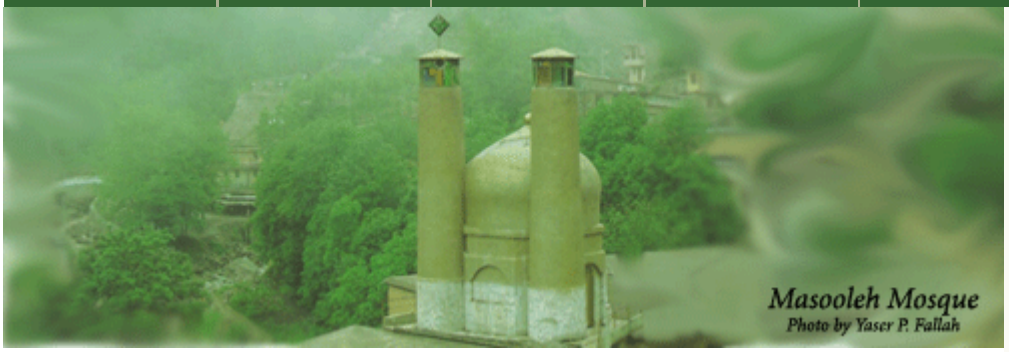

Hospice: An Interfaith Perspective on its Past, Present, and Future

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I. Recent History

Hospice Today

History is the story of how we got from there to here. First we will cover the recent history.

In recent history, “there” was only thirty years ago, when there were no hospices in America and there was no concept of hospice care. “Here” is today, when reportedly 8,000,000 patients go into hospice care in America every year. At any one time more than a million are in hospice. This would seem to suggest that the average length of such care is six weeks. Eighty percent of the one million patients in hospice care at any given time are elderly, and 80% are funded by Medicare.

When I first worked in hospice care as the first Muslim director of the Dialogue Commission of the Interfaith Conference of Washington, D.C., in 1983, hospice was one of our main volunteer initiatives. That year Congress passed a Medicare benefit for hospice care, providing significant advantages for patients, as well as for free-standing hospices, nursing homes, and hospitals, over non-hospice care.

Today, in America there are 4,000 hospices and 150,000 caregivers. Eighty percent of them are volunteers averaging 50 hours of volunteer work a year. But, 90% of care-giving hours are paid by the government.

The Role of Modern Science

These are the statistics. Hospice is a relatively brand new industry. Its recent history parallels that of computer science, genetic engineering, the meteorology of global warming, and other disciplines that were but distantly glimpsed forty years ago when I first became a professional in long-range global forecasting.

Modern science and technology have transformed the world, particularly in the field of medicine. Before the 1950s, which is only yesterday for me, most of the deaths in North America were caused by infections, like pneumonia, polio, and various childhood diseases. Final illnesses were short.

Fast forward to the twenty-first century today. Like in Star Wars, people can survive for many years incapacitated by chronic diseases, such as advanced metastatic cancer, which accounts for more than half of all hospice patients, irreparable organ failure, congestive heart failure, sepsis, stroke, and dementia. It has become almost difficult to die. In order to delay immanent death, the current generation is the first to have ventilators, defibrillators, parenteral feeding tubes, and other medical marvels readily available as personally cost-free treatments of choice.

This material progress, however, has come at a human cost. Some of the elderly, who used to die naturally and quickly at home, have been imprisoned on life support for months and even years in advanced care facilities merely because some institution is profiting from the private or government funds available for continued treatment. Such artificial prolongation of life by extraordinary means is increasingly considered to violate the person’s right to die painlessly with dignity.

The same progress in medicine that made it possible artificially to extend life also made possible the modern hospice movement, because advances in psychotropic medicine and other innovations to palliate cancer and other pain have made it possible to die painlessly with dignity. As so often is the case, the bad effects of scientific advances gave rise to their own cure through a cultural revolution. This is the historical key to understanding the past, present, and future of the hospice movement.

The cultural transformation in America both within and outside formal religious institutions has been leading for several decades toward greater appreciation for quality of life. Medical schools previously taught only curative care in the war against disease, but in recent years they have introduced courses and even degrees in hospice care designed to promote the quality as distinct from merely the quantity of life.

This new trend in professional education has been necessary to reorient medical professionals from the paradigm of extending life at all costs toward a new approach that aims at improving the well-being of care recipients as long as life lasts.

This necessarily requires a holistic approach to addressing the pain, not merely physical but psychological and spiritual, of both patients and their loved ones. This requires an entire team of professionals, the hospice team, to help the person live as fully and comfortably as possible in order to maintain the quality of remaining life.

II. Ancient History

Links to the European Past

The ancient history of hospice is important because its ancient history is what is being revived today, even though few medical professionals, including hospice historians, are aware of the links between modern hospice and its ancient past.

The hospice movement to avoid the prolongation of suffering from useless effort to conquer death or from the opposite extreme of ignoring the dying was not invented thirty years ago in America.

