

Virtual Mentor

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VIEWPOINT

Dying Poor in an Urban Hospital

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End-of-life care for the dying poor challenges me, empties me and yet fills me with great satisfaction for the privilege of being a doctor to these patients. In 1995-96, the Open Society Institute's Project on Death in America awarded a grant to Wishard Health Services that allowed us to study the problems the urban poor face at the end of life. One major hypothesis: it is difficult to be poor and it is difficult to be dying, so it must be doubly difficult to be poor and dying. This study provided a thick description of the problems and desperation of the dying urban poor. Recommendations following this study led Wishard to begin a Palliative Care Program.

One noteworthy finding from our study was that many of the poor patients who come to our inner-city hospital accept the bad news of their fatal diagnosis and approaching death with a dignity and grace that is remarkable. "Well, doctor, that is the fifth bad thing that has happened to me this week." Given such bad news, how many of us could honestly make a statement like that? Raymond Carver's poem "What the Doctor Said" offers a glimpse into one such mind and heart. Carver recounts receiving the bad news about his metastatic lung cancer: "he said something else/ I didn't catch and not knowing what else to do/ and not wanting him to have to repeat it / and me to have to fully digest it / I just looked at him. . . may even have thanked him habit being so strong"¹.

Despite the resignation we encounter, I know that dying and death could be better for poor and vulnerable patients. Hospice programs have shown us that it is possible to die peacefully at home surrounded by family and friends rather than in the hospital surrounded by strangers and medical technology. However, the road to the good death is rather narrow compared to the six-lane superhighway that leads to our hospitals and ICUs. Everything about our current health care system directs the dying patient to our hospitals rather than to hospice care. That is why almost 80 percent of Americans (rich and poor) still die in our hospitals (60 percent) and nursing homes (20 percent). Many private foundations have recognized that "the nation needs the moral equivalent of a Manhattan project on care of persons with serious and eventually fatal illness"².

Disparities in Care for the Urban Poor

More often than not, the urban poor seeking health care find themselves in the crowded and hectic environment of the hospital emergency room. It is tragically

unfortunate when they come there at the end of their lives. While the door to the ER remains the only open door for poor people who are dying, in almost every circumstance it is the wrong place to be if you know you are dying. Yet, that is where the dying poor find themselves, diagnosed too late at too young an age, lacking health insurance or even life insurance that they might use for a funeral. About 50 patients die each month in our hospital, 20 in the ER and another 30 after admission. Many of these latter 30 patients die in the ICU after a decision is made to stop treatments that should have never been started.

The list of reasons why terminally ill patients die in our hospitals and ICUs is lengthy and might be debated by health policy experts. The simple and most direct reason that I see is that there are not enough people who care to be involved in the lives of these patients as they approach their final days. But there are many other reasons: problems with health care financing, strained city budgets, over-burdened community health centers, public expectations about EMS and 911, lack of coordination between specialists and primary care physicians, dependence on medical students and residents to staff our city hospitals, and a failure to teach our medical students and residents how to do things differently.

A different scenario would unfold *if* each of those impoverished patients had a physician whom he or she could call and trust, one who could prognosticate and provide advance care planning, deliver bad news, conduct a family conference, provide adequate pain and symptom relief at home, and understand what patients or family mean when they say "do everything—for nothing is impossible for God"; if they had a physician who could call on nurses, chaplains, and social workers for assistance; a physician who could pray with patients and their families, make home visits, attend funerals, send sympathy cards, and not forget the courage and grace that we all hope we have when it is time to go—and could do all these things with compassion and understanding.

Wishard Health Services Palliative Care Program

Our hospital-based palliative care program builds a bridge from the complex and chaotic hospital system to local nursing homes and home hospice programs (involving local churches and volunteers in this hard work). The program redirects efforts in a way that presents real choices for dying patients, allowing providers to create an individual plan of care centered on the needs of each patient and his or her family. We have found that a small interdisciplinary team can sometimes slow down the locomotive that is pulling dying patients to the ICU. First, we try to get involved with patients as soon as possible, even at the time when they are told about terminal diagnoses. Early involvement and consistent support lead to a degree of trust essential to help patients and their families cope at this time. Second, we listen to patients in order to determine what is important to them. Seldom is the decision of whether or not to be resuscitated important. In fact, we often don't ask whether or not they want CPR. Instead, we engender trust by showing up, calling, and checking on them. We commit to non-abandonment by making home visits and by providing them with cards that include our pager numbers so that they can contact

us at anytime they have a question or problem. Not many patients leave city-county hospitals with a physician's card that includes a pager number for emergencies. In fact, most patients who show up in the Emergency Room do not know their doctors' names. Our patients are shocked but overjoyed to learn that we will make home visits to see them so that they don't have to return to long waits in the clinics or ER.

This work is not for the faint-hearted, and team members need compassion and humor as much as they need scientific knowledge. Our patients' spirited strength ennobles them and also carries us through this tough time. We all need to become forceful advocates for change in the care of the dying, especially for marginalized populations with limited access to the care that you or I want when we are at the end of life.

References

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