From the Editor
Compassionate care at the end of life

In the world of modern medicine dying can be, and too often is, a dehumanizing process. Paradoxically, death is also the most human of moments, rife with sadness, joy, revelation, forgiveness and closure. One of few universal experiences, death is a certainty. Yet the individual experience of it varies greatly. For some, death is embraced as one stop in the natural progression that is life. For others, it lacks meaning. In each case, and in the great spectrum of experience that lies between, suffering emerges as a common theme and hurdle. Hence, an exploration of suffering is central to the discussion of care at the end of life.

Despite countless advances in treating disease, we often seem to falter when addressing “illness,” the lived experience of disease within the context of an individual’s life and personhood. This is especially true with regard to suffering, which defies empirical measurement despite biomedical advances. As Eric Cassell so eloquently wrote, “Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity” [1]. Sadly, physicians are not taught to recognize suffering, nor do we typically know much about how to address it. After all, such an assessment is hardly part of the standard history and physical. Thus, as we preoccupy ourselves with “pain scores,” we often fail to consider the meaning of this pain in our patients’ lives. We also forget that the absence of pain hardly rules out suffering, and we shy away from exploring the meaning of illness in our patients’ lives.

Understanding the nature of suffering is particularly central to the experience of dying. While medications can treat physical pain, suffering may persist and can lead to far worse anguish. Tolstoy’s story of Ivan Ilyich famously illustrates this notion. It is told through the eyes of a man whose last days are haunted by the frightening thought that he has not lived as he believes he should have and that much of his life has been a lie [2]. His doctors know nothing of this thought, nor does his wife, and no one bothers to explore his fears as death approaches.

This issue of Virtual Mentor directly addresses a number of common but rarely discussed difficulties faced in the care of dying patients. At this level, it is practical. But I hope it serves more than this practical purpose. Underlying each of these articles is the essential tenet of humanism: the assertion of human dignity. The humanist physician believes that ignoring suffering is an offense against human
dignity. This issue of VM challenges us to be more holistic, for we cannot respect human dignity if we fall into the Cartesian trap of mind-body dualism and fail to treat the body and spirit of the whole human person. Doing so forces us to recognize and “treat” suffering. Only then can we be true physicians, and true healers.

Ivan Ilyich eventually finds comfort through the compassionate care provided by his servant. In practical terms, the servant does very little other than spend time with Ilyich. Tolstoy’s character can teach us a great deal about therapeutic presence, the power of good communication and the importance of just being with a patient, particularly at the end of life. This is true compassion, whose root meaning is literally “to suffer with.” The humanist physician is called to be like this servant and to suffer with his dying patient. While even modern medicine may exhaust its supply of treatments at times, there always remains this one proven therapy. It is the therapy of human companionship, the power of listening, the healing embrace.

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References

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