All the world religions at their core have always viewed death as a

natural phase of life, as something that should be accepted without fear and even as the greatest moment of one's life. This contrasts with the modern triumphalist attitude toward the conquest of nature and disease, which has undermined the traditionalist reverence for the human transition from this life to the next.

The culture of accepting the inevitable in order to focus on easing the path from one phase of life to another has roots extending back centuries and even millennia to periods when dedicated spiritual leaders gave nurturing refuge to those in need because God loves every person and because hospice is a beautiful means for care givers to return this love.

Every child has heard of the giant Saint Bernard dogs in the European Alps who used to rescue travelers caught in blizzards by providing a little whisky in a flask to warm them up while the dogs led them as sure and powerful guides to the closest hospice. In Medieval Europe, monasteries, both large and small, served as multi-functioning sanctuaries for everyone in need, the stranded wayfarers, orphans, and religious pilgrims, and for women in labor at the beginning of life and for both women and men at its natural end.

The most famous hospice care-givers in history, at least in Western culture, were the Knights Hospitalers of the Order of St. John of Jerusalem, who in their monastery on the island of Rhodes established a separate hospice for the incurably ill. This may be considered the origin in Europe of the modern hospice tradition, whereby caring for the dying is not considered to be so much of a burden as an opportunity to ease the path of one's fellow beings from this world to the next.

Links to the East

The closing of religiously motivated hospice care two or three centuries ago in Europe as part of the campaign against monasteries and formal religious institutions gradually separated the concept of personal commitment from collective governmental responsibility. Hospitals became efficient laboratories to combat disease, but were seldom equipped to offer comfort to a "traveler" near his or her journey's end.

As formal religion lost influence in the "West," the cultures of spiritual awareness from "Eastern" and even Native American cultures began to help fill the gap. The concept of hospice in Eastern cultures has

been a source in recent years for adaptation through such works as David Clark's Traditions in End of Life Care: Hospice and Related Developments in Eastern Europe and Central Asia (Facing Death), by Terese Maruyama's Hospice Care and Culture: A Comparison of the Hospice Movement in the West and Japan, and by Sylvia Crossman's Hozho, peintures de guerison des Indiens Navajo.

The turn-around in emphasis from curative medicine to the palliation of both physical and spiritual pain came to fruition during the cultural turmoil of the 1960s, when Dr. Cicely Saunders defined and pioneered a hospice program in 1968 at St. Christopher's Hospital in London, and when the next year Elisabeth Kubler-Ross published her On Death and Dying in America, which now ranks with Rachel Carson's book, The Silent Spring, from the same era as a classic in developing new perspectives on life and death. These pioneers, perhaps unknowingly, revived the original concept of hospice that has existed in all cultures since the beginning of human communities but had died out under the onslaught of radical secularism.

Cultural and Political Dynamics

As with all new paradigms of thought, the modernized version of the ancient hospice concept caught on fast. The concept and practice of hospice care as a new, holistic discipline is a permanent part of modern life, because it is an important response to changing cultural conditions. Perhaps the most important of these cultural conditions are: 1) a reaction against the impersonal secularization of society and the accompanying desacralization of life, as I have just suggested; 2) the renewal of spirituality in all religions as part of a broader cultural transformation; 3) greater awareness of the availability of assisted suicide and of hospice care as a better alternative at the end of life, similar to the choice between abortion and adoption at its beginning; 4) organized grass-roots efforts to provide life-affirming answers to such ethical questions; 5) demographic changes evident in the burgeoning elderly community, combined with the emergence of an educated and organized majority demanding better value and service through alternative methods of care and treatment; 6) the revolution in all fields of social science toward emphasis on quality of life; 7) technological and pharmacological advances that make quality improvement possible; and 8) advances in the health care delivery system demanded by the tax-payers who want better care at a fiscally and politically sustainable cost.

Traditionalist Wisdom

The future of hospice, as distinct from the curative medical model, may follow the existing trend toward the recovery of traditionalist wisdom. This is best reflected in a caring community of family and hospice team members sensitive to the patient's needs so that the person cared for may remain in familiar surroundings and better prepare mentally and spiritually for the major transition from this life to the next.

Most persons as they approach the end of life lose interest in the present and focus on a higher vision. Sogyal Rinpoche observes that the major challenge during this transition is the loved one who tries to control the patient by holding on tighter. Reflecting the universal wisdom of traditionalist cultures, he reminds us that life is a gift, so to hold on out of fear is to deny the gift and the Giver. Holding on is impossible and brings the very pain one is seeking to avoid.

The most famous expression of this wisdom is Reinhold Niebuhr's Serenity Prayer: "God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."

Or consider the words of Henry Van Dyke:

I am standing on the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I start and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then someone at my side says: "There, she is gone!"

"Gone where?"

Gone from my sight. That is all. She is just as large in the mast and hull and spar as she was when she left my side and she is just as able to bear her load of living freight to her destined port.

Her diminished size is in me, not in her. And just at the moment when someone at my side says: "There she is gone!" there are other eyes watching her coming, and other voices ready to take up the glad shout:

"Here she comes!"