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LOVING THE CHRONICALLY ILL CHILD: A PEDIATRICIAN'S PERSPECTIVE

The doctor-patient relationship has historically been viewed as the most important aspect of the practice of medicine. Indeed, in the preantibiotic era, medical training and practice often had little else to offer. The enormous scientific advances of this century, especially in the last three decades, however, have shifted that focus substantially. Likewise, there are few who would deny that the relationship is seriously threatened and needs our attention.

The public's reaction to the dehumanization of medicine may be largely responsible for one of the profession's most visible problems, the malpractice crisis. To some, an ancient covenant seems broken; the patient no longer entrusts himself willingly into his doctor's hands, no longer is secure in the knowledge that his physician is his committed servant. He looks instead to a complex health care apparatus supervised by his doctors, who, if they push all the right buttons, will heal him. It is a silly twentieth-century, science-fiction fantasy, a uniquely American one, and the expected failures occur with discouraging regularity. The patient is left disappointed at best, and angry and vengeful at worst.

Beyond this anger, I believe, lies a deep yearning for the healing touch, the soothing voice and the listening ear. Nowhere is this more important than in the care of those children whose lives are qualitatively and quantitatively altered by chronic disease. Love is a word rarely used in medical textbooks, and that is exactly why it is in the title of this paper. Love sets the tone of the doctor-patient relationship. Indeed, it is where that relationship must begin, grow, and end. It is a posture of humility, matched with genuine commitment of the physician's physical, mental, and emotional resources to the child and family he serves.

If I were to paint a portrait of the ideal physician, I would draw considerably upon my long-term memory. I see this person at the sick child's bedside, perhaps auscultating the chest; the picture of patience, of kindness, of competence. The setting is not the hospital intensive care unit, but the child's bedroom. The faces of the child and parents reflect the comfort and relief brought on simply by the doctor's presence. In the physician's black bag are the few most useful diagnostic and therapeutic instruments of the
profession. Before and after office hours each day, travelling with it from house to house, the doctor ministers to his or her patients.

I have quite purposefully placed my doctor in the child’s bedroom. The house call is almost a dinosaur in the 1980s; my own children have only vague familiarity with the term. It is warmly remembered, though, by those of us who are a little older, and has come to symbolize for many the sense of personal commitment that sometimes seems to have disappeared from medicine. I have spent many impatient hours in the front seat of a 1953 Oldsmobile, waiting while my mother or father attended some sick infant, or child, or invalid grandmother. It was there that I first began to comprehend the business of chronic illness. The compromised child was usually kept at home. It was a safer environment, and the difficulty of transportation to the office or hospital was simply too great. Although thirty years have passed, I remember those times in vivid technicolor. It was much later when I realized how profoundly they had affected me.

There was an infant girl who had a brain tumor. Her death was perhaps days away, and it was cold and snowing. Transportation was limited. So my mother, her doctor, brought her to our home to spend her final days, her family tromping up the snow-covered steps to visit several times a day. These “reverse house calls” did not seem odd or uncomfortable at the time, nor did the sick baby’s presence in our home. There were three children with cystic fibrosis, rural residents of a coastal county some distance from the eastern North Carolina community where my parents both practiced medicine. Our family’s summer cottage was much closer, so our vacations were punctuated by their visits, or we might all drive over “just for a little while” to check on them. I feel as if I have a hundred such stories I need to tell, all of them reminders of the very personal relationship that existed between patients (especially the chronically ill) and their doctors thirty years ago. The relationship has changed significantly, and the care system dramatically, since that time, but the problem of chronic illness may even be greater than before. While we have made significant strides in children’s cancer and cystic fibrosis, both of these remain very serious chronic health problems for children. Other diseases such as rheumatic fever, post-streptococcal glomerulonephritis, and tuberculosis are relatively rare now. It is good that they are gone, but they have been replaced by a flood of new problems and entities. Children who did not survive in the 50s, 60s, and even 70s are surviving today, but may continue to survive only through extraordinarily complex management regimens. The surviving very small premature infant is, indeed, fortunate if he can escape chronic cardiopulmonary problems or