Dying Cling to Hope,.. despite Living Wills

By GINA KOLATA nytimes.com

MANY Americans state adamantly that they do not want to die in a nursing home or a hospital or, worse yet, in an intensive care unit. They say that when their time comes, they want to slip away gently, surrounded by loving friends and family.

That, of course, is not what usually happens. A study of 4,124 deaths, published today in Annals of Internal Medicine, finds that most elderly and seriously ill patients died in acute care hospitals with severe pain, fatigue and other symptoms, but not because of poor medical care.

The study, by Dr. Joanne Lynn, director of the Center to Improve Care of the Dying at George Washington University School of Medicine in Washington, and her colleagues, involved an analysis of data from the largest study of death and dying ever done in this country.

Previous reports from this study, known by the acronym Support, widely misunderstood the data and contributed to a myth that terminally ill patients were begging to die in peace but that doctors kept on doggedly treating, Dr. Lynn said. But that is not what happened, she emphasized. In fact, she reported in her new paper, 90 percent of dying patients in the study agreed with the care they received.

This, experts say, is the real reason the nation has struggled for years with the medicalization of death. It is why, despite the hospice movement, despite the death-with-dignity slogans, despite the promotion of advance directives and living wills, aggressive care until the very end is often the norm.

Study after study has concluded that many healthy people often say they would never want to die in an intensive care unit, but may change their minds when they are very sick. Researchers are finding that healthy people often say they would never want futile care, but that it is often all but impossible to define a point when care becomes futile.

Many doctors who care for the terminally ill say it can be hard for healthy people to imagine how tenuously sick patients cling to shreds of hope and how difficult it is for many to admit that nothing more can be done to keep them alive longer.

Dr. I. Craig Henderson, a breast cancer specialist who is adjunct professor at the University of California in San Francisco, said, ''I find that very few of us, very few indeed, when it actually comes to the point of making a decision are prepared to give up all hope that they're going to live for another day, another month, another year.''

''These are very very tough decisions,'' said Dr. Maurie Markman, a cancer specialist at the Cleveland Clinic. ''You are asking patients to make a conscious decision not to undergo treatment when someone says there is a very, very small possibility that it will help. It takes a lot to say, 'Well, I am simply going to accept the inevitable.' ''

Dr. Henderson said he was profoundly affected by a paper published in The British Medical Journal in 1990 in which Dr. Morris Slavin and his colleagues at St. Bartholomew's Hospital in London asked people what they would go through for a small chance of benefit. For example, they said, if a grueling course of chemotherapy would give you three more months of life, would you take it? No radiotherapists said they would want it. Only 6 percent of oncologists and 10 percent of healthy people said they would want it. But 42 percent of cancer patients said they would.

Dr. Marion Danis, chairwoman of the ethics committee of the American Society for Critical Care Medicine and a professor at the University of North Carolina in Chapel Hill, found that seriously ill American patients were also willing to grasp at any hope for a prolonged life. In a study directed by Dr. Danis, published last month in Critical Care Medicine, she and her colleagues interviewed 244 patients with serious illnesses, like advanced heart, lung or liver disease or cancer. Fifty eight percent said that when death was near, they would want treatment, even if it prolonged life only a week.

Even after they have been subjected to the most advanced medical technology and have seen little long-term benefit, dying patients and their families may have few regrets, Dr. Danis found. She interviewed 160 elderly patients who had survived a time in intensive care. If, as was usually the case, the patients later died or were incompetent, she interviewed their families. Otherwise, she interviewed the patients.

Dr. Danis found that 70 percent of the patients and their families were completely willing to undergo the experience of intensive care again, even for one more month of life. And their responses were not affected by how ill or debilitated the patients were or even if they had died in intensive care.

Dr. Danis also asked patients and families if there were circumstances when intensive care would not be worthwhile for a chance of living slightly longer. Forty percent said there were such situations, ones of extreme impairment, like being in a vegetative state or being severe brain damaged.

''We've tended to think that patients don't want high tech care,'' Dr. Danis said. But now, she said, ''it's often the case that doctors are inclined to stop before patients are.'' Doctors, she added, ''are saying, 'I understand you may not want this,' and patients are saying, 'But I do.' ''

Dr. Danis said these findings and others cast doubt on a widely held belief that if healthy people just issued advance directives rejecting aggressive care when all hope for a meaningful life was gone, they could avoid a high-tech, medicalized death.

''The whole premise on which advanced directives are based is that you want a person to articulate what their wishes are so that you can act on them at a future time,'' Dr. Danis said. But, she said, ''that presumes that the wishes you express today will be applicable at a time when your health is really different.''

Despite what healthy people think the seriously ill would want, Dr. Danis said, studies indicate that, ''many are not prepared to let go.'' Moreover, what may seem futile care to a healthy person looking on can suddenly seem like one last chance of life to the dying.

''One of the problems with a futility policy is that very little of the treatments we do can be labeled absolutely futile,'' Dr. Danis said. And so, she said, if futility is the criterion, ''you're in a very big dilemma.'' Dr. Lynn said the Support study showed how very difficult it could be for doctors to decide how long a seriously ill patient would live.

Doctors had the hardest time predicting the life spans of dying patients with congestive heart failure, the most common cause of death in the United States. In a paper for the November issue of The Duquesne Law Review, now in press, Dr. Lynn and her colleagues report that 28 percent of patients with congestive heart failure who were expected to die in six months were still alive a year later. Doctors were most likely to guess right about patients with lung cancer or coma, Dr. Lynn said. But their guesses still could be far from accurate. Among lung cancer patients, for example, 13 percent who were expected to die in six months were still alive a year later and a very few even lived for two years.

Yet, Dr. Lynn discovered, doctors also tended to be overly optimistic about the chances of patients who really were about to die. She and her colleagues looked at doctors' prognoses the day before patients' deaths. Almost never, she said, did the doctors believe there was no hope. Doctors gave patients with congestive heart failure a 50 percent chance, on average, of living another two months. As a group, on the day they died, the patients in the study were expected to have a 17 percent chance of living for two months and a 7 percent chance of living six months. A week earlier, they were thought to have a 35 percent chance of living six months and a 51 percent chance of living two months.

Dr. Lynn and her colleagues wrote, ''It is not clear that society desires to categorize individuals who still have a '50-50' chance to live two months as 'terminally ill' and certainly not as imminently dying.'' Dr. Lynn said, ''What we forget in our myths and our stories is just how ambiguous these situations are.'' She added: ''If you write a living will and say you don't want anything done when your situation is hopeless, my question to you is, 'How hopeless?' '' When, she asked, do you want your doctor to say it is hopeless?