as well as the law surrounding informed consent and advance directives. From a legal perspective, this session is crucial.

Session IX: Volunteers

Volunteers are in a unique position to assist in the palliative care process. They provide three vital services:

1. They are the stranger in whom the patient can confide without fear of offending family, friend, or hospital employee.
2. If the volunteer shares the interests or life experiences of the patient, the volunteer can help the patient focus on subjects other than his or her medical condition. Death will be in the background of discussions with friends, family and staff; not so with volunteers.
3. Volunteers—properly trained—may be

able to assist staff in such activities as feeding, thus freeing them to focus on other duties.

Volunteers can be a key part of the palliative care team. Staff need to appreciate both their capabilities and limitations, as well as to respect the bonds that develop between the volunteer and patient. On the other hand, the volunteer must understand and respect his or her responsibilities and obligations toward the institution and the patient.

Session X: Grief and Bereavement

Palliative care is not limited to the patient's stay in the nursing home; it continues with aid to the family and friends after the patient's death. At this session staff are informed of the services available to families to help them cope with their loss.

The idea of including friends in the grief and bereavement process is important as it recognizes the role of community. A good example, from Jewish ritual, is the concept of the *minyán* (quorum) that is required for the recitation of numerous prayers, including the *kaddish* (mourner's prayer). As noted by the chief of the Psychiatry Service at New York's Memorial Sloan-Kettering Cancer Center, Dr. William Breitbart (1998), "The concept of the *minyán* recognizes the critical importance of relationships to others or 'connectedness' in the experiences of life, particularly in the conduct of a spiritual life and in confrontation with death."

CONCLUSION

In the past, nurses and other health care professionals entered the nursing home field not to oversee death but to maintain life. Today we see the beginning of a new trend in nursing home care. Residents are older and sicker. They arrive at the nursing home already in advanced stages of illness. Staff need to be retrained to deal with this reality. The "Not on My Shift" training program will provide all staff with the understanding needed to confront this new reality.

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