Martin Reflects on Approaches, Trends in Hospice/Palliative Care

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PROVIDENCE – Edward Martin, MD, MPH, medical director of Home & Hospice Care of Rhode Island (HHCRI) since 2008, said he feels incredibly fortunate to be working in this subspecialty at this time. “I don’t think I could ask for more rewarding work in medicine. One of the nice things about working in hospice and palliative care is that we work as a team.” Currently, his team serves more than 450 patients statewide and in the 24-bed inpatient unit at the HHCRI center on North Main Street.

“Yesterday, I heard peals of laughter coming from a patient’s room as the family reminisced about the good times in their lives,” Dr. Martin said. “Patients and families are so grateful for the assistance we offer to them at such difficult time.”

Dr. Martin, a ’79 Brown medical school graduate and clinical associate professor of medicine at Alpert Medical School, heads the palliative care consultation service at The Rhode Island and Miriam hospitals.

Recently, he reflected on the work of hospice and palliative-care professionals.

Q. When you started out in your career, there was no such thing as hospice and palliative-care medicine. Now it’s board-certified subspecialty and growing field of medicine. How will the increased demand for hospice and palliative care be met here in Rhode Island?

A. In two ways. We now have a Fellowship program at Brown, for one physician. We certainly have faculty to train more but are limited by funding. There’s sort of been a cap for a number of years on training slots and although there’s legislation in Washington to free up monies for hospice and palliative...
care medicine given that it’s a new and emerging specialty, it’s clearly understaffed at this point. Subspecialists will not be able to meet the entire demand. The other focus will be on training in primary palliative care so that basically all medical disciplines get some training in hospice and palliative care medicine, since they are the ones who have the initial conversations with their patients.

Q. Where do practicing physicians learn how to initiate palliative care conversations with patients and their families, who are often unprepared and reluctant to have these conversations?
A. Last year, we participated in as many CME programs as possible. This year I was invited by The Miriam to participate in cardiology grand rounds. It’s a work in progress. But going forward, the critical area is in residency and fellowship training in palliative care skills.

Q. What is the difference between hospice and palliative care?
A. It’s confusing, even for physicians. One problem is we don’t have the elevator pitch for palliative care. The big difference is hospice care is, by medical regulation, restricted to patients with a six-month life expectancy. Palliative care is not. They both have attention to symptom care and quality of life. But in palliative care we may be seeing patients in the intensive care unit who may have a life-threatening illness but need attention to symptom control.

Q. Is time an issue here for most clinicians?
A. Yes, I have had a resident ask me why the attending physician ordered a palliative care consult. The answer was that the physician said, ‘this patient is going to need a lot of time going forward.’ We provide that. First, we make sure their symptoms are well under control in terms of pain, anxiety so that whatever time they have left they are as comfortable as possible. That’s one thing we don’t often address in the hospital, and medicine in general. We get so focused on treating an illness it can be easy to miss the fact that the patient is miserable in this process. That’s one area that’s fundamental to palliative care – making sure that the symptoms are well controlled. There’s often a sense that people associate palliative care with Dr. Kevorkian and that it’s somehow a slippery slope. There’s enough evidence in the medical literature to suggest that patients who got palliative care had prolonged survival rates. We don’t know exactly why, but clearly it doesn’t hasten death and can improve quality of life.

Q. What do you do when families disagree about treatment options or even about having a conversation about hospice or palliative care with a loved one?
A. With all of the conversations we have with patients and families, we try and get at what the patient wants. So if I’m sitting with a family member, I am asking: ‘What would your dad want at this point?’ Not: ‘What do you want for your dad?’ First it begins with a conversation about prognosis. It changes a great deal when the patient’s time becomes shorter. Ideally we go to the patients and assess their wishes and speak to the family about honoring their wishes. We want to be sure the patient’s wishes are paramount in this process.

Q. Is it usually a one-time consult that you do, or several?
A. It’s a process. Often we’ll see patients on their fifth or sixth hospitalization, and then on their eighth hospitalization, when it’s finally clear to the patient or family that things, in spite of coming back to the hospital, are not improving. In fact, they’re getting a little worse each time. At that point, they may decide to have a different focus for their care.

Q. For repeat cases such as the ones you have just described, is palliative care a component of the discharge planning in hospitals?
A. It’s not mandatory. Many times it’s the nursing home population with advanced dementia coming back. There is very little evidence that’s there’s a great benefit from going in and out of the hospital at the end of life. But sometimes family members seem to be unaware that their parent does not have to go to the hospital.

Q. Why do you think hospice care is sought so late in Rhode Island compared to other states?
A. I wish I had a good answer for that. We have one of the shortest stays in the country, the median length of stay is 8–9 days. It’s been called “brink-of-death” care. We tend to get patients late. One issue in our state is that there are a large number of older patients without caregivers who are living alone. When these patients wind up in the hospital with a serious illness, and are ready for discharge, they go to a skilled nursing home, which Medicare pays for.

For us, the biggest source of short-stay patients are ones that have gone through all of their days in the skilled nursing home and have continued to decline
and now are actively dying and switch to hospice with days or just hours to live. Hospice was designed for the final months of life and often there’s a much more limited benefit when they get hospice care for 48 hours as opposed to 48 days. But there’s a financial disincentive to seek hospice care earlier.

Q. Do you think that non-cancer disciplines under-utilize hospice care?
A. Yes. There’s a study looking at a large number of patients with cancer as compared to those with heart failure. About half of the patients with cancer received hospice care. But only about 15 percent of the heart failure patients did. I think part of it is the nature of the non-cancer diagnosis. Patients see themselves as chronically ill and not terminally ill, even when they’re terminally ill. I’ve yet to hear a cardiac patient say, ‘I’ll never forget the day my ankles swelled up or the day my doctor told me my ejection fraction was reduced.’

Q. What is the opinion of what is termed ‘Death with Dignity’ programs such as the ones in Oregon and Washington among hospice/palliative-care physicians?
A. I think there is very little support in the hospice and palliative care community for this. And I think it’s poor public policy. At least in my experience we still don’t do a good enough job of controlling symptoms in patients near the end of life. It seems a tragedy that people would take their life because we didn’t control their pain or nausea or anxiety or given them the kind of support they needed.