Panel Discussion

Palliative Care and Hospice

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Care of the Terminally Ill from Religious Perspectives: Role of Palliative and Hospice Care

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Abstract

Health care should make an attempt to understand the different religious principles that affect end-of-life decisions in patient care. With advanced illness, defining an ethical framework is essential to understanding sensitive issues. Compassionate care is crucial in all end-of-life care settings. Physician awareness is a key principle in inculcating the religious values of patients. Cultural and religious awareness on the part of the health-care team is needed to provide patients with effective end-of-life palliative and hospice care.

Key words: End-of-life, religion, Islam, palliative care, hospice.

When we talk about different religions, cultures, belief systems, and faiths, two very important things come to mind. One is that all patients are not homogenous. Patients are different, and their belief systems are different. People may be religious in their own way, but it is very important not to stereotype any religion, culture, or society. When engaging patients

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and their families, it is crucial to be well prepared before meeting with them. Care of each patient needs to be individualized. What do our patients want? What can we offer? What are the limitations of medical management or technology? It is only after answering these questions that we can negotiate a plan of care, a plan that fits within the cultural and ethical framework of the patient as well as our health-care system.

As a health-care provider, my background is enriched by who I am and where I was educated. I know a little bit about different faiths because I was born Muslim, I practice Islam, I went to a Catholic school for many years, I trained at Long Island Jewish Hospital, and I have practiced in Long Island. As part of New York, Long Island is a melting point, and its residents are exposed to a large multicultural multiethnic society. For example, at my hospital, on any given day we may see patients from five to seven different cultural, religious, or ethnic backgrounds. This is a source of enrichment and learning for all. In addition, it is a great teaching service for residents and fellows.

The second important area I would like to focus on is that I am also a gerontologist and a palliative care consultant. These roles provide me the opportunity to explore situations where cure is not possible, but where good care can be provided. One of the newer programs we have initiated at Long Island Jewish Hospital is called the Hospital Eldercare Life Program (HELP). Program volunteers are retirees from the community as well as highly educated executive-type retirees from large companies. They all undergo formal training and provide bedside companionship to our critically ill patients in the hospital. They read them stories and bring in music, books, and movies. They provide small stuffed animals to children and comfort them and reorient patients with dementia. The volunteers are a great resource, and we are very proud of this service to our patients. In the future we will involve them in enhancing bedside care.

When we talk about medicine we are usually focused on a prescription, a drug, a technology, a left ventricular assistive device (LVAD), and other similar procedures. As a palliative physician, sometimes my job is to help deactivate Implantable Cardioverter Defibrillators for comfort and when they are indicated. My job is to determine if a patient in a New York Heart Association (NYHA) Class IV heart failure is not a candidate for a LVAD. Medical armamentarium and technology are so vast; we need to understand what fits an individual patient's needs. Some of the variables are the patient's quality of function, memory, and cognition. Age is by no means a barrier to any procedure or treatment, but there are limitations related to functional and cognitive decline and comorbid conditions at any age.

End-of-life principles are very important, and they have to be individualized. We conduct Schwartz rounds at our facility. A patient's family started these rounds after there was a discordant outcome based on communication issues between the patient, family, and health-care providers. The family, rather than seeking legal action, resorted to an educational exercise. Through a grant, the family funds different institutions to provide a venue where health-care professionals can talk informally about difficult end-of-life issues and see how outcomes can be changed. These rounds are conducted monthly, and it is one of the better teaching exercises.

Here is an example of the program at work. I was involved, along with the pediatric team at Cohen's Children Hospital, in a case involving the withdrawal of a child's ventilator support. This child had a condition that was incompatible with life, and the young parents made the decision after a year of aggressive therapy and care in the intensive care unit to withdraw the ventilator and stop the suffering. We had all the child's life support team present, and the staff provided support. It was a good outcome.

The act of teaching compassion is one of the places where all of our students, residents, fellows, and faculty members can learn compassionate care mutually. When we talk about traditional faiths and healing systems, it is very important to understand the burden of suffering. Eric Cassel, one of the master clinicians and ethicists in New York, talks about suffering as being the most confounding issue in modern bioethics in his book *The Nature of Suffering and The Goals of Medicine*.[1] The Georgetown principles in Bioethics[2] are great guidelines, but the decision for each patient has to be individualized. The most important fact is that when you talk about the burden of suffering for the patient or for the family, the best intervention you can provide is trying to alleviate that burden, whether it is short-term or long-term, to provide "comfort care." Suffering can be physical, emotional, spiritual, or the experience of total body pain, which is all three. Dame Saunders was the inaugurating physician of the modern hospice movement at St. Christopher's Hospice in England. She described total body pain as the experience of spiritual pain.[3]

When patients have not attained closure on issues in their life – whether financial or a relationship with a loved one – they experience total pain. We may need to intervene at all levels in order for them to die peacefully. Identifying and negotiating a plan for these issues takes the suffering away; it is not the morphine that will help that patient.

