

# Let's talk about dying

Former French president François Mitterand, who died in Paris last month, apparently had a hand in his own death. According to accounts in the French press, Mitterand, declining after a long siege with prostate cancer, asked his physician what would happen if he stopped taking all medicine except painkillers. *Le Monde* reported the doctor's prediction that death would come within three days, whereupon Mitterand stopped chemotherapy and died just as expected.

To have such control over the timing and circumstances of one's death has become an ideal widely embraced in societies where high-technology medicine is often seen as an obstacle to dying peacefully. Mitterand was lucky. He lived to the age of 79, had a physician with whom he could talk about death, and did not linger for weeks following his decision to refuse treatment.

Mitterand's story brings to mind a recent and disturbing study of a carefully conceived attempt to help terminally ill hospitalized patients and their families engage in discussions about whether to deny treatment (such as cardiopulmonary resuscitation) when it could best be considered death-prolonging rather than life-saving.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) included an analysis of treatment of 4301 patients at five medical centers in the United States, followed by a controlled study of another 4804 patients whose care included features designed to enhance physician-patient communication. Participating doctors received statistical data about the likely prognosis of their patients, and skilled nurses associated with each study group were engaged to help patients and doctors talk to each other about Do-Not-Resuscitate orders, admission to intensive care units, and other medical options to sustain life.

The SUPPORT study, published in the 22/29 November 1995 issue of the *Journal of the American Medical Association*, was undertaken on the premise that "better" communication would lead to better outcomes — that is, earlier acceptance of death, fewer days in intensive care, a reduced incidence of pain in the days before death, and less futile care overall. But to everyone's surprise, the outcome revealed that the well-intentioned efforts to foster straight talk about life-threatening illness were a total failure. The incidence and timing of DNR orders were similar for the observational and study groups, as were the other indices meant to signify better or more sensitive care.

For instance, among the study group, only 59 percent of physicians acknowledged that they had received reports about the patient's prognosis and only 34 percent remembered receiving reports about their patients' stated preferences about treatment. Even more astounding, only 15 percent of physicians said they discussed the information they did have with patients and families. As the authors conclude, "The study certainly casts a pall over any claim that, if the health care system is given additional resources for collaborative decision making . . . improvements will occur. [SUPPORT showed that] improved information, enhanced conversation, and an explicit effort to encourage use of outcome [prognostic] data and preferences in decision making were completely ineffectual . . . ."

Why? Is the goal unobtainable or misplaced? Is the question of how doctors and patients behave so idiosyncratic as to defy logic? Are the decisions too personal and individualized to preclude cohesive analysis?

One answer, which the eight principal investigators recognize, is that doctors, patients, and families are generally satisfied with the way things are. Alternatively, decision-making based on even statistically valid generalizations may not be useful at the bedside. The number of reasonable choices varies significantly and subtly in individual cases. The *JAMA* article does not contain case studies that would enable the reader to assess the nuances that are pertinent in any individual situation.

The premise implicit in the SUPPORT project is that if people talked more about dying, they would reach common decisions about inherently difficult choices. But there is no commonly held view about decisions that are affected not only by medical status but by family, class, and religious values among many others. Despite the death and dying movement of the past 20 years, there is no consensus about what to do at the end of life except, perhaps, in a handful of clear-cut cases. For instance, most people would not want to see a terminally ill cancer patient with disseminated intravascular bleeding and organ failure put on a respirator. But beyond the "easy" cases, we have a long way to go before we can decide for others (physicians or patients) what is ethical in cases in which it is the subtle details, not the ethical generalizations, that count most.

— Barbara J. Culliton