

My name is Dr. Linda Emanuel; I am a general internist with a special focus on end-of-life care. Thank you for the opportunity to provide perspectives that may help you complete your duties as State Senators.

Introduction to End-of-life care in Context

As you listen, please think of this: often we talk about 'they', the dying population, or about 'patients' rather than people. But it is not only they or patients who die. It is we. We all will. So think of the people you have loved or known who have faced serious illnesses, some of whom may already have died, and think of their stories. Think of the care that you would like to have or have had for each of these people. And think too about what you would like as you too face illness and dying. After all, if we get the policy and medical care right, we have one last all-important opportunity to be a part of civilized humanity and write our script the way we think it should be.

This presentation focuses on three themes: 1. The steps needed to close the gaps in end-of-life care today - the contrast between what happens and what people want; 2. The nature of our program to Educate Physicians and End-of-life Care (EPEC); 3. Some thoughts about how this Committee might be able to focus helpful attention in the Senate to promote effective Congressional action.

I. Needed Steps to Close the Gaps in End-of-life Care

You have heard from prior testimony the striking gaps that exist between the manner of dying that most of us would seek and the manner of dying that we provide and impose of people in the US. We have made some progress in the last decade, but we are working on the effects of an entire era that denied death and found suffering invisible or at best annoying, and we have a long way to go.

i. Society needs more. Society needs to feel free of the taboo that prevents healthy discussions on dying and what that implies. Society to know what people can expect from quality care at the end-of-life. People need to know that dying well is not an oxymoron and they need to have opportunities to develop their ideas about what it is they or their loved ones will seek as they write their last legacy and take their final bow. People can then become active in finding supportive programs, in keeping their ill loved-ones productive as long as possible, in keeping their family psychologically robust even as they face bereavement.

For the aging population there are some places that will provide the most promising outreach. These are *houses of worship and community settings*. Two reasons for this have strong merit. One is that the aging populations often gravitate to their religious community. The other is that the least served and much deserving population in end-of-life is, sadly, that of people-of-color. Leaders of the communities that fit this category often note that churches are the places to find and to gain the trusting ear of people needing this kind of care.

ii. The health delivery systems need to provide services that include the relief of suffering as an integral goal in any illness care. Relief of physical suffering means that social, psychological and spiritual well-being can be pursued. A complete, integrated program for palliative care will also support this pursuit in the realms of mental and social and spiritual well-being. This wholesome well-being means continued social productivity for both the patient for as long as possible (which is much longer than currently permitted by our narrow medical focus on illness and possibly on physical symptoms, and our inadequate attention to function and overall well-being) and for the caregiver.

This philosophy is distinct from a simple pro-hospice philosophy. Hospice is fabulous and must be

preserved. It has brought us to the point where we can taste and experience in all ways what truly professional care is like at the end-of-life. It has preserved the true interdisciplinary team. It has preserved the respect for the psychological and spiritual and social care of the patient. *But more is needed than comfort for the last moments of life. Palliative care should be available 'upstream.'* People should not have to choose between hospice and cure. People should not have to choose between fighting to live and letting entirely go. Palliative care, and hospice care when done as it seeks to be done, involves providing relief of suffering as an integral part of illness care whether cure is the primary goal or the secondary goal.

In this approach, comfort and maximal function are preserved as long as possible and as a smooth continuum of shifting goals as death and loss of function become finally inevitable. In this approach, there is a *triple win: patients stay out of the expensive care setting of hospitals longer; patients and families stay socially and economically productive as long as possible; and the experience of dying can leave a lasting positive legacy.*

iii. Professionals from all fields need core competencies in end-of-life care. If these goals are to be accomplished, the professionals providing hands on care need core skills. While it is important to have specialty training programs to keep the discipline rigorous and to keep it progressing along with all the unprecedentedly powerful technical possibilities in palliative care, the key issue now is that few of our practicing professionals have been trained in the core skills. Core skills need to be defined and disseminated to physicians, nurses, social workers, pastors, pharmacists, and administrators. Within the nursing and physicians professions, these skills need to be defined and disseminated among all generalists and all specialists. There is no group of nurses and physicians who should be ignorant of the needs of palliative care toward the end of life. Dermatologists care for those with skin cancer. Radiologists perform comfort-motivated x-ray or laparoscopically guided procedures to relieve fluid build up. Surgeons care for the dying routinely. Many die in intensive care. Nurses have specialized skills for each of these and other categories of service.

II. The Program to Educate Physicians in End-of-life Care

The program to Educate Physicians in End-of-life Care (EPEC) is a Robert Wood Johnson Foundation funded initiative that takes as a key premise that *physicians all over the country* need the core skills of end of life care now. It is not possible to solve the problem with physicians alone but it is not possible to solve the problem without physicians. As physicians, we started this program to take proactive steps toward that portion of the solution that we bear responsibility for. Another key premise is that it is *not possible to wait* for medical school education to improve matters and send better trained doctors into the field. A third premise is that physicians learn best with forms of adult learning that involve *collegial transmission* of skills. A fourth premise is that the substance of the education should be *high quality* clinical material that is readily applied to practical issues in patient care.

With these premises in mind we designed a *train-the-trainer program*, using a national and international panel of experts in the end-of-life field and in physician education to write modular materials that could be taught in a variety of settings and that could also train the learning physicians to become teachers of the material. This grass-root professional model was complemented by a top-down approach that included involvement of the leadership in medicine, whether from the American Medical Association, our founding partner, from specialty associations, from college Deans or from highly respected individual physicians.