Negotiating the goals of care is universal across all religions. Most faiths support the concept that life needs are to be preserved, but overall, all religions, all faiths, and all belief systems support that suffering should be minimized. Therefore, we seek cure for the treatable. Sir Francis Peabody said: "caring for the patient is in caring for the patient."[4] ... The significance of the intimate personal relationship between physician and patient cannot be too strongly emphasized. The failure of the young physician to establish this relationship accounts for much of his or her ineffectiveness in the care of patients, particularly in advanced illness. What does that reference to care mean? Sometimes a cure is not the answer, so supportive treatment and managing the principles of that patient, is good. Let us preface that by saying that humans are mortal; we have not seen an immortal human being to date. We had a patient on Long Island who claimed to be the longest survivor, and she was 122 years old. For her birthday, big banners decorated the long-term care facility, and clearly there was a celebration of life because modern technology, good health, and good measures have allowed us to live that long. What was very important was that when she died at the age of 122, we were able to provide the family, and her children who were in their 80s and 90s, with the support that was needed.

Christianity, Judaism, and Islam all view righteous living in a material world and eventual union with God in eternal bliss as the goal. We are all mortal. The end will come, therefore, the best thing we can do for our patients is to prepare them for that end and not try to prolong their life indefinitely. What do they desire, and what are their hopes and wishes? If life-prolonging measures are utilized in the form of ventilators, procedures, and sedation, the question of what these therapies do for the spirituality of that individual is a difficult one to answer. Is human dignity preserved? If a patient is lying in bed and is attached to several machines and tubes, is he being helped spiritually?

We talk about religions and their attitudes towards withholding and the withdrawal of life-support measures. In general, people do understand when the hope for cure is not there; religion is not a factor in determining the outcome. Spirituality is very important at the end of life. As clinicians, when we are faced with the withdrawal of ventilators or other similar life-support measures, one of the most important people who should be at the patient's side is not the intensivist or the chief of the hospital, but the person offering pastoral care or spiritual care. I think everybody has a right to spiritual care. It could be nondenominational because a basic fundamental premise is that both at the time of birth or the end-of-life people have a right to have a spiritual focus of care. When a cure is not possible, we redirect or shift our goals towards being more palliative or more supportive. Understanding limitations of technology is important. "Do everything" is meaningless when the patient is dying. We can do everything and utilize all technologies and procedures, but that will not change the outcome. This patient will continue to die because he is on five pressors, hemodialysis, a ventilator with 100% oxygen, and blood pressure support, etc. We cannot change the outcome because he has an underlying incurable condition. One of the greatest studies that appeared in the *New England Journal of Medicine*[5] recently showed that combined early palliation with the standard treatment in patients with metastatic nonsmall cell cancer actually not only improves the quality of life, but it also prolongs life. The survival benefit is ensured if symptoms are well-managed. Therefore, we need to pool resources. We need listservs, and we need supportive means to show that good data is good data and outcomes are great. However, care needs to be individualized. This is a definition of palliative medicine. We are shifting from aggressive interventional care to palliative medicine in the appropriate setting. Most of us who practice in this area are board-certified and credentialed in this specialty. Palliative care is a holistic approach to caring for the patient and the family that looks at the psychosocial, medical and spiritual aspects of patient care. When we look at standards of palliative care, it is very important to know that religious beliefs are a great determinant in the discussion of the goals of care. These will include life-preserving and life-limiting therapies. One must weigh them, discuss them, and implement them. If needed, it is very important to have someone else present in the room to help guide the patients to the right path if they are strong believers.

When we look at optimal care of patient and family, every family is different, and every loss is different. When we talk about the loss of a baby, the parents are suffering. When we talk about loss of life in a 48-year-old, one has to consider the financial burden for the spouse and children he or she is leaving behind. What is the support team that is left behind for that family? Both hospice and palliative medicine use an interdisciplinary team approach where everyone works together. Spiritual and pastoral care is a big part of it. Counseling is provided to families for up to 13 months after the loss of a loved one.

I will now talk about the case that Dr. Athar mentioned, the woman who had a malignant bowel obstruction. In gynecological oncology, one may see gastric cancers, lymphoma, renal cell and bladder cancer, malignant bowel obstruction or carcinomatosis. The best palliation may be provided by our interventional radiologist, who will place a venting peg to drain the stomach. We use a combination of IV Sandostatin, which reduces the cytokines, IV steroids, morphine congeners for pain, and scopolamine as a way of reducing the cholinergic symptoms. These patients have a fairly decent quality of life, and they are not subjected to open surgery. They can be discharged to an inpatient hospice unit or they can go home with hospice, and the outcome is better in terms of symptom management and psychological impact of comfort being an achievable goal. Again, it is a team working closely to maximize the comfort of the patient.

Data has shown that we do not do a good job at the end of life. Hospice is still used by only 11-23% of the population.[6] Places such as the Cleveland Clinic in Ohio have great hospice utilization, but in New York the hospice numbers are the lowest in the country. When we talk about application of palliative care, the old model was that it was used at the end of life, but now we can start palliation along with curative therapies. If a patient starts chemotherapy, we can manage their pain. Cancer patients on an average may have five to seven symptoms that need to be addressed.[7]

Patients come from different health-care settings, and we could do better by taking care of patients and preparing them. When we assess our patients for hospice and palliative purposes, it is very important to focus on all dimensions, including spiritual care.

