

For Dying Patients and Their Families

It's the only hope he has," said the cardiologist as he ordered his moribund sixty-eight-year-old patient with cardiomyopathy placed on a ventilator for transfer to a university hospital an hour's journey away, for what he apparently hoped would be a dramatic rescue-in-the-face-of-death heart transplant. The patient died within an hour of reaching the university. Until becoming too weak to protest, he had persistently refused intubation. Having been hospitalized and intubated several times for this condition, he wanted assurance that he would get better before he agreed to accept the painful and unpleasant experience again. By telling the family that a heart transplant was his only hope of escaping certain death, the physician was able to gain their consent for intubation and transfer.

"It's her only hope," lamented the intensivist as he intubated the eighty-pound, thirty-two-year-old woman with pneumonia who was dying from Huntington's Disease, an inherited and untreatable, progressively and universally fatal, degenerative neurologic disease. She died on a ventilator with a Swan Ganz Catheter in her heart, while receiving maximal doses of antibiotics and vasopressor medications. Her father had died from the same condition; her mother was hoping against hope that the physician's skill would somehow miraculously allow her daughter to live a little longer. She died in the intensive care unit three days later.

I'm not making this up. These are two actual cases from my recent experience, and in the hospital where I work, cases like this happen regularly. There has been no apparent change in the way many physicians care for seriously ill and dying patients.

What does it mean for dying patients and their families to have hope? And were these doctors providing it? I want to explore briefly the notion of "hope" in situations where patients are critical or terminally ill, and what physicians can do to offer hope, before concluding that these physicians actually destroyed whatever potential for real hope these patients and their families had.

Focus on the Dying Experience

Death is a three-in-one occurrence: personal life experience ends, the final chapter of a biographical life story is completed, and biological existence ends. I won't pretend to provide a complete and exhaustive list of what all patients might possibly hope for when they are critically ill and/or dying. Some hopes are self-evident; others can be reasoned.

Attaining and maintaining comfort is a primary hope for dying patients and their families. The relief of physical pain and other troublesome and distracting symptoms like shortness of breath or nausea is the foundation on which the dying rest other hopes. But comfort is a larger concept than merely the absence of noxious and disturbing physical sensations. Many patients, during at least part of the dying process, hope for the company of their loved ones. They want to be touched; they want to hear expressions of love and affection; they want someone to moisten their lips and give them their favorite food and drinks. Other environmental amenities, for example, one's favorite books and photographs, music, fresh air, a pet, a familiar scent, even certain fabrics, can also help fulfill one's hope for dying comfortably.

Spiritual ease, making and maintaining peace with God or another source of ultimate meaning, is an important aspect of dying comfortably. Religious rituals and ceremonies, for example, confession, communion, and absolution, help

achieve that hope. So does an environment conducive to meditation or prayer and the presence of religious or secular symbols that can unite patients and families with their deepest meaning and ultimate reality.

Approaching the End

A second hope for dying patients and their families is for time and help: time to complete the important tasks that death brings, and help for putting order and closure on interrupted, perhaps unfinished life projects. Many, if not most, patients and families seem to intuit approaching death; however, they also benefit from, and are reassured by, open and honest communication with their physicians. They want to know, what to expect in terms of time remaining, and how disruptive the symptoms of their condition will be to their concentration on these tasks. Will they encounter, for example, loss of consciousness, difficulty in breathing, debilitating pain, nausea, or bleeding? And will someone help them complete or review their advance directives for health care decisions? What steps can they take to secure their treatment preferences even when they can no longer personally direct their own health care? Other tasks include reviewing wills and giving personal belongings and prized possessions to others.

Perhaps the most important personal task of dying patients is making peace with the self and others. This task involves saying "goodbye"; giving and receiving blessings; forgiving, and being forgiven for, past sins and transgressions. These most private and sacred transactions are more readily accomplished in a peaceful and comfortable environment.