Now in its fourth year, EPEC has produced *core curricular materials* that have defined the core competencies for end-of-life care and that are available as clinical learning material, as teaching manuals complete with handouts, as slides in electronic or acetate versions, and accompanied by clinical teaching

trigger video tapes. All this is also available as a CD-ROM (50 have been made available to you) combining all of the above and can be found and fully downloaded from the web. The RWJ Foundation holds the copyright for all the EPEC materials, and license to use and modify the materials for educational purposes with acknowledgement of the source is automatically granted in writing on the bottom of each page of the curricular materials.

To date, the program's *implementation and dissemination* has come close to our outrageously ambitious dreams. Our team has directly trained about 600 physicians. Physicians were selected to cover all the states, and to meet our criteria for showing evidence of respect among colleagues, having institutional backing to implement EPEC training and having a realistic plan for its effective implementation. Each of these physicians has qualified as an EPEC trainer and a vast majority have gone on to teach EPEC materials in their own setting. We have had trouble tracking the full impact of EPEC, largely because the impact appears to be much larger than our tracking system was set up to allow for. We can calculate a conservative estimate that if an average of 100 physicians has been trained by each of our trainers, then some 60,000 physicians in the US are now EPEC trained, or approximately 10 of physicians. Possibly a more accurate estimate would more than double that, for more than one fifth of physicians in the US having received EPEC training. In addition to this direct and second-tier colleague-to-colleague training, last year we mailed the CD-ROM to all the Deans of US medical schools and to approximately 300,000 physicians, *reaching half the practicing physicians and all the medical schools in the US* in this fashion. We surmise that many others will have been gleaned indirect learning through some of the less formal and formal activities that will have been influenced by EPEC. Ultimately, we hope to have reached all physicians in the US in one fashion or another.

Currently our program is in a developmental stage that we refer to as *Partnership Development*. We are continuing our own trainings, we are supporting our trainers who are implementing the program, we are providing faculty development for a select group of master teachers, and we are developing partnerships with managed care groups, with business groups on health care, with specialty societies, with medical schools and others who are interested in making EPEC into something of their own for their own professionals or constituencies.

III. How this Committee may Provide Helpful Themes to Focus on

In these final words, allow me to point to a few key thoughts for the Committee that can helpfully focus attention.

i. The relief of suffering is an integral part of medical care

This always has been so in the history of the profession but tragically got lost in the scientific enthusiasm of our 20th Century. We omit it at our own peril and at the peril of society. The end result has been anger among patients and citizens, revolutions in healthcare delivery systems and accountability demands that are more aggressive than targeted. And still we have not really understood the point. The task of this dawning new century is to rebuild true, trustworthy care into medical care. All policy and legislation should support the relief of suffering as an integral part of medical services.

ii. Relief of suffering should occur across the spectrum of illness and all venues

Hospice and palliative care for the actively, imminently dying is good, but not enough. The people and their families who suffer from the effects of severe arthritis or progressive dementia should not have to wait until their prognosis renders them hospice eligible to get relief of suffering. The relief of suffering should be taught to physicians and other professionals in all disciplines from pediatrics to primary care

medicine to surgery, cardiology and oncology. It should be taught to all medical professionals from nurses to social workers, pastors, pharmacists and physical therapists. It should be available in Intensive care units, ambulatory clinics, long-term care facilities, and in the home. The relief of suffering should be an expected part of service delivery design and quality control among medical administrators and medical industry or policy designers in all service settings.

iii. Quality care preserves economic productivity of patients and caregivers

The suffering of a patient with serious illness affects not only the patient but also those who are connected to that person - his or her loved ones, his or her dependants, his or her work colleagues, and his or her community. You have heard the data that shows how many quit or lose a job, take a second or new job, forgo an educational program, become depressed, or otherwise materially suffer because of these unsupported caregiver burdens. We have all heard of people with serious illness remaining fulfilled and productive in the workplace. I have described our experience with the EPEC Operations Director who has worked as or more productively than other team members throughout her chemotherapy for a supposedly aggressive disseminated breast cancer. To support those who suffer allows those who are economically and socially productive to continue to be so. It allows the social fabric to remain knit even when a person is dying, and reknits it after a person dies. It is both basically civilized and economically sensible.

iv. End-of-life Care Provides a Promising Model for US Medical Care

If we can solve these problems, we can solve the problems in medical service delivery in the US today. As we all sink into illness and face our own mortality, we can imagine that if things go as we would wish - so that we can say goodbye, leave our house in order, leave our loved ones with a way to go forward, leave a story about ourselves that we have written with those we choose to write with until the very last chapter - then we will have achieved something in the delivery of medical care that goes beyond just end-of-life care. Right now, the problems in medical care pose you with political problems - seemingly greedy professionals who respond to accountability by being demoralized and resentful, angry citizens driving managed care backlashes, legislative responsive rather than proactive solutions. When you are dying our current problems could likely pose you challenges of depersonalization, spiritual truncation, social abandonment, physical and mental pain. But if we can implement quality end-of-life care, this can provide a model for the proactive rebuilding and revitalization of medical care in the US and beyond as it should be. We can rebuild the whole approach to the patient and family that integrates science with care; we can rebuild the interdisciplinary team; we can rebuild service delivery that involves the family without destroying it and that provides continuity from the intensive care unit to the home; we can remodel and revitalize our existing administrative and institutional structures accordingly; we can reimbursement right so that it works for patient care and for the national economy.

v. Quality End-of-life Care makes Financial Sense.

Finally, the bottom line. If we do it right, quality end-of-life care, including upstream relief of suffering for the long term seriously ill, it will cost less than or not more than the current system. And as noted above it will yield social and economic productivity that will further offset health care costs.

Thank you for your time and attention. We in this field look forward to being of assistance to you in any way we can as you move forward with your leadership to improve end-of-life care for all of us.