Perspectives

Moral Compass in the Care of Patients Who Choose Aid in Dying

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How can an individual's Moral Compass address the question of whether or not to help a patient to shorten and end his or her life? Moral Compass has been defined as that set of values and experiences that guides each individual's decisions and conduct in relation to others and to society. Can a robot be programmed to have a moral compass? If we were only considering rules of conduct, then perhaps yes, that would be possible. We could establish a series of rules and sanctions that a computer assisted robot could rigorously apply for any violation. The state and many religions already do that, and many individuals are quite comfortable with rigorous, unbendable rules. Most rules, however, have exceptions, so perhaps the robots of the future can be designed to be flexible, that is, human.

So for the moment, only human beings have been recognized to have a capacity for developing a Moral Compass. Do all humans have such a capacity? Is it like empathy or intuition? Is it learned or innate? Do some have this ability and others not? I don't know, but these are questions to consider. More important, can we develop a Moral Compass in ourselves and in our students?

Last year, I had the privilege of giving the graduation address at a School of Medicine and Public Health in New York. To prepare, I had been thinking about what makes a good physician, and by inference, any excellent healthcare professional. I suggested to the graduates that Medicine is both an art and a science, what the Greeks called Techne. And at one time they were one and the same thing. But as science comes to encompass so much of our modern lives, we risk losing the art of medicine: the ability to listen, to recognize the signs and symptoms of each disease, to empathize, to care, to touch, to be ethical, and to be present. In effect there is a risk that each of us could be distanced from our *Moral Compass.*

I suggested that it is in the humanities, not the sciences, that we find our moral ground, and I would argue that we must remain committed and return frequently to the humanities for emotional and intellectual healing and nourishment. The care of patients is not a risk free process. In the care of patients, if we are to give of our selves, we cannot but become wounded healers. A paradox indeed: to care, to be compassionate, is to take on the suffering of the patient; but without caring, how can we heal both others and ourselves?

I asked the graduates if they will experience moral distress as they try to take care of patients in this new world where time is so constrained. Moral distress occurs when what you should do, such as sit down and listen to a patient or a colleague, conflicts with what you are asked to do, which is to be efficient. How will they maintain control of their personal and professional lives? How will they assure that their patients are respected and retain control of their lives and decisions?

So returning to the question of Moral Compass and the patient that requests Aid in Dying (AID). I have been learning about the experiences of an unusual colleague. Not a nurse or physician or

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any kind of clinician, who discovered during the AIDS epidemic in the 1980s and 1990s, that she had a gift for helping patients, often gay, to die with dignity in the face of suffering that is very difficult to treat. As new and successful treatments changed the disease from an acute to a chronic malady, she continued to respond to calls for help from patients with other diseases such as ALS, and certain very painful cancers, but always remained within the law. She at times suggested the use of 100 percent helium inhalation. When a supportive physician and pharmacist were available, she would suggest barbiturates that have become more and more difficult to obtain for other than hospitalized patients.

While learning about her experiences, I of course have had my own. You might well ask about hospice and palliative care, and indeed most, but not all, end-of-life situations are greatly helped by palliation. So let me mention a few of my experiences.

In my first week as an intern some fifty years ago at Roosevelt Hospital, I was assigned to an attending Doctor Henry Schaffeld. I found him in a patient's room. The patient was sitting up in bed, looking emaciated and very uncomfortable as he struggled for air. Doctor Schaffeld introduced me, and I learned that the patient had won a Silver Star in the Pacific War against Japan.

Outside the room, the attending told me that the patient was dying of a widespread lymphoma and in great distress, and he taught me a lesson that I never forgot. He said in such a case you order as much morphine as needed and at the frequency necessary to stop all discomfort, unless respirations fall to less than six per minute. This was my first introduction to terminal sedation. Over the years, and especially during the AIDS epidemic in the 1980s and 1990s, I would come to learn that there are situations in which the physician may have to do more than terminal sedation to ease a patient's suffering, but that first lesson has remained with me.

Some years later, a very distinguished Shakespearean scholar from the English Department at my university asked me to take over his care. He had a pancreatic cancer and he too was dying; but he wanted to return to Europe and to France for one last visit to cities, cathedrals, and museums that he had loved. I was worried that on his travels and far from home, he would be in pain, although we had arranged for him to receive chemotherapy at the Pasteur Institute in Paris. Before he left, I gave him a bottle of 150 Demerol Tablets, an opiate that we often prescribed at the time. He returned home a month later, after a stop in Chicago to visit the Chicago Art Institute. Following a short stay in the hospital, he went home and died two weeks later. Remember that this was before hospice, palliative care and biomedical ethics committees were widely available. His wife then called me to say, "David, please come and take away his left over medicine." I returned to their home and found the original bottle of Demerol. How many tablets do you think were left of the original 150? Yes, 150. He had never used a single one. Why? Because when people are trusted they have control. And control is necessary and essential for each person's dignity. It has long been my impression that patients who have the means to end their own lives peacefully are much less likely to do so than patients who have no easy means.

Another patient, an elderly man, widowed and alone, requested comfort measures after he chose to stop eating and drinking. After a discussion with the family and the nursing home staff, we agreed to his request. The nurses and aides in the nursing home agreed. We provided sufficient opiates to ease any discomfort, and helped him to restrict all food and water. He slipped into a coma and died.

I can go on with cases, but let me return to my initial question about Moral Compass.

I have needed the arts and humanities to function as a physician. I have also needed to make the time to run or swim each day. These days, my wife and I just walk. Every clinician must find his or her own solution, a healing private space. Whether it will be in philosophy, art, history, literature, dance or music, yoga, baseball, fishing, or whatever, you must find that space for enriching your imagination with stories and experiences that resonate with those of your patients and that also heal you, the healer.

But there is something else, which I cannot deny. Unless the patient's suffering is extreme, and perhaps even when it is, I have had difficulty being the person who helps end another person's life. Is that a setting on my Moral Compass? Do the settings change with years and experience? Let me ask the reader: imagine your own demise, and what your own preferences would be at the end of your life. Yet, it seems to me that whatever a physician's personal ethics he or she must inquire as to the patient's wishes, and if the patient requests Aid in Dying, the physician must refer the patient to someone who is willing to assist the patient. Pondering these issues is daunting, but very much a part of the good practice of medicine.