

Caring for Patients at the End of Life: Reflections after 12 Years of Practice

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Physicians have the privilege and authority to assist patients and their families at the end of life. Regardless of diagnosis, commonalities occur in the dying process, and palliative care benefits patients and families. This perspective chronicles my experience over 12 years caring for 95 patients at the end of life, illustrated in part with six vignettes. I describe interactions with families, discuss logistic issues around dying, examine the do-not-resusci-

tate issue, and highlight experiences with home visits. I also touch on how I communicate with the family after a death. I hope to express the significance of what I have learned while assisting patients and families at this critical juncture.

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Quality end-of-life care benefits patients, families, and physicians. Fear of abandonment, indignity, pain, discomfort, and the unknown trouble most of us when we contemplate dying and death. In my primary care practice at an urban teaching hospital, I have cared for 95 patients who have died over the past 12 years. I believe that relationships among the patient, physician, and family built over time usually allow a “good death” and almost always prevent unwarranted resuscitation, futile interventions, and unnecessary suffering. I view the end of life not as a failure for the patient or physician but as a valuable opportunity for growth, insight, and closure.

Death is the bookend experience to birth, yet we are far from our agrarian roots, where this cycle of birth and death was a normal part of daily life. Our society celebrates and worships birth but flees death as if it were avoidable. As the only person empowered to directly assist in navigating life’s end, the physician, with skill and caring, must bring meaning and solace to patients and families as death looms.

My experience suggests that the varied circumstances leading to death culminate in a single pathway, with patients and families experiencing a reasonably predictable set of emotions, fears, and conflicts. I find that proper emotional and physical support affords patients the opportunity to reflect and share with family and friends in a profound way. Moreover, I have learned that good palliative care usually circumvents requests for euthanasia or assisted suicide. To perform end-of-life care, I have had to explore my feelings about death so that I could be open to patients’ anxieties, ideas, and questions. In my world view, I accept dying and death as

part of the “package deal” of living. This acceptance of the inevitability of death shapes the construct from which I listen to my patients.

VIGNETTES

These vignettes demonstrate the unique circumstances of each dying person and suggest that a flexible approach to end-of-life care is required.

Ms. N.

Ms. N. was a 22-year-old woman with spina bifida complicated by osteomyelitis and paraplegia. Often infected, she spent about 4 months each year in the hospital. Complaining rarely and usually exhibiting a lovely smile, she captured my heart and the hearts of the nurses. I came to know her parents well, and her grandmother even better, since she spent every night in the hospital room on an uncomfortable cot. In the days before Ms. N. died, she became blind and incoherent. On her last night, the nurses called me when she was about to stop breathing. Everyone was crying. I felt my own tears and a lump in my throat. As the attending physician, should I cry? No one had taught me what to do in that situation. I attended Ms. N.’s wake and viewed her in an open casket in a dark funeral home. She looked beautiful and peaceful, adorned with a red rose. Caring for Ms. N. was draining and uplifting.

Dr. K.

Dr. K. was a 47-year-old physician with AIDS. He lived alone with his dog and requested inpatient hospice care after he could not look after himself. As his systemic

cytomegalovirus infection, refractory diarrhea, and weight loss progressed, he asked to be admitted to the new palliative care unit. Dr. K. did not like the room, the food, the staff, the medications, or anything about the place. I dreaded visiting him daily and would brace myself for his withering complaints. Already angry about dying and losing his independence, he felt that this “incarceration” was the ultimate indignity. After several weeks, he decided to leave the unit. He cobbled together a schedule for friends to care for him, and he died peacefully at home with the assistance of hospice. His experience illustrated the need for flexibility; I accommodated his change of plans.

Ms. T.

A 73-year-old heavy smoker with severe emphysema, Ms. T. was skinny and spoke with pursed lips. I traveled to her charming, shuttered old house in Boston, where she lived with her lap dog, housekeeper, and two unmarried sisters. In her last year, Ms. T. was rushed to the hospital several times for respiratory failure. She was intubated and always squeaked through. The time came, however, when it seemed that she would not survive another intensive care unit stay. Her Catholic beliefs forbade her to refuse life-sustaining treatment; the idea of do not resuscitate, or DNR, was anathema to her. Frustrated, I felt she suffered needlessly, both physically and emotionally, but I did not feel that I should impose my beliefs on her. One day, another patient, Sister M., came in for a physical examination, and I asked her for advice about this dilemma. She offered to visit Ms. T. in her hospital room, and as a result, Ms. T.’s priest became involved and gave her permission to “let go.” Ms. T. died peacefully that month. Spirituality plays a central role in the lives of many people, and I might have helped her sooner by finding an interdisciplinary team to address this.

Mr. S.

Mr. S. was a widely respected artist dying of metastatic pancreatic cancer at home with hospice services. Miserable with pain, he hated to rely on others. Mr. S. asked me to admit him for a brief hospital stay to control the pain. On admission, I wrote a modest morphine order to make him comfortable. With his family present, he said emphatically, “Give me enough morphine to make me comfortable—I don’t care if I am not

alert or even conscious.” A nurse thought my morphine order was excessive and asked me to rescind it. I declined. The nurse did not understand that prior doses of morphine had created tolerance, protecting him against respiratory depression. She called the hospital lawyers; they insisted on meeting with me.

On a hot Friday afternoon, the nurses, resident physicians, two hospital lawyers, and I discussed Mr. S. Our opinions differed radically—was this medically acceptable comfort care or assisted suicide? Some did not accept my explanation of “double effect”—palliative doses of morphine possibly hastening but not intended to cause death. Because we could not agree, I insisted that the lawyers come to Mr. S.’s room and explain why he could not receive this dose of morphine. The lawyers presented their case in a straightforward, anxious manner. Flanked by his wife and daughter, Mr. S., gaunt but with his dignity intact, sat straight up in bed as if holding court and announced, “We’re leaving.” They packed up and left that evening. A week later, he died peacefully at home. Mores have changed since then, and the staff and I probably would not have such differing opinions today. At the time, while attempting to protect the interest of my patient, I felt pitted against the hospital.

Mr. E.

Mr. E., a 60-year-old man, did not look a day older than 45. He was incredibly fit, tanned, and very opinionated about his health. Disparate symptoms brought him to my office frequently and, to our surprise, a stress test and angiography revealed significant coronary disease. He adopted a strict low-cholesterol diet supplemented with herbs, seeds, and oils. He began to control his emotions with behavioral meditation techniques and group therapy. One summer day, he angrily disagreed with the carpenter at his home about some aspect of renovations. During the shouting match, he dropped to the ground and died. We had never discussed DNR status.

Mr. B.

Mr. B. was the only patient who, along with his family, insisted on “doing everything” to the very end, despite my admonition that he would not survive attempts at resuscitation. At age 94, he suffered a myocardial infarction complicated by congestive heart failure. I doubted he could be weaned off the ventilator with any quality of life, and I suggested a DNR status. His elderly

wife and son (also my patients) believed that he would persevere and recover. Because he was “a fighter,” his family remained certain that Mr. B. would have chosen this course for himself. When the predictable terminal ventricular fibrillation occurred, his frail, depleted body was repeatedly shocked to the dismay of the nurses and residents. I silently debated how forcefully I should assert my opinion to desist from such futile resuscitation versus allowing patient and family autonomy to rule the day.

OBSERVATIONS

At the time of death, DNR orders were in place for 78 of 95 patients under my care, including all 32 patients with cancer, all 8 patients with congestive heart failure, and all 7 patients with AIDS. These orders were in place for all patients dying in the hospital, except for Mr. B., who insisted on resuscitation, and 1 patient who had cardiac arrest during cardiac catheterization. Of 78 patients with DNR orders, 40 died at home, 34 died in the hospital, 3 died in community hospices, and 1 died in a nursing home.

DNR Status

Contrary to popular belief, I find that discussing end-of-life issues rarely takes a lot of time. Most chronically ill patients have considered dying and issues of resuscitation, and they are usually prepared (and relieved) to discuss it. In my experience, very few patients and their families have declined to discuss dying.

Although physicians are exhorted to discuss end-of-life issues with healthy patients, I find I can address the issue more naturally when the patient is significantly ill and more likely to be thinking about dying. I experienced only one situation in which an advance directive was useful in resolving a family conflict. I favor advance directives as a stimulus for patients and families to clarify their feelings rather than as a tool needed at the end of life.

Hastened Death

In my experience, patients rarely ask for euthanasia or assistance with suicide, although many think about it. Only one patient in this series made an explicit request. This elderly man with life-long depression and escalating cancer symptoms allowed me to speak directly with his psychiatrist. Changes in his antidepressant regimen

and more frequent visits with his psychiatrist and me diminished his wish to immediately end his life.

Many patients or their family members have expressed anxiety about potential physical suffering, such as intractable pain or suffocating. They have benefited most from specific information about how morphine, lorazepam, and other medications alleviate these symptoms. Although I emphasize that dying patients can usually be kept comfortable, I warn patients to expect some pain and discomfort and explain the tradeoff that may occur between pain control and lucidity.

Logistics

Logistic challenges present formidable barriers to end-of-life care. A patient may wish to die at home, but family members may be unable to handle the physical or emotional burdens of such care. Financial and insurance limitations may influence decisions about staying at home versus being in a freestanding hospice or hospital setting. The process works best when physicians collaborate with the hospice nurses, family, and social worker.

If a family chooses to avoid a home death, facilitating transfer to an inpatient or freestanding hospice can be invaluable. An inpatient hospice must also be flexible by allowing a patient to come in for “respite” care and then to return home to die (as in Dr. K.’s case).

Home Visit

For patients who have chosen to die at home, I visit at least once if they live within a reasonable distance from the office. It gives me the chance to assess the patient’s physical and emotional status and the effects of medications. For the family, the visit reinforces my commitment to the patient’s care and comfort and helps diminish fear of abandonment and isolation. Invariably a moving experience for me, this seems extremely valuable to patients and families.

Often, a patient will ask, “What is dying like?” As physicians, we often forget that many people have never witnessed someone dying and may harbor a variety of misconceptions. I explain that disordered breathing accompanied by odd sounds and gasps is normal and does not signify pain. I liken the process to a clock no longer wound every day that gradually runs out of energy. When the clock runs down, all the parts stop. This sim-

ple explanation reassures most people, and a calm demeanor reduces anxiety.

In this fragile and vulnerable time, the patient may express regrets about family relationships or concerns about how a spouse or child will fare. Often, family members are also my patients, and this visit enhances our bonds. How wonderful to sit with the family in the kitchen having a cup of coffee and sharing memories of the person who is slipping away. Distant from the headaches of managed care paperwork, incessant messages, and telephone calls in the office, such moments epitomize the essence of the patient–physician relationship. I believe that a home visit at the end of life should be required in medical school and residency curricula. I hope that clinicians will incorporate this signal event into their practices.

Death

Frequent communication with family members in the final 1 or 2 days is vital. An extra telephone call to the home or an extra visit to the hospital room greatly reassures anxious and fatigued family members. Medications often need adjustment several times per day. For logistic reasons, I have been present at the moment of death more often in the hospital than in the home. Sometimes being in the room with the family feels right; other times, waiting nearby and being available to the family immediately after the death seems more appropriate. It can be a searing time, and I need to remain near the family.

After Death

I always write a letter or call the family to express my sadness and some of the joy I had serving as the physician. Often a family member may have lingering questions about why certain events happened or may express guilt about a role they did or did not play. A brief conversation is helpful. On a few occasions, when I felt particularly close to a patient and family, I attended

the funeral and always benefited from that powerful experience. On these occasions, the families seemed to appreciate my presence; physicians need closure too. Regardless of denomination, the service welcomes and heals us, bringing home the gravity and importance of our work.

CONCLUSION

Daily, physicians strive to comfort, diagnose, treat, cure, and extend life with quality. Yet, we must recognize when to shift to palliative care. Patients expect, hope, and trust that their physicians are versed in dealing with end-of-life issues, but physicians need to learn and practice these skills. How ironic it is that as physicians, we rarely talk about dying amongst ourselves—even though our patients expect us to be expert in such care.

Keeping a record of all my patients who have died helps me to honor their memory and reminds me of the lessons they have taught me. Collecting this history also sheds light on issues deserving improvement, such as instituting a home visit near the end of life. Regardless of the inexorable march of technology, birth and death will continue to bound our existence. Our society awards to physicians the authority and privilege of caring for people at the end of life. I have learned that caring for patients in the last chapter of their lives is the most important part of my job.

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