

# Our patients—our mentors

If we can learn how dying patients are feeling and coping with their illness, we can begin to understand how to provide the care they need.

**ABSTRACT: The care of individuals who are dying has never occupied a large part of medical school curriculum, mostly because dying was a rapid process until the 20th century, and previously physicians were not involved once death became inevitable. Now, with most people dying after a prolonged illness, there is more need for end-of-life education for all physicians. Numerous studies have documented inadequacies in education and the inability of physicians to feel comfortable with this area of medicine. While control of physical symptoms is essential, the ability to communicate effectively and provide psychosocial support to our patients is equally important. Along with physician mentors who have developed these skills, our greatest teachers can be our patients.**

Looking at medical school curricula over the centuries, end-of-life training is clearly a new phenomenon. From the time of the first medical schools physicians were counseled not to intervene with dying people. The Hippocratic tradition defined medicine as “to do away with the suffering of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless.”<sup>1</sup>

While physicians might stay away because a dead patient was bad advertising, a more likely reason for not intervening with the dying was that death was seen as a mystery that no physician had a right to interfere with. As Hippocrates goes on to say, “For if a man demand from an art a power over what does not belong to the art, or from nature a power over what does not belong to nature, his ignorance is more allied to madness than to lack of knowledge.”<sup>1</sup>

Dying in centuries past was a quick affair, lasting a matter of days. Even at the beginning of the 20th century, the major cause of death was infectious disease. The average life span was 33 years in the 12th century, and by separating sewage from drinking water over the ensuing centuries the average life span was extended to 40 years by the early 1900s. A 1903

home encyclopedia of health proudly reports that in 16th-century Geneva only 3% of the population lived to 70 years, while now more than 18% reach this age.<sup>2</sup> The high rate of childhood mortality from infectious causes meant that the average person was very familiar with death. Death generally occurred at home, with the patient surrounded by loved ones. The spiritual advisor, not health care professionals, gave comfort to the dying who, having witnessed the deaths of a sibling, parent, or friend, had learned from them how to behave in their final days. Thus, any medical student of that time would have had firsthand experience with death.

Our society is strikingly different today. The average person will be in their late twenties or thirties before they experience the death of someone close to them. A study of third- and fourth-year medical students in Birmingham, UK, in the early 1990s<sup>3</sup> showed that most of their death experience came from distant family members, acquaintances, and pets, and that only 6% had experienced the death of a sibling or parent.<sup>3</sup> During their training, only 42% of the students had an opportunity to speak with patients who knew they were dying. This has cer-

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tainly been the author's experience in clinical teaching of undergraduate medical students at the University of British Columbia.

In addition to little familiarity with death and dying, today's students must deal with a very different kind of dying experience. Medical technology has extended our living and in doing so has also extended our dying. Most of us will die from a prolonged illness featuring marked functional decline over a period of months or years. Our medical system, well suited to rescuing individuals with sudden catastrophic illnesses, is poorly designed to support those with chronic illness and declining function.

Increasingly, there is a fine line between prolonging living and prolonging the dying process. Patients clearly fear this, as demonstrated in a Canadian study of those facing the end of life.<sup>4</sup> Quality end-of-life care consists of five elements: relieving pain and suffering, avoiding inappropriate prolongation of dying, involving the patient in decision making, relieving the burden of loved ones caring for the patient, and strengthening relationships with those the patient loves. For all medical professionals, learning how to maintain good *quality* of life rather than *quantity* of life takes knowledge, skills, and an ongoing dialogue with the individual who is dying.

Thus, physicians today need a number of skills that their colleagues of earlier years did not. Medical student surveys have revealed that students feel inadequately prepared for end-of-life care of their patients.<sup>5,6</sup> This is partly because palliative care is not a mandatory subject with adequate exposure to cover the curriculum. It would be highly unlikely for any medical student to graduate without having delivered a baby, yet it is common for students to graduate without having managed a death. Fewer than half of

our patients will have babies, but all of us will die.

Feeling inadequately prepared also comes from a lack of mentors in end-of-life care. Family physicians with expertise in palliative care have an excellent opportunity to mentor medical students and residents, but they are becoming scarce. Full-time palliative care physicians are a relative rarity in Canada at this time. Therefore, many of the mentors that students and residents interact with on the wards of the hospital may have no training in palliative care.

Without education and exposure to palliative care we are likely to fall back on our societal training. In our society it is taboo to speak openly about dying and the end of life. The many euphemisms for death and dying in our language attest to the difficulty of speaking directly about these issues, and the physician's use of these expressions and discomfort about these issues makes patients even more reluctant to raise the issue themselves. The culture of modern medicine has equated cure with success, and death is thus often seen as a failure of our technology rather than a natural part of life.

