

Good afternoon, my name is Dr. James Tulsky. I am Director of the Program on the Medical Encounter and Palliative Care at the Durham VA Medical Center, and Associate Professor of Medicine at Duke University. In addition, I help lead the newly established Duke Institute on Care at the End of Life. In these roles, I take care of patients facing life threatening illness, teach physicians and other health professionals about palliative medicine, and conduct research to improve doctor-patient communication and the care of dying patients. I am extremely grateful to the Committee for holding these hearings. In my testimony, I would like to focus on the difficulties we observe when doctors communicate with dying patients, describe several exciting new programs to address these and other shortcomings in care at the end of life, and identify the need to train more health professionals with expertise in palliative care.

In 1961, only 10% of doctors preferred to tell their patients that they had a diagnosis of cancer. Even fewer discussed with them the fact that they might die. Today, only the rare physician does **not** share the diagnosis of cancer with his or her patients. However, many still never mention the likelihood that this disease will lead to their death.

The fact that norms for disclosure about cancer have changed so dramatically attests to the success of a movement that has placed patients' rights and autonomy in the forefront of the public's conscience. However, the fact that many patients today will never hear a discussion of the prognosis of that cancer is a tragedy. And even when patients are told their diagnosis or prognosis, the quality of the communication may be so poor that the patients' needs are not met.

We have an intelligent and demanding public that expects to receive as much information as possible, in a manner that is sensitive, clear and compassionate. However medical education has not kept up with the public's expectations and many physicians are simply ill-equipped to communicate effectively about these issues. Few among us, including physicians, are born knowing how to deliver tragic news or to discuss a person's impending death. Unfortunately, many people attend medical school and are never taught these skills.

Let me give you some examples of the communication problems to which I am referring. We audio taped over 150 actual conversations between doctors and patients about decisions at the end of life, and learned that the quality of communication is sorely lacking. We found that physicians often did not provide sufficient information to allow patients to make an informed decision. The potential outcomes of treatment, an integral component of informed consent, were rarely discussed. When asking patients whether they would want to undergo resuscitation if their heart or lungs failed, only 13% of physicians mentioned the patient's likelihood of survival after resuscitation. We found that conversations about advance directives averaged less than six minutes each and physicians spoke two-thirds of this time. They used vague language, did not explore patients' values and, for the most part, ignored the tremendous emotional impact of these discussions on patients. I encourage you to visit the website of the Program on the Medical Encounter and Palliative Care (see bottom of cover page), where you can download a reenactment of one of these actual conversations between a doctor and patient about end-of-life treatment choices. It is eye-opening and will give you a first hand feel for the challenges we must assume to improve communication.

What is the current state of medical education about end of life care that has led to such deficiencies? A recent review from the Journal of the American Medical Association stated that "while nearly all medical schools offer some formal teaching about end-of-life care, there is considerable evidence that current training is inadequate, most strikingly in the clinical years. Curricular offerings are not well integrated; clinical experiences are mostly elective; there is little attention to home care, hospice, and nursing home care; and, **role models are few.**" One of our goals for improving this system must be to create professionals trained in palliative care who can pass on their knowledge to students and other

clinicians.

We surveyed young physicians at a major academic medical center and learned that although they have conversations with dying patients on a weekly or even daily basis, they have infrequently had the opportunity to observe more skilled physicians talk with their patients. In fact, one third had never been observed by a more experienced physician while discussing end-of-life treatment preferences with a patient or family member. Health care skills are taught predominantly using the apprenticeship model, or "see one, do one, teach one," as the students themselves refer to it. In truth, one needs to see and do many more prior to being well trained, however, the general model is successful and has led to highly skilled clinicians. Unfortunately, communication skills are not regarded with the same scrutiny that we use for other procedural skills and oversight is insufficient. We must recognize that one can hurt a patient with misplaced words just as severely as one can hurt a patient with a misplaced scalpel. Research shows that poor communication leads to worse patient outcomes.

Clearly, we have a problem in medical education. But even the experienced clinician who turns to a typical medical or nursing text is unlikely to find much help in caring for a dying patient. Last year, a study of the major medical textbooks revealed that information on end of life care was sorely lacking. These textbooks were missing nearly 60% of the appropriate content that would help one manage the physical, psychological and spiritual distress of the dying patient. Even oncology textbooks were missing this information. After reading some of these chapters, one might conclude that people simply don't die from congestive heart failure, colon cancer or dementia!

Although nursing has frequently been ahead of medicine in this regard and, as a profession, has spearheaded the development of hospice care, nursing textbooks don't fair much better. A similar review of nursing textbooks also found striking deficiencies in the content related to the care of dying patients. The good news is that both of these projects have led to collaborative efforts with the textbook editors to include more content on end of life care.

Clearly, an extremely high priority for improving the care of dying patients must be the education of physicians and other health care providers. The Institute of Medicine highlighted this need in its 1997 report on Improving Care at the End of Life. One of the Institute's primary recommendations was that "educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients."

The good news is that the last few years have seen a proliferation of efforts to accomplish these goals. I will accent several of these initiatives that are particularly interesting and with which I have direct experience; they are only a small sample of the many innovative programs that have recently emerged. Also, as another witness will represent the Department of Veterans Affairs, I will not address the truly remarkable commitment that agency has made to advance this agenda.

