Demand of Words

In medicine, there is a brittle demand of words—once spoken, they cannot be called back, for their footprint is forever—particularly at the end of life. They embed themselves in the hearts of patients and families and hold dominion over understanding or uncertainty, acceptance or denial. They can also hurt or heal, or harm or help, and bear witness to the suffering of disease—and the manner of the physician.

“Mr Jones” is a good example. He was a 68-year-old man with sepsis and multiorgan failure and a poor prognosis. Everyone knew that he was dying, but the family wanted “everything done.” During a somewhat contentious family meeting, the attending physician asked about “withdrawing care.” The family looked at each other with surprise and dismay. “You mean pull the plug?” they asked. “Just let him die?” For all intents and purposes, a line in the sand had been drawn. Two words—withdrawal care—shifted the tone of the meeting and compromised any hope of decisional cooperation. To the family, the physician had asked to forgo all care for Mr Jones, to abandon their loved one. They were now distanced and, in all likelihood, distrustful. It was clearly a poor choice of words.

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Jane Poulson called these conversations “bitter pills,” a term she coined after being diagnosed as having breast cancer and being told the hard and discomforting facts of her disease. Recalling the bitter pills she had unwittingly delivered during her 15 years of practice, she lamented that she did not truly understand the emotional rollercoaster precipitated by these conversations until she herself was on the receiving end. These bitter pills, and how they are worded, can affect the outcomes of all clinical encounters, be they good or bad, including the grief and bereavement of surviving family members.

Clearly then, these are difficult conversations. Patients and families are often distressed, in shock, and grieving, and frequently waiting to hear the words they don’t want to hear. And physicians don’t want to say the words—it’s disheartening and stressful. Moreover, the emotional content of words and the asymmetrical and oftentimes paternalistic relationship between physician and patient can become overwhelming and unbearable, exaggerating vulnerability and fear, and further contributing to difficult and uncomfortable conversations.

Unfortunately, many physicians have a “dis-ease” caring for certain ailments and may be adversely affected by a clinical impotence to cure a life-threatening illness. This clinical impotence can bring about an unintentional detached remoteness, and far-too-often, time away from the bedside. Moreover, the practice of medicine can unknowingly harden a physician through years of practice, fostering a protective distance from the presence of death. In both cases, there is a scarcity of words and an uneasy relationship between physician and patient. That said, this is not a vilification of physicians, but rather an acknowledgment that it is so very hard to watch the relentless decline and death of a patient as disease takes its toll—it’s a loss for both family and physician, and both grieve in their own ways.

In contrast, other physicians, like Poulson prior to her diagnosis of cancer, may have never endured the personal insecurity of illness and the want of a tomorrow, limiting an intimate understanding of the delicate emotions of a life-threatening disease. Like anything in life, the old adage “if you haven’t walked in the shoes” may be true, even though physicians confront disease on a daily basis. The difference is, it is not the betrayal of their own bodies, it is the disease of others, and as such, there is an obvious segregation between the well and the sick. Nevertheless, it’s during these difficult times that the demand of words is greatest, when the bitter pills of disclosure dissolve and leave a bad taste. Yet it’s also the time when words can be the most difficult to find.

So when living becomes dying, I think it’s time to step back from the physician-patient hierarchy and peer into the inherent bond between one human being and another—to see and feel the suffering, to promise nonabandonment, and to stand as equals. It’s the art of medicine and the essence of healing, and most important, the primal need of us all—to be cared for and cradled as we leave this world. It is then that the demand of words lessens, and the bond between physician and patient matures.

In Anatole Broyard’s insightful tome, Intoxicated by My Illness and Other Writings on Life and Death, written while he suffered from the ravages of prostate cancer, he said: “To the typical physician, my illness is a routine incident in his rounds, while for me, it’s the crisis of my life . . . whether he wants to be or not, the doctor is a storyteller, and he can turn our lives into good or bad stories, regardless of the diagnosis.”

To turn “lives into good stories”—what a humbling gift, and one that physicians must nurture and embrace. For if we can do that, if we can turn lives into good stories irrespective of diagnosis, in time, with time, things will be okay—they will be as they must.

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REFERENCES

Correction