Hospice utilization is lower in African American and Hispanic patient populations because of their access to care and their conventional beliefs that patients should be dying in the hospital, not at home. Populations at risk of not receiving good palliative care are minority groups, patients with impaired cognitive function, dementia, and the mentally disabled.

The burden of pain is very important. We need to assess pain, we need to manage pain, and again psychological and spiritual pain needs to be assessed at all times. We live in a very multiethnic diverse community, but we do not want to stereotype cultures.

We want to ask a patient about his symptoms and what we can do for them. The personal touch in the physician-patient relationship is very important. Studies[8] have shown that physicians communicate better with patients if they sit in a chair and talk to the patient at eye level rather than standing above them at their bedside. The patient is more satisfied and feels that the doctor has spent more time with him, when, in fact, the actual time spent is the same. Traditionally, physicians do not know how to listen.

Access to good pain-management is a basic human right, yet the undertreatment of pain is an issue with minorities. End-of-life care may be suboptimal in certain populations. Those at risk are Arab-Muslims, Arab-Christians, Hispanics, African Americans, and Caucasians, which includes almost everyone. Studies[9] have shown preferences are very different in each patient population. Most Hispanic and Asian populations feel the hospital – with all the tests, all the doctors, all the consultants – guide them to the right path to pursue.

I would like to conclude by pointing out that hospice and palliation are available to everyone. It is a Medicare benefit that covers the last six months of life and can be extended. Hospice settings can be in the home or inpatient as long-term or continuous care where the patient can be managed with constant nursing supervision.

Hospitals do not manage symptoms at the end-of-life well, due to their curative focus. We are fortunate that our health-care system supports palliative medicine. We try to collaborate as a team; the hope is that we are able to help others as well.

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Question from the audience

What I have heard is very different from what I am accustomed to hearing from my training in terms of palliative care. One of the things that bothered me a lot about bringing up palliative care, and I was one of the most aggressive residents about doing this, was that patients had to sign a form saying they understood that they would no longer be getting certain aspects of care. Your presentation gave the impression that palliative care can be applied much earlier, and even as part of regular ongoing treatment, which sounds terrific to me. When I was in the hospital, I had the sense that the palliative care team was the only group of people who are advocating for patients or family members with the day-to-day problems such as getting blood drawn every 30 minutes, getting woken up 20 times a night, and other things that just make life in the hospital miserable. Are there ways palliative medicine can address some of these more practical issues? And how does it work? It seems very awkward when the team that is dealing with the acute problems is the one asking for blood every 30 minutes. How do you address that with them?

Dr. Mir's response: It is very important to know that we, as palliative care team, have a very big role in the hospital. We have to speak to the patient and the family and conduct a family meeting. The next goal is to speak to the physicians and the consultants and having a series of grand rounds for the subspecialties: the cardiologists, heart failure specialists, and neurologists. Unfortunately, we have a specialty for each system and each disease of the body. I think it is a very productive exercise in the sense that a lot of questions are answered, and the subspecialists are able to understand what we do in a better sense. We collaborate with them because we tell them that we are meeting the family of a patient. We recently had a very sad case of West Nile virus with multiorgan failure, and in the patient's family there were two health-care workers whom we knew closely. The patient's wishes were clear about not having life-sustaining therapies, but he did not have the capacity at the time to make this known. Through the negotiation of goals of care, the only way we could deliver what was needed to the family was to have the neurologist in the room to present all the information we could, both from Centers for Disease Control and Prevention and from the New York State Department of Health. We asked the family members what they wanted and what kind of outcomes they were looking for.

Palliative care is work in progress. It does not limit therapies; for example, palliative care can partner with oncology care. Hospice has open-access, which means hemodialysis or palliative chemotherapy can be offered under the hospice benefit. As long as the focus is symptom palliation, we do whatever it takes to make that patient comfortable.

Question from the audience

You said something about "open access" can you comment on that some more?

Dr. Mir's response: The hospice benefit recommends that patient sign a waiver to forego aggressive treatment. Hospitalization and aggressive workup under open access can be covered within reasonable limits. Dr. Smith pointed out that hospice gets paid $174 a day to cover certain services. Those services are for durable medical equipment, including a bed, oxygen, and whatever else is needed, including lab tests and nurse visits. They include wound care, which may be daily, and may include hydration and nutrition. Therefore, the cost may be way beyond $174. Most hospices are nonprofit; they are not in the money-making business. It is a balancing act to see what is appropriate for each patient and trying to individualize the plan of care.

Clearly, a time will come that we will have programs or plans for Medicare, which is called bridge to hospice. I think the data from the New England Journal of Medicine's article will show that we can have good palliation and good symptom control along with chemotherapy in improving the patients' outcomes.