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Clinical Rounds

involvement doesn't stop of diagnosis

End-of-Life Care Takes Compassion and Finesse

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NEW ORLEANS When the 43-year-old man checked into the hospital with severe stomach pain, 2 months later it wasn't his doctor who told him and his family that he was dying. It was a palliative care consultant they had not met before.

"When I talked with the family they told me that they hadn't talked with the doctor. They didn't know anything except that this relative was terribly ill," said Dr. John P. McNulty of the Palliative Care Institute of Southeast Louisiana, Covington. "They were quite upset that things were this bad, and they had not been included."

The man died that day. "This really left a bad taste in my mouth," Dr. McNulty said at the annual meeting of the American Academy of Family Physicians.

For a variety of reason, physicians don't always do such a great job of caring for terminal patients. Dealing with death in general is difficult; dealing with the coming death of a patient is even more difficult, said Dr. Steve Taylor, Hospice of St. Tammany, Covington.

Without realizing it, physicians sometimes rely on distancing tactics to insulate themselves. "We use some very sophisticated, subtle defense mechanisms rather than face-in our eyes-the failure of death," Dr. Taylor said. Some physicians give premature or false reassurances, normalize the situation, pay selective attention, "jolly" along, pass the buck, turn a deaf ear, concentrate on physical tasks, or disappear altogether.

But patients don't see terminal illness as the physician's failure. "They don't expect us to have the answers about death. They expect us to have the answers about pneumonia and what foods to eat, but nobody expects us to have the answers about death," Dr. Taylor said.

"I like to think of our position as the coach of a losing team. A losing team can be held together by the coach or they can fragment and start to point fingers at each other. It's our job to prepare them for that last journey," he said.

Over the last few years, Dr. McNulty has talked with many dying patients and their families about their needs and how physicians can improve care during the dying process. The same themes came up over and over.

First and foremost, dying patients want their physicians to talk to them and their families openly. "Often we throw up barriers. We have time constraints or we're not trained to be comfortable talking with these patients and their families. But it's so terribly important."

Keep the lines of communication simple. Patients or families shouldn't have to go through several people to get answers.

It's important to be aware of cultural differences as well. All cultures have developed their own customs surrounding death and it's important to respect these.

Breaking the news of a terminal illness can be the hardest thing that physicians will have to do, but more than 90% of patients want to know if they have a terminal illness, Dr. McNulty said. He recommended the following process for breaking this news to patients:

- Set the stage by finding a quiet private place, where you won't be disturbed.
- Acknowledge everyone in the room and ask their relationship to the patient; maintain eye contact.
- Ask the patient and the family what they already know.
- Find out how much they want to know.
- Give them the news, pause, and wait for a reaction.
- Establish a plan of action.
- Answer their questions.
- Pledge your support.

Let them know that you will be there. "It's important for the patient and family to know that you're there as their advocate," he said.

Terminal patients tend to feel that their physicians and medicine in general are abandoning them. "This phrase 'There's nothing more that we can do'--there's got to be a better way to say that," Dr. McNulty said. For the patients, that phrase connotes that the physician is abandoning them and moving on to the next case. Patients in this situation feel very vulnerable and need to know that they have someone they can trust.

Dr. McNulty also said that patients tell him that they want their wishes to be respected. To this end, it's important for a patient to have a set of advance directives, though he notes that it's difficult to get patients to think about this.

It's important to teach patients and family what to expect, Dr. Taylor said. "In hospice, the more we tell people what to expect--no matter what it is-they feel better if they know." Explaining the death process helps to reduce fear by reducing pain and suffering, it improves compliance, and it removes the intolerable uncertainty.

This is also a time for healing relationships with family and friends, he said. There are four things that you need to tell your patients to say to those who are close to them: You are important to me. Please forgive me. I forgive you. Goodbye.

Lastly patients want someone to help relieve their suffering, Dr. McNulty said. It's often easy enough to relieve physical pain, but remember that there are all kinds of pain-physical, psychological, emotional, and spiritual.

Spirituality is a subject that makes some physicians uneasy, Dr. Taylor said. It doesn't matter what the physician believes; what matters is what the patient believes. He recommended asking patients about FICA: faith, importance, community, and address. Ask them what they believe in, how important it is to them, whether they have a community of faith that they want to involve in their dying process, and how they want you as their physician to address their spirituality.

To better understand the stages of dying, Dr. Taylor recommends "On Death and Dying" by Dr. Elisabeth KublerRoss (New York: Scribner Classics, 1997).