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# Comfort

Palliative Care
Gains Ground by
Guiding Patients in
Difficult Stages of Life

TAREK MAHDI, MD Palliative Care Riverside

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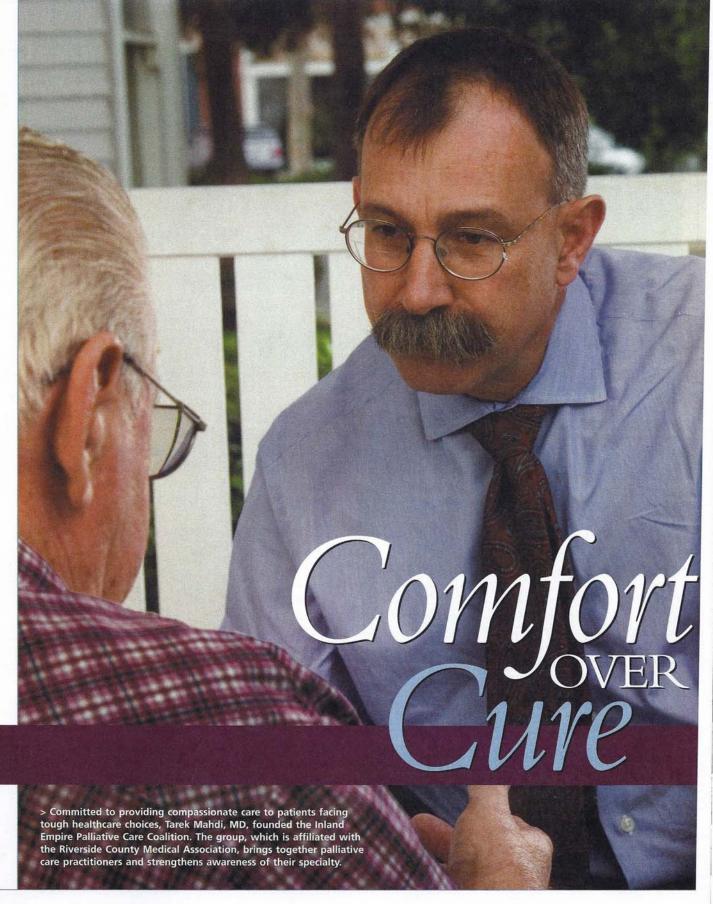
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DESPITE FUNDAMENTAL MISUNDERSTANDINGS ABOUT

its practice and goals, palliative care is expanding across the nation at a rapid pace. Practitioners say that's because society and the healthcare industry traditionally overlook—or want to ignore—the most difficult stages of life.

BY CHRIS WOMACK

here's definitely a gap in understanding the end of life, both from a physician's perspective and in our community-our patients, our families," says Tarek Mahdi, MD, director of Parkview Community Hospital's Palliative Care Unit and a family practitioner in Riverside.

That blind spot makes it difficult for society in general, and the healthcare field in particular, to deal with matters associated with chronic disease and death that shouldn't be ignored. "The hospitals, especially, are having a hard time transitioning from the acute setting," Dr. Mahdi says.

But acute care doesn't work for many patients. "Hospitals are admitting patients in their 80s who have pneumonia, or patients who have end-stage emphysema are being admitted again and again and again," Dr. Mahdi says. "We're dealing with a lot of chronic illness, for which there really is no cure, and palliation is the key. It's about improving their quality of life, improving their functionality, making it possible for them to live independently for as long as possible."

Most people who need palliative care have heart disease, lung disease, cancer, HIV or neurological disorders, such as Alzheimer's or Parkinson's disease. And palliative care deals directly with the difficulties associated with these conditions using a highly interdisciplinary approach. "Along with treating [a patient's] pneumonia, which I think is important, more important is integrating social services and physical therapy, and trying to rehab the patient so that after three or four days of sitting in the hospital, he can hopefully go home in a better state or in the same state as when he came in," Dr. Mahdi says.

After gradually gaining ground in the healthcare field during the past two decades or so, palliative medicine took a major step toward broad recognition in October 2006, when the American Board of Medical Specialties recognized it as a subspecialty and scheduled the first palliative-medicine board exam for October 2008. Advocates for palliative care argue that it deals head-on with topics that nearly everyone tends to avoid. The field aims to improve care and restore patient dignity by gently forcing patients, who probably will not get better, as well as their families, to deal honestly with healthcare options. But these things change slowly, and palliative care is still beset with difficulties that hinder its progress.

#### UNDERSTANDING THE FIELD

"One of the biggest barriers to the field is that people still have this misconception that palliative care is the same thing as end-of-life care—and it's not," says Sean Morrison, MD, director of the National Palliative Care Research Center and vice chair for research at the Mount Sinai School of Medicine Brookdale Department of Geriatrics and Adult Development in New York. "You shouldn't have to be at the end of life to benefit from or receive palliative care."

Palliative medicine's professional and advocacy organizations in the United States define the field as an interdisciplinary specialty focused on improving the quality of life for seriously ill people and their families through interventions, such as managing pain and other symptoms, including emotional, psychological and spiritual distress. "What differentiates it from end-of-life carewhat came before—is that palliative care can be applied and should be applied at the same time as all other appropriate therapies," Dr. Morrison says.