Four months ago we established the Duke Institute on Care at the End of Life. Made possible by a generous gift from the Foundation for End of Life Care, VITAS Healthcare and other donors, the Institute's mission is to improve care at the end of life through interdisciplinary scholarship, teaching and public outreach. What makes this effort unique is that the Institute is based in the Divinity School at Duke, rather than the Medical Center. To some, this may seem odd. However, our recent research would suggest that this may help us respond to what many our patients are looking for.

We conducted a national survey of 1,000 seriously ill patients and recently bereaved family members. We learned that after pain control, finding spiritual peace was the primary concern for those facing

death. In fact, these two goals were of nearly equal importance to patients and families. Spiritual peace was more important than having treatment choices followed, having one's finances in order or dying at home!

If spiritual needs of patients at the end of life are paramount, then what better way to ensure that this voice gets heard than to establish an Institute on Care at the End of Life in a school whose focus is theological education and the training of pastors? At Duke University we can do this and remain a one block walk from the medical school. The faculty of the Institute are drawn from all corners of the University, and our programs are truly interdisciplinary. The Institute's director is a psychiatrist and theologian with a primary appointment in the Divinity School; I am an internist based in the Medical Center; and we have representatives from nursing, social work, ethics, counseling, and the social sciences. Some of our initial programs have included a highly successful symposium on Access to Care at the End of Life, an intensive two day palliative care educational retreat for Duke health care providers, a pastoral care residency focused on the care of dying patients, a visiting scholars program and several new health services research projects. In the fall, we will be holding a symposium to provide training for pastors, chaplains and lay leaders so that they are equipped to facilitate a dialogue about death and dying in their faith communities. As a measure of the interest in this area, this program is already oversubscribed. We have an ambitious agenda ahead of us, as we try to find ways to truly integrate and improve both the medical and spiritual care of patients.

I would also like to mention efforts to improve physician communication skills. The following story illustrates what we have learned about the power of words and what we need to teach. Several years ago I arrived in the emergency room to admit a patient to the hospital with widespread, advanced lung cancer, and found that he had been hooked up to a mechanical ventilator. I wondered why this had been done, given that the patient and his wife knew that he was dying and had not intended for him to spend his last hours or days dependent on life support machines. I discovered that when he arrived in the emergency room short of breath, the patient's wife had been asked, "Do you want us to do everything for your husband?" She had been forced to give the only response that a loving spouse can give and answered "yes." Instead, if that doctor had said, "This must be a terrible time watching your husband die. Let's talk about how we can make things most comfortable for the two of you," this wife would have made very different choices about the treatments he would receive, and his last hours would have been less burdensome and more meaningful. What if we could teach clinicians to instinctively address patients' and families' emotions, rather than talking about doing "everything" or "nothing?"

Through a variety of programs, we have found ways to disseminate this different model for communication. Last month I spent a week in Rochester, NY with 80 other doctors, nurses and social workers at a meeting of the American Academy on Physician and Patient, where we focused exclusively on improving communication at the end of life. We used role play, standardized patients (patient-actors), and real patient volunteers to practice and observe the methods that work best. Through focused and supervised practice, clinicians learned about themselves, their own reactions to patients, and how to communicate most effectively. They learned to elicit concerns and to demonstrate their empathy for the patient.

At the Durham VA and Duke University Medical Centers we have been conducting a palliative care education program for several years called PREPARE, Program on Resident Education to Promote Awareness and Respect at the End-of-Life. In this project, funded by the Robert Wood Johnson Foundation, we bring the medical residents to an intensive retreat on palliative care, during which they learn pain and symptom control and also learn how to talk with patients at the end of life (see attached retreat agenda). Another project, also supported by the Robert Wood Johnson Foundation, is attempting to disseminate this type of education by training faculty from medicine residency programs across the nation to teach palliative care skills. This training has been accepted, in part, because of the commitment

of the American Board of Internal Medicine to making palliative care a core competency for practicing internists.

Many excellent programs are clearly surfacing to educate health care providers about pain and symptom control, communication with patients and attending to psychosocial and spiritual concerns. These are the beginning of what needs to be an even broader agenda. All medical trainees must be taught the basics of pain and symptom management. Excellent communication skills must become a core competency for physicians, and not a pleasant surprise for patients. We must develop multiple centers of excellence to promote and teach the best principles and practices of palliative care.

Is this agenda achievable? Yes, but only with ongoing support. All of the programs I have described have been funded by private foundations that have engaged this issue in an effort to create a cultural shift in the way we view death and dying. The priorities of the foundations will eventually change and I predict that many will withdraw their support for palliative care. Government must step in and become a leader in the areas where it has traditionally assumed responsibility. Mechanisms already exist for the federal government to support the training of experts in palliative care. For example, the Health Resources and Services Administration (HRSA), the Department of Veterans Affairs, or the National Institutes of Health could create fellowships to train future leaders in palliative care. The National Cancer Institute could require and support cancer centers to offer palliative care clinical services and training programs. These are relatively small interventions that could result in potentially huge results.

Everyone in this room is going to die. And, when that time comes, we hope to be cared for by health professionals who are well trained to meet our complex needs and by a health care system that allows them to do so. Although the barriers can sometimes seem overwhelming, the tremendous progress we have made these past few years inspires optimism. If the federal government becomes a partner in these innovations, there is no limit to the improvements we can make for dying patients and their families.