Dying patients also hope for respect and autonomy. This hope obligates health care workers to treat the seriously ill and dying — and their patients and families — humanely and gently, to be honest and forthright with them, and to honor their health care decisions regarding the limits of care in extreme circumstances. Because these circumstances occur in important and probably difficult times, extra measures of patience are called for when giving information and providing

assistance to others about these decisions. Manipulation of information and/or overt or implied intimidation, for example, threats of professional or personal abandonment are *prima facie* disrespectful, and both are destructive of autonomy.

Timeliness

Patients and their families also hope for timeliness in dying. This hope is for appropriate and sufficient time to complete as much of the necessary work as can be done, with not a lot left over. The work of dying is physically and emotionally draining, and can also be financially draining. A timely death conserves survivors' personal reserves of emotions, health, and wealth and facilitates their incorporating positive memories into the process of grieving. A protracted and inordinately prolonged process of dying serves nobody well, leaves bad memories, depletes reserves, and makes survivors' transitions more difficult.

Families and health care providers must exercise moderation and cooperation in their care of dying patients to help them realize their hopes for a timely death. How much better for them if their families recognize and accept their approaching death and prepare to let go. Physicians can, and should, help them accomplish this acceptance. Physicians, too, need to accept that their patients' are dying and adjust their medical care accordingly. Though prognoses may be unclear, it is important to keep focused on the proposed treatment's ratio of benefits to burdens and distinguish treatments that promote and prolong meaningful life from those that prolong the process of dying.

Most important, physicians need to provide competent palliative care. If and when patients continue to suffer physical symptoms despite their physicians' best efforts, it is time to get appropriate consultation with palliative care specialists.

Conclusion

Within their sphere of influence, physicians ought to promote and provide an environment where patients and families can find comfort and

spiritual ease, do the work of dying, and begin healthy grieving. Such care requires that they understand and take into account the values, goals, and hopes of their dying patients and their desire for a timely death. Accordingly, the therapeutic options that providers develop and recommend ought to maximize palliation and minimize discomfort and inconvenience. Hospitalization and invasive procedures or frequent radiation or chemotherapy are impediments to comfortable dying. These treatments ought to be used only when less burdensome palliative measures are not available.

Finally, patients and their families hope that their physicians will embody the traditional virtues that characterize physicians as healers, those that first year medical students describe as having drawn them to their calling as physicians. These virtues include sensitivity, compassion, respect, and a willingness to listen and communicate openly and honestly as conditions change and new decisions need to be considered.

These physicians see themselves as partners with their patients, and dying as a natural and sacred process. They recognize that a bit of them dies along with their patients, and find it natural and important to say goodbye, to ask for and accept forgiveness for shortcomings, and to bestow blessings on each other. Living this process with their patients helps them grieve their patients' deaths and reconstitute themselves as better physicians.

In the two cases cited at the beginning of this reflection: what did the patients actually experience? To the extent that they were aware of their surroundings, they must have found themselves surrounded by strangers in a tense, anxious, and alien environment. Further, though we cannot know how much physical pain they suffered, it is clear that their physical comfort was subordinate to the full use of medical technology.

It follows, therefore, that they could not have been very comfortable. Since one of them died literally in transit, and the other in an intensive care unit, neither of them died in the presence of

loved ones. No one was with them who could provide the subtle comforts and communication of love or friendship. Medical machinery and technicians prevented these patients from receiving the loving physical, psychological, and spiritual support that dying patients want and need.

By waiting until the heart patient was too weak to protest, the provider violated the patient's expressed desire not to be intubated and used guilt to intimidate the family into violating his autonomy and agreeing to intubation. And in the case of the Huntington's patient, no best interest determination was made to justify prolonging her dying in the intensive care unit for three days.

Though her mother did not want to lose a daughter, as she had lost a husband, to Huntington's disease; the protracted agony of watching her daughter die slowly can hardly be a reasonable way for the mother to begin accepting inevitable death.

The anxiety that both families experienced watching loved ones die in a medical madhouse, with a constant parade of strangers providing medical care in a losing battle to forestall death, had to be physically and emotionally draining for them. It is impossible to see how their memories can facilitate healthy and constructive mourning and grieving.

May it not be so with us.