Palliative care's focus on comfort over cure, the physical, emotional and spiritual, has spawned perhaps the most interdisciplinary of all hospital specialist teams. Such teams generally consist of a physician, a nurse or nurse practitioner, a social worker and a chaplain, Dr. Morrison says.

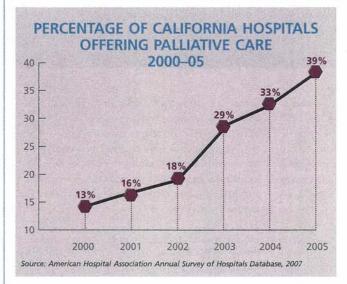
#### MEASURING PALLIATIVE CARE

Demand for palliative care will probably grow with the aged population. "I have a lot of patients in their 90s and two in their 100s," Dr. Mahdi says. The U.S. Census Bureau expects the number of Americans over 65 to increase to 55 million by



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-Sean Morrison, MD, National Palliative Care Research Center



2020, from about 38 million today. "The vast majority of older adults and a minority—but an important minority—of children will develop a serious advanced illness and will need palliative care," Dr. Morrison says.

Hospital involvement in palliative care is also growing. Although the field has roots going back to the 1982-vintage Medicare benefit for hospice care, the best data on palliative care begins in about 2000, according to Dr. Morrison. In that year, 632 hospitals reported a non-hospice palliative care program, according to research Dr. Morrison and colleagues published in the December 2005 issue of the *Journal of Palliative Medicine*.

Five years later, 1,240 hospitals reported having such a program. "It's been absolutely linear growth," Dr. Morrison says. "The most recent number is that about 30 percent of hospitals in the United States report a hospital palliative care program." Larger hospitals and not-for-profit hospitals are much more likely to have programs than smaller hospitals and for-profit hospitals, he adds.

Statistical models run by Dr. Morrison and colleagues reveal that a typical palliative care program will see about 1.5 patients per year for each bed in the hospital. "For my hospital, which is a 1,000-bed hospital, we see about 1,200 to 1,300 patients a year," he says.

To serve those patients, most doctors going into the field typically come from another specialty in which they have personally seen a need for palliative medicine, says Neal Slatkin, MD, director of supportive care, pain and palliative medicine at City of Hope in Duarte, and a member of the Los Angeles County Medical Association. He believes these physicians "have become a bit jaded with what they've done, and have decided that they, in some ways, want to go back to the roots of why they went into medicine in the first place."

Dr. Mahdi started this way, after directing two long-term

Alzheimer's disease facilities. He says that although he realized that medications can only slow down dementia in day-to-day management, the big problem was really helping families meander through the healthcare system. "Obviously, with Alzheimer's patients—especially end-stage—many families don't want them in the hospital and don't want them being tube-fed. There are a lot of ethical issues going on there, and if they end up in an acute hospital, many times they get things done that the families never wanted."

#### FACING BARRIERS, RAISING AWARENESS

Dr. Mahdi and most of the other experts interviewed for this article believe that palliative medicine needs to raise its profile among physicians and the public. That's one of the reasons why Dr. Mahdi founded in 2005 the Inland Empire Palliative Care Coalition, a group affiliated with the Riverside County Medical Association that brings together local palliative care practitioners so they can strengthen awareness of their specialty.

"[The] problem is getting the word out to the community that if treatment isn't working, you don't have to continue with it," says Robert Taub, MD, medical director of the palliative care program at Cedars-Sinai Medical Center in Los Angeles. "If it's only causing problems, and it's not causing any improvement, you don't have to keep doing it because it's there." Getting that same mes-

# TURNING PATIENT WISHES INTO MEDICAL ORDERS

wishes would be transferred when they moved from home to the hospital to the nursing home," says Tarek Mahdi, MD, director of Parkview Community Hospital's Palliative Care Unit and chair of the Inland Empire Palliative Care Coalition. Dr. Mahdi and the IEPCC found a way to do that by introducing Riverside healthcare institutions to the Physicians' Orders for Life-Sustaining Treatment, or POLST.

Although it differs from state to state, a POLST is a standardized document that functions as an immediately actionable medical order, listing a patient's preferred intensity of treatment using a range of life-sustaining interventions.

"[POLSTs] have been in use in Oregon for a number of years, but there's a big trend nationally," says Judy Citko, executive director of the California Coalition for Compassionate Care in Sacramento. To bring POLSTs into this state, the California Healthcare Foundation gave about \$94,000 to her group, which plans to look for legal barriers to them, as well as legislative changes that would encourage their use, she says.

The CHF will also grant additional awards to spur the adoption of POLSTs. "The foundation has committed to using \$120,000 each for up to six communities to work on POLST in their local community at the grassroots level," Citko adds. Interested organizations can find an application at www.finalchoices.org.

sage to doctors is also difficult, because they often feel that their job is to do everything possible, he adds.

