



PALLIATIVE CARE CASE OF THE MONTH

Dying at Home: Honoring the Patient or the
Family?
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Case: The O'Toole family had always been known in their small town as being a large, close-knit group of kin with many siblings, cousins and others in the extended family who spent time together often. So, when the patriarch of the family was diagnosed with lung cancer, it was no surprise that the family rallied together to talk about how he would beat this disease and what they would contribute to the cause. They volunteered to give rides to and from chemotherapy and radiation, they volunteered to make meals and lead prayer groups, even the youngest in the family made cards and gifts to help cheer up their grandfather.

Following several months of treatment, the cancer had metastasized to Mr. O'Toole's liver, and his fatigue, pain and frequent falls were cause of multiple hospital admissions. While in the hospital, Mr. O'Toole's caregivers discussed with the family his prognosis and the available treatments to keep him free of pain and other distressing symptoms. Mr. O'Toole expressed a wish to his care team to go home and stay home, hence avoiding further hospitalizations, and to spend the remainder of life at home. The care team introduced home hospice to Mr. O'Toole and described the benefit as a team of professionals who will come to your home and help the family with caregivers and psychosocial support. He agreed, and the hospital team began to arrange home hospice for Mr. O'Toole and plan for his discharge.

Mr. O'Toole's daughter was notified by the care team of the discussion with him and his desire to die at home and his wish for hospice. They told her that he will need around the clock care and that the hospice would make daily visits, but not be able to be there all the time.

Much to the surprise of the care team, Mr. O'Toole's daughter was outraged. "I cannot take him home, and you should have asked me before you offered! Of course he wants to be at home, who wouldn't, but there is no one to care for him. I can't do it. I can't have him die in my house."

The care team was stunned and upset; they could not believe that the daughter would not be willing to honor her father's wish to die at home.

Discussion: Many studies and public opinion polls have documented people's overwhelming wish to die at home. Some indicate that as many as 83% of the population wish to die at home, in familiar surroundings with family and friends close by. Fewer studies have documented families' true desires, willingness or ability (physical to emotional) to care for a dying loved one at home.

Most clinicians (physicians, nurses, social workers, care managers, etc) see themselves as advocates for the patient, and attempt to make all things possible to honor patients' wishes. But, what is the role of the clinician when the patient, who is dependent on the family for caregiving, wants one thing and the family wants something different?

The patient who is seriously ill and dying is never the only person who is affected by illness and death. Often, entire families or even communities are affected and are involved in decision-making and caregiving. The entire community that the patient is a part of will often have to make decisions that will affect many people's lives and also need to support each other. As health care providers we are privy to a lot of personal information about people, but what we often do not have is the true history, context or reality of what that patient and their family unit is emotionally and logistically able to do when it comes to caring for a dying loved one at home. It is important to understand the larger family unit when helping patients plan for discharge and future care options, and to not make judgments about the family's decisions not to care for a dying loved one at home. Only those who are part of the patient's family and community can know what is best for them with regard to caregiving.

References:

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