It is stressful caring for seriously ill patients, and the lack of mentors who can demonstrate how to care for the dying makes it worse. A recent study showed that the mechanisms used by physicians to cope with this stress include medicalizing their language, dehumanizing the patient, being angry at the patient for wanting information, denying their need as physicians to learn communication skills, using euphemisms, using humor, going numb emotionally, and talking with each other.<sup>7</sup> While some of these coping mechanisms, such as talking with each other and using humor, may be positive, the majority lead to inadequate end-of-life care for the patient and family. They also lead to a physi-

cian whose personal growth is limited by resentment, cynicism, and fear of illness and death.

In fact, the physician is surrounded by mentors—the patients who are living and dying from an illness. We can all learn from those who go before us. For if we understand how they are feeling and coping with illness and all its losses, we can begin to understand how best to provide them with the care they need.

Take a few extra minutes to ask how patients feel about their illness and how they are coping with it. By initiating this conversation you are telling them that their psychological and spiritual well-being is as important to you as their blood work or pathology report. You will also have opened the manual of human experience—one of the best mentoring texts around.

Don't be afraid to feel the emotion that comes with hearing some of your patient's stories and working with them. Reflect on why you might feel sad or angry about a patient. Is the patient similar in age to you? Does the patient remind you of a relative or friend in a positive or negative way? Why are you changing the topic or avoiding the patient's room? It is not "professional distance" from the patient that we need, but understanding of our emotions and the role that they play in our relationship with the patient.

Consider yourself a lifelong learner—about people and about yourself. If self-reflection leads you to discover unhealthy emotions, then do something about them. Many clinicians and volunteers involved in palliative care are asked about how they can stand this "depressing" and sad work with everyone who is dying. My favorite response has become a quote from Kahlil Gibran's *The Prophet*: "The deeper that sorrow carves into your being, the more joy you can contain."<sup>8</sup>

It helps to remember that the sadness comes from saying goodbye to someone you enjoyed knowing and sharing meaningful experiences with.

Some patients have coped surprisingly well with their illness. How have they managed to heal themselves emotionally and spiritually, despite the fact that their body is dying? You will see that there are myriad ways that people can achieve growth through suffering. Many of the most healed people I have met have seen meaning in every facet of their life—whether it was pleasure, happiness, suffering, pain, or loneliness. As Viktor Frankl said in *Man's Search for Meaning*, "What matters, therefore, is not the meaning of life in general, but rather the specific meaning of a person's life at a given moment."<sup>9</sup> What Frankl noted in his fellow concentration camp prisoners was that some people survived and continued to grow emotionally and spiritually, while others were shattered. He saw that even in the worst of circumstances there is still freedom. "Everything can be taken from a man but...the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way."<sup>9</sup>

How can physicians help others truly live until the moment they die? As you talk with more people about their illness you will see many who are suffering physically, emotionally, and spiritually. If someone is suffering severe physical symptoms you must address these first. Learning to manage pain and symptoms is essential, as almost no one can find any meaning in uncontrolled pain or dyspnea. Then by taking some time to ask about the patient's experience of illness you can begin to facilitate the healing. By listening in an empathetic way you can help patients voice their needs. Involve palliative care teams and other colleagues to address these needs in a col-

laborative way. As you learn from those who die healed, you may also be able to help others to see that they are free to choose the way that they respond to illness and loss—and that death can be the "final stage of growth."<sup>10</sup>

Learning to communicate involves lifelong learning, ideally from those with excellent communication skills. However, we can also learn from our own mistakes, other's mistakes, and literature on effective communication. In this process you will realize that "the spoken language is the most important tool in medicine."<sup>11</sup> The study of healing and its incorporation into medical education is improving, as is our understanding of whole person care.<sup>12</sup> Palliative care is at the forefront of this learning and should be mandatory for all medical students.

Palliative care is a scenic tour along the highway of chronic and terminal illness, where we sit beside the driver, stop to look at the road signs, and catch the view from the driver's angle. It is being there for the journey: helping to interpret the confusing road signs offering treatment options, and being understanding of the delays caused by the road repair needed after psychological washouts. It is helping to avoid potholes created by health care system problems and spotting the wildlife of pain and fear before they jump in front of the car. It is listening to the driver and assisting with physical and emotional comfort so that he or she can see beyond pain and anxiety to reconciliation, gratitude, and peace.

When you step out of the car at the end of the journey, even though it has been a tough ride you are willing to take another trip with someone new because you realize that watching through the windshield of death has made your life more present, more real, and more meaningful than before.

### Competing interests

None declared.

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