Further, some physicians think that many

aspects of palliative care are already part of their duties, so they are hesitant to refer patients to a specialist for care they could be providing themselves, Dr. Slatkin says. "The kicker there is 'could' be doing, not 'is' doing or 'doing with a high level of expertise," he says. "One of the biggest barriers is convincing people that there's a special knowledge and level of service that a true practitioner expert in this area can bring to the care of patients that other practitioners, however well meaning, cannot bring-simply because they don't have that background or experience."

"There's a physician reluctance to utilize palliative medicine, and we don't really know why," agrees Dr. Mahdi, although he speculates that other physicians may see the specialty as competitive with their own practices. "It's a nationwide phenomenonthere's a definite reluctance to calling a palliative-care consult," he says. "They all think it's hospice, or they all think, 'He's coming in to give morphine."

#### FINDING A NICHE

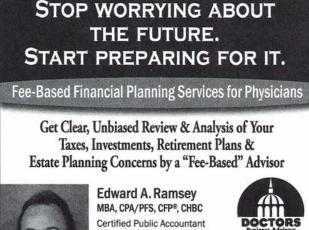
Despite resistance to their chosen field, palliative care practitioners make a strong case that palliative care fulfills genuine needs. Patients need counseling about their treatment goals and values in order to make intelligent healthcare decisions. Dr. Taub explains: "[If a patient] values being independent, then his goal might be 'I need to play golf and take care of my own needs.' If that's possible, then we need to go for it. But if it turns out to be med-

#### DOES PALLIATIVE CARE COMFORT THE BOTTOM LINE?

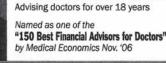
alliative care seems to make economic sense. But its advantage doesn't come from the payment side of the equation-Medicare does not reimburse specifically for palliative care, and its hospice care reimbursement is only for patients having a prognosis of six months or less who forego curative treatments. And although insurers like Kaiser Permanente, Aetna and UnitedHealthcare offer some incentives, thirdparty reimbursement for palliative care isn't universal.

Instead, palliative care appears to save money, according to research published in the October 2003 issue of the Journal of Palliative Medicine. For 123 patients admitted to Virginia Commonwealth University's Massey Cancer Center Thomas Palliative Care Unit, daily and direct costs fell 66 percent, compared with their stays elsewhere in the facility. For 38 Palliative Care Unit patients matched by diagnosis and age to patients outside the unit, total costs were 57 percent lower.

"When you sit down with patients and identify what their goals are, and you match their treatments to their goals, and you have an effective team that can coordinate care in a fragmented care system, costs go down," concludes Sean Morrison, MD, director of the National Palliative Care Research Center in New York.









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ically impossible—the person's going to be permanently dependent on someone else—he needs to know that, because it will change the treatment."

Sometimes palliative care workers are the only people able to broach the difficult topics. In a typical situation, "we get called in as a consult in palliative care on a patient in her late 80s or 90s who's been in the ICU for 40 days," Dr. Mahdi says. "She's really clinically dying, but she is being supported by dialysis and a ventilator. Nobody has sat down with the family and told them, 'Your mom is dying,' or 'She's at a point where we need to let her go.'

"I'm not saying we shouldn't be aggressive at the end of life ... but we want to respect the patient's wishes, and many times we don't know what the patient's wishes were, because we never had that discussion," Dr. Mahdi continues. "It's not something that comes across easily, and I think the goal is to start having these discussions with our patients early on, so that the type of care that they want at the end of life, they get."

With the benefit of patient wishes as guidance, palliative care can even prevent death or stave it off a little longer. "It's been recognized in recent years that if you don't effectively treat people's symptoms, they may drop out of very promising chemotherapy or other therapies that stand a chance at putting their tumor in remission or potentially even curing them," Dr. Slatkin says. "This actually happens, and I've seen it happen. I've had many patients who've gone on to do very well with their cancer treatment tell me that they almost dropped out, that they were on the verge of dropping out of their therapies because they were so miserable."

#### PHYSICIAN-ASSISTED SUICIDE UPDATE

The California Medical Association opposes physicianassisted suicide and successfully blocked a bill on the Assembly floor this year. However, resolutions to modify the association's policy were due for consideration at the CMA House of Delegates meeting last month.

The CMA spearheaded opposition to Assemblywoman Patty Berg's Compassionate Choices Act, AB 374, with the help of oncologist groups and Californians Against Assisted Suicide, a coalition including disability rights, religious and ethics organizations. Lacking Assembly votes this year, the bill is eligible for consideration in 2008. "We felt it would detract from the patient-physician relationship, and call into question whether doctors are really trying to do the best for their patients," says Brett Michelin, CMA associate director of government relations. The association believes that physician-assisted suicide is inconsistent with doctors' goal of curing patients or keeping them comfortable near the end of life, he says.

A group called Compassion and Choices backed Berg's bill, along with allies including the American Civil Liberties Union, the state Democratic Party and several seniors' organizations. Berg sponsored the bill out of privacy and civil rights concerns, according to Will Shuck, the assemblywoman's chief of staff.

At press time, the CMA House of Delegates had not yet considered four resolutions aiming to move the association into a neutral position on physician-assisted suicide, Michelin says. All resolutions submitted in 2006 aiming to shift the CMA toward supporting the practice failed.



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