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INTERVIEW WITH DIANE E. MEIER, MD, FACP

Training Doctors, Combating Myths

HP: How would you describe the present status of palliative care in this country now? Are you pleased with the progress? What more needs to be done?

Meier: The present status is an exponential increase in recognition and availability of palliative care in the last 10 years, to the extent that I would say the field is at a tipping point, going from something that was unusual, exceptional, available only at the most progressive, sophisticated health care institutions to a place where, if not already, very soon it will be a *have* to have, not a *nice* to have. That has occurred in a very short time frame, I would say about 10 years. I am very pleased with the progress of the field.

HP: Who pays for palliative care? You noted in your book, *Palliative Care: Transforming the Care of Serious Illness*, that much of the cost comes from the operating budgets of hospitals.

Meier: The two main streams of financial support for palliative care are [Medicare] Part B billing

and hospital operating budgets.

Doctors and nurse practitioners bill fee-for-service under Medicare, commercial insurance and Medicaid for palliative care, just as if they were billing for a routine visit for any other medical service.

CMS [Centers for Medicare and Medicaid Services] approved palliative care as a distinct medical specialty under which we can bill this year, but for example, I am board certified in internal medicine, in geriatrics and in palliative medicine. If I see a person for their high blood pressure, I bill, and the diagnosis code is high blood pressure. If I see a person for a palliative medicine consultation, I bill, and the diagnosis code will be whatever the reason for the consult was, so it might be pain, it might be debility, it might be shortness of breath, so that is a source of income for palliative care teams.

Not all members of the team are allowed to bill. Only physicians and nurse practitioners can bill, so at present, social workers, chaplains, other members of the team are supposed to be supported by the overall hospital Medicare reim-

bursement, and they don't bill fee-for-service. But those members of the team who can bill fee-for-service do so, or should, and that is a major source of income.

But it is insufficient in and of itself because there are many members of the team who don't bill, can't bill, and also because the income is not enough to support the salaries and benefits of the staff. So that is why a substantial fraction of the cost of the team is supported through hospital operations.

HP: Is there anything in the new health reform that you anticipate will be a support for palliative medicine?

Meier: There is nothing specific in the health reform bill about palliative care. There are some specific provisions having to do with hospice, but that's different from non-hospice palliative care, which is what you see in hospitals.

HP: Has Catholic health care played a role in the growing acceptance of palliative care?

Meier: Yes, Catholic health care has been at the vanguard from the beginning. Catholic hospitals and Catholic health systems have recognized the importance from a patient-centered perspective of delivering high quality palliative care.

I think in part this is because of the very explicit commitment to mission Catholic health systems have always had at the core of their identity and at the core of their driving principles. My sense is that is a big part of why Catholic health systems were not only very early adopters of palliative care, before the rest of the health systems woke up to it, but also are much more likely now, even in 2010, to have palliative care services available to patients than any other segment of the health care system.

HP: What do patients most stand to gain from greater acceptance of palliative care? What does it bring to patients

DIANE E. MEIER, MD, FACP

Dr. Diane E. Meier, a 2008 MacArthur Fellowship recipient, is director of the Center to Advance Palliative Care (CAPC) and an editor of a new book called *Palliative Care: Transforming the Care of Serious Illness*. (See review, Page 74.) She is director of the Lilian and Benjamin Hertzberg Palliative Care Institute, professor of geriatrics and internal medicine and Catherine Gaisman professor of medical ethics at Mount Sinai School of Medicine, New York.

The John D. and Catherine T. MacArthur Foundation's prestigious fellowships award a \$500,000, no-strings-attached grant to individuals with a record of significant creativity and achievement and who show manifest promise for important future advances. The foundation noted Meier's work as a geriatrician "transforming treatment for the seriously ill into more humane and effective care."

As one of the leading figures in the field of palliative medicine, Meier has published extensively in all major medical journals and edited the first textbook on geriatric palliative care.

Among her many honors, she has received the National Institute on Aging Academic Career Leadership Award, the Open Society Institute Faculty Scholar's Award of the Project on Death in America, the Alexander Richman Commemorative Award for Humanism in Medicine and the American Academy of Hospice and Palliative Medicine Lifetime Achievement Award. Meier is principal investigator of a National Cancer Institute-funded, five-year, multisite study on the outcomes of hospital palliative care services in cancer patients.

