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Ethical Imperatives and the New Physician:
III. Responding to the Handicapped Patient

Commencement Address by
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I began by thanking Baylor for the support, kindness, and criticism given me during my two-terms as Surgeon General. I acknowledged that I got a great deal of credit for knowing a lot about many problems in medicine and suggested that “Surgeon Generalist” would probably be a more accurate title for my position. But, I came to that knowledge because of a sizeable army of friends, critics, and partisans all over the country who contributed to my store of information...people like the faculty there at Baylor.

After announcing the planned gift during the summer of all six ethical lectures, I got into my subject at Baylor concerning the ethical response of physicians to patients who are handicapped or disabled in some way. Fortunately, recent advances in biomedical technology have given us a greatly enhanced ability to successfully treat disabling conditions of all kinds. There is no list of official handicaps, but there are many more of them than young physicians can imagine.

The list includes everything from mental retardation, hypertension and cardio vascular diseases, diabetes, asthma and cystic fibrosis, orthopedic handicaps, developmental disabilities, etc., etc. But, in addition, there are a number of conditions that don't neatly fit into any one category. These are emotional and behavioral, such as substance abuse and addiction, and certain immobilizing phobic responses to the human or physical environment.

Which patients tend to have these? Definitely, older patients. Statistics are hard to come by, but it is our belief that there are approximately three million men and women over the ages of 65 at the time that this talk was given who were living in their own homes, despite one or more handicapping or chronic health aberrations, be that cardiovascular, orthopedic, sensory, and so on. That figure would double over the next 20 years.

I then talked about some of the technological advances and gadgetry that we have accumulated in our armamentarium for the help of such folks. And, indicated that these changes were taking place at both ends of the life span.

Then, by way of example, I talked about the infant born with Down's Syndrome or spina bifida and how the parents turn first to medical staff with questions that seem at first unanswerable. Here the physician-patient relationship is no longer casual or short-term and physicians need to be prepared for involvement in long-term relationships with handicapped patients and their families – relationships that can be highly sensitive on both a medical and a personal level.

Unfortunately, our educational system – good as it is – measures success almost exclusively in terms of curing and repairing patients and returning them to a so-called “normal” state for the rest of their lives – be that brief or long. Each graduate will have to understand and come to terms with that. We might be outraged at parents who physically abandon their children, but I am outraged at physicians that intellectually abandon their patients. Sophisticated diagnostic equipment may label a case “hopeless”, but the survival power of the human being, even in its tiny newborn state can be truly awesome.

One of the great advances we've come upon is thinking of children as children. We went through the period of thinking they were chattel (along with animals and furniture) and more recently we stopped seeing them as tiny adults. Children from the very moment of birth should be given the full protection of the law – the same protection that is afforded all adults. A newborn whose life is put at risk by a parent, a physician, or whomever is still a citizen and must be given the full protection of the state. Baby Doe was a prime example of this and I went into that in some detail, because it's as good as an example of what I'd been saying as we've had in this country. Baby Doe's memory prods us into revealing whether we are – or are not – the friends of the helpless, the weak, the hurt, the injured, and the troubled. It also reminds us that for some things we have no cures, but we have something just as valuable and that is genuine care.

Statistics sometimes bring things home and I mentioned that we had six to eight million adolescents or one in every five that has a significant chronic health problem or a handicapping condition. Only a small percentage of them acquired their disease at birth. About a million of these youngsters, the illness is chronic and severe, such as muscular dystrophy, seizure disorders, cystic fibrosis, diabetes, and so on. The other millions of American children became disabled as a result of automobile, playground or household events, or as a result of physical abuse and neglect. It is sad to say that these statistics are probably gross under-counts.

I closed with an observation about yet another important outcome of our ethical response to infants, children and older people. As I've grown older, I've become more and more concerned about the effects upon the families of the handicapped: the parents and siblings, in the case of children; and the children and grandchildren, in the case of handicapped elderly people. Remember what Tolstoy said, “Happy families are all alike, but every unhappy family is unhappy in its own way”?

The impact of what I'm saying can be financial, social, emotional, or medical. That means the physician has to know a great deal about more than just medicine, but of economics, sources of funds, and community services.

I think we as physicians need to resolve that we will do what we can to correct the fragmented and disjunctive medical and social service systems that exist in many communities...systems that cruelly wear down and crush the very families with the courage and the heart to return home with a handicapped or disabled relative. My own experience tells me that the physician is the best possible person to at least initiate this process. I begged the class, whether they welcomed it or not, to accept the mantle of leadership for resolving a variety of profoundly serious ethical issues. I hoped that they would find it possible to do it with wisdom and with honor.