Meier received her B.A. from Oberlin College, her MD from Northwestern University Medical School, and she completed her residency and fellowship training at Oregon Health Sciences University in Portland. She has been on the faculty of the Brookdale Department of Geriatrics and Palliative Medicine and Department of Medicine at Mount Sinai since 1983. Meier lives in New York with her husband, Dr. Warren Sherman, and their two children.

that normative good health care does not?

Meier: Where to start? [First,] it brings expertise in the identification and treatment of symptoms, not just pain, though it includes pain. Pain, depression, spiritual and existential distress, shortness of breath, worry, feelings of hopelessness, loss of appetite, insomnia, nausea.

The fact is that most doctors (a) have no training in the identification of these symptoms and (b) have no training in their treatment. I know this is hard for the public to believe, but physicians are trained to treat a very specific disease of a specific organ, and the symptoms, both of the illness and its treatment, [have] never been, at least in recent years, a primary focus of training. And that's why patients suffer so much.

The second component that palliative care teams bring that really doesn't exist anywhere else in the health care system is skilled capacity to work with patients and families to understand who they are, what they need, what their fears are, what their hopes are, and help them establish achievable goals for care. These conversations are not five-minute conversations. They are 30- to 90-minute conversations. No one else in the health care system has either the training or the time to engage in that kind of communication with patients or their families.

HP: What about chaplains? Social workers? Isn't that what they are trained to do?

Meier: The chaplain doesn't have the medical background. The chaplain can't go through the risks and benefits of the treatment options. The chaplain can't link up the patient's hopes, fears and goals with achievable treatments because he or she has no training in medicine. They are medical discussions.

HP: So the medical comes first in these conversations.

Meier: Well, it depends on the patient, what comes first. It depends on their stage of illness, their treatment options. There's no one approach. It's very patient- and family-centered, beginning with who this patient is, who this family is, what the disease is, what stage the disease is in, what are the treatment options, how does that fit within the patient's specific goals and hopes and fears, and through that very deliberate and patient process, working out a care plan that is realistic and meaningful. And you have to know medicine to be able to do that. You have to also be very skilled in soliciting what patients know, what they want to know, what their goals are, to try to match those worlds together, the medical world and the patient-centered world. That's something you don't find anywhere else in the hospital.

HP: And what is the third component?

Meier: The third component is the commitment to making sure that when the patient and the family leave the hospital, the meticulous plan laid out in the hospital is actually carried forward. So we spend a huge amount of time making sure there is a reliable safety net and support for patients and families when they leave the hospital, that they will not end up back in the emergency room two days later because there was no safety net, there was no one to call who knew what to do at 3 in the morning, the equipment that was needed

wasn't in the home, the nursing home the patient was sent to was not comfortable managing pain. We prevent those things from happening.

That takes a lot of work on the part of the palliative care team, and you might ask why discharge planners or social workers don't do that, and it's for the same reason as what I said about chaplains. It's that they don't understand the medical situation, so they are not able to understand that sending a patient home with a severe pain syndrome that requires a very carefully laid-out plan of management [won't work]. We have access to those drugs in the hospital, but we send the patient home with a prescription [for instance], and none of the pharmacies are able to fill it. They don't have the drug.

We will not let somebody go home until the prescription has been filled because we know how hard it is to find these drugs. We know that if a patient goes home without this prescription, the likelihood he or she will end up back in the emergency room is very

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high, and we go the extra mile, even if it means keeping the person in the hospital longer to be sure that discharge will be successful, that it's sustainable and safe for the patient and the family.

And that also requires a lot of medical knowledge and sophistication, not only medical knowledge about what this patient needs now and is likely to need in the future, but also very sophisticated knowledge of the weaknesses and failings of the health care system outside the hospital, figuring out how to compensate for that, so that we're not abandoning very sick patients and their exhausted family caregivers into a system that simply cannot support them.

So those are the three components

of palliative care that you don't really find anywhere else in the hospital.

HP: There seems to still be a fair amount of misunderstanding of and resistance to palliative care. Where is it? Is it doctors, is it patients?

Meier: Yes, all of the above, in terms of the audiences where there is misunderstanding, although I think doctors have among the worst misunderstanding, and because their misunderstanding is so pervasive, it conveys itself to their patient and families.

[Doctors'] misunderstanding is that palliative care is the same as hospice, and it's what you do when there's nothing more [medically] that can be done. To the contrary, palliative care should be diagnosed at the beginning of life-threatening illness, whether a person is going to live with it 10 years or 10 days. It could be Alzheimer's disease, emphysema, kidney failure, heart failure, Parkinson's, as well as cancer; diseases we can't cure, for the most part,

and that they live with for a long time.

And the primary burdens on the part of patients and families are quality-of-life issues: how can I continue to function, how can I manage the side effects of the disease and the treatments, how do I cope with the burden my disease is imposing on my family and loved ones, how can I find meaning and purpose when what I used to do for meaning and purpose is no longer possible?

We now have data, quite a bit of data, that demonstrates palliative care not only improves quality of life, it also lengthens life. (See story on Page 16.) That is completely counter to what most people believe. What most people believe, [that aggressive treatment is

incompatible with palliative care; that palliative care is the same as hospice], is myth, and it's false, and the consequence of that is patients and families are not getting care they have a right to and care they deserve

HP: What is needed to gain the trust of physicians for palliative care?

Meier: There are multiple steps, and they start with medical school and residents' training. I believe palliative care should be a mandatory component of both medical and nursing education, that physicians and nursing students and those in graduate education programs should be required to work on and have exposure to palliative care, to non-hospice palliative care programs in hospitals and other community settings, as well as hospice palliative care programs, which are restricted to patients with a prognosis that is short. I think if physicians and nurses had mandatory exposure to these models of care during their training, many of the myths that have restricted access for patients and families would go away, and patients would get the care they need and deserve much earlier and more appropriately.

HP: Are any medical schools offering palliative care at this point?

Meier: Yes some are, but not enough, and it's not mandatory. Mount Sinai [School of Medicine], where I work, has a one-week mandatory rotation on palliative care for medical students. That's better than nothing, but not a whole lot. Yet every medical student spends six weeks on ob-gyn, even though only a tiny fraction of those

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medical students are going to go on the practice ob-gyn — and all of them are going to need palliative care skills. That's not because anybody has really thought it out, but just because that's the way we've always done it, and it's very hard to change those patterns of behavior. Medical students spend huge amounts of time on clinical rotations and in course work, frankly, on things that will have little to no relevance to their work when they are released into the world of care for patients. [They] spend almost no time on the things that virtually all of them will need in order to take good care of patients. Palliative care is one of those things that ought to be mandatory, ought to be central, ought to be substantive in time and quality of content and is at this time primarily an afterthought, if it occurs at all in medical education. And I don't think the public understands that their doctors are not trained in these things. I think the public assumes their doctors know these things, and the public needs to understand that is not the case. We need public demand to change that.

HP: What else would you like to for people to know?

Meier: I think you've got the main points, which is that palliative care is about matching treatment to patient goals, and if the patient goals are full-bore, aggressive, life-sustaining treat-

ment in an ICU, palliative care teams support that because what we support is care that is matched to patient and family goals — informed patient and family goals. And [palliative care] is not end-of-life care. It is care aimed at quality of life.

HP: Some of the confusion related to palliative care seems to be that often it does kick in at the end of life.

Meier: Yes, but the problem is when it kicks in at the end of life, we don't think about all the misery and suffering that occurred before that, and that could have and should have been addressed and wasn't addressed because of our lazy thinking about palliative care.

We have all taken care of patients for whom the goal was cure, so for example, a young person with leukemia, where we have every hope of cure for that person, and yet when she presents in the emergency room, she has excruciating pain, shortness of breath, panic attacks, devastating anxiety about this diagnosis, a distraught set of parents and brothers and sisters and she needs palliative care from the moment she arrives in the emergency room, even though we plan to cure her.

You see what I'm saying? The needs have nothing to do with prognosis. Prognosis is not the basis on which we decide who needs palliative care. Patient need